Lisa Diedrich

INTRODUCTION: GENEALOGIES OF DISABILITY

Historical emergences and everyday enactments

As Lennard Davis notes in his introduction to *The Disability Studies Reader*, disability, as a representative category of human identity, has only recently emerged in conjunction with those other identity categories: race, class, gender and sexuality. Only in the last 20 years, according to Davis, have people with disabilities seen themselves as a 'single, allied, united physical minority', and this perception of unity has brought both the struggle for civil rights through the disability rights movement and the struggle for a new discourse on the experiences of disability through disability studies (1997, p. 3).

   Not surprisingly, with the emphasis on disability as a category of identity, much of the early focus in the disability rights movement and disability studies has emphasized an identity-based politics and forms of activism over and often against what is perceived of as exclusively theoretical work. Some recent work in disability studies perhaps signals the beginning of a shift in emphasis from identity politics to a critique that might be understood as 'post-modern' or post-structuralist (see, for example, Mitchell & Snyder 1997, Corker & Shakespeare 2002, Davis 2002, Shildrick 2002). In their important volume on the uses of a 'postmodern approach' for disability studies, Mairian Corker and Tom Shakespeare assert in their introduction that, 'It is our contention that disability studies, particularly in Britain, has suffered from a theoretical deficit, and has been reluctant to take advantage of this [post-structuralist] scholarship' (2002, p. 1).[1] Like Sandra Harding, who considers three stages in the development of feminist epistemology – including feminist empiricism, feminist standpoint epistemologie, and feminist postmodernism (Harding 1991; see also Maynard 1994) – Corker and Shakespeare investigate post-structuralism as an alternative epistemological framework for disability studies. Post-structuralism, according to Corker and Shakespeare, challenges both the medical models of disability, 'which perceive and classify disability in terms of a meta-narrative of deviance, lack and tragedy, and assume it to be logically separate from and inferior to "normalcy"' (2002, p. 2), and the social model

of disability, which has 'roots in historical materialism' and understands disability as 'socially . . . constructed on top of impairment' (2002, p. 3). Although Corker and Shakespeare understand that accessibility, in terms of the built environment and social structures, as well as in terms of language, is a crucial focus of the disability rights movement, they are also concerned that a dismissal of post-structuralism on the grounds that it is often inaccessible to those untutored in its particular language and practices is not a prudent move for either disability studies in the academy or the disability rights movement. They insist that many post-structuralist theories and methods are useful for both disability studies and the disability rights movement because they offer 'a different view of the subject, arguing that subjects are not autonomous creators of themselves or their social worlds. Rather, subjects are embedded in a complex network of social relations' (2002, p. 3).

I agree with Corker and Shakespeare that post-structuralism in general offers many useful tools for disability studies and the disability rights movement. One such useful tool is genealogy, which I will delineate as a method and in relation to disability in more detail below. However, rather than claiming that disability studies in its current form suffers from a 'theoretical deficit', I would instead argue that disability studies has for the most part not yet adequately problematized the category of experience.[2] It seems to me that the general current trend in the disability rights movement and disability studies is to make visible experiences of disability that have been previously hidden from history and not addressed politically. While this approach brings to light alternative modes of being and alternative spaces that more conventional history and politics fails to acknowledge or even see, it does not necessarily reveal the ways that experience itself is a category of representation that emerges and operates within a particular socio-cultural and historical milieu. In her essay on the use of experience as historical evidence, feminist historian Joan Scott challenges the notion of 'writing as reproduction, transmission [, or] the communication of knowledge gained through (visual, visceral) experience' (1992, p. 24). Rather than relying on 'experience as the origin of knowledge' of the individual subject, Scott prefers to emphasize 'the constructed nature of experience' (1992, p. 25). She is interested, therefore, in the 'categories of representation', and how these categories operate within given ideological systems. 'Experience' itself is an explanatory category, Scott asserts, and reinforces her point by placing it in quotes (1992, p. 26).

Scott begins and ends her influential discussion of 'experience' as historical evidence with readings of Samuel Delany's memoir, *The Motion of Light in Water*, about being homosexual in New York in the early 1960s. According to Scott, Delany's memoir is evidence of alternative modes of being (homosexual) and alternative spaces (for the practices of homosexual sex and community) that are not recorded in conventional histories. Yet, Scott also understands Delany's memoir as an example of a text that 'drastically raises the

problem of writing the history of difference, the history, that is, of the designation of 'other', of the attribution of characteristics that distinguish categories of people from some presumed (and usually unstated) norm' (1992, p. 22). What is important about the rendering of 'experience', according to Scott, is not simply to make visible experiences previously invisible, but rather to reveal the ways that 'experience' is not a reliable or self-evident source of knowledge, and that certain discursive regimes allow certain 'experiences' to emerge in history while others get covered over or denied.

