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# UNDERSTANDING THE SOCIAL MODEL OF DISABILITY

## Past, present and future

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### Introduction

As someone with a congenital visual impairment with working-class disabled parents, I grew up with impairment and disability. I found the social model of disability in the 1980s in a book by Mike Oliver (1983), *Social Work with Disabled People*, when I went to university to study disability. The book summarised what I already knew about disability: that people with any form of accredited impairment are disabled by an unjust and uncaring society. This notion has influenced my work ever since. Subsequently, thinking inspired by the social model has had a major impact on policy circles and universities around the world. Yet in many respects there remains a general misunderstanding about what the social model actually is and what it is for.

This chapter will address this unfortunate state of affairs, in particular the debates surrounding the usefulness of the social model within the academy. It is divided into three main sections. The first section will examine the origins of the social model. This is followed by a review of the influence that the social model has on insights within and beyond the academy. The final section will address the various debates that have emerged since the late 1990s and argue that, without the social model of disability, disability studies will be rendered meaningless. Therefore, the struggle for a fairer and more just society will be that bit harder.

### The origins of the social model

In order to understand the significance of the implications of social model reasoning it is important to remember that until very recently ‘disability’ was viewed almost exclusively as an individual medical problem or a ‘personal tragedy’ in Western culture. Yet there is a wealth of anthropological and sociological evidence to suggest that societal responses to people with impairments or long-term health conditions vary considerably across time, culture and location (see, for example, Hanks and Hanks 1948; Lemert 1951; Ingstad and Whyte 1995; Miles 1995, 2001; Ingstad 2001).

The philosophical and cultural basis upon which the individualistic negative response to impairment rests is rooted firmly in the foundations of Western culture. While the vast majority of people with impairments were integrated into the community prior to the Industrial Revolution, there is substantial evidence that oppression and prejudice was widespread (Ryan and Thomas 1980; Garland 1995; Stiker 1999). There is also general agreement that the economic and social upheavals that accompanied the coming of industrial capitalism precipitated the institutionalisation of discriminatory policies and practices. Industrialisation, urbanisation, changing work patterns and accompanying ideologies, liberal utilitarianism, medicalisation, eugenics, and social Darwinism – all of these things contributed to and compounded ancient fears and prejudices. Taken together, these structural forces provided intellectual justification for more extreme discriminatory practices, notably the systematic removal of disabled people from mainstream economic and social life (Finkelstein 1980; Oliver 1990; Barnes 1990, 1991, 1997; Gleeson 1999; Borsay 2005).

Since the mass 'euthanasia' policy for disabled people, defined as 'useless eaters', introduced by Germany's Nazi government in the 1930s and 1940s (Gallagher 1995; Burleigh 1994), there has been a general 'softening' of attitudes in policy circles in wealthy states such as the United Kingdom, Europe and the United States. This led to an expansion of community-based services provided by state and voluntary agencies and a proliferation of professional helpers underpinned by traditional deficit understandings of disability (Oliver 1981; Brisenden 1986; Barnes 1991; Morris 1993; Priestley 1999).

This policy change was the result of several factors. These included a moral obligation felt by politicians and the general population towards the large number of civilians and military personnel who had been injured during the Second World War. There was also unprecedented growth in the number of disabled and elderly people due to increasing affluence and medical advances. All of this contributed to the politicisation of disability by disabled people and the organisations that represented their interests during the latter half of the twentieth century in countries as diverse as Sweden (Höjer 1951; Nordqvist 1972), the UK (Hunt 1966a; Campbell and Oliver 1996; Barton 2001), the United States (De Jong 1979; Scotch 1989; Shapiro 1993) and Japan (Tateiwa 2010).

In the UK, disability activism revolved around a rejection of 'residential care' and control by what Finkelstein (1999) termed 'professionals allied to medicine', poverty and the exclusion of disabled people from mainstream economic and social activity. Until the late 1960s support for 'severely' disabled people was generally unavailable outside institutions and there were no disability-related welfare payments. Consequently, 'severely' disabled people were either incarcerated in residential homes run by professionals or lived within the community in relative poverty and social isolation. A crucial factor for all disabled people and their families at this time was a lack of money, which resulted in the formation of the Disabled Incomes Group (DIG) by two disabled women in 1965 (Campbell and Oliver 1996).

DIG attracted the attention of disability activists across the country. These included future key figures in the UK's disabled people's movement: Paul Hunt, Vic Finkelstein, Maggie Hines and Ken Davis. They soon rejected the narrow incomes approach favoured by DIG and later the Disability Alliance (DA). The DA brought together several disability organisations to campaign for a comprehensive disability income. Disillusioned by this approach and its domination by non-disabled 'experts', Hunt, Finkelstein and Davis, along with other like-minded disabled activists, set up the Union of the Physically Impaired Against Segregation (UPIAS) in 1974 (UPIAS 1976).

Undoubtedly the most influential organisation in the history of social model thinking, UPIAS functioned mainly through confidential correspondence and circulars distributed among its members. Drawing on personal experience and sociological insights, UPIAS members, none of whom were trained sociologists, argued that disability was a complex form of social oppression similar to that encountered by women, ethnic minorities, lesbians and gay men. An early expression of this view is found in *Stigma: The Experience of Disability*: a book of 12 personal accounts of living with impairment by six disabled men and six disabled women, initiated and edited by Paul Hunt, then a resident of the Le Court residential home in Hampshire, UK (Hunt 1966a).

Hunt selected the chapters from over 60 responses to a letter he had published in national newspapers and magazines requesting contributions. His aim was to avoid 'sentimental autobiography' or a 'preoccupation with the medical and practical details of a particular affliction'. In his chapter, Hunt argues that 'the problem of disability lies not only in the impairment of function and its effects on us individually but more importantly in our relationship with "normal" people' (1966b: 146, emphasis added).

Disabled people 'are set apart from the ordinary' in ways which see them as posing a direct 'challenge' to commonly held social values by appearing 'unfortunate, useless, different, oppressed and sick' (ibid.).

Thus, for UPIAS, lack of income is a symptom rather than a cause of disabled people's individual and collective disadvantage:

> Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from society. Disabled people are therefore an oppressed group. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation in every area of social life, such as education, work, mobility, housing etc.
>
> *(UPIAS 1976: 4)*

In contrast to previous definitions that cited impairment as the cause of disability and 'handicap' (Harris *et al.* 1971), UPIAS produced a sociopolitical definition of disability that made the crucial distinction between the biological (impairment) and the social (disability). Hence, 'impairment' denotes 'lacking part or all of a limb, or having a defective limb or mechanism of the body' but 'disability' is 'the disadvantage of restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities' (UPIAS 1976: 14).

Subsequently, the restriction to 'physical impairments' was dropped to incorporate all impairments – physical, sensory and cognitive. This is because some conditions, both congenital and acquired, affect all bodily functions and in a disablist society all impairments – whatever their cause – have to a greater or lesser degree negative physical and psychological implications. Also, impairment-specific labels may have relevance when accessing appropriate medical and support needs, but they are usually imposed rather than chosen and are therefore socially and politically divisive (Barnes 1996; Oliver and Barnes 1998).

Thereafter, the UPIAS definition was adopted and adapted by national and international organisations controlled and run by disabled people. These included the British Council of Organisations of Disabled People (BCODP), the national umbrella for organisations controlled and run by disabled people in the UK, and Disabled Peoples' International (DPI), an international body for national organisations like BCODP (Campbell and Oliver 1996).

Other important developments during the 1970s included increased disability activism in the United States and the emergence of the Independent Living Movement (ILM). The ILM emerged partly from within the campus culture of American universities and partly from repeated efforts by American disability activists, swelled by the growing number of disabled Vietnam War veterans, to influence US disability legislation. During the 1960s some American universities introduced various self-help programmes to enable students with 'severe' physical impairments to attend mainstream courses. Such schemes were rarely available outside university campuses. This prompted some disabled students to develop their own services under the banner of Centres for Independent Living (CILs) (De Jong 1979).

Unlike conventional services *for* disabled people, CILs are self-help organisations run and controlled by disabled people. Traditional professionally dominated provision focused almost exclusively on medical treatments and therapies within institutional settings that effectively removed disabled people from everyday life. In contrast, CILs provided a new and innovative range of services designed to empower people with impairments for a lifestyle of their own choosing within, rather than apart from, the local community. The activities of the ILM had a significant impact on activists in the UK and led to the establishment of user-led organisations that provided services and support for disabled people and their families. Early examples include the Spinal Injuries Association (SIA), established in 1973. The UK's first CILs, the Hampshire Centre for Independent Living (HCIL) and the Derbyshire Centre for Integrated Living (DCIL), opened in 1985 (Barnes and Mercer 2006).

The 1970s also witnessed the introduction of various legislative measures and policy initiatives to address disability issues. In the UK, the Chronically Sick and Disabled Person's Act entered the statute books following a Private Members' Bill by a Labour Member of Parliament, Alf Morris, in 1970. The Act is widely regarded as the first piece of legislation in the world to introduce policies to improve equal opportunities for disabled people in community-based services, education, housing and public buildings (Topliss and Gould 1981). Three years later, the US Congress passed the 1973 Rehabilitation Act, which included Section 504 prohibiting discrimination against disabled people in any federally funded programme. The United Nations (UN) introduced its Declaration on the Rights of Mentally Retarded Persons in 1971 and the Declaration on the Rights of Disabled Persons in 1975. The latter states that:

> Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.
>
> *(UN 1975, Art. 3)*

Growing interest in disability at the international level led in 1980 to the World Health Organization's (WHO) first attempt to provide a universally acceptable definition of disability – the International Classification of Impairment Disability and Handicap (ICIDH) – and a year later the UN's International Year of Disabled People.

The ICIDH was developed by a group of social scientists led by Philip Wood at the University of Manchester without the involvement of disabled people. Published in 1980, four years after the launch of the UPIAS definition, the stated aim of the ICIDH was to clarify concepts and terminology surrounding disability in order to facilitate accurate and comparable research and policy within and across nation-states (Bury 1997). Designed to complement WHO's International Classification of Disease (WHO 1976), the ICIDH separates the concepts *impairment, disability* and *handicap* as follows:

- Impairment: any loss or abnormality of psychological, physiological or anatomical structure or function.
- Disability: any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
- Handicap: a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role (depending on age, sex, social and cultural factors) for that individual.

*(Adapted from WHO 1980: 29)*

The ICIDH has been subject to several criticisms by disabled activists and allies. First, it relies exclusively on individualistic medical definitions and biophysical assumptions of 'normality'. However, 'normality' is a contentious concept influenced by various historical, cultural and situational forces (Abberley 1993; Davis 1995). Second, 'impairment' is identified as the cause of both 'disability' and 'handicap'. Although handicap, or social disadvantage, is presented as neutral and the inevitable consequence of either impairment or disability, this is difficult to sustain. Many impairments do not inhibit an individual's physical or intellectual capability. Examples include short stature, hair loss and skin blemishes. What is and what is not an impairment is historically, culturally and socially variable. For example, homosexuality is no longer considered an impairment in some cultures but in others it is (Weeks 1991). Handicap is therefore ideologically and culturally determined; neither ideology nor culture is politically neutral.

Finally, this approach places people with an actual or accredited impairment in a dependent position. Their condition is individualised and medicalised and therefore assumes that they are reliant upon professional experts and others to provide therapeutic and social support. As impairments are presented as the root cause of disability, logic dictates that they must be eradicated, minimised or 'cured'. But where 'cures' are ineffective, which more often than not is the case, people labelled 'disabled' are viewed as economically and socially inadequate and in need of 'care'. This has resulted in the generation of a thriving and costly 'disability' industry comprising state institutions, private businesses, charities and voluntary agencies staffed by vast armies of professional helpers. The result is that disabled people's assumed inadequacy and dependence is reified and assured (Stone 1984; Wolfensberger 1989; Albrecht 1992; Oliver 1990).

The growing interest in disability issues at the international level led to the UN declaring 1981 the International Year of Disabled People. This signified a formal recognition that national governments are responsible for securing equal rights for disabled people. The following year the UN General Assembly adopted by consensus a World Programme of Action Concerning Disabled Persons and a global strategy on the prevention of disability. Other international initiatives quickly followed, including the African Decade of Persons with Disabilities (2000–2009), the European Year of People with Disabilities 2003, the Asian and Pacific Decade of Disabled Persons (2003–2012) and the Arab Decade of Disabled Persons (2003–2012) (Albert 2006).

Also in 1981, disabled activists formed DPI. This was established because of Rehabilitation International (RI)'s refusal to accept the equal participation of disabled delegates on its controlling body. Formed in 1922 as the International Society for Crippled Children, RI is an international organisation for rehabilitation professionals (Driedger 1989: 18). DPI's first world congress was held in Singapore in the following year and attracted 400 delegates representing national organisations run by disabled people from around the world, including representatives of BCODP. As well as adopting a sociopolitical definition of disability, DPI's stated policy revolves around the promotion of grassroots organisations and the development of public awareness of disability issues in the struggle for equality. Its slogan 'Nothing About Us Without Us' has been embraced by disabled people's organisations around the globe (Charlton 1998). Taken together, these forces were instrumental in the thinking behind the use of the phrase 'the social model of disability'.

## The arrival and impact of the social model

Prior to the 1970s, apart from one or two notable exceptions, academic interest in disability was limited almost exclusively to conventional, individualistic medical explanations. An important example is Talcott Parsons's (1951) functionalist analysis of the role of the medical profession. For Parsons, 'health' is 'normal' and 'sickness' (and by implication 'impairment') is not and is therefore socially deviant. The role of medicine is to regulate and control sickness by curing and returning 'sick' people back to good health. Although this account is concerned with 'acute' rather than 'chronic' conditions, it has dominated sociological analyses of reactions to and the management of ascribed social deviance, including disablement, ever since (Barnes and Mercer 2003, 2010).

A notable example is Erving Goffman's (1968) account of the interactions between 'normal' and 'abnormal' people. Also during the 1960s, particular attention was paid to the social construction of 'mental illness'. Examples include Scheff (1966), Szasz (1971) and Rosenhan (1973). The idea that mental illness and other forms of ascribed social deviance are little more than social constructs generated by an increasingly dominant and moralistic social order was given a further boost by the writings of the French philosopher Michel Foucault (1976, 1977).

Consequently, academic interest in the general area of 'disability' increased. Notable publications in the UK include *The Meaning of Disability* (Blaxter 1976) and *Poverty in the United Kingdom* (Townsend 1979); American examples include *The Making of Blind Men* (Scott 1969), *The Sociology of Physical Disability and Rehabilitation* (Albrecht 1976) and *Handicapping America* (Bowe 1978). But while each of these studies drew attention to the various economic and social consequences of the ascription of a conventional 'disabled' identity, none made any serious attempt to question its ideological and cultural underpinnings. The theoretical insights applied to the concept of cognitive impairments were never extended to address other conditions and, particularly, 'physical disability'. The groundwork for this endeavour was laid by writers such as Finkelstein (1980), *Attitudes and Disabled People*; Ryan and Thomas (1980), *The Politics of Mental Handicap*; Shearer (1981), *Disability: Whose Handicap*; Sutherland (1981), *Disabled We Stand*; and the emergence of what is now referred to as disability studies.

The UK's first 'disability' studies course, 'The Handicapped Person in the Community', was conceived and produced by an interdisciplinary team at the Open University (OU) in 1975 as an optional module on the OU's Health and Social Studies Bachelor's degree. A key figure in the development of this course was Vic Finkelstein, a clinical psychologist and founding member of UPIAS. Initially aimed at professionals and voluntary workers, the course's primary objective was to help students to improve their 'professional and social skills in order to assist handicapped people to achieve *maximum autonomy*' (Finkelstein 1997: 41, emphasis added). From the outset the course was criticised for its 'sociological bias' (ibid.: 46). It was updated twice before its abolition in 1994, and each time more and more disabled people were involved in the production of course materials. The final version of the programme was retitled 'The Disabling Society' to reflect its wider content. Over the years, the OU team generated a wealth of material that provided the basis for the development of a whole host of disability studies-related courses and professional training schemes at both undergraduate and postgraduate level in mainstream colleges and universities across the UK (Barnes *et al.* 2002a).

Disability studies was pioneered in American universities by disability advocates and academics. The first course, structured around 'living with a disability', was situated in the general area of medical sociology (Pfeiffer and Yoshida 1995: 476). In 1981 Irving Zola, a disabled sociologist and chairperson of the medical sociology section of the American Sociology Association, founded the *Disability Studies Quarterly* and co-founded the USA's Society for Disability Studies. At the turn of the 1980s 12 disability studies courses at various levels were offered by American institutions. By 1986 the number had risen to 23 (Pfeiffer and Yoshida 1995).

Taken together, these developments led Mike Oliver, a disabled activist and lecturer, to coin the phrase 'social model of disability' in his contribution to a collection of five papers edited by a practising social worker, Jo Campling, in 1981, entitled *The Handicapped Person: A New Perspective for Social Workers.* Campling's previous work had included *Better Lives for Disabled Women* (1979) and *Images of Ourselves: Women with Disabilities Talking* (1981); both of which focused on women's experiences of living with impairment in the UK during the 1970s. Oliver's initial aim was to provide an accessible key to understanding the importance of UPIAS's definition of disability and its implications for policy and practice for social work students. Hence, 'This new paradigm involves nothing more or less fundamental than a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environment impose limitations upon certain categories of people' (1981: 28).

It is therefore an 'heuristic device', or aid to understanding, which entails the adoption of the following key principles.

First, a social model perspective is not a denial of the importance or value of appropriate individually based interventions, be they medically, re/habilitative, educational or employment-based. Instead, it draws attention to their limitations in terms of furthering disabled people's empowerment. Second, the social model is a deliberate attempt to shift attention away from the functional limitations of individuals with impairments onto the problems caused by disabling environments, barriers and cultures. In short, the social model of disability is a tool with which to provide insights into the disabling tendencies of modern society in order to generate policies and practices to facilitate their eradication. For advocates, impairment may be a human constant but 'disability' need not and should not be. Although the concept 'social model' has been linked to several sociological theories of disability (Priestley 1998), it is generally associated with materialist perspectives (adapted from Oliver 1996, 2004; Barnes 1996; Barnes and Mercer 2003, 2010).

Even so, social model insights were ignored by many social scientists in the UK until the turn of the millennium. Sociologists in particular continued to favour a 'conventional' functionalist deviance approach, albeit within a broader sociological framework. This has generated a growing literature on the mechanisms and processes by which people adapt to the onset of 'chronic illness' and impairment (see, for example, Anderson and Bury (1988). This burgeoning 'sociology of chronic illness and disability' has dampened down sociological interest in the wider social processes that create disability and as a result produced little by way of theory and research (Thomas 2007: 40).

The bulk of this literature focuses almost exclusively on the 'failing body' and 'personal troubles', disregarding the significance of social barriers to inclusion. This has recently been acknowledged by some medical sociologists such as Gareth Williams (2001) and Graham Scambler (2004). The latