Articulating a Sociology of Desire Exceeding the
Normative Shadows

by

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**Abstract: Articulating a Sociology of Desire: Exceeding the
Normative Shadows**

Drawing from the work of Deleuze and Guattari, this dissertation offers a new way of 'doing'
and 'thinking about' sociology. Rather than concentrating upon sociological categories and
identities, a sociology of desire focuses upon considering the flows of desires that emanate from
people, bodies and things. Thus, subjectivity is not restricted to an essentialist self-contained
person, but subjectivity consists of connections (assemblages) between people, animals and
objects.

Most people are restricted by what I term 'normative shadows' that suppress desires that do not
conform to accepted norms. In this work I examine how to exceed these normative shadows
through a sociology of desire. A sociology of desire could pragmatically be incorporated into
the fields of sociology of the body, sociology of knowledge, sociology of health and illness,
sociology of education, sociology of deviance. As well as offering an interesting take on
disability by exceeding the dichotomy of ability and disability; a sociology of desire with its
emphasis on singularity and machinic assemblages offers a new dynamism for disability studies.
My use of the term exceed is not meant to signify a separation from various established
sociological theories and methods rather it notes that a sociology of desire launches itself from
these sociological understandings of the social world.

While my main methodological approach is autobiographical, many different sensibilities have
informed this dissertation. From a theoretical perspective this investigation has benefited from
the insights of feminist theorists, theorists of racial inequality, scholars from disability studies,
postcolonial theorists, cultural theorists, queer theorists, literary theorists, and poststructuralist
theorists. Rather than approach this study through a singular methodology, I have drawn from a
wide-range of sources, theories, and experiences. First-person accounts, third-person accounts,
narrative descriptions, and theoretical investigations weave and intermingle throughout this
dissertation. Such an approach does not exhaust this study, but rather it lays the groundwork for
a continued analysis of the possibility for a sociology of desire.

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Dedication

This dissertation is dedicated to my mother, Doreen Overboe, who always knew I thought differently than others. She worried about my 'different thinking,' but encouraged my convictions and dedication. Without your love and encouragement this doctorate would not be possible. To the memory of my father who acknowledged the courage and sacrifice needed for me to live beyond the normative shadows.

CHAPTER ONE
INTRODUCTION AND OVERVIEW: RETHINKING SOCIOLOGY BY EXPOSING THE NORMATIVE SHADOWS IN MODERNITY AND POSTMODERNITY

This dissertation is an attempt to rethink pragmatically the discipline of sociology by exploring the possibility of doing sociology differently. Simply put, this study proposes a sociology of desire, as excess in flight from humanistic sociology with its knowing subject, and its emphasis upon identity politics. Applying a sociology of desire may illustrate how sociology can move beyond the restrictive notion of humanistic essentialism with its basis in phenomenology and its limited view of personhood. A dynamic sociology of desire with its emphasis on social assemblages that derive from desire offers an alternative to the analysis of the dialectic between individualism and community (Bauman, 1988). Moreover such an approach offers a diagonal way (Deleuze, 1994) to organize society as an alternative to the hierarchical structuring that is prevalent today.

Introducing a Sociology of Desire

Ann Game (1991: ix) asks, 'What are the possibilities of a different sociology, a sociology concerned with the immediate, the lived of everyday life and experience, and with transformation in the now? Concerned, then, with a sociology of human possibilities now, or moments of redemption in a world of commodification ... [by taking] up themes that have been excluded from the discipline - desire, memory, and time, and the body.' Game (1991: xi) adds, 'Is this a desire to return to origins, or might we discern something of another desire, a desire that gives the prerogative to the other, a desire without end or goal - in short, a desire not structured around binary oppositions?' A sociology of desire that has no end goal and is not structured by binary oppositions resonates not only with my views but also with my pragmatic approach.

For me, desire is a matter of ambivalence; more often than not, any desire on my part is construed by others as my attempt to overcome my disability[1]. Consequently my desire is defined by others as driven by my lack of able-bodiedness. The prefix 'dis' in disability reinforces the belief that disabled people continue to strive to compensate for something they lack. Yet for me desire has been driven by a positive, affirmative force that has allowed me to think about and act upon different ways of living in the social world. Whenever I mention that I consider desire as a positive force, many people express the opinion that I am in denial and cannot accept my inferior position as a disabled person.

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[1] Throughout this dissertation I will use the terms able-bodied, disabled, non-disabled, but I do not want to infer that my analysis is restricted to physical disabilities. Often my cerebral palsy is equated with a lack of intelligence or emotional equilibrium, and with developmental problems. Therefore, for the purposes of this thesis the terms 'disabled', 'cripple', and 'gimp' are used in the broadest sense and can refer to psychiatric, developmental, as well as physical disabilities. Similarly, the terms 'non-disabled' or 'able-bodied' are interchangeable and privilege an aesthetic and sensibility that negate the experience of people who are considered disabled, whether mental, emotional or physical.

Too often the existence of disabled people is seen as a 'problem' requiring, if not some sort of intervention, an explanation, a justification, or a need to educate the able-bodied other. Throughout my life, including my academic career, I continue to give myself a presence in the social world - requiring no explanation, no apology, and no need to educate others. In a Nietzschean sense, I have contemplated whether I could create such a 'presence' (or more correctly a hyper-presence, as my colleagues Richard Ingram and Joy James have pointed out that the term hyper-presence is more appropriate because it does not carry the inference of essentialism, which I reject) by exceeding the Apollonian rationality which underscores the notion of presence within humanistic essentialism. This would allow the Dionysian desires that emanate from me (including my spasms) to be released from the confines of the collective 'normative shadows' of humanistic essentialism, personhood, and phenomenology. Or more correctly, I may step back from the illusion of an individual subjectivity as presumed by humanistic essentialism and let my desires create a subjectivity for an indeterminate duration and at a level of intensity that cannot be pre-determined.

In his study of Deleuze and Guattari, Philip Goodchild (1996) refers to their work as a politics of desire. In my search thus far, Deleuze and Guattari are the strongest proponents of seeing desire as primarily a positive force. They are referred to as poststructuralists but they are very material in their thinking which allows the body to be central to their work (although a body without subjectivity and lacking deference to phenomenology). Their work is a pragmatic allowing for a sociological application to the lives of people. In this dissertation I primarily focus on my own life as a person who experiences cerebral palsy, but the same analysis could be used for any other persons who wish to release their desires that have been shackled by normative expectations and regulations.

Speaking about desire, Felix Guattari (1996: 46) states,

> For Gilles Deleuze and me desire is everything that exists *before* the opposition between subject and object, *before* representation and production. It's everything whereby the world and affects constitute us outside ourselves, in spite of ourselves. It's everything that overflows from us. That's why we define it as flow. Within this context we were led to forge a new notion in order to specify in what way this kind of desire is not some undifferentiated magma, and therefore dangerous, suspicious or incestuous. So we speak of machines, of 'desiring machines', in order to indicate that there is as yet no question here of 'structure', that is, of any subjective position, objective redundancy, or coordinates of reference. Machines arrange and connect flows. They do not recognize distinctions between persons, organs, material flows, and semiotic flows.

Having spent my life 'representing' the fragility of humanity, and having my 'subjectivity' reduced to a disabled 'pathology', I am now allowing desires that exist prior to the imposition of subjectivity and representation to come to the forefront. These 'desires', as are all of Deleuze and Guattari's concepts, 'entirely deterritorialised they have no meaning, and only express a kind of nonsense, [and according to Deleuze] deterritorialisation means "outlandish"' (Goodchild,

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1996: 56). He continues, "'Desire" is such a deterritorialised concept: it does not refer to an attraction or interaction between bodies, but designates a pure, social relation, a change in direction that could not have been anticipated'. Thus, the freeing of my spasmodic desires may result in new possibilities that could never have been imagined.

According to Goodchild (1996) the philosophy of Deleuze and Guattari has little to do with resistance, transgression, or achieving the status quo. Instead it is interested in new life-affirming worlds, people, and possibilities. Goodchild (1996: 150 - 151) elaborates:

> Deleuze and Guattari's simple technique is to replace conjugations with connections. An oedipalized subject is defined by a series of boundaries or prohibitions that limit the possible range of thought and desire; one is told what one is allowed to think and whom one is allowed to desire. Each conjugation reinforces the sense of identity. For Deleuze and Guattari, transgressing the boundary, adopting the daring stance of rebellion, has little importance in itself, for whether one accepts or rejects the prohibition; one's identity is still formed on its basis. Instead of directing desires towards either permissible or forbidden persons, Deleuze and Guattari encourage the connection of desires determinations which are not signified by the range of statements at all. One enters pacts with non-humans - animals, molecules, bodies of knowledge, aesthetic products - the necessary condition is that such flows can never become the subjects of statements, even though they may be territorial and expressive. Desire, no longer flows between subjects who to a greater or lesser degree express a majoritarian ideal; desire is no longer simulated by the resonance of subjects of statements. Instead, desire is territorial and machinic: one desires something together with which one can function in order to produce something. There is no need to dismantle the assemblage which has produced a subject; desubjectification works immediately on any kind of stratified assemblage. For as soon as one reterritorialises on a heterogeneous mode of life, then the machinic assemblages which had produced the strata is significantly changed by gaining another component with which it will function. Resonance and subjectification are blocked, and the new assemblage begins to produce statements escaping from dominant discourse. The subject of enunciation cannot be identified, for it is a collective, resulting in from the connection of various heterogeneous parts. New kinds of subjectivity which are closer to the modes of existence of animals and rocks than humans. (1994: 75). At this point, Deleuze and Guattari invoke modes of consciousness which are excluded from majoritarian reason: dreams, pathological processes, esoteric experiences, intoxication, rapture, or excess (1994: 40). The aim of desubjectification is not to deconstruct consciousness, but to discover other modes of consciousness beyond the confines of normalisation.

As mentioned earlier, for Deleuze and Guattari desire exists before subjectivity and representation. Desire makes connections with other desires to create machinic assemblages that are life affirming. These assemblages can consist of humans, animals, things, concepts. The diversity of the connections increases the chances for new types of life, forms of expression and

different worlds. This expression of the 'incomprehensible', this singularity is a minoritarian becoming that is a type of existence that has not been imagined. As Deleuze and Guattari (1987), Patton (2000) and Rajchman (2000) argue this concept of minoritarian has nothing to do with the minority politics invoked by either 'politics of difference' or 'identity politics'. Rather, it is an irruption that causes a 'new becoming' that creates new assemblages that are new subjectivities with differing intensities and at varying durations. In terms of singularity, Steven Shaviro (2002: 12) believes that gender is an example of a singularity becoming. The two polarities of male and female are conceptual categories that are particulars in relation to a larger generality above them - gender. Human beings are judged to be either male or female. But singularities develop when the concept of the male and the concept of the female breakdown causing an irruption 'at any moment'. The intuition of gender exceeds the concept resulting in a scattering of singularities (Shaviro, 2002: 13). In effect, transgender singularities are scattered. Similarly, from the perspective of sexuality, homosexuality and heterosexuality are the conceptualised categories that are particulars in relation to the generality, sexuality. Consequently, individuals are either gay or straight. However, the mutually exclusivity of the homosexual and heterosexual particularities break down, resulting in singularities called bisexuality (Udis-Kessler, 1991).

Both the singularities of transgender and bisexuality are lines of flight of desire escaping from a restrictive overarching view of gender and sexuality, respectively. The irruption of desire resulted from the fact that desires cannot be contained within an all-encompassing generality. Desires will leak out and create new assemblages with new possibilities.

Yet there is no utopian vision for Deleuze and Guattari. New people, new worlds, or flows of desire operate within the social world they tried to exceed. No line of flight allows for desire to escape the social world completely. For example, bisexuals must live in a social world where some members of both the gay and the straight community question the 'authenticity' of their sexuality. The social world is comprised of lines of strata, and places of segmentation that try to contain or capture desires (Deleuze and Guattari, 1987) and incorporate them into the perspective of the majority - or what Deleuze and Guattari call the 'majoritarian perspective'. Nonetheless, desire leaks out and tries to make connections flowing away from containment (territorialisation), and by following its line of flight is escaping the majoritarian perspective (deterritorialising) and connecting with other desires to form machinic assemblages that result in 'new becomings' (reterritorialisation). As soon as this becoming is assembled there are desires that are escaping the confines of this 'territorialisation' and 'deterritorialising' and 'reterritorialising'. Put another way, as soon as desires form a machinic assemblage they are already in the process of 'dis-assembling' because desires are flowing again, beginning a process of re-assembling.

The Concept of the 'Normative Shadow'

In 2001 I presented a paper, 'A critique of the ableist model of disability as lack' (Overboe, 2001b), where I invoked the concept of the 'normative shadow'. Ironically, this concept was not part of my original presentation; rather it was an 'irruption' that took place during my talk. This irruption of desire flowed from me and began to create a 'new way of thinking' about marginalised politics. My colleagues on the panel, who are members of the *Excess/Access theory*

group, each addressed the concept of the normative shadow during their presentations. Given that this concept had just irrupted, I was surprised at its incorporation into their presentations.

The concept of the normative shadow struck a nerve with conference participants. I attended a session following the *Excess/Access* panel and was surprised that a presenter rewrote and framed her paper around the concept of the normative shadow. Intermittently throughout the conference, both formally and informally my colleagues heard the concept of the normative shadow invoked. This concept took on a life of its own. From the perspective of sociology of desire it could be said that desire flowed from the concept itself creating, if not new orientations, new ways to express things, perhaps more precisely new expressions of thought.

I relate this anecdote to illustrate the profound effect the normative shadow - a somewhat enigmatic and elusive concept - can have upon social theory and sociology. Like most shadows, normative shadows cannot be grasped in a material way. They remain a feeling, a sense that one is constantly being judged according to differing criteria of normality. Like all shadows, normative shadows are elusive yet always present. For the purposes of this thesis, I confine my analysis to the normative shadow of humanistic essentialism, the normative shadow of personhood, and the normative shadow of phenomenology.

This normative shadow of humanistic essentialism can impact upon people on its own, and it also lays the foundation for the normative shadow of personhood. Humanistic essentialism is thought of in terms of its generalities. These generalities form the foundation from which specific characteristics associated with personhood come into play. Yet the membrane between the shadow of humanistic essentialism and the shadow of personhood is porous. I have been called 'less than human' because I am perceived to be lacking autonomy, a characteristic associated with personhood.

For the purposes of this dissertation, phenomenology encompasses 'an anonymous body' (Merleau-Ponty, 1962: 354) which is similar to the humanistic essentialist shadow, and the 'habitual postures and actions' (Merleau-Ponty, 1962: 87), that are in turn comparable to the 'personhood shadow' that signifies to others that we are able to perform the tasks required for certain functions. Thus, there is a sense of what is 'real' concerning the functional human. For example, the normative expectations of being a student rely upon this phenomenological understanding. However, this normative understanding remains unnoticed until normative expectations are unsettled, by the 'presence' of an 'unreasonable' facsimile passing itself off as 'real'. Throughout my academic career I have been perceived to be an unreasonable facsimile trying to be a 'real' student.

For the most part, a phenomenological analysis of disability is considered in terms of disability and ability (see Diedrich, 2001 and Murphy, 1987). While I critique the normative shadow of phenomenology, it is exactly the field of phenomenology that in an ironic twist allows space for me to elucidate a sociology of desire. If this dissertation is to be read through a phenomenological lens, it is to be understood as exceeding the normative shadows that support the dichotomy of ability/disability.

The Normative Shadow of Humanistic Essentialism

Polkinghorne (1988: 15, 16) argues that human responsiveness proceeds from experience, and is not simply an unmediated reaction to the environment. My experience differs greatly from my able-bodied counterpart: I can mimic his embodiment but I must control my spasms in order to stop others from questioning my humanity. For example, at times my tongue spasms resulting in a lack of control of saliva, so that I have to speak clearly without choking. My experience of disability cannot be told because there is no language that can convey the meaning for me. I realise that I am using a first-person narrative here but I am restricted by the will to coherency, order and form. Moreover, there is a process of transcendence where 'others' understand you because of shared experience real or imagined.

I feel tremendous pressure to put on the charade and try to present myself as human and subsume my spasms. In the documentary film, *Storm Reading*, Neil Marcus states, 'People are always watching me... [Ellipses in original] they're watching to see how well I do this thing... [Ellipses in original] this thing called "human".' (Brueggemann, 2002: 322) This thing called 'human' requires adherence to a humanistic essentialist normative shadow that is simultaneously everywhere and nowhere.

The Normative Shadow of Personhood

John Paul Eakin (2001: 19) asserts that people 'have an obligation to display a normative model of personhood.' He argues that if individuals transgress this obligation they face serious sanctions. It may not be their fault, because these 'rule-breakers' cannot control who they have become (not in a Deleuzian sense of the word). For example, one who experiences Alzheimer Disease transgresses societal obligations because one is unable to display a normative model of personhood. In a narcissistic turn, Eakin is looking at himself, in the mirror as the arbitrator of what constitutes personhood. Or he looks at others like himself and they all agree that they are normal. Eakin (2001: 114) writes, 'Social accountability conditions us from early childhood onward to believe that our recognition as persons is to be transacted through the exchange of identity narratives. The verdict of those for whom we perform is virtually axiomatic: no satisfactory narrative, no self.'

At differing times of my life, I would have difficulty displaying a normative model of personhood. Even when I have considered myself a 'reasonable facsimile' of personhood, I am still scrutinized. I have never had a chance to speak with John Paul Eakin, but rather than accepting his position as judge over my personhood, I might question his restrictive view of it. Unfortunately, Eakin's position seems 'natural' and is 'unquestioned'. Moreover, there is a sense in the text that it is his 'right' to pass judgement, as a person with all his cognitive and rational abilities intact. Young (1990) argues that the attributes favoured by white able-bodied heterosexual males - autonomy, independence, rational, cognitive thought are exactly the same characteristics preferred for personhood.

Discussing the concept of personhood, Lorraine Code (1995e: 98-99) writes,

> It is tempting to think of the term 'person' as a purely descriptive, neutrally designating term, and to see as a central strength of the Kantian doctrine it's recognition of this function. But I am drawing attention to the troublesome truth that 'person' can function as a normative, and by no means merely descriptive designation. The idea is not so new. It goes back to at least as far as Aristotle, for whom slaves, children, and women, were not persons in any meaningful sense. Women's struggle to achieve full personhood continues, and promises to be long and bitter. All manner of injustice towards Blacks, Jews and 'non-white' races has been rationalized on the basis of claims that these are really not persons in the appropriate sense, and hence, (on sort of a derived 'natural kinds' doctrine) that they deserve different treatment.

Contemplating the concept of personhood, Eakin sees only himself and others like him as neutral, failing to see that his 'neutrality' is a normative value. Throughout my life the normative shadow of personhood has imposed itself upon me. Through the spoken word, gesture, grimace, or look of pity others have conveyed to me their doubt that I can 'measure up' to this neutral concept of personhood which privileges an able-bodied sensibility.

The Normative Shadow of Phenomenology

Gail Weiss (1999: 19) asserts,

> Merleau-Ponty introduces the concept of the 'habit body' to refer to habitual postures which we immediately 'fall into' when driving a car, sitting at a typewriter or a computer keyboard, walking, etc. and he claims that, 'it is an inner necessity for the most integrated existence to provide itself with a habitual body' Merleau-Ponty (1962: 87).

My 'habitual body' is different then most. My walking constantly changes as my spasms interact with my legs causing my gait to shift constantly. While writing my dissertation on my computer keyboard my hands and other parts of my body do not 'fall into' a habitual posture. The integration of my body with the task at hand may be essential for an integrated existence, but it is impossible for me to achieve. My existence is not based upon integration as a coming together, or a coherent self. My spasmodic differences from moment to moment allow for me to see my existence as 'difference' without privileging one state of embodiment over another. At times my spasms coincide with this state of 'integrated essentialism' but I realise that like all other manifestations of my spasms, these moments will pass.

The phenomenology of Merleau-Ponty (1962: 354) perceives that there is commonality among bodies that we all share. In essence, before our own unique bodies there is an 'anonymous bodily structure' that we have in common. This 'anonymous body structure' provides the initial

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template from which our interaction and communication with others begins. Similarly, Merleau-Ponty argues that there are parts of the body which it is assumed we share. This knowledge of identical functioning body parts allows people to recognize the 'other' in them. Merleau-Ponty's position of the 'anonymous body' template and the identical functioning body parts allows people to 'infer' intentions in other people's actions (Sullivan, 1997: 6).

Shannon Sullivan (1997: 7) believes there are problems with Merleau-Ponty's characterisation of the body and its pattern of behaviours as anonymous.

> By appealing to the anonymous body in his explanation of intersubjectivity, Merleau-Ponty adheres to the very philosophical tradition with which he was trying to break. Throughout the history of philosophy, philosophers have claimed that there is an essential 'core' in humans that underlies all of their cultural (and other) differences. Some have called this core 'Reason'; others, 'the Universal Mind'; and still others, the Transcendental Ego.' Merleau-Ponty differs from these philosophers merely by locating this fundamental core in the body. On his account, individual bodies have some sort of universally shared commonality that is then overlaid by the differences that our particularities give them. While such an account eliminates our concern about how community might be possible in the face of differences between people, it does so at the expense of the differences themselves.

For disabled people it is not a matter of our differences being negated. Our differences are pathologised to the extent that we are unable to demonstrate that we have the commonalities of the body that Merleau-Ponty conceptualises. For example, most able-bodied people are not assured that I, as a disabled person, have an 'anonymous body structure' that is equivalent to theirs. Nor are they confident that I have identically functioning body parts. Instead of being free to 'infer' the attentions of my actions, most people begin by trying to ascertain whether or not I fit within an acceptable range of normality. People's lack of confidence in my similar 'anonymous body' and 'identically functioning' body parts may not be completely appeased if I am deemed to be barely 'normal'. Under these circumstances I am tolerated by people but not engaged by them. Thus, these two concepts of Merleau-Ponty help to cast a 'normative shadow' of phenomenology over my existence.

Moreover, Merleau-Ponty offers that a disabled existence is a 'pathological' anomaly that provides proof of the 'normal' for him. He argues for a 'projective human experience,' that with its basis in 'normal' functioning creates a backdrop of a meaningful world. In this position the phenomenological body concentration is outward from itself, grasping, seizing and understanding the world. In contrast, Merleau-Ponty argues that the disabled body orientation is inward towards itself. The disabled person's focus on their disability as a pathology inhibits them from engaging the world. Conversely the world does not 'beckon' the disabled person, as it does the able-bodied individual, because it's meaning is derived from an able-bodied existence. Lacking an able-bodied experience the disabled 'other' is forced to dis-engage the world. Only through a restoration of normality (either through rehabilitation or curative intervention) will the disabled other be fully able to engage the world.

There are two important implications for a disabled sensibility. First, there are the codes and practices that over time have become naturalised in our world (Bourdieu, 1990; Foucault, 1990). This 'naturalisation' process outlines the pragmatic element of the 'normative shadow' of phenomenology. For example, to be self-controlled in an integrative manner is a matter of 'common sense'. One does not have to ponder its validity because it seems to be self-evident as a pragmatic way of being. Moreover, we observe that others who fail to follow this prescriptive pattern of embodiment and behaviour are likely to be failures in society.

The normative shadow of phenomenology also casts a spectre over society that is intangible and elusive. As disabled people navigate through society they are often required to make others believe that they belong. Iris Marion Young (1990) makes a distinction between private behaviour and public behaviour. In public I have always attempted to control my spasms, whereas in private my spasms have free rein. From an early age, I sensed a predominant ableist attitude and realised that it would be detrimental for my spasms to be unencumbered. On a daily basis, I am aware of how the normative shadow of phenomenology shapes other's perceptions of me as well as my ability to move freely in this world. These shadows overlap: For instance, I have been called 'less than human' when the individual was questioning my ability to fulfil the tasks required for 'personhood'. Another time, my personhood was questioned because my body failed to meet this person's view of a functioning body. His assertion seemed to be based upon Merleau-Ponty's concept of the anonymous body.

Disability and Deviance

When choosing my courses for my first year of university, I opened an introductory sociology textbook and noted that the topic of disability was covered in the chapter titled 'deviance'. As a disabled person, I have never considered myself as deviant, and for that reason, I closed the book and chose not to take introductory sociology or pursue a sociological degree. However, fellow students and some professors encouraged me to engage in sociological theory, which eventually led me to pursue graduate degrees in sociology. In spite of this academic decision, I am concerned by the effect of the normative shadows that cast a pall over the pedagogy in sociology. It has led to me consider a sociology of desire as an alternative.

While perusing text books for an introductory sociology course I was teaching in the year 2000-2001, I was appalled that these sociology texts continue to frame the topic of disability in a deviant context. Similarly, many mainstream deviance textbooks continue to include phenomena such as deafness, blindness, or physical deformities (Titchkosky, 2000: 201). Tanya Titchkosky (2000: 201) writes, 'There are very few academic conferences devoted to, or that even include, Disability Studies, especially in Canada. Unlike Women's Studies, Race Relations, or Minority Studies, Disability Studies is not (yet?) regarded as a hiring, research or curriculum interest within Sociology - at best there are deviance, health and illness, and aging.' Sociology 'sequesters' (Giddens, 1991: 156) the experience of disability from aspects of ordinary daily life and relegates it to the areas of deviance, health and illness, and aging. According to (Titchkosky, 2000: 208), 'Medicine studies pathology, sociologists study deviance, and both begin with a similar conception of the disabled body - the condition of having, and thus being, a problem.'

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Presently, the prominent discourse of Disability Studies is the 'Social Model' (Oliver, 1996; Barnes, 1990) which is a response to the medical model. Mike Oliver (1983: 23) coined the phrase the 'social model of disability' to refer to 'nothing more or less fundamental' than a shift away from an emphasis on individual impairments towards the ways in which physical, cultural and social environments exclude or disadvantage people labelled disabled. The medical model perceives the problem of disability as residing in the individual's body or mind. This orientation requires an intervention to resolve the 'problem', allowing the individual the opportunity to participate in society. Proponents of the Social Model, invert the medical model asserting that the problem resides in the societal reaction to disability, not in the disabled body or mind. From this standpoint an intervention is required to change the legislation, attitudes, and behaviours that are ableist in today's society. From my perspective, both models remain confined to, and constrained by, the dichotomy of ability and disability. By emphasising the social reaction to disability, the Social Model neutralises bodies, including the disabled body. This neutrality maintains the status quo, and unintentionally privileges an able-bodied sensibility. Moreover, by not emphasizing the 'vivacity' of disabled people's bodies and minds, the social model continues to 'defer' to its able-bodied counterpart.

Like the Social Model, I refuse to pathologise my own body or mind, or the spasms that influence them. By exceeding neutrality, I contend that a disabled sensibility offers a vivacity or expression that affirms our lives. My thinking and pragmatic approach go beyond the restrictive dichotomy of ability and disability. Simply put, I believe my disabled sensibility should not defer to able-bodiedness. However, even resisting the privileging of able-bodiedness is a manner of 'deference'. Addressing the question of resistance, Linda Martin Alcoff (1999: 67) writes, 'There is a kind of quest purity in the attempt to maintain only a resistance which is itself defined as a reaction to power rather than a fight for power. Resistance so circumscribed suggests a desire to inhabit a space free from criticism, responsibility, and accountability, to be always a critic never the advocate.'

Always 'reacting against' ableism, rather than 'fighting for' the affirmation of my spasms, left me feeling empty. When articulating positions from the dichotomy of ability and disability, I felt restricted by the incessant need to respond to the normative shadow of able-embodiment that was omnipresent in discussions, and influenced the parameters for the 'rules of engagement', as well as the means of articulation. In order to advocate, I emphasize a 'singularity' that exists beyond the dichotomous positions of ability and disability. My spasms emanate desires which create a singularity that is neither 'able' nor 'disabled,' and affirms a disabled sensibility. On a larger scale, a sociology of desire offers disability studies an alternative way of viewing disability that exceeds the ability/disability dichotomy.

The problem of deviance is faced by other marginalised groups. Historically women were considered 'deviant' and pathologised for being 'overly' sexual (see Groneman, 1995) Gay men have been considered deviant and responsible for 'polluting' a heterosexual society (Seidman, 1997). Early on during the AIDS epidemic there was an 'overload theory' which postulated that 'the gay lifestyle' associated with multiple partners, drug abuse, a history sexual disease, and poor health habits resulted in a vulnerable immune system. Later the virus theory, which held the virus is transmitted through bodily fluid to the blood stream, was recognised as a more valid

explanation of AIDS. As Steven Seidman (1997: 169) asserts, 'both the Overload and Viral theory emphasized the tight link between sexual behavior and AIDS among homosexual men. Indeed, these two theories highlighted the role of sexual 'promiscuity as the intermediary causal link to both disease and death.' Gay men were considered deviant because of the inherent promiscuity that was 'evident' in their lifestyle. Even liberals marginalise certain homosexual activities, while endorsing others. Seidman (1997: 167) explains:

> Liberals also used AIDS to promote a specific moral and political agenda. Many liberals were prepared to describe homosexuality as falling within the moral boundaries of American society only if it approximated a 'middle-class' intimate ideal. In this regard, they enlisted AIDS in their campaign to construct an image of the 'respectable homosexual,' and to legitimate a monogamous, marital, sexual ethic where eros is justified only in this context. Liberals frequently used AIDS to legitimate a sexual and social order that allowed for 'liberation' within a fairly limited range of normalized social control. They defended their ethic of choice and constraint against both the 'conservative repressive' and left liberationist politics.

Similarly, the image of the 'respectable person with a disability' is personified by Rick Hansen who embodies 'middle class' values. He is athletic, heterosexual, and married. Moreover, he has demonstrated that he has 'overcome' the limitations of his disability by circumnavigating the world using his wheelchair. Thus, the image of Hansen reinforces an ableist norm while justifying the labelling of other 'less fortunate' disabled people as deviant.

Broadly speaking there is a difference in how the general public views these two deviant populations. Gay people's deviance is a matter of 'choice' as demonstrated by the phrase 'choice and constraint' (Seidman, 1997). In contrast, for the most part deviance is imposed upon disabled people either by 'an act of God', (as in the case of congenital disabilities), or an accidental mishap (as in the case of acquired disabilities). For gay people deviance is framed in the rhetoric of a lifestyle choice that lacks constraint. From the perspective of charity some disabled people are considered 'deserving' recipients because their misfortune is perceived to be a matter of chance. Gay people who are HIV are often perceived to be 'undeserving' charity because their 'lifestyle choice' led them to 'risky' behaviour that is directly responsible for their 'affliction'.

The spectre of my being deviant cast a pall over my everyday life. As a child, I remember looking at a picture of the 'ideal' human body. I recall the symmetry of the muscles, how everything appeared to be in place. I looked down at my body and felt ashamed because it was impossible for me to achieve such an appearance. Every time I attempted to draw a picture I was reminded of my degradation, because for me the steady hand required was impossible due to my lack of fine motor skills. The abstract ideal body that is the epitome of the phenomenological body is both 'everywhere' - providing a template for people to strive for - and 'nowhere' - an idealised platonic concept that is unattainable. Similarly, the idea of a perfect body and a sensibility to match creates a continuum of humanity with this ideal at the pinnacle. This

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continuum of worth demarcates and subsequently organizes and judges people according to the extent to which they adhere to the phenomenological ideal body and sensibility.

From the perspective of Deleuze and Guattari, Nicholas Fox (1999: 127, 128) claims that, 'Humanistic sociology, with its roots in symbolic interactionalism and phenomenology, is predicated upon an essentialist conception of the human subject as prior: the entity which experiences, makes sense of, and thereby has a hand in constructing the social world around it.' There is an all-embracing transcendental prototype for this phenomenological body - that is able-bodied and, as (Young: 1990b) points out, male. John Rajchman (2000: 131) adds, 'But Deleuze thinks there remains a Kantian element in phenomenology - it, as it were, reinserts transcendence into the "life world", and so, retains something of the poisoned gift of transcendental philosophy; it still wants conditions of judgement rather than experimentation.' Applying this notion of a 'poisoned gift' to disability, the concept of being is restricted by a normative shadow cast by a phenomenology which judges this body as a lack and fails to consider or acknowledge that disabled sensibility is life affirming. By judging and reifying a disabled embodiment and sensibility as lack, phenomenological discourse constitutes a border of abjection that maintains or contains what is judged to be the representative normative experience.

As a point of clarification, I would like to explain what I mean by the phrase 'disabled sensibility'. My use of the term 'disabled sensibility' resonates with the term 'different centre', as it applies to deaf culture. From the perspective of deaf culture there is a differing centre for understanding the world (Lane, 1992; Padden and Humphries, 1989). Harlan Lane (1992: 5) explains, 'They see themselves as fundamentally visual people, with their own visual language, social organization, history and mores in short, with their own way of being, their own language and culture.' Presently, I have no language to express myself. I have no culture (and I am reluctant to embrace one). I prefer to think of myself as 'becoming' rather 'being'.

I stress the positive aspects of disability because its negation has been so predominant throughout history. I am not suggesting that disability be seen as simply positive or negative. Rather, my purpose is the recognition of desires that emanate from a disabled sensibility. Perhaps such recognition can exceed the dichotomous thinking of ability/ disability or normal / abnormal that is so pervasive. The negative perception of disability extends from infanticide in ancient Greece, (Scheer and Grace, 1988), to entertainment value in the Middle Ages (Bedini, 1991), through to modernity and postmodernity (as discussed later).

I am not privileging a disabled sensibility over other sensibilities such as race, gender, or sexuality. Nor can a disabled sensibility be defined or categorised because its manifestation differs among people, making it fluid by nature, affected by environment, other people, and so on. Thus, for me, a disabled sensibility is desire that emanates from various spasms that have been (ab)normalized under the interpellation cerebral palsy. These desires are not either good or bad, but have been subsumed under, and pathologised by, an able-centric society. As mentioned earlier, it is possible for transgendered singularities to emanate from desires that exceed the dichotomy of male/ female gender. Similarly, a bisexual singularity is created out of desires that exceed the heterosexual/homosexual dichotomy.

Many different sensibilities have informed this dissertation. From a theoretical perspective this investigation has benefited from the insights of feminist theorists, theorists of racial inequality, scholars from disability studies, postcolonial theorists, cultural theorists, queer theorists, literary theorists, and poststructuralist theorists. Rather than approach this study through a singular methodology, I have drawn from a wide-range of sources, theories, and experiences. First-person accounts, third-person accounts, narrative descriptions, and theoretical investigations weave and intermingle throughout this dissertation. Such an approach does not exhaust this study, but rather it lays the groundwork for a continued analysis of the possibility for a sociology of desire.

My use of autobiography[2] as a sociological methodology helps me ground my theoretical views. Autobiographical research, like all research, requires a selection process in the information given; there are always omissions and holes (Stanley and Morgan, 1993; Aldridge, 1993). I have selected some experiences over others to illuminate and clarify my theoretical position, just as any social scientist chooses her or his empirical data to illuminate her or his position. My data, like other sociological data, cannot be a matter of caprice. They must be grounded in a rigorous methodological process that has a sound knowledge base (Stivers, 1993: 410). Consequently, to ensure that my interpretation is not a matter of whim, I have attempted to find examples of other disabled people who have experienced similar incidents. Throughout this thesis I refer to findings by other theorists to ensure that my sociological findings are "usable" for a broad spectrum of scholars. I document instances where the ableism I encounter is similar to the discrimination experienced by women of colour, as well as gay and lesbian people, and so on.

Furthermore autobiography, like other sociological methodologies, must be open to critical attention (Stivers, 1993: 410). Rarely can autobiographical research be considered as a chronological account. Rather, each memory invokes other memories of events that may or may not have taken place in a chronological order. It would be impossible for me to document my life in chronological order of events. My autobiography cannot be regarded as a self-contained disclosure because each autobiography contains the biographies of other people who figure in the subject's life. Throughout this dissertation the biographies of differing instructors, rehabilitation staff, and other students interact with my own. Even when I write of being alone, their influence is felt.

This discussion on the interplay between biographies brings to light the problem of representation. One can question whether an autobiographical experience is a true representation of life. As Evans (1993: 12) asserts, 'Much autobiography tells something about a person, although readers expect (and often get) evasion.' My interaction with others sheds light on perceptions that I recall from my particular circumstance. The reflections of various instructors,

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[2] The use of autobiography as a sociological methodology has a rich history. See David Morgan. (1987). *'It Will Make a Man of You': Notes on National Service, Masculinity and Autobiography.* ; Stanley, Liz, and Sue Wise. (1983). *'Studies in Sexual Politics, Breaking Out: Feminist Consciousness and Feminist Research.* 17 London: Routledge & Kegan Paul; Plummer, Ken. (1995). *Telling Sexual Stories: Power, Change and Social Worlds* London & New York: Routledge; William I. Thomas and Florian Znaniecki (1995) [1919]. *The Polish Peasant in Europe and America.* Chicago University of Illinois Press.

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rehabilitation and medical staff, and students remain hidden. While being involved in the same event each person can construct different and often competing descriptions. What I have produced might well be called in part a social - autobiography (see Zola, 1982).

Friedman (1990: 65) elaborates on the value of autobiography for sociology:

> Therefore, just as it has been said that history is too important to be left only to historians, so autobiography should not be limited to nonsociologists. For sociologists overly to exclude themselves from the autobiographical mode would be to the detriment of the overall knowledge and insights that can be obtained in this special manner. Sociologists in recent years have increasingly recognized the value of constructing autobiographies/biographies ('life histories') of others (Bertaux 1981; Denzin 1989b, pp. 49- 83) and of scrutinizing the contents of published autobiographies (Friedman 1989). The imperatives prompting those trends should apply equally well to more writing of the autobiographical sociology of our own experiences, on the assumption that our autobiographical contributions are as important as those of others.

This thesis chronicles not only my acknowledgment of the impact of these normative shadows upon my life, but also my growing awareness of how the desire that emanates from my spasms creates a 'singularity' that exceeds the dichotomy of ability and disability. However, this work does have broader implications for sociology, because aspects of my theoretical analysis can be extrapolated to the lives of others. Moreover, my autobiographical pieces may resonate with the life experiences of readers.

Agreeing that autobiography is not simply a reflection of one's life, but a valuable tool for the analysis of the social world, Camilla Stivers (1993: 418) writes, 'The social scientist who is prepared to entertain the notion that human beings and social structures mutually shape one another can also see as germane an exploration of the processes by which context constitutes the knowing subject – in other words, to see subjects in their own right (not as 'group members') as fit material for social science.'

Applying the insights of Stivers to this thesis, my autobiographical methodology attempts to see my subjectivity 'in its own right' not in the sense of a disabled category. I differ from Stivers, in that my subjectivity emanates from a flow of desires rather than a 'knowing subject'. Nevertheless, her project shows an affinity with this dissertation, and Deleuze and Guattari, as Stivers (1993: 425) suggests that autobiography as a can articulate innovative ways of seeing ourselves.

From a sociological position, C. Wright Mills (1959: 227) summarizes the importance of life writing:

> Know that many personal troubles cannot be solved merely as troubles, but must be understood in terms of public issues - and in terms of the problems of history making. Know that the human meaning of public issues must be revealed by relating them to personal troubles - and to the problems of the individual life. Know that the problems of social science, when adequately formulated, must include both troubles and issues, both biography and history, and the range of their intricate relations. Within that range the life of the individual and the making of societies occur; and within that range the sociological imagination has its chance to make a difference in the quality of human life in our time.

The Normative Shadow in Modernity and Postmodernity

Lennard Davis (1997b: 10) argues that the ideal body was an artistic representation of a compilation of preferred body parts of living models. During pre-modern times this idealised body could never be achieved but was to be admired. Conversely, the common people were the opposite of this ideal body because of their imperfect bodies which were labelled as 'grotesque'. However, even this grotesque population excluded disabled people. Davis (1997b: 11) asserts that the 'grotesque permeated culture and signified common humanity, whereas the disabled body, a later concept, by definition was excluded from culture, society, and the norm.'

My embodiment epitomises the image of the disabled body that is unable to attain the stature of either the ideal or the grotesque. Earlier in my life, no matter how hard I tried I could not affirm my lived embodiment because I had internalised a normalised view of the body that I could not ever expect to emulate. Moreover, during my teen-age years many of my able-bodied peers were beginning to attempt to move beyond their 'grotesque' normative status in order to become more like the 'idealised body'. Throughout my teenage years I felt tremendous anxiety because this grotesque normative body that other boys were dissatisfied with was beyond my reach; attaining the idealized body was out of the question. Media images reinforced both the desirability of the idealised body and the abjection of my disabled embodiment (Norden, 1994).

The Privileging of Vision and Aesthetics

Chris Jenks (1995a) and Iris Marion Young (1990a) argue that the template for the progressively productive individual according to the values of modernity is the white able-bodied male. Jenks (1995a: 150) writes, 'It is not surprising, though not comforting, to learn that the predominant "view" of the cosmos from within modernity - epistemological, aesthetic, and literary - has been a masculine view. The male gaze has been formative of the cultural products and traditions of modernity.' As a performer for whom performance and theory are inseparable, Allucquere

Rosanne Stone (1997: 62) is acutely aware that the privileging of vision and the maintenance of social order are linked through the medium of political power.

Michel Foucault (1984e: 124-125) asserts that the liberal rhetoric of individualism is based upon a belief in a 'founding subject' who gives meaning to an 'empty' world, judging, categorising and shaping this world. Agreeing with Foucault, Richard Jones (1990: 81) asserts that since the seventeenth century liberal individualism has been dominant in Western discourse. Bill Hughes (1999: 163) argues that the vision of the white-able-bodied-heterosexual male defines 'truth' through a description of the world based on one specific experience of it. This view has authority that allows its proponents to invalidate other embodiments, as they affirm their own.

Young (1990a) explores this social construction of bodies, showing how 'other' bodies are ranked in relation to privileged bodies (primarily upper-class, white, heterosexual, able-bodied, males). The ability of 'inferior' bodies to move up the scale of human development and social standing is correlated to their ability to incorporate the characteristics, attitudes and behaviours of the elite privileged bodies. My appearance is the antithesis of the control associated with rationality, linearity, productivity, and normality (Hughes, 1999: 157; Young, 1990a: 124). Simone Fullagar and Kathryn Owler (1998: 443) assert that intellectually disabled people are similarly excluded from the norm when referred to as 'inferior' or 'special' to designate their status as lesser people.

Within modernity a benchmark of normality developed that became the standard by which people were judged (Davis, 1997b: 11). Believers of modernity felt that by applying rationality eventually the as yet unattainable idealised body could be achieved, but initially the goal was for members of society to reach the 'average' benchmark of normality. The prototype for this benchmark was the biologically correct male body (Urla and Swedlund, 1995: 288). Within the United States of America, by the late 1940s there was a search for the anthropometric models of the century - 'Norman' and 'Norma', the average male and female who could represent statistical composites of the perfect body (Urla and Swedlund, 1995: 290). Like the idealised picture of 'the human body' earlier, 'Norman' and 'Norma' did not reflect normative embodiments, but an idealised notion of masculine and feminine bodies. While people may be aware that these 'desired bodies' may be unattainable, there is tremendous pressure on individuals to strive to reach this level of desirability.

Darren Newbury (1996) and Alexa Wright (2001) both attempt to subvert this ableism. Newbury invites disabled people to photograph wheelchairs from their perspective rather than being defined as 'in' a wheelchair. Wright (2001: 506) problematises the image of disabled people in a series of photographs by digitally manipulating various portraits of her that illustrate different disabilities. Wright hoped that these images of her would force viewers to realise that they often see the disability before they see the person. Moreover, Wright intends to challenge public perceptions of, and attitudes toward, physical disability, and to question the boundaries of what is considered beautiful or acceptable with regard to body form. Newbury attempts to affirm a disabled sensibility and aesthetic that is considered an anomaly in relation to the normative standard of phenomenology. Wright illuminates how ableism is so pervasive with the aesthetics of phenomenology that privileges an able-bodied sensibility.

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The Body in Postmodernity

Efrat Tseelon (1992: 121) asserts that both the modern and postmodern self are a 'fragmented, fractured identity'. The former attempts to rescue 'the self' from chaos while the latter makes no attempt to do so. In the postmodern world there is no individual essence, but rather an individual's identity is continuously emergent, re-formed, or redirected as one navigates through the sea of ever-changing relationships (Bauman, 1992; Tseelon, 1992; Gergen, 1991). Kenneth Gergen (1991: 228) claims that with postmodern consciousness comes the belief that people are capable of rewriting their identities as they wish. A person's capability to reconstitute her or himself is dependent upon her or his ability to acquire the symbolic goods required to rewrite her or his identity.

Within postmodernity, imagery and advertising stimulate needs and desires. Most desired are the symbolic goods that require considerable investment in time, money, or knowledge. The need to consume the latest symbolic goods often overrides the actual acquisition of them. There is always a 'new and improved' symbolic good to strive to obtain. Thus, consumers of · postmodernity are manipulated by symbolic goods; the seduction of the elusive, of the unattainable, whets their appetite (Baudrillard, 1988; Bauman, 1987; Featherstone, 1991). Each consumer attempts to 'convey the appropriate and legitimate signals through his or her consumption activities' (Featherstone, 1991: 48).

Within postmodernity the social order is an outcome of the manipulation of symbolic goods. Symbolic goods signify to themselves and others what one's identity is at any time. Thus, social ills are interpreted as the failure of the individual to acquire the symbolic goods required to resolve the problem (Bauman, 1987: 187). For example, disabled people who look unhealthy are considered failures because of their inability to acquire the symbolic goods (for instance the latest health enhancement regime) to make themselves appear healthy (Edgely and Brissett, 1990 in Overboe, 1994). ·

Such 'flawed consumers', including disabled people are, caught in a double-bind: Often they · have limited access to necessary resources because they are unemployed or underemployed, and they are unemployed or underemployed because they lack the resources to participate fully in society (Wendell, 1992; Matthews, 1983). However, this stratum of imperfect consumers is needed to maintain a social order within postmodern society (Bauman, 1988). When groups on the lower rungs of the social ladder attain goods that were previously prohibitive, those above will supply new, fashionably desirable goods, to maintain the original distance (Featherstone, 1991: 18, 19). In this consumer-orientated society of postmodernity the upper-class are able to acquire the latest and possibly rare products. Many people in the lower classes want to emulate the upper class and strive to attain goods with 'social capital' (Bourdieu, 1990). When the product in demand creates a need for mass production, the upper class moves on to even newer or rarer products and the cycle of consumption begins again (Bauman, 1987). Whether these trendsetters are trying to maintain a separation between themselves and others, or are just consuming, the fact remains that a distance between them and the others is preserved (Overboe,

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1994). Nevertheless, there is a constant within this consumptive society - that is the able-bodied template.

Cultural industries reinforce specific notions of what is desirable in women, in men, in sexuality, in clothing and in what can be imagined (by controlling cultural mediums). Kim Sawchuk (1987: 68) asserts that 'while promising Nirvana to all, the restricted economy limits the flow of goods and services to those with access to capital thus reproducing forms of class domination; It creates desires while denying them and making them dependent upon the flow of capital.' Faurschou (1987: 82) claims,

> Postmodernity then is no longer an age in which bodies produce commodities, but where commodities produce bodies: Bodies for aerobics, bodies for sports cars, bodies for vacations, bodies for Pepsi, bodies for Coke, and of course, bodies for fashion, - total bodies, a total look. The colonization and appropriation of the body as its own consumption/ production machine in late capitalism is a fundamental theme of contemporary socialisation.'

Sawchuk (1987) makes some interesting observations about paintings which pertain to our notion of the human body. Sawchuk (1987: 70) argues that nude paintings do not reflect the natural body but only the artist's representation, which is informed by the limitations of fashion. Thus it is impossible for an artist to capture an objective reality or 'natural body' through an artistic depiction because the 'natural world' does not exist prior to representation. Again, this representation defers to the phenomenological concept of what it means to human. Within the sensibilities of modernity and postmodernity the representation of 'natural' bodies changes but still resembles the conceptual ideal of phenomenology. Consequently, the devaluation of disabled bodies continues within the eras of modernity and postmodernity.

Within postmodernity, to have a body that appears to signify a healthy lifestyle conveys status (whether the lifestyle is healthy or not, as is the case of injecting steroids). If an individual appears to have an unhealthy body she or he loses status and is considered a moral failure. Thus, a healthy body in turn becomes a symbolic good with enormous exchange value (Bauman, 1987; Featherstone and Hepworth, 1991). Some disabled people 'appear' to be unhealthy. If to appear unhealthy necessitates the loss of status, then being in the category of the disabled means that one loses status. Wendell (1996: 44) argues that the postmodern argument that sees the body only as a product of inscription denies the physical reality of disabled people (Overboe, 1994). Wendell (1996: 43) believes that in our culture that often values a woman's appearance above her other characteristics, the 'physical imperfection' of a disability denotes that disabled women are 'spoiled' or, to use Bauman's term, 'damaged goods'.

Featherstone (1991: 26) contends that postmodernity is 'widening the range of contexts and situations in which behaviour is deemed appropriate and acceptable.' This continuum runs the gamut from appearing as if one is a controlled person to appearing like a free-flowing person. Featherstone makes the point by showing the same model dressed in a business suit and then in a free-flowing caftan. These visual images illustrate that people do not have to choose between

these two options, they can be both. Underscoring both images is a model whose embodiment is closer to the aesthetic ideal of phenomenology. As Hahn (1997: 187) argues, there is a need for an acceptable image of humanity in our era of consumption. If an individual cannot conform to this image he or she is marginalised, placed in a category excluded from this area. No matter how hard we try or how many symbolic goods we acquire, some disabled people (including me) cannot conform to this acceptable comportment. I remain a disabled body that is marginalised in postmodernity.

The Techno/cyberworld of Postmodernity

Jean Baudrillard (1988: 52) predicts that disabled people and their sensibilities will have a pivotal role in the hyperreal world and postmodernity in which bodies are reconstituted through technology. But Vivian Sobchack (1995: 213) maintains that she prefers her imperfect fleshy body over her techno-perfect prosthetic leg. Ironically, her prosthesis allowed Sobchack to conform more closely to an embodiment and mobility that has become normalised as the prototype for what is human. However, the prosthetic solution that offered her 'normalisation' proved unsatisfactory for Sobchack because it failed to meet the requirements of her lived experience.

Many advocates of the cyberworld contend that the future seamless posthuman body of the cyborg will be free from oppression, because cyberworld bodily differences are situated knowledges located as sites on the equal textual plane of postmodernity (Caddick, 1995; Clark, 1995). Alison Caddick (1995) and Nigel Clark (1995) both point out that such situated knowledges - such as body image - are not equal sites on the playing field because these new technologies are concerned only with the surface of the body [in essence its image] and negate its visceral depth. They contend that the difference between ugliness and beauty is not diminished but heightened by a greater fetishism of a particular body - the body beautiful.

With regards to the modification of the body, Rosemarie Thompson (1997: 287) makes a distinction between how disabled and non- disabled women are treated. In this age of 'spectacular bodies' (Clark, 1995), Thompson (1997: 287) argues that magazines 'cast the unreconstructed female body as having abnormalities that can be corrected by surgical procedures which improve one's appearance by producing natural looking noses, thighs, breasts, chins and so on.' Women undergoing cosmetic modification of their bodies and disabled women undergoing invasive medical procedures both experience pain. Yet there are differences in how disabled women's and non-disabled women's bodies are 'read' after surgery. 'Within the visual economy in which appearance has come to be the primary index of value for women, feminizing practices normalize the female body that is sculpted to conform to the feminine ideal, while disabilities abnormalise it' (Thompson, 1997: 287). The non-disabled female prompts the admiring gaze, while disabled females prompt the horrified stare. Alterations to increase feminization increase woman's social capital, while disabilities reduce it.

bell hooks (1990: 165) observes that 'postmodern white culture looks at itself somewhat critically, revising here and there, then falling in love with itself all over again.' To echo hooks,

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I believe the able-bodied culture criticises humanistic essentialism and through cyber/techno body revises here and there, then falls in love with a 'new improved' spectacular self all over again, a self that continues the negation of disabled sensibilities. If we are on the cusp of modern and postmodern sensibilities, I find both alternatives lack the necessary will for the validation of a disabled sensibility.

The Normative Shadow of Phenomenology as an Apparatus of Capture

Some theorists of disability, such as Bill Hughes and Kevin Paterson (1997), see phenomenology as a means to incorporate the body into disability theory that, in their mind, has concentrated on systemic ableism at the expense addressing the embodiment of disabled people. They call for a sociology of impairment that combines the body (as emphasized in phenomenology) and attention to discursive practices (as in poststructuralism), to integrate causes of systemic ableism with the lived experience of disability. For Hughes and Paterson a phenomenological approach allows them to ground a critique of ableism in the 'lived experience' of disability. In another article, Paterson and Hughes (1999) employ Leder's notion of dys-appearance to validate the experience of embodiment.

A psychologist who uses phenomenology, Drew Leder (1990: 53) argues that in everyday life the body that is fully functioning is not noticed and, in Leder's terms, 'disappears'. When the body fails to function smoothly we become aware of it, and, as Leder (1990: 84) suggests, dys-appearance occurs. With impairment, along with the embodied dysfunction there is the added dimension of the 'profound oppression of everyday life' that one must face. Thus, in the context of impairment, dys-appearance is an intercorporeal phenomenon rather than solely an intracorporeal phenomenon (Paterson and Hughes, 1999: 603).

The following section from Paterson and Hughes (1999: 606) illustrates the concept of intercorporeal dys-appearance as it applies to impairment.

> An integral part of the 'dys-appearance' experience by disabled people is the everyday reality of condescension, in particular being perceived as the 'eternal child'. The next story is an example of how patronising behaviour produces my 'dys-appearance' and brings home to me my homelessness in the order of everyday life. A delivery person arrived with a package and said (when I opened the door) 'Oh is your mum not in.' She obviously thought I wasn't a 'responsible adult' and, therefore, not eligible to participate in the partnership required to complete her task. It is highly unlikely that she would have arrived at such a conclusion had I been a non-disabled person in their late twenties. Such exclusions from responsibility are a stark reminder of the oppressive logic of the carnal hierarchy; they are a palpable denial of 'social competence' based on a knee-jerk aesthetic judgement. This assumption/conclusion about my ('lack of') 'social competence' was reached in an instant as an embodied reaction to my bodiliness.

I believe that Leder's point is that disability causes dys-appearance, whereas Paterson and Hughes (1999: 606) see dys-appearance stemming from people's reactions to the disabled body's lived experience. However, I am less inclined to adopt this approach because within the discourse of phenomenology disabled people have been invoked as exceptions from the 'normal' that prove the rule. In short, one could understand the normal body (read able-bodied white male) by looking at the exceptions to the normal body (read disabled person). Also, there is an ableist current which I believe underscores Leder's phenomenological writing. For example, Leder (1990: 81) writes, 'In disease, one is actively *dis-abled*. Abilities that were previously in one's command and rightfully belong to the habitual body have now been lost.... There may be nostalgia for lost possibility, hope for its return, fear that disability will further spread.'

By focussing on the concept of 'dys-appearance', Paterson and Hughes are validating the rhetoric which views the disabled body solely as a devalued entity. Why does it necessarily follow that a negative experience causes disabled persons to become aware of their body? Moreover, such a statement implies that pain is more or less a constant for disabled people. The prefix 'dys' in dys-appearance defers to dysfunction and abnormality. I suggest that my cerebral gives vivacity and texture to my life, and thus informs it positively. Paterson and Hughes who urge us to 'bring the body back' into disability studies, may be misguided with their emphasis on impairment with its negative implication (read dysfunction) which ignores the positive and sensual aspects of experiencing the disabled body. I would argue that Leder's concept of 'dys-appearance' does not subvert ableism but acts in its service.

Generally speaking, for me, my physical experience of cerebral palsy consists of spasms that occur at varying times with various intensities. They are most obvious when I walk or when I attempt to transcribe some of my thoughts, whether long-hand or by keyboard. I walk slowly to allow my spasms to move throughout my body at leisure. If I move too fast (and attempt to conform to a non-disabled gait) my spasms seem to become agitated, acting like a python they wrap themselves around my muscles constricting them and my subsequent actions.

Rarely am I faced with problems as a result of my spasms. Unfortunately, experiencing spasms cannot be isolated and occurs in interaction with an environment and society that devalues such physical reactions. Problems occur when I face this devaluation and subsequent marginalisation. Many other disabled people face similar devaluation of their corporeality. For example, Nancy Kerr (1979: 179), who uses a wheelchair, entered a hospital as a professional and was mistaken for a patient. Immediately she and her chair were moved without her consent. Like Kerr, in my capacity as a professional social worker I have often been mistaken for a client. In each situation, through the objectification of the 'normalising stare', we were reduced to a perceived corporeality that was deemed inferior by others. The 'normalising stare' of others not only negates my corporeality but fails to consider its positive aspects.

I mentioned previously that I walk slowly to allow my spasms to move throughout my body at leisure. Friends of mine have slowed their pace to match mine and have noted nuances in both the physical and social environment that they missed at their previous pace. Thus my spasms have offered me and others who accompany me an opportunity to consider the environment from a differing reference point in terms of temporality (see Jenks, 1995b; Game, 1991). Both a

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nondisabled and a so-called disabled way of negotiating the environment have positive aspects, but the latter is still held as inferior by most members of our society.

Moreover, my spasms add a dimension to my interpretation of the differing phenomena that I encounter. Spasms often shade how I respond to events and situations, including academic ventures. These spasms affect my body in a multitude of ways that cannot be controlled (why would I want to?) or predicted, and affect my interaction with phenomena. I cannot confirm that these bodily movements offer me a unique or better perspective on phenomena than a normal bodily experience, because I cannot step outside my own corporeality to compare them. But throughout my life any interpretation (that had credence) of some specific phenomenon or the world in general has been framed within a non-disabled context.

Leder (1990: 72) argues that chronic pain is called to our attention because of its intensity that cannot be overcome. Moreover, he (1990: 75) asserts that pain is an *alien presence* that intentionally disrupts and constricts the activities of the body. The attention of the body becomes absorbed and obsessed with chronic pain. Usually pain requires that the spatial environment is lessened. Leder's impression of pain typifies the normative view that pain must be eradicated because it is an anomaly to bodily function.

Barbara Duden (1991: 18) asserts that the experience of the body has been subordinated by the normative term 'health' that originates from the rationalist approach to medicine. Wendell, who experiences chronic pain, maintains that the physical and social environment uphold the normative standards that informs the Leder's view of pain. For example, the chronic pain felt by my inner body is ignored by others unless it interferes with my ability to interact with my non-disabled environment. Wendell (1989: 111) writes:

> I believe our understanding of pain can be greatly enriched by experiences of chronic pain. By chronic pain I mean pain that is not endured for some purpose or goal (unlike the pain of intense athletic training, for instance), pain that promises to go on indefinitely (although sometimes intermittently and sometimes unpredictably), pain that demands no action because as far as we know, no action can get rid of it.

To Leder and others who see 'health' within a limited context, pain means something is wrong and must be acted upon. Wendell and myself, like many people who experience chronic pain, might choose to accept pain and to some extent embrace it like an old friend that is part of our lived experience. By claiming that pain is an invasion of the body Leder is negating our lived bodily experience. For many years I agreed with Leder and considered pain an intrusive enemy rather than an old friend. Later I realised that to eradicate pain is to eradicate a bodily experience. By accepting pain as a legitimate rather than an invasive bodily experience I could focus on its positive repercussions. By embracing pain, for example, I have been able to switch to bodily time from linear time. In the beginning bodily pain forced me to listen to my body and realise that imposed artificial linear time is detrimental to my own productivity. Now my pain is one of many bodily experiences that reinforce my commitment to my own bodily time.

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Leder (1990: 69) contends that when the body is healthy and normal it is removed from our consciousness. For him disease, like pain, causes the body to come to the forefront of our consciousness. Disease, a complex pattern of dysfunction, prohibits the body reaching out and engaging with its environment. He calls this imposition the 'I cannot'. Essentially, a disease of the body stops a person from using his or her body in a normal healthy way. This disruption not only causes a physiological dysfunction but also prevents the individual from engaging with the world (Leder, 1990: 81).

Leder makes a distinction between being 'unable' and 'disabled' in reference to bodily function. To be 'unable' means one can not control certain aspects of the body, such as liver function. Being 'disabled' means one suffers the loss of control over bodily functions that one had previously managed (such as the ability to walk). Having been born with cerebral palsy I cannot consider it as a 'loss' of functioning because I have no other referent to measure it against. But again, I stress that the subtle nuances of my cerebral palsy give me not only pleasure but a different perspective and an appreciation for the world around me and my lived experience. Unfortunately, most non-disabled people paint my life with a wide brush coloured with misery, deformity, and tragedy, failing to see my life through a prism that allows the brilliance and vivacity of my cerebral palsy to be illuminated. Consequently Leder is privileging his own corporeality (able-bodiedness) over mine; by invoking the dichotomies of can/cannot and ability/disability, he fails to consider the grey area between these polarities.

My profound sense of embodied vitality is negated in his examination of the disabled body; by restricting the concept of disability to a negative connotation Leder fails to consider the positive effects of the cerebral palsy that inform my corporeality. It follows that people who Leder perceives as disabled are faced with a lesser state of corporeality. If, as Leder argues, corporeality is the foundation of human existence, then disabled people, because of their defective embodiment, have a flawed existence. Given that Leder is relying on a phenomenological analysis, to what extent should phenomenological sociology be employed in the study of disabled people? The operative term is 'in studying' disabled people; such an approach leads to a wide-brush approach that results in a categorisation of our lived experience under the rubric of dys-appearance which is not only facile but dangerous.

The Interplay between 'Lines of Stratification' and 'Lines of Flight'

The smooth space of a sociology of desire, like my validation of my spasms, does not happen in a vacuum. Lines of stratification or segmentation exist in our society. Deleuze and Guattari (1987: 474) argue that the hierarchical lines of stratification, as well as the sedentary or established areas of the privileged dominant perspective (such as humanistic essentialism with its basis in a phenomenological sensibility), are opposed to smooth spaces or lines of flight. This oppositional stance fails to recognise the complexity in understanding their concepts of stratification or lines of flight. Smooth spaces over time may become stratified or stratified spaces may become smoother.

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For example, western medicine, with its emphasis on treating a specific ailment, created a sub-discipline called rehabilitation to help disabled people to become normal. Thus, there is a territorialisation of disabled people within the stratified lines of normality or the continuum of humanity. In effect, this rehabilitation system in conjunction with other lines of stratification, creates an 'apparatus of capture' (Deleuze and Guattari, 1987; Patton, 2000; Goodchild, 1996) which relegates disabled people who fail to reach normality to a peripheral existence as the 'abject other' (Kristeva, 1982). Within the theoretical view of Deleuze and Guattari, desire cannot be contained and there are 'lines of flight' from its territorialisation. Lines of flight or deterritorialisation may be created by 'private thinkers', also known as nomadic thinkers, who stretch the boundaries of acceptable thought, and, in doing so, sometimes create new lives or new ways of becoming through desire. These desires create new machinic assemblages which again may have differing intensities and durations (Deleuze and Guattari, 1987; Patton, 2000).

The medical model of Western society could not contain the desire for alternative views on health and sickness. These alternative views, brought to public attention by nomadic or private thinkers who have experienced life in a different way, resulted in the creation of the holistic health movement (body, mind, spirit connection). This movement was initially seen as a desperate attempt to find a cure by desperate people.

Often deterritorialisation results in a reterritorialisation whereby the line of flight creates a machinic assemblage that forms its own lines of stratification. For Deleuze and Guattari (1987), social change does not happen as a large-scale event; rather, it is incremental in nature. They suggest that a minoritarian becoming will latch itself onto the majoritarian perspective and through this machinic assemblage make a change in society. Over time the holistic belief in the mind, body, spirit connection made a machinic assemblage with Western medicine which created a shift in terminology in regard to holistic medicine. For the most part, holistic medicine is no longer referred to as alternative medicine, but as complementary medicine. Thus, holistic medicine, which originally developed as a line of flight from Western medicine to varying degrees has been incorporated into the dominant majoritarian perspective.

From a disability perspective, Wendell (1996) asserts that the notion of balance has resulted in people believing that if they follow the right regime or alternative, holistic medicine they can be cured. What follows is the belief that the person is not only at fault for being out of balance, but is also to blame for not finding the appropriate remedy. Again, disabled people are caught within an 'apparatus of capture' because, like Western medicine, holistic medicine has its roots in the restrictive concept of the 'autonomous body' favoured by Merleau-Ponty's phenomenological stance that forms the 'normative shadow' which influences what it means to be essentially human.

The stratified areas may combine with lines of flight to create new assemblages. For example, I have incorporated some of the techniques of rehabilitation (an institution that arose out of the stratification of people) to help me understand my spasms (a line of flight) and create a singularity - a new assemblage which rejects the ability/ disability dichotomy. My article '"Difference in Itself": Validating Disabled People's Lived Experience' created its own 'line of flight' and has been read by a Disability Studies class at a university in the Maritimes. The class

considered the concept of 'difference in itself' to be a new way to think of disability. If this enthusiasm translates into a pragmatic way of understanding disability, then a new line of stratification may develop.

Yet this new way of understanding disability would not guarantee a 'life-affirming existence' as a singularity, a machinic assemblage, or an established way of being which creates its own line of stratification. From the perspective of Deleuze and Guattari, Paul Patton, (2000:66) asserts that allowing desire free rein carries with it the greatest creative reward but also the greatest danger. Notwithstanding this uncertainty, I believe that I can unleash the spasms that flow from my cerebral palsy and break free from restrictive humanistic essentialism. Like Nietzsche (1992) in his autobiography, I do not want to suggest that I am offering a blueprint for the 'improvement' of society in a prescriptive manner, but offering this slice of life as 'a new possibility' with no utopian promise.

The Paradoxes Involved in Writing This Dissertation

In this dissertation, from the perspective of disability, I move beyond the binary opposition of ability/disability. Following Game (1991) my dissertation is written through my lived experience and my body, more specifically through my spasms. This writing entails ironic twists: I am using my lived experience while rejecting an essential subjectivity; I am writing while maintaining that it is impossible for me to write; I attempt to affirm a disabled sensibility while shunning the very notion of disability and the subsequent disabled/non-disabled dichotomy. MacDonald (1991) argues that although the concept 'woman' may not exist, however, as long as others treat her as a woman she must react to this subjectivity. Similarly, I must react to a world that continues to create an environment that restricts my existence to primarily a disabled subjectivity.

My writing is not a response to an able-bodied representation of life. Arthur Frank (2000: 137) asserts that autobiographical work related to illness is a performance by which an ill person carves out a place or space and establishes a community with others who share the experience and values of illness or disability. To claim a space implies that there is someone or something to which you are illustrating that this space is yours, even if this someone is you! A claim, in this context, infers *this* (illness or disability) over *that* (health and able-bodiedness), but in doing so it defers back to privileging health and non-disability as the primary referent and disability and illness as 'lack'. In this dissertation I am not claiming a space which implies ownership, but 'becoming in a space or a place of becoming' whereby I occupy a space because of the intensity of a machinic assemblage. Of course I cannot help it if this dissertation is read within a 'this' or 'that' context, because the language of the social world, and thus the language of this dissertation, lends itself to such an interpretation.

Also, the writing style of this dissertation may differ from most because of rhizomatic writing flows from my bodily spasms. Consequently, there is a chaotic assemblage; for instance, discussion shifts from sexuality to education. Because my writing emanates from my spasms, at times it may seem to be lacking academic rigour, as it relies upon 'stories' that may seem similar or at other times disjointed. However, this rhizomatic writing allows for the questioning of humanistic essentialism, phenomenology and personhood, as pillars of sociological thought. Such writing is risky but is similar to comments made by made by Brian Massumi (2002a: 18):

The writing tries not only to accept the risk of sprouting deviant, but also to invite it. Take joy in your digressions. Because that is where the unexpected arises. That is the experimental aspect. If you know where you will end up when you begin, nothing has happened in the meantime. You have to be willing to surprise yourself writing things you didn't think you thought... You have to let yourself get so caught up in the flow of your writing that it ceases at moments to be recognizable to you as your own.

Massumi (2002a: 18) believes that individuals have to risk being thought of as 'stupid' (even in the academic sense) in order to create openings for different ways of thinking. In writing and reading this dissertation as a book there are 'lines of articulation or segmentary, strata, and territories; but also lines of flight, movements of deterritorialisation, and destratification' (Deleuze and Guattari, 1987: 3). But readers may also develop their own lines of flight or deterritorialisation, destratification from the perspective offered in this dissertation. Moreover, there are different flows and intensities that readers may notice in the dissertation as well as in themselves. While reading this dissertation, hopefully, there is an opportunity to create new ways of thinking about sociology, in particular, and life, in general.

In Chapter Two I begin by critiquing the restrictive continuum of humanistic essentialism. In the same manner, I argue that phenomenological liberal individualism and a universal humanistic essentialism stifle diversity, including a disabled sensibility. Drawing on my own experience as well as that of others, I contend that rehabilitation is underscored by the privileging of a restrictive notion of humanity. Like rehabilitation, telethons and other efforts by charitable organizations are believed to be based upon benevolence; in contrast I argue that these institutions continue the devaluation of a disabled sensibility.

In Chapter Three I outline how the 'normative shadow of personhood' results in a limited view of what it means to be a 'person'. I critique the concepts of pre-personhood and post-personhood, through which some individuals are deemed to have a 'life not worth living'. But this quality of life debate is framed within a view of 'what a person is' that devalues disabled people unless they can, or at least have the potential to, overcome their disability. I end this chapter by analysing the murder of Tracy Latimer. I examine how the normative shadow of personhood impacted upon both positive representations of Robert Latimer, the murderer, and negative representations of Tracy, who experienced cerebral palsy.

In Chapter Four and Chapter Five I examine how the sociology of desire has implications for our educational system. Like humanistic essentialism and phenomenology discussed in Chapter two, the education system could be analysed as an 'apparatus of capture'; instead I will examine it using the theoretical concepts of the 'old idiot' and the 'new idiot' (Deleuze and Guattari, 1996: 62-63). For Deleuze and Guattari the concepts of the 'old idiot' and the 'new idiot' result from a critique of the Cartesian 'cogito'. Deleuze and Guattari (1996) felt that the Cartesian model of humanity with its emphasis on rationality as demonstrated by the phase 'I think therefore I am' was too restrictive. Cartesian philosophy excluded people who could not think rationally, as well as those who refused to limit themselves to living under rationality as a specific type of

reasoning. Differentiating between the two types of idiot Deleuze and Guattari (1996: 62-63) write:

> The old idiot wanted indubitable truths at which he could arrive by himself: in the meantime he would doubt everything, even that 3+2=5; he would doubt every truth of Nature. The new idiot has no wish for indubitable truths, he will never be 'resigned' to the fact that 3+2=5 and wills the absurd - this is not the same image of thought. The old idiot wanted truth, but the new idiot wants to turn the absurd into the highest power of thought - in other words, to create.

Chapter Four relates my experience as an 'old idiot' as I tried to find rationality within my experience of cerebral palsy. My experience of being an 'old idiot' is contextually grounded in my 'mainstreaming' in the provincial education system. Underscoring the mainstream education experience is a sensibility and embodiment of phenomenology. I critique policies in the education system that see accommodation as a means to alleviate the deficits that people experience because of their disabilities. This chapter recounts my experience as a student and how the embodiment and sensibility of phenomenology act as a normative shadow that dictates who, and what behaviours, are acceptable. Although I struggled against, and was ambivalent towards, this normative shadow I could not escape it.

In Chapter Five I move from the status of student to that of instructor which gives me, in a pragmatic way, an opportunity to implement a 'sociology of desire'. Rather than being restricted by the ability/disability dichotomy - derived from the normative shadows - I call for the validation of desire through exposure. The concept of exposure allows for a validity of a sensibility to be expressed that has been supplanted by a rational one which is buttressed by the normative shadows of humanistic essentialism, phenomenology, and personhood. To illustrate this validity I discuss sexuality and teaching as a matter of exposure. By exposing oneself (that is allowing dormant desires to come to fruition) one moves from the somewhat predictable position of prescriptive identity to subjectivity that is in flux. Beyond the classroom I call for the recognition of desire (or the exposure of desires that emanate from a disabled sensibility) within disability offices that would precipitate a shift from the deficit model (that has its basis in normative expectations which sees disability as a lack) to a machinic assemblage, with desires flowing from instructors, students, and technology creating new subjectivities and new ways of thinking.

One of the major beliefs of phenomenology is that through intersubjective communication, or through education, we will be able to understand one another. In this chapter I call into question this need to educate because of the inherent power relation that goes unnoticed - that is the right of the dominant group to demand that the exotic 'other' educate them about the effects of marginalisation. In addition, the 'other' is expected to conform to pedagogical discourse and discursive practices in order to 'legitimise' their critique of ableism, homophobia, sexism, or racism. In contrast, my teaching style is to encourage students to have a presence in the classroom that requires no explanation, no apologies, or even, dare I say, no mutual understanding - the 'common ground' that is a pillar of phenomenology. In Deleuzian terms, students are allowed to withdraw, which is a folding back of desire that causes turbulence. The

following discussions between individuals result from desires that flow from other people, machines, texts, etcetera which are caught up in this turbulence. The interplay between desire and turbulence with an unspecified intensity or duration creates a fluid subjectivity. Thus, a sociology of desire as an educational process has its roots in a non-prescriptive dynamic subjectivity rather than the essential self of identity politics (with its positionality) which underscores a sociology based upon humanistic phenomenology where personhood is central.

In the Conclusion I expand the notion of sociology of desire to examine the benefits for a non-disabled population. I briefly review my experience and then relate how the freeing of desire can create a different sociology. Similarly, I relate how the concept of exposure allows for my hyper-presence, and how the exposure of unrecognised desires can create 'new understandings' for non-disabled people too. An aspect of the sociology of desire is withdrawal and silence (not a silence that can be taken for tacit agreement). The turbulence caused by either withdrawal or silence can change the rules of engagement that we have become too comfortable with. I end the dissertation with an invitation: Generally, I ask everyone to risk losing the subjectivity of phenomenology and instead embrace the notion that desire creates subjectivity with its unpredictability and nonsensical flow. Specifically, I ask sociologists to embrace a sociology of desire that breaks free from the normative shadows of humanistic essentialism, phenomenology and personhood.

CHAPTER TWO

EXPERIENCING THE 'NORMATIVE SHADOW' OF HUMANISTIC ESSENTIALISM

As argued earlier, there is a restrictive normative shadow that casts a pall over humanistic essentialism. The following vignette illustrates my feelings about being trapped within humanistic essentialism. A few years ago, members of a project entitled, *An Intradisciplinary Inquiry into Narratives of Disease, Disability and Trauma,* of which I was a part, were asked what 'narratives of disease disability and trauma' meant for them. For me, diseased, disabled, and traumatised people are trapped in a glass prison. As we attempt to escape this prison we are recaptured by the disciplines of medicine, the social sciences, and literary theory that each functions as arbitrator, assessing our stories and our lives, deciding not only their validity but their underlying meaning; assessing whether they 'make sense' and are coherent, and ultimately finding a purpose not only for the story but for our lives.

Medical practitioners shoot us down as we try to go over the wall. After we fall to the floor, with the greatest of care they patch us up and give us a prescriptive prognosis that will be the benchmark for our recovery. Social scientists lasso us around the neck (effectively silencing us), and pull us down to the floor. Under the auspices of giving us 'voice', social scientists interpret our stories and consequently our lives. Literary theorists cage us turning our lives into tropes and metaphors of what may go wrong for a fragile humanity; we become spectacles for them to analyse.

The metaphors of the glass walls indicate two important elements of my criticism. First, the glass barrier points to the detached observation of other's narratives (the dissonance between the observed and the observer (Jenks, 1995a) and the power relations inherent in this 'seeing'. The glass wall also signifies the barrier between the healthy/sick, the able/disabled, the non-traumatised/ traumatised. The project on *Narratives of Disability, Disease, and Trauma* was supposed to be a medium to help individuals to connect with each other through sharing their stories and in doing so to see themselves in each other. But over the horizon lies the 'normative shadow of humanistic essentialism' that shapes narratives of lived experience. For the most part, the diseased, the disabled, or the traumatised are expected to undergo some form of rehabilitation in order to achieve normality. If normality cannot be achieved then they must 'make sense' of their lives, in order to find underlying 'meaning' for, or 'purpose' to, their tragic existence. One is expected to go on a journey, or a quest, depending upon the urgency you put on the endeavour. Personally, if I had to use a trajectory metaphor to explain my life, I would choose an endless lying down of the gauntlet, where ableist attitudes and ableist behaviours attempt to beat me into submission to this 'normative shadow'. Thankfully, I do not live my life in terms of a journey, a quest, or taking up the gauntlet.

Moreover, for many years I carried out a charade as I tried to be 'human'; to raise my status on the scale of bodies from the less-than-human to the human. Often I could mimic the embodiment and thinking of what is perceived to be human, but try as I might, I could not 'pass' (Goffman, 1963: 84). Throughout my life I have been perceived as being 'less than human', as a problem or an anomaly to be scrutinized, and managed, and often I have had to 'prove' to others that I am worthy of acceptance into the community of humanity. But my invitation to that community may

be revoked at any time if I regress to a state of being 'less than human'; in other words, it is provisional and conditional.

The Normalising Tyranny of Human Development

From the perspective of psychology, Kurt Danziger (1990: 186) explains, 'More than the contributions of other social scientists, the work of psychologists represented a kind of celebration of the myth of the independent individual in a pure form.' But sustaining the power of this myth of the independent individual requires discursive practices and a system of knowledge that impose this concept. Through institutions and legitimised by statistical knowledge, certain life practices have been 'naturalised' and 'normalised' as psychological standards. As Danziger (1990: 190) puts it,

> Eventually, the knowledge-generating potential of these kinds of practices became realized in an increasingly systematic way, and the knowledge so produced was fed back into the original disciplinary institutions to increase their efficiency. This kind of knowledge was essentially administratively useful knowledge required to rationalize techniques of social control in certain institutional contexts. Insofar as it had become devoted to the production of knowledge, mid-twentieth-century psychology had been transformed into an administrative science.

The shift to an administrative science means that each individual must adjust to the recognised states of human development. Concerning adolescence, Guattari (1996: 63) asserts,

> In my opinion it's something in adults' minds; something that exists for them on all sorts of levels, as a fantasy, as a segregative social practice, as a collective assemblage etc. But adolescence as a lived experience can't be defined in terms of age groups. I prefer looking at it as made up of different sorts of 'becomings': becoming-child, becoming-women, becoming-sexual .... These becomings can occur at any time; not necessarily at a fixed age. It is well known that one can become a child again at the age of seventy -five. One can also never become a child. A twelve year old can be an old dotard. One can become a woman, one can become a potted plant. One can become all kinds of things, but I don't think it depends on genetic programming.

From a feminist perspective, Jerilyn Fisher (1989) notes male bias in the concept of human development. She writes (1989: 136) 'Life cycle theorists commonly chart adult development by studying different, successive periods which follow an age-related sequence of tasks and expectations. Most of these studies reflect a male-bias, basing their frameworks and conclusions on the milestones men cite in their descriptions of the developmental journey from one stage to the next.' Feminist research and writing must question the masculine assumptions that underscore theories of human development, and promote revisions to such perspectives through the inclusion of women's life experiences. Fisher (1989) calls for a cyclical rather than linear

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understanding of human development. In contrast, neither cyclical nor linear notions of human development work for my sensibility of cerebral palsy, because each sensibility imposes a sense of continuity upon me. Earlier on in my life cerebral palsy was considered to be a degenerative disease. Later I was told that my cerebral palsy would not get better or worse, that it was a constant condition which needed to be controlled. Today, cerebral palsy has been reclassified as a head-injury. No matter how my cerebral palsy is defined or classified, it can never be considered stable. For me, my cerebral palsy consists of a continual play of connecting and splicing as a desiring sensibility.

As Bauman (1993), Cheal (1990) and Featherstone (1991) have argued, the promise of modernity was a linear progression of human development which would result in a utopian society. Both linear and cyclical belief systems adhere to a vision of the world that suggests that if we could achieve the highest possible self-actualisation, individually and collectively, then we will reach our utopia. Within modernity, this utopian vision could be achieved if we rigorously applied scientific knowledge. For believers in the cyclical view of human development, through balancing the body, mind, and spirit within ourselves and by balancing our collective societal responsibilities, we can be part of a utopian process. Often, appeals to a cycle - whether aboriginal or feminist - have been based on a cosmology that attempts to bring a sense of balance to the world. I believe that underlying these approaches there also lies an appeal universalism, based on notions of self and actualisation that restrict us to a very narrow template.

This narrow template is discussed by Deleuze and Guattari (1987: 379), who state:

> The classical image of thought, and the striating of mental space it affects, aspires to universality. It in effect operates with two 'universals', the Whole as the final ground of being or all-encompassing horizon, and the Subject as the principal that converts being into being-for-us. *Imperium* and republic. Between the two, all of the varieties of the real and of the true find a place in a striated mental space, from the double point of view of Being and the Subject, under the direction of a 'universal method'. It is now easy for us to characterize the nomad thought that rejects this image and does things differently. It does not ally itself with a universal thinking subject, but on the contrary, with a singular race; and does not ground itself in an all-encompassing totality but is on the contrary deployed in a horizonless milieu that is a smooth space, steppe, desert or sea. An entirely different type of adequation is established here, between the race defined as 'tribe' and smooth space defined as 'milieu.' A tribe in the desert instead of a universal subject within the horizon of all-encompassing Being.

From my perspective the all-encompassing horizon of humanity would allow for my inclusion only if I buried or hid aspects of my cerebral palsy that others consider inhuman (that perhaps would be associated with a tribe in the desert). The future spectre that lies over the horizon does not promise me a fulfilling life, but rather anxiety that I would not be able to keep up the charade of being human, and my spasms, my desires that flow from what has been labelled as cerebral palsy would burst from this imposed normality and expose aspects of my life that typically have

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been considered abject. Perhaps, I would be able to censor my 'crippledness' and thus 'pass' (Goffman, 1963) as an imperfect facsimile of what is meant to be human, to be forever presented as a role model of overcoming, an example of both the human spirit to overcome tragedy while at the same time epitomising the fragility of the human experience.

If I slipped and fell off this tightrope called humanity and became more crippled in the sense of returning to a state of inarticulation, which I experienced as a baby, then possibly my 'invitation' to this inclusive club called humanity may be revoked. As Bauman (1993: 179) writes, 'The others who enter the aesthetically spaced world must apply for admission displaying their fun-making value. Tickets, if issued, are for one entry only, and the length of stay is not determined in advance.' Disabled people, as the 'other', must continue to prove their value in order to remain members in a world which favours an able-bodied aesthetic. By their existence disabled people may have value as setting the parameters for inclusion in this humanistic world, but to move from the border of otherness disabled people must overcome their disability and to some extent disavow their previous (and ongoing) existence as cripples. To maintain inclusion in the club of humanity, disabled people must continually prove that they are human and therefore worthy of acceptance.

Perhaps, some might argue that I am being too harsh and that disabled people are considered human. But what does it mean to be human for disabled people? Many able-bodied people have expressed to me that they would rather be dead than 'suffer' from cerebral palsy. Ironically, at times this statement is meant as a compliment, acknowledging my courage in the face of adversity. Other times, it is expressed as a fear and loathing of disability. Other disabled people have had similar experiences. For example, Christine Malec (1993: 23) expresses, 'I am a human being, a woman, a student, a friend, a lover, a daughter. I know this in myself, but my self-perception cannot help but be injured by overhearing (as I have done) the emotion-laden voice of a passing stranger say, "I'd rather die than go blind".'

Such comments, blatantly claiming that to be disabled is a fate worse than death (Morris, 1991; Oliver, 1990) are uttered without regard for the feelings of either Christine or myself, as if they were statements of fact. For many people, whether disabled are not, their belief in a trajectory of human development means that at all costs they must adhere to this path: divergence is allowed only as long as you keep your goal, the utmost self-actualisation, in mind. Acquiring or having a disability will prohibit you from achieving the highest degree of self-actualisation, except in the cases of exceptional and heroic disabled people who overcome their disability.

The presence of disabled people is a constant reminder to non-disabled people of their precarious position upon this trajectory of human development. On a daily basis I encounter the 'normalising stare' (Thompson, 1997) from people who are repulsed and fascinated by my body. For many years their reaction bothered me, until I realized that more often than not the stare is based on their own fear about disability. My presence causes them to reflect on their deepest fears and ask themselves, 'What if "that"- namely my cerebral palsy- had happened to me? Or in the case of blindness, what if "that" happened to me: Would I cross the threshold of the human, to the "less than human"?' Encountering Malec (1993) or I brings the unspoken fear of what catastrophe might befall them when others (or themselves) perceive that they are less than

human, living a life 'not worth living'. But how can I be sure that people feel that way? After all it is only a passing moment and there is no verbal confirmation. I cannot be sure, and I believe we can never know definitively what people mean either verbally or non-verbally, but the facial expression of disgust, fear, and loathing does convey a message to me.

In my capacity as an instructor of courses dealing with social inequality, I have attempted to bring this fear of disability from the place of unspoken fear, fortified by the walls of common sense, to an engagement of 'that' disability, whatever disability 'that' conveys. When I ask most people if they would choose to be disabled, they respond with an incredulous look of disbelief that I would even ask such a question. When I admit to others that I would not want to be able-bodied, with few exceptions my pronouncement is met with shock or disbelief.

While teaching a class on disability I told the class that I would not want to be able-bodied. After class a student approached me and asked me 'Why?' I asked why would I want to be like her? Her face flushed with embarrassment, as she realised that she had subconsciously placed her own sensibility above mine. Moreover, she admitted that she was horrified that I would not want to be 'normal' like her. After some discussion she acknowledged that it was very frightening for her to realize that my way of being might be equal or even superior to her 'normality'.

Yet this inversion of the ability/disability dichotomy is a rarity. The commandment one must 'overcome' one's disability must be obeyed in the secular world, as well as in the non-secular world. Overwhelmingly, most people in our society feel that there is a universalism, whether that be a holistic view of the world epitomised by a balanced connection between an individual's mind, body, and spirit, or the universal faith in scientific reason with its projection of a progressive linearity. So pervasive is the holistic belief in a mind, body, and spirit balance that on various occasions my presence has caused consternation for other people's holistic sense of balance and their evaluation of their lives.

Silvers (1998a: 3) observes that,

> Classical liberal thought has not regarded serious corporeal or intellectual impairment as merely accidental to a person's moral status. Nor have individuals' disabilities been considered negligible in deciding whether they deserve a full array of opportunities for social participation. Furthermore, whatever their personal accomplishments, people who are impaired bear the burden of membership in what has traditionally been viewed as a 'weak' class, one defined as requiring heightened protection because its members are feeble and incompetent. Insofar as they are being defined as being helpless, they have been exempted from contributing to, but also pre-empted from profiting from, the collective good. That is, their being disabled has been taken to justify a drastic reduction in their opportunities and also their obligations.

To achieve the status of citizen with all its opportunities and the obligations, disabled people must prove their normality. Non-disabled people may have behaviours that pre-empt their access

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to both opportunities and obligations. But their embodiment and sensibility falls within the range of normality, allowing them full access to society until such behaviours are recognised. Disabled people must prove that they are worthy of admittance to society, whereas those individuals who can conform to the norms of phenomenology must prove through behaviours, such as criminal acts, that they are unworthy of access to society.

Thus there is an 'imagined' sense of what it means to full-fledged member of our society. Benedict Anderson (1993: 5-7) understands this notion of community as imagined because members of the community never know their fellow-members. Simply put, nationalism invents nation. The community is imagined as limited because there are finite boundaries. The nation-state founding imagination is itself limited. There are competing imaginations that territorialize other lands. The community is imagined because with the diminished power of church and Royalty the free individual was willing and able to take over power. As Foucault (1990) suggests, governmentality of free individuals displaced the power of Royal destiny, as well as that of the church. This sovereign state holds power because there is deep seated belief that, while all are not equal, members of the community hold a common vision. Our societal vision privileges the liberal individualist.

This imagined common vision of liberal individualism negates the disabled sensibility, and the lived experience of disabled people who are interdependent on others (Erevelles, 1996; Overboe, 1999). This exclusion of disabled people can be traced to the fact that dependency has been, and continues to be, devalued and attributed to persons perceived as inadequate and incapable of autonomy (Siegal, 1988: 113–114). De Felice (1986: 13) notes that 'the disabled movement has purchased political visibility at the price of physical invisibility. The cripple and the lame had bodies, but the handicapped, or so the social workers say, are just a little late at the starting gate. I don't like that; it's banal. When we speak in metaphorical terms we deny physical reality. The further we get from our bodies the further we get from the body politic.'

Certainly social workers, whose professional normative expectations fall in line with this liberal individualistic imagination, have difficulty with people who have no control over their bodily function, and are dependent upon others, because these characteristics do not conform to their vision. Sharon Gertz (*Beyond* Mar.18, 1994: 14) speaks of her reluctance to 'place' Arthur, who was born with cerebral palsy, in a position of officially greeting people at a bakery. Arthur spits, and stutters, which in Gertz's eyes made him inappropriate for the job. After being placed at the bakery, other staff realised Arthur lacked control over his bladder and he sometimes 'wet himself'. Upon hearing this, Gertz felt maybe Arthur did not belong there and was willing to remove him. When Gertz (*Beyond*, 1994: 15) proposed to Fran, a co-worker of Arthur, that he be removed from the bakery, Fran replied, 'I wasn't calling you to get rid of Arthur. What do you mean he doesn't belong here? He belongs here! I'm just calling to see if there's anything that we can do to help.'

Frequently, professionals do not give disabled people the 'right to fail'. But, it is only through reaching for their goals that they, like all humans, learn to test, to temper, or achieve their aspirations (Soyer, 1975). As a professional, Gertz would not allow Arthur 'the right to fail'. After talking with Fran, Gertz realised that the things she had seen as problems and labelled

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deficiencies were interpreted differently by the community. She had interpreted Arthur's bodily existence as negative, whereas his community saw it as an integral part of his social interaction with them. From a Deleuzian perspective, Gertz as a professional had continued to territorialize Arthur in the devalued position of a person who could not control his body. To paraphrase Bauman (1993) Arthur was for her, in effect, a tourist whose visa was acceptable only if he could control his body and his bodily functions. Gertz felt it was her professional obligation to revoke Arthur's pass into the community of the bakery.

Arthur's interaction with the community at the bakery illustrates Deleuze and Guattari's (1987) concept of reterritorialisation. Arthur was able to make an assemblage with other people at the bakery, including staff and customers, allowing him not to be seen as a charity case or damaged goods but as an integral member of the community. As Fran's telephone conversation with Sharon Gertz illustrates, the desire of Arthur's fellow employees allowed for a machinic assemblage to take place which was beyond the disabled/non-disabled dichotomy which restricted Arthur's desires. In Deleuzian terms the customers and employees at the bakery had been nomadic in their thinking and actions. Nomadic positioning allowed them to go beyond dichotomous thinking of disabled and non-disabled, and the point of abjection, to a place where they could accept Arthur without disembodying him by ignoring his sensibility of cerebral palsy.

Perhaps the staff had realised the harm in categorizing people and were willing to consider a 'new and greater health' through embracing machinic assemblages that value rather than devalue disabled sensibilities. The staff's acceptance of Arthur affirms his experience of cerebral palsy. The desires of the staff interacted with Arthur's desires, including those that emanated from his spasms, creating an assemblage that was 'a line of flight' from the 'imagined community' of liberal individualism. Perhaps this 'line of flight' will be the impetus for a different 'imagined community', even if it is on a small scale.

The New-Age Holistic Body as an 'Apparatus of Capture'

An imagined- holistic society has been envisioned in recent years. A few years ago I attended a conference on body-mind connections within the field of education. Many of the participants were bothered by my presence. Whenever I walked into a room some participants would purposely turn away from me. One woman confronted me, stating that my participation at the conference was not only an affront to the spirit of the conference - that is, the balance between the mind/body- but also my existence as an obviously damaged individual was an affront to her, an example of the perfect human specimen who treated her body like a temple.

Later, after giving my paper, a critique of holistic virtue, the father of a daughter who worked with disabled children spoke about his bright daughter wasting her talents on 'damaged' individuals. His utilitarian argument pivoted on the premise that his daughter could not reach the pinnacle of her self-actualisation by working with such unfortunate souls. He said my being disabled was an example of what could go wrong with a society that did not adhere to holistic practices or principles. Moreover, he argued that persons like me were a liability in other people's pursuit of their self-actualisation. In both instances I continued to articulate that this

holistic vision of the world, with its underlying values of balance and purity, not only devalued the existence and experiences of certain populations but put tremendous and unrealistic pressure on all people to achieve the ultimate level of self-actualisation.

From the perspective of Deleuze and Guattari there are desires coming into contact and interacting with each other. The majoritarian (Goodchild, 1996) or dominant desire of a holistic worldview demonstrated itself in the language, beliefs, and actions of many of the participants at the conference. The minoritarian position, based on my desire to expose the ableism inherent in this holistic cosmology, required a presence as well as an articulation. This presence - or perhaps more correctly, a hyper-presence - conveys a substantive and alternative becoming that eschews this rigid holistic way of being. To some extent, my hyper-presence was a virus whose presence created an imbalance in a holistic milieu. Yet, I could not escape the influence of this holistic world-view. Goodchild (1996: 54) asserts that once a majoritarian perspective is adopted, one's thoughts are not one's own but shaped by the dominant view. This cultural predicament is not ideological: one does not have to believe in this dominant perspective, but if one desires status one must conform. From the perspective of Deleuze and Guattari, this holistic view maintains power, not as much through force, but through frequency and the redundancy of repetition (Goodchild, 1996: 54).

Throughout the conference belief in both the benefits and infallibility of a holistic view was reiterated frequently. For the majority of the people attending the conference the main concern was how to nurture a holistic self-actualisation for each individual and society as a whole. From the perspective of Deleuze and Guattari (1987) there is a flow of desire which may shift because it meets another desire that either stops, redirects, or incorporates the desire into a new becoming (Olkowski, 1999: 103). My interaction with the woman who saw 'her body as a temple' or 'the father concerned about his daughter's self-actualisation' attempted to stop my desire to question the overbearing sentiment of holistic thinking. Yet desire cannot be contained or completely extinguished. Other bystanders who witnessed my interaction with these two people began to consider the unintended negative consequences of adhering to a holistic belief system. Many of them were willing to discuss the restrictive aspects of holistic thinking with its humanistic essentialist underpinnings that devalue a sensibility that others might perceive as chaotic, fragmented, and unfocused. Moreover, the benevolent aspects of their holistic vision were troubled by how 'quality of life' was invoked as a measurement to decide which individuals are worthy of inclusion.

For Deleuze and Guattari (1987) a territorialisation is taking place in that the holistic belief system creates an assemblage that is constituted of certain bodies (able-bodied) with the accompanying attitudes, practices, and behaviours associated with self actualisation. The greater one perceives that they are self-actualising, the greater the degree of legitimacy in this holistic milieu. My experience of cerebral palsy was unacceptable when we speak about the body, and about self-actualisation as it applies to a holistic belief system. For many participants I was expected to be the abject other situated on the edge of the conference. My presence (to be seen not heard) was a reminder of what could go 'wrong' with humanity if a holistic lifestyle is not adopted. This territorialisation of my disabled body is the desire to maintain the majoritarian assemblage that privileges an ableist perspective. However, my desires that emanated from my spasms could not be contained and flowed from my body, mind and spirit. They created 'a line

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of flight', or a de-territorialisation that resulted in assemblages with others. This assemblage resulted in an irruption caused by the criticism of the inherent ableism which was predominant at this conference on holistic education and human development.

Offering another critique of human development, Guattari (1996: 68) asserts, 'A widespread anxiety accompanies every incident in the development of the child. And it's getting out of hand. For the most part it results from psychoanalytical drivel concerning psychogenesis, all of these nameless stupidities that not only postulate intellectual stages of development, but also stages of behaviour, and emotional stages. Now isn't this too much already'.

For me, it was too much already; from my earliest recollection physicians were quick to point out that I was behind in my physical development. And although I was integrated into a school for non-disabled students the impression that I was incapable of fulfilling the tasks required for proper human development continued. For example, two of my elementary school teachers claimed that because of my physical disability I was incapable of completing one of the primary tasks of human development - that is, finding a job, with the possible exception of repairing shoes. The spectre of this restrictive notion of development (and subsequently what it meant to be human) hung over me like an albatross.

From an able-bodied perspective, the notion of human development has been naturalised. Everyone goes through the stages of childhood, adolescence, adulthood, and old age with recognised expectations for each stage. Certainly, the degree to which each person achieves these expectations varies according to their 'life chances' in a Weberian sense. Similarly, the process of how to fulfill certain expectations may vary among people. But the end-goal of achieving an appropriate level of human development remains the same for most members of our society. Simply put, there is an expectation that one moves through the stages of childhood, adolescence, adulthood and old age until death. The notion of a life with progressive stages has become naturalised and institutionalised. As Jan Walmsley (1993: 129) suggests the notion of human development that most people adhere to excludes disabled people whose trajectory does not conform to this pattern.

I am not surprised that these stages of development did not seem natural for me. In many ways, except for my family, others did not expect me to achieve these so-called levels of human development. Or if I were to achieve these levels, it would likely happen because of the charity of others. Throughout my life supposedly well-meaning acquaintances or strangers would suggest that I be satisfied with whatever I could get in my life. In other words, I should be thankful if I got any type of paid employment or had any semblance of relationships, platonic or otherwise. What was particularly exasperating for me was that others would frame any achievement of mine within the context of standard human development. Most prominently, any positive change in my body was measured against a normative template.

I was deemed as lacking, whether it meant lacking the capability for employment or lacking sexuality. Simply put, I was lacking what was needed to be considered a desiring and desirable human being. With benevolence people suggested I just get by. I was trapped in a box of striated

lines that labelled me as being less than human. At the time I believed that the only option left for me was to prove to others that I belonged in the human race, which meant my undergoing rehabilitation to become normal.

The Rehabilitation Model of Modernity

My experience with the rehabilitation process reflects beliefs central to modernity. Within the rehabilitation discourse of modernity 'my body' becomes *'the* body,' (Frank, 1991: 12), to be measured and thus objectified to eradicate or lessen my ongoing experience of cerebral palsy. If I were not concentrating on my therapy, my physiotherapist would scold me and ask me if I wanted to play, run and jump like other children. I would comply because I wanted to run, jump, and play like other children. I felt the coercive pressure that I must become normal for others to consider me worthwhile. As I furtively glanced at the other children with cerebral palsy who were exercising I noticed we were involved in a 'ballet to achieve normality' complete with uniform contortions orchestrated by physiotherapists (Overboe, 1994; Overboe, 1999).

This ballet that we disabled children participated in followed the tenet of modernity that the body became a tool to be deconstructed and reassembled for its maximum efficiency (Foucault, 1978, 137) in order for society to progress to its maximum potential (Bauman, 1987; Bauman, 1991; White, 1991; Featherstone, 1991; Lemert, 1991; Cheal, 1990). The body became demarcated according to its utility (Foucault, 1980: 172) which devalued disabled people (unless rehabilitated) because their bodies have been pre-determined to be of 'little worth' (Davis, 1997a; Barnes, 1990; Lonsdale, 1990).

This idea that, as a disabled person, I was of little worth was reinforced by the medical model that wanted to cure me. As a child my vulnerability was heightened by an unknown fear of my body that professional people spoke so negatively about. For a period of time, as a youngster, I had a fear of being close to anything hot, but kept quiet because it seemed like something I had to keep to myself. One day my mother asked me to get a pot from the top of the stove. I refused trembling with fear. My mother explained that the pot was empty and the elements on the top of the stove were turned off so there was no danger. I told her that the oven was on. She told me that the oven door was closed and I would be fine. I put my arms around my mother and cried, 'I do not want to melt'. I explained that I had to stay away from hot water radiators and the stove. She told me I would not melt and asked me where I had gotten such an idea.

As she held me and comforted me, I explained that on television I had heard that plastic would melt if it got too close to heat. Because I was plastic, I believed I would melt if I got too close to heat, too. She asked me why I thought I was plastic. I told her I had overheard the doctor say, I was plastic. Holding me closer she smiled and told me that the doctor said I was spastic and not plastic, and she assured me that I would not melt. Comforting me, my mother said, 'you poor thing, no wonder you have been staying away from the hot water radiators and the stove.'

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As a child, Rod Michalko (1998: 36), who experiences blindness, had a similar experience.

> I lay there on my bed crying a little, but only a little which surprised me
> because I was quite worried. I couldn't see the blackboard for the last couple of
> days now. But today, today was really tough. A line-drive was hit right to me
> and I saw it and then I didn't see it hit! It hit me right on the cheek. That had
> never happened before. I couldn't believe it - I saw it then I didn't see it.
> Leaving there I didn't know what was wrong. Remember, I was only nine-
> years old.

> I could hear my mother and my grandmother talking in the kitchen. They were
> speaking their first language, but I could understand. My grandmother said she
> was getting old and that she couldn't hear well any more nor could she see
> well. She said that soon she would die. My body froze in fright. I thought, I
> really thought, that I was dying. What else could it be? It seems silly now, but I
> spent the next few days testing my hearing making sure it was holding up.

For Michalko and I our fears extended beyond our immediate disabilities to our imagined
terrifying futures. I believe that each of us was afraid that we were to be abandoned, thrown off
the vehicle of human development and discarded on the slag heap where the 'dross of humanity'
(Nolan, 1987) is exiled. Or perhaps we were to die. Moreover, at least initially our fears were
unspoken and we tried to make sense of our circumstances and our projected fears. From my
perspective, on one hand I felt that if I spoke about my fears somehow they would come true. On
the other, I was concerned at being considered foolish. But perhaps more damaging was my fear
of facing the truth that I might find out nothing could be done and at any moment I could burst
into flames. After all, even at that early age, I had received the message from an able-bodied-
centred society that I was less than adequate because of my cerebral palsy. Perhaps people
(other than my family who, I knew, loved me) would see my death as a blessing, a somewhat
harsh one, but a blessing just the same.

The societal pressure for the achievement of the body beautiful (Synnott, 1993) or at least a
normative embodiment in the case of disabled people, often results in the self-imposition of
disciplinary techniques on their bodies (Wendell, 1996: 86-87; Paterson and Hughes, 1999: 607).
Nevertheless, this societal pressure that culminated in my desire 'to be like everyone else' was
tempered by a disquieting ambivalence about the rehabilitation system. Still, these were the rules
I must live under and obey (the commandment that thou shalt become as normal as possible).
After all, I had heard my parents (especially my mother) being chastised for allowing me to get
carried away with my desires and allowing me to crawl outside the safety of her protection.
What might happen to me if these people took me away from my family for my own good? After
all, I had heard that children who had spasms like me were placed in 'special homes' for their
own good. To preserve my life with my family and to have a chance to succeed in society I had
better be successful at rehabilitation.

My ambivalence about the rehabilitation process of modernity (as demonstrated by my 'desire' to be 'normal' like other children and my anxiety over its coercive nature and its negation of my cerebral palsy) places me squarely in the middle of the debate concerning 'Conductive Education'. I will begin by defining this debate. Originally developed in Hungary, Conductive Education - a system of habilitation, special education and rehabilitation for individuals with motor disorders - was developed to help disabled people with motor disorders 'to learn how to achieve a greater degree of bodily control and, through this, to acquire one means of managing significant features of everyday living successfully' (Read, 1998: 81). According to Janet Read, Conductive Education is not, as some critics' charge, prescriptive blueprints that demean disabled people.

Disagreeing with Read, Michael Oliver (1990, 1996) charges that Conductive Education continues the oppression of disabled people by maintaining its allegiance to the ideology of the able-bodied individual. The aim of Conductive Education is to teach children with cerebral palsy to walk, talk, and engage in all other activities as closely to normal as possible. No consideration is given to the issue of the ideology of 'normality' or to the view that the environment could be modified rather than the disabled person. A disabled woman comments on the inner/outer dilemma inherent within rehabilitation, 'In rehab, you're very positively programmed about your ability to be independent. But while someone was programming you, no one was programming society to accept you' (Matthews, 1983: 39). 'And scant regard is paid to the costs involved in terms of pain, coercion, loss of childhood, disruption of family life, acceptance of alternative ways of doing things and so on' (Oliver, 1990: 55-56).

Read remarks that although critics of Conductive Education often point to its harsh and coercive nature, her research indicates that adult service users and the parents of disabled children found the practice anything but harsh or coercive. However, I would argue that Read fails to consider that the coercion or harshness of therapy is not just physical but psychological, as it reiterates the constant belief that disabled people are 'damaged goods' (Bauman, 1988) in need of 'fixing' that is inherent in therapy.

Read (1998: 286-287) points out how often relatives are pleased by the improvement in the coordination of disabled clients. My family had a similar response to my progress in rehabilitation. I, too, felt a certain amount of pride in my progress that concealed my anxiety at being the centre of an abnormal routine removed from my experience as a sibling and a son. As Foucault (1984c: 191-193) suggests, all information about us patients, our behaviours, and our attitudes was considered only within the context of the rehabilitation model. Thus, my rehabilitation often disrupted my family life (Oliver, 1990). My rehabilitation team would send home a set of scheduled exercises with specific instructions. The disciplinary techniques that had permeated my body had now seeped into my home-life. My mother became my therapist, my father, my brother and my sisters had to adjust their schedules to allow time for my therapy. My family came under the scrutiny of the rehabilitation system because if I failed to progress they too were blamed by professionals.

The rehabilitation system encroached upon the family assemblage and formed a different type of assemblage machine. This territorializing action formed a nuclear family-medical treatment

assemblage with priority given to treatment. Thus aspects of my family life were transmuted to the extent that all other activities were supposed to orbit around my treatment sessions. Again, my rehabilitation with its normative expectations was undertaken to reinforce a majoritarian position which underscores social reality.

Read comments that Conductive Education has helped disabled people improve their interaction with able-bodied members of society. At times during rehabilitation I too had improved interaction with non-disabled people. However, usually this 'improved interaction' was associated with my being seen as achieving a greater degree of normality in their eyes. After such interactions I often asked myself why my prior embodiment or sensibility was unworthy of their interaction. Furthermore, I still often ask to what extent my present state as a person who experiences cerebral palsy and thus is considered 'damaged goods' (Bauman, 1988) precludes my interaction with others. Caught on the eternal treadmill, will I always have to continually improve in order to be considered normal and worthwhile in some people's eyes?

Many years later I came to the realisation that my lack of communication and interaction with others is often rooted in their negative assumptions about disabilities and their limited view of what it means to communicate adequately. For example, often people interpret my embodied spastic body as signifying that either I am unable to communicate or that any communication with me would be unproductive for them. Echoing Oliver (1990), I argue that in order to include those of us labelled as 'damaged goods' people should expand their notions of what constitutes 'worthwhile' human existence as well as adequate communication.

While undergoing therapy, I was in a constant state of anxiety because on one hand I feared I would not become able-bodied, but on the other I was unsure of whether I could (or wanted to) endure continued therapy that might (or might not) help me reach that goal. To adhere to the view of normality proposed by modernity meant that I would deny myself the ever-changing experience of cerebral palsy in favour of the elusive and perhaps unattainable 'brass ring' of normality. For example, I remember that when I crawled I had a freedom of movement that I have not experienced since I began to walk. Yet, I was forced to abandon the freedom of crawling in favour of an unbalanced, constricted gait in order to become a 'better' person who is respected and acknowledged as an upright member of society, both figuratively and literally. I had no choice, because crawling is seen as a prior or an inferior stage to walking on the scale of human development. For me, there was a sense of loss as I moved from the freeing movement of crawling to an unbalanced restricted gait when I walk (Overboe, 1994).

My experience supports the contention that the rehabilitation agenda uncritically accepts the concept of walking as one of its primary goals. Oliver (1996: 105) claims,

> Not-walking can be tolerated when individuals are prepared to undergo rehabilitation in order to nearly-walk or come to terms with their non-walking. Not-walking or rejecting nearly-walking as a personal choice is something different however; it threatens the power of professionals, it exposes the ideology of normality and it challenges the whole rehabilitation enterprise.

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As Oliver (1990), Morris (1993), Wendell (1989), and Turner (1984) argue, the onus remains on the disabled person to reach normative expectations. Rarely is it even postulated that the rehabilitation model's proven scientific routines could be suspect. The rationalist approach dealt with classes of diseases rather than individuals. For the rationalist physician his approach was validated by theory. If the cure failed it was because the patient failed to follow the medical instructions. 'The patient, not the theory, was responsible for lack of curative success' (Turner, 1984: 72). Following the ideology of the rational medical model, if a disabled person fails to become as 'normal as possible' in the eyes of the rehabilitation ideology they are deemed as lacking will power (Oliver, 1990: 57).

As a child Harilyn Rousso had a strong sense of the value of her cerebral palsy. When growing up she incorporated her cerebral palsy into her identity despite her mother's efforts to normalise her. Rousso (1988: 9) writes,

> She made numerous attempts over the years of my childhood to have me go for physical therapy and to practice walking more normally at home. I vehemently refused all her efforts. She could not understand why I would not walk straight ... My disability with my different walk and talk and my involuntary movements, having been with me all my life, were part of me, part of my identity. With these disability features, I felt complete and whole. My mother's attempt to change my walk, strange as it may seem, felt like an assault on myself, an incomplete acceptance of all of me, an attempt to make me over.

Game's (1991: 131) analysis of 'places in time' reflects bodily movement for disabled people. She points out that there has been a distinction made between purposive and wandering movements, with the former being productive and the latter considered a waste of time and energy. As Young (1990a, 1990b) points out, purposive behaviour is linear and goal-directed. It requires a certain body comportment that exudes authority, rationality and control over oneself and one's environment. Often persons who cannot attain this comportment are excluded from having purposive goals, so they deviate from a purposive path and are uninterested in reaching a goal (Game, 1991: 149). Game undertakes to mix purposive and wandering walking. Because of their bodily comportment disabled people mediate the experience of purposive and wandering motility. For example, Harilyn Rousso's position as an executive (which is defined as purposive) is juxtaposed with her bodily experience of cerebral palsy, which often seems to have 'a mind of its own'.

The rehabilitation system of modernity, armed with the goodness of charity, attempts to reforge the bodies of gimps[3] and cripples into respectable, productive, normal members of society (as

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[3] Many people may be offended by my use of the term 'Gimp'; however it conveys the 'proper' meaning for me. I especially enjoy the irony of the term Gimp. In the 1998 edition of the *Canadian Oxford Dictionary* (Barber, 1998), there are two definitions for the term Gimp. The first definition of Gimp applies to a pathological embodiment to the extent that (a) a persons leg is abnormal and (b) that the person with this lame leg is stupid and/ or is a contemptible person. My experience of cerebral palsy has resulted in me having what the dictionary defines as a 'lame leg'. Often

opposed to abnormal) who are to be grateful to this benevolent society. Yet such an endeavour was doomed to failure. There is an inherent contradiction within modernity. Bauman (1993: 5) describes, 'A society which is "modern" in as far as it constantly but vainly tries to "embrace the unembraceable", to replace diversity with uniformity and ambivalence with coherent and transparent order - and while trying to do this turns out unstoppably more divisions, diversity and ambivalence than it has managed to get rid of.'

Perhaps rehabilitation and the medical model can be salvaged if they refrain from continually seeing disabled people as damaged goods; if they quit trying to embrace the unembraceable and wanting to reforge us into normative bodies and minds. This transparent need for commonality is doomed to failure because diversity cannot be contained. In the same manner, in his critique of rehabilitation practices Oliver (1996) is trying to force the rehabilitation model to consider a central issue that it has not even been aware of - namely its ableism. Oliver (1996: 107) believes that appropriately addressing these issues will make rehabilitation a more relevant venture for all concerned. Without the tyranny of seeing ourselves as inferior and the pressure to reach the 'brass ring' of normality, disabled people may choose to employ the rehabilitation system and its techniques as a means to understand and enjoy our bodies. Unfortunately, the understanding or enjoyment of our bodies is secondary to the goal of developing our bodies, our minds, and our persons to a level that places us within the normative range of human development.

To critique a mechanism which is supposed to help disabled people be more productive members of society seems to border on being ungrateful. Often people have responded to my critique by remarking that if I were 'less fortunate' and 'confined' to a wheel chair then I might be more grateful. In many ways my body became disembodied, as people negated my lived experience and reduced my life to some sort of representation of disability.

This representation of disability serves a purpose by reinforcing the belief that the state should have control over our bodies. The state-sanctioned rehabilitation system acts as an 'apparatus of capture' (Patton, 2000:111). This 'apparatus of capture' involves the incorporation of other bodies, either through assimilation into society or because the specific characteristics of these bodies increases or enhances the power of the state. Thus, disabled bodies are incorporated into the social matrix of an able-bodied centred society in two ways. First, through rehabilitation disabled bodies may be able to reach normative expectations, therefore increasing society's

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other people have taken my experience of cerebral palsy as a justification for believing that I am stupid and/or worthy of contempt.

The second definition of Gimp applies to clothing and fabric as in (a) a twist of silk etcetera with cord or wire running through it especially as trimming of clothing and (b) a coarser thread outlining the design of lace [Dutch, origin unknown]. Metaphorically, the second definition of gimp resonates with my embodiment. My spasms that reverberate internally throughout my body are like the wire or the cord that runs throughout the silk. Just as the invisible wire running through the silk allows the trim to take shape, my internal and invisible spasms not only shape the aesthetics of my body but also inform my interaction with others. Externally a gimp contains the embroidered design of a piece of lace fabric. Externally, the gimpy aspects of my spasms both repel and attract other people. If, as Baudrillard suggests, that repulsion and attraction are differing sides of the coin of seduction, then my spasms embroider my sensibilities.

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productive and consumptive population. Second, and perhaps more insidious, is the use of disabled bodies as personifications of the fragility of humanity which act as constant reminders to 'able others' that it is their obligation to remain healthy (that is to remain non-disabled both physically and mentally) in order to be productive and consumptive.

An 'apparatus of capture' is not confined to a system of materiality that shapes bodies and minds, such as the rehabilitation system. As Deleuze and Guattari (1987) maintain, an apparatus of capture can also be abstract. Often my experience as a person who values his spasms has been negated by an abstract disembodied self (the idealised image of the human body); again normativity territorializes me into the abject other. Whether material or abstract both 'apparatuses of capture' are employed in the service of maintaining the majoritarian perspective which privileges an able- centred sensibility over a disabled sensibility.

The Documented Disembodied Self

Michel de Certeau (1987) has argued that society and its people over the past four centuries have been produced as a text. Thus, the bodies and minds of disabled people function as texts. In terms of the body, de Certeau (1987: 139) claims, 'What is at stake is the relation between the law and the body, a body is itself defined, delimited, and articulated by what writes it.' From birth to death the body becomes the body as we perceive and experience it through the written word. Through this process of written words norms are set that define the boundaries not only of the proper behaviour of the body but of the body itself.

Disabled people's bodies are textually read as a negation of what it is to be human. Thus, disabled people's judgement about their own bodies often is questioned, especially if it contradicts professional opinion (Oliver, 1990; Lonsdale, 1990; Davis, 1997b). The bodies of disabled people as a text are shaped and restricted by professional documentation, which is one of the information-gathering activities that help to monitor the behaviour of clients and develop routines that ensure their compliance (Dandeker, 1990; Rodwell, 1983; Hasenfeld, 1987). Therapists used the legitimacy of documentation to attempt to control both my behaviour (Dandeker, 1990; Rodwell, 1983; Hasenfeld, 1987) and my body (de Certeau, 1987). They told me I had better become more compliant, because case records proved that the more obedient children were doing better than me.

In her analysis of documentation and case studies, Dorothy Smith (1990: 171) writes, 'The ideological circle as a method of producing an account selects from the primary narrative an array of particulars intending the ideological schema.' She adds that this factual account may be entirely accurate, but its logic and grammatical form relate to an ideological discourse rather than the lived experience of the client or patient. Thus the narratives of individuals are transformed by the ideological method, resulting in the 'objectified account' displacing the subjectivity of the client or patient (Smith, 1990: 187).

In my case, documentation shaped by the schema of rehabilitation ideology subsumed my explanation of my embodiment. After I failed to meet my goals of rehabilitation these records

could be invoked as legitimate justifications to devalue my embodiment as well as my personhood. I was mortified that these disembodied texts could conceivably haunt me throughout my life. My self, my being, my bodily experience were pitted against the personified documented case study. As I see it, there is a major difference in perception between myself and the personified case study. The documented case study focus was on my failure to rehabilitate my (perceived) disabled body, whereas I concentrated on validating my experience of cerebral palsy as difference rather than disability.

Throughout my life officials within the medical field have created a disembodied identity for me, socially constructed through my case history. Whenever other physicians were consulted about my disability they were introduced, at least initially, through my case history to this disembodied identity. For their purposes, through this documentation I became transparent, visible and exposed, which allowed them access to all the information. For them these medical files were not representations of me but were me- they constituted my identity.

This bureaucratic documentation to some extent absolves or at least lessens human accountability. If there was incongruence between my body (as I presented it to the physician) and the personified documents, the latter account was perceived to be a more accurate assessment. Specialists I had seen earlier were never held accountable for any incongruence and in effect their signatures only signified the authorization of the personified documentation that had a life of its own.

The disembodied identity of the documented text was based on different doctors' differing interpretations of aspects of my 'objective' 'disabled' body that could be calibrated and measured. These specialists would have more difficulty in measuring my subjective lived body. Consequently, I believe incongruence between my lived experience and the categorised textualised body would be the rule and not the exception.

There is an immediacy that is missing when physicians rely upon my 'case history' as the primary means of diagnosis. The case history reconfigures the notions of time and space in the interaction between patient and physician. The documentation (the body of the text) was the medium used to broadcast the personified simulated body. Although dates were included, in order to fix time within the documentation, I was surprised how many doctors considered these details less significant. It seemed to me that for them time was reduced to the moment when they read the documentation.

The disembodied body of the text required the imagination of the doctor to match my embodied body to the written records. Other doctors who read my report often would accept the report as a verbatim account of my existence. Consequently, imagination was transgressed by a combination of disembodied documentation that was framed and contextualised within a 'proven' rehabilitation discourse which would not accept any deviation from the format. The formatted disembodied documentation meant instantaneous communication and information that makes a transparency of the patient's world.

The creation of this disembodied body negated, or at least lessened, the restrictions imposed by space because it could be reproduced for other doctors to scrutinise. It became possible for doctors with differing specialities and from various geographical sites to simultaneously examine my disembodied self. Distance between professionals becomes less of a problem if one has the technical expertise to produce and disseminate the disembodied self as portrayed in the documentation.

After leaving the rehabilitation system and exploring other ways of knowing and appreciating my body, the dissonance between the disembodied self of the medical field and my lived experience was even greater. For example, as I was being fitted for insoles the orthopaedic specialist noted that my left leg was longer than my right. Given that my left leg was more spastic than my right, 'logically' it should be shorter. I offered an explanation that she dismissed, instead bringing in other medical professionals to consult. They all reviewed my case history and 'the body' (Frank, 1991); the ideological circle (Smith, 1990) of the rehabilitation discourse closed ranks as the professionals agreed that there was no 'logical' explanation for my longer left leg and I was an anomaly to recognised rehabilitation or medical knowledge. I kept silent because any emotional outbursts, utterances, or acts of protest can be reconstructed as constituting pathologies (Smith, 1990: 195).

In reading my case history these various doctors deployed the rehabilitation discourse that is underscored by the principle of normality as the method of reading required to understand the text (Smith, 1990: 181). The past, present, and future experiences of my lived experience are seen through a lens consisting of the rehabilitation discourse (Smith, 1990: 180). My lived experience becomes a facile surface interpretation, with the 'real truth' represented by the rehabilitation discourse dwelling underneath the surface (Smith, 1990: 184-86). Castel (1991: 281- 282) notes a shift in medicine, making the formal interview between patient and practitioner now almost dispensable: 'The examination of the patient tends to become the examination of the patient's records as compiled in varying situations by diverse professionals and specialists interconnected solely through the circulation of individual dossiers.'

Castel (1991: 282) identifies a shift 'from presence to memory, from the gaze to the objective accumulation of facts.' The accumulated memory in my medical records supplanted the body work I was doing at the time. There was no signature from an 'authorised knower' (a medical specialist) that could 'authenticate' my claim. The accumulated facts of the medical records not only took precedence over but distorted the normalizing gaze which inspected my body. The 'accumulated facts' of this disembodied self were 'rational scientific truths' resulting in my opinions being considered falsehood. But the fact remained that my left leg is longer - an observable fact which could not be explained by rational medical expertise. Nevertheless, the ideological discourse of rational medicine maintained its hegemonic position by labelling my leg a medical 'anomaly'.

Along with the 'normalising gaze' of medical expertise the validation of the 'disembodied documentation' made me feel I was absent from the rehabilitation process. The subjugation of my lived experience of cerebral palsy to this disembodied documentation manifested itself in a

numbing of my body. Ironically, documentation that was supposed to help my body resulted in its negation.

The Illusion of 'Timmy' and the Performative Aspect of Charities

I have given a speech which begins with the following introduction: 'I had won the contest. I was elated but confused. You see, I had not entered any contest. I discovered this contest was a preliminary round and I had a chance to be the big winner. Alas I lost for I was not crippled enough. I lost because I was too crippled.' The speech is about my career as a 'Timmy for the Easter Seals'. This introduction had the desired effect on my audience. They were elated when I won, and despondent and confused when I told them I was 'not crippled enough' and yet 'too crippled'. As my speech continued, their certainty in the belief that telethons and charities are altruistic was shaken. It also illustrated how the notion of charity works in our society.

I had been chosen as the Timmy for the borough of St. James in Winnipeg, Manitoba, Canada. One of us Timmys from the various boroughs of Winnipeg was to be selected to take part in the national Easter Seals Telethon in Toronto. We 'Timmys' were part of a publicity photograph with the Mayor of Winnipeg. As a child I sat in the backseat of a car as the organizers of the photography session discussed which child should represent Winnipeg at the national Easter Seals Telethon in Toronto. They felt that although I had the right visual attributes (with my cherubic face, platinum blond hair, and dimples) required for a photo-op, I lacked the maturity to convey the right mix of a pathos and courage at the appropriate time. In order to be a 'deserving' recipient of charity a person must exhibit the right amount of hardship while paradoxically presenting the potential ability to overcome the hardship. In a telethon setting such as the Easter Seals, one must be able to project this paradoxical image in order to elicit contributions from the audience members. At the beginning of my involvement with the 'contest' I believed charity was about me and other deserving crippled children.

I had to contain my excitement as I sat on the lap of the Mayor of St. James (a borough of Winnipeg) for the photographic opportunity to publicise the Easter Seals Campaign. I was proud because I believed the rhetoric that I was helping other disabled children. Later, when I watched a ventriloquist act on television, I felt troubled and uneasy but I did not know why. Upon reflection I realised the professional photographer who had positioned my body in relation to the mayor had mimicked the way the ventriloquist held his dummy. At that age, I could not articulate my ambivalence about this event in my life. On one hand, I socially and intellectually felt a certain amount of pride as my schoolmates, family, and friends congratulated me on this honour. On the other, I felt a sense of shame in my body, as my identity of 'Jim' with its vivacity had been displaced by this disabled poster child. With this identity of 'Timmy' I had been placed squarely within a position - that is, a disabled context with its inherent devalued position in society - which I continually tried to escape from. Yet I could not escape because the newspaper photograph froze this poster-child identity in time. Or perhaps more correctly I could not escape the framing of the photograph as an advertisement for a charitable event.

According to Barthes (1981: 4) 'What the photograph reproduces to infinity has occurred only once: the photograph mechanically repeats what could never be repeated existentially'. The photograph always carries its referent within itself. It only refers back to itself. Barthes (1981: 6) argues:

> Photography is unclassifiable because there is no reason to *mark* this or that of its occurrences; it aspires, perhaps, to become as crude, as certain, as noble as a sign, which would afford it the dignity of language: but for there to be a sign there must be mark; deprived of the principle of marking, photographs are signs which don't *take*, which *turn*, as milk does. Whatever it grants to vision and whatever its manner, a photograph is always invisible: it is not what we see.

As Barthes (1981) points out, what the photograph reproduces occurs only once. The signification of my being a Timmy is dependent upon not only the caption but the accompanying written text which signifies a figure of pathos. Without the captioning and written text the photograph is a moment in time when the mayor was joking with a nervous little boy. The overlaying of the photograph with this charitable pathos allows for its ableist souring. Consequently, the signification of me and the mayor making an advertisement requires the classifying or overt coding of the title which signifies that the child on the older gentleman's lap is an advertisement for the Easter Seal campaign.

While the role of Timmy as a disabled icon is central to the telethon, disabled people do not produce or reap the benefits of the endeavour. Morris (1991: 109) writes, 'Other than providing the image which the charity and the advertising agency decide on (and very often even the actor is a non-disabled person), disabled people are not the clients (the charity is), they are not the audience (non-disabled people are - the givers of the funds), and they are not the product (the charity is).' The act of 'Timmy' is an illusion which is required for the Telethon to be productive. Morris (1991) and Baird (1992) argue that telethons require a pitiful victim, a victim to evoke a sense of guilt which is soothed by a donation of money. Furthermore, people who privilege an able-bodied sensibility consider donations to telethons as safeguards to prevent them, or their loved ones, from acquiring any similar tragic disability.

In effect, the position of 'Timmy' required a performative act that these fund-raisers felt I could not accomplish. As Butler (1997: 159-160) writes,

> The 'constructive' power of the tacit performative is precisely its ability to establish a practical sense of for the body, not only a sense of what the body is, but how it can or cannot negotiate space, its 'location' in terms of prevailing cultural coordinates. The performative is not a singular act used by an already established subject, but one of the powerful and insidious ways in which subjects are called into social being from diffuse social quarters, inaugurated into sociality by a variety of diffuse and powerful interpellations. In this sense

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the social performative is a crucial part not only of subject *formation*, but of the ongoing political contestation and reformation of the subject as well.

Applying Butler's (1997) insights to my experience, both the organizers and the audience of the telethon, with their bias against a disabled sensibility restricted our space to a devalued position in relation to them. The rhetoric of overcoming and the theory of the personal tragedy of disability, coupled with the certainty of normality, provided the coordinates, by which the 'social being' of Timmy and other similar pitiful and abject characters are brought into being. Former 'Timmys', such as myself, are contesting the political authority of telethons, and in doing so reformulating our subjectivity, and refusing to be considered as pitiful and abject characters. Today many of us are 'proud' 'gimps' who value our disabled sensibilities.

The premise of the telethon was that I needed help. I found it (and still do) demeaning to plead and beg for help. The process of proving whether I am a 'deserving' gimp or cripple presupposes that the 'problem' resides in my body or my sensibility. Most people involved in telethons, whether they are the organizers, volunteers or donors, are not willing to entertain the thought that the problem may reside in the physical environment or the social world. Nor did they have any idea how ableist their remarks and attitude are. Being superior beings on the continuum of humanity, it was their birthright as 'normal' people (or at least that was the impression they gave me) to pass judgement on whether I was a deserving or undeserving gimp. Their behaviour is not an isolated incident. Davis (1997a: 2) observes,

> When it comes to disability, 'normal' people are quite willing to volunteer solutions, present anecdotes, recall from a vast array of film instances they take for fact. No one would dare make such a leap into Heideggerian philosophy for example or the Art of the Renaissance. But disability seems so obvious - a missing limb, blindness, deafness. What could be simpler to understand? One simply has to imagine the loss of the limb, the absent sense, and one is halfway there. Just the addition of a liberal dose of sympathy and pity along with a generous acceptance of ramps and voice-synthesized computers allows for the average person to speak with knowledge on the subject.

Whether we speak of Davis' (1997a) observations or my experience, because of their superior position on the scale of humanity most non-disabled people would see these actions as not only appropriate, but beneficial for such poor unfortunate souls. Yet I and other crippled individuals serve a purpose for non-disabled people. This society which privileges an able-bodied, liberal-individualist persona requires an abject other to devalue. In effect, many able-bodied people's positive sense of self is heightened when they compare themselves to disabled people. The success of charities, with their emphasis on raising funds in order to help 'fix' disabled people, reaffirms the embodiment and sensibility of the 'grotesque normal' (Davis, 1997b: 11).

In his analysis of the relationship between the master and bondsman, Hegel (1967: 234) argues that the consciousness of the Master is mediated and affirmed by the inferior position of the bondsman. This relationship is self-evident because the bondsman is dependent upon the master

for his life. Yet the bondsman realises his own consciousness through his own work and toil (Hegel, 1967). Hegel (1967: 238) explains how the bondsman has a mind of his own.

> In the master, the bondsman feels self-existence to be something external, an objective fact; in fear self-existence is present within himself; in fashioning the thing, self-existence comes to be felt explicitly as his own proper being, and he attains the consciousness that he himself exists in its own right and on its own account... By the fact that the form is objectified, it does not become something other than the consciousness moulding the thing through the work; for just that form is his pure self-existence, which therein becomes truly realized. Thus precisely in labour where there seemed to be merely some outsider's mind and ideas involved, the bondsman becomes aware, through this re-discovery of himself by himself, of having and being a mind of his own.

In the same manner, the consciousness of able-bodied people is mediated and affirmed by the inferior position of disabled people. The relationship between non-disabled and disabled people is also self-evident as disabled people's chance of an 'improved quality of life' is dependent on non-disabled people with their charities or service clubs. Often disabled people, including myself, have felt an obligation to accept the abject position in relation to non-disabled people. Moreover, disabled people feel tremendous pressure to 'prove' that they are worthy of charitable donations or assistance from service clubs. The success of the recipients reflects upon the charitable organisations, just as the bondsman's labour reflects the wishes of the Master. As Hahn (1997) asserts, the image of a successful recipient sends the message to potential donors that this organization is worthy of support. Thus, the 'common sense' belief that disabled people are inferior pervades how we see ourselves and each other. Yet, like the bondsman, as Hegel asserts, the re-discovery of myself by myself, of having a 'mind of my own' was planted in my attempt to 'overcome' my tragic circumstances. Today I would reject the subjectivity and the notion of self-actualisation with its linearity that underlies Hegel's analysis. Nevertheless, his position that a supposed superior being in part forges his identity in his relationship with a supposed inferior being still has resonance for me.

I came to realise that my body, as well as my sense of self and worth, are positive. As I was publicly congratulated for overcoming my tragic circumstances, privately I questioned why my cerebral palsy was considered abhorrent, and if possible, to be eradicated from my existence. Initially, the rhetoric of overcoming allowed others to respect me and, paradoxically, allowed me the space to begin to find a sense of self while giving some able-bodied others an assurance that I was a 'normal' individual who suffered from a disability. Yet my place in this space was dependent upon me disavowing my 'lived experience' of disability. Kitchin (1998: 347) argues that with some exceptions disabled people have been encouraged and forced to live in different spatial spheres. Even within public spaces they are separated and marginalised. Kitchin (1998: 351) observes 'the social order is thus legitimised through a "natural" or a "common sense" classification where exclusionary practices are understood as acceptable.'

Similarly, Rod Michalko (1998) asserts that because of his blindness he is extraordinary in ordinary places. If I understand Michalko correctly, what it means to be blind is not simply an

absence of sight but a different orientation, and understanding, a sensibility to the world that does not require 'fixing' in order for a blind person to live as a facsimile of a sighted person. Rather, sighted people could learn from blind people a different orientation to the social world. Some might argue that, similarly, blind people must learn about the sighted world. But I would argue that the subordinate position of blind people (as well as other disabled people) in relation to sighted (or non-disabled) people gives them a knowledge of the sighted (non-disabled) world.

Feminists such as Nielson (1990: 10 - 11), Harding (1991: 124), and Smith, (1990, 1987: 106), believe that a subordinate position is potentially more complete, because the awareness of subordination gives the potential for a double consciousness - a knowledge, awareness of, and sensitivity to, both the dominant world view and a minority perspective. The dominant group's view remains partial and perverse, because so long as the group is dominant, it is in the members' interest to maintain, reinforce, and legitimate their own dominance and particular understanding of the world, regardless of how incomplete it might be.

As Davis (1997a: 2) asserts, above all it is not a matter of simply providing accessible accommodations, but a paradigm shift in thinking is required. Yet among most sighted people the pervasive notion that the world of the blind is a cruel, depressing and unjust place remains a foregone conclusion. Previously, I quoted Malec (1993) whose pain derived from the discrimination she experienced, not her blindness. Even when sighted people imagine themselves in the land of the blind they cannot shake their ableist belief in the naturalness of the sighted world and the burden of being blind until confronted with a different reality. For example, Oliver Sacks documents how Virgil - a newly-sighted blind person - is unable to distinguish figures without feeling them. After watching Virgil examine objects in order to understand them, Sacks (1996: 133) declares,

> It came to me...how skillful and self-sufficient he had been as a blind man, how
> naturally and easily he had experienced the world with his hands, and how
> much we were now, so to speak, pushing him against the grain: demanding that
> he renounce all that came easily to him, that he sense the world in a way
> incredibly difficult for him, and alien.

Yet media reports that affirm a disabled sensibility and devalue a non-disabled sensibility are rare. Our lived experience is more often subsumed by iconic images of disability.

How an Iconic Image can Supplant the 'Lived Experience of Disabled People'

Morris (1991: 101) writes,

> The non-disabled world finds disability, or injury difficult to confront or to understand. Other people's pain is always frightening, primarily because people want to deny that it could happen to them. Lack of control over one's body is also very frightening, particularly as it can mean dependence on others. 'Overcoming' stories have the important role of lessening the fear that disability holds for non-disabled people. They also have the role of assuring the non-disabled world that normal is right, to be desired and aspired to.

Wendell (1987) and Morris (1990) assert that there are some disabled people whose images support the assurances of the non-disabled population. Wendell (1987: 16) observes that some people have transformed their disability from a perceived detriment to a positive iconic leader by becoming 'disabled heroes'. With a few exceptions like Helen Keller and Stephen Hawking these 'disabled heroes' are wheelchair or amputee athletes who perform feats of endurance and strength. This transformation from regular 'gimps' to 'disabled heroes' is beneficial for them as it usually results in greater access to social, economic, and physical resources. For example, Rick Hansen who travelled around the world using a wheelchair parlayed his 'overcoming' narrative into a business which includes public speaking, publishing and the creation of his own charitable foundation. The narrative of 'doing' the Man in Motion Tour, and the related image of him sweating with determination while wheeling around the world resulted in Rick Hansen being named the newsmaker of the world for both 1986 and 1987 in Canada (Ehlers, 1994). By placing Rick Hansen on a pedestal, the media and most of the public are complicit in lessening a deep-seated fear and guilt that are part of the mind-set of most able-bodied people. Because he is a heroic individual with a disability the signs 'disabled' and 'paraplegic' defer to the signs 'heroic', 'inspirational', and 'athletic'.

In addition, Rick Hansen has many of the attributes which are valued in personal appearance. When he is sitting in his wheelchair, people see a controlled individual who has 'normal' speech, projects a presence that is both athletic and attractive, and does not markedly deviate from 'normal' appearance. Moreover, Rick Hanson is also heterosexually attractive and heterosexually successful (married) which enhances his 'normality'. One could easily forget Rick Hansen's disability and imagine he is a 'normal' individual sitting down. In contrast, disabled persons who appear to have no control over their body or its functions are deemed to be 'lesser human beings' (Kitchin, 1994; Wendell, 1996).

Many non-disabled people who fear a life with a disability for themselves or loved ones are heartened by the ability of Rick Hansen ability to overcome his disability. The narrative of the disabled hero is plausible because it relieves much of the public's angst. Discussion about disability among most able-bodied and some disabled people centres on the heroics of Hansen. Baird (1992) and Hahn (1986) argue that such representations often help alleviate both the fear

and guilt felt by non-disabled people in regard to disabilities. As Hahn (1986: 125) points out, the widespread aversion toward disabled people may result from an aesthetic anxiety which narcissistically rejects marked deviations from normal physical appearance, and an existential anxiety, which may find the implicit or projected danger of an unnerving disability even more horrific than the inevitability of death itself.

In order to sell their communications, the media presents or represents truths and facts in a way that makes them more receivable to their audience. According to Woolgar (1988), adjectives can enhance or diminish the signification of a fact or a portrayal. Woolgar (1988: 71) writes, 'The main focus for our observations about the operation of modalizers is the way they draw attention to the existence and role of an agent in the constitution of a fact or factual statement.' Woolgar (1988) contends that the veracity of a statement can be enhanced (or lowered) by the deletion (or inclusion) of modalizers. At the beginning of the Rick Hansen tour many individuals used modalizers to exclaim their disbelief that he would complete this monumental task. By its conclusion, however, modalizers were not required to enhance the feat. Nor could modalizers be used to criticize the venture or the persona of Rick Hansen, because his accomplishment reached mythical and epic proportions.

Hartley (1993: 153) suggests that journalism fictionalises news events to the extent that its representations can never reflect 'the truth in its entirety'. Hartley (1993: 153) believes that '[The function of news reports] is precisely representative, and any truth-impression results not from their existential status but from the plausibility of the anecdote in relation to the reader's experience.' In our able-bodied-centred society, most readers' experience of disability is a projected fear. Therefore the image of Hansen overcoming his disability has a receptive audience because this 'truth' alleviates the fears of most people. Wendell (1987: 116-117) believes that, 'While disabled heroes can be inspiring and heartening to the disabled, they may give the able-bodied the false impression that anyone can "overcome" a disability.' Paradoxically, the image of the disabled hero affirms the lived experience of a few disabled people and invalidates the lived experience of the majority of disabled people because they cannot meet such expectations (Wendell, 1987; Doe, 1997).

At times, the image of the disabled hero displaces the lived experience of the disabled person who is the basis for this iconic reflection. Moreover, this disabled hero image can deflect criticism of ableist behaviour and practices. In the summer of 1995 the *Vancouver Sun* ran an article about the opening of the new Student Recreational Centre at the University of British Columbia. Accompanying the article was a picture of Rick Hansen cutting the ribbon. In the text of the article Mr. Hansen proclaimed that this centre would be accessible to all disabled people.

At differing times, to our mutual dismay, Mr. Hansen and I discovered that any accessibility features of the building and equipment dealt with the concerns of only wheelchair athletes. Whenever I protested the exclusion of other accessibility features that would take into consideration the concerns of disabled people with other or multiple disabilities, the picture of Rick Hansen opening the centre was invoked as 'proof' of its accessibility. Accompanying this explanation was the rebuff, 'if it's good enough for Rick Hansen, its good enough for the management of the facility.'

From the perspective of Hartley because the article showed a picture of Rick Hansen opening the facility, the individual reader and the general public felt it plausible that it was a state-of-the-art accessible centre when in 'truth' it is only partially accessible. Ironically, the icon of Rick Hansen was invoked to silence any criticism put forth by Mr. Hansen himself. The imagined public image cultivated by both Rick Hansen and the media in a symbiotic relationship displaced the human Rick Hansen who began the endeavour.

From the perspective of race, Patricia Williams' (1991) 'lived experience' was supplanted by a media representation. Her opinion about affirmative action was misconstrued in a newspaper article. Williams clipped the article for fodder for another law review article. The problem for Williams is that the article would be considered a 'primary source' and its citation within academia would be given more legitimacy than Williams own current opinion. Williams (1991: 50) writes, 'it will take precedence over my own citation of the universifiable testimony of my speech'. Effectively, both the testimony of Williams and me can be displaced by the 'truth' of a newspaper article.

Williams' (1991: 11) experience echoes mine, as she places the device of rhetorical objectivity within a racial context. For example statements like 'Our maid is black and *she* says that blacks want ...' both universalize the lone black voice and disguise, enhance, and 'objectify' the authority of individual white speakers. Similarly, the device of rhetorical objectivity legitimises and universalises the icon of Rick Hansen as the sole voice for disabled people. This icon was invoked to legitimise the perspective of the manager of the Student Recreational Centre while silencing any criticism from other disabled people including myself. The conflation of the image with identity can have profound effects on disabled people's ability to negotiate a presence.

Conclusion

The act of abjecting allows one to make sense of something or someone that is paradoxically meaningless yet disturbing (Kristeva, 1982). Kristeva (1982: 4) argues that abjection is not the lack of either health or cleanliness but the disruption of identity, system, and order. Butler (1993: 190) asserts that the strategy of social abjection produces the *un*symbolizable, the unspeakable, the illegible. The construction of the human through regulatory and normative practices produces the less than human, the human, and the humanly unthinkable (Butler, 1993: 8).

The regulatory and normative aspects of humanistic essentialism are evident in both the scientific realm of psychology and the holistic milieu of mind and body connections. Both forms of humanistic essentialism encourage self-actualisation, although the means to reach the goal differs in each ideology. Drawing on my own experience, I illustrate how a restrictive holistic humanistic essentialism categorises disabled people as illegible, by abjectifying them.

With faith in scientific reason, believers in modernity felt that 'rehabilitation' practices could transform disabled people (with their 'less than human' potential) into 'reasonable facsimiles' of

able-bodied people, and increase their potential to be productive members of society. In order for rehabilitation to maximize my potential (which meant my becoming as normal as possible) my docile body was manipulated in hopes of improving it. Foucault (1984c) delineates three interrelated areas that are a necessity for the 'docile' body (in this case the disabled body) to be reformed as productive (a resemblance of the able-bodied human): normalizing judgement, hierarchical observation, and examination. Through normalising judgement medical physicians calibrated to what extent I deviated from the standardized 'human being'. In accessing my capabilities they were able to conclude, in a utilitarian sense, my capacity for rehabilitation. Consequently, from the time of my birth my 'lived experience' was measured against this 'normative shadow' of humanistic essentialism.

Both Harilyn Rousso and I were subjected to examinations and hierarchical observations which enlisted our families to 'track' our progress in our transformation from 'less than human' to human 'facsimiles'. Our spasmodic desires had to be quelled and supplanted by disciplinary practices that adhered to an able-bodied hegemonic normative. Certainly I consented to these disciplinary measures because the 'normative shadow' of humanistic essentialism, that seemed to be 'everywhere' and 'nowhere', provided a template for 'being' that was 'naturalised' and unquestioned. However, my spastic desires could not be contained and their irruption led to my initial ambivalence and later rejection of the rehabilitation model, with its privileging of a restrictive humanistic essentialism, and its abjective categories of the 'less than human' and the 'humanly unthinkable' (the dross of humanity who are judged incapable of benefiting from either medical or rehabilitation intervention).

Telethons and other charitable events provide funds for both rehabilitation and medical research. My image as a Timmy was to elicit an emotional response from the donors that has exchange-value which can be converted into financial donations. This image portrayed the potential to move from a position of 'less than human' to acceptance as a human facsimile, in the realm of humanity.

The 'normative shadow' of humanistic essentialism took the form of the 'disembodied' image that was portrayed in my medical records. Against a backdrop of 'standardized' or 'normal' characteristics of human beings, my cerebral palsy was measured. It was not my lived experience that was measured, but only the accumulative affects of my cerebral palsy that could be calibrated as 'pathological'. In effect, 'less than human' aspects of my body and mind were compared to a model that reflected what a 'normal' human body could achieve. The abstract disembodied 'pathologised' body was compared to the abstract body of the prototypical human. The vivacity of my spasms, as well as other aspects of my 'lived experience,' was a moot point during medical examinations.

CHAPTER THREE

THE EFFECTS OF THE NORMATIVE SHADOW PERSONHOOD: A DISCUSSION CONCERNING THE CONCEPTS OF POST-PERSONHOOD, PRE-PERSONHOOD AND NON-PERSONHOOD

As mentioned earlier, John Paul Eakin (2001: 19) asserts that people 'have an obligation to display a normative model of personhood.' He believes that people who lose the ability to conduct the tasks associated with personhood move into the realm of post-personhood. In this chapter, I extend the discussion beyond post-personhood to include the concepts of pre-personhood and non-personhood. For the purposes of this dissertation, there is a continuum of personhood. The normative centre consists of a range of personhood whereby an individual demonstrates the ability to negotiate their lives as a person. If an individual loses the ability to negotiate her or his life appropriately, she or he is said to be experiencing post-personhood. Prior to birth, the detection of genetic defects means the interpellation of person will not be inferred upon prospective 'pre-persons' unless a genetic intervention eradicates the defective gene. Unfortunately, the eradication of the defective gene can entail the eradication of its biological host. Non-personhood reflects the state of those disabled people who are unable to fulfill the tasks associated with personhood.

The Compassionate Killing of Post-persons

This section is informed by a particular incident in my life. In the sixth grade we were discussing the possibility of shrinking resources for our society. A classmate, named Burt, stood up and said 'Jim, might have to be killed if there was a shortage in food and water. Nothing personal, Jim, but you are a burden on society.' With great difficulty I rose to my feet, telling him that I wanted an opportunity to fight for my share of food and water, and for my life. And if he agreed, could we fight barehanded. Burt stated, 'I am healthier and I would win!' With contempt I replied, 'Maybe not, and even so at least I would get the satisfaction of you having to see the disgust and contempt I felt for you as my last breath was strangled out of me.'

Even at that young age, I wanted to communicate to people that it is easy to speak of someone's death if you are placing their life's worth on some abstract ledger of credits and debits. Over the years many other people have remarked that for the good of society I should have never been allowed to live, or that I should be killed. Constantly disabled people must either explicitly or implicitly prove to others (and in some cases to themselves) that they have lives that are worth living.

During the past two years I have attended two academic conferences on narrative where the subject of post-personhood has been discussed. Within the context of narrative, the state of post-personhood comes about when circumstances of disease, disability, or trauma are perceived to rob an individual of his or her personhood. If individuals are perceived as lacking personhood, then the ethical debate about their 'quality of life' begins. The notion of post-personhood frames

the debate in a way that presupposes that those people labelled post-persons may merely exist and are not persons.

Bogdan and Taylor (1988: 146) conclude that whether severely disabled people (people with severe and profound developmental handicaps or multiple disabilities who sometimes soil themselves, drool and cannot walk or talk) are to be considered human is dependent upon their interaction with the other. If the other accepts the severely disabled person as human, communication is achieved. If the other assumes that the severely disabled are less than human then communication is impossible. In either situation one cannot definitively prove that one's perception is flawed because of a faulty belief system.

As an inarticulate baby I heard people mention their belief that it might have been better had I not been born. My anxiety over what might happen to me if people failed to see that I had a life worth living was intensified by their inability to communicate or understand me. At that time I swore to myself that if I were ever in the position of interacting with an individual who has been labelled as never achieving personhood, or someone experiencing post-personhood, I would broaden my communication skills to include the meta-communication of inarticulation. Drawing on my experience as an 'inarticulate' baby who was communicating but was not understood; I argue that people who are comatose are attempting to communicate with us. In order for their communication to be received by us we must move to a different level or way of communicating - the meta-communication of inarticulation. My belief in the concept of the 'meta - communication of articulation' is premised on the opinion that desire emanates from us whether others or ourselves are aware of this flow. The flow of desire makes connections with other desires unless it is diverted or blocked. In the case of communication with comatose people the flow of desire is blocked by our limited view of communication.

Similarly, Bogdan and Taylor's (1988) observations re-frame the post-person argument in that it is not the post-person's supposed inability to communicate that is the problem, but it is the caregivers' inability to see the other as communicating that is the crux of the matter. As a person who experiences dementia, and is often considered a post-person, Gloria Sterin (2002: 8) has identified three reactions. These reactions are: 'the process of becoming invisible', 'the gesture of dismissal' and 'the act of smothering,' they all are variations on the same theme. Sterin explains,

> Now, nobody wants to be rude; nobody wants to be mean or unkind; but neither do they want to be uncomfortable. I think that's the key word. They are just acutely uncomfortable with you and do not to deal with that discomfort. I've seen withdrawal on the part of many people, many old friends who just couldn't handle this disease comfortably, and shied away from contact as much as possible. They are being made very uncomfortable... For they don't know how to deal with somebody who is not 'fully human'. So how do you treat such a person? You try not to see them; you avoid them as much you can; or treat them as if they are not there, as if they are invisible.

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Let me give you an example, you are sitting in a room and people talk to each other, but they tiptoe around you. When you look at someone, that person looks away from you, and talks to the next person. People simply stop talking to you in the way that they used to. You are in a different category from the normal population. There's a discomfort and you can almost sense the reason is not that they're angry or upset..... they are just uncomfortable.

At times Sterin (2002: 8) has tried to barge in on the conversation; in response the person answers her very briefly and then turns to another person and engages them. If she addresses a person by name they will respond to Sterin and listen to what she has to say. But, they will not engage her in conversation. Sterin (2002: 8) elaborates,

Nobody wants to be impolite. But you're not engaged in the process; and that's what makes a person human.... the process. In any other circumstances, for example, if you said, 'I broke my leg, it's hard for me to get around', people will be sympathetic and engage you in conversation and say, 'How do you manage? Or that's too bad, is it going to take long to heal?' And that's within the realm of normal conversation. However, if you say you have Alzheimer's, if you have dementia, it's the kiss of death... it's that word dementia.

For Sterin (2002: 8-9) the second reaction is 'the gesture of dismissal', which is a series of facial expressions and gestures that devalue her existence. She explains that it is surprising and yet sad to recognize the same gesture and the same tone of voice from different caregivers who otherwise have varied characteristics. Again Sterin reiterates that there is no malicious intent involved in these interactions. The third reaction is 'the act of smothering' where the person has no chance to be themselves because their personhood is being suffocated by kindness.

Being 'suffocated by kindness,' 'dismissed by facial expression,' or 'rendered invisible' are all ways in which members of society deal with dementia; however, as Sterin points out these strategies are not working. In Sterin's intersubjective relationship with non-disabled people the latter are imposing their own subjectivity as the measure of effective communication. As Sterin so eloquently illustrates, it is not the person experiencing post-personhood that has the failure to communicate. It is the 'uncomfortableness' of the privileged persons, not the abject other, that causes communication to break down between persons and post-persons. Consequently, what is required is the political will for a paradigm shift that begins to see post-persons as persons who communicate differently.

I make a similar point in my analysis (Raoul et. al, 2001: 193) of Jean-Dominique Bauby's autobiography, *The Diving Bell and the Butterfly*, which explores his life with locked-in-syndrome (LIS): 'The diving- bell for me, does not represent Bauby's imprisonment by LIS but rather the oppressive practices of those who privilege an able-bodied embodiment. They see the problems of the lack of communication, of lesser embodiment and absence of selfhood, as residing with Bauby as a result of LIS. In contrast, I see the problem as lying in such readers'

inability to understand his attempts at communication, their failure to appreciate his embodiment, and finally the refusal to recognize his selfhood.'

When I have tried to advocate for the personhood of supposedly 'inarticulate' post-persons and have invoked my experience of non-personhood (related above) I have been criticised as moving beyond my non-person experience, thus invalidating both my experience and my subsequent opinion. My critics argue that the fact that I can communicate through language invalidates my position and experience as an 'inarticulate' pre-person. Yet this criticism rests upon the belief that personhood and disability are on a continuum. That is a position that I feel is ableist, because it reiterates the belief in both the non-personhood and post-personhood as less-than-persons bookends for both the categories of disability and personhood.

Lorraine Code (1995a: xvii) believes that a 'rhetorical space' must be developed in order for certain topics to become a matter of public discussion. Some might argue that that is exactly what discussions about post-personhood attempt to do - to open up a rhetorical space for discussion about people's lives. In these discussions I am aware of the privileging of language. For example, literary theorists and social scientists who work in narrative have a great affinity for both the spoken and the written word. I contend that their reification of language, if I dare say it, feeds into their own fear of losing their cherished ability to speak and write, which skews their ability to make judgements on post-personhood.

Language is political because the forming of grammatically correct sentences is, for the normal individual, the prerequisite for any submission to social laws. If one cannot master or is ignorant of grammaticality, one belongs in a special institution. This dominant language or pattern of communication is in itself a strategic site of normality. It paints normality with broad strokes, or, under the guise of diversity, it may allow for diversity within a range of normality, but it never–the-less rejects any sense of communication that is deemed abnormal. Thus, post-persons who cannot express themselves in either the dominant language or communication style (Deleuze and Guattari, 1987: 101; Colebrook, 1999: 117) may be eradicated for their own 'good'.

Discussing conditions under which post-persons exist assumes that the 'thing', post-personhood, exists. Perhaps one might protest that literary theorists and social scientists are only discussing the issue. However, discussing the issue gives credence or validity to the concept of post-personhood. According to Pierre Bourdieu academics achieve 'cultural capital' through distinction in academic endeavours (Bourdieu, 1990; Fowler, 1997). This discussion is not simply an exchange of opinion but carries immense influence, according to how the discussion is framed (as discussed earlier). In this postmodern world intellectuals are interpreters of our social world (Bauman, 1987; Bauman, 1993). Their opinions give weight or cultural capital to the position that there are, indeed, people whose lives are 'not worth living.' At the conferences I attended the primary issue was what characteristics might signify a state of post-personhood.

Given that most people have a greater fear of disability than of death (Morris, 1991; and Oliver, 1990) I argue that the prior assumption that there is some form of 'post-personhood' is

problematic in itself. Unfortunately, the question of whether the concept of post-personhood reflects an ableist position is rarely considered by scholars who come from a position that privileges an able-bodied perspective. The tacit agreement that some persons are in a state of post-personhood may give some individuals the moral authority to justify the murder of someone in their care, deemed to be in a state of post-personhood. Because of the influence of a restrictive personhood, coupled with a fear of disability we must consider the unintended consequences of uncritically invoking the concept of post-personhood as a given. What part does our discussion, and this invoking of post-persons play in reaffirming the boundaries of normality/abnormality, disability/ability, person/non-person, and so on?

Concerned that these rhetorical spaces be receptive to alternative and marginalised narratives, Code (1995b: 4) writes,

> My questions are not merely about whether it is possible to say just
> anything at all, indifferently, in the discursive spaces that epistemology
> calls its own, but about the conditions for flourishing there. And they
> are about territoriality, from different directions: about how domains of
> inquiry are staked out so that certain things can be said and others
> cannot, not because of any explicit prohibition or because they are
> clearly beside the point, but because of ossified perceptions of what the
> point is; because they do not fit, do not mesh with what the participants
> in the established discourse know how to respond to - and because of
> reluctance to reconsider boundaries.

In 'The Order of Discourse', Foucault (1984: 110) observes that individuals who are deemed less than human are prohibited from having their speech or communication taken as rational. Most people would see a 'compassionate killing' by definition as an act of love and compassion. Often I have found that the seductive sweetness of the potions of compassion, care, and love masks their insidious poison which robs the disabled, the sick, and the traumatized of their vitality. In discussing agape love, Bauman (1993: 97) argues, 'Stooping to' the weak by the self-confident strong is in the end the birth-act of domination and hierarchy: the re-forging of difference into inferiority. From the beginning this love is contaminated by patronising and condescending behaviour that is masked by benevolence.' The re-forging of the cripples, the mad, the diseased, the traumatized into inferiority is based on the belief that they must be recast with care into at least adequate facsimiles of humanity in order to be accepted into the realm of personhood. In extreme cases, as in the case of post-persons, this love, this compassion, manifests itself in their eradication in the name of benefice.

The executioners of the proclamation of post-personhood may have a heavy heart but it is soothed by the balm that they did all that was humanly possible. And there lies the problem. Perhaps we have to look beyond our taken-for-granted humanness to see the person within the post-person (as the excerpts from Sterin illuminate). Perhaps we have to step out from behind the empty terms of love and compassion that mask and sterilize our fear that we too may be closer to post-personhood. But as long as we are able to label others as post-persons, then we can whisper to each other and to ourselves that at least for now we remain human. The encroachment of post-personhood upon our lives is held at bay by the eradication of this loved one (even if this loved one is you, a self sacrifice for the common good); the constant reminder is gone and, perhaps over time, even the memories (yours, or those of your loved ones) of post-personhood can be supplanted by the memories of when you or your loved ones were persons.

In the last chapter, I pointed out that the act of abjection is central to the negation of disabled people who are considered 'less than human'. Similarly, it is essential in the understanding of how people are viewed as 'not having a life worth living' and are labelled as either non-persons or post-persons. I reiterate, the act of abjecting allows one to make sense of something or someone that is paradoxically meaningless yet disturbing (Kristeva, 1982). Kristeva (1982: 4) argues that abjection is not the lack of either health or cleanliness but the disruption of identity, system, and order. Butler (1993: 8) asserts that the construction of the human through regulatory and normative practices produces the less than human, the human, and the humanly unthinkable.

People defined as in post-personhood typify what Butler (1993: 190) calls the ultimate 'abject other' - the 'unsymbolizable, the unspeakable, the illegible' whose lives are 'paradoxically meaningless yet disturbing'. The invocation of 'living wills' is the active imagination of people who see the spectre of post-personhood in their future, a life not worth living, a meaningless life, a burden for others - that fuels their belief that they must banish themselves to the realm of death if faced with post-personhood . Or it is the active memory of a caregiver who can relate to the vibrant person, to the paradoxically distant but ever-present past that haunts the present relationship; in such a way that the caregiver tries to make sense of the inarticulate person's lived experience, but only in terms of what they lack. Whether looking to the future or dealing with the present which is tinged with a longing for the past, this state of post-personhood is disturbing. In a 'compassionate killing' we eradicate the disturbance and restore the person's vitality in memory. We restore order and our faith in humanity. Can we ever be sure that a compassionate killing is better than a 'life not worth living?' Unfortunately the dead are silent on this issue.

Death is always interpreted by the living. Bauman (1993: 100) writes,

> Death means that nothing will happen any more. No miracles, no surprises, -
> no disappointments either.' The death of a loved one is the safety of the lover.
> They are free without a single 'but' to paint the portrait of the dead. With their
> own palette and their own brushes they will be able to paint not only the
> portrait of the dead, but also the act of dying, and perhaps most importantly the
> life of the dead. What comes under their brushes is a death mask that remains

forever.

Others (including scholars of disease, disability, and trauma) may interpret or re-interpret this death, but this initial death mask of post-personhood, which is underscored by the normative shadow of personhood, is the reference point that the story hinges upon. Whether the life and death of the post-person is interpreted and re-interpreted, what comes from their brushes will forever remain a portrait of the dead - a death mask.

My active imagination has its own fear of the future. I see myself as having LIS and my caregivers believing that I am unable to communicate (none of them have read Bauby's book or Raoul et. al, 2000). They believe that my suffering from cerebral palsy has caused me to be shackled with this useless body. Now LIS has robbed me of my mind. After careful consideration, they decide that I have lost the last vestige of my humanity, along with my personhood, and that my life is not worth living. They proclaim, 'I have endured enough' (and compassionately kill me). These people have no idea that I have returned to a place that I enjoy and knew when I was a pre-person: A place without language, without metaphor, without a need to give my life meaning or purpose. Where my spasms, and my sensations run freely without restrictions.

As I write this I realize that perhaps ironically I am speaking of a place, a state of consciousness that persons try to achieve for themselves. Is this state of pre-personhood not similar to a state of meditation? If I am right in my belief that the state of pre-personhood and post-personhood are similar experiences, then might not a state of post-personhood be a meditative experience, too? Unfortunately, if we 'compassionately kill' post-persons they will be silent on this issue, too.

Perhaps, as Bogdan and Taylor (1988) suggest, any position on post-personhood depends upon an individual's belief system. My viewpoint on post-personhood is a minoritarian position (Goodchild, 1995). I cannot expect that my view will be adopted by those that accept and cherish the ranking of human persons. From a religious perspective people have suggested to me that if I had a 'merciful death' I would be able-bodied in heaven. Personally, the idea of me losing the vivacity of my cerebral palsy would be my idea of hell. Thus, I cannot bet against the finality of death, the clock cannot be turned back if it is discovered that there is a plane of immanence or a line-of-flight (Deleuze and Guattari, 1989) that is rich, vital, and vibrant for the people who experience post-personhood.

Having been told many times throughout my life that 'my life was not worth living,' I am very cautious in making that diagnosis for either myself or others. Nor do I feel that I have the right to do so, because that normative shadow of personhood at times permeates my existence. On such occasions I find myself being swayed by the argument that a continuum of personhood is a valid way to measure human existence. So pervasive is ableism that I must be vigilant that I do not secure my ranking on the scale of personhood by internalising the belief that some other 'gimp' or 'cripple' is a lesser life form than me. Some other scholars of narrative are becoming aware of the inherent abjection/ableism which they must guard against. Raoul et al. (2001: 206) write,

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Literary experts, just like medical specialists, can treat a person/text as a 'case' to be dissected and analyzed and, in the process, eliminate the life in the person, denying his or her right to consideration as a unique individual rather than simply as a representative of something 'bigger.' Similarly, attempts to impose 'meaning' on a life and admiration for those who succeed in doing so in difficult circumstances can devalue the lives of those who are not able to express or develop such a coherent 'message' about their experiences but nevertheless have lives that are of value.

In the past when I have spoken about meaning being imposed on me because of my disability, others have argued that everyone has meaning imposed on them or wants to find meaning in their lives. Yes, I would agree with Gergen (1991) that many people are tormented by trying to make meaning of their lives and are faced with 'a sense of failure, of being unable to realize "what could have been," "should have been," or "wanted to be".' But for disabled people 'the meaning' imposed on us by ourselves or others has more to do with being accepted as persons and not slipping back into the realm of the 'non-persons'. This is not simply a matter of our feeling frustrated by not attaining 'what could have been', 'should have been', or 'wanted to be'; but the ceaseless necessity to prove that we are persons. In order to keep at bay that possibly inevitable moment when someone will not only say 'Your life is not worth living!' and feel justified and compelled to act upon that proclamation by ending our lives.

The Compassionate Killing of Pre-persons

To resolve the problem of post-personhood there has been a growing interest in genetic intervention to identify prospective genetic 'abnormalities'. Under the auspices of eradicating prospective pain and suffering from the world, disabled sensibilities are at risk of being exterminated. This belief in the need to eradicate people who are considered diseased or disabled is not a new phenomenon. For example, Angus McLaren (1990: 165) writes that a 1915 Board of Inquiry in Ontario felt that average citizens must be productive and maintain their economic value, hence remain a helpful member of society rather than a burden for the community. 'Few active in public life spurned the idea of striving for a perfectly rational world purged of physical and mental, medical defect' (McLaren, 1990: 165). Often practitioners implementation of, and proponents attitude towards, eugenic interventions exceeded the original intent of the public policy. Researching the extermination of the psychiatric patients during the Nazi regime, Proctor (1995: 172) writes,

> It is important to recognize the banality of the program in 1941, the psychiatric institution at Hadamar celebrated the cremation of its ten thousandth patient in a special ceremony, where everyone in attendance secretaries, nurses, and psychiatrists received a bottle of beer for the occasion. Even after the end of the gas chamber phase of the operation, the killings continued albeit in different forms. Whereas earlier killings had been primarily by means of gas chambers, killings after the summer of 1941 were performed through

injections, poisoning, and starvation. Euthanasia took on less the character of a singe Reich-wide 'operation' and more the character of normal hospital routine. Equally disturbing is the fact that doctors were never *ordered* to murder psychiatric patients and handicapped children they were *empowered* to do so, and fulfilled their task without protest, often on their own initiative.

The continuities linking the various phases of the Nazi's program to destroy 'lives not worth living' were both practical and ideological. In the fall of 1941, with the completion of the first major phase of the euthanasia operation, were dismantled and shipped east, where they were re-installed at various concentration camps. 'The same doctors, and technicians, and nurses often followed the equipment, bringing with them the skills in how to murder covertly, extract teeth, recycle valuables, and cremate bodies - all in assembly line fashion. Germany's psychiatric hospitals forged the most important practical link between the murder of the handicapped classes 'as lives not worth living' in Germany's hospitals and of Germany's Jewish and Romani (Gypsy) populations (Proctor, 1995: 186). Support for forcible euthanasia waned in America as word of German atrocities was reported in the media. However, in 1942 as Hitler's psychiatrists were sending the last of their patients into the gas chambers, Dr. Foster Kennedy Professor of Neurology at Cornell Medical College wrote an article, calling for the killing of retarded children age five and older – 'those hopeless one's who should have never been born - Nature's mistakes.' (Proctor, 1996 ff: 171).

Consequently, the concept of eugenics not only became 'normalised', but respected within academic circles. Similarly, the genetic intervention proposed by the Human Genome Project is becoming 'normalised' and has 'cultural capital' within academia. Both eugenics and the Human Genome Project offer the 'promise' of a world where disease and disability have a lesser impact. Underlying both the eugenic movement and the current genome project is the purging of physical and mental defects. The former chose to segregate the defective population and control reproduction through sterilization or, in the case of Nazi Germany, the eradication of defective people (Proctor, 1995). The premise of eugenics was that for the greater good of society certain types of populations would be sacrificed either by causing their eventual extinction through sterilisation or by immediate extermination. The premise of the genome project is that to improve the 'quality of life', parents may undergo genetic testing in order to stop possible genetic abnormalities from coming to fruition. If it is discovered that a foetus is carrying the marker of a genetic abnormality that may result in a 'deplorable' 'quality of life' for the child, as 'good parents' the tested couple should pro-actively take action and abort the foetus for its own good. Genetic testing and intervention differs from eugenics in the means but the end goal remains the same: a homogeneous society with no 'defective' members.

Utilitarianism and Parenting: The Eradication of the Unwanted

So strong is the belief that the eradication of disabled people through genetic intervention would benefit our society that a media campaign has developed to persuade prospective parents of disabled children to comply. Stanley Hauerwas (1995: 197) writes,

I first became aware that compassion can kill watching a film sponsored by the National Association for Retarded Citizens. The film shows a couple looking into a crib. The young mother looks up and says, 'Don't let this happen to you. Our baby was born retarded. Our lives are crushed and yet we don't know where to turn. Don't let this happen to you. Get prenatal counseling. Help us eliminate retardation.'

He continues,

I was absolutely stunned by that commercial. It had been developed with the best intentions. The National Association for Retarded Citizens thought this was a way to mobilize support for research monies from the government to help find cures for retardation. Just as people think we ought to try to eliminate cancer so we ought to eliminate retardation. Of course there is one difficulty. We can care for the cancer patients by trying to alleviate their cancer without destroying the patient, but we cannot eliminate retardation without destroying the person who is retarded.

In the name of compassion, utilitarians believe that it is necessary to sacrifice present generations in hope of securing a better future for those who are left (Hauerwas, 1995: 198). According to Hauerwas this is as a form of extreme liberalism. The forecasting of a bleak future for disabled people, placed outside normality, legitimises the eradication of prospective disabled people. Hubbard (1997), Elshtain (1995), Lewontin (1995), Shenk (1997) and Weiss (1999) foresee the darker side of genetic technology. They all claim that genetic engineering, under the guise of progress, is concerned with human self-assertion and the desire for power. Shenk (1997: 41) argues that proponents of genetic engineering believe that humanity 'knows better than Nature what we want out of life, and we owe it to ourselves and future generations to seek genetic improvement as a component of social progress.' According to Shenk, such social progress would see genetic modification as the plastic surgery of the next century. Cosmetic modification is the manipulation of genes to create designer babies.

Concerning the topic of designer babies, the Critical Art Ensemble (1998b: 125) believe that within the current consumer society parents may choose genetic testing as one of many products and services offered them to enhance their children's potential and 'quality of life'. Today many members of society argue for genetic testing for disabilities, because they believe that the 'quality of life' for both the 'afflicted' individuals and their 'caregivers' is diminished. Moreover, women are perceived to be inhibited from self-actualisation because they are often the primary caregivers for disabled people (Morris, 1993; Thomas, 1993). But as Morris (1993) argues, such a viewpoint is ableist, because it defines disabled people solely as a burden. Morris (1993) considers the provision of care as part of a reciprocal relationship between individuals which benefits both parties. Policy discussions concerning genetic engineering are informed by the belief that disabled people are a burden on 'caregivers'. For instance, the Canadian Advisory Council on the Status of Women submitted a brief to the Royal Commission on Reproductive

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Technologies that states, 'Genetic therapy on embryos, fetuses, and adults with serious genetic defects (such as cystic fibrosis or Tay Sachs Disease) would be of great good to humanity and particularly to women in our capacity as primary caregivers on a global level' (RCRT, 1993: 40). They maintain that 'The decision to abort or bear a child with genetic defects should remain exclusively with the woman' (RCRT, 1993: 46).

Jean Bethke Elshtain (1995) asserts that the cornerstone that buttresses this philosophical position of ultraliberalism is the rhetoric of choice, without considering responsibility or obligations. Each individual remains responsible to only his or her desire to self-actualise or the desire to replicate those that mirror him or her. Elshtain (1995: 35) claims that supporters of the primacy of the 'right to choice' for women have seemingly contradictory positions. On one hand, they advocate genetic testing for disabilities, while on the other they are appalled at any suggestion of testing for the sex of the foetus.

Many people might argue that women are not necessarily self-serving but make decisions based on the information provided them. The discourse concerning disability as it applies to the proliferation of reproductive technologies, in particular prenatal testing for detectable foetal anomalies, is not inclusive. According to Rayna Rapp and Faye Ginsburg (2002: 538) 'While U.S. genetic counselors are trained to express neutrality about the choice a pregnant woman and her partner may make around amniocentesis testing, the very essence of such technology and the offer of such tests under the terms of consumer choice are premised on the desire for normalcy and fear of unknown abnormalities.' Maria Barile (1993) argues that non-disabled men and women who have been fed misinformation that each individuals quality of life is diminished by a disability cannot make an informed choice. Moreover, the offices of genetic counsellors, along with the over-all environment, weigh the decision in favour of genetic testing (Ettores, 2001).

At a certain level both the negation of a disabled presence through the changing of the faulty gene or the elimination of the host (the potentially disabled person) stem from a conflation of various components: the availability of ableist technology, the populist notion of an idealised community, and the validation of liberal individualism. This idealised view of community does not merely balance out liberalism and the constraints of group membership but transgresses both extremes (Bauman, 1988: 53). According to Bauman this yearning is not simply a manifestation of nostalgia, but is embedded in privileged interpretations of present realities. These present realities privilege an able-bodied interpretation of what constitutes citizenship, in the sense of one who complies with normative standards that allow an individual to self-actualise and not be a burden to others.

Against this position, some disabled people privilege their own versions of community and liberal individualism to justify genetic testing which discriminates against an able-bodied sensibility. Davis (1995: 165) reports that some members of the disabled community are validating a disabled existence at the expense of an able-bodied embodiment. Davis (1995) points out that some members of the deaf community are advocating that deaf expectant parents undergo testing to determine if their unborn child can hear. If the child is presumed to be hearing then an abortion would be encouraged. The argument follows that the birth of a hearing child

within a deaf community would require accommodation that would not only upset the homeostasis of the community but put an unnecessary strain on its resources (Davis, 1995: 163). They argue that a child's quality of life is enhanced in a deaf community if he or she is deaf. Similarly, the gene for a certain type of dwarfism has been isolated. Some dwarfs are undergoing this genetic test to ensure their children are dwarf. They argue that the strain of raising a non-dwarf child for dwarf parents who live in an environment that has been adapted to suit their stature is an unfair burden.

The argument presented by some members of the deaf community and some dwarf couples is identical to the solution presented by the majority of the able-bodied community in respect to the 'disability problem'. Advocates arguing for both genetic testing for disabilities and the abortion of disabled foetuses claim that the quality for both the 'afflicted' individuals and their families is diminished. They assert that the physical and social world require an able-bodied embodiment. The life of a disabled person is not worth living unless an intervention or accommodation raises their existence to an acceptable 'quality of life'. Of course such an intervention or accommodation puts a strain on the limited resources a society has to offer. Moreover, as many feminists point out, caregivers of disabled people are mostly women. The care of disabled people does not give women the freedom to self-actualise which is an important tenet of liberal individualism. But should we eradicate all prospective hearing children from the deaf community because they potentially make life more difficult for deaf parents? Certainly, within an able-bodied centred society such an intervention would be considered a cruel and unusual solution to the problem.

Both the 'quality of life' and 'self-actualisation' arguments that underscore the 'disability problem' are based on the sacrifice of the problematic minority (the prospective disabled child) in the name of the common good (an able-bodied and privileged society). In regard to the deaf community and dwarf parents, the normative argument remains although it is inverted. The minority (the prospective able-bodied child) is sacrificed in the name of the common good (for the good of the deaf community and for the good of the dwarf family unit). From a utilitarian sense the eradication of prospective people that may be burdensome for others has an appeal.

The pressure to have normal babies has resulted in the advent of parents filing 'wrongful birth lawsuits' for physicians failing to identify genetic maladies. The parents and grandparents of a girl who experiences CHILD syndrome are suing a hospital and radiologist for the cost of her on-going care. van Wageningen (1998: A3) writes, 'In seeking compensation they have acknowledged Sarah Mickle, who they love and adore, might not have been born had her physical deformities been detected in prenatal tests.' van Wageningen (1998: A3) records, 'Kelly Mickle, Sarah's mother, testified she would have requested a therapeutic abortion had she known. Now, she would never give up Sarah, who she described as 'the centre of our lives' [plaintiff's] lawyer John Corrent said. 'Sarah, 6, was born with a rare genetic condition that affects the right side of her body. She has no right leg and arm, and suffers from a painful skin condition.' The parents and maternal grandparents 'testified how shocked they were to find out about her physical deformities when she was born in November 1991.' As the parents and a grandparent testified Tuesday 'The courtroom was in tears half a dozen times.' The article

focuses on Sarah's disability and in passing mentions that she is attending Grade Two in elementary school.

Williams (1991) details the case of a white mother who loves her daughter but is suing a fertility clinic because her child was born black. On the grounds of wrongful life and emotional distress the family is trying to recover the cost of rearing the child. Williams, who is black (although her great-great grandfather was a white lawyer/plantation owner) (1991: 187), poignantly writes,

> I try to concoct a suit out of my own life's experience. What mistake can I blame for having been born into an intolerant world? Whom can I charge with the damage that will not be healed for many generations?' 'How profound the hatred, how deep the bigotry that lives beneath the skin, that wakens in this image of black life blooming within white. It becomes an image not of encompassment but of parasitism. It is an image that squeezes racism out from the pores of people who deny they are racist, or who say it's not racism that makes them fear blacks but the high crime rate or some such.

As I read the story of Sarah Mickle I could not help but think of Williams trying to concoct a suit based on her life as a descendant of a slave owner. Applying this exercise to my own life I might ask, 'Who can I blame for being born into a society that is not only intolerant, but also devalues cerebral palsy to such an extent that our lives are often considered not worth living?' 'Who can I charge for my legacy that is not even being attempted to be healed, when our society supports Robert Latimer?' To paraphrase Williams, how deeply embedded is the aversion towards and fear of disability that would have a family paradoxically profess love for a child while filing a wrongful life suit.

The parents could argue that it is only a matter of recouping some of the financial burden of raising a disabled child. But as I have outlined above, such a utilitarian argument assumes that the disabled child does not add to the family's life. Utilitarian thinking reduces the child's life and experience to a prospective cost-benefit analysis, where Sarah began her life in the deficit column. How will each of these parents explain to the child that her life was wrongful? If parents are initiating 'wrongful life' lawsuits is it possible that in the future parents will be initiating 'wrongful characteristics' lawsuits against physicians? They might argue that their child is disadvantaged because the desirable characteristics promised by medical specialists did not come to fruition.

The rhetoric of choice becomes a territorialisation of the notion of parenthood under the capitalist desire to produce the most productive offspring. In effect, the consumptive need for 'new improved' babies moves from being a choice to an obligation. As I have argued elsewhere in this dissertation the body and the self are textual signs to be read and consumed. The disabled body is read as defective and non-productive, which makes it difficult to consume. Therefore within this consumer-driven society it makes sense to eradicate disabled people. Genetic testings would become a dominant consumer service once the public considers these procedures an act of

benevolence, rather than an invasive attack upon what makes us essentially human. As the Critical Art Ensemble (1998b: 121) remind us,

> The eugenic visionary Frederick Osborn ... argued that the public would never accept eugenics under militarized directives; rather, time must be allowed for eugenic consciousness to develop in the population. The population would have to come to eugenics rather than vice versa. Further, eugenic consciousness did not have to be aggressively and intentionally micro-manufactured; instead, it would develop as an emergent property as capitalist economy increased in complexity. All that was needed was to simply wait until a specific set of social structures developed to a point of dominance within capitalist culture. Once these structures matured, people would act eugenically without a second thought. Eugenic activity, instead of being an immediately identifiable, monstrous activity, would become one of the invisible taken-for-granted activities of everyday life (much like getting a vaccination).

The Critical Art Ensemble (1998b: 125) add, 'To be sure, once eugenics is perceived as a means to empower the child and the parent, it loses its monstrous overtones, and becomes another part of everyday life medical procedure. Capitalism will achieve its goals of genetic ideological inscription, while at the same time realizing tremendous profits for providing the service.'

The Human Genome Project: The Search for the Holy Grail

Richard Lewontin (1995) asserts that the possibility of eradicating 'faulty genes' is a mythical quest rather than a realistic goal. Ruth Hubbard and Elijah Wald (1993: 159) warn that it is impossible for the genome map to tell us 'exactly where... every genetic inheritance of humankind is to be found'. They argue that a DNA molecule is an inert molecule, not a living thing, and thus contend that genes are not an absolute predictor of disability. Because a 'pathological' gene may be marked it does not necessarily follow that it will have a bearing on a future life. Moreover, cells and organisms can compensate for 'genetic mistakes' (Hubbard and Wald, 1993: 11 - 12). Thus, cells or organism might compensate for a 'maladjusted' gene. Even if this 'pathological' gene could be eliminated or altered by genetic therapy, it may begin a chain reaction that may result in disastrous consequences for the individual and society. It becomes a vicious cycle: The technological genetic intervention may solve one problem while creating another that then requires more technological intervention with its own unintended consequences (Bauman, 1992; Hubbard, 1997).

In their analysis of the effects of genetic engineering on race and gender, Nelkin and Lindee (1995: 387) argue, 'The gene in popular culture is not a biological entity. Though it refers to a biological construct and draws its cultural power from science, its symbolic meaning is independent of biological definition.' Similarly, Hubbard (1997) argues that the symbolic meaning for genetic perfection in popular culture is not based upon a biological entity; it draws

its cultural power from a science that devalues a disabled sensibility (Davis, 1997a; Davis, 1997b; Wendell, 1996; Bedini, 1991; Baird; 1992; Morris, 1991).

Applying genetic intervention to race rather than disability, Hubbard (1997: 187) concludes that most of us would be alarmed if there were a project devoted to developing pre-natal testing to diagnose skin colour. If proponents of the project claimed that genetic testing would alleviate the future pain or discrimination resulting from skin colour, people would argue that this project reinforces racial prejudices. Yet genetic testing for disabilities is seen as beneficial, as a benevolent measure implemented to reduce human suffering. Hubbard (1997: 187) argues that this justification seems more appropriate for speed limits, seat belt laws, and laws to further occupational safety and health than for tests to avoid the existence of certain kinds of people.

From the perspective of personhood race and disability are read differently. Broadly speaking, people of different races are seen as high functioning people who do not deviate from our inscribed definition of what is to be a 'person'. Some disabled people (especially those that are deemed inarticulate) are defined as deviations from the acceptable range of characteristics associated with being a 'person', and in need of interventions to raise their 'quality of life' to an acceptable level of personhood. Such interventions may or may not work, and in either case they are perceived as a drain on economic resources of society. Moreover, as pointed out earlier there is tremendous amount of time and energy invested in rehabilitation. Therefore, genetic testing and possibly the ensuing intervention offer the promise of being both 'cost-effective' and 'humanitarian'. Thus, the normative range of personhood is restored through therapeutic intervention that eradicates the pathological gene.

Shakespeare (1998: 665-668) believes that the broader cultural and social context in which informed choices occur must be examined. He agrees with Hubbard that it is not simply a matter of eugenics being either bad science or misapplied, and gene therapy being beneficial, but that science impacts upon and sometimes reflects societal beliefs and attitudes. He argues that there is a continuum of impairment, from states such as being deaf that may have mainly social consequences, to the other end of a continuum, with conditions like Tay-Sachs disease which causes major suffering and leads to a very premature death. This must be taken into account when discussing the concept of choice in genetic intervention. Shakespeare (1998: 670) contends that when Hubbard compares disability with ethnicity, she does not take into consideration this continuum of impairment.

Echoing Shakespeare's belief in a continuum of impairment, Morris (1991: 70) writes, 'In asserting our right to exist, we have sometimes been forced into the position of maintaining that the experience of disability is totally determined by socio-economic factors, and thus deny, or down play, the personal reality of disability'. Morris continues, 'We can thus fall into the trap of trying to prove our lives are worth living by denying that disability sometimes involves being ill, in pain, dying or generally experiencing a bloody awful time'.

In her attempt to bring the body into disablement analysis, Morris argues against the disabled community rejecting any genetic testing. Morris (1991: 81) believes that 'a woman with the knowledge that her unborn child has the gene with associated Lech-Nyhan syndrome - a very rare condition in which the child develops a compulsory tendency to bite off their own fingers and tongue - may well feel that it would be cruel to allow the child to be born'. Furthermore, Morris (1991: 81) asserts that genetic testing should not be imposed upon a community, rather that a community may 'choose' to have genetic testing to improve or ensure the quality of its population.

Challenging the validity of genetic testing, I object to the positions of Morris and Shakespeare in that they both assume that a genetic marker will necessarily result in a debilitating condition. This is not a matter of going with or against the probabilities and losing the wager. This is not a flip of the coin with a heads or tails outcome. There is no plea for the best two out of three if one's assumption is incorrect. With Morris's and Shakespeare's assumption the coin disappears as is the chance of life is denied because of the assumption that this genetic marker will come to fruition. Or, put another way, this discussion is not about an absence of potential pain or potential mutilation but the eradication of a chance at existence because of a 'possibility' of a disability.

Some people can appreciate both Morris's and Shakespeare's concern about some horrific impairments. I cannot. I remember people imposing their view upon me - that I am a tragic mistake with a life not worth living. Consequently, I believe that as advocates for the disabled we must be cautionary in advocating any genetic testing based on a continuum of impairments that easily can be conflated with a continuum of disability. I believe we risk falling under the spell of the normative shadow which privileges able-bodiedness over a disabled sensibility.

In our society there is a scale of bodies that measures all others in comparison to the 'able-bodied white heterosexual male' body that is privileged (Young, 1990a). By judging the lives of people who experience Lech-Nyhan syndrome as totally negative when compared to her existence, Morris is invoking her own scale of disabled bodies. I believe Morris is imposing her own abjectifying values on the other who is different from her.

Butler (1993: 7 - 8) makes some interesting observations about technology and the labelling of humans.

> To claim that the subject is itself produced in and as a gendered matrix of
> relations is not to do away with the subject, but only to ask after the conditions
> of its emergence and operation.... In this sense, the matrix of gender relations is
> prior to the emergence of the 'human'. Consider the medical interpellation
> which (the recent emergence of the sonogram notwithstanding) shifts an infant
> from an 'it' to a 'she' or a 'he,' and in the naming, the girl is 'girled,' brought
> into the domain of language and kinship through the interpellation of gender.
> But that 'girling' of the girl does not end there; on the contrary, that founding

interpellation is reiterated by various authorities and throughout various intervals of time to reinforce or contest this naturalised effect. The naming is at once the setting of a boundary, and also the repeated inculcation of the norm.

Similarly, I would argue the subject is produced in and as an ableist matrix. One must ask under what conditions the disabled person emerges as being 'less than human', or a subject where its ability to achieve a state of personhood is in doubt. Conversely, under what conditions does a non-disabled normative human become constituted? Just as Butler (1993) argues that the matrix of gender relations is prior to the emergence of the 'human', so too is the matrix of ableist abjection prior to the emergence of the human. Just as the 'girling' of the 'girl' is achieved through the sonogram; the 'disabling' of the 'disabled' is achieved through a positive result from genetic testing. From the perspective of gender, the 'it' represented by the sonogram has (if the mother chooses) the potential to be born, and be a 'person' - a 'girled' person restrained by the gender matrix, but nevertheless be a person once she is born.

With the interpellation of a 'positive' response from genetic testing for disabilities the indeterminate 'it' shifts to a categorization of disability. This 'it' with its interpellation of disability (if the mother chooses) has the potential to be born. But to be born disabled does not mean that this child is automatically expected to achieve the status of personhood. The infant undergoes testing to assess if, or to what extent, she or he falls within the 'normative range' of capabilities expected of non-disabled babies, who are trusted to attain the status of 'personhood'. If the disabled baby does not meet these expectations, then medical or rehabilitation practices intervene in an attempt to help the baby attain a level of normality, required for them to reach the expectations of personhood.

The 'it' represented by a positive outcome from the genetic testing becomes a signification of what can go 'wrong' with a fragile humanity. Thus, the 'girling' of the 'girl' (or the 'boying' of the 'boy') is overshadowed by the 'marker' disability and its present and future implications. The interpellation of the 'girling' (or the 'boying') results in an 'it' having the signification of a 'girl (or a 'boy') upon 'it', and at birth the expectations of 'personhood' bestowed upon her (or him). In contrast, the interpellation of the 'disabling' on the 'it' does not result in the expectation of personhood, instead, the 'it' becomes the 'abject' other requiring medical or rehabilitation intervention to initially sustain its life, and then to 'overcome' the effects of its disability, if possible. The level of personhood that the disabled 'other' achieves is proportional to the extent that one 'overcomes' one's disability.

By 'naming' the infant 'disabled', he or she is abjectified. Making the infant the 'abject other' to varying degrees paints the future not only of the infant but also of the family and the community at large as a series of problems and catastrophes that derive from the unfortunate circumstance of disability. Yet, as Eliot (2001) and Skidmore (1994) argue, it is impossible to accurately predict the future 'quality of life' of a disabled person. If the disabled baby is born, then the marker 'disability' looms over the child's life, or as Butler (1993) suggests 'the founding interpellation' is reiterated by various authorities and throughout various intervals of time to reinforce or contest this unnatural state. The naming of the disabled demarcates or places them outside

normality and in doing so repeatedly reaffirms the norm. Thus, the binary of disability and non-disability serves to reinforce normality within our society.

From the perspective of a sociology of the body, pathologising certain types of people leads to a displacement of their 'lived experience' into the 'abject other' assumed to be a problem. Both the eugenics movement and the 'human genome project' are solutions to the 'problem' of disabled people. Once such a solution to the problem (i.e. the disabled) is discovered, through institutionalised procedure it becomes commonplace. No longer is it a matter of eradicating a 'differing sensibility' or a potential life; rather it is simply a medical procedure to curb the spread of pathology throughout society or within the individual's body. In both cases the 'host' person or biological entity ceases to be and instead is reduced to a 'pathological' state. Consequently, the eradication of 'potential' types of people becomes 'matter of fact' and 'common sense', and creates a guilt-free atmosphere where the initiative to get of rid a pathology is deemed necessary.

The pathologising of a range of characteristics could extend to the point where humanity will destroy itself. Baudrillard (2000: 16 - 18) warns that humankind, in its desire for a knowledge that will lead to perfection, may indeed destroy itself. By making itself a guinea pig, humankind subjects 'the entire species to limitless experimentation'. Ironically, in its attempt to create a deathless alternative to itself by wresting control from natural evolution, humankind may quicken its demise because artificial forms of life expire sooner than natural forms. I agree with Baudrillard (2000) and argue that the eradication of disabled people, as happened historically in the holocaust (Proctor, 1995), may be the beginning of the end of humanity.

Weiss (1999: 113) writes, 'In a strange sense, there seems to be a natural progression in the category of the monstrous. Once we have ceased to be horrified and fascinated by alleged pathologies of the human, the impetus to create new monsters, new sites of horror and fascination seems almost inevitable.' Genetic interventions could lead to new characteristics of abjection that would precipitate a greater narrowing of the normative range of personhood.

The Denial of Life: How the Normative Shadow of Personhood Affected the Latimer Case

Robert Latimer murdered his daughter Tracy, in the following manner:

> On Sunday, October 24 he waited for Laura to take the other three children to church at 11a.m., leaving him to take care of Tracy. While Tracy sat alone in the house in her wheelchair, he ran around the yard for half an hour getting the rags, coat, sleeping bag, hoses and clamps his plan required. Then he returned to the house, picked her up out of her wheelchair carried her to his blue GMC half-ton truck and drove to the quonset at the north-end of the yard.

There he propped her behind the wheel with rags, coat and sleeping bag leaving her face uncovered. He connected a hose to the tailpipe and ran it into the cab through the back sliding window, started the motor and closed the door.

For half an hour he sat on a tractor tire in the box of the truck outside the sliding window watching as Tracy jerked several times while the carbon monoxide levels in her blood climbed to 80 percent....

Around noon, half an hour after he started the motor, Latimer turned it off. He drove back to the house carried Tracy's body, limp and reeking of exhaust fumes, back to her bed in the room she shared with her ten year old brother, Brian. He arranged her body to make it appear that she had died in her sleep and waited for the family to come home (Enns, 1999: 11-12).

In the days following the murder I was shocked and appalled by the public support for Robert Latimer. Many people who supported him claimed that his actions are understandable because he was a Saskatchewan farmer who would logically 'put down' an animal that was suffering. Yet some of Enns' (1999) interviewees who live in rural Saskatchewan found Robert Latimer's actions illogical and inexcusable. From a personal perspective, my father, who grew up on a Saskatchewan farm, was outraged that Latimer murdered Tracy. Moreover, he was offended that rural people from Saskatchewan were perceived to be so simplistic in their thinking. Over the years after Tracy's death I am amazed at how people, even those who find Robert Latimer's action deplorable, feel sorry for him. My point in discussing my father's opinion is not to invoke him as the 'real' truth but rather to point out how simplistic and stereotypical views that appeal to normalcy overlay ableist beliefs and opinions.

I imagined the reaction of the Canadian public had the victim been an able-bodied child. In Canada, if a father confesses to the premeditated murder of his child and shows no remorse, he would normally be sentenced for first degree murder. Such a sentence would be supported by the general public. In fact an outraged public might call for a return to the death penalty. Without any remorse, Robert Latimer murdered his daughter in a premeditated act; yet the general public called for leniency for him, because they perceived his child to be 'severely' disabled and experiencing 'intolerable' pain.

In studies of violence, dehumanization, and objectification are called 'depersonalization' (Sobsey, 1998). The fact Latimer would have to depersonalise Tracy in order to kill her, calls into question his position that he loved her. Some people might argue philosophically that Latimer did not kill his daughter but simply 'put an end to her suffering'. Yet he took the extraordinary measure of killing Tracy, even though other options were at his disposal, such as placing her in a group home (Enns, 1999: 11) Latimer felt that he and only he had the right to decide Tracy's future. Obviously, he felt Tracy's life was not worth living, but not every caregiver who may believe this is so kills the person in their care. In order to carry out a murder, the perpetrator must be detached from the victim, especially if the latter is helpless. Yet parents

who murder their children, like Latimer, express love for their children. In his research of child killing, Sobsey (1998) argues that because of their vulnerability disabled children are more likely to be abused than other children. Sobsey (1998) concludes, 'Excusing this abuse on the basis of "parents know what is best for their children" or "that the demands of a child with a disability are too much for parents" to cope with would be totally inconsistent with this research on child killing.'

Often people have argued that Latimer simply put Tracy 'to sleep', and did not commit murder. But suffocating a person by carbon monoxide poisoning is an act of cold-blooded murder. Tracy had complete trust in him and he repaid that trust by allowing her to be slowly suffocated. The body has an amazing ability to resist its eventual demise. Consequently, the brain would delegate oxygen reserves to the most precious organs in the body (Davidson, 1999: 1). While Tracy lay there, her body was suffocating one cell at a time. Ironically, her brain - which throughout her life had been the focal point of discussions about her intelligence and by extension her ability to attain personhood - would be the last organ receiving oxygen. Her murder was not a matter of her going to sleep with her father's assistance, but rather of oxygen being denied her as the result of a pre-meditated plan to quite literally rob Tracy of her last breath and vitality. Consequently, Latimer is a typical cold-blooded killer.

In his second trial, on November 5, 1997, Latimer was convicted of second-degree murder for killing his twelve year-old daughter, Tracy, by carbon monoxide poisoning in 1993. Latimer then applied for a constitutional exemption from the minimum sentence of life imprisonment with no chance of parole for ten years. Justice Noble granted the exemption and ruled that Latimer killed Tracy out of mercy and the minimum sentence would be cruel and unusual punishment. Noble then sentenced Latimer to two years less a day with half to be served in a provincial jail and half on his farm (O'Hanlon, 1997: A1, A14).

In her discussion concerning 'hate speech', Butler (1997: 77) explains that the state defines the parameters of what constitutes 'unacceptable' speech and 'acceptable' speech. In her discussion about Anita Hill's testimony, Code (1995d: 76) argues that Hill was unbelievable because she did not fit the script expected of a black woman; since she was not subordinate to the masculine dominated court system. Hill's testimony was heard through a racist and sexist filter which devalued not only her testimony but her 'lived experience'. Similarly evidence in the Latimer trial was heard through an ableist filter whereby any testimony that validated Tracy's lived experience was overshadowed by the ableist rhetoric that she was in horrific and constant pain with no chance of being a person. Like Anita Hill, Tracy Latimer did not meet the requirements for being perceived as a victim. The constant and overwhelming rhetoric that her life 'was not worth living' meant that much of society, as well as many jurors and Judge Noble, who had an ableist centred perspective, could not perceive her to be a 'person' who had been murdered, but rather they saw her as an 'unfortunate circumstance.'

The Crown appealed Judge Noble's decision to grant a constitutional exemption to Latimer, and Latimer's counsel appealed his conviction. On November 23, 1998, the Saskatchewan Court of Appeals rejected the defence's appeal by upholding his conviction. It accepted the Crown's

appeal by overturning the sentence and imposed the mandatory term for second degree murder - life in prison with no chance of parole for ten years.

Latimer's defence then appealed to the Supreme Court of Canada, reiterating that the imposition of the mandatory sentence was cruel and unusual punishment. The Supreme Court of Canada's decision states that Robert Latimer had other alternatives to alleviate Tracy's pain (the surgery scheduled for November 4) and to improve her quality life (the feeding tube which he and Laura refused) and the option of placing Tracy in a group home (which he rejected). By choosing not to exhaust all other possibilities and deciding to murder Tracy, Latimer committed the most heinous crime, the taking of another's life. Also the court argued that the sentencing of Latimer to ten years without parole would act as a deterrent to other like-minded individuals, thus ensuring that the disabled and other vulnerable people would be protected under the law.

The Supreme Court of Canada rejected the defence that Latimer's actions were necessary. It asserted that the ending of Tracy's life was far more serious than the pain resulting from her operation or her lived experience. No matter how much Latimer was discomforted by Tracy's 'suffering,' his killing was unjustified and unnecessary. In considering the defence of necessity, the Supreme Court of Canada is aware of the need to respect the life, dignity and equality of all individuals.

The 'normative shadow of personhood' permeated Judge Noble's courtroom. Butler (1997: 75) argues that the courts discount African-American and Gay and Lesbian self-representation by labelling them obscene. Likewise I contend that by assuming that Tracy's life was an 'obscenity', Judge Noble would not allow for her 'human representation'. Fortunately, the Supreme Court of Canada's decision forestalled what John Stuart Mill (1975: 6) called the 'tyranny of the majority' - the tyranny of prevailing opinion and feeling - by imposing the mandatory sentence.

Unfortunately, a higher court, the Supreme Court was not immune to the influence of the 'normative shadow of personhood'. It reasoned that while Robert Latimer's actions were misguided his intent was admirable as he tried to do what was best for his daughter. In many respects, Robert Latimer typified a morally autonomous individual who, of sound mind and of sound body, takes responsibility for his actions. He felt his actions were just and rational given Tracy's situation. Although the court felt that Robert Latimer made the wrong decision in murdering Tracy, his behaviour, embodiment and his being meant he was a person in their eyes. According to the Canadian Charter of Rights, Tracy was also considered to be a 'person'. But she achieved 'personhood' only in the abstract legal sense of the term. Not being able to feed herself, her inability to walk, and her 'perceived' lack of communication skills meant that her ability to achieve 'personhood' in everyday interactions with others was in doubt. Thus, the Supreme Court of Canada identified with Latimer's position by suggesting that parliament might intervene and pardon Latimer for compassionate reasons (Coyne, 1999).

Thus, Latimer's rationale for murdering Tracy is plausible because many Canadians, including some parents of disabled children (see Edelson, 2000), and some disabled people (see Baker,

1995), adhere to the 'tragedy theory of disability' (Leonard, 1984: 188); it seems 'compassionate' to kill Tracy to relieve both her and his suffering. Like his body, Robert Latimer's life mirrored the life of most Canadians in that it is controlled and normalised, well within the range of acceptable personhood. Most Canadians had no doubt that he was a person; in fact they had elevated his persona to that of a tragic hero. In contrast, Tracy Latimer's life, like her body, is perceived as disorderly, less than human, a tragedy that should never have happened (Jenish, 1994:18). After her death she was portrayed as a mass of bones and flesh in constant pain. Simply put, a non-person. The lives of both Robert and Tracy Latimer were affected by the normative shadow of personhood.

The normative shadow of personhood affected media portrayals of both Robert and Tracy Latimer. In his analysis of news media, de Certeau (1988: 206) writes, 'The story which speaks in the name of the real is injunctive. It 'signifies' in the way the command is issued.' Through its reiteration the boundaries are set in terms of 'what must be said, what must be believed and what must be done'. In effect the repetition of the narrative allows for it to become perceived as factual. 'But in setting forth what must be thought and what must be done this dogmatic discourse does not have to justify itself because it speaks in the name of the "real"'(de Certeau, 1988: 207). Furthermore, Hartley (1993: 153) believes that the function of news reports is precisely representative and any truth-impression is not a result of the topic's existential status but from the plausibility of the anecdote in relation to the reader's experience.

Most of the public following the proceedings of Latimer's trial felt that he was an 'ordinary man' faced with a difficult decision and most followers of the trial felt that Tracy led a tragic life that was mercifully ended. The 'normative shadow of personhood' affected people's perception. Robert Latimer's personae as a 'salt of the earth' farmer, a man of action who spoke little, fell well within the range of acceptable behaviour for a person. Tracy's lack of control of her body, her inability to feed herself, and her perceived inability led most people to believe that she lacked the characteristics of personhood. Thus, Robert Latimer's defence that it was necessary to kill Tracy in the 'court' of public opinion does not come from the authenticity of his beliefs and his actions. Rather his position is derived from the extent that other people can identify with his beliefs and his actions. The normative shadow of personhood cloaks him in a rhetorical image that is a representation that is both comforting and familiar for most Canadians. During both trials witnesses testified that Tracy communicated and led a worthwhile life. Yet the public and the media concentrated on negative interpretations of her life. The debate is informed and framed by a 'normative shadow' that effectively causes most people to see Robert Latimer as a person, who faced with severe circumstances, was forced to take drastic measures and kill his daughter. These people considered Tracy to be a suffering non-person who only survived because of extraordinary medical interventions.

The normative shadow is not some ephemeral entity that envelops society, but a system of practices, beliefs and attitudes that have become 'naturalised' over time. Bourdieu (1990) and de Certeau (1984) assert that normative practices are not legislated but over time become law and 'inscribed' upon the body. Normative practices inscribe the disabled body, and 'mark' it as less worthy. This coding is negatively juxtaposed with the heroic coding of the 'ordinary person' fighting the system. Tracy's life becomes a trope illustrating the fragility and often times horror

of the human condition. In contrast, Robert Latimer epitomizes the hero who can be crystallised in a line often repeated by movie actor John Wayne: 'a man's got to do what a man's got to do'. Instead of riding off into the sunset like a mythical cowboy hero, Robert Latimer returned to his prairie farm where he gave interviews reiterating that Tracy was less than human, speaking in a manner that touched the hearts of many Canadians who were infected by the populist nostalgia that both Robert Latimer's demeanour and the prairie backdrop evoked.

So pervasive is the 'normative shadow of personhood' that it affected an investigative reporter's ability to 'press' Robert Latimer, and resulted in perpetuating the belief that Latimer committed a compassionate killing. *The Magazine* portion of the *C.B.C. National* broadcast across Canada an interview with Robert Latimer and his wife the night before the jury was to come back with a verdict. This television interview was framed by a nondisabled rhetoric which constructed a narrative of a loving father who 'nobly' took part in a mercy killing. Interestingly, during the interview (Gartner, 1997) a telling image was projected. Over the shoulder of Robert Latimer a singular picture of Tracy Latimer appeared. When the camera turned its attention to the interviewer, I noted that pictures of Latimer's other children were displayed over her shoulder. I believe that in most families, Tracy's picture would be included with those of the other children. But the placing of the pictures and the camera angle left the viewing audience with a particular narrative that painted Robert Latimer in a favourable light. It could be 'read' as her father being in front of Tracy symbolic presence, still willing to do the best for her. This reading is reinforced by the visual symbiotic relationship between Tracy and Robert Latimer that excluded other members of his family. Thus the visual message demarcating Tracy and Robert from the other children symbolically demonstrates that only Robert Latimer, as the father, knew what was best for Tracy.

This signification also played out in the audio interaction between Hanna Gartner, the interviewer, and Robert Latimer. She asked what Latimer would say if his other children asked him if he would murder them if they were in excruciating pain. He never answered the question and went on a tirade about everyone calling him a murderer. After his outburst the conversation shifted back to how only he knew what was best for Tracy. It seemed to me that the interviewer could not press Latimer because she was a guest invited into the Latimer home. Moreover, unlike most individuals charged with murder who lose their right to the privileges of personhood as they are incarcerated, Robert Latimer's personhood was enhanced by the sympathetic tone in Ms. Gartner's voice. Perhaps if Latimer were being interviewed behind bars, the morality of the narrative would allow the interviewer to focus on the murder and its repercussions, and not be overcome by sympathy. Unfortunately, the visual and audio messages reinforced the narrative that Latimer was a 'simple man' forced to become an extraordinary person who took extraordinary measures to correct the mistake of Tracy being born.

Let us imagine that Ms. Gartner had conducted a prison interview with a father charged with killing his able-bodied daughter. Like Latimer, he admitted to killing her, but in his mind the killing was justified because she was in a relationship that went against the religious doctrine he followed (or more correctly his interpretation of the religious doctrine). When asked the question: 'what would he say if his other children asked him if he would murder them if they were in a relationship without his approval?' He shouted, 'I am not a murderer, I am following

the will of God! In the eyes of God, she became a non-person when she disobeyed me!' Not only would Gartner be able to press him for an answer to her question, she would confront him about his angry outburst. In this instance his incarceration and the heinous death of his daughter would mean that Gartner would not have to treat him like an 'ordinary' person, but as an unrepentant murderer. In fact his personhood, or his right to personhood, could be called into question during the interview. Ms. Gartner might feel morally obligated to press the accused murderer because of the 'vulnerability' of an (able-bodied) daughter who 'trusted' her father.

Conversely, Tracy Latimer was considered to be living 'a life not worth living'. Because she lacked the ability to reach the normative levels associated with personhood, her premeditated murder by her father, whom she trusted, is deemed to be a less severe crime. Because they are affected by the same 'normative shadow of personhood', the scrutiny of the media is less severe, too. Under the spell of this 'normative shadow' Ms. Gartner was uncomfortable with pressing Robert Latimer for a response to her question, or for an explanation about his outburst.

Death is always interpreted by the living (Bauman, 1993: 100), which explains how Robert and Laura Latimer's narrative of a 'compassionate killing' has taken precedence over any other interpretation of Tracy's death. As parents, Robert and Laura Latimer's intimate relationship with Tracy allowed them to portray her life and the subsequent justification for her death. The vividness of this portrait, with its emphasis on her pain and suffering, struck a nerve with the majority of the Canadian public and took precedence over the positive aspects of Tracy's 'lived experience'. By reforging Tracy's embodiment as inferiority rather than difference Robert Latimer was able to transform himself from a convicted murderer to a caring father who killed his daughter out of compassion.

Latimer's position was supported by his wife, Laura, who said she grieved the day that her daughter was born and that her death by carbon-monoxide poisoning brought a sense of peace to the household. She testified that she and Robert had basically given up on their daughter after repeated operations to address deformities caused by the cerebral palsy (Roberts, 1997: A5). de Certeau (1984: 151) has said that, '[T]he wild is transitory, it marks itself (by smudges, lapses, etc) but it does not write itself. It alters a place (it disturbs), but it does not establish a place.' Tracy's smudges (her spasticity), her lapses (her inability to walk and talk) destabilized the normative canvas that permeated the Latimer home. Unfortunately for Tracy, her parents viewed this destabilization as an abnormality which must be eradicated. Tracy was dependent on her parents to inscribe her, and through this inscription they justified her death. I believe this inscription is indicative of the parents of Tracy Latimer having a limited view of personhood, not to Tracy's worth as a human being.

Tracy may have been in close physical proximity to the family but I would argue that she was not part of it. She hovered in the background receiving minimal care. As Enns (1999) relates, Laura Latimer refused to stimulate Tracy's language capacities because she felt she could not and would not ever be able to communicate. Given that both Laura and Robert Latimer had discussed the killing of Tracy, her life was tolerated but to paraphrase Bauman, (1993: 155- 56) it was only the 'courtesy' and 'good judgment' of Robert Latimer and his wife that kept Tracy

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alive. Given Robert Latimer's lack of remorse and Laura Latimer's statement that Tracy is better off dead, Tracy's life was not a matter of her right to live, but a matter of her parents 'generosity' - a generosity that enabled one parent to murder her, possibly with the blessing of the other.

Here again, ableism can be compared to racism. Ware (1997) writes about the pervasiveness of Whiteness in her household and her obsession with it, and speculates how this 'whiteness' creates a covert racism that one cannot articulate. Similarly, I would argue that the 'normative shadow of personhood' permeates the Latimer household. The difference between the two households is that Ware becomes cognizant of the racism, whereas the Latimers are not only unaware of their ableism but rejoice at the absence of Tracy. The fact that Tracy's parents felt there was no 'mutual understanding' or empathy led them to the fallacious conclusion that Tracy's life 'was not worth living'. Backed by the 'common sense' of what it means to be a person, both parents would not consider that the problem lies in their belief system. Moreover, the normative shadow of personhood justified their feeling relieved when Tracy was murdered.

Tracy Latimer's portrayal as a pain-ridden disabled mass has allowed for the normative shadow of personhood to envelop this case in ableist fear. Andrew Coyne (1997: A23) writes,

> Suppose rather than gas his disabled daughter and plead for leniency afterward, Robert Latimer had done things the other way around. Suppose, that is, he had sought approval from the relevant authorities before killing her: a permit, as it were, such as one might obtain before cutting down a tree. How many of those who say they believe, as Latimer does, that he 'did the right thing' would have voted to put the girl to death, had she been allowed to appear before them? What if, instead of the disembodied list of disabilities of so many media accounts, they had been confronted by a living, breathing human being, pleading, in effect, for her life to be spared?

Suppose Robert Latimer videotaped Tracy instead of murdering her. Suppose he released these images to the Canadian public to demonstrate that she was a person. Unfortunately, Robert Latimer painted a narrative that led many Canadians to feel that Tracy led a life not worth living.

Often my views on the Latimer case have been dismissed because I am considered to be a more evolved cripple. Derkson (1998) relates the views of two women, Shelly and Catherine, whose experience are similar to Tracy.

> Shelly is a single mother in her mid 20s, living in her own apartment with the support of her family, friends, and visiting home-care staff. Like Tracy, her disability is related to cerebral palsy -- she cannot talk or move anything but her eyes and facial muscles, and requires complete physical care assistance. Unlike Tracy, she does not have significant trouble eating, nor is she labelled 'mentally handicapped'.... Shelly was well informed of the Latimer court case. Using eye gaze and her Plexiglas symbol board, she told me without hesitation that she felt Robert Latimer must be found guilty of first degree murder.

Catherine, 33 years old, lives in a co-op home with two roommate attendants. Her disabilities seem to be very similar to those of Tracy Latimer. She has a seizure disorder as well as cerebral palsy- related spasticity; she is not able to communicate in language as we know it, and needs complete physical care. Catherine, like Tracy, experienced chronic hip dislocation when she was about 12 years old, which was relieved by surgery. Although Catherine endures severe illness at times, and she is unable to tell us in so many words that she prefers life over death, those of us who know her see the joy she obviously finds in living.

Perhaps the human spirit is stronger and more flexible than most people care to admit. Among those whom I know who have disabilities, regardless of the nature and degree of these, there is about as much enjoyment of life, proportionately, as there is among people in my acquaintance without disabilities. It seems that while those seeing our experience from the outside are only able to imagine tragedy, grief, fear and pain, we ourselves can accommodate severe limitations, very difficult circumstances - and still find our share of happiness.

Tracy Latimer was a vivacious child, Enns (1999: 45-46) explains: Laura Latimer wrote in the communication book that at a sleep-over, Tracy was laughing and vocalising. Tracy loved hockey, loved to tease people by grabbing their glasses. She had personal preferences. She would choose red nail polish, and loved spending time with her siblings. She was the best bowler in her class. The soft touch of the kitten prompted Tracy to try to pick her up. Ironically, most of this testimony comes from the pen of Laura Latimer who in the end failed to see that Tracy had a life worth living. So pervasive is the normative shadow of personhood that most Canadians choose to ignore Tracy's vivacity, and focus on the ableist rhetoric instead. Perhaps it is time to recognize the desires that emanate from our spasms, our blindness and various other disabilities move beyond a restrictive humanistic essentialism with its normative shadow of personhood.

Conclusion: Living a Life as a Deficit

The concept of personhood associated with humanistic essentialism demarcates the lives of disabled people as a deficit. I began the chapter by outlining a continuum of persons. Ranging from pre-persons whose potential embodiment is considered a deficit, failing to reach the normative expectations of personhood, at the other end of the spectrum is post-personhood where an individual has slipped from the normative range of personhood to the point that the 'individual' is reduced to an assortment of deficits. Proving that they have the appropriate characteristics for personhood allows disabled people to be included within the fold of humanity. Other disabled people are either deemed as living lives not worth living, or in extreme cases, killed for their own good. Moreover, I examine how the ideal body and sensibility of phenomenology results in a holistic universality whereby the disabled body is considered to be an affront to holistic sensibility. Disabled people are considered to be in need of resources to

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compensate for their deficits. Some people argue that the resources spent on lessening these deficits would be better spent helping able-bodied people reach their potential as the rhetorical self-actualising individuals emphasized by the concept of phenomenology and the doctrine of liberal individualism.

In chapter one, Davis (1997) makes the distinction between the 'grotesque' body (less than perfect humanity) and the 'idealised body' (the pinnacle of human aesthetics and efficiency). With the advent of genetic intervention, scientific reasoning promises that eventually this 'idealised body will be obtainable. Yet this notion of idealised bodies - free of genetic defect - is a search for the 'Holy Grail' (Lewontin, 1995) that is underscored by a privileging of an able-bodied aesthetic and sensibility that is inherently ableist. The conflation of nostalgic yearning for a non-disabled community (Bauman, 1988) and an extreme sense of liberal individualism with its mantra of utilitarian self-actualisation creates an atmosphere and a discourse that not only devalues disabled people, but offers testing and interventions to eradicate a disabled sensibility from the face of the earth. Davis (1995) inverts this ableism when he chronicles how some members of the Deaf community as well as some Dwarf parents are undergoing testing to ensure their children are deaf or dwarf respectively. While this intervention inverts the privileged position of normality, it does not change the conflation of nostalgic yearning for a homogenous community (free of hearing and tall people respectively), or the extreme sense of liberal individualism that such decisions are predicated upon.

The eradication of people who have disabilities is enveloped by the 'normative shadow of personhood'. Robert Latimer personified the 'grotesque' human - that is well within the range of the normative expectations of personhood, in embodiment and communication. Tracy did not.Tracy Latimer personified both the fragility of humanity and an overzealous and intrusive medical institution. Most people felt that Tracy was incapable of an intersubjective relationship with others. People were left with the image of Tracy as a mass of disabilities, not a human being. There was no way that Tracy could be either a self- actualising individual or personify a nostalgic reminder of community. Instead she reminds others of the fragility of their lives and how demeaning it is to be dependent upon others.

Like Tracy Latimer, people who experience post-personhood are considered incapable of intersubjective relationships. Unlike Tracy, before experiencing post-personhood individuals had the characteristics that fell within the range of normality. Becoming post-persons result in people being ostracized to the realm of the abject other. Both Tracy and post-persons experience purposeless pain (that does not improve the individual's life or society as a whole) that must be eradicated. After death both the lives of Tracy and post-person's are told by the living who look through a particular lens - the normative lens of personhood - a lens which reaffirms the boundaries of normality by demarcating who is to be abjectified. Thus, the normative shadow of phenomenology casts a pall over a disabled sensibility whether it manifests itself in the stage of pre-personhood, (the denial of) personhood, or post-personhood.

CHAPTER FOUR
AN 'OLD IDIOT' ATTEMPTS TO BE INCLUDED IN THE RATIONAL EDUCATION SYSTEM

Our education system has its roots in the Cartesian thinking of the Enlightenment and shares a belief that through applying rational thought individuals will be able to discover truths and improve society (Bauman, 1987). Deleuze and Guattari (1987: 75-76) argue that there is an emphasis on a Cartesian self which is associated with the rational, and cognitive thought. But they also (1996: 61–62) contend that Descartes only expressed part of the picture of thinking. They argue that there is an 'idiot' that appears throughout history, alongside the 'rational thinker'. The first idiot was a private thinker, in contrast to the public thinker (schoolmaster): the teacher refers constantly to taught concepts (man as a rational animal), whereas the private thinker forms concepts which derive from alternatives to the rational thinking of Descartes. Originally this idiot was only interested in finding indubitable truths from his or her private thinking, or, put another way, finding reason within her or his thinking (Deleuze and Guattari, 1996: 61-63) that could conform to the 'logic' imposed from outside.

This chapter relates my struggles with being an 'old idiot' trying to be included under the umbrella of Cartesian rationality with its emphasis on liberal individualism and a humanistic normality by which populations are measured. Neither my body nor my understanding of the world would be considered rational. I learned at a very age early that I must attempt to find the rationality within my own spasms and, in the words of Deleuze and Guattari, become an 'old idiot'. In Crippled Children's school we were learning to write, or more correctly to print. Our teacher stressed that our printing needed to remain between the lines. My cerebral palsy causes me to have difficulty with fine motor movements including writing or printing. I had great difficulty printing between the lines and a rap on my knuckles with a ruler assured that I received the message that any outward display of my spasticity was unacceptable. I began to dread writing class. To this day, I still have problems writing between the lines: In my particular case behaviour modification did not work.

I remember the day that I left the Crippled Children's school to attend public school. My teacher knelt down in front of me, placed her hand on my shoulder, looked into my eyes, and solemnly explained, 'Jimmy, it is not good enough for you just to attend public school. You must do your best to prove that crippled children belong in public schools. After all, all the crippled children that might follow you are depending on you.' I was excited and happy that I was attending public school like my older brother and sister. I was glad that my teacher seemed to be happy for me. Her support for me in her belief that I was intelligent helped me immensely. Her support, and of course the support my family, had made the impossible perhaps possible.

At first glance these stories relate to differing views about my experience in a Crippled Children's school. In the first story the teacher's rapping of my knuckles seems to denote the coercive nature of a system trying to make me normal. In the second story the teacher's anxiety

about me blazing a trail for other disabled students connotes her belief that we are the abject other ready to be welcomed into the realm of humanity if we can prove that we are 'worthy'. Yet in both stories the normative shadow of 'the anonymous body' of phenomenology hung over me like a shroud. My ambivalence began when I wondered why I was chosen rather than many of my classmates who were intelligent enough to attend normal school. Why was I chosen over them? While my new life in normal school would be exciting, I felt apprehensive about leaving the Crippled Children's school which I knew well and attending a normal school that seemed so foreign to me. I realized that there was a possibility that I would never return to the Crippled Children's school, that possibly I would never look back once I left, that my life might change forever.

I had lingering doubts about whether I belonged in public school. I knew I was intelligent, but would my spasms be accepted within this normal world? At that early age I had already endured cruel remarks by children and had overheard the demeaning whispers of some adults. My sisters and brother had fought other children who had physically hit me or verbally taunted me. What would it be like for me in a normal school? I knew some of the other students would see me as a 'freak'. Silently I wondered whether my teachers would be like other adults whom I overheard whispering that my life was a tragedy. If my teachers felt even slightly this way, what would this mean for my chance to grasp the brass ring of normality? And would reactions to my transition to the public school system be permanent or would the situation change when normal people became bored with the novelty of having a disabled child in the classroom? Even then I realised that an able-bodied centred society often sees me as a spectacle for their amusement. Would my inclusion in the public school system be another example of me being the new exotic entertainment for the moment, only to be tossed on the trash pile of damaged goods (Bauman, 1988) when my entertainment value ceased?

Put another way, was I that tourist in the educational system whose visa may be revoked for not meeting the requirements of normality? These requirements are not documented or codified but rather are part of a socialisation process in which I was not asked to partake. I spent most of my time in a world designed by, and designed for, people who are considered normal, privileging both cognitively and aesthetically a nondisabled population. But this normality is ever elusive for me. It is something I witness in the everyday actions, beliefs and attitudes of society. My family has given me a certain amount of familiarity with normality, but it is not something that I know intimately. Normality is like quicksilver, it has a brilliance that I might want to grasp, but as I reach out it slips through my spastic fingers. I can be touched by it, affected by it, and even confined by it but I never will experience normality.

Quicksilver, otherwise known as Mercury, is poisonous if it is ingested into the body. Like quicksilver, if I ingest too much normality I am poisoned, too. This ingestion may take the form of my taking on the behaviours, and characteristics of normality. Or I may be slowly poisoned by breathing in ableist attitudes, behaviours, or remarks that I encounter on a daily basis. The notion of normality is so insidious and pervasive within our culture that it seems natural, and a matter of common sense, for things to be this way and not another.

Yet this thing called normality is not something that I can avoid, brush aside or ignore. Normality, in Deleuzian terms, is a majoritarian perspective that works as a grid of our social world. As Goodchild (1996: 54) asserts, the majoritarian milieu or habitus affects our lives whether we like it not. We have no choice, because this dominant view becomes incorporated into our lives through frequency and repetition. Individuals within societies learn at an early age that adherence to normative values is necessary for success. Goodchild (1996: 54) explains that by accepting the majoritarian perspective people achieve status and establish relations with other members of their society. In my case, being judged as being able to succeed in normal society has allowed me to attain status and relations with so-called normal people. This poison called normality can be intoxicating and sweet, but at what cost?

As in the rehabilitation system, the cost within academia can be measured by the degree to which I have to disavow my experience of cerebral palsy. Within the rehabilitation system my cerebral palsy was a given that must be overcome. I was told within the context of my education that it mattered little whether I had cerebral palsy, it only mattered that I demonstrate the proper cognitive ability. Yet, as I was to learn early on, in order to demonstrate the 'proper cognitive ability' I have to refuse to acknowledge the wisdom that stems from my cerebral palsy. I realized that my cerebral palsy would inform other people's opinions of me, and subsequently affect their behaviour towards me. Simply put, the act of abjection would seep into the education system. This normative shadow has been a spectre that has followed me around since my education began in a crippled children's school, up to my status as a doctoral candidate. Before I had heard of the theories of Michel Foucault, I was aware of the normalizing gaze and the disciplinary techniques that my body must endure to succeed within the education system.

While undergoing testing to see if I were an appropriate candidate for integration, I realised the extent to which I must bury or hide the wisdom and understanding that evolved from my spasticity. These tests were difficult and I had to use my own way of thinking to succeed. I got enough questions right to make the adjudicators of the tests believe that I was capable of doing well in a regular school. However, they asked me how I had arrived at some of my answers. I explained to the best of my ability how my thinking worked, but I was only six years old. They looked puzzled and asked me again to explain how I arrived at my answers. At this point I realized that I must figure out not only the right answer, but how able-bodied people arrived at their right answer. In effect, what I had to do was translate my process of intelligence into a process they could understand. Again, my experience of spasms had to be subsumed by normative values. I realized there was a particular person that they wanted to see, an individual who thus far had overcome his disability, and more importantly had the potential to eradicate it from his life.

But *this* particular person favoured by my examiners was not to be the author of his or her statements, but rather a vehicle for the thoughts and language given to us by the paradigmatic conditions of normality (Goodchild, 1996: 148-149). Behind the correct responses required for my acceptance into public school was the tyranny of normative expectations imposed upon me. It was not disputed that to be able-bodied and to think rationally was preferable to being disabled and a non-rational thinker. This normative belief is part of the paradigmatic landscape of language, thoughts, and practices in which we live. In the particular situation of my testing, the

aspects of me being favoured were part of the cognitive, rational, side of me that fitted within the normative parameters of the education system. Other aspects, which included characteristics that are manifestations of desires which emanate from my spasms, were and are not only out of favour but considered detrimental. I realised that I must be able to 'mimic' the behaviours of the able-bodied students.

The normative shadow of phenomenology, like a virus, affects the education system. Even at a young age I was perplexed because if 'normal' people were superior to me, then why could they not understand disabled people's 'inferior' way of thinking? Put another way, why did I have to demonstrate that I was capable of discerning their method of understanding the world? This method of integration has little to do with helping disabled students reach their maximum potential and more to do with maintaining the social construction of normality (Overboe, 2000). I had to subdue my knowledge and continually translate my wisdom into rational knowledge.

'Mismeeting' Within the Public School System

My father was in the armed forces and consequently our family moved from one community to another, resulting in my parents having to arrange several times for my inclusion into the public elementary school. As I entered the next grade level, the school administrator would be reluctant to enrol me in classes and would insist that regular school would be difficult for me. They would also argue that my presence would be disruptive for the other students. I realized that, at least initially, I must try not to draw attention to myself and be careful not to be a disruptive influence on a class. This proved to be very difficult for me; my presence was noticed but not acknowledged. When the teacher asked the class to answer questions, I was called upon only as a last resort. When given the opportunity I would answer promptly and correctly. The teacher explained to me that she didn't want the other children to feel slighted by overlooking them and giving me the opportunity to answer the question. Of course it did not seem to concern her that I felt slighted. I remembered that my teacher at the Crippled Children's school had said that I should do well in school. I tried but ableism reared its ugly head.

I had mimicked the appropriate behaviour exhibited by 'excellent' students, but that was not enough. My spastic body betrayed me. My teacher's allegiance was to her able-bodied students who fell within an acceptable range of the prototypical student. No matter how well I did on tests or other assignments, I was considered to be 'inferior' to the other students.

The grades I received reflected my subaltern status. The first test I wrote, I finished only 80 percent of the questions; due to my spasticity I could not complete the test within the allotted time. The teacher told us the correct answers before handing the test back to us. I knew I had answered the questions I was able to finish correctly, however, at the top of my paper was a mark of 50 percent. Dismayed, I asked my teacher for an explanation of why I received such a low mark when I had correctly answered the questions? She explained to me that she felt the other children would feel bad if I got a higher mark than them. I quietly protested to her that I

thought I deserved my true grade, but I did not want to make a fuss for fear of being labelled disruptive.

I suspect that my teacher, if not explicitly then implicitly, was holding fast to the 'anonymous body' which underscores the 'normative shadow of phenomenology'. She was certain that the other student's bodies were similar to hers, and adhered to this phenomenological template. It was obvious to her that my body was abnormal. The empirical fact of my higher grade as compared to others mattered little, normative expectations needed to be restored, and consequently my score was lowered. My lowered grade reflected the reality of my abnormal body.

This encounter with my teacher illustrates what Bauman (1993: 155-156) would call the art of 'mismeeting' which entails the act of preventing the physical space in which one moves from becoming a social space - a space with rules of engagement and interaction. Like Tracy Latimer as mentioned in the previous chapter, my remaining in this place was dependent upon others tolerating my existence. The teacher and the other students tolerated me as long as I knew my 'place'. The teacher and other students set the limits of their interaction with me. When I have related this story to others they have protested that I had rights, but in order to exercise one's rights a person has to have choices. My parents and I realized that with only one elementary school in the community, if I wanted to change I would have to be transported to another school in another town. Given that such a move would place added physical pressure on me, my parents felt the option was unacceptable. Moreover, there was no guarantee that my school life would be better at a new school. I would still be the crippled student among an able-bodied population and might have to endure discriminatory actions, with the added physical toll on my body brought about by travelling to school thirteen miles away.

Ironically, while I was the faceless shell of humanity within the confines of the classroom, outside its parameters I was the repugnant abject other that must be put in its place. When I walked to elementary school a group of boys would throw stones at me. Sometimes I would fall but have to stand up before they pounced on me. Even when I maintained my balance I felt the sting of the stones on my face as I proceeded, running the gauntlet. Whether in the classroom or walking to school I was shunned. The act of mismeeting was a cognitive reaction to my presence within the class. The teacher and the students had to make sense of my presence or ignore it. By ignoring my presence they effectively re-established the normative parameters of the classroom. My being stoned was a response to my actively forcing myself upon individuals and the education system. With limited resources, some of my classmates relied upon physical violence to try to dissuade me from entering their space.

Day after day while this ritual was repeated, I glanced over and noticed that another group of boys would be engrossed by this spectacle. I was afraid to make eye contact with them as I did not want to exacerbate the situation by bringing attention to myself and provoking them to join my antagonists. Eventually, these spectators intervened on my behalf and protected me. Initially, they were drawn to me because they thought I was either brave or crazy; either way they wanted to be friends with me. Over time the speculation about me as crazy or brave was replaced by an

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engagement with me which facilitated an acceptance of my 'different way of being' and resulted in a solid basis for friendships that, with few exceptions, still last today.

Certainly, most nondisabled people have to adjust to a different way of being in the world if they want to engage with a disabled person. In order to prevail over my isolation I had to help other students overcome their anxiety about my being the abject other. Having some of my schoolmates consider me as either brave or crazy allowed an opening from which I could engage with them. In Deleuzian terms, we formed machinic assemblages whose desire spread and made connections with desires emanating from other students. Over time the other students accepted me as a member of the class.

One incident stands out in my mind as an example of my acceptance. Our teacher allowed us to exchange our tests with other students for marking. After marking each other's papers we handed them to our teacher to be checked for accuracy. Originally, I exchanged papers with a fair-minded, strong-willed girl named Grace. Having marked my paper, Grace knew I had answered all the completed questions correctly. Upon receiving my paper from the teacher I was saddened to see my mark had again been readjusted to a barely passing grade. I took action and let my paper with its adjusted grade fall close to Grace's desk. As she picked it up from the floor, she noted the lower grade the teacher had given me. She rose from her desk and asked why I had received an undeserved lower mark. The teacher explained to Grace that she did not want to embarrass her and the other pupils by giving me a higher grade than them. Grace led the other students in their insistence that my papers be marked like those of all the other students. In this particular incident my engagement with others led to my being graded fairly.

It seems ludicrous to suggest that a fundamental shift in the attitude towards me was brought about by a becoming that derived from a fleeting glance between me and those boys watching me on the hill; however, a glance can be powerful. Casey (1997) claims that the glance can be subversive as it disrupts the prescriptive social order and unsettles the norm. He asserts that (1997: 92) 'the glance can topple whole kingdoms, just as it can also build them up.' In respect to my situation, the glance which is underscored by desire allowed for the boys from the hill to tear down the ableist attacks perpetuated by other boys in my class. This assemblage between me and my rescuers allowed me, in the nomadic sense, 'to build up', if not a kingdom, a sense of community based on friendship.

Casey (1997: 92) adds, 'But the glance is not just a wary surveyor of the possible future: the glance not only goes out to the future in advance but also *awaits* its happening and actively *escorts* it into the present. Beyond the active reaching out of its initial action, the glance engages in a receptive moment of attending to what is beginning to happen, taking in the new surface of its emergence.' Years later I remember having a conversation with one of my benefactors who intervened that day. He told me that he and three other boys would watch me waiting to see if I would notice them. The day that he saw me glance towards them he knew we would be friends in the future.

As Casey (1997: 92) suggests, the insertion of the glance can result in a destabilising not only of the social world, but also of its inhabitants. The glance can create a space for restless subjects. Perhaps I was like a virus that indirectly inserted itself into the social and perceptual world which, prior to my arrival, had been purely able-bodied (to the extent that there were no other physically disabled children in the public realm). Or perhaps I served as an inoculation to the mundane normality experienced by those 'restless subjects' on the hill who gave me, or returned a glance.

Like the 'old idiot' who strived to find the rationality of his own sensibility, I tried to find my place in a world that privileges an able-bodied sensibility. The glance led to an assemblage which provided the impetus for Grace to confront the ableism of my teacher. With my acceptance I realised that my understanding of the world could be incorporated into this society. My continued acceptance and incorporation into this able-bodied centre required that I continually prove that I am rational in being and thought.

With the exception of when I was an infant, the medical profession has never labelled me as a 'developmentally handicapped' person. However, in my daily interaction with strangers I have often been mistaken for a developmentally handicapped person and subsequently have experienced humiliation at their hands (Clare, 2001 has faced similar discrimination). One incident in particular illustrates how the categories of 'special' and 'inferior' have been invoked simultaneously as a reason to invalidate my recognition as a human being who is capable of making my own decisions.

Presence and Absence within the University

At the University of Victoria as a graduate student my course of study was year round. During two weeks in the summer the university's track and field facilities were used by an organisation sponsoring athletics for developmentally handicapped people. The cafeteria usually used by students for these two weeks was reserved for these athletes. We students had to dine in a smaller cafeteria located below the cafeteria where the members of the track meet dined.

One evening I had walked to my table with my tray in hand and sat down to begin my supper. As I was taking a bite of my meal, I felt two pairs of hands grabbing me. As they grabbed me and attempted to separate me from my seat, they scolded me for being in the wrong cafeteria. Shocked I looked up at the people accosting me and politely told them they were making a mistake: I was a student at the university. They told me, 'Now, now! We know you're special and you may want to be a student, but there is no way you could be a university student. Now be a good boy and come with us.' Somewhat sternly and in a patronising manner they had invoked the identity 'special' to coax me to leave the cafeteria. When this ploy did not work for them they made an attempt to lift me again and tried to forcibly remove me from the premises. When I vehemently protested their treatment of me by yelling, they became angry with me and told me that these students were too busy and I had no right mixing with them. In effect, they were invoking the continuum of humanity to emphasise my inferiority, to shame me in order to make

me compliant to their demands. I freed one hand and reached for my student card and made an attempt to prove my identity. Without looking at the picture on the card, they accused me of stealing it.

A floor-mate of mine happened along and vouched for my identity as a student. They let me go but warned they would be back. Later, with another individual they reappeared at the doorway to the cafeteria and began pointing at me and talking excitedly. Finally with a shrug of their shoulders they left. I never received an apology; perhaps they felt I was unworthy of one. By the shrug of shoulders, I can only surmise that they still felt I was an inferior being who was a problem for someone else, not for them. After all, whether I was 'inferior' or 'special' in their eyes I could never be a bone fide university student or even an 'ordinary man'. They read my body and sensibility through the filter of the 'normative shadow of phenomenology'. For them it was inconceivable that I could be a student, because they felt my 'appearance' and 'embodiment' was typical of a 'developmentally handicapped' person. This normative shadow was so ingrained in their psyche that they believed their only mistake was assuming responsibility for me.

Based on their own aesthetic views of what it meant to look and be a 'fully -functioning human', these individuals who accosted me had invoked the dichotomous and mutually exclusive categories of disabled (inferior) and nondisabled (superior). While I was angry about the disrespectful treatment I endured, I was frustrated by the fact that my life and those of other disabled people must continually be justified. Because most people uncritically accept a nondisabled sensibility as 'normal' and as the privileged position, I must justify my presence by proving that I am not developmentally handicapped.

In having to prove that I am not developmentally handicapped, and thus drawing attention to this distinction between them and me, in the eyes of my antagonists I unwittingly justified the belief that developmentally handicapped people are inferior. In doing so I reinforced the continuum of disability and humanity that I vehemently oppose. To remain silent (in this circumstance), however, would have meant non-resistance to their coercive and demeaning behaviour. In the minds of the people who accosted me, both I and the other developmentally disabled individuals present on campus were the abject other, a status which warranted their control over our bodies and our personhood. For the staff responsible for the participants of the track and field games the dichotomous view of disabled / nondisabled remains intact with the privileging of a non-disabled aesthetic over that of a disabled aesthetic. Such a dichotomous position fails to even consider or question this notion of normality or the act of abjection. The people who grabbed me restricted my identity to the being of a developmentally handicapped person. In order to continue my striving for acceptance in this rational society, my only recourse was to deny this being framed as a developmentally handicapped person and reframe my being as a legitimate university student.

As I have mentioned already, Deleuze and Guattari (1987) make a distinction between being and becoming, and in the above incident the discussion was framed within the concept of being. This notion of being leads to ranking or scaling of bodies (Young, 1990a). At the time of this incident

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my focus was on being an 'old idiot' and trying to assert that I could be rational within the dichotomous framework of disability/ability, to the extent that I was responding to the dominant ideology of normality. Unfortunately, unwittingly I was placing myself at a higher level on the continuum of humanity by producing my student card, which to some extent I had hoped to give me legitimacy in the eyes of my accusers.

Being out of 'place' within academia was not an uncommon experience for me. During my doctoral studies I was waiting outside a lecture hall to meet a friend for supper. A woman walked by me and asked if I was attending the talk in the lecture hall. I replied that I was not there for the lecture. For the first time she surveyed my body and said, 'Of course not. You're the janitor'. She excused herself as she brushed by me. I was flabbergasted and left speechless at her presumptuous attitude. I peered through the window at the audience that prepared to listen to the lecture and noted it was a diverse crowd with one notable exception, there were no visibly disabled people. Ironically, the lecture was on how to encourage diversity in the humanities. The above incident reminded me of the experience of Patricia Williams (1991: 44), who writes:

> Buzzers are big in New York City. Favored particularly by smaller stores and boutiques, merchants throughout the city have installed them as screening devices to reduce the incidence of robbery: if the face at the door looks desirable, the buzzer is pressed and the door is unlocked. If the face is that of an undesirable, the door stays locked. Predictably, the issue of undesirability has revealed itself to be a racial determination.

Williams was denied entrance by a salesperson who assumed that, since she was African-American, she was potentially a robber. She became enraged and explains (1991: 45-46):

> I am still struck by the structure of power that drove me into such a blizzard of rage. There was almost nothing I could do, short of physically intruding upon him, that would humiliate him the way he humiliated me. No words, no gestures, no prejudices of my own would make a bit of difference to him; his refusal to let me in the store - it was Bennetton's, whose colorfully punish ad campaign is premised on wrapping every one of the world's peoples in its cottons and woollens - was an outward manifestation of his never having to let someone like me into the real of his reality. He had no compassion, no remorse, no reference to me; and no desire to acknowledge me even at the estranged level of arm's - length transactor. He saw me only as someone who would take his money and therefore could not conceive that I was there to give him money.

> The violence of my desire to burst into Bennetton's is probably quite apparent. I often wonder if the violence, the exclusionary hatred, is equally apparent in the repeated public urgings to blacks to understand the buzzer system by putting themselves in the shoes of white store owners- that, in effect, blacks

look into the mirror of frightened white faces for the reality of their undesirability; and that then blacks would 'just as surely conclude that [they] would not let [themselves] in under similar circumstances' (That some blacks might agree merely shows that some of us have learned too well the lessons of privatized intimacies of self-hatred and rationalized away the fullness of our public, participatory selves.)

There are differences between my story and that of Williams. The salesperson had a position of authority (albeit misguided), whereas the woman who spoke with me had no authority. Williams had a purpose, the purchasing of a gift, for entering the store. Her exclusion stopped her from concluding her task at hand. My exclusion was not a matter of blocking my entrance to a place or space but a prior imposed sanction against me because of my physical appearance. Nevertheless, there were similarities in Williams' and my stories. We are both outsiders in the figurative and literal sense. Bauman (1993: 162) argues that 'outsiders' are ascribed traits that signify ambivalence, irrationality, uselessness. They epitomize the chaos that all social spacing aims staunchly yet vainly to replace with order. Thus there was a need for the person who denied us access (in a literal sense in Williams' case and a metaphorical sense in my circumstance) to make sense of our being in a 'place' where our ascribed traits meant we were excluded from participation.

Both of us told our stories more than once. Williams' (1991: 46) first story consisted of a big poster which she posted on the window of the store. The second story consisted of her attempt to publish an article about the incident. The emotion and any reference to the Bennetton store or to race was edited from subsequent drafts of her article. Her third story addresses what Williams (1991: 48) calls, the 'era of double-speak-no-evil' where exclusion from participation in society is done with a 'smile, a handshake, and a shrug,' where the phantom-word race is never mentioned.

Since the time I was mistaken for a janitor I too have related the story to individuals and groups of people. Often when I speak to a group the reaction depends upon whom they identify with. Some people are outraged by the insensitivity shown me. Others argue that I am overly-sensitive and that her evaluation of me has nothing to do with ableism. After the crowd disperses others have related that they have encountered similar experiences. I have related this story to individuals in an attempt to continue to reflect critically about ableism. One particular conversation illustrates the polite exclusion of my disabled presence.

I met a professor who in the past had expressed some interest in disability issues. I related my experience outside the lecture hall. When we talked, I happened to be wearing a blue-jean shirt and blue-jean pants. He listened to my story and then asked if I were dressed similarly the day of the incident. Perplexed, I replied that I didn't remember, but it was entirely possible that I was wearing similar clothes. In a condescending manner he replied that the woman's response was not only understandable but justified, because to her I would look working-class, like a janitor. I smiled as I noticed he had on both a blue denim shirt and blue denim jeans. After drawing his attention to his clothing I asked him, when was the last time he had been mistaken for a janitor?

Looking insulted, he retorted, 'That's different' I replied, 'Exactly' and walked away. My retort 'exactly' was not meant to be or was not taken by him as an affirmation or an agreement with his position, but seemed to unsettle his assuredness in his position. He hurried away visibly uncomfortable in my presence.

By invoking the phrase 'that's different' the professor was making a clear distinction between himself and me. The distinction between us was not our clothing but my sense of being that designated me as the abject other. In his eyes it seemed that it was entirely possible for her to mistake me for a janitor, but it was implausible for him to be mistaken for a janitor. Both of us are white middle-aged men, the only difference between us is our bodies and how each is read. My disability does not allow me to carry myself in a manner that can be read as rational and authoritative; his nondisabled body is read as the pinnacle of rationality and authority. The explanation of my being a janitor, with its working class connotation, glossed over and obscured the underlying ableism that many people experience when they face a disabled person. Williams notes the polite handshake, the smile that deflects attention from the issue of racism; so too the invocation of working- class as an explanation deflects any criticism of the act of abjection.

If she were to challenge the underlying racism behind the smile and the polite handshake, Williams (1991) would be labelled as being ungrateful for not accepting the friendly gestures from other people. For me to inform the woman who entered the lecture that I was a doctoral student instead of a janitor would reduce the discussion to a matter of a mistaken identity without addressing the underlying issue of why she would make such an assertion. Moreover, when I have corrected people's ableist assumptions from the perspective of individual interaction, my intervention has often been interpreted as my attempt to raise my stature in their eyes. For example, had I protested to the woman and informed her that I was a doctoral student, more than likely she would have assumed that I was ashamed to be considered a janitor and wanted to set the record straight in terms of my status. In similar circumstances, others like her have congratulated me for overcoming my disability instead of examining their own ableism. Assured by the normative shadow of phenomenology, people recognize students intuitively and feel free to 'pass' judgements on those individuals who do not fit this prescriptive mould.

By ending my conversation with the professor with the retort 'exactly' to his assertion 'that's different', I attempted to shift the focus from the rhetoric of my 'overcoming' a disability to emphasize his use of the phrase 'that's different'; I hoped perhaps to force him to examine the normalising assumptions which underscore that difference and by extension the ableism that creates a gulf between us. By removing myself from our interaction both physically and intellectually, I refused to be drawn into an explanation of this difference from the perspective of the 'exotic' disabled person. My distancing myself from the conversation placed the onus and the impetus on a nondisabled person to examine the ableism inherent in his attitudes and beliefs.

Initially, I had believed in rhetoric, that through dialogue I could possibly educate people who devalue a disabled sensibility and their ableism could be overcome. But now I follow the lead of Guattari (1996: 23), who believes that nothing can be accomplished by an exchange of information between speaker and listener. Often I noticed a disturbing trend whenever I attempt

to partake in any discussions concerning disability. At some point during the conversation the focus will shift from the systemic and individualistic problems of ableism to a discussion about how disabled people, including myself, can continue to overcome their own personal tragedy. My moving away from such interactions allows me to choose whether it is better to be present or absent from the discussion.

Furthermore, I reframe a power differential whereby in the past other people have used my presence as a means or a foil to discuss overcoming narratives. Instead, I reinstate my own power and presence by refusing to engage in a dialogue that often deteriorates into reaffirming ableist assumptions by seductively confirming my ability to overcome. For example, by disengaging I left the professor to wallow in his own ableist assumptions and offered him the chance to question what I meant by my invocation 'exactly'. By leaving I had turned on its head the assumption that I eagerly awaited his affirmation of my presence or my interpretation of the event. Whether he realised it or not, I was telling him that the validation of my presence was not dependent upon his acknowledgement of me. Moreover, it did not matter whether he realised why I had left; my presence or absence is determined by my validation of my cerebral palsy, not his estimation of the validity of my explanation. As an 'old idiot' who wanted to be accepted in this rational world I could not have confronted this professor for fear of being outcast.

Accommodation and Accessibility Within Universities

The education system encourages 'an old idiot' mentality in its integration of disabled people. There is reliance upon an ideology that continues to sees someone who has a disability as having a deficit. Accommodations are implemented in order for the disabled student to compete as if she or he were able-bodied. Second, a cost effective analysis is conducted to determine if the financial commitment required for the student is acceptable. Emily Eaton, who experiences cerebral palsy, was denied access to a regular school because accommodations for her were deemed too expensive. Her parents have sued for the right for her to continue to attend an 'ordinary school'. (Claridge: 1995, A2) states that in her decision, appeal court Judge Arbour observed that in a segregated class Emily 'would have fewer opportunities to learn how other children work and how they live. And they will not learn that she can live with them and they with her'. Claridge (1995: A2) continues, also, Judge Arbour argued that 'forced exclusion is hardly ever considered an advantage. Indeed, as a society, we use it as a form of punishment'.

Throughout my university life there has been an assumption that if any accommodation concerning a person's disability is granted then they have achieved either academic equality or have an advantage. Earlier in my life accommodations were negotiated informally between me and the teacher. Today accommodation has been institutionalised. In all Canadian universities there is an office that disabled students are referred to in order to apply for accommodations for their disability. On the positive side, this institutionalised accessibility policy allows for people to have accommodations for their disabilities if they have appropriate documentation. However, the shift from informal negotiations to institutionalised accommodations becomes an apparatus of capture (Deleuze and Guattari, 1987).

Applying for accommodations is not a simple process because pedagogical discourses that underpin our educational system continue to privilege an able-bodied sensibility over disabled sensibilities. The premise of accommodating 'students with disabilities' (the official jargon for most universities) (Titchkosky, 2000) is that the accommodations level the playing field, in that the disabled student's testing procedure and means for evaluating his or her work will be equal to the standards of his or her able-bodied peers. On the surface, this procedure seems to be equitable, but I would argue that the process of providing accommodation, as well as the assumptions that underscore this process, devalue a disabled sensibility and in Deleuze and Guattari's words create an apparatus of capture.

At my current level of education I have been registered at three universities. At each of these universities I had to provide medical documentation and segregate myself from the rest of the student population in order to receive accommodations, submitting myself to an ancillary process of bureaucracy. Moreover, during my undergraduate and Master's degrees the office for students with disabilities was incorporated in the counselling services department. As I explained earlier, I reject the concepts of disability and non- disability. I reject the concepts of normality and abnormality. Yet, in order to receive accommodations I must not only accept the category of disability but provide proof that I am disabled. I explained to one counsellor my reluctance to see a medical physician. I stood up and said, 'Can't you tell that I am disabled?' She agreed with me but reiterated that I required medical documentation. Before standing I too realized that I would have to acquire medical documentation, but I wanted to stress that sometimes bureaucratic procedures are in themselves obstacles for disabled people. The process of acquiring medical documentation can be very difficult for some disabled people, such as me, who have not seen a specialist for many years. Moreover, even if a disabled student has a physician whom they see regularly it requires some investment in time to acquire documentation. If the student already has legitimate documentation, then the student must decide whether or not they want to self identify as a student with a disability, especially if she or he has an invisible disability such as a learning disability or a less visible disability as chronic pain.

Furthermore, throughout my university career I have come across the perception that disabled students are not really academic scholars but are there to fill a minority quota. So pervasive is this opinion that when I applied for my M. A. I did not inform the sociology department about my disability until I was accepted into the program. Ironically, it did not matter that I had not self identified; other students assumed that my acceptance (at least partially) was based upon my disability (Overboe, 1994). Ironically, this experience planted the seed for my topic for my M.A. thesis.

Butler (1997: 136) asserts that, 'The link between survival and speakability is delineated in the speech that constitutes the inauguration of the self-denying and repentant homosexual into military ranks: I am not what you suspect me to be, but my not being that is precisely what I have become, thus, determined by my denial, my new self-definition'. For disabled students, especially those with less visible disabilities, there is tremendous pressure to 'pass' as able-bodied. The offices for students with disabilities that I have dealt with all had policies to maintain the confidentiality of the student. But, as I mentioned earlier, at two of the universities the office which dealt with disabled students is located within counselling services. So the

student who enters this department is either receiving counselling or accommodations for a disability. Given that some people are stigmatized because of their disabilities students may decide not to register with the office. Or perhaps they may not want to be perceived as needing counselling. Even if the student is not bothered by being perceived as disabled, the process of being registered as a student with a disability is a bureaucratic procedure that other nondisabled students do not have to endure. The process of acquiring and receiving accommodations adds an extra burden to what Wendell (1996) calls 'doing disability'. I have heard from disabled students who have opted out of registering as a student with a disability because they feel it is another bureaucratic hoop they must jump through.

Often when I have presented this argument to the appropriate officials I've been told that all students throughout their university careers are faced with obstacles that impinge upon their studies and must be overcome, including deaths in their family, a break-up with their girlfriend or boyfriend, financial difficulties, relocating from one place to another. While disabled students may or may not have to deal with precisely the same issues a death in the family, a break-up with a significant other, and relocation, all of these are more difficult for them given their disability. Such traumatic events, as well as the mundane aspects of life such as eating, and getting from one place to another, are often exacerbated by the process of acquiring and receiving accommodation. As McIntosh (2002) and Overboe, (1994) argue, disabled students are subject to Foucauldian surveillance, examination and the 'normalising gaze'.

Throughout my university career I have been concerned about the number of disabled students who choose not to register with disability services. At each stage of my university career I have been actively involved with student participation in trying to improve life for disabled students, which has included my input in services for disabled students. When I have mentioned my concern about the number of disabled students who choose not to register with disability services, people involved with the services have pointed out how unfortunate it is that even one student with a disability would decide not to register with their services. But they argue that it is a trade-off: the hassle of registering for the benefit of receiving accommodations. They invoke the principle of self-determination and the concept of 'freedom of choice', pointing out that each student has the right to refuse services.

But this rhetoric of rights does not recognize that the refusal of accommodations or acceptance is not much of a choice for students with disabilities. Having to choose between feeling devalued by exposing yourself to stigmatisation, or feeling exacerbated by the Foucauldian disciplinary practices of the bureaucracy, or writing a term paper and exam without accommodation is not much of a choice. Ironically, at times without further stigmatisation or the added burden of 'doing disability', I have been able to negotiate accommodations informally with the instructor, only to discover that my arrangement contravenes university policy. I have been forced to meet with the disability counsellor in order to receive previously agreed accommodations for my disability.

The second difficulty I have with the institutionalisation of accommodation for disabled students is the underlying normative expectations of a meritocracy that contravene the acceptance of

diversity within the university. The accommodation of disabled students is premised on the of a hierarchy of merit, the assumption being that if we level the playing field in regard to impairments, we would legitimately be able to rank students. But, as Young (1990a) points out, embedded in the concept of meritocracy are the practices, behaviours, and attitudes which favour a rational demeanour often associated with white able-bodied males.

I want to be careful here and not leave the impression that I am suggesting that other people are incapable of being rational like white males. People of other cultures, other ethnicities, other races and other genders, and disabled people may of course have attributes valued by the notion of meritocracy. However, my point is that when meritocracy is defined in such a narrow template only those people whose intelligence can conform to this template (people who are able to operate within a rational context) can compete; others who may have another way of accessing intelligence must subsume their 'ways of knowing' (both physically and mentally) in favour of an intelligence which privileges rational thought. As pointed out earlier, those who cannot conform to rational thinking, or refuse to, are deemed inferior.

Applying the insights of Deleuze and Guattari (1987) to the topic of accommodation, I argue that while on the surface accommodations seem to be beneficial for disabled students and often are, their bureaucratic function is to act as an apparatus of capture which restores the normative values of the majoritarian view of the university. The apparatus of capture works in the following way: first a disabled student applies for accommodation and is accepted as a student with a disability with certain rights and obligations. This acceptance legitimizes the student's right to accommodations. Then the process begins on how to even the playing field, so that the student can demonstrate his or her ability to think rationally. As a doctoral candidate who has successfully completed two degrees, I am often invoked as the success story for accommodations for students with disabilities. I am able to argue rationally, logically, and with some critical insight, which is given me considerable cultural capital. But what part of myself do I avow? What part of my other intelligence have I had to subsume and lose in order to succeed? This apparatus of capture is not coercive, nor is it detrimental to disabled people who succeed. In fact, some disabled people or people who work with disabled people have argued with me that these normative values are positive for people with disabilities. But again, such an argument reiterates a continuum of disabled people and devalues the differing sensibilities of other disabled people whose intelligence gives real meaning to diversity and difference.

The consequent affirmation of successful gimps and cripples has immediate consequences for the reification of the status quo. As Butler (1997: 137) explains, 'Regimes of confessional discourse structure the way in which policy issues are framed ... narratives of individuals who heroically overcome adverse circumstances ... triumph over any analysis of systematic institutional discrimination in education.' At a conference to improve the Faculty of Graduate Studies, two administrators at a forum for disability issues invoked us successful disabled graduate students as evidence that the university is successfully implementing a program of inclusion. Our silence would have been construed as tacit agreement. I argued that our success as graduate students has been in spite of institutional efforts. We all agreed that the road of our success was strewn with equally deserving disabled people who had failed to achieve. A university education remains an obstacle course for disabled students.

Addressing the issue of racism within universities, Williams (1991: 49) argues that there is a pervasive racism that people attempt to avoid, brush aside, and do not acknowledge. Moreover, she asserts that there is emptiness in the formal equal opportunity policies which facilitate avoidance by circumventing the issue. Williams argues that this pervasive racism in which the tradition of the university is steeped, its culture and ambience, needs to be acknowledged. Similarly, I would argue that formalized accommodations for disabled students often circumvent the lived experience of disability by failing to recognize that it is dynamic, and ever-changing. Moreover, I contend that an unacknowledged and unspoken culture of ableism permeates all aspects of university education. I believe this ableism must be acknowledged within universities. There is a need to acknowledge a disabled persona or presence that cannot be reshaped as a reasonable facsimile of able-bodiedness, conforming to the liberal individualistic notion of a successful university student, or refuses to do so. Nor is there acknowledgment of the wisdom which may derive from a disabled sensibility. Instead there are formal procedures and regulations to which prospective disabled students must adhere. Too often I have heard from students that the vivacity of their lives and their disabled sensibility is lost within this bureaucratic maze.

The Ableism Inherent in Mentoring Programs

I have been reluctant to act as a mentor for novice students within these institutionalised settings. My reluctance stems from the inherent ableism which underpins this utilitarian process of self-actualisation. These mentoring programs emphasize the modeling of characteristics that mirror those of the able-bodied rational human - the prototypical successful rational university student - while devaluing any wisdom that stems from the student's disability (especially a wisdom that contradicts this rational discourse). Certainly one can argue that the mentee is not obliged to follow the exact course of the mentor. But by focusing upon aspects of the mentor's behaviour, attitude, and being that reflect the qualities of an able-bodied person, to what extent does the mentee learn to subsume the vivacity of his or her disability (or even worse devalue it) in order to follow a pattern of success? I also question to what extent my success in academia deflects any criticism of the systemic ableism inherent within it. Put another way, how do the reasons I was asked to be a mentor - that is, my successful image - make me complicit in maintaining the obstructions that often negate the validation of other disabled sensibilities? Lastly, a formal institutional program of providing a mentor for other disabled students inherently distances me from the fledgling students because of the imposed hierarchical relationship.

Harilyn Rousso had an experience that changed her life. I believe it exemplifies the notion of making a machinic assemblage with another disabled person. Rousso (1988:2) writes,

> When I was about twenty-two, I had an unexpected important experience. I worked one summer for a prominent woman economist who happened to have cerebral palsy. I can't tell you my surprise when I met her at the job interview. It was a bit like looking at my self in the mirror. Betty had a powerful effect on me. I was impressed that a woman with cerebral palsy, not a very socially

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acceptable disability in our culture, could become so successful in her career, particularly in a 'man's-field,' anti-trust economics. I was even more impressed that she was married.

The relationship between Betty and Harilyn illustrates Deleuze and Guattari's (1987) concept of becoming. A connection that creates an assemblage between Betty and Harilyn resulted from an improbable meeting - what Deleuze and Guattari would refer to an 'improbable chance' making the impossible possible. This improbable chance created an assemblage that allowed for the embodiment of cerebral palsy to find a place within the field of economics and the institution of marriage.

The improbable chance of Harilyn meeting Betty confirmed for Harilyn that it is possible not only to be successful in your chosen career, but also to be married as well. The machinic assemblage between the field of economics, Harilyn, and Betty allowed a line of flight or reterritorialisation from normative expectations that devalue the lives of people who experience cerebral palsy. This machinic assemblage results in a minoritarian becoming and allows for a different expression of life. In the specific lives of Betty and Harilyn there is a singularity of becoming. The singularity of Harilyn came to the forefront and exceeded the restrictive template of normative shadow of phenomenology, which is an able-bodied, heterosexual and presumably male prototype, especially in the context of the field of Economics. While this singularity of Harilyn Rousso allowed Rousso to marry and have a career, I do not want privilege heterosexual normality. As Pat Califia (1997) and Eli Clare (2001) point out some disabled people seek out, and are content with relationships that do not conform to the heterosexual normative.

But, as Patton (2000) and Massumi (2002) attest, the singularity of becoming can manifest itself into a larger expression of life. Consequently, the pragmatic experience of Harilyn and Betty, both having children and careers, can create in other people's minds a revisionist view of cerebral palsy which values its sensibility rather than devaluing it. The convergence of disability with queer 'sexuality', as demonstrated by Califia and Clare, creates a singularity that exceeds the heterosexuality normality.

There are differences between the bureaucratic mentoring for disabled people which takes place in universities and the machinic assemblage that took place between Harilyn and Betty. First of all, the mentoring exercise in universities is somewhat prescriptive. There becomes a recognized way in which disabled students can become successful - the taking on of characteristics of the body and sensibility of phenomenology that are valued, while understating or down playing characteristics of a disability which do not correspond with characteristics associated with normality, such as the uncontrolled body. One might argue that of course an individual wants to be able to control his or her body, but I have argued elsewhere (Overboe, 2001) that my spasms have an 'embodied wisdom' that is devalued within university settings, as well as elsewhere.

From the perspective of Deleuze and Guattari, the relationship between Harilyn and Betty is based on the desire that flowed and created the machinic assemblage which flew in the face of

conventional wisdom and normative expectations. In this sense the relationship between mentors and mentees is majoritarian in nature, in that it is a process of helping another disabled student become successful within the university - an institution of socialisation which privileges an able-bodied sensibility. In contrast, the relationship between Harilyn and Betty is minoritarian in nature because this becoming unsettled the established worlds of economics and marriage and in turn values the less - privileged sensibility of cerebral palsy. Admittedly, this assemblage may make it easier for Harilyn to navigate the field of economics but this is a secondary benefit.

I began this section by stating that I did not care for formal mentoring programs for disabled students. This does not mean that am not willing to help or be helped by other disabled students. Like the relationship between Harilyn and Betty my relationship with other disabled students is usually defined by our mutual desire to look beyond common sense and the normative and be open to new possibilities for expressions not only of new life, but of those lives that have been devalued. These machinic assemblages are not created through a formal process, but through either me or someone else desiring to make contact and having the courage to initiate an engagement, or perhaps more correctly allowing the desire to flow.

The Facile Acceptance of Difference Within the University

Within the university the rhetoric of difference and diversity creates a facile acceptance of differing peoples. But this acknowledgment of difference does not necessarily result in the overcoming of oppression. For example, Hennessey (1993: 11) maintains that plurality within universities is a method of crisis control. Rather than examining the political and economic powers that exclude different cultures and peoples, difference in cultures is celebrated. By honouring cultural difference, hegemonic members of institutions such as the university are able to deflect criticism from the political, economic, and social structures of the institution. In effect, if the oppressive nature of such structures remains unnoticed and unchanged, then members of the hegemony absolve themselves from any responsibility for oppression.

Agreeing with Hennessey (1993), Erevelles (1996: 522-523) argues that within the articulations of a plurality of difference there is a belief that if only we learn to value difference and realise its position within society all will be well. However, celebrating particular 'roles' by permitting them to coexist within a terrain of difference only speaks to a particular form of 'lifestyle politics' which strengthens the basic ethical tenets of bourgeois individualism. Left unquestioned are the historical, political, and economic conditions that permit only a small minority (read white heterosexual, bourgeois and able-bodied male - the phenomenological prototype) to exercise this material freedom to choose. Others, who either acquiesce or are able to resemble characteristics of this phenomenological prototype, may acquire material goods or status, including a university education.

From the perspective of Gay and Lesbian Studies, Martindale (1997: 145-146) argues that authors must examine the differing theoretical perspectives involved within gay and lesbian studies. Writers should critique the facile acceptance of lesbian and gay studies as either 'a

special event' or 'a celebration of an alternative lifestyle,' both of which diminish and effectively erase the political and intellectual accomplishments of many women working in feminist and lesbian studies. Effectively, lesbian and gay studies are relegated to the margins of university courses or added on as an afterthought. Best and Kellner (1991: 213) warn that the politics of identity can be utilised to re-marginalise minority people by redefining their difference as a 'harmless politics of style and personal identity that leaves relations of domination intact and unchallenged.'

Baudrillard (1993:125) asserts that 'the other is all of a sudden no longer there to be exterminated, hated, rejected or seduced, but instead to be understood, liberated, coddled, recognized'. Earlier, I argued against the utopian vision of modernity and agreed with Baudrillard (1993), who seems to argue that the 'politics of difference' is like a utopian puzzle. First, dichotomous pairs are artificially created through the press of categorization and then the challenge becomes how to assimilate these pairings into one utopian picture. He asserts that (1993: 128) 'difference itself is a utopia: the idea that ... pairs of terms can be split up is a dream- -and the idea of subsequently uniting them is another.'

But in order to have assimilation there must be a currency of commonality which can be exchanged. Invariably, able-bodied people try to make sense of disability and in doing so seek this currency of commonality. If they are unsuccessful in their search, then it is best for everyone concerned to eliminate or obliterate the damaged goods. As Baudrillard (1993: 128) argues,

> 'Wherever exchange is impossible, what we encounter is terror. Any radical otherness at all is thus the epicentre of a terror: the terror that such otherness holds, by virtue of its very existence, for the normal world. And the terror that this world exercises upon that otherness in order to annihilate it.' In short, underscoring the celebration of difference is potential violence if individuals cannot prove that they are able to achieve the common currency of normality.

Just as normality requires the abject other to confirm their status position, inclusion requires exclusion, and representation requires discrimination (Baudrillard, 1993: 128). Or as Deleuze and Guattari (1987) argue, there is a 'this' and a 'that' categorization which maintains the social order. Baudrillard, (1993: 129) writes, 'Racism does not exist so long as the other remains Other, so long as the Stranger remains foreign. Racism comes into existence when the other becomes merely different. Underlying this 'mere difference' is a fear that the other is 'dangerously similar'. I argue that a 'politics of difference', or even more specifically disability politics with its insistence upon the categorization of a 'person with a disability', creates a bland facsimile of the able-bodied person. The difficulty for able-bodied society is when a disabled person cannot reach normative expectations, so that again there is terror. Or the disabled person refuses to accept the position of abject other and encroaches upon the normative world, but on her or his terms. These terms entail the validation of a disabled sensibility and rejection of ableist attitudes which privilege an able-bodied sensibility. In short, I agree with Cheryl Wade (1994) who argues that this emphasis on independence has created a new image for disabled people - the abled -

disabled. Wade (1994: 35) writes, 'What was missing in the political identity, abled - disabled crip identity was a true esteeming of the Cripple body.'

The new image of the 'abled-disabled crip' has its roots in the valorisation of the liberal autonomous individual of the civil rights and other minority movements. Gadacz (1994: 80 - 81), who employs Habermas's framework, believes the disability movement would benefit from a sense of community that within a 'life-world' recognises differing societies as having differing types of collective discourse. Each of these differing societies learns to interact with each other through 'purposive-rational' discourse. However, I feel that the purposive-rational discourse can be criticized because it relies on a normative liberal individualism cloaked in humanistic essentialism which negates certain disabled people.

Similarly, early on in the course on social inequality which I have taught, I confess to the class that I am unsure whether or not teaching about social inequality reifies social inequality. In Chapter Three, I critiqued the invoking of the category of post-personhood, because its invocation creates a discourse or frame reference that is merely ableist. Likewise, in studying racism, sexism, homophobia, and ableism there is always the normative shadow which privileges a white, male, heterosexual, able-bodied template - the benchmark by which all others are judged - and creates a normative shadow which affects the perception of the other. As Baudrillard (1993: 129) writes, 'The biological claims of racism are without foundation but, by making the racial reference clear, racism does reveal the logical temptation at the heart of every structural system: the temptation to fetishize difference'. He continues, 'The fact is that the 'scientific' and rational critique of racism is a purely formal one, which demolishes the argument from biology but remains caught in the racist trap because it addresses a biological illusion only, and fails to deal with ideology *qua* illusion' (Baudrillard, 1993: 131).

There is a disembodiment in the studying of social inequality when it becomes a discussion about categorization. Again, the 'this' rather than 'that' creates a 'difference' that is very disembodied, allowing for a highly cognitive analysis of racism, sexism, ableism, homophobia and so on. Such an analysis creates an illusion of destabilizing the oppression of the other while maintaining a detached examination of the process of creating the 'other'- the rational or scientific critique. As a Nietzschean, Baudrillard has to expose the resentment underlying the benevolent approach of respect for difference. He (1993: 128) elaborates, 'The risibility of our altruistic "understanding" is rivalled only by the profound contempt it is designed to conceal.'

The problem is that the other cannot be completely exterminated, nor can the other be completely assimilated because then they would be completely normal with all the privileges that entails. Yet left alone, the other presents a danger so that through the humanistic essentialism of modernity the other is re- forged. This reforging is a subtler violence that domesticates the 'other'. The colonized become assimilated and their 'vitalism' or singularity that is associated with their own sensibility disappears. During the next stage they are categorized as a 'stranger' using the white able-bodied heterosexual male as the referent point. Finally the 'other' internalises normative expectations in order to move from being a stranger. The 'other' loses himself, and his sensibility, as he or she uses the characteristics associated with

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white able-bodied heterosexual male as a template for success (Young, 1990; Baudrillard, 1993; Bauman, 1993; Sarrup, 1996).

The acceptance of, and accommodation for, students with disabilities in a university is a perfect example of benevolence masking the loathing for a disabled presence that refuses to conform to normative expectations which privilege nondisabled sensibility. By the time disabled students are admitted to university most of them have lost themselves (as disabled persons who value their own aesthetic and sensibility) and have become, to varying degrees, examples of 'overcoming narratives' which give them 'cultural capital' (Bourdieu, 1990) and provide an incentive to internalize values associated with a society which privileges able-bodiedness.

Universities also perpetuate the pathologising of Deaf culture, language and literature. Bauman and Drake (1997: 307) illustrate this:

> When Dirkson [Bauman] crossed the border into a Deaf cultural space as a dormitory supervisor at the Colorado school for the Deaf and Blind, he began to redefine his own pathological notions about Deaf persons. The Deaf students and faculty were not isolated and linguistically deprived as he had assumed; rather, they enjoyed a strong sense of community based on an 'official' language. He, not the Deaf became the linguistic outsider. Upon returning to a university setting, Dirksen found that even 'progressive' language and literature faculty did not recognize American Sign Language as an 'official' language or Deaf identity as a cultural identity.

From the perspective of examining the possibility of a queer pedagogy, Haver (1997) and Martindale (1997) argue that the pedagogy of humanistic phenomenology often undermines the incorporation of Gay and Lesbian sensibilities. Haver (1997: 288) believes that within enlightenment pedagogy there are two ways to achieve cultural subjectivity or identity. First, a student becomes her or his cultural self through a mode of abjection, whereby through examination the student learns the error of his or her ways and strives for perfection in order to 'overcome' her or his imperfection. Second, the model of pedagogy Haver (1997: 288) calls sentimental education manifests itself in requiring a student to develop 'self-esteem', which produces comfortable victims and tragic heroes. In both types of pedagogy the student begins and is defined as a lack, she or he must strive to reach a certain type of self - the self of phenomenology. The striving for this phenomenological self is reinforced by 'role models' who are successes at university. Haver (1997) argues that this circulatory process has 'domesticated' queerness.

Similarly, despite some institutional advances (accessibility and accommodation improvements) for disabled people that derive from either a 'politics of difference' or a 'politics of identity' position, I contend that in some respects these concepts in practice replicate the injustices they attempt to subvert. I argue that for disabled students, difference is measured according to its variation from the nondisabled norm. Offices for students with disabilities help to groom a

professional service corps which can work in an able-bodied centered society, and also create a validation for an able-bodied sensibility. Throughout these offices there are informal exchanges of 'overcoming narratives' of successful disabled students which insidiously and subtly provide a template from which other students are expected to acquiesce to in order to be successful. Yet the difficulty is how to find a forum for a presence that is not only different from, but often opposed to, the normative rational voice. bell hooks (1990: 146) asserts,

> Often when the radical voice speaks about domination we are speaking to those who dominate. Their presence changes the nature and direction of our words. Language is also a place of struggle. I was just a girl coming slowly into womanhood when I read Adrienne Rich's words, 'This is the oppressors' language, yet I need to talk to you.' This language that enabled me to attend graduate school, to write a dissertation, to speak at job interviews, carries the scent of oppression. Language is also a place of struggle. The Australian aborigines say, 'that smell of the white man is killing us'.

hooks (1990: 146) remembers how her language was different when she was growing up at home.

> Dare I speak to oppressed and oppressor in the same voice? Dare I speak to you in a language that will move beyond the boundaries of domination - a language that will not bind you, fence you in, or hold you? Language is also a place of struggle. The oppressed struggle in language to recover ourselves, to reconcile, to reunite, to renew. Our words are not without meaning, they are an action, a resistance.

As I mentioned earlier, the language of the university, of everyday life, and of articulation does not express my life, or my sensibility. For me the issue is not a sense of renewal, reconciliation, or even a re-unification of the dichotomous polarities of disability and non-disability. Rather, it is a matter of the sensibilities of disabled people, whether articulate or inarticulate, having a presence within our society without having to prove our normality. Returning to the question of accommodation for disabled students, and taking note of hooks' critique of language, to what extent do universities, through disability offices, reinforce the privileging of certain ways of articulation (both verbal and embodied) over others? Moreover, how does the privileging of language prohibit intelligent but in some sense inarticulate individuals from engaging in higher education? Is it only when disabled people can translate their intelligence into recognized pedagogical expression that they are able to participate in the educational process of university?

Today accommodation for disabled people often concentrates on technology to help level the playing field (Johnson and Moxon, 1999). These technological aids provided for students with a disability are tools to help them compensate for their lack, or remedy the deficiency caused by their disability. Rarely is it even considered that technology should and could be developed to change the normative aspects of the university. Never is it even postulated that this form of

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rehabilitation is wrongheaded and discourages an appreciation of a disabled sensibility (no matter what disability we are speaking about). Consequently, the creation of the pathological disability may be masked by this acceptance of a facile difference, but it still retains its demeaning signification of the abject other no matter how much that other is celebrated.

Conclusion

In this chapter of my life, my reaction to the normative shadow of phenomenology was compliance. Throughout I tried to 'fit in'. At the public school where standardised testing may have been the norm but standardised marking was not, I had to move strategically from the background and find acceptance within the realm of the normative phenomenology. Similarly, at the university cafeteria I felt restricted in that I had to justify my existence to others. But as Deleuze and Guattari (1987) note, desire cannot be contained and I began to critically examine how the education process favours and helps to create facsimiles of the able-bodied phenomenological self which remains the role model for disabled people. The ideology of a 'politics of identity' and institutional offices for 'students with disabilities', assured by common sense and governed by the normative shadow of phenomenology, suppress, repress, and tame the desires that emanate from disabilities. The disabled student learns in order to succeed the desires that he or she suppresses must be supplanted by characteristics that conform to the phenomenological self.

CHAPTER FIVE
A 'NEW IDIOT' EXCEEDS RATIONALITY BASED EDUCATION

Later, another type of private thinker materialized: this 'new idiot' 'has no desire to find truth, instead he or she wants to embrace the absurd, the lost, the forgotten' (Deleuze and Guattari, 1991: 63). Today, I am living a life of the new idiot, in that I have no desire to trace what has been lost in comparison to what has been saved. Nor do I wish to provide reasoning for what is or is not rational. Rather than containing my spasms and trying to become normal, I am nomadic and push 'private thinking' beyond the normative parameters of ability and disability.

To illustrate the difference between the 'old idiot' and the 'new idiot' I will return to the cafeteria story mentioned in the previous chapter. If I were faced with the same situation today, I would shift my thinking from that of the 'old idiot' to that of the 'new idiot'. From the perspective of Deleuze and Guattari (1987), trying to physically force me to leave the cafeteria is an example of striated and hierarchized forces that inhibit desire and my becoming. Becoming entails the navigating of interrelated planes that combine to create our social reality in a pragmatic sense: ones which are striated (those forces that inhibit my desire and my becoming) and others that are smooth (those forces which allow for desire and becoming to flow). Pragmatically speaking, I could have responded to my abuse by giving validation to the non-rational aspects of my life that I shared with developmentally handicapped people; by giving myself a presence, or more correctly a hyper-presence, allowing my spasms and my cerebral palsy to create machinic assemblages. Today, instead of trying to prove my legitimacy to those who wish to exclude me, I would perhaps confront their ableist attitudes.

Confronting the people who accosted me, this notion of machinic assemblages would allow me to consider the subtleties and nuances of my embodiment as well as my lived experience. For example, my viewing myself as becoming allows me in a practical and engaged way to valorise my interdependency on others. Moreover, like developmentally handicapped people I often process information differently than able-bodied people. Also, I have noticed that like me many developmentally handicapped people process information primarily through their bodies. Today, I might have accepted the invitation to sit with the developmentally handicapped athletes and attempted to create an assemblage with them. Perhaps this assemblage would allow for a minoritarian becoming that would perhaps produce a differing type of existence that is not confined to the disabled / non-disabled dichotomy.

Sexuality and Disability

Often I do not have the opportunity to decide whether to confront or withdraw from ableist practices. Often these practices are camouflaged by other concerns. For example, two years ago I was asked to be a discussant for a film in a series about disease, disability, and trauma to be presented at the university. I was unfamiliar with the actual room location and when I arrived on the floor I asked the department secretaries for directions to the screening room. Icily one of them asked, 'Do you need to know the location of that room and what business do you have in

the room?' I explained that I was the discussant for the film to be shown in the room later that afternoon. Reluctantly, they directed me to the room. As I entered the room, I could feel the presence of someone watching me. I looked back and noticed the three office people watching me. I surveyed the room, searching for a clue for their behaviour towards me. I noted that there were three couches in the room and quickly realised that they thought I was a vagrant looking for a place to sleep. They finally relaxed when Alison Pryor, the organizer of the film series who had asked me to be a discussant, arrived and acknowledged me.

Later I related this story to two individuals who were familiar with these staff members. They confirmed that the staff probably thought I was a homeless person because the department had a problem with vagrants sleeping in that room. They provided me with an explanation and a justification for the departmental staff's treatment of me. While it was acknowledged that the incident may have been upsetting for me, the staff's actions were deemed appropriate. The fact that my appearance as a disabled person made it plausible that I might be a vagrant also meant that it was also highly improbable that I had the intelligence to be a university student, let alone a discussant or expert on the film's topic as I had declared. In the eyes of the office staff I was out of 'place'.

Being labelled as a stranger allows for complete disregard for one's humanity (or perhaps it is the restrictive sense of what constitutes humanity that precipitates the notion that a person is a stranger) and thus requires no need for interaction. Bauman (1993: 167) writes,

> In the cognitively mapped social space, the stranger is someone of whom one knows little and desires to know even less. In moral space, the stranger is someone for whom one cares little and is prompted to care even less. The two sets of strangers may, or may not, overlap. So in all likelihood we will go on committing both irrational and immoral deeds - as well as deeds which are irrational while moral, and as such, are rational yet immoral.

Cognitively, speaking as a spastic person whose body broadcast irrationality (Young, 1990a see Introduction); I was deemed out of place. Thus, it may seem completely rational for the office staff to see me as a stranger whom they did not know and had little desire to know, although I had introduced myself. From a moral perspective, my embodiment was a signification that allowed them to care little for me and resulted in them mistaking me for a vagrant. Their response was deemed natural enough; after all, there had been problems with vagrants before.

The films *Sixth Happiness* and *Double the Trouble, Twice the Fun* dealt with sexuality and disability. Like my excursion into the department, the topics of disability and sexuality were 'out of place' in an able-bodied centred society. Ironically, in my view, the theme of presence was prevalent in the films presented. The film *Sixth Happiness* is an autobiographical fiction about the life of a man who experienced octegenia imperfecta. Featuring the same actor in the lead, the second video, *Double the Trouble, Twice the Fun,* deals with sexual intimacy for disabled people. Beginning the discussion, I spoke about how disabled people are presented as a presence

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to be reckoned with, sexually and otherwise. From an able-bodied point of view, some others felt the films are meant to educate the audience about sexuality and disability. I was uncomfortable with the voyeuristic undertones of this educational experience. The analysis of the narrative of the film was secondary to discussion about the fascination/horror that results from the recognition that disabled people are sexual. Or even more disturbing or titillating was the witnessing of this 'unnatural' behaviour on screen.

During the discussion, for example, one participant suggested that able-bodied people might have ulterior motives for their relationship with disabled people. Explicit in this statement is the belief that non-disabled people must have another motivation for having a sexual relationship with a disabled person, because sexual desire for a disabled person did not 'make sense'. Implicitly, the non-disabled person must be compensated in some manner, because having a relationship with a disabled person necessarily would be an unsatisfactory relationship. I offered an obvious explanation, that maybe the non-disabled people are sexually attracted to their disabled partner. She replied that she would have to think more about the issue of disability and sexuality. It seemed to me that there was a desire to 'make sense' of, or understand, something that is deemed problematic or deviant.

Later we discussed specific aspects of each film, and the need to 'make sense' of 'deviant' sexuality continued. The lines between ableism and homophobia blurred, as someone who screened the movie suggested that the disabled lead character, in the film *Sixth Happiness,* had a homosexual relationship because he was unable to sustain a heterosexual relationship. Later, an audience member hypothesized that his bisexual lover could have been a gigolo. Underscoring this observation was the ableist belief that financial reward would be the only reason an attractive man would have sex with a gimp. Simultaneously, the homophobic script that bisexual men are promiscuous and have lesser morals was invoked.

Another participant mentioned that she had previously viewed the film *Double the Trouble, Twice the Fun* that dealt primarily with sexuality. After her initial viewing, she was uncomfortable and felt that the sexual relationships bordered on fetishism. Her opinion of the film changed upon seeing the fictional autobiography that concentrated on family life as well as sexuality. After watching both films she felt that she had a better sense of the disabled actor's humanity, which made his sexuality more palatable. Sadly, another able-bodied person needed to 'make sense' of a disabled person's sexuality. And it was only after this disabled person was shown to have normal familial relationships that able-bodied people could imagine him as having sexual relationships. Thus, establishing familial relationships shifted the lead actor from a 'less than human' signification with deviant sexual desires to being recognised as a human being, albeit a less fortunate one.

Again I reiterated that possibly the film was not meant to educate others or help people understand disabled people's sexuality, but rather it is giving a presence to the fact that disabled people desire and are desired by both non-disabled and disabled others, which may result in sexual relationships. After the discussion I spoke with another disabled person who was present and we both lamented the voyeuristic aspect when non-disabled people discussed, viewed, or

portrayed our lives. We both felt our lives were ordinary and were perplexed when non-disabled people continued to view our lives as fodder for their voyeuristic need to experience something fascinating and horrific. On the voyeuristic tendencies of non-disabled people, Morris (1991: 129) comments:

> We often experience the fascination that non-disabled people have with 'just how do we *manage?*' They have a consuming curiosity about how we pee, how we shit, how we have sex (*do* we have sex?) Many of us have experienced the total stranger or slight acquaintance coming up asking the most intimate things about our lives. Our physical difference makes our bodies' public property.

Silvers (1998a) argues that philosophy does not consider the routine aspects of living with a disability. She (1998a: 3) asserts that by concentrating their enquiry on the extremities, and almost never the routine of living with a disability, philosophical practice depicts living this way as a marginal existence. Thus the predominant view of marginalisation sustains these tendencies to want to view disabled person as exotic, whether the fascination is repulsion or attraction. By trying to give voice to the presence of disabled people, I was attempting to move the discussion away from these exotic margins to a more central position of validating disabled people's sexuality.

Throughout my discussion about these films I have alluded to the theme of absence and presence. Because of my pivotal role as the discussant for the movies, I should have felt a strong sense of presence, instead of feeling a strong sense of absence. The voyeuristic approach to the discussion disavowed the lived embodied experience of the disabled people on the movie screen, and by extension disembodied myself and other disabled people present. The discussions about non-disabled people having ulterior motives and fetishes failed to consider that such talk negated our embodiments. We became 'talking heads' or for some people 'listening heads', partaking in a discussion that was framed from a deviance perspective. Being a member of this deviant group (the disabled), I was a reminder of the 'problem' - sexual relationships with disabled people - to be discussed and perhaps 'come to terms with'.

Paradoxically, as a discussant my intellectual expertise was validated while simultaneously my embodiment was neglected, except as an example of a deviation from the norm. Drawing from the work of Deleuze and Guattari one could say that the question of sexuality and disability was being territorialized into a majoritarian view that continually tried to capture disabled bodies in the audience, as well as the disabled bodies in the films, as deviant. As Deleuze (1988), Butler (1997) and Code (1995) argue, when we accept the parameters of a discussion we inherently start from a premise that not only excludes other notions of what a topic means, but in doing so silence other voices. By accepting the parameters of a discussion about sexual relationships with disabled people as starting from the premise of the lack of desire (the notion of ulterior motives), or its perversion (fetishism), these propositions are to some extent legitimated. To take exception to these positions creates an environment where the question of the desirability of disabled people in sexual relationships is considered appropriate.

However, like any disabled person, I risk being marked as being overly-sensitive and defensive if I speak up against these assumptions. Moreover, in challenging these supposedly self-evident propositions I risk being labelled as a maladjusted individual who has failed to comprehend my own lack of desirability or my own uneasiness at being a fetish. Nevertheless, with my new outlook as a 'new idiot' at the film series, I continued to confront the ableist assumptions that underscored this common sense understanding of the convergence of sexuality with normality, and how each overlays the other, resulting in the constitution of the deviant cripple.

Yet the film series was not an isolated incidence. Whenever I am in the company of a woman, our relationship often is considered a 'problem' to be figured out both cognitively and morally by members of a society who privilege able-bodiedness. Often people may not be aware of this subtle covert assessment of my relationship with a woman (that statement in itself points to how ableism and homophobia converge). Ironically, gay friends of mine also have had to clarify their relationship with me. Whether the 'perceived' relationship is heterosexual or queer, I remain a problem for others to decipher. From the perspective of race, W. E. B. Du Bois (1999: 9-10) eloquently addresses the subtleness and covert nature of being the unspoken problem.

> Between me and the other world there is ever an unasked question: unasked by some through feelings of delicacy; by others through the difficulty of rightly framing it. All, nevertheless, flutter round it. They approach me in a half-hesitant sort of way, eye me curiously or compassionately, and then, instead of saying directly, How does it feel to be a problem? They say, I know an excellent coloured man in my town; or, I fought at Mechanicsville; or, do not these Southern outrages make your blood boil? At these I smile, or am interested, or reduce the boiling to a simmer, as the occasion may require. To the real question, how does it feel to be a problem? I answer seldom a word.

From a cognitive perspective, in Bauman's (1993) sense, my presence with an attractive able-bodied woman seems out of place and requires an explanation. Depending on the generosity of the spectator, I am either pitied (as a person who must endure tragic circumstances) or vilified (as a lecher who doesn't know his place). Depending on my portrayal, my companion is often seen as either a kind-hearted soul who has taken pity on me, or as a victim needing rescuing from a lecher.

What I find interesting is that the emphasis is on why the woman would be with me. My partner is often under scrutiny, while I remain a stranger who is a spectacle for others but never to be engaged in answering the question, 'Why would I be with a person who is attractive?' Others assume my companion is simply not interested in a sexual relationship with anyone and our relationship is platonic. Or there is a mind/body split in that she is normal with an attractive and sexual body, but there is something cognitively, morally, or emotionally lacking in her psyche as she is not interested in a 'normal' and 'healthy' sexual relationship. Or outwardly my companion is seen as attractive, but there is a

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suspicion that appearances can be deceiving and she probably has a hidden disease or defect that would make it plausible that she would be with me. People coming from a perspective which privileges an ableist perspective would, thus, be able to 'make sense' of two defective people being together. Or, at the other extreme, she is an angelic, pure individual who has no need for carnal lust, or sexuality, and is dedicated to a less messy and more pure agape love.

For me this convergence of ableism and sexuality is similar to being 'the problem' that Du Bois refers to above. People skirt around disabled people's sexuality, or often tell me with great enthusiasm of some disabled friend or acquaintance who is married and has children (the subtext conveying to me that they want to give me the impression that they are aware, and approve, of my having a normal sex life). Their enthusiasm conveys to me that they want to be counted on the pro-disability side of the ledger, while still being uncomfortable with, and not knowing what to make of, the problem - sexuality and disability.

Critiquing this limited view of sexuality, Deleuze and Guattari (1987: 154) claim, 'Every time desire is betrayed, cursed, uprooted from its field of immanence, a priest is behind it. The priest cast the triple curse on desire: the negative law, the extrinsic rule, and the transcendent ideal.' First, the priests enforce the negative law that sees desire as lack, and therefore castration is carried out. Second, they establish the extrinsic rule which requires that pleasure be purged from desire. Third, the priests with piety define the transcendental ideal, proclaiming that no one can enjoy desire because it is unattainable.

Deleuze and Guattari (1987: 154) argue that today the most recent figure of the priest is the psychoanalyst, with his or her three principles: pleasure, death, and reality. For some disabled people, including myself, metaphorically the high priests of normality have castrated us, in that we are often considered either asexual or nonsexual. Earle (1999: 317) found that disabled students who displayed a wide range of sexual experiences and expectations were aware of the fact that others considered them to be asexual. Disabled women are often considered outside the realm of sexual activity, which leads to various assumptions: They are considered non-sexual. They will never have sexual relationships either straight or gay, marry or have children. This belief that they are nonsexual results in them receiving little or no information regarding their sexuality. If they receive any information on sexuality, it may be incomplete or have a negative bias towards disability (Fine and Asch, 1988; Morris, 1993; Thompson, 1997, 2000; Driedger and Aubin, 1992; Earle, 1999; Lonsdale, 1990; Odell, 1993; Silvers, 1998a). Even when we are involved in a relationship, the spectre of a disabled person being somehow inadequate hangs over it. For example, Odell (1993: 57) writes, 'I figured I'd never marry, but if I ever did, I'd just let my husband have a mistress so he wouldn't be deprived.' Nolan (1998) relates the story of a couple who refute the common notion that the developmentally handicapped are not interested in either sexuality or intimacy. From the overwhelming view of the priests of normality, more often than not, even if sexuality is considered part of our lives it is posited as a relief of tension. Thus, for them our sexuality becomes a means to purge ourselves of a burden, instead of being an enjoyable experience for us. Like the participant at the film series, others have expressed to me that an able-bodied person could not enjoy a sexual relationship with a disabled person and must have an ulterior motive for becoming intimate with him or her. The priests of normality have ordained that desire of or with disabled people is not a matter of enjoyment, as for others, but a

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matter of utilitarian motivation.

In effect, employing Frank's (1991: 12) terminology, *my body* with its lived experience as a sexual desiring and desired being becomes *the body*, to be categorised as either not being sexual or as asexual, in either case not deserving a sexual relationship. *The body* is reduced to a signification of that 'thing' which is repulsive and unworthy of a sexual relationship. Similarly, our able-bodied partners (whether gay or straight) bodies are called into question. In my particular case, my partner's body with her lived experience that may or may not have a sexual relationship with me is displaced by *the body* that is read by others and is vulnerable to the ableist assumptions which contaminate and negate her lived experience and her body. Certainly it can be argued that people make judgements about all couples for all sorts of reasons. My point is to underscore the pervasive ableism which either explicitly or implicitly frames any relationship, whether sexual or not. Often, from an ableist perspective, when my relationship with a lover ends it is assumed that my lover is again of a 'right mind' or her life is back in balance, or that she has again achieved normative acceptance and will naturally leave me for a more suitable lover.

Similarly, the discussion about the first film centred on why a secondary character (an able-bodied person) would have a sexual relationship with the lead character (a disabled person) that the audience knew better. The character of the disabled person was portrayed favourably in the film, yet the focus of many of the audience members remained on the motivation of the non-disabled person. This is similar to the Latimer trial, where the jury and much of the general public identified with Robert Latimer and dismissed or negated Tracy Latimer's lived experience. Therefore, although the character of a disabled person was primary and fleshed out within the storyline of the film, he remained a stranger in the eyes of most of the audience; a stranger whose embodiment was reduced to a signification of personifying the abject other. *His body* with its lived experience became *the body*; a disembodied signification of the abject other under the scrutiny of what (Thompson, 1997) calls 'the normalising stare'. Like me, within the context of the film, the disabled actors were perceived as being out of place and reduced to a spectacle.

Over the years, when I have been accompanying an able-bodied partner both of us have felt the normalising stare with its accompanying whispers. At times my companion and I have felt like exhibits at a freak show; all that is missing is the 'carny' enticing the audience to see the 'spectacle'. But no 'carny' is required to entice people. The fascination and repulsion of me exposing that I am a sexual being coupled with my companion, acknowledging that she may be not only attracted to me but having sex with me, is enough to create the audience whether desired or not.

Yet I do not want to leave the impression that the film discussion was a completely negative experience. Differing people expressed to me their discomfort about the film discussion. I was fortunate to take part in conversations that gave validity to the reality that disabled people desire and are desired by others. Simply put, we considered the possibility of the idea of having sexual relationships with disabled people as an ordinary activity, not a deviant behaviour. Again

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referring to Deleuze and Guattari (1987), my body as a 'machinic assemblage' interacts with other bodies to react against ableist practices, while validating the desires of and desires for disabled people as productive drives. Such an assemblage gives disabled people a presence, rather than making them out of 'place'. But such moments are few and far between as my desires, my sexuality and my being disabled remain a problem and, like Du Bois, I rarely get asked what it means to be a 'problem'. And like Du Bois (1999), often when faced with attitudes, gestures, comments, or a general uneasiness about my disability and/or sexuality, at times I will show anger, or interest, simmer at the boiling point, laugh at the outrageous comments, perhaps even convey compassion for the other's discomfort. More often than not, or passions overwhelm me and, like a new idiot, I create a new space by being sexual as a matter of becoming, not as a matter of proving or justifying either my sexuality or my disabled presence.

Suppose we were to shift the onus of responsibility for the 'problem' of dealing with sexuality and intimacy from the disabled person to the non-disabled person. What I am suggesting is that able-bodied people stop trying to make sense of my sexuality and intimacy and confront their own fears. Throughout my life women have expressed that they have found me attractive in spite of my physical disability. They often would express how my courage, intellect or character was attractive to them. More often than not such encounters lacked the intimacy and sensuality I desired. I could not help asking myself, why the body I loved and spasms which I experienced intimately could not be a positive aspect of our intimacy, rather than something that my partners felt that my other attributes could compensate for. Or put another way, was I considered more human (and by extension more sexually acceptable) if my cerebral palsy could be overshadowed by characteristics associated with able-bodied people?

Becoming (in a Deleuzian Sense) Sexual

I remember in particular a lover who took responsibility for her own ableism. Catherine was attracted to me but was unsure about how cerebral palsy manifested itself. She did some research to find out whether I was capable of a sexual relationship. Later she told me that the material she found depressed her because it portrayed sexuality with people who experience cerebral palsy as horrendous if not impossible. From the perspective of the medical profession our bodies (those of people with cerebral palsy) are negated because it is difficult to perceive us as being capable of being sexy or performing a sex act. So pervasive is this normative view of sexuality that even some disabled people internalize this belief and negate their own existence as sexual beings (see Odell above). Still Catherine was willing to go beyond the normative opinions and common sense that devalue my sensibility of cerebral palsy.

Catherine pushed our relationship beyond the customary boundary of abjection to a different level of experience and becoming which valued our relationship, a relationship which included my cerebral palsy as an important aspect of our desire, not something which needed to be overcome. In effect, we both were nomads in that we went beyond the limits of what most people would believe are acceptable partners for each of us. Deleuze (1994:36) sees nomadism as an open concept without enclosure or the need for measurement. Rather it is an open space - a space which is unlimited, or at least without defined limits.

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Rajchman (2000: 20) writes,

> An originality of Deleuze is to free empiricism from the assumptions of a
> 'common sense', and to say that the consistency or coherence in philosophy
> owes its existence to the problems by an 'outside' that comes before things
> 'settle' into agreements and persists within them. He pushes the experience or
> the experimentalism of thought into a zone before the establishment of a stable,
> intersubjective 'we'.

For us there was no need for normative measurement or to compare our relationship to that of others. Our assemblage, like all others, was passionate, and was a composition of desire. Desire came before our subjectivity and therefore there are no two individuals coming together and consequently no intersubjective 'we'.

We were becoming, not in the sense of reaching the highest pinnacle of actualisation - a trajectory of progress that Deleuze and Guattari (1987) reject - but rather in the sense that through our sexuality I was becoming Catherine with her womanness, and Catherine was becoming Jim, with my spasticity. It is not a matter of either of us having empathy for the 'other', or simply each other imitating the other. Rather it is a symbiotic relationship which creates another existence that emanates from our assemblage (Deleuze and Guattari, 1987: 238). This symbiotic relationship is materially based, in that it has an aspect of sensuality that takes into account the body and the messiness that such a coupling involves: 'Whenever someone makes love, really makes love, that person constitutes a body without organs, alone and with the other person or people' (Deleuze and Guattari, 1997: 30). Weeks (1997: 330) asserts, 'there is something important to the messiness, the chaos, the come, the blood, the shit, the piss, the sweat, of actual physical contact, I don't think there's any alternative to that sort of messiness and the joy of messiness.' To this joy of messiness I suggest adding that there is nothing like the sensation of spasms.

Billy Golfus (1997: 420) who is brain-damaged relates his apprehension about making love to a woman who experiences paraplegia. He writes:

> Look, everybody's been taught that sex is about put tab A in slot B. You were
> taught that, I was taught that, songs and movies are about that, that's how
> people think. Tab A in slot B. So what do you do when you can't feel slot B?
> Forget it? If it's not acrobatic and aerobic, then it's not real sex. How big and
> how many times is what counts to most people. Many don't even have to feel
> much, just keep counting and measuring.

To paraphrase Weeks (1997), with spasms joyfully running amuck it is difficult for me or Catherine, or any future lover, not to feel something.

Throughout my life I have noticed a restrictive interpretation of what it means to be sexual. As Sarrup (1996: 91) explains, 'We have the body and its pleasures instead of the subject and its desires; love is a technique without reference to tenderness, affection, and emotion.' Consequently, our sexuality as a couple would not conform to techniques which are designed for an able-bodied centred coupling. Yet there is room for sexual diversity (if not acceptance), as Weeks (1997: 321-322) suggests:

> I think there are many kinds of sex that are not subversive. I'm a great believer in not judging an act by what it is, but by the context in which it takes place. And the same act can have different meanings in different contexts. .... Fucking can be extremely aggressive, it can be destructive. It can also be affirming, loving, caring. It can be transgressive, and it can be reactionary and from the act itself you can't judge anything. You have to see the context, the meaning, implications of that act in order to say whether it's – I'm trying to avoid using the words 'good' or 'evil' – whether it's life-affirming or life-denying.

I agree with Weeks and his avoidance of good and evil, preferring his terminology - life-affirming or life-denying - because disabled people's bodies and minds have often been taken to be personifications of evil. Similarly, our sexuality is seen as the manifestation of evil, the mixing of either an egg or seed that is impure or defective with the genetically superior able-bodied person. But I would like to extend Weeks' notion of life-affirming by differentiating between transgression and exposure as it pertains to the erotic and sexuality.

Michael Hardt (2002: 80-81) makes a distinction between the erotics of transgression and exposure.

> Transgression always functions in relation to (or in complicity with) a norm or taboo, negating the dictates of the norm and yet paradoxically re-enforcing the norm's effects. The transgressive act does not simply refuse the norm, but rather negates it, transcends it, and completes it. It exceeds a limit, but in its excess verifies the limit itself. Transgression always operates through a dialectic of negation. If the norms were destroyed, the transgression itself would lose all value.... [E]xposure of all operates rather on a purely positive logic of emanation. It involves casting off, or really, emptying out all that is external to its material existence and then intensifying that materiality. What is exposed is naked flesh, absolute immanence, a pure affirmation.

> Exposed flesh is not a transgression but a scandal. In other words exposure does indeed oppose and negate the norms of propriety, but its effect does not depend on that opposition as a support. Violation of the norm is not primary to exposure; the negation is secondary, an accident. It turns its back on a norm-that is its great offence. Exposure operates in ignorance of the norm, and thus

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conducts, in the only way possible, its real destruction.

In a Nietzschean sense, the way Catherine and I exposed ourselves is Dionysian (chaotic with an indeterminate future) in nature rather than Apollonian (with a prescriptive formulaic rationale not only of how to make appropriate love but who would be the most appropriate lover). Our intimacy allowed us to replace the old morality with a new Dionysian possibility (Nietzsche, 1998): Exposing my flesh with Catherine and her desire for my touch with its spasmodic stroking. The intimacy that we felt in each others arms when my pulsating spasms provided the percussion to the rhythm of her regular heart beat. The look of desire illuminated Catherine's face as she watched my walk and commented on how she is lusting after my twisted body that others devalue. She traced the lines of my misshapen body. I am amazed as I explore Catherine's body at how her body contrasts with mine, in the tenderness of her body and its fluidity whether she is moving or lying down. When I was with Catherine, whether holding her intimately in my arms or standing beside her, I noticed a change in my spasms. By exposing ourselves to each other we were destroying the norm not transgressing it. Neither one of us has an interest in becoming models for a transgressive movement that offers a dichotomous alternative to able-bodied normality. Our intimacy was simply an exposure of a coming together which is not usually considered a sexual possibility.

Our desire for each other was not constant or consistent and was affected by the ableist 'normative shadows'. Our relationship was marked by hesitation and retreat that our desire for each other had to overcome. Initially, my hesitation was precipitated by a strong sense of disbelief. You see, the presentation of self is very important to my lover. People had always suggested that the way I had cast myself was an affront to a refined 'presentation of self'. In other words, while my lover's appearance conveys that she is confident, refined and sophisticated; my appearance states that I am careless, uncontrolled, and unsophisticated. At various times, fear of the unknown or fear of rejection caused one of us to back away from the other. In spite of our fear our overwhelming desire would bring us together. This constant interplay of backing away and coming together creates an atmosphere that is anxiety ridden and tension filled. This love differs from the disembodied spiritual love of agape; it could not be contained or controlled.

But the anxiety and tension we felt, in a Nietzschean sense, points to the difference between a Dionysian and an Apollonian appreciation of the world. The world today appreciates the rationality, linearity, progressive, logical, controlled structure of an Apollonian space, over the chaotic, indeterminate, passionate, indefinable Dionysian sensibility. At times this majoritarian view intruded upon our relationship. The cold rationality of the Apollonian wind sent shivers down my spine. My deliciously deformed back straightened like a Dionysian serpent threatened. My tongue spewed venom at the Apollonian intrusion.

Unlike the mythology of Christianity, where the snake epitomises chaos and evil and threatens goodness, purity and the sanctity of the Christian belief system, in this temporal world of validation through intimacy and love this metaphorical snake protects me from the prying eyes that view me, if not as the 'forbidden fruit' at least as the personification of sin or the world gone

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awry. In this world, for the moment, by desire, my being and embodiment offer a respite from the world that privileges an Apollonian view and negates my Dionysian passions.

Eli Clare relates how she has worked, and continues to work to appreciate her body and overcome the homophobia and ableism which continue to devalue her sensibility. Clare (2001: 363-364) began by shattering 'her belief that her body was wrong' when she found a community committed to both pride and resistance, which allowed her to appreciate and to know 'the grace in my shaky hands, the rhythm of tremor and tension in my muscles, the joy in my transgendered butch body, sun on my back, a lover's hand on my belly.' Clare asserts that her body has not changed, just her perception of it. Earlier in her life she would have given anything to be normal, when people stared and tried to make sense of her cerebral palsy and her transgendered body. Today people stare but Clare's perception of herself has changed. She is working on loving her difference.

Clare (2001: 364) writes, 'I am still in the middle of this work. I think of my lover cradling my right hand, saying, 'Your tremors feel so good'; saying, 'I can't get enough of your shaky touch'; saying, 'I love your C.P.' Shame and disbelief overwhelm me until I stop and really listen to the words. Another layer begins to shatter.'

Weeks (1997), Hardt (2002) and Clare (2001) stress the importance of not just having but also fulfilling life affirming desires. Yet, 'normative shadows' can cast a pale upon these life affirming desires. In terms of sexuality, as Foucault (1986) has pointed out, the high priests of normality have indoctrinated people to the point that most of us have internalised a prescriptive notion of whom or what are considered desirable. This normalisation process becomes internalised in the techniques of discipline that we impose upon ourselves.

Foucault (1986) argues that the disciplines of the self are so seductive and insidious that they permeate the way we act, what we eat, how we regulate our behaviour, how and to whom we make love. By transgressing the normative expectations that permeate the body and psyche the able-bodied lover constantly has to battle with the 'normative shadow' which insidiously regulates our behaviour with its commandments of 'oughts' and 'shoulds'. These normative commandments become 'naturalised' and are internalised by some disabled people resulting in the prohibition of life-affirming desires.

Clare (2001) points out, that our work is constant. Where I differ from Clare is that I do not see a utopian conclusion where my body will be accepted. Today I concentrate on making assemblages for different durations and with different intensities that are life affirming in that they do not simply accept my cerebral palsy but embrace it. Nestle (1997) relates the dangerous position her mother exposed herself to in order to satisfy her sexuality. Nestle (1997: 160-161) asserts that no woman, whether gay or straight, 'should feel shame or fear because she likes to fuck'. Likewise I maintain that no disabled person, whether gay or straight, should feel shame or fear because he or she enjoys their body, whether sexually or otherwise.

This slight digression from the topic of education to sexuality and disability may seem odd to the reader. Alison Pryer (2001) considers the erotic to be essential to the education process. Like Clare (2001) my purpose in placing the embodied sensibility of sexuality here is to bring the materiality of disability to the forefront of a discussion about education. For me it is not enough to educate others, rather one must engage others in a very material sense. The denial of my vivacity, sensuality, and sexuality is similar to the negation of my body or other differing bodies within the education system.

An Alternative to the Scaling of Bodies

In the previous chapter I invoked the position that my way of thinking is that of the private thinker, while other able-bodied students followed rational, public thought. But I would like to unsettle this dichotomous thinking. I believe that I had imposed a 'politics of identity' upon these students which does not allow for their own manifestation of private thinking to thrive or for their own sensibility to come to the forefront. In effect, I imposed my own version of the 'scaling of bodies' that Young (1990a) critiques. Like me, all people on the scale are judged by the extent that we acquiesce to the characteristics as scripted by phenomenological 'autonomous body' professed by Merleau-Ponty.

I believe we must move away from a facile 'politics of identity' or 'politics of difference' that is restricted to the concept of scaling of bodies. Deleuze and Guattari (1987), Massumi (2002a), and Patton (2000) reverse this scaling by giving priority to the movement between the positional points (or nodules signifying identity or difference) rather than giving precedence to moving up to higher levels or positions on the scale. Moreover, if a machinic assemblage is formed it is possible that there will be a movement (a line of flight) from that trajectory. Consequently, people do not rid themselves of these positional points on a normative grid, but people through their desires can deviate from these normative expectations - or, more correctly, desires may shift their direction away from a trajectory of normative expectations and create a new subjectivity that is less dependent upon, or even not dependent upon, a normative trajectory.

Spasms Can Create the Lecturer

As an example, my teaching is informed by desires that emanate from my spasms. The position of being both a teacher and a disabled person becomes secondary to these flows of desire which become part of the educational process. I am reminded of the concept of 'exposure' and how Catherine and I risked exposing ourselves and, in doing so, broke free from the normative expectations of who is an appropriate sexual partner. As an instructor of sociology I ask myself, 'Am I ready to allow myself to be exposed to the class in order to create an atmosphere for other new idiots or private thinkers, as Deleuze and Guattari would say, to express themselves?'

In risking exposing my spasms and my different sensibility I am unsure of the outcome. In effect, it is a nomadic expression which reaches beyond the limits of security, a line of flight that may be considered irrational and be disqualified by students. On the positive side, exposing my

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spasms may enable me to create assemblages with other people that may result in 'lines of flight' for me and my students. But as Patton (2000), Deleuze and Guattari (1987) and Massumi (2002) warn, these lines of flight can also lead to destruction. Deleuze and Guattari (1987: 229) caution that lines of flight may not connect with other lines, may not form assemblages that are life affirming. Instead they may lead to a *passion of abolition.* Yet we humans need to create, and some of us will risk, 'lines of flight' to create and form new assemblages and new possibilities.

My exposure is not a conscious endeavour, nor would I be aware of it except that students react to such exposure. This exposure of my spasms creates a shift in the sociological experience. Usually, sociology would be taught from the perspective of the interaction between points of positionality (Massumi, 2000a) on a social grid. An interesting phenomenon occurs when, after a few days of encouragement from me, the students will begin to expose themselves and articulate sociology from a position of what Deleuze and Guattari would call desire rather than positionality.

As mentioned earlier, students must contend with my spasms. Nelson (1999: 341) argues for a conceptualisation of performative bodies within a particular space. For disabled people, our relationship with space affects how others read our bodies and subsequently has ramifications for us. For example, I have taught two courses with different spatial dynamics. In one classroom I sit while lecturing. Often while sitting my spasms cause my hands and arms to be affected and that, in turn, informs my lectures. Generally, I experience more freedom and vivacity in my lecture if I sit. Moreover, the response from students is favourable if my performance includes my body. In another class, I have an enrolment of seventy-five students which requires me to stand. The performative aspects of my lecture are restricted by my need to attend to maintaining my balance while standing. I feel the spontaneity and the vivacity of my lectures suffers by my embodiment being restricted. The environment or the place in which I lecture affects the effectiveness of my lecture. Nevertheless, whether sitting or standing my spasms only enhance the vivacity of my lecture and my embodiment does not detract from my ability to teach.

Stewart (1999) examines how George Simmel's embodiment informed his style of lecturing. Stewart (1999: 13) asserts that the lecturer's body is an example of 'first and foremost, the body which is perceived and consumed as spectacle by the audience.' My students read, perceived, and consumed my body and were left with the conclusion that my embodiment did not typify that of an instructor. In one course I taught I encouraged students to examine their own beliefs that may reinforce social inequality. Over the period of the course some students admitted that they were initially unsettled by my disability. They wrote that over time they came to the realisation that my spastic cerebral palsy had a positive effect on my teaching ability.

Rod Michalko (2000) has written about his experiences as a blind instructor. Initially, his students were unsettled by his blindness, and only admitted this to Michalko when they became comfortable with him and his blindness. From a sociological perspective, the presence of Michalko (2000) as an instructor creates an atmosphere where students interrogate their own belief in the naturalness of a social world which privileges sight, just as my presence creates an atmosphere which allows for students to not only question the privileging of an able-bodied

sensibility, but also how they themselves have internalized and are devalued by normative expectations.

Stewart (1999) asserts that Simmel had an extra performative aspect to his lecturing style. Through his body Simmel was able to convey the meaning of his lectures. Moreover, his particular style of lecturing, which was informed by his embodiment, attracted students to his classroom (Stewart, 1999: 2). Yet his embodied style was not comfortable or familiar to his students. Stewart (1999: 9) asserts that Simmel's intensity of thought resulted in a contorted body. Stewart (1999: 9 - 10) elaborates on Simmel's contortions:

> Many of the reports of Simmel's lectures mention that the intensity of his thought was expressed in his body, repeatedly emphasizing the manner in which he would raise his arm, point his fingers and twist his body as he spoke (for example, Gassen and Landeman, 1958: 229) .... Other reports describe Simmel's 'strange appearance' in detail, maintaining that Simmel's manner of lecturing was 'just as ugly and as fascinating as he himself was' (1958: 156). The continued repetition of adjectives such as 'ugly', 'gaunt', 'twisted', and 'awkward' suggests that reactions to Simmel's physical appearance were as ambivalent as those to his voice. Just as his voice appears both to have attracted and repulsed sections of his audience, so his 'grotesque' body image fascinated his students, perhaps because, in Bahktinian fashion, it underlined the 'counter-cultural' experience and content of many of Simmel's lectures.

For me there is a contradiction in how my embodiment informs my teaching. On one hand, my spasticity is the antithesis of the professional, controlled body associated with most university lecturers. On the other, it is an important factor in my life and my critical thinking which is a major contributor to my acquiring the credentials required for my teaching position. Just as Simmel's performative personae allowed for his students to access the message of his counter-cultural lectures, my embodiment created an alternative to a type of thinking that is solely based on rationality and logic. The surplus movement of my body has been characterised as unnecessary, or a distraction from important issues with real meaning. But my excessive corporeality, which can not be separated from my lecturing to some degree, gives legitimacy to my students by validating their own embodiment.

Stewart (1999) asserts that Simmel's performative style of lecturing was not as spontaneous as it seemed. She relates how a review of one of Simmel's public lectures was similar in detail to another given a few years earlier, in respect to the performative aspects of his body. Thus, Stewart surmises that Simmel's gyrations had less to do with spontaneity and more to do with a tried and true technique. My embodied performance differs from Simmel's, in that any technique I incorporate into my lectures has to with my trying to control my spasms which affect my tongue and saliva. My gyrations or contortions are not predictable, as my spasms travel down different pathways within my body and with different levels of intensity. Thus, my spasms do not create a definitive style of lecturing through my body. My spasms continually shift in how they manifest themselves, and accordingly in how they affect my teaching. Moreover, my

students' bodies or their reactions to my body are always in flux. The result of the interaction between us remains uncertain, but allows for and creates a space for our mutual noise from the interaction of our rarely used private thinking.

Being disabled within the university, I have a unique opportunity to facilitate flows of desire by interacting with other desiring students. Our interaction enables our desires to create machinic assemblages of de-territorialisation that created openings for private thinkers. When I entered the academy, I began my education as an outsider who lacked the control and embodiment usually associated with 'rational' intelligence (Bauman, 1993; Baudrillard, 1993) Bauman (1993: 162) argues that the 'outsiders' are ascribed traits that signify ambivalence, irrationality, uselessness. They epitomize the chaos that all social spacing, including academia, aims staunchly yet vainly to replace with order. Now, as a doctoral candidate who has credentials, I have moved beyond the position of outsider and have become what Bauman (1993) refers to as a 'stranger'. As a stranger I must continually reinforce my legitimacy at the university by proving that I have the 'intellectual rigour' required to remain there (Bauman, 1993: 179). If I choose to affirm my own embodied wisdom, my colleagues may question my legitimacy within the university.

I have constantly to determine to what extent I can affirm 'private thinking' without jeopardizing my position within academia. On one hand my presence gives validation to 'private thinkers' and might create a space for this type of articulation. But as an instructor I have moved from the position of an outsider to that of a stranger, and to the extent that I allow other voices or communication to emerge, I put my own presence at the university at risk. There is tremendous pressure on me to keep the noise down (see Shotter, 1997).

A broadening of the notion of intelligence would be beneficial to nondisabled as well as disabled students. The privileging of rationality and logic often leads to adversarial debates within academia. By demonstrating superior logic and rationality one academic scores pugilistic points over another. Shotter (1997) argues there are two different ways in which we relate to one another. The first, the intellectual way, is characterized by the abstraction, distance and observation that apply within the confines of a disciplinary space. The second, the conversational way, is more relational with an exchange of lived experiences between individuals. This latter style of communication is 'an open, unfinalized, and dialogical form of talk in which new 'spaces' may be opened up and others closed down, freely moment by moment' (Shotter 1997: 21). Shotter (1997: 22) explains that what happens in this 'interactive moment is to be ascertained by a non-intellectual, embodied knowledge that eschews both predetermined means of communication and institutionalized formulations which confine discourse.'

The Pragmatic Promotion of 'Private' or 'Nomadic' Thinking Through Lecturing

Allowing people's 'noise' to become prominent results in the validation of abject others rather than their domestication. However, my purpose is not to call for a facile identity politics in the classroom which re-establishes positionality and the social grid. Haver (1997: 288) argues that one must risk the presumptive autonomy and integrity of a self which has already come to its

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subjectivity through producing an abject object - the comfortable victim, the tragic hero - of the pedagogy of the Enlightenment.

The ebb and flow of desire from the students creates a dynamic subjectivity for me and for them. Students have remarked to me that they would begin a class assured of their position as a subject, or as Massumi (2000a) would argue, their point of positionality on a grid, but they would later change their mind. What is interesting for me is the fact that often the shift is not because of a sociological insight, but rather because desire that emanates from a sociological insight flows with other desires, including those of students and myself, to create a new subjectivity.

As an undergraduate student I was struck by the revelation of a professor who told us that he experienced writer's block when he tried writing his book. To overcome this he shifted from word-processing to writing long-hand. He told us that he had regained a connection with his work that had not been present before. As I listened to him, I interpreted his admission as giving me permission to listen to my spasms and incorporate them into my writing. More and more, throughout my academic career, I have increased my level of writing through my body.

In a lecture concerning technology and education, I was surprised that some students admitted that they also wrote through their bodies. Moreover, these students were amazed that other students wrote through their bodies. My point here is not to suggest that my teaching was particularly successful, but to emphasize how different bodies, and the subsequent 'noise' (Shotter, 1997) from their corporeality, provide an opportunity to create another way to examine sociological issues. For example, the expression of opinion from either a written or oral form of expression manifests itself through the body. Visual clues, such as reddened faces along with louder voices enhanced the vivacity of the issues that are articulated on various levels. As the instructor, one of my responsibilities was not only to ensure the integrity of my class but also to make certain that none of my students suffered from what Shotter (1997) refers to as 'textual violence' in the academic tradition of scoring pugilistic points over one another (as mentioned above). Thus, interactions followed what Shotter (1997) would argue is a conversational, albeit often intense, way of discussing sociological theory, rather than the usual academic style which favours a disembodied intellectualism with a somewhat ironic tendency towards pugilistic debate.

Earlier I referred to allowing noise to infiltrate the classroom. Again, by noise I am referring to the type of discourse which does not fit the objective approach usually associated with academia (Jenks, 1993; Shotter, 1997). By encouraging 'noise' I am not condoning textual violence (Shotter, 1997) but a type of articulation that is not associated with academia. Young (1990a) makes a distinction between public and private speech. Within academia there are perceptions of how a student should express him or herself. Again, this behaviour can be associated with this person (a student) within this context (the university) realizing normative expectations that include a certain manner of speaking and embodiment. As students began to expose themselves (again not in the manner of necessarily transgressing social norms, but allowing aspects of themselves to be presented) their private sides and private ways of communication came to the forefront.

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Thus, no matter how 'noisy' their narratives became I encouraged my students to write or speak through their bodies or in other ways to access their thoughts which derive from their own 'private thinker' that within institutional education, more than likely, is dormant. For example, students from different ethnicities were accused of becoming angry when debating topics. The class addressed the topic of 'what is wrong with anger?' The performative aspects of my teaching emanate from my desires that are often perceived to be more emotional than those of other instructors. Looking at the topic of anger from the perspective of power relations allowed us to see how power works in our everyday lives. As Lorde (1984), hooks (1990), Williams (1993) and Thompson (1984) assert, privileged people often accused the 'other' of being angry, when they themselves are just 'passionate'. But as the aforementioned theorists also point out, anger is not necessarily a negative reaction to being treated as signifying the abject other. What was more interesting is that often students who were accused of being angry were not. Over time they had become comfortable in the class, to the point where one of the students admitted to taking off a mask and talking with the vivaciousness usually reserved for private interactions.

As an instructor I have to ensure that the classroom milieu provides an environment that is conducive to taking off masks and risking 'exposure'. Often I will address the overt power relations that are present in the classroom, especially when emotions, such as anger or passion, are expressed. At other times, I will facilitate and shift the tension, making myself its focal point. Certainly, there may be times when tension may seem overwhelming for students; but during such times I draw upon my experience facilitating a large crowd of diverse people. Thus far, I have been able to create an atmosphere in the classroom that is both challenging and safe.

If desire rather than identity becomes the focal point of sociological practice it may be very difficult to establish consensus. With desire displacing identity as the primary focus of their sociological imagination, students were able to expand their thinking. Because of the ebb and flow of desire many students would find themselves shifting positions during class. Moreover, most of the students admitted to me that the class was very physical in nature. When I asked them to elaborate, many said that they felt as if they had gone through a physical workout at the gymnasium. Another student pointed out that the class required more than cognitive abilities. From the perspective of identity politics, one can use one's cognitive imagination to put themselves in the place of the other. If one allows desires to flow, to be rerouted or even to be stopped, this requires a material and, dare I say, embodied response.

What was particularly interesting for me was to watch students form machinic assemblages with each other, with the articles under discussion, with me, or any combination within the classroom. The machinic assemblages were not static and there was an ongoing process of territorialisation, deterritorialisation, and reterritorialisation. Consequently, machinic assemblages were formed, broke down, and reassembled in other assemblages.

Earlier, I briefly addressed how teaching a sociology of desire is not incompatible with providing a safe environment where students are willing to risk 'exposure'. The shift from identity politics to a dynamic flow of desire which created machinic assemblages often resulted in what some

might call an uncivilized process. Olkowski (1999b: 118) argues that for Deleuze and Guattari social change is an irruption that destabilizes the social order. Often a student would be almost literally 'bursting at the seams' and would need to interrupt the flow of conversation. Usually the topic under discussion would become integrated into the students' understanding of themselves, and these outbursts were more than simply emotions left unbridled (I want to make it clear that I believe that the inclusion of emotions is integral to the learning process). These eruptions were a combination of the flow of intellectual processing with the flow of something else which emanated from the student.

One student in particular confessed to me that she was often unsure of where that particular voice came from. For her, this voice was different from her voice of rationality and reason. The voice which erupted, she felt, was more embodied and authentic. As I mentioned earlier, flows of desire can be blocked, diverted or made more intense by assembling with other flows. In my capacity as an instructor I would try to facilitate a continuation of flows. Certainly, if the flow was diverted down a course that seemed worth exploring from a sociological perspective I would encourage that divergence. Similarly, if a student attempted to block the flow of another student by textual violence or some other strategy which demeaned the student I would intervene and create an assemblage that would allow the flow to proceed.

When you teach from the perspective of Deleuze and Guattari's concept of desire, the flow is never controlled by you. There are always lines of flight from the classroom. For example, students continue to speak with other students about the topic discussed in class or students would go home and discuss the topic with their family or roommates. The second time I taught the class a student brought her mother to meet me. The mother explained that she wanted to meet me because her daughter had talked so much about the class. Another student introduced me to her partner because he wanted to meet the instructor of this odd class. Although at times this class would be very intense and quite emotional to the students' credit I have only noticed two of them make a literal 'line of flight' from the classroom. One student thought I was being too progressive and liberal in my thinking and departed, while another exited because she thought I was not challenging right-wing views. Ironically, both students used the same lecture as an example of my bias. This simultaneous accusation of left and right leaning perhaps demonstrates that I was giving each perspective its do.

In another class, a student claimed I was making the class uncomfortable, and I immediately offered to adjust my teaching style (in effect trying to find the means to allow the desires of the students, and both 'private thinking' and 'rational thinking' to flow). Over the next few classes the majority of students came to see me and reported they enjoyed the class and that the tension was caused by the student who complained. The student was intimidating others. For the rest of the term, while respecting the 'noise' of this one student I attempted to create a machinic assemblage which would allow her intellectual divergence not to block the 'private' or creative thinking of the other students. Once other students' desires engaged, or integrated, or intersected with her intellectual flow, I would allow them to confront or join with her position. I remained vigilante and tried to ensure that no student felt intimidated, and felt comfortable in risking 'exposure'. Moreover, as an instructor, I actively discouraged 'textual violence' or 'pugilistic

scoring' from taking place.

Perhaps the most difficult aspect of teaching in this style is facilitating an atmosphere for the flow of desire as opposed to seeing each student as a subject of identity. After all, our social world conceptually positions people on a grid. When teaching I must be attuned to the moments when the 'normative shadow' of positionality creeps into my thinking. The notion of 'this' as opposed to 'that' is very seductive in trying to think of the social world. But as Deleuze and Guattari (1987), Patton (2000), Olkowski (1999), and (Rajchman, 2000) argue, the 'this and that', should be replaced by the continual 'and' which allows for the flow. Of course, like all other flows at times the topic of conversation in the class would run its course. But from the perspective of Deleuze and Guattari (1987) the flow of desire is never completely diminished from topics that petered out; there is always a line of flight which creates new assemblages of desire. In terms of teaching sociology, when a line of investigation or a topic of discussion runs its course there is always a student who is thinking 'but what about this?' At times, thinking from that point of desire can be tiring and students may be too exhausted or too intimidated to voice that question or addendum.

As an instructor who believes that desires are not confined to a space and time, or to put it another way that desire transcends temporality although it is very material in nature, I would note the emerging irruption that lay dormant and perhaps revisit it later. I say perhaps, because there may not be a machinic assemblage of desire created to allow for this dormant state to be revisited. As anyone who has watched a strong current in a stream knows, it may be impossible to control the flow. Nevertheless, I am aware that my position as an instructor allows me the advantage of being able to set in motion a machinic assemblage of desire. Equally, my position allows for me to cut off the flow of desire, as I have when a student has been intimidating others.

Often these classes became a site of 'nomadic' learning whereby students would encourage each other, in Deleuze and Guattari's terms, to be open to whatever comes 'knocking on the door' (Rajchman, 2000). The students were especially keen to stretch their limits if there was an open discussion. What would happen if one refused to discuss something? Deleuze (1993) has the concept of folding and unfolding: unfolding is the unravelling or stretching oneself to one's limit or perhaps beyond, whereas folding is the bringing oneself back into the fold. Deleuze (1993: 8) writes, 'The simplest way of stating the point is by saying that to unfold is to increase, to grow; whereas to fold is to diminish, to reduce, "to withdraw into the recesses of a world".' The concept of folding/ unfolding is central to any discussion concerning the imperative to educate. I told the following story to my classes to provide a context for discussion about the perils of the imperative to educate, with its latent power relations that are unspoken.

A Critique of the Privileging of Dialogue

An owner of a boutique asked me if I would like to join her in the food court for coffee some time. With a smile I accepted and said I would drop by later that week. She had certain expectations of me because I attended university and had a part-time job. On other occasions, in

my capacity as a social worker, I met with another woman, Sarah (a client). We decided to go for coffee. We made our way to the food court mentioned above. Sarah has an appreciation for fine clothing, especially the texture. When we met I noticed she was wearing her finest fabrics and had taken great care to layer her clothing to take advantage of the texture of the cloth. For Sarah 'going for coffee' was not a casual event, it was an occasion.

As we walked to the food court, I noticed that with much consideration she slowed her pace to fall in line with my tempo. Continuing to attend to our conversation, with a dignity and grace that belied the arthritis in her ankles, Sarah would bend down and delicately swoop cigarette butts from the gutter or the sidewalk and carefully deposit them in a plastic sandwich bag. We spoke about the grace and dignity required to maintain a sense of self. We were both amazed at the wonderment of the autumn leaves with their vibrant colours during our stroll and the crispness in the air. While we walked other people gave us considerable room on the sidewalk. Sarah remarked with a wry grin and a gleam in her eye that it certainly was nice of these people to give us extra room. We both laughed, which resulted in people almost straddling the edges of the sidewalk as if on a tightrope. Judging by the expression on their faces we both knew that these people were giving us a wide berth for fear they might become contaminated with whatever ailment had befallen us. Yes, it might have been a beautiful day, but there was an uglier reality that Sarah and I faced in venturing out into public spaces.

At the food court I went to buy coffee for us while Sarah found a table. As Sarah sat, I noted a security guard walking towards her, and catching his eye I indicated that she was with me and not a vagrant. For Sarah and me the act of going for a coffee is not a simple act of meeting. We had to create a public space that would not only accept us, but be acceptable for us. In effect we had to strip away the 'normalizing stare' that results in us being labelled as undesirable. In Deleuzian terms, by 'going for coffee' Sarah and I created our own line of flight from the restricted concept of normality that placed us on the margins - as the abject other. Our machinic assemblage created a minoritarian becoming which had been sanctioned by the security guard giving us respite from the normative shadow which often suffocated our vitality. Ironically, a few months earlier, the same security guard had mistaken me for a vagrant, forcing me to prove that I was a respectable consumer and not an undesirable vagrant. During my exchange with him I legitimised my presence by confirming my status as a social worker. In essence I was forced to justify my presence not only in the mall, but in his eyes.

While we talked, with her arthritic hands, Sarah separated the paper from the minuscule amount of tobacco. Meticulously she would lay a cigarette butt on the table to separate the partially-moist tobacco from the paper and filter, and then evenly spread the tobacco onto a fresh paper filter. After repeating the process with several butts Sarah would carefully roll the paper into a cigarette. She noted when other smokers would finish their food and leave their table. Very discretely (as discrete as rummaging through dirty ashtrays can be), Sarah would gather the cigarette butts out of the ashtrays and place them in her plastic bag. Returning to the table she would repeat the process of rolling cigarettes. While gathering and preparing her smokes, Sarah ensured that she was attentive to our conversation. It was a very busy day at the food court so we did not linger and left forty-five minutes later.

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A couple of days later I returned to the boutique and asked the woman if she was still interested in going for coffee. She replied that I had lied to her, and that she knew I wasn't a university student but a homeless person. I asked her what she meant. She continued, stating that some friends of hers had seen me rolling cigarettes with a bag lady. She told me never to bother her again or to return to her boutique. I was stunned but I refused to justify why Sarah and I were together. I walked away. We never spoke again. For the boutique owner 'going for coffee', in Deleuzian terms, meant the re-affirming of a majoritarian status quo; her desire to create a machinic assemblage with me was dependent upon my meeting her expectations (aesthetic as well intellectual) of what it meant to be a university student.

I have related this story to various people. Some people questioned why I hadn't simply informed the woman at the boutique that I was doing my job, as a university-educated social worker. Surely, they argued, a simple *explanation* could resolve the misunderstanding. But an explanation is not so simple an act. Throughout my life I have had to either explain or justify my existence or my being in a particular situation or place. Similarly, I have noticed that other people who have been subjected to an act of abjection have been forced to explain or justify their existence if they are given the opportunity. For the most part I now refuse to explain or justify my presence. Certainly, with the security guard I was forced to legitimise my being in a particular place and to *justify* and *explain* my position as a social worker. Nevertheless, justifying or explaining myself in interaction with others has often left me feeling that my existence and self-worth were dependent upon others view of me. More often than not, this view is informed by ableist assumptions.

Butler (1993: 3) believes the task will be to see this abjection as a 'critical resource in the struggle to rearticulate the very terms of symbolic legitimacy and intelligibility.' The act of 'going for coffee', with its underlying abjection illustrates the act of rearticulating the terms of symbolic legitimacy and intelligence by (re)claiming a place and a presence. For me the story of 'going for coffee' has different layers of meanings. On the surface it means the special relationship between people (such as Sarah and me) with a respect for each other which was forged in our mutual acceptance of each other. On a wider scale it denotes the refusal to be placed in a position of abjection and not having to explain or justify either our presence or our relationship.

With three different classes I have used this story to discuss the reaction of my students to my withdrawal from following one major tenet of humanistic education - the insistence that dialogue between people will result in enlightenment for both. Many of my students became angry and argued that it was my responsibility to offer an explanation for my being with Sarah. But I explained, 'if I had to explain why I was with Sarah, then would not our relationship be tarnished and to some extent my behaviour would be hypocritical?'

Some argued that I was afraid to explain myself to the woman who owned the boutique. When I asked them to elaborate on why I would be afraid, they had no answer, but felt it was the only logical explanation for why I would not engage in dialogue with the woman. One person said

that I wanted to sabotage my relationship, but when pressed would not elaborate. Repeatedly they argued that only through open communication and dialogue will we find social justice. Against this view, I argue that the parameters of what might be acceptable communication, or put another way, the means of articulation and rearticulation (Hennessey: 1993), already 'defer' to an able-bodied sensibility.

Recently, I read of artist Matthew Jones, who, like me, has been criticised for withdrawing from dialogue. Jones celebrates 'the elusive silences of homosexuality' (Zagala, 2002: 26) and eschews the audible voice of activism. His critics have misconstrued his silence and withdrawal as arrogance or cool indifference and failed to recognise the subversive nature of silence and removal: 'Rather than establishing a safe distance, the withdrawal creates turbulence in its wake. Twists and folds of matter are drawn out along the movement of bodies and this instability complicates any clear division between subject and object, speaker and audience, artist and art work, or active and passive roles' (Zagala, 2002: 26). Jones' art as activism stands on its own and creates assemblages that are sensual and dynamic which require no explanation (Zagala, 2002: 27).

In my class, my refusal to provide explanation dares to question the sanctity of the belief that the abject other must educate the privileged about ableism, racism, sexism, ageism, and heterosexism. I also strike a nerve by challenging the humanistic belief in the educational process that we have inherited from the Enlightenment (the notion that through applied education we will reach utopia). In pragmatic terms, only through dialogue which educates the other will we change the world.

Like Jones I did not withdraw to a safe distance, but waded into the turbulence remaining silent without explanation. In one particular class I was surprised at the anger from some students. Like Jones I was called arrogant, too sensitive, stupid, and my masculinity was questioned: 'I was not man enough to explain myself' (I suspect the pathologising went further in that some students felt I backed away because they perceived that I was sexually inadequate, but this was not explored further). There was turbulence in the wake of my story, which resulted in my being pathologised as being more than physically disabled but also lacking both the intellectual ability and the moral fortitude to grasp the consequence of my withdrawal from dialogue (after class other students reaffirmed my suspicions and were offended by my being pathologised). I ended the class by asking the students to ask themselves whether they have felt the pressure to justify or explain their presence; or inversely to ask themselves how they put pressure upon others to explain or justify themselves.

The following week I addressed the discussion and the anger within the class towards my actions. I analysed the pathologising of the other when one refuses to take part in the humanistic discourse of the Enlightenment. I also addressed the issue of textual violence within academia. The danger of employing the strategy of withdrawing and allowing for the 'noise' of the private thinker may result in a misguided textual violence. I had to address this issue and confront one individual who continued to pathologise me. What I was able to demonstrate was how the act of pathologising is a means of controlling me and re-establishing the status quo (territorializing).

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Ironically, invoking the rhetoric of human liberalism usually associated with escaping from tyranny, reminiscent of 'lines of flight' or deterritorialisation (Deleuze and Guattari, 1987), may result in its opposite - an attempt to create an 'apparatus of capture'.

For the rest of the term students would relate how they felt pressure to respond to justify or explain their presence, because they felt that others perceived them to be 'out of place'. Other students began to examine how their own privileged position creates an atmosphere where others feel obligated to explain or justify their presence. The turbulence of this issue allowed students to consider not only social inequality but how the rhetoric of emancipation and social justice masks a 'territorialisation' of people which creates the 'abject other'. Some students started to practice this 'withdrawal' and folding back (in Deleuzian terms) and experienced a difference in their social relations. They informed me that other people were disturbed by their [the students'] 'withdrawal', but then the students noticed that these people began to examine their own prejudices. Thinking back, I wonder to what extent these students were able to 'become' something different by forming new assemblages based upon a folding back.

The concept of the 'new idiot' can facilitate a new understanding of what has been called 'learning disabilities'. A student with learning disabilities is often considered to be lacking intelligence. Within most universities a student applies for accommodations to lessen the effects of a learning disability. But what if we were to consider a learning disability as a manifestation of a 'new idiot'? As Felix Guattari (1996: 22) puts it, 'Society being made as it is, even in a completely liberated school, one can hardly imagine refusing to teach children how to write or to recognize linguistic traffic signs. What matters is whether one uses this semiotic apprenticeship to bring together power and the semiotic subjugation of the individual or if one does something else.'

Conclusion

Writing about her experience of dyslexia, Victoria Littman (1993: 42) explains, 'The order of letters escapes me like a rattler no matter how many tools I use to grab, it slithers away.' When she reads meanings get lost in the jumble of letters placed out of order or reversed on the page. Even with the familiarity of her name, Littman jumbles the letters. Littman's metaphor of a rattler is reminiscent of my metaphor of mercury. We both are unable to grab or grasp normality. Littman fell into a spiral of self-blame, calling herself lazy. 'During her academic career, an instructor made the following statement: "How can someone as smart as you turn something in like this"' (Littman, 1993: 43). Furthermore, her paper was handed out to a class as an example of unacceptable work'

Having written through my own spasms and finding them to be a wealth of wisdom, I wondered whether the same can be said for the experience of learning disabilities. A student expressed that she felt she only learned differently from others, and like Littman, she had been ridiculed for the way she learned. She told me that in trying to fix her grammar and the sequencing of words she often lost grasp of her critical thinking, and her sociological perspective suffered. I suggested

that if she wanted she could submit an essay that was true to her own thought process. During my class I gave her opportunity to explore what Deleuze and Guattari would call the 'nomadic' or 'private thinker'. Of course, as Goodchild (1993), Deleuze and Guattari (1987) argue, we cannot step outside the majoritarian perspective completely, and when she submitted the essay for marking the student told me she had made some corrections because she realized that I was marking her paper for a substantial part of her grade. For her it was too risky to become completely attuned with her learning disability within academia.

Still, even with the adjustments, she and I discussed how her learning disability informed her wisdom. During this discussion it became quite apparent to both of us that there was a difference between the public persona she provided for academia and the 'private thinker' which was communicated in this paper. She expressed to me that this was the first and only time she had felt she could be herself within academia. Given that Deleuze and Guattari's work is supposed to be pragmatic, this student pragmatically created a machinic assemblage with myself and her paper which allowed her a line of flight, or deterritorialisation from the tyranny of being labelled 'learning disabled' which carries its own normative shadow. It allowed for another way, the emergence of a new manifestation of a 'private thinker'.

I have been asked whether a student's work that allows for an expression of a 'learning disability' is 'comprehensible'. But there is a 'normative shadow' that underlies the evaluation of comprehension. Within our education system successful comprehension requires that students adhere to the 'normative' rules that have been ingrained in both our educational pedagogy, and in the way non-disabled persons people go about their every day lives. As mentioned earlier, after undergoing tests to determine my suitability for a 'mainstream' education, I was perplexed because if 'normal' people were superior to me, then why could they not understand disabled people's 'inferior' way of thinking? Being in the position of assigning a grade to her paper, I realized that now I was the superior 'thinker' who could demand that she conform to pedagogical normative values and make her paper 'comprehensible' or suffer the consequences of a lower grade. Instead I chose to employ my 'nomadic' thinking, and attempted to 'engage' the essay on another plane of intelligence, other than the pedagogical approach with its basis in rationality that is favoured by our educational system.

Remembering that both she and I had to translate our thinking in order to be understood, I read her paper through the lens of my spastic thinking. However, the translation could not be 'exact', because my spastic reading differed from her 'learning disability'. I extended my 'nomadic thinking' beyond my own spastic understanding to make an assemblage with the 'intuitive wisdom' embedded within her 'learning disability'.

My purpose in relating this story is not to privilege a wisdom deriving from a disabled sensibility over rational thought. The inversion of knowledge basis and the inherent privileging of one over another would maintain a 'this' over 'that' orientation to the world, a position I reject. By accessing the paper through my spastic knowledge, I created a 'line of flight' that exceeded the pedagogical system that allowed me to access this written expression of the wisdom which underscores a 'learning disability'. After accessing both the critical thinking and academic rigour

through of the paper, I wrote notes in the margins that conformed to a 'pedagogical' thinking that is 'rational'. In effect, after making a connection with her wisdom which underlies her 'learning disability', I translated my findings into rational thought. Deleuze and Guattari (1997) argue it is impossible to completely escape or exceed the normative values of society. Consequently, for the student it was important that her work be recognized within the parameters of academic grading.

As mentioned earlier, I have constantly to determine to what extent I can affirm embodied wisdom without jeopardizing my position within academia. My presence gives validation to 'private thinking' which might create a space for a new way of thinking. But as a university lecturer I have moved from the position of an outsider to that of a stranger (Bauman, 1993) with its more accepted but still tenuous position. To what extent can I allow other voices or communication to flourish without putting my own presence at the university at risk? There is tremendous pressure on me to keep the noise down.

Yet the memory of that young boy who had to disguise his 'private thinker' and the memory of other disabled students whose own 'private thinking' remained unrecognized by the non-disabled world linger in my body. Daily within my spasms the feelings of fear, shame, and ridicule are recalled. Since that day of testing I have had a perhaps unspoken desire to make the conditions possible for 'private thinking' and 'nomadic teaching' to come to realisation, no matter what the risk (Overboe, 2001). Agreeing with Shotter (1997), I believe that the embodied interactions between those who communicate primarily by making noise (the private thinkers) along with those who primarily communicate rationally and logically would create a rich creative environment. Within the university my responsibility as a teacher is to facilitate a space for such interactive moments. In creating such spaces I am not interested in developing consensus, because I feel that consensus too often falls back on familiar patterns of rhetoric and rationalization that stifle the noise of the 'private thinkers'. Instead, my interest is in nurturing desire and passion in myself and my students that may or may not result in conflict and contested claims. But as a lecturer my job is to ensure that such conflicts and contestations do not result in 'textual violence', whereby communication is reduced to gamesmanship and students score pugilistic points over others by showing their prowess at following certain patterns of intellectualism. Rather, my job as an instructor is to be keenly aware of 'new possibilities knocking at the door' (Rajchman, 1999; Deleuze and Guattari, 1987).

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CHAPTER SIX

CONCLUSION LIVING AS A DESIRING MACHINE AND TEACHING FROM THE PERSPECTIVE OF A SOCIOLOGY OF DESIRE

I begin this conclusion with an admission and an invitation. I do not want to restrict either a sociology of desire or this new way of 'becoming' to issues of disability. From the perspective of race, gender, age or sexuality a sociology of desire could move sociology from the restrictive positionality of 'identity politics' to a dynamic machinic assemblages that are maintained at different levels of intensity and duration. The flows of desire between the categories of race, ethnicity, sexuality, and disability can create different understandings of the social world. This dissertation is a 'splice' that flows from a machinic assemblage and, in itself, is another machinic assemblage. The relationship between this dissertation and the reader offers an opportunity for a 'line of flight', 'private thinking' or 'nomadic thinking' to form assemblages.

As much as I have been critical of the 'normative shadows' of humanistic essentialism, personhood, and phenomenology, try as I might I cannot escape from them. While I have tried to articulate a new way of living, I am aware in an ironic twist that I must live in a society that persists in being shaped by these normative shadows. Since the Enlightenment, within Western society there has been a dominant notion of what constitutes humanity (Bauman, 1988). As pointed out in the Introduction, Young (1990a) asserts that all other types of people have been judged by this aesthetic since the Enlightenment. With the continued domination of Western culture, I doubt if the 'the anonymous body structure' of Merleau-Ponty's phenomenology will be displaced by any other type of body structure. But by articulating a sociology of desire perhaps we can begin to be pragmatically critical of: a restrictive humanistic essentialism, a limited concept of personhood, and a phenomenological template that defers to a white, masculine, heterosexual, and able-bodied aesthetic, that forms a normative hegemony.

In Chapter Two I address how the 'normative shadow of humanistic essentialism' operates as an apparatus of capture. The universalism of humanistic essentialism (Deleuze and Guattari, 1994) creates a vortex which all people are drawn into. Through the ranking of different types of bodies, individuals are assessed on whether they fit within the normative range of humanistic essentialism. In the case of disabled people, we undergo rehabilitation to help us achieve inclusion in the normative range in spite of our disability (Oliver, 1996; Rousso, 1988; Overboe, 1994).

The phenomenological 'anonymous body' as a template takes precedence over lived experience such that a 'disembodied self' is created through medical documentation. Medical records, through clinical expertise and scientific reasoning, have an authority that displaces the 'lived experience' of the disabled person. On an emotional level, telethons and other charitable endeavours, through pathos and an ethos of overcoming, create the 'tragic hero'- a model that most disabled people do not and cannot adhere to.

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In Chapter Three, I illustrate how the 'normative shadow of personhood' limits the concept of personhood, and fails to recognize the (potential) 'quality of life' of those perceived to be living a 'less than human' existence. The ranking of humanity has led to the measuring of one's 'quality of life' as compared to a normative stand. This normative standard refers to one's ability to achieve the characteristics associated with personhood. At the stages of pre-personhood and post-personhood a disabled sensibility places the potential person or person at risk. Similarly, the assuredness of what characteristics a person exhibits both as a sensibility and an embodiment characteristic of personhood creates a culture where some disabled people are judged as having 'lives not worth living', and may result in 'compassionate killings'. This is the logical conclusion that takes us as superfluous, expendable and a burden on others.

Chapter Four describes how a negation of disabled sensibilities informs the education system. The normative shadow of phenomenology creates a particular body, way of conducting oneself, and a rational way of thinking. There is a pre-existent condition of cerebral palsy which is the antithesis of the controlled rational person to be educated. My embodiment and sensibility are read as lacking the characteristics required for the rigours of education, unless of course I could overcome these deficits. In sum, my body falls out of the acceptable 'normative range' which requires an intervention to bring me within the normative range. I critique the ideology of phenomenology that dictates that offices for 'students with disabilities' focuses on 'deficits ' as the model for providing service. Moreover, this model is legitimised by successful disabled students who blaze a trail for others. Followers are not obligated to emulate these successful students but the culture within the education system encourages others to follow prescriptions for success.

In Chapter Five, through exposing my spasms, I offer a different approach to sexuality and relate a method of teaching that both are not reliant upon a phenomenological sensibility. My teaching derives from my spasms. Similarly, I create a space for desires of students that cannot be incorporated into a phenomenological sensibility. In this chapter I question the effectiveness of 'dialogue' as a tool for social change. Instead I argue that withdrawal or silence with a presence (as opposed to tacit agreement) creates an atmosphere that questions both the favouring of humanistic essentialism with its basis in phenomenology.

An Illustration of how the Problem of Representation Stymies Attempts at Education

My questioning the value of educating others about disability began outside the school system. Throughout my life in my everyday interactions I attempted to educate others about the ableism that exists in our society. My attempts to educate other people about the 'lived experience' of cerebral palsy were continually subverted by a representation of disability that could not be overcome. The damage the concept of representation causes is illustrated by my experience as a technical advisor for the play called '*Creeps*', (Freeman, 1972) which was performed in London Ontario in 1984. The play focussed on the problems faced by institutionalised disabled people. My participation in this play illustrates both Foucault's concept of disciplining of the body and Baudrillard's concept of simulation. In Foucauldian terms, through functional, continuous and hierarchical surveillance (Foucault, 1984: 192), Tom McCamus - who played a person with

cerebral palsy - had to discipline his body in order to mirror the spasms that are inherent in people who experience spastic cerebral palsy. For Tom these disciplining techniques became all-encompassing, as they permeated his body and caused him to experience pain which, ironically, is similar to that felt by many people who experience spastic cerebral palsy as they contort their bodies in an attempt to appear normal. Often audience members stated that they had a better appreciation of cerebral palsy because of the play. At first I thought this was only natural, as the play concentrated on the discrimination against disabled people. However, these same people always remarked on Tom's disabled/non-disabled personae. Both Tom and I felt other people were losing a sense of us as individuals in their appreciation of this simulated disabled/non-disabled persona (Overboe, 1999).

For Baudrillard (1988: 20-21), appearance is the only thing that matters in the realm of hyperreality. In short, the concept of representation is no more; it has been replaced by simulation that becomes 'reality'. Baudrillard (1988: 16) asserts that in the era of hyperreality we no longer exist as playwrights or actors on the world's stage, but as terminals of multiple networks. Tom was no longer an actor portraying a person who experiences cerebral palsy. He had become a terminal that broadcast disabled and non-disabled networks. Tom's simulation had become 'more real' than 'real'. Tom had become a vulnerable, non-threatening person who had the strength to overcome any (imagined? real? perhaps simulated?) disability. Agreeing with Linda William, Martin Norden (1994: 6) believes disabled people embody the paradoxical objectification of being both an object of desire and an object of horror for non-disabled people. Whenever the audience found his disability repugnant or grotesque, they easily perceived Tom as 'really' having a nondisabled identity (Overboe, 1999).

Within the hyperreal world, the audience 'desires' the exotic, but only if such desire takes place in an environment that is safe for them. For example, in his discussion about the San Diego Zoo, Umberto Eco (1983: 51) argues that in the world of hyperreality one can witness savagery in a fabricated jungle setting while still feeling safe. In the same manner, I argue that the audience with an able-bodied sensibility satisfies their 'desire' for the exotic 'disabled' by witnessing the simultaneously 'absolutely fake' but 'real' spectacle of Tom's wild and savage disability within a safe environment. They could be immersed in the experience of disability and feel the heightened titillation of the exotic without risk. In contrast, to speak with disabled people the audience risks having to confront their own fear of disability as it manifests itself in our experience (Overboe, 1999). While I cannot speak for all the audience, many people who saw the play would stop me and comment on the play. I was struck by the inherent ableism in their well-intentioned comments. My experience as a technical advisor on *Creeps* echoes my discussions about films more generally that concern disability.

My theatrical experience illustrates how the obscene simultaneously fascinates and horrifies people. Baudrillard (1988: 26) contends that in the world of hyperreality the obscene fascinates us. Obscenity is the point where people as a network become completely transparent. As mentioned earlier, we disabled people are either objects of fascination or horror (Norden, 1994). Under the glare of the 'normalizing stare' (Thompson, 1997) which objectifies us, we become transparent an obscenity that is driven by the salacious imagination of many people who privilege an able-bodied sensibility. As Davis (1997b) reminded us earlier, it only takes a little

imagination for non-disabled people to understand what it is like to be disabled. For disabled people there is nothing outside the continuum of fascination and horror. Thus the non-disabled fascination with the disabled within our society mirrors Baudrillard's all-encompassing obscenity. But this obscenity is exacerbated by a ceaseless desire for more.

This desire for more drives the urge to hyperreality. Eco (1985: 7) writes, 'This is the reason for this journey into hyperreality, in search of instances where the American imagination demands the real thing and, to attain it, must fabricate the absolute fake; where the boundaries between the game and illusion are blurred, ... and falsehood is enjoyed in a situation of 'fullness,' of *horror vacui.*' Along these lines my theatrical experience illustrates the insidious nature of the desire for 'more' within the public's understanding of embodiment.

Returning to my analysis of the audience's reaction, I believe that their response to Tom's performance typifies what Derrida (1978: 235) calls 'the theological stage [that] comports passive seated public, a public of spectators, of consumers, of "enjoyers" ... attending a production that lacks true volume or depth, a production that is level, offered to voyeuristic scrutiny. But what is this God who not only controls the audience but is also simultaneously "nowhere" and "everywhere?"' The audience that attended *Creeps*, in Derridian terms, 'defers' (perhaps unwittingly and without awareness) to an able-bodied sensibility with its 'normative shadow'. This 'normative shadow' that privileges able-ness in fact is a 'God' that is both 'everywhere' and 'nowhere,'; it is so pervasive that it permeates every pore of their being and in doing so is 'naturalised' and 'normalised'. The audience compliance to naturalisation and normality is not restricted to the experience of theatrical performance (Overboe, 1999).

I agreed to participate in the play because, in Deleuzian terms, I thought it would be an opportunity to present an affirmation of a disabled sensibility. Tom and I formed a machinic assemblage which created the lead character in the play. In the terms of Deleuze and Guattari, I hoped that this machinic assemblage would lead to other assemblages that would help to eradicate the abjection of disabled people. Instead, people's reaction to Tom and his character created a 'domesticated cripple' that was more palatable for them. Underscoring this facile 'acceptance' of disability is a continuation of the view that disability is a negative sensibility. People created an 'apparatus of capture' which reified normative behaviours of humanistic essentialism that privileges an able-bodied aesthetic. Tom's representation of disability, which is overlayed by his lived experience of able-ness supplanted my lived experience of cerebral palsy.

Massumi (1993: 23) argues that each person has a limited range of characteristics that he or she broadcasts through his or her body which then is either visually or aurally received by others. These aural or visual images are filtered through the receiver's preconceived categories of identity. Thus the body is a medium that helps people define each other's identity. I believe that these preconceived categories of identity devalue a disabled embodiment and sensibility. I tried educating people but I could not change their opinion of me. Even as a published doctoral candidate, as I go about the mundane routine of everyday life I am aware of the ableism which permeates my world. In my daily interactions with strangers or acquaintances my characteristics signify that I am an abject other. My lack of bodily control emphasised by spasmodic outbursts

(desires running amok) often results in me being 'tolerated' as background scenery on the stage of social interaction, noted by people (perhaps even feared), but rarely engaged by them.

Baudrillard has argued that we live in age of simulation not representation. In the case of Tom, this is true; his identity proved malleable shifting back and forth from a disabled individual to an able bodied person. For me, as well as other disabled people, our identities remain fixed in the world of representation, as frightening symbols of what can go wrong with the human experience. Of course if we 'overcome' our disabilities, we become facsimiles of able-bodied people. However, we are forever vigilante of our precarious status, and must always be ready to prove to a sceptical public (which privileges an able-bodied sensibility) that we have 'truly' overcome our disability, and are unlikely to backslide to the positions of being a 'gimp' or a 'cripple'. Thus, this normative shadow, whether it takes the form of humanity, personhood, or phenomenology, casts a pall over our present, our past, and our future.

In the Introduction I related an anecdote about the anxiety and shame I felt as I gazed upon a paint-by-numbers illustration of the body. Later my attitude changed, as I realised the illustration of the body that appeared on the paint-by-numbers box was an illusion - an ideal that no one could equal. I began to see the overlapping of my muscles through spasms as a freedom, a breaking away from the restrictions of conformity. I imagined my frenzied muscles as a palate that provided a turbulent blending of colours whose vivacity and brilliance could only be matched by the feeling of my cerebral palsy as it moved through my body. In essence the desire that emanated from the spasms created a brilliant, vivacious kaleidoscope changing constantly without any predetermined pattern or steadfast purpose. I kept these views to myself because it was scary to imagine what it might be like if a society which privileges being able bodied over disabled discovered that I did not perceive my spasms as a curse, but rather as an avenue to a new vista - a new way to experience the world.

Living in a society that privileges an able-bodied sensibility I found myself questioning my belief in the value of my spasms. However, an event occurred which forced me to look at my spasms and my sensibility in a different light. At the age twelve, during my six month check-up, I walked through the gauntlet of white coats (assorted students, physicians and specialists) including the head orthopaedic surgeon. I experienced (a rather ironic) disembodiment rather ironic as they scrutinised my cerebral palsy. They watched me walk back and forth stripped down to my under shorts. They left me alone for the moment and returned. The students were informed that they had an opportunity to witness an unusual case. I was lying on an examination table being prodded, manipulated, and poked by these specialists who spoke of the inconsistencies of my condition. I felt like a slab of meat being inspected. My whole body felt hot and uncomfortable. The head orthopaedic surgeon ended this spectacle by lecturing the medical students. He told them, 'Although this patient in some areas of physical development is superior to many other cerebral palsy patients, he shows marked underdevelopment in other areas. The apparent contradictions in his physical development are rare. This patient has been unresponsive to proven surgical and rehabilitative methods. Therefore there is nothing more that we can do'. He left, his team and the students followed. I was left with my thoughts and my anxieties.

I was shattered because not only was I not 'normal', but now I was also judged to be a 'freak' among people who experience cerebral palsy. My body was hot from the pain of their manipulation. I remember placing my hot, flushed face against the cool steel frame of the examination table for comfort. At the time I remember wondering if I were even human. I dressed and left. My father and I proceeded with the hour-long drive home. I never mentioned my anxiety to my father but I told him I never wanted to go back there (although I had been given the opportunity to have future examinations to ensure I maintained the level I had achieved). I realised that my family loved me and that I had a place with them, but I was still disturbed by the head orthopaedic surgeon's pronouncement that I was a 'freak' among people who have cerebral palsy (Overboe, 1999).

Patton (2000:16) cites Nietzsche's (1979 section 1) comments about all-encompassing categorisation: Nietzsche argues that while there are many types of leaf the differences between them are neglected under the all -encompassing category of 'leaf'. In my case the surgeon did not neglect my differences from other types of cerebral palsy. He noted them and placed them outside the category of cerebral palsy, banishing them and by extension me to a 'place of abjection' that exists even beyond the abject place where many non-disabled people situate people who experience cerebral palsy.

In terms of cerebral palsy or able-bodied embodiment there was no prior template from which I came. It could be argued that I was born into a family that through genetics and socialisation left me with some sort of 'blueprint' to follow. But, as I have pointed out, the representation of disability often negated the lived experience that includes my genetic background as well as my familial influence. Moreover, it is not a given that a family will provide a supportive environment for disabled people, as the Latimer case illustrates. The difference between my upbringing and that of Tracy Latimer stems from my family's willingness to affirm my lived experience (Overboe, 1999).

I felt anxious because I did not seem to fit in anywhere within the larger society. Previously, I was judged to be abnormal in comparison to the able-bodied population (Foucault, 1980). In some ways I could accept this designation because I was classified (albeit negatively) as having cerebral palsy, which gave me a sense of 'identity' (albeit devalued) and 'place' (albeit marginal). Now I seemed to be left adrift without any moorings. The only thing I was sure of was my desire to live. But how was I to live? For many years I tried to find a place in this community called humanity. Yet, as Bauman (1993) has suggested the invitation into this community of humanity could be revoked at any time if my behaviour, or my being, is deemed to be unacceptable. At that time this seemed to be enough to desire to live and be accepted within the humanist model. Yet no matter how hard I tried I could not escape the 'normative shadow' that confined my 'lived experience' to a representation that is the dichotomy of ability/ disability.

Now I realise that what really is happening is that desire is taking its place prior to and supplanting the 'I' (the subject) directing the way my life flows. Desire does not emanate from

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me, but rather my subjectivity at any moment flows from my desire. The manifestation I become and continue to become is a desiring machine continuing to flow. The desires that flow from me can be rerouted, stopped or incorporated in to other desiring machines. Nevertheless, desire can never be totally contained.

I began to explore if there was a way to exceed representation which is a foundational component of abjection. Zourabichvilla (1995: 190) understands Deleuze as saying that perception is not simply a matter of seeing something. Rather than seeing the fixed image of representation which is constrained by our preconceived notions of what a phenomenon is, we must be willing to look beyond our preconceived notions and perceive something differently, even while these preconceived notions haunt us. The disabled person is invisibly wrapped in the shroud of our pre-conceived notion of humanness that only allows our state of disabled-ness to be the abject other. Rather than being haunted by this humanistic essentialism and a limited notion of communication associated with being a person, society or individuals in it could be open to differing types of personhood and communication. The anxiety would not be removed from the interaction, but perhaps we would understand that this anxiety is not a matter of a person being uneasy with the disabled other. Rather it is the realisation that intersubjectivity is flawed by its reliance upon representation that accompanies its firm belief in, and understanding of, humanness that limits our experiences.

The desires that emanate from my spasms bring forth a subjectivity that had been suppressed by the normative expectations. In effect, this subjectivity is a 'singularity' that exceeds the restrictive dichotomy of ability/disability. Moreover, this 'singularity' is a 'difference' that eschews representation. Deleuze considers how 'difference' is limited by representation. For example, in his discussion about opposition and revolution, Deleuze (1994: 268) writes, 'Contradiction is not the weapon of the proletariat but, rather, the manner in which the bourgeoisie defends and preserves itself, the shadow behind which it maintains its claim to decide what the problems are.' Similarly, by framing the argument within a non-disabled/ disabled restriction the able-bodied have been able to preserve and defend their superior position, because their normalized embodiment and sensibility not only sets the parameters of 'what the problem is', but also the limits of the discussion and the type of communication required to take part in the dialogue. Thus, an able-bodied sensibility often excludes a disabled embodiment (such as a spastic embodiment), which is interpreted by others as conveying that this individual lacks the intelligence to partake in a discussion in any 'meaningful' or 'appropriate' manner. (Overboe, 1999: 25).

Our identity that is defined as disabled (read abnormal) in relation to able-bodied (read normal) restricts our desires. As mentioned earlier there is tremendous 'social capital' for people who 'overcome' their disabilities and take a prominent position in the circle of humanity. But in order to be included into humanity the disabled person must meet normative expectations. Erevelles (1996) argues that by endorsing liberal individualism identity politics devalues the lives of disabled people who have interdependent relationships with others. Our difference has been reduced to a state of abjection.

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In respect to the topic of 'identity', Deleuze (1994: 266) writes: 'To restore difference in thought is to untie this first knot which consists of representing difference through the identity of the concept and the thinking subject.' Applying Deleuze's insights to disability, I believe that by untying this knot that garrottes our lived experience and imposes an identity on us, we can begin to rid ourselves of the twin concepts of ableism and extreme liberal individualism that often lead others to see us as an abomination. Rather than an 'equality of rights' based on identity politics, I call for a sociology of desire that affirms a disabled embodiment and sensibility. Our physical, mental and emotional manifestations of disability, as well as the social, political, moral and physical environment, will continue to have an impact upon us. But if we accept a sociology of desire then no longer would we be 'done to', and 'done for', or even 'done with,' as so often happens within nondisabled and extreme liberal individualism parameters and with the restrictions of an ableist sensibility.

Second, difference is subordinate to resemblance. Deleuze (1994: 266) believes that 'difference' necessarily tends to be cancelled in the quality of the concept which covers it, while at the same time inequality tends to be equalized within the extension in which it is distributed. Thus the 'difference' that reveals itself in the embodiment and sensibility of disabled people is cancelled (as the prefix 'dis' designates) in favour of an able-bodied corporeality and 'common' sense. When we overcome our disabilities, as in the case of 'disabled heroes' (Wendell, 1989: 116), we necessarily feed back into this loop by not validating our previous sensibility and by accepting the great equalizer – normality, the benchmark for humanity. I believe that the term 'person with a disability' demonstrates and is underscored by a 'normative' resemblance that we can attain if we achieve the

status of being deemed 'people first' (with the term's emphasis on independence and extreme liberal individualism) in the eyes of an ableist-centred society.

But our negation or inequality is equalized and extended because other disabled people fail to meet normative expectations and are deemed 'damaged goods' (Bauman, 1988). For those disabled people who fail to achieve this status there is a legitimization of their position because of the fairness of distribution. One has failed because one does fall within an acceptable range of legitimized basic standards (typified by the 'anonymous' phenomenological structure which is the foundation for an 'idealised' embodiment and aesthetic) required for acceptance into the realm of able-bodiedness. The decision is not based on discrimination against this particular person but is perceived to be a matter of 'objective fact'.

The 'naturalness' of the notion of the able-bodied liberal individual, coupled with the negation of a disabled sensibility, makes many disabled people queue for the chance to be anointed as 'people first', while simultaneously disavowing their previous embodied positions as 'gimps' and 'cripples'. Ironically, disabled people who achieve 'people first' status are not achieving full normative status, but are only legitimizing an able-bodied resemblance through their desire for normality. Moreover, they reinforce an extension of the legitimacy of this resemblance by validating a continuum of disabled persons ranging from the successful 'people first' to the pitiful 'gimps' and 'cripples' who are deemed worthless failures.

To facilitate a notion of 'difference' that affirms a disabled embodiment as well as a disabled sensibility I use the term 'disabled persons,' rather than 'persons with a disability' because it implies that their disabilities not only inform their lives but may also be a positive factor in many aspects of their lives. Employing the term 'disabled people' allows for the desires of all 'gimps' not only to be recognised but also affirmed, allowing them to reject the normative benchmark and its reliance on the phenomenological resemblance which sets the parameters of what constitutes a favourable difference. Disabled people may or may not choose to reject the notion of resembling this phenomenological able-bodied template. Hopefully, through desires that emanate from their embodiment and sensibility will affirm their own disabled sensibility.

Thus, Deleuze (1994: 267) calls for a 'diagonal' approach that recognizes difference without negation. A diagonal approach would allow a disabled embodiment and sensibility to be perceived as one way of being without its automatic negation, or without inversely giving it prominence over non-disabled continuance. If we were to look at difference as 'diagonal' rather than 'hierarchical' then disabled people's embodied sense of temporality and thinking would be neither valued or devalued but only exist. Existence would not be reduced to biological determinism, but rather a 'becoming' that exceeds the 'normative shadows' that inhibit our desires.

Perhaps the best way to describe my exceeding the disability/ability dichotomy is by giving illustrations of my transformation (but not a transformation in the prescriptive sense). After the pronouncement of the orthopaedic surgeon, for many years I tried to make sense of not having a category, and not having any moorings. If I was not authentically disabled and not able-bodied then where did I belong? Fortunately, I had the support of family and friends to provide me with a sanctuary from this anxious question. Over time I tried various avenues and outlets to resolve my uneasiness. It was only when I finally discovered that my life did not have to be resolved or make sense that I experienced a loss of anxiety.

I decided that rather than trying to resist my cerebral palsy I would discover what my spasms meant for me. As an adult I learned to swim. Unbeknownst to people who thought I was trying to overcome my disability (and disavowing my 'disabled heritage' as a colleague in the M.A. programme accused me of doing), in reality swimming helped me to begin to better understand the fluidity of my spasms. One day another swimmer approached me and offered to teach me how to understand my body. I was excited about learning more about my body, my spasticity.

When we met, Miri began to manipulate my body, as she explained that she was trying to release my body's understanding of itself. I was supposed to let go of my body and allow it to find its own sense of movement. At one point Miri stopped and scolded me for trying to reach a predetermined goal. I thought I was allowing my body the freedom to find its point of becoming, but subconsciously I had a preconceived notion of what I should achieve. The normative shadow which manifests itself in the drive to normality, as expressed through both the medical model and the rehabilitation system, had a magnetic pull upon me. Miri told me to leave my ambitions at the door and allow her to work with my body. All I was required to do was notice the differences in my body. Often these 'differences' did not conform to the goals of the rehabilitation system.

Miri's idea of working with my body was not a prescriptive procedure to make my body normal, but rather a way to open up my desiring body and allow it to flow and find its own way of working that incorporates my cerebral palsy instead of trying to negate my spasms. Once I was able to relax and enjoy my body-flow, I was able to discover that my body did not have to conform to either an able-bodied or an ableist negation of a disabled sensibility. What I am speaking about here is not a typical inversion of the categories of disability and ability, although this inversion is a positive process. For example, Deborah Abbot (1985: 273), a disabled woman, writes about looking at her body and feeling it while showering. She compares her alive human body with the stone statuette-like bodies of two women who are able-bodied. Abbott inverts the ability-disability dichotomy that devalues people with a disability. She transgresses normative expectations with her notion of 'bodily control' that opposes the 'regularised control' that permeates an able-bodied embodiment that constitutes the normative template. Rather, Abbot relishes the

'displaying' of her body - a body that refuses to conform to an able-bodied requirement of controlled regulation and rejects the imperative of a body that has its basis in humanistic essentialism.

While I appreciate Abbott's valorising of her own body and her inverting of the non-disabled/ disabled dichotomy, this is not what I am trying to accomplish. By inverting the dichotomy, disabled people remain captured within an able-disabled aesthetic that I reject. Wanting to remove myself from this restrictive dichotomy, I have no intent to affirm my cerebral palsy by claiming its superior position over an able-bodied sensibility. The validation of my cerebral palsy is an ancillary outcome of letting my desires flow. Just as the reading of me as exemplifying an overcoming narrative says nothing about my intent, a projection of the normative shadow affects how others perceive me. It is a virtual becoming where there is no assurance that my desires will lead to an affirmative outcome rather than a negative outcome, even to the point of my destruction (Deleuze and Guattari, 1987; Patton, 2000).

Discussing dance as an artistic performance, Jose Gill (2002: 126) believes that there is some part of the body which escapes representation and the production of signs. This body can never fully empty itself and achieve a 'degree zero of movement' or a 'degree zero of gestures'. Something resists prior to representation - a virtual body in the Deleuzian sense. This part of the body that resists is a vitalism that escapes signification or representation. The dancer may not be aware of this embodied remainder that cannot be contained within the dance performance. Moreover, this vitalism that escapes is not a matter of the dancer wilfully attempting to subvert the containment of the movement of the dance. Rather, this vitalism stems from desire that exists prior to subjectivity.

In her discussion about dancing, Šumič-Riha (1997: 226) asserts that the body oscillates between being reduced to a signification, and enjoying its own sensation. Yet there is an embodied movement that cannot be contained within this oscillation from signification to dancing that remains coded. For example, Šumič-Riha argues that modern dance, which rebelled against traditional dance, created its own foundational convention to affirm its own existence. Whether doing traditional or modern dancing there is 'a missed encounter with the body, a living body, an enjoying body' (Šumič-Riha, 1997: 228).

In the same manner I argue that modernity, with its clinical rigour, defines the disabled body as an abjection which demarcates what is 'acceptable' and 'normal' by simply being what they are not. The clinical discourse in fact displaces the 'lived body', a body that 'experiences' with 'the body' that is 'objectified'. Within postmodernity or poststructuralism the disabled body is reduced to a signification, a trope, or a text to be read. Thus the disabled body results in, in the words of Šumič-Riha, (1997: 228), in 'a missed encounter with the body, a living body, an enjoying body' whether it is situated in modernity or postmodernity.

Šumič-Riha (1997: 234) goes on to argue that while an enjoying body is missing in dance, there is an enjoyment which cannot be contained and often is not recognised, as this desire does not conform to the prescriptive requirements of dance whether traditional, modern, or postmodern. This enjoyment has no other reason to exist except as a 'surplus enjoyment' without any goal or signification. Yet, this enjoyment fails to be recognised as it cannot register within the concept of dance, or refuses to do so.

From an able-bodied perspective, as it manifests itself in either modernity or postmodernity, like the dancing body the disabled body cannot be an enjoying or living body that affirms a disabled sensibility or experience. One can enjoy a disabled body only if one can 'overcome' it. Enjoyment or satisfaction with life can be achieved only if one concentrates on his or her mental capacities and ignores the body. Disabled people often express a strong desire not to be identified with their bodily weakness, inabilities, or illnesses. To be identified with their disability often leads to low self-esteem. Therefore it is better not to identify with our bodies but to identify with our intellectual and/or emotional experiences (Wendell, 1996: 176). In sum, embodied enjoyment for disabled people can only be recognised if it falls within an able-bodied registry of embodiment.

Šumič-Riha (1997: 235) believes that the dancing body is subversive in that aspects of embodied enjoyment cannot be contained in the dance. Similarly, the ignored part of the disabled body that is the enjoyed-body is subversive in that it exists. This disabled body traverses the institutionalised abjection which prevails in the attitudes, beliefs and practices of most non-disabled people. The presence of a disabled body that is an enjoyed-body at least questions the self-assuredness of non-disabled sensibilities which continue to see a disabled embodiment as tragedy. Moreover, the fantasy of the disabled person overcoming their disability and becoming normal through rehabilitation may be abandoned in favour of a notion of a healthy embodiment which affirms a disabled presence.

But perhaps the notion of being subversive places me in the middle of the disability /ability dichotomy. Consequently, I favour the vitalism advocated by Gil (2002) rather than the subversive tone of Šumič-Riha (1997). In my body work with Miri there was no agenda, subversive or otherwise. If desires exist before subjectivity then the notion of identity is a fabrication, a means of categorisation that again often leads us to abstract dichotomous pairings- man/woman, white/ non-white, heterosexual/homosexual, non-disabled /disabled (Golding, 1997a). As mentioned earlier, Massumi (1993: 23) believes the body is a medium that helps people define each other's identity. It is the 'non-representational' elements of me, the desires through spasms (that are not confined to identity), that refuse to be a representation or represented, that flow, attempting to make social assemblages with other desiring machines. Through my desires I enjoy my spasms which are the remainder, the virtual vitalism that preserves non-representational and chaotic movement while escaping the world and representations and, for the moment (or even continual moments), creates a space for the creation of 'new earths and new peoples' as proposed by Deleuze and Guattari (1993, 109).

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I articulate a life-affirming existence that is not confined to dichotomous thinking. Moreover, my subjectivity stems from desires (including those that flow from my spasms) rather than from a sense of being based upon an 'anonymous bodily structure of phenomenology'. Consequently, to acknowledge the validation of my spasms I call myself a cripple or a gimp. This is not simply an inversion of the dichotomy which I reject, but a way to reinforce my presence. However, in trying to give myself a (hyper)presence, I may self-destruct. Thus, life-affirming desires are indeterminate. The singularity I achieved by exceeding the dichotomy of disability/ability differs from the singularity of transgender, mentioned in the Introduction. The singularities of transgender and bisexuality developed from an interpenetration of the respective conceptual polarities. If there were an interpenetration of the polarities of disability and ability, then Rick Hansen or some other iconic 'overcoming hero' would personify it. My singularity is a result of an irruption that follows the singularity of 'difference in itself' that is not a development from an interpenetration disability/ability, or any other dichotomous manifestation.

Illustrating the Indeterminancy of Life-affirming Desires

The indeterminacy of life-affirming desires is illustrated by my experience at a symposium concerned with social justice. To sustain 'nomadic thinking' requires a high level of intensity. At this conference I refused to be 'the problem' and stretched nomadic thinking to its limit by questioning the ableism of the audience who thought of themselves as being sympathetic to disability rights. I argued that there was a fear of disability which permeated how they perceived social justice for 'gimps', 'cripples' and 'crazies'. This was a line of flight from the territorialisation of a social justice which sees us as an abject other to be 'done with, done for, or done to' (Overboe, 1999) requiring disabled people's spoken (or unspoken) eternal gratitude. By calling into question their need for gratitude, their need to feel benevolent, and their need to quietly feel superior, while espousing comradery, I stripped away any protective covering which insulated the audience from realizing their own fear of disabilities. In effect, these advocates of social justice were still 're-forging difference into inferiority' (Bauman, 1993: 97).

I refused to engage in the process of explaining my position or educating anyone. Rather I put forth my position and waded through the turbulence of its wake. The turbulence of this wake created a 'safe' space for another disabled presenter to admit that she felt pressure to continually apologise for her existence and obligated to continually thank an able-bodied society for favours rendered. Members of the audience were uncomfortable with her observations. The passion in her voice along with the message unsettled the audience who often were recipients of gratitude from her, and other disabled people.

I had no idea how my 'line of flight' from the celebration of social justice would be perceived by my audience. One person who I thought understood my perspective left

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before any discussion, without acknowledging me as she usually did at conferences. Considering that prior to my presentation we have spoken about social justice issues, I am surprised that to this day she never has spoken to me about my talk. Given her reaction, I wondered if I had gone 'too far' and in Deleuze and Guattarian terms (1987) had reached a point of oblivion. Yet I could not censor the desires that emanated from my spasms. Nor could I hold back the intensity of these desires. During a break some other members of the audience offered that my talk forced them to look at their own ableism. Lines of flight can create a reterritorialisation which cannot be predicted or prescribed.

I invited the participants at the conference (as I now invite the readers of this dissertation) to consider if they would free themselves from a restrictive humanistic essentialism and take a chance. Can we risk setting ourselves adrift from the life raft of the restrictive humanity prescribed by phenomenology, personhood, humanistic essentialism? Allow ourselves to be carried away by the flow into the turbulent, indeterminate, chaotic, unknown desiring seas of becoming? Can we allow ourselves to write about meandering and simply 'becoming' through desire, instead of being on the predetermined path of humanity? For the moment, can we resist the compulsion to write about finding the meaning for, or making sense of, our lives or those of others? Can we risk discarding the restrictive notion of this humanistic 'quality of life' which we believe anchors us, but in reality weighs us down like a diving-bell? Instead, the waves of desire may cause us to make connections with other desiring machines that are not concerned with abstract issues like quality of life, but only interested in living and desiring. Can we risk allowing our singularity and those of others to be exposed by letting our desires for new possibilities flow?

At the time of the symposium I was working at the university where the conference was held. I missed the post-symposium discussion, but some colleagues expressed that my critique of social justice was the impetus for others (including aboriginal peoples, poverty groups, feminists, students, and elderly people interested in social justice) to discuss how the ideology of social justice is oppressive. A colleague suggested I had 'hit a nerve' in the collective consciousness of the people there. This was not a rational exchange of ideas. Rather, my presentation with its passion and intensity cut through the veneer of social justice and identity politics with its rational intersubjectivity and (re)opened wounds that had been anaesthetized by the collective 'normative shadows' that privilege normality. Groups of people began to question how their organizations inhibited others by caring for them, creating abject others. Moreover, they began to consider how their naturalised notion of humanity within their own community (what I consider the normative shadows) suppresses the vitality of the 'other' through the process of abjection. Individuals discovered a 'voice' that emanated from desires that had been either suppressed or undiscovered. Some heard themselves muttering that in helping the 'downtrodden' they too were guilty of 're-forging difference into inferiority' (Bauman, 1993). Others began to question the dichotomous thinking - male/female, white/non-white, ability/disability, and so on - that constricts people (and desires) [as Golding 1997a; 1997b attests]. Some began to question the pejorative aspects of the call for a 'universal humanistic essentialism' that frames the 'Social Gospel'. I was sorry I missed

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this discussion. Instead of rational compartmentalised 'talking heads' representing marginalised 'politics of identity' groups, there was a visceral exchange of passions, discomfort, and messiness.

Pat, one of the organizers of the symposium, complimented me on the risk I had taken in my presentation. He said at the beginning of the conference that there was a general belief that systemic poverty was the common enemy. All the symposium participants were seen to be in solidarity against this common, if ubiquitous, adversary. 'Then you came out swinging like Ali (the boxer), setting people back on their haunches'. Pat said that power and passion erupted from me and seemed to be unrehearsed. I explained that 'the voice' he heard was not 'my voice,' but a voice that emanates from desires that need to be expressed (or more correctly escape from ableism).

In fact it is not simply ableism that my desires must escape from but rather the humanistic essentialism that is constrained by these 'normative shadows'. Similarly, I believe all people have desires that are constrained by these 'normative shadows'. What is required are machinic assemblages of desire to create new paths, new worlds, and new ways of thinking. At the post-conference discussion there were differing machinic assemblages created by various lines of flight that possibly are continuing today if the desire remains and is not blocked by other desires which may or may not impose sanctions to maintain the status quo.

Leaving the symposium early, I did not know the depth of the positive reaction towards my presentation and had to rid myself of the ableism experienced. Later, preparing for bed, like a snake I shed my skin of this restrictive phenomenology (a ritual that I go through daily to interrogate my own racism, sexism, ageism, homophobia, classism, and ableism). By shedding my skin, hopefully I can rid myself of the scars of the affects of these normative shadows which are reminders of the ableism (often couched in benevolence and compassion) which continues to bring down its lash upon my back. These lines of flight have cost me friendships (or perhaps they never were friends, but rather I was a political convenience, or an exotic other), ended relationships with lovers who found the intensity too much, and at times employment has been difficult because I do not conform to the 'overcoming narrative' expected of me.

Like everyone, earlier in my life, I found myself clinging to the raft of humanity. But there was only room for those who could pass the requirements of phenomenology. The surgeon who adjudicated threw me overboard. Soon the waves of desire overcame me and I became a new subjectivity. The brine of the sea of 'becoming' exfoliated the markings of the attitudes and behaviours seared to my skin, along with my deeply felt disappointment at living in a world with a disposition that devalues my existence; my sensibility, with a sparkle in my eye, remains open to machinic assemblages with friends, lovers, and work, as well as other unimagined possibilities that allow for the affirmation of desires. My 'singularity' which emanates from my spasms creates new possibilities,

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and a new way of life, could other disabled people find new ways of 'living' their lives, by discovering singularities that stem from their own disabilities?

Can You 'Become a Desiring Machine' If You Acquire a Disability

Over the years, whenever I have spoken about my perspective on disability issues, people have said that the perspective of people who acquire a disability probably differs from mine. This statement has made me cautious about imposing my particular views or experiences upon other disabled people, whether their disability is acquired or congenital. I was at one time a group facilitator in a rehabilitation centre for people who have acquired brain-injuries. One day, I walked into the group session and the group asked me how I manage to have a 'presence' (as mentioned earlier my presence is more of a hyper-presence). I explained to them that for many years I have tried to find a place for myself within an able-bodied world. Over time I realized that I did not have to find a place for myself in the world; that I am in this world and wherever I am is my place (although not in an essentialist manner).

We spoke about strategies I employ to give myself a sense of presence, not necessarily belonging but presence. Belonging assumes that you're entering a place where you are acceptable. A sense of belonging is positive if you're accepted. If you do not feel accepted you're always looking for your invitation to be revoked, either figuratively or literally. In contrast, if you think of presence rather than belonging, the desires that flow from you will connect with other desires which emanate from persons, inanimate objects, or intellectual endeavours such as ideology. Of course, when I spoke with group members I expressed the concept of presence as arriving at a place and being open to making connections with others. Put another way, Bauman (1993) has argued that for the most part the abject other is relegated to being a backdrop to the social action of people who fall within the range of normative expectations. The concept of presence shifts the positioning of the abject other from the backdrop to a central referent point. The group remarked that this explanation made sense to them, as they sensed that neither verbally nor in my actions did they ever perceive me to be asking permission to be somewhere.

From the perspective of rehabilitation, the notion of presence is something that one might acquire as a result of a successful stint of rehabilitation (where success is defined as having the ability to be integrated into a normative range of humanity). As the group pointed out, I did not see myself as being abnormal. Therefore, the point of having presence has nothing to do with being considered normal or being considered as acceptable for the normative range. I suggested that because I was born with a disability, perhaps it would be easier for me to have a sense of presence. After all, I did not have a prior life as a non-disabled person. They surprised me when they said that I seemed to live for the moment (the expression 'for the moment' differs here from the New Age vernacular), without a preoccupation with my past or the future on the horizon. I explained that rather than looking at life as a linear trajectory, such as a journey, I preferred to look at life as a matter of making connections with differing people at

various levels with differing intensities. Today I realize that I was invoking Nietzsche's (1974) doctrine of Eternal Recurrence, whereby there is no past and there is no future, only the present. One can choose to explore an assemblage, and if this assemblage proves unsuccessful one has an opportunity to choose a differing pathway or connection.

If the Nietzschean doctrine of Eternal Recurrence seems difficult to grasp or believe in, then de Certeau's (1987) theory concerning the past and present may be more palatable. de Certeau (1987: 87) asserts that memory is not the trash-can of the past but actively comes into play and offers alternative possibilities of the future. Consequently, in terms of rehabilitation the loss of the past life as an able-bodied person is a matter to be reconciled by the person who acquires a disability. But if we take de Certeau's observations seriously, then the reconciliation of the past embodiment with the present may be impossible. The memory of the past territorialises the present and impacts on the future for the moment. This is an elusive moment that cannot produce, and refuses to be, any type of synthesis - such as a making sense of acquiring a disability that would be employed to bring together a fractured identity. We spoke about the guilt group members felt when the concept of reconciliation failed to put to rest the memory of the past.

Perhaps the most intriguing aspect of this episode was my admission to the group that my being Jim is not dependent upon the dichotomy of disability/ability. The difficulty in not defining myself in the disability/ability matrix; it is that others will nevertheless pigeon-hole me as disabled. If the imposition of a 'master narrative' on me impedes my becoming a desiring machine and creating a social assemblage, I might confront their misconception. If it has little or no bearing on my life, I may allow others to label me as disabled.

Near the end of the three-day sessions the group members decided the artificial demarcation that separated past life as able-bodied, present life as disabled, and the future as unknown was less than helpful for them. Rather, they chose to give themselves a presence by not limiting themselves to the dichotomous categorization of disability/ ability. This does not mean that they ignored their own sensibility of brain injury or simply 'reframed' it (in the latest mantra of New Age positive thinking), but rather that their own sensibility became an important aspect of how they connected with others. In retrospect, I encouraged the group to find their own 'singularity' that affirmed their own experience of brain-injury (as I had found with Miri).

This 'singularity' may be seen as an alternative plane of immanence, a 'line of flight' allowing for freedom from the dichotomous pairing of ability/disability which exists as the dominant plane of immanence within our society. Deleuze and Guattari (1994:70) explain, 'conceptual personae and psychosocial types refer to each other and combine without ever merging.' Thus the conceptual personae of this 'singularity' may combine under the conceptualisation of disability studies without merging with the 'ability/ disability' dichotomy. These two differing planes of immanence may intersect for pragmatic reasons, but this 'singularity' has its own 'line of flight.'

No list of features of conceptual personae can be exhaustive, since they are constantly arising and vary with planes of immanence. On a given plane, different kinds of features are mixed together to make up a persona. We assume there are *pathic features*: the Idiot, the one who wants to think for himself [sic] and is a persona who can change and take on another meaning. But also a Madman, a kind of madman, a cataleptic thinker or 'mummy' who discovers in thought an inability to think; or a great maniac; someone frenzied, who is in search of that which precedes thought, an Already-there, but at the very heart of thought itself. Philosophy and Schizophrenia have often been associated with each other. But in one case the schizophrenic [sic] is a conceptual persona who lives intensely within the thinker and forces him to think, whereas in the other the schizophrenic is a psychosocial type who represses the living being and robs him of his thought. Sometimes the two are combined, clasped together as if an event that is too intense corresponds to a lived condition that is too hard too bear. (Deleuze and Guattari, 1994: 70)

I am less than comfortable with Deleuze and Guattari invoking the experience of schizophrenia as being polarised into personae (good) or psychosocial type (bad), a division which seems to reify both subjectivity and pathology and contradict a philosophy of desire. Nevertheless, the above quotation, if read differently, can question the notion of thinking. Desires that flow from my spasms create an Idiot who wants to think for himself and also is capable of change. Moreover, often I fold-back into myself, in the Deleuzian sense, creating a cataleptic state where I withdraw to a state before thinking. In Chapter Three, I related my experience of pre-personhood and correlated it to meditation, but my experience also resonates as a cataleptic state when I must retreat from being over stimulated by a society that does not appreciate my spasms. If I were not able to have these moments of 'respite' from this ableism, then perhaps my life would be too hard to bear. Conversely, my spasms are nomadic and frenzied as they lead me on a search for 'that' which precedes thought. Moreover, the spasms that affect my thinking process rob me of my thinking - a thinking which privileges rationality over all other thought, and is part of a normative belief concerning being which privileges humanistic essentialism above all other types of becoming. The concept of personhood sees my sensibility of cerebral palsy as a deficit to be overcome. A sociology of desire allows for sensibilities that have been pathologised to be recognized as differing personae that weave throughout my life and create differing subjectivities at various moments in time.

These two differing sensibilities are not formed only through the interplay of personae that come to life through desire, but can also come to fruition through machinic assemblages. An illustration of a machinic assemblage and the resulting 'becoming' can be found in the relationship between blind people and their guide dogs. Referring, if not explicitly then implicitly to this notion of 'becoming' in his relationship with his guide dog, Smokie, Michalko (1999: 9) writes:

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Whatever Smokie and I do, whatever kind of life we experience together and whatever else we mean to each other, we are 'person and dog' sharing a life together. We are 'human and animal' living in the world and moving through it together. Smokie's presence in my life has reminded me that 'nature' is as much a cultural construction as 'blindness' is, and that distinctions like human/ animal, society/ nature, nature/ nurture are themselves human inventions.

From the perspective of Deleuze and Guattari (1987), the closeness of Michalko and Smokie is an assemblage which allows for a 'line of flight' from the devalued position of blindness to a reterritorialised state which consists of Michalko becoming Smokie, and Smokie becoming Michalko. From a normative perspective, Michalko would be experiencing a deficit because of his experience of blindness. Smokie would be considered a compensatory device to counterbalance his loss of sight. In the previous chapter I pointed out that blindness is a sensibility that differs from a sighted understanding of the world. Michalko's relationship with Smokie creates a sensibility that differs from both Sack's (1996: 133) comments on blindness and a sighted view of the world.

Another illustration of machinic assemblage and 'becoming' has implications for the concept of post-personhood. A few years ago I visited a high-security facility for patients with Alzheimer's disease, and within the first few minutes a patient approached me and smiled and touched my cheek. During my stay the same woman repeated this action. Two nurses who observed our interaction remarked that it was simply a reflexive somatic reaction that had nothing to do with her making a connection with me. Another nurse witnessing their response told me that she believed I had made a connection with the woman and my way of seeing the world was needed there. From the point of view of Deleuze and Guattari (1987), I had not only become nomadic in my thought process, but had ventured to the point where the possibility of new life, a new sense of becoming, would be appreciated and accepted. But for me this nomadic excursion was not simply a foray into new territory, but rather a return to my own past as an inarticulate individual (my cataleptic experience). In effect, the woman and I created a social assemblage which allowed for both of us to escape into a line of flight, away from the territorialising effect of rational grammar and communication at least for the moment. This nomadic expression of desire differs greatly from a restrictive personhood, with its limited view of existence that underscores a humanistic essentialism which is inclusive only if the person adheres to the rules of grammar and subjectivity that remain unspoken and unquestioned because they are 'naturalised' and taken for granted.

This notion of what constitutes 'naturalness' or 'normality' is something that requires no explanation or thought. Similarly, people are aware of what constitutes abnormality. Yet people do not want to be seen as mundane 'normal' or ordinary, banal beings but as unique individuals. At the same time, they do not want their uniqueness to be perceived

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as being so extreme that other people choose not to interact with them. I am reminded of Simmel's (1904) essay on fashion. He asserts that there is a cycle of fashion; a product may begin as avant-garde, but through the process of mass production and consumption it becomes normalised and mundane. Eventually, to be seen with this product means one is deemed to have bad taste because there is now a new and exciting avant garde product to own or consume. In our desire for uniqueness we must be careful not to cross the line that separates avant garde from bad taste. If the cry 'everyone is not normal' can be considered a desire for each person to assert their own uniqueness or even a potentiality for an avant garde individualism, then this differs from the labelling of non-normalness or abnormality that some disabled people experience on a daily basis. Often we are considered the abject other relegated to the realm of bad taste. Of course, the exception arises if we gimps become 'disabled heroes' and become avant garde. To paraphrase Wendell (1989:116), this new-found status is helpful for the individual, but does little for the ordinary cripples who are relegated to the realm of 'bad taste'.

Social or Machinic Assemblages That Affirm a Disabled Sensibility in a Family

There is an ableist assumption that disabled children are a burden on their mothers. Second, disabled women are often considered to be unworthy sexual partners or 'unfit' mothers. Thus, my exposition centres on the role of disability in the mother-child relationship. Before beginning this section I would like to issue two caveats. I do not mean to infer that disabled males or disabled fathers are unable to parent.

When prospective parents are asked what kind of child they prefer they often answer, 'It does not matter as long as the baby is healthy'. This commonplace value judgment reinforces the notion that to be disabled is less desirable. As mentioned in the previous chapter, societal attitudes have led to technology and the medical practices that undermine a disabled sensibility. Berubé (1994) explains how he and his wife were given outdated information concerning Down Syndrome; when they decided to have the baby the hospital staff suggested they were guilty of intellectualising the situation. Concerning the matter of reproductive rights, Verges (1991: 4) writes, 'Feminists have been divided between those who argue that women should not be defined by their bodies and those who argue that women play a specific role in society because of their ability to bear children.' Critics of the first stance argue that it claims to represent women as 'persons' whose prototype is the rational-thinking male, a model that fails to consider 'any cycle of life peculiar to the female'. Critics of the second position contend that glorifying childbirth feeds into the patriarchal construction of sex and gender thereby maintaining the ownership of women by men (Verges, 1991: 4).

Closely tied to the above debate on childbearing is the debate concerning reproductive technology. Supporters of reproductive technology argue that it has allowed women the freedom of choice, whereas its detractors assert that it is another technological tool used by patriarchal society to control women. According to Verges (1991:11) '...[T]hese new technologies [are devised] to master life's processes (including childbirth) until none of

its aspects can escape ... to regulate production according to masculinistic and capitalistic ideas'. Verges (1991:12) calls for

> A feminist project that situates itself beyond these dichotomous locations [either the glorification, or the rejection, of childbirth] and instead affirms the symbolism of the dyad women-fetus. It would take as its theoretical foundation the questioning of our denial of dependency and the desire to forego our origins. Understanding the interdependence of two beings could offer a community in which the autonomous individual would be aware of her or his origins and the aspiration for autogenesis that supports most liberal claims would be challenged.

Along with the debate about whether childbirth provides a power base for feminism or is submissive to patriarchal control, disabled women are faced with the negation of their right to reproduce. Often their families and the medical profession feel that disabled women either lack sexual control or are asexual. In either case, these social institutions deny disabled women their right to become sexually active or to reproduce. When families and professionals support a disabled woman's right to be sexually active and to choose childbirth, often society fails to provide the necessary resources for her to raise the child (Fine and Asch, 1988a; LeMaistre, 1985; Finger, 1985; Hyler, 1985; Lonsdale, 1990).

For disabled women, reproductive rights encompass more than the right of access to birth control. They also include the right to choose what to do with their foetuses, to retain their reproductive organs, and to not have their bodies used to test unproven contraceptives and questionable new reproductive technologies. Disabled women also fight for the existence of future people with a disability, by arguing against reproductive technologies that are used to identify foetuses with disabilities which then are routinely aborted (Fine and Asch, 1988b; Lonsdale, 1990; Ridington, 1989b; Finger, 1985).

The following remarks from disabled women quoted by Lonsdale (1990:78) illustrate how they employ the concept of the 'reclaiming of origins'. One woman described her deafness as a family heritage: 'Every time we fall in love and make babies, we pass it on'. Another woman with osteogenesis imperfecta described loving her baby with the same condition as 'learning to completely love myself... [rather than] trying to make up for the mistake of existing'.

Children of disabled women develop various strategies that take into account their mothers' disabilities. One mother who could not use her arms to lift her children out of their cots would position herself so that they could hold onto her neck and be lifted. At an early age her two children adapted to her disability and learned to 'scramble up her and hang around her neck' (Lonsdale, 1990: 79). Studies have shown that infants with either one or both parents disabled adjusted to the situation, and were more cooperative and patient with their parents than infants with able-bodied parents. For example, videotapes show the cooperation between a paraplegia mother and her baby. Her difficulty with balance meant she had to lift him with one hand; at one

month of age he would adapt by curling up like a kitten and being very still during the lift. As time progressed, the cooperation intensified (Ridington, 1989b: 14).

Certainly, there are negative repercussions for children with disabled mothers. Everyday children who fear inheriting a disability from their mother must face their potential future manifested in her. Similarly, mothers who have a genetic disability fear the possible repercussions of passing on their genetic disease to their child. But these fears are perpetuated by an ableist society which fails to affirm or support a disabled existence. When the disease impacts on a mother's life she becomes acutely aware that in the future her offspring may suffer in the same way, which in turn magnifies her present strain. The mother's outlook concerning her past experience with disability resonates through the present and the future. For both mother and child anxiety over their future impacts on the present and thus the future is not considered at a distance, but is a factor that rivals the present for their attention. Such anxiety, however, can be lessened by concentrating on the connectedness between the mother and child. Janice Fuller, who has a fifty percent chance of inheriting Huntington's disease, articulates the importance of being connected with her mother. She writes, 'Times are sometimes painful and sometimes bitter, but mostly they are hopeful and we relish the special moments .... We still do connect and I'm content that we can both still know us' (Fuller, 1985: 40). In effect Fuller and her mother created a 'line of flight' from ableism which developed from a reterritorialisation, based on a desire for who and what they are.

In the film *Towards Intimacy,* a support group for disabled women broaches the problem of 'passing on' a disability to their offspring. One group member expresses her fears, and immediately another member responds, 'if I happen to pass on my spina bifida to my child, then she will have to handle it just as I did' (Towards, 1992). She emphatically endorses the belief that spinal bifida is a state of normality. Moreover she understands that her child would have the advantage of her mother's experience that would also be 'passed on' to her. Thus the disadvantage of 'passing on' a disability within a patriarchal able-bodied world is countered by the advantage of 'passing on' the experiences of the mother immediately to the daughter.

Whether children of a disabled woman are at risk to inherit a disease or not, they have an opportunity to be interconnected with their mother. Ridington (1989:26) claims that at an early age, children of disabled parents learn the value of interdependence and interconnectedness. She believes that in a world where individualism and selfishness are seen as prerequisites for success, this alternative way of relating is needed.

Her view that interconnectedness between 'imperfect mothers' and their infants ['imperfect' or otherwise] enriches the world echoes Verges' belief in the interconnectedness of the mother-child dyad. Both Verges and Ridington see this relatedness based on childbirth as an alternative to the patriarchal mastering of the birthing process, specifically, and of (able-bodied and disabled) women generally.

In the following passage cited from Franks, a family with a child with Fraser syndrome relates how they risk going against both normative assumptions and expert advice in order to affirm the

life of their son, Max, when faced with a negative perception of Max's 'quality of life'.

> 'I don't know what this is, I just don't know,' a doctor said as he put the baby into her [Max's mother's] arms. Beneath the lush head of hair, the baby's face was like a child's unfinished drawing. He had only one, unnaturally small eye, on the right side of his face. On the other side, there was a concave blankness beneath the brow. His nostrils were separated by a deep cleft, and his nasal ridge was squashed. Penelope took his curled fist and felt for fingers, but none were there [later Bernard discovered Max had fingers and toes] (Franks, 1999:68).

The medical staff's negative attitude towards Max was another factor that Penelope and Bernard had to overcome. As Penelope kept watch over Max, she noticed clusters of interns and residents came to look, and she heard some of them referring to him as 'it'. Finally, Penelope had enough. 'This 'it' is my son, and he wants to be left alone,' she said. Penelope persuaded a reluctant nurse to put the child to her breast, and he began to suck vigorously. The nurse said firmly, 'It's only instinct. *Any* baby will nurse.' Then she pointed out another nurse who was unhooking a plump baby from a ventilator and rushing out the door with him, 'That baby has been on life support for months,' the first nurse said, 'It has been unending agony for the mother, and she's decided to end it. She's waiting in a private room so the baby can die in her arms' (Franks, 1999: 69).

The negative attitude of medical practitioners was not confined to the hospital. Max required various health professionals for his on-going home-care. 'The original day nurse was fired after Lulu, the babysitter, caught her washing Max's bottles in dirty dishwater. "What's the difference? He is going to be a vegetable," the nurse said with a shrug.'(Franks, 1999: 69)

The predominant attitude towards Max epitomises the belief that some disabled infants', existence is 'not worth living'. Franks (1999: 71) reports,

> At a meeting to discuss Max's future, with the support of out-dated information a hospital official advised, Max's parents might be better off warehousing him for his sake and theirs. Armed with positive research on Fraser Syndrome, Penelope jumped in. "We do not intend to warehouse our son," she said icily, "There's only one option we'd like to discuss, and that is aggressive medical intervention."

Franks (1999: 77) asserts,

> Max has had a profound positive effect on his mother: "The truth is that Max has made me more deeply happy than I have ever been," she explained. "He changes everyone who meets him. He changes their ideas about beauty, about

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worth. He has made every member of our family - immediate as well as extended - grow up and change their life view in some essential way." Max also changed the attitude of many members of the hospital staff. ''We think everyone has to be perfect, physically, mentally," Dr Flaum said, "It's easy to write people off, say, this one's so abnormal forget it. Max has reaffirmed that you cannot look at a person and know for sure he has no ability to learn and be a good member of our society.''

Sullivan (1997:13) argues that when our own embodiment and our subjectivity become the standard for our interpretation of others, the notion of inter-subjectivity is problematic in that 'I encounter only myself and my own meaning.' The problem with inter-subjectivity is that nondisabled caregivers cannot see themselves in non-persons (in this case Max) or perceive any meaning in their existence. The breakdown with inter-subjectivity occurs because of a phenomenology which privileges a non-disabled aesthetic and cannot perceive its embodiment or aesthetic reflected by a disabled sensibility, unless that sensibility is subsumed by a 'normative facsimile', as represented by people who 'overcome' their disabilities. Unless this subsumable process takes place many non-disabled people consider the lives of disabled people as lacking any meaningful existence. The article by Franks ends with Max talking with another boy about toy fire trucks, thus illustrating Max's worthiness to be included into the community of humanity. For me there is more to the illustration. The toys, Max, and the other boy create a social or machinic assemblage that moves beyond the restrictive notion of humanistic essentialism with its phenomenological representation.

Disabled people, who are often interdependent upon others, can create machinic assemblages with people, animals, or objects. I illustrate machinic assemblages by considering the relationship between blind or visually impaired people and guide dogs. The relationship between parents and children changes when a disabled sensibility is included. I argue that if this relationship is life affirming, it creates machinic assemblages that exceed the normative shadow of phenomenology.

Exposing Oneself Rather than Educating Others

Often I find myself sitting in my apartment listening to the radio, trying to lessen the effect of the pervasive ableism that permeates my life. At times this sanctuary is corrupted as ableism seeps in. On September 28, 1997 I was listening to the radio program *Cross Country Check Up*, and the topic for that week was 'Should we screen embryos for genetic defects?' At the beginning of the show the host amended the show topic to 'When should we screen embryos for genetic defects?'

I listened for a while and finally felt compelled to respond. In the pre-interview process that determines who will be interviewed on air by Rex Murphy, I explained that the question, 'When should we screen for genetic defects?' had assumptions that devalued a disabled experience. Implied in the statement, 'When should we screen for genetic defects?' is the belief that genetic

intervention is not only permissible but preferable in certain cases. In terms of so-called genetic abnormalities that may cause illness and disability, 'common sense' would suggest that some intervention is not only desirable but is a societal goal. When I was on air I spoke about the positive aspects of my cerebral palsy, not in the sense of a 'gift' from which other people learn, or as God's chosen 'crippled angels', but rather how my spasms give me great joy and how they inform my life. In short, any success I have is not despite my cerebral palsy but because of it.

I also argued that the positive aspects of cerebral palsy cannot be 'measured,' because the ways and means of measurement are developed from the perspective that cerebral palsy is a negative sensibility that must be overcome. Moreover, I spoke about the similarities between myself and Tracy Latimer to forestall the invocation of a continuum of cerebral palsy with myself at the pinnacle (the poster-child for overcoming a cerebral palsy) and Tracy Latimer (symbolising victims of cerebral palsy with 'a life not worth living') shackled to the lowest rung in life and memory.

Two colleagues heard the program and commented that I spoke eloquently and that my argument was well-articulated. Both on and off the air, Rex Murphy expressed his gratitude for my criticism of the topic question. Off-air Murphy explained that a friend of his family has cerebral palsy and his spasticity not only enriched his own life but that of his family and friends. While I was pleased with Murphy's support I was dismayed but not shocked that with few exceptions respondents continued to call for the genetic interventions which would eradicate people such as myself. Ironically, some callers questioned my 'authenticity' as a spokesperson for people with cerebral palsy. They argued that I was too articulate and that my experience should be discounted. Others were more extreme in their criticism of me. Some challenged my right to express such outrageous opinions. A few others suggested that I might be crazy.

Since I was a disembodied 'voice' over the radio, ableist rhetoric and anger could be vented. One caller screamed, 'How dare I question normality!' Others said, 'I should be thankful that they allowed me into a regular school' and 'I repay their generosity by making such outlandish statements!' No matter what I said the ableism was pervasive. Believing that I was too intelligent, some callers questioned my ability to comment on the lives of severely disabled people. Others maligned me for being outrageous and lacking rational thought. Paradoxically, I was either too intelligent or too stupid. Either way, the status quo which favours the body and sensibility of phenomenological anonymous body remains intact.

As my segment concluded, Rex thanked me for educating him as well as others. I corrected Rex, stating my intention is not to educate others but to give cerebral palsy a life-affirming presence. I explained that my life is not dependent upon able-bodied people understanding me or giving me their blessing. I explained too that often people who privilege an able-bodied sensibility have demanded an explanation for my presence. Today, by having a presence I conveyed to the audience that no longer did I have to explain, justify, apologize for, or educate others about, my cerebral palsy. In effect, just as I had exposed the vivaciousness of my cerebral palsy during my rehabilitation and teaching, my segment on the radio was another occasion to do so. During each event, I reiterate that I am moving beyond the dichotomous pairing of disability and ability.

At different times others in a minority have attempted to try and establish a 'presence' rather than educate the majority. One of my students, who is Canadian and of South Asian descent, travels by public transit. Often on these trips people will ask her where she is from. Prior to my lecture about exposure rather than education, she would respond 'Canada'. When the person insisted that they wanted to know 'where she was *really* from, she would either become involved in a discussion about the underlying racism in the questioning or seethe in silence. When she finds herself in public she feels confined by the dichotomy of race. She has a public persona that is presented for the consumption of a society which privileges a Caucasian sensibility, where only the 'domesticated exotic other' is allowed. Often she feels that she has to suppress the vivacity of the desires that emanate from her cultural sensibilities that cannot be incorporated into her public persona. Confronting racism or seething in silence, she is still tethered to her public persona because the rules of engagement are defined by the white/non-white dichotomy meaning that individuals must respond to a white sensibility (Ware, 1997; Chambers, 1997; Sarrup, 1996).

After the lecture she endured the same inquisition, but her attitude was different. She exerts a presence that allows her to remove herself from the dichotomy of being white or non-white. She does not feel the obligation to defend, justify or educate other people. Desires that emanate from her cultural sensibilities flow from her, as they are not censored. Ironically, these desires that emanate from what was her private persona draw attention to her. She has moved beyond the racial dichotomy and created a presence. Her attitude and new-found presence means that fewer people feel they have a right to ask her personal questions.

My exposure of my spasms, whether during my rehabilitation or my educational experiences, has been and continues to be scandalous (see Hardt, 2002) to others, as it unsettles the affirmation of able-bodiedness with its basis in phenomenology. From my perspective this exposure is a hyper-presence which requires no explanation, no justification, or apology. Similarly, the student's exposure of her previously inhibited 'cultural sensibilities' is scandalous to others as it unsettles the privileged position of a white sensibility anchored in characteristics associated and phenomenology and a restrictive personhood.

People have asked her where she is from, and she refuses to engage in conversation with them. Her silence or withdrawal from engagement causes a turbulence that is similar to that of my classroom. People have become angry and have accused her of not knowing her 'place'. She informed me that one woman became angry with her and then exclaimed, 'It really is none of my business. Is it?' To the student's credit, still she refused to engage in conversation with her. Later she explained to me that the transit traveler's racism is not her problem. Nor is she responsible for this person's need to overcome it. We spoke about how educating others about racism or ableism to some extent made us responsible for the problem and absolved our inquisitors of any culpability.

The Doctrine of Eternal Recurrence and Phenomenology

In outlining the difference between my student's experiences on public transit, before and after her change of attitude, I have used present tense. I do not want to leave the impression that the concept of 'exposure' is a progression from education. Rather, exposure is a way of 'becoming'; it maintains that subjectivity emanates from desire that is in constant flux. In that phenomenology is a way of 'being', it maintains that desire emanates from a subjectivity that can choose various roles, and re-invent itself as Madonna does (Gergen, 1991). The two exist on differing planes; the subject of phenomenology, with its common 'anonymous structure' is being, whereas 'exposure' is becoming.

Throughout this dissertation I have referred to my experiences as a youngster, whether discussing my experience with the education system or the rehabilitation regime. But these anecdotes are not a matter of the past; as I point out, they have been played out over and over again. Rather than a continuum I prefer Nietzsche's concept of the eternal recurrence. Referring to his doctrine of Eternal Recurrence, Nietzsche argues that you desire over and over again. One can return to the same place and be taken by desire down a different path, a path that may lead to our 'greatest joy' (Klossowski, 1997: 60).

To forestall any misconception, I am not invoking the pinnacle of self-actualisation (that I believe is confined by a restrictive humanistic essentialism) as the 'greatest joy'. Rather the Eternal Recurrence can find the 'greatest joy' in a singularity that is transforming constantly. Nietzsche believes that if we can 'traverse many types of health' we continue to 'become' different singularities. However, there is a risk that we cannot ignore. Nietzsche (1974:36) writes, 'Life -- that means for us constantly transforming all that we are into light and flame - also everything that wounds us; we simply can do no other.'

Like Nietzsche, but as a sociologist rather than a philosopher, I have had to traverse many types of health and continue to do so. Each venture has allowed me to create different assemblages with different people, different animals, different things, including concepts which in turn have informed my own subjectivity. Kaufman (1999: 152-153) writes, 'While all the forces of sickness would serve to withhold or deplete energy and lucidity, there is a counterforce at work to respond to the new and enhanced form of lucidity.' Thus desires from my cerebral palsy simultaneously deplete my energy - when trying to inscribe my thoughts - and create an enhanced form of lucidity - when my thoughts form a 'line of flight' from phenomenological humanistic essentialism. Although this becoming is chaotic, indeterminate, and unpredictable it may be worth the gamble.

How Phagic and Emic Strategies Affirm the Privileging of a Nondisabled Sensibility

According to Bauman (1993: 163), in each society and every social interaction the twin pairings of phagic and emic strategies are indispensable and effective. The phagic strategy is inclusivist which results in the assimilation of the strangers within the community. The emic strategy is exclusivist with the emphasis on members of the community moving into the space of the stranger and merging with them. From the point of view of individual interaction, I critically examine how disabled people are accepted when people gloss over their lived experience by uttering the statement, 'I don't think of you as disabled'. Or people diminish the vivacity of a disability and trivialise the underlying lived experience of disabled people by exclaiming, 'Everyone is disabled - I can't see without my glasses.' In both cases, by trivialising the disabled experience non-disabled people reconstitute disabled persons in order for them to be more palatable.

Far too often the invocation of the phrase 'I don't think of you as disabled' conveys in a matter-of-fact manner that there is 'social capital' (Bourdieu, 1990) in becoming normalised which then results in the inclusion of disabled people. Dianne Pothier (1993) faced similar negations of her disability when a colleague told her that because she taught at university he did not think of her as disabled. Pothier (1993: 16) writes, '[His] explicit assumption was that people with a disability are not expected to achieve anything of significance. If you have achieved anything of note you cannot really be disabled'. Similarly, from the perspective of race, Patricia Williams (1991: 9-10) relates that others do not think of her as being 'black' because she has the status of being a university professor, demonstrating her ability to overcomes her blackness.

Pothier (1993) argues that underlying this phrase is the belief that disabled people cannot achieve anything. Thus, as Wendell (1996) and Kitchin (1996) have argued, disabled people who overcome their disabilities have access to greater symbolic, economic, and cultural capital (Bourdieu, 1990). This capital sets up a continuum of disabled people. Ironically, disabled people who get satisfaction from being told that others 'don't see you as disabled' are not achieving full normative status, but are only legitimising an able-bodied resemblance through their desire for normality. Moreover, they reinforce an extension of the legitimacy of this resemblance by validating a continuum of disabled persons, ranging from the successful people who 'overcome' their disabilities to pitiful 'gimps' and 'cripples'. This continuum is part of the universal phenomenology whereby a particular embodiment sets the standard for acceptable humanity. Furthermore, phagic strategies that include other people as long as they give primacy to recognised phenomenological characteristics of success further naturalise as the 'proper' way of being.

The emic strategy expands the influence of phenomenology by 'domesticating' vivacious aspects of our life, reducing disabilities to ancillary incidentals, non-essentials that do not define one's humanness, as in the phrase 'person with a disability'. Insidiously, not through coercion but

through kindness - the acceptance of the other - phenomenology expands its hegemony by territorialising the disabled through the social graces of emic and phagic strategies that are part of everyday life. While these strategies are meant to integrate disabled people into society, effectively they 'flutter around' the real problem: what do we do with the disabled people within our midst? Thus the vortex of universal phenomenology seductively pulls disabled people into a system with its ideology and ensuing practices that privilege an able-bodied sensibility over a disabled sensibility. This universal phenomenology is so insidious, that in Derridian terms it is simultaneously is nowhere and everywhere. Disabled people are placed on the perimeter of society, waiting either for others to join them, which affirm their humanity, or for an invitation to come into this phenomenological circle.

Such 'kindness'- the grand gesture of inclusion into the community of humanity (with its 'anonymous phenomenological structure') is also bestowed upon others, such as 'domesticated queers' (Haver, 1997) or people of colour whose racial heritage is seen as incidental to their being (Williams, 1993). In the following story, I analyse how the vivaciousness of being elderly is considered incidental to older people's personhood. I choose the sensibility of aging because with the exception of the few who experience premature death all people experience old age. With a preamble about the elderly 'not being destitute, but respectably poor,' Ignatieff (1984: 9) writes,

> I came upon one old man once doing his shopping alone, weighed down in a
> queue at a potato stall and nearly fainting from tiredness. I made him sit down
> in a pub while I did the rest of his shopping. But if he needed my help, he
> certainly did not want it. He was clinging to his life, grasping for breath, but he
> stared straight ahead when we talked and his fingers would not be pried from
> his burdens. All these old people seem like that, cut adrift from family, slipping
> away into the dwindling realm of their inner voices, clinging to an old barrow
> as if it were a raft carrying them out to sea.

Ignatieff (1984: 13) goes on to say that humans are more than 'right bearing' individuals. He argues that prisoners and the mentally ill may be given rights but 'yet in every waking hour, inmates may still feel the silent contempt of authority in a glance, gesture, or procedure.' But Ignatieff fails to appreciate the breadth of the 'silent contempt' felt by disabled people in their everyday interactions. Ignatieff (1984) is making a distinction between making a human connection - demonstrated by finishing the old man's shopping - and institutionalised rights. I would argue that institutionalised help and human connectedness are differing sides of a 'poisonous' care that reduces 'difference' to 'inferiority'. The normative shadow of phenomenology impacts upon the interaction between Ignatieff and the old man. Ignatieff sees the old man as human despite his deplorable living experiences, which are ancillary to the old man's worth as a human being. Ignatieff has formed an intersubjective relationship whereby he sees himself (Sullivan, 1997) in the old man. The elderly man's poverty must be reshaped by Ignatieff as an intrusion upon the old man's humanness. But poverty seeps back into this intersubjective relationship, Ignatieff's provision of care, in an altruistic manner, reforges the difference (Bauman, 1993) of the elderly man into an inferior existence.

The old man is faced with the spectre of the normative shadows as 'kindness' is forced upon him. Like myself, the old man is aware that others, including Ignatieff, have reduced his life to that of an 'unfortunate soul' who is 'respectably poor.' Such an interpellation carries with it, at one extreme, the loathing captured in that understood look that conveys the essence of the phrase 'there but for the grace of God go I'. At the other extreme, a patronising and condescending attitude is affirmed in these gestures of kindness. But the 'old man' realises that he is powerless, and not wanting to incur his benefactor's anger; he stares back in silence. As the deliverer of kindness, Ignatieff restores his own humanistic essentialism, as well as maintaining his position atop each of the continua of phenomenology, personhood, and humanistic essentialism. Being faced with agape love (Bauman, 1993) reminds the old man of how far he has fallen, now being relegated to a lower position on these aforementioned continua.

Like the liberal individualist in the Introduction (see Foucault, 1984e), Ignatieff looks out through the lens of phenomenology and shapes and creates his world. Based upon his 'natural' and 'common sense' evaluation of what it means to be human, armed with the assuredness of phenomenological rationality, Ignatieff declares the man is 'living an unworthy life' - a deficit existence. Ignatieff with empathy understands the old man's plight and overcome by liberal consciousness intervenes. Moreover, both 'the old man' and Ignatieff accept that their relationship is intersubjective in nature, with a phenomenological basis. Never is it postulated that there may be other ways of considering life.

Guattari (1996: 63) argues that 'old age' is not dependent upon genetic programming but is based on desire. Unfortunately, desires that do not fit the prescriptive phenomenology do not resonate with society. Just as the desires that emanate from my spasms are devalued, the desires that emanate from the old man's sensibility are either devalued or do not resonate with society. To overcome this limited view of humanity people must obliterate the dichotomous thinking that perpetuates a sensibility of phenomenology which produces the abject others.

Moreover, we must examine what blocks the desire that emanates from the vivaciousness of abjection, preventing it from flowing and making social assemblages (as in the case of interaction with the respectably poor elderly). Deleuze and Guattari (1987) suggest that desire creates subjectivity. The insights of Deleuze and Guattari could create a shift in the interaction between Ignatieff and the elderly man. Ignatieff could examine how he has internalised a continuum of existence based on the normative shadows of humanistic essentialism, personhood, and phenomenology. Or, simply put, he could examine how his preconceived perceptions of the 'old man' obstruct him from recognizing and engaging with desires that emanate from the elderly man. Ignatieff could admit to the old man his own bias concerning the elderly, instead of 'domesticating' him as 'respectably poor'. From the perspective of phenomenology, Ignatieff is continuing the Enlightenment tradition of judging others by a prototype of humanistic essentialism (that is a reflection of himself), with accompanying ancillary characteristics (such as race, ethnicity, age or ability). Acknowledging the desires that emanate from the vivacity of aging may create an assemblage that is diagonal (Deleuze, 1994) in nature rather than hierarchical. Once the old man realises that Ignatieff is not there to offer help in the form of

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agape love, but has an interest in his vivacity, a connection could be made.

On a larger scale, suppose this phenomenological intersubjectivity - the understanding of the other - is a fiction, invoked as a means to organise the world to impose order, a hierarchy that devalues the vivacity of others who are thought to be living 'lives not worth living'. Nietzsche (1988:5) writes, 'Let us speak it aloud, this *new challenge*: we need a *critique* of moral values, *for once the value of these values must itself be called into question.*' The morality of this universal phenomenology, as well as humanistic essentialism and personhood must be called into question.

Earlier I argued that one could not escape the influence of the normative shadows. Neitzsche (1966) asserts that in passing judgement there is a prior set of assumptions that frame the criteria for judgement. Thus, it is not the truth or falseness that is the litmus test for a judgement. For Nietzsche (1966:11), 'The question is to what extent is it life-promoting, life-preserving, species-preserving, perhaps even species-cultivating'. The individual of the sociology of modernity is dependent upon the phenomenological template with its 'anonymous body' (Merleau-Ponty, 1962). This individual is the essential self of modernity that studies, categorises and shapes one's world creating hierarchical order (Bauman, 1993), or the re-constituted self of postmodernity that acquires symbolic and material goods to reinvent oneself to continually self-actualise and improve one's status (Gergen, 1991). Both of these sensibilities are life-promoting, life-preserving, species- preserving, perhaps even species-cultivating (if one considers the human genome project). But it is only lives or species that fall within the normative range of phenomenology, personhood, and humanistic essentialism that are promoted, preserved, or cultivated. Other lives are only tolerated as the abject other until that species can be eliminated.

Exceeding Humanistic Sociology through a Sociology of Desire

I contend that a sociology of desire offers a different way of conceptualising sociology. Rather than community based on identity, sociology of desire calls for assemblages. Rather than striving for an intersubjective understanding, sociology of desire calls for 'exposure' of singularities - the unappreciated and unrecognised desires that have been ignored, or discarded, by normative expectations. Rather than categorization - the 'this' from 'that'- a sociology of desire understands the social world in terms of flowing, with differing durations and intensities, unfolding outward as well as a folding back into oneself.

While modernity offers individuals the promise of utopia and postmodernity offers the possible exhilaration of experiencing constant self-actualisation, the sociology of desire offers them nothing. The individual does not exist as an essential subjectivity but is constantly assembling, dis-assembling, and re-assembling with desires to be in a state of constant state of 'becoming'. There is no certainty of utopia or goal of self-actualisation because desires create the environment that is liable to break down, and be reassembled by the flows of desire.

People fall back upon the prescriptive continuum of phenomenology that identifies some as abject others and as obstacles to the ability of some others to 'reinvent' themselves and reach the pinnacle of self-actualisation. A 'sociology of desire' would not rid us of this continuum or the relentless pressure for us to self-actualise in a prescriptive manner. However, it might allow us, at least initially, a respite, a different way of organizing our lives - the creation of machinic assemblages upon plateaux. It offers the possibility of a thousand or more plateaux, held together for different intensities and varying durations with no past, no future, and even no present (because with no past or future there is no way to measure the present), only an eternal recurrence that is a life-affirming desire. But I promise no utopian vision or guarantee of a better future among these plateaux, because they derive from lines of flight that can result in disaster.

Why would anyone trade the security and promises of humanistic essentialism, personhood, and phenomenology (even with their normative shadows) for a sociology of desire that is indeterminate, chaotic and without promise? The point is that a sociology of desire is not a matter of choice, rather flowing desires that have varying intensities and last for differing durations. But this is not an essentialism where desires create a monolithic subjectivity. Subjectivity is always being approached by other desires and its desires flow creating other assemblages resulting in a constant state of becoming rather than being. The interaction of differing desires allowed for my spasmodic desires to irrupt and be recognised. The surgeon's pronouncement caused irruptions in me that led to a 'singularity' - a vitalism and exposure that led to assemblages. This vitality led me to exceed the normative shadows of humanistic essentialism, personhood, and phenomenology to a greater life with a new and 'greater health' (Nietzsche, 1974; Kain, 1996; Deleuze and Guattari, 1987).

Perhaps the silent stare that Ignatieff feels from the old man is not a silent contempt for the situation. Instead, the 'old' man has arrived at a point where desires are now forming his subjectivity. Yet he struggles with his ambivalence towards this human condition. I have documented my ambivalence about the phenomenology of humanistic essentialism, as it is expressed through the institutions of education and rehabilitation. It is a scary proposition to let it go. But of course I never let go: I was overcome with the desire to rid myself of the collective normative shadows. Perhaps the 'old man' will be overcome by this same desire. But this speculation about the 'old man' is unfair, for this conjecture is much too prescriptive and judgmental. In the same manner, I must revoke my invitation to the reader to embark on 'a line of flight' from this dissertation because I cannot predict or prescribe the desires that may form your subjectivity. All that I can be sure of is that this dissertation is a desiring machine in its own right, willing to make assemblages with readers. This dissertation outlines an assemblage, including a singularity that emanated from my spasms, which resulted in a 'sociology of desire' that offers pragmatically a means to exceed humanistic sociology with its normative shadows. Although it is not prescriptive, it hoped that others may find an impetus to discover new people, new sensibilities, and new ways of thinking.

Instead of a sociology based upon the trajectory of the modern world or the consumptive choices of postmodernity that still stress self-actualisation, a 'sociology of desire' has its basis in the

flow of desires with no pre-existing criteria, or eventual goal. Experimentation without judgement, experimentation through irruption marks the flow of desire. There can be no being, only assemblages of varying, intensities and durations. Presently, I would like to map out, or point out, different flows that have informed this 'sociology of desire'. The becoming of Michalko and Smokie is an example of an assemblage with long duration and high intensity.

My assemblage with the woman at the centre for Alzheimer patients was low duration, low intensity. However, its low intensity and low duration may be the result of me reading the interaction from a 'normative expectation' of intensity and duration. For me, this passing caress on my cheek had a profound effect. Desires irrupted from the dormant state of pre-personhood that I experienced as a baby, and nomadically made a connection with the desires from the woman. The machinic assemblage affirmed desires that had been pathologised. Thus, this connection illustrates Goodchild's (1996: 150) point that pathologies can form a 'line of flight'.

Years ago, in public school the assemblage of myself, my fellow student Grace, and the test paper flowing together created an assemblage with a minuscule duration but high intensity. The intensity was profound to the point that other students became involved, forming an assemblage which resulted in me exceeding my abject position, and my intelligence being recognised.

Goodchild (1996: 150) writes of another component changing the strata of an assemblage through addition. The teacher's intuitive belief in the phenomenological 'anonymous body-structure' allowed her to see Grace's humanness and feel assured that I was 'less than human', in spite of my intelligence. The component that led to a disassembling of the stratified hierarchy of humanness was Grace's interaction with the final mark that led to her realisation that the teacher was negating my intelligence, as well as my existence. After Grace confronted the teacher there was a 'collective' voice from the class that forced the teacher to accept me.

The Michalko-Smokie becoming, the Alzheimer patient-Jim becoming, and Grace-Jim-test paper becoming are all examples of 'nomadic thinking' pragmatically being exercised. Each component of these assemblages had to let desires flow and meet other desires for that moment of experimentation over judgement (where previous 'beings' of abjection had been judged inadequate, through experimentation there is a chance that these 'abject' others exceed their negative status) to allow for an expression or irruption of 'becoming' - a new way to think, and to live exceeding the normative shadows.

Whereas, the assemblage of Catherine-Jim created a becoming that was a matter of nomadic thinking which created a 'becoming' that resulted in a new sexuality. However, the Catherine-Jim 'becoming' also illustrates a folding-back into our becoming. Our assemblage exposed ourselves to the public but refused to educate them. We refused to take part in any queries whether verbal or non-verbal. The level of intensity and the duration of this exposure and folding-back were minimal for us.

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When I refused to provide an explanation about my behaviour during the 'going for coffee' incident, the intensity level increased to the point of causing turbulence. From a sociological perspective, my act of heresy was my refusal to provide an 'explanation' or to educate people about a disabled sensibility. If an explanation can be considered an attempt at an intersubjective exchange, then my pragmatic experimentation shows a marked disdain for a valued tradition of sociology, the belief that if we only used the right form of communication understanding each other would be achieved. What I am calling into question is not whether it can be done, rather why is the understanding of the 'other' so important? I want to uncover the normative rules of articulation which negate the desires of the abject other.

Similarly, educating or learning about the 'other' is seen as an important way to lessen discriminatory actions, and to learn about other cultures. By folding-back my desires into my self and remaining silent, refusing to educate, explain, or justify my position I illustrated how quickly the act of abjection can take place. I also illustrated how normative expectations restrict the so-called free-speech involved in the education process.

More and more, I find myself living in terms of flows rather than positionality on a scale of bodies (Young, 1990a). I notice intensities and durations, folding back into myself (especially relishing desires that emanate from silence, particularly those silences that are pure inarticulation, as opposed to those times of simply not speaking). I find little *use* (in the Deleuzian sense that theories must be *used* or *experienced/experimented with* rather than interpreted) for the concept of 'identity' and its companion, 'community' because each exist through inclusion/ exclusion. This inclusion is perpetuated through the fear of 'other', or the fostering of a fascination with the 'exotic' other (a fascination) that remains distant and removed, as my analysis of the play *Creeps* illustrates.

Rather than physical coercion, the process of inclusion and exclusion is more a matter of one's ability to adhere to the social codes (Bourdieu, 1990a; de Certeau 1987), and follow the 'rules of articulation' (Hennessey, 1993) required for intersubjective understanding. A pragmatic approach to a 'sociology of desire' makes connections with other modes of consciousness, as well as other desires, that exceed both these 'social codes' and 'rules of articulation'. In effect, this approach moves beyond the confines of normalisation, creating social assemblages that affirm the lives of 'pathologised' new people or inventing new people, exposing new worlds, and expanding thinking beyond rational thought. This dissertation has outlined how a sociology of desire can exceed the 'normative' confines of the concepts of humanistic essentialism, personhood, and phenomenology. My work with the *Excess/Access* and the *Ephemeral Theory Collective* theoretical groups, as well as the social assemblages that emanate from my spasms, have helped me shed the liberal individualist being for a collective becoming which has its basis in the singularity exposed during the physical examination I had many years ago.

My status as a doctoral candidate gives me privileges that other pathologised or marginalised people may not enjoy. Will people with less status 'risk' exposing their inhibited desires, given that such a flow could have negative repercussions for them? Before returning to university as a

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'mature' student, I had spent many years living below the poverty line with no foreseeable future. What sustained the vivacity of my life was the nagging feeling that this pathologising of my existence was a creative 'fiction' that reduced my life to a personification of 'humanity's fragile existence'. As I have documented in this dissertation, throughout my life I have attempted to affirm my experience of cerebral palsy. At the lowest points of my life, what I now call my singularity has given me a 'hyperpresence' - a vivacity that emanates from spasmodic desires. In making connections with other people at their lowest point, this interweaving of singularities (supposed pathologies) creates assemblages that exceed 'normative expectations.' A 'sociology of desire' exposing singularities for other disenfranchised people remains a distinct possibility.

'Sociology of desire' has implications for sociology of the body. Exceeding the societal notion of what is an acceptable body in both modernity and postmodernity, it recognises other bodies and sensibilities that cannot or will not conform to normative expectations are valid in their own right. Similarly, a sociology of desire offers an alternative way to perceive marginalised positions. Deviance as a sociological sub-discipline 'defers' to a normative sensibility and embodiment. In effect, all people are judged in relation to this abstract 'anonymous' body. In the spirit of Deleuze and Guattari, (1997) a sociology of desire looks for singularities among marginalised people, identifying assemblages that are life-affirming. From my perspective, 'sociology of desire' flows to discover other modes of consciousness and ways of becoming that exceed the confines of normalisation. Desires eschew having meaning imposed upon them or requiring an explanation. There is no need for statements of any kind. Assemblages only require that they be functional and have purpose for all components. Generally, a sociology of desire shifts the onus from a knowing subject who attempts to understand sociological patterns within the social world to a fluid subjectivity which along with the social world, is shaped by the ebb and flow of desire of varying durations and for differing intensities.

I am not calling for a sociology of desire to displace humanistic sociology; rather, I am arguing for an excession, a new way to perceive and do sociology. Such an approach would allow for other desires to be recognized and legitimized within the discipline. Moreover, the encouragement for new assemblages may help sociology move from a facile positionality based upon categorisation to the incorporation of the study of flows, intensities, and durations which inform social interaction (social assemblages).

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