Scott's assertions about 'the problem of writing the history of difference', and her analysis of Delany's memoir as an exemplary case of this problem, are useful in considering the particular (and multiple) histories of difference that disability studies seeks to write, especially because, as David T. Mitchell and Sharon L. Snyder note in the introduction to the edited volume, *The Body and Physical Difference: Discourses of Disability*, the 'discourse of disability has been largely defined by the genre of autobiography' (1997, p. 9). Partly as a result of the dominance of the autobiographical mode in discourses of disability, disability is often perceived as an essentially private and individual experience that other disabled and able-bodied individuals can have insight into through the medium of personal narrative. According to Mitchell and Snyder, while these narratives provide 'an understanding of disability on an individual level', they are less likely to give the reader a sense of the social and political structures that bring the disability category, and the 'experiences' of that category, into being (1997, p. 9).

In this special issue of *Cultural Studies*, the focus of the essays as a whole is on the ways that specific 'experiences' of disability come into being and are articulated within specific cultures, institutions and practices. I have gathered together several essays that contribute generally to the emerging scholarship on disability by, in particular, working with and against the theoretical/methodological framework of genealogy. In this introduction, I argue that genealogy, as Foucault delineated it, is an especially useful methodology for disability studies and activism, and I consider, conversely, how the multiple experiences, events, and practices of disability provide new understanding of what it means – theoretically and practically – to 'do' genealogy.

In *Disability/Postmodernity*, Corker and Shakespeare acknowledge that Foucault's work and his genealogical method provide resources for understanding disability. According to Corker and Shakespeare,

> [a] Foucauldian perspective on disability might argue . . . that a proliferation of discourses on impairment give rise to the category 'disability'. Though these discourses were originally scientific and medical classificatory devices, they subsequently gained currency in judicial and psychiatric fields of knowledge. 'Disabled people' did not exist before this classification although impairment and impairment-related practices

certainly did. Thus Foucault shows us that social identities are effects of the ways in which knowledge is organized, but his work is also significant for its explication of the links between knowledge and power.

(2002, pp. 7−8)

And in another essay in the Corker and Shakespeare volume, Shelley Tremain states that '[t]heorists and researchers in disability studies should adopt . . . [a] genealogical approach to their work' (2002, p. 33), and she herself provides a genealogical analysis of 'the emergence of impairment as an object of know-ledge/power' (2002, p. 34) through various disciplinary domains, including the disciplinary domain of disability studies itself.[3]

Similarly, although they do not necessarily use the term 'genealogy' to describe their methodology, many scholars in disability studies have done important work that I would maintain is genealogical. Several focus on the relationship between the normal and the pathological or abnormal that Foucault following Canguilhem sought to diagnose. For example, Lennard Davis's *Enforcing Normalcy* (1995) offers a genealogical account of the emergence of the concept of the norm in the nineteenth century, and Rosemarie Garland Thomson's important work on the representation of disability in literature and culture, *Extraordinary Bodies* (1997), denaturalizes the normal by inventing the term 'normate'. According to Thomson, 'This neologism names the veiled subject position of cultural self, the figure outlined by the array of deviant others whose marked bodies shore up the normate's boundaries. The term *normate* usefully designates the social figure through which people can represent themselves as definitive human beings' (1997, p. 8). Several scholars of deaf culture, moreover, have delineated competing discourses of deafness, and have historcized the changing 'experience' of deafness in Western cultures from the eighteenth to the twentieth centuries (see, for example, Harlan Lane 1984, 1997, Oliver Sacks 1989, Baynton 1997, Davis 1995, 1997). Finally, in *The Disabled State*, Deborah Stone diagnoses the emergence of the disability category in the social policy and laws of several Western nations, including the United States, Britain and Germany. In her genealogical investigation, Stone explores 'how the concept of disability came to be associated with clinical medicine and clinical reasoning' (1984, pp. 27−8).

In order to demonstrate further what I take to be an intimate relationship between disability and genealogy, I now want to introduce several key terms in Foucault's work − antisciences, descent and emergence − that I believe will help clarify what I mean by the phrase 'genealogies of disability'. By approaching disability through the framework of genealogy and genealogy through the framework of disability, I am interested in demonstrating an interdisciplinary methodology, as well as diagnosing the moments of arising, of forces and figures of disability within history. I not only believe genealogy

helps to locate some of the lost events of disability, even or especially those events covered over by the emergence of disability studies and the disability rights movement in its current form, but I also believe genealogy gives us a mode in which to imagine into arising other domains, practices and figures of disability. Finally, in the conclusion to this introduction, I will consider briefly the ways that the essays in this special issue do genealogy but also how they supplement and expand the genealogical method as demonstrated in Foucault's work, and as I present it here. In particular, I will consider how a shift from an analysis of the forms of being disabled and the methods of knowing disability to an analysis of *how disability is done* – through multiple and often divergent practices and by several doers at once – allows us to understand how disability is enacted in various domains, not just in the past but in the present as well.

Antisciences

In his recently published lectures at the Collége de France presented in 1975−6 and entitled 'Society must be defended', Foucault provides one of his clearest delineations of what he means by the term 'genealogy'. In his first lecture in this course, which would introduce such concepts as 'disciplinary power' and 'normalizing society', Foucault describes one of the effects of the various social movements of the 1960s and early 1970s as 'the insurrection of subjugated knowledges' (2003b, p. 7). For Foucault, this insurrection of subjugated knowledges is both a return of historical knowledges that have been repressed or buried, and the emergence of 'a whole series of knowledges that have been disqualified as nonconceptual knowledges, as insufficiently elaborated knowledges: naive knowledges, hierarchically inferior knowledges, knowledges that are below the required level of erudition or scientificity' (2003b, p. 7). These buried and disqualified knowledges are knowledges first and foremost of struggles, struggles that have been covered over by the tyranny of totalizing discourses, and especially the totalizing discourses of science. What is most interesting for my purposes here is that Foucault explicitly 'give[s] the name "genealogy"' to this coupling together of scholarly erudition and local memories, which allows us to constitute a historical knowledge of struggles and to make use of that knowledge in contemporary tactics' (2003b, p. 8). For Foucault, '[g]enealogies are, quite specifically, antisciences' (2003b, p. 9). This notion of *an antiscience born from struggle* resonates, it seems to me, with the projects of disability studies and the disability rights movement. The tactics utilized by both projects challenge the expert knowledges of scientific institutions, and in particular the institution of medicine.

The biomedical model of disability approaches disability as a problem that science and medicine can and must fix; disabled people must be normalized

through the disciplinary practices of medicine. Disability studies scholars and disability rights activists have sought to replace, or at least supplement, the biomedical model of disability with a social model of disability (Oliver 1990, 1996, Wendell 1996, Davis 1998, Shakespeare 1998), or, more recently as discussed above, with a postmodern model of disability (Corker & Shakespeare 2002, Shildrick 2002). These anti-science models of disability that are opposed to the biomedical model consider the ways in which social attitudes, conventions and physical surroundings disable individuals, and work to deconstruct normative attitudes and conventions and reconstruct the material world to better enable the full social participation of people with disabilities. As we will see in the essays in this volume, investigating disability allows us to ask big questions, questions that science often claims to be best positioned to answer, including: What makes humans human? What is the relationship between thought and language? How do we articulate experiences of the body? What is considered normal and abnormal within a particular culture? What are the multiple and changing ways of living a disabled life?

As Foucault makes clear, genealogies are not a celebration of 'the lyrical right of the ignorant' nor 'some immediate experience that has yet to be captured by knowledge', nor, for that matter, do they reject 'the contents, methods, or concepts of a science' (2003b, p. 9). Rather, genealogies oppose the 'centralizing power-effects that are bound up with the institutionalization and workings of any scientific discourse' (2003b, p. 9). This challenge to the 'rise of power that is bound up with scientific knowledge' is a challenge to disciplinary power, and thus Foucault believes we must struggle for a new right that is 'both antidisciplinary and emancipated from the principle of sovereignty' (2003b, pp. 39−40). Disability studies, in its marginal position in the university and its struggle to bring a new object of study into being through multiple and sometimes conflicting perspectives, is necessarily interdisciplinary. But, perhaps it is more useful to think of it as antidisciplinary, which, in Foucault's formulation, brings into being a method that is inventive and always unfinished, and necessarily on the outside of the institutionalization of scientific discourses.

Foucault's opposition to the principle of sovereignty might also be understood in relation to disability. Because the 'experiences' of disability are so varied (the concept covers physical and mental disabilities; visible and invisible disabilities; congenital, sudden or progressive disabilities; permanent or temporary disabilities), and because most of us will, at some point in our lives, become disabled, investigating the 'experiences' of disability gives us insight into the complicated and changing relationship between selves, bodies and worlds that we all live all the time. Selves and bodies in the world are not autonomous and sovereign, but always come into being in relation to others, are often vulnerable, and fail to fit the norm in one way or another at one time or another. In their essay entitled 'Bodies together: touch, ethics and

disability', Janet Price and Margrit Shildrick explore what they understand as 'the permeability between bodies and between embodied subjects' (2002, p. 62). They do so both by writing together (as Janet/and/Margrit) and by scrutinizing critically their experiences as a woman with MS (Price), who has 'decreased sensation across large areas of her body' (2002, p. 69), and as a woman, who does not have decreased sensation (Shildrick), but who nonetheless wonders why her own hand suddenly feels clumsy when it holds Janet's hand, which cannot press back in return (2002, p. 72). For Shildrick and Price, 'the instability of the disabled body is but an extreme instance of the instability of all bodies' (2002, p. 72). By recognizing the relational aspect of embodiment, they begin to posit an alternative ethics not based on the principle of sovereignty, but one in which responsibility lies 'in the uncertainty and risk of response to the unknowable other' (2002, p. 74).[4]

Descent

Genealogies are antisciences, in Foucault's formulation, and they are also anti-histories, or at least anti-historicist histories. In his analysis of the genealogical method as it emerges in the work of Nietzsche, Foucault notes first that genealogy 'opposes itself to the search for 'origins'' (Foucault 1977, p. 140). A genealogist is not interested in discovering the origins of things, or their continuous, linear development from a locatable historical origin; rather, the genealogist seeks to discover moments of 'the dissension of other things' (1977, p. 142). What is important for the genealogist is not the essence of things, but the fabrication of essences 'in a piecemeal fashion from alien forms' (1977, p. 142). What are the accidents that become essences, and how does this historical process happen? What other things are lost in the pursuit and founding of historical origins?

A genealogist of disability would look for the invention, not the essence, for example, of the concepts of the normal and the abnormal, and their relationship to the categories disabled and able-bodied. And, of equal importance, the genealogist of disability would look for what Foucault called 'the invention of positive technologies of power' – the 'positive technique[s] of intervention and transformation' (Foucault 2003a, p. 48, p. 49) – that emerge with the idea of the norm, or bring that idea into being through practices. As Davis (1995, 2002) does, a genealogist of disability might thus describe the invention of the norm (along with that which is determined to be outside the norm) through various technologies and practices, including, for example, statistics, which Davis characterizes as a technology of industrialization. At the same time, the genealogist will listen for those 'fleeting articulations that the discourse [of the origin, of the normal] has obscured and finally lost' (Foucault 1977, p. 143). What alien forms have been covered

over by the forms that we now take to be familiar? What singular events have
been lost in the telling of a progressive history? What experiences of the
body – 'its conditions of weakness and strength, its breakdown and
resistances', as Foucault would say (1977, p. 144) – might the genealogist
be able to discern underneath or from within the 'distant ideality of the origin'
(1977, p. 145)?

While the historicist examines and instantiates origins, the genealogist
traces lines of descent in all their complexities. The genealogist looks for
discontinuities, but also, paradoxically, surprising continuities, those echoes of
counter-narratives that reverberate across time and space, if only we could
hear them. Such an examination requires that the genealogist 'identify the
accidents, the minute deviations – or conversely, the complete reversals – the
errors, the false appraisals and the faulty calculations that gave birth to those
things that continue to exist and have value for us; it is to discover that truth or
being do not lie at the root of what we know and what we are, but the
exteriority of accidents' (1977, p. 146). Disability – often linked quite
literally, as well as metaphorically, to accidents – illuminates Foucault's shift
of emphasis from some interior truth of identity to the exteriority of accidents.
As John Hockenberry explains in his memoir, *Moving Violations*, about his life
marked by a car accident when he was 19 that left him paralyzed from the
waist down, 'From the beginning, disability taught that life could be
reinvented' (1995, p. 79). 'In fact', he continues,

> such an outlook was required. The physical dimensions of life could be
> created, like poetry; they were not imposed by some celestial landlord.
> Life was more than renting some protoplasm to walk around in. It was
> more than being a winner or a loser. To have invented a way to move
> about without legs was to invent walking. This was a task reserved for
> gods, and to perform it was deeply satisfying. None of that was apparent
> to the people who stared. To them, I was just in a wheelchair. To me,
> I was inventing a new life.
>
> (1995, p. 79)

The genealogist of disability is concerned, then, not with discovering the truth
or being that lies at the root of what we know of disability and what we are as
disabled, but at demonstrating the heterogeneity and multiplicity of the
experiences, events and practices of disability. By attempting to show the
multiple lines of descent, the genealogist acknowledges that the experiences,
events and practices of disability – and the disabled body – have a history and
a geography, and that disability and the disabled body – and all human
existence and embodiment – may yet be thought otherwise, may yet be
reinvented. All the essays in this volume show the experiences and events
of disability as providing an impulse for reinvention, through various

technologies, stories, and affective responses, and within multiple institutional structures.

The genealogist, according to Foucault, must articulate a history of the body, in particular a history of the body as it is inscribed by events, manifests 'desires, failings and errors', and becomes debilitated (1977, p. 148). Foucault's interest in the body inscribed by history connects with disability scholars and activists who assert that able-bodiedness is always a temporary condition. In *Extraordinary Bodies*, Thomson notes that because anyone can become disabled at any time, disability is 'more fluid, and perhaps more threatening, to those who identify themselves as normates than such seemingly more stable marginal identities as femaleness, blackness, or nondominant ethnic identities' (1997, p. 14). Foucault emphasized this too, asserting that, theoretically and methodologically, the diagnosis of descent rather than the fixing of an origin brings the body 'and everything that touches it' into view (1977, p. 148).

Emergence

Along with descent, the genealogist is concerned with the emergence, the moment of arising, of forces and figures in history. Like the practice of tracing descent, the concept of emergence challenges the notion of history as a record of continuity and progress, and acknowledges discontinuity in history and as an aspect of 'our very being' (Foucault 1977, p. 154). The genealogist of disability might consider the moment of arising of disability activism in the public sphere and of disability studies in the academic sphere, and attempt to articulate the confrontation between these two emergent figures: the disability activist and the disability studies scholar. In his introduction to *The Disability Studies Reader*, Davis describes such a moment of arising when he writes, '[T]here have been people with disabilities throughout history, but it has only been in the last twenty years that one-armed people, quadriplegics, the blind, people with chronic diseases and so on, have seen themselves as a single, allied, united physical minority. Linked to this political movement, which is detailed in Joseph Shapiro's *No Pity*, David Hevey's *Creatures Time Forgot* and Oliver Sacks's *Seeing Voices*, among other works, has been the political victory of the passage of the Americans with Disabilities Act (ADA) of 1990, which guarantees the civil rights of people with disabilities' (1997, p. 3).

Besides the disability rights activist and the disability studies scholar, there are countless other figures of disability: the grotesque, the freak, the monster, the poster child, the crip, the supercrip, the person with AIDS (PWA), the AIDS activist, the long-term care patient (at home and in a care facility), the disabled person who is heroic, overcoming or embittered, the disabled person who, like Christopher Reeve, is determined to walk again and the disabled

person who does not care if she walks again, the wheelchair athlete, etc. Besides the disability rights movement and disability studies, there are also multiple domains of disability: the rehabilitation clinic and other domains within and alongside the institution of medicine, the long-term care facility, the deaf school that trains students to sign and the deaf school that is oralist in approach and does not allow signing, the special education class, the paralympics, the special olympics, the telethon, the law before and after the Americans with Disabilities Act, etc. Disability is multiple; it is *enacted* between multiple figures and across multiple domains. Genealogy as theory and method recognizes this multiplicity, and is interested in understanding this multiplicity not in order to fix (in both senses: to repair and to fasten or make stable) disability once and for all, but to open up disability as a myriad of experiences, events and practices that tell us something about what it means to be human, and about the relationship between bodies, selves and worlds.

Enacting disability after Foucault

Although I have focused primarily on Foucault's work in order to demonstrate what genealogy might do for disability studies and what disability does for genealogy, I want to briefly consider an approach that is inspired by Foucault's genealogical work, but also attends to work in science studies and feminist science studies developed after Foucault. Exploring the conjunction between science studies and disability studies has only just begun, and I hope this special issue will encourage further borrowings between, minglings among, and overlappings of these fields of inquiry. It appears that there has been some resistance to science studies within disability studies, and this may be because of the attempt in disability studies and activism to understand and analyse disability outside of the biomedical model. Yet, science studies, as formulated by Latour and others (see, for example, Latour and Woolgar 1979, Latour 1987, 1993, Haraway 1991, 1997), is indeed, in Foucauldian terms, an antiscientific study of science. Rather than conceiving of science as engaging in some pure practice of discerning facts about things apart from 'interest, justice and power', science studies demonstrates that the knowledge of things and human politics and forms of power cannot be separated from each other (Latour 1993, p. 3). In science studies, according to Latour, 'we are always attempting to retie the Gordian knot by crisscrossing, as often as we have to, the divide that separates exact knowledge and the exercise of power – let us say nature and culture' (1993, p. 3). Disability studies clearly attempts to retie this knot too, by crisscrossing multiple domains of nature and culture, or nature/culture.

   Because Foucault's own work was always historical, and because he explicitly cautioned about the difficulties of diagnosing one's own archive, his

genealogical method on the surface seems less adequate at discerning contemporary discursive regimes and their enactment in practices.[5] Yet, recent work in science studies has begun to attempt to diagnose the present, to bring into view contemporary discursive regimes, and the modes of ordering that create supposed unities, such as for example, 'the medical profession', 'Western medicine', 'present-day medicine' and 'science' (Berg & Mol 1998). What happens when we disaggregate a concept, event or experience we have formerly understood as unified? This is what Annemarie Mol (1998, 2002) attempts to do in her work when she demonstrates the ways in which a particular disease, atherosclerosis, is never just one thing, but multiple things. In her book *The Body Multiple* (2002), Mol is concerned not with how medicine knows a particular disease or how a patient knows her illness, but rather how that disease is enacted through practices. Mol calls her work 'empirical philosophy'; though it is also a genealogy of atherosclerosis that 'foregrounds practicalities, materialities, *events*' (2002, pp. 12−13). Illness, for Mol, 'is something being done to you, the patient. And something that, as a patient, you do' (2002, p. 20). I find this approach very useful for understanding disability; the question here is precisely, how do we do disability? The essays that follow give us a sense of this doing of disability: they demonstrate the complex practices of caring and curing, the multiple activities that disabled people do and have done to them, and the multiple modes of representation that disabled people utilize or deconstruct. Like disease, disability is multiple. In order to understand its multiplicity, we must not try to simplify it, but attempt instead to sketch out its complexities (see Mol & Law 2002, p. 20). Sketching the complexities of disability is what I think all of the contributors to this issue begin to do.

All of the essays here follow Foucault's call for genealogy as a 'coupling together of scholarly erudition and local memories' (2003, p. 8). I have organized the essays in such a way that they trace back historically, beginning with histories of the present experience of disability within specific and everyday contexts before moving into histories of past struggles. 'Genealogies of Disability' opens with two scholars whose work theoretically and methodologically is influenced not only by Foucault and genealogy, but also and perhaps more particularly by Mol's attempt to do 'empirical philsophy' and John Law's concern with 'modes of ordering' (Mol 1998, Law 1994). Ingunn Moser came to disability studies when she was at a Norwegian research centre doing feminist science and technology studies over a decade ago. She was invited to participate in a study of the Norwegian government's information technology policies for disabled people. She became interested in 'how people become, and are made, disabled . . . in a series of discourses running through disabled people's associations as well as Norwegian welfare state policies', and in practices, including medical and rehabilitation practices, and everyday life practices (personal communication, 1 September 2005).[6] In

her essay, 'On becoming disabled and articulating alternatives: the multiple modes of ordering disability and their interferences', Moser delineates several modes of ordering disability among people living with disability after traffic accidents in Norway. Moser names these modes − normalization, lack, fate and passion − and attempts to discern how this ordering is enacted. By gathering ethnographic evidence of how disability is enacted in everyday activities and practices, Moser demonstrates that disability is not ordered in a unitary and singular way. As she shows, there is not one particular mode of ordering that disabled people have access to, rather 'people tend to slip and move between different modes of ordering disability. And become enacted in multiple and shifting ways, in shifting spaces and times'. The questions that Moser returns to persistently are, 'How does it work? How is disability done in practice?'

These are questions that Rita Struhkamp also returns to persistently in her essay, 'Wordless pain: dealing with suffering in physical rehabilitation'. Struhkamp investigates modes of suffering in the rehabilitation practices at a Dutch rehabilitation facility for people with spinal cord injuries and multiple sclerosis, and she considers as well the reasons why suffering has been avoided for the most part in the rhetoric of disability advocates. According to Struhkamp, doctors, rehabilitation specialists and patients negotiate disability and the suffering that arises from it in several ways, including making translations that transform suffering into something else, learning how to manage suffering and creating a space for suffering simply to be. Crucially, then, Struhkamp shows both attempts to deal with suffering through translations and management, as well as situations in which suffering cannot be translated into something else or managed away, but must still be allowed to be acknowledged − or given space − as a part of the experiences, events and practices of disability. I find Struhkamp's argument that in many instances suffering cannot be transformed compelling because in my own work that analyses autobiographical accounts of the experience and event of illness, I have tried to demonstrate that there are some approaches to loss that attempt to hold onto loss, rather than convert it into something else, such as for example an opportunity for improvement or gain (see, for example, Diedrich 2005). Such approaches exemplify what I call an ethics of failure, and Struhkamp seems to suggest something similar, an ethics of suffering perhaps. This sort of ethics has for the most part been denied or covered over in disability studies and the disability rights movement, perhaps because it can be read as further stigmatizing disability by emphasizing the negative affects associated with it. Struhkamp notes that the creation of a space for suffering is often most difficult for practitioners, because they 'tend to find it hard to step back and tolerate the full dimension of suffering, because they cannot do what they understand as their task: provide help and relieve the pain and suffering caused by disease

and disability. The paradox of creating space for suffering is that it is an active way of letting go'.

   Although her work is not empirical, as is Moser's and Struhkamp's, Monique Lanoix, in 'No room for abuse', also attempts to describe some of the ways disability is enacted, in particular in long-term care facilities in Quebec. Lanoix's interest in these particular institutions has emerged out of her work as a member of both the ethics and users' committees of one of these facilities. Trained as a philosopher, Lanoix wonders why philosophers have traditionally overlooked such sites for analysis (with the notable exception of Foucault). She believes an analysis of these designated sites of care provides a 'unique opportunity to study the complexities of care and care practices' (personal communication, 1 September 2005). In her essay for this volume, Lanoix investigates recent reports in the Canadian media of abuse at these care facilities, and attempts to understand such abuse not as exclusively the result of particular evil individuals, who do not care for or about those in their care, but rather as inherent to the structure of the care facility itself, situated as it is within recent neoliberal state policies. Lanoix considers such practices of abuse in terms of Foucault's concept of biopower, as well as in relation to Agamben's and Claudia Card's uses of Primo Levi's concept of the grey zone. She is concerned throughout her essay not simply with the abuse in these facilities *as such*, but also with the way this abuse is represented in the media, and how this translates into policy.

   In 'Diseased pariahs and difficult patients: humour and sick role subversions in queer HIV/AIDS narratives', Katrien De Moor analyses the representation of the experience and event of HIV/AIDS among gay men in various western locations − including the United States, Britain and Australia − in the early days of the epidemic in several autobiographical accounts, as well as in the queer 'zine *Diseased Pariah News*. De Moor focuses on work that resists − through humour and what she calls 'sick role subversions' − the hegemonic narratives of shame and redemption that surround and contain the experience of living with and dying of AIDS. Humour is subversive, as these texts demonstrate, because it does not fit easily into the genres usually reserved for writing about the experience of a debilitating and, initially at least, almost certainly deadly disease. By refusing the normalization of sentiment, these writings also refuse to offer psychological comfort to those persons who believe there is a good and heroic way to be ill and die. De Moor shows how these narratives function culturally, and how writing is a practice that itself counters some of the disabling and stigmatizing effects of HIV/AIDS, and therefore might be considered a form of cultural activism. She explains that her own approach to this literature is shaped less by conventional literary studies than by several overlapping interdisciplinary fields, including queer cultural studies, literary sociology, medical sociology and science studies. Unlike most of the other authors in this issue, De Moor's

interest in the HIV/AIDS narratives that resist stigmatization and moralism did not emerge by looking at the experiences and events of HIV/AIDS close to home in a Belgian context, but only through contacts beyond Belgium (personal communication, 2 September 2005). Although the cultural studies of the experience and event of AIDS are usually not included within the current formulations of disability studies, I think various genealogies of AIDS must be traced as part of a larger genealogy of disability.[7] Because AIDS initially most often resulted in relatively quick death, it was seen not as a chronic and disabling illness but as an acute and deadly illness. With the new treatment regimes, AIDS, at least in some populations in the West, might now be better understood as a chronic disease with disabling effects, which can be managed, and this new mode of being ill with AIDS might now be understood within a broader context of the multiple experiences, events, and practices of disability.

Finally, in 'The disabled body, genealogy and undecidability', Margrit Shildrick develops further her work mentioned above that seeks to explore the ethics that emerges out of an understanding of all bodies as essentially vulnerable, and her belief that postmodernist approaches offer challenges to conventional thinking in disability studies as well as bioethics (see also Shildrick 2005). In her essay here, Shildrick complicates the analysis of particular social forms of exclusion and integration enacted through the cultural distinctions between self and other and abnormal and normal with a deconstructive approach that emphasizes the interiorization of the binary as the self's fear of the other within the self. Although Shildrick does not seek, contra Foucault, some interior truth of identity, she is nonetheless concerned with the way cultural fantasies are interiorized psychically. In particular, Shildrick believes that disability, and the vulnerability that it signifies, creates a 'deep anxiety ... at the level of both the individual psyche and the cultural imaginary'. According to Shildrick, then, both the biomedical and the social models of disability disavow this anxiety towards bodies that are perceived as different and vulnerable, and therefore they cannot account for the affective responses to disability, including anxiety, pain and desire. One of the anonymous reviewers of this issue noted that Shildrick's essay was closest in spirit to the genealogical approach that I sketched out above. I should explain that this is no accidental confluence, but the enduring imprint of a teacher's thought on her student's: Shildrick's thought on mine.

All of the essays collected in 'Genealogies of Disability' attend to the affective aspects of disability, and, perhaps surprisingly, they look frankly at the negative affects that often swirl around disability, including depression, suffering, anger and anxiety. All of the essays show the influence of Foucault and his genealogical method, but they also point to places where Foucault and genealogy do not quite give us everything we need to understand the

experiences, events and practices of disability. But, of course, this reckoning with the failure of genealogies of disability might itself be understood as an important – if not the essential – aspect of the genealogical method.

Acknowledgements

Notes

1   Corker and Shakespeare do acknowledge the problem of the conflation of 'post-structuralism' with 'postmodernism', and admit that many of the theorists who they categorize as post-structuralist, including Foucault, refuse this label for their work.

2   This criticism is often leveled against women's studies and black studies and other interdisciplinary minority studies. While I certainly think there is a tension between theory and activism in all of these interdisciplinary fields of studies (which relates to a tension between theory and empirical work in these interdisciplinary fields as well as in more traditional disciplines, such as sociology, political science, history and literature), I find it interesting that these interdisciplinary fields of study are often perceived from the outside as untheoretical, and also, relatedly, lacking in rigor. It is true that sometimes theory is critiqued from within as well, but in both instances – in the case of the critique from the inside as well as the critique from the outside – such a critique can only be made by ignoring or covering over a long history of theoretical work.

3   As this special issue was in its final stages of being prepared for publication, a collection entitled *Foucault and the Governmentality of Disability* (2005) edited by Tremain was released. This volume focuses more generally on Foucault's work for disability studies rather than on the particular practice of genealogy, but it is similarly motivated by a desire to use the tools Foucault provides to advance disability studies and activism.

4   In her discussion of the biopolitics of immunity, Donna Haraway also articulates an ethics of vulnerability. According to Haraway, 'Life is a window of vulnerability. It seems a mistake to close it. The perfection of the fully defended,'victorious' self is a chilling fantasy . . . whether located in the abstract spaces of national discourse, or in the equally abstract spaces of our interior bodies' (1991, p. 224).

5   Foucault believed that it is impossible to describe one's own 'archive', or 'the general system of the formation and transformation of statements'

(1972, p. 130), precisely because one is within it. The archive, in other words, is that which delimits what one can and cannot say; there is no thought from the outside of one's own archive. And, yet, Foucault also submits in the introduction to *The Archaeology of Knowledge*, 'I have tried to define this blank space from which I speak, and which is slowly taking shape in discourse that I still feel to be so precarious and so unsure' (1972, p. 17).

6   I asked each contributor to provide a brief description of how she came to disability studies, and to contextualize her work within particular institutional, theoretical and/or methodological frameworks. I did this because it seems to me that these essays, as a group, decentre the Anglo-American hegemony of disability studies. They do not, however, succeed in decentring disability studies beyond a western context. There is still much work to be done.

7   Most of the readers and edited volumes on disability studies do not include essays about living with HIV/AIDS.

References

Baynton, D. (1997) 'A silent exile on this earth: the metaphoric construction of deafness in the nineteenth century', in *The Disability Studies Reader*, ed. L. Davis, Routledge, New York, pp. 128–150.

Berg, M. & Mol, A. (eds) (1998) 'Differences in medicine: an introduction', in *Differences in Medicine: Unraveling Practices, Techniques, and Bodies*, Duke University Press, Durham and London, pp. 1–12.

Canguilhem, G. (1989) *The Normal and the Pathological*, trans. C. R. Fawcett, Zone Books, New York.

Corker, M. & Shakespeare, T. (2002) 'Mapping the terrain', in *Disability/ Postmodernity*, Continuum, London and New York, pp. 1–17.

Davis, L. (1995) *Enforcing Normalcy: Disability, Deafness, and the Body*, Verso, New York.

Davis, L. (ed.) (1997) *The Disability Studies Reader*, Routledge, New York.

Davis, L. (2002) *Bending Over Backwards: Disability, Dismodernism and Other Difficult Positions*, NYU Press, New York and London.

Diedrich, L. (2005) 'An ethics of failure: anti-heroic cancer narratives', in *Ethics of the Body: Postconventional Challenges*, eds M. Shildrick & R. Mykitiuk, The MIT Press, Cambridge, MA, pp. 135–152.

Foucault, M. (1972) *The Archaeology of Knowledge and the Discourse on Language*, trans. A.M. Sheridan Smith, Pantheon, New York.

Foucault, M. (1977) *Language, Counter-memory, Practice: Selected Essays and Interviews*, trans. D. Bouchard & S. Simon, Cornell University Press, Ithaca, New York.

Foucault, M. (2003a) *Abnormal: Lectures at the Collége de France 1974–1975*, trans. G. Burchell, Picador, New York.

Foucault, M. (2003b) *'Society Must Be Defended': Lectures at the Collége de France 1975—1976*, ed. M. Bertani & A. Fontana, trans. D. Macey, Picador, New York.

Haraway, D. (1991) *Simians, Cyborgs, and Women: The Reinvention of Nature*, Routledge, New York.

Haraway, D. (1997) *Modest_Witness@Second_Millenium.Female_Man*©*_Meets_Oncomouse*™*: Feminism and Technoscience*, Routledge, New York.

Harding, S. (1991) *Whose Science? Whose Knowledge: Thinking from Women's Lives*, Cornell University Press, Ithaca.

Hockenberry, J. (1995) *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence*, Hyperion, New York.

Lane, H. (1984) *When the Mind Hears: A History of the Deaf*, Random House, New York.

Lane, H. (1997) 'Constructions of deafness', in *The Disability Studies Reader*, ed. L. Davis, Routledge, New York, pp. 153–171.

Latour, B. (1987) *Science in Action: How to Follow Scientists and Engineers through Society*, Open University Press, Milton Keynes.

Latour, B. (1993) *We Have Never Been Modern*, trans. C. Porter, Harvard University Press, Cambridge, MA.

Latour, B. & Woolgar, S. (1986) *Laboratory Life: The Construction of Scientific Facts*, 2nd edn, Princeton University Press, Princeton, NJ.

Law, J. (1994) *Organizing Modernity*, Blackwell, Oxford.

Law, J. & Mol, A. (eds) (2002) 'Complexities: an introduction', in *Complexities: Social Studies of Knowledge Practices*, Duke University Press, Durham and London, pp. 1–22.

Maynard, M. (1994) 'Methods, practice and epistemology: the debate about feminism and research', in *Researching Women's Lives from a Feminist Perspective*, eds M. Maynard & J. Purvis, Taylor and Francis, London, pp. 10–26.

Mitchell, D. T. & Snyder, S. L. (eds) (1997) 'Introduction: disability studies and the double bind of representation', *The Body and Physical Difference: Discourses of Disability*, The University of Michigan Press, Ann Arbor, pp. 1–31.

Mol, A. (1998) 'Missing links, making links: the performance of some atheroscleroses', in *Differences in Medicine: Unraveling Practices, Techniques, and Bodies*, eds M. Berg & A. Mol, Duke University Press, Durham and London, pp. 144–165.

Mol, A. (2002) *The Body Multiple: Ontology in Medical Practice*, Duke University Press, Durham and London.

Oliver, M. (1990) *The Politics of Disablement: A Sociological Approach*, St Martins Press, New York.

Oliver, M. (1996) *Understanding Disability: From Theory to Practice*, MacMillan Press, London.

Price, J. & Shildrick, M. (2002) 'Bodies together: touch, ethics and disability', in *Disability/Postmodernity*, eds M. Corker & T. Shakespeare, Continuum, London and New York, pp. 62–75.

Sacks, O. (1989) *Seeing Voices: A Journey into the World of the Deaf*, University of California Press, Berkeley, CA.

Shakespeare, T. (ed.) (1998) The Disability Reader: Social Science Perspectives, Cassell, New York.

Shildrick, M. (1997) *Leaky Bodies and Boundaries: Feminism, Postmodernism and (Bio)Ethics*, Routledge, New York.

Shildrick, M. (2002) *Embodying the Monster: Encounters with the Vulnerable Self*, Sage, London.

Shildrick, M. (2005) 'Beyond the body of bioethics: challenging the conventions', in *Ethics of the Body: Postconventional Approaches*, eds M. Shildrick & R. Mykitiuk, The MIT Press, Cambridge, MA, pp. 1−26.

Thomson, R.G. (ed.) (1996) *Freakery: Cultural Spectacles of the Extraordinary Body*, New York University Press, New York.

Thomson, R. G. (1997) *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, Columbia University Press, New York.

Tremain, S. (2002) 'On the subject of impairment', in *Disability/Postmodernity*, eds M. Corker & T. Shakespeare, Continuum, London and New York, pp. 32−47.

Tremain, S. (ed.) (2005) *Foucault and the Governmentality of Disability*, University of Michigan Press, Ann Arbor.

Wendell, S. (1996) *The Rejected Body: Feminist Philosophical Reflections on Disability*, Routledge, New York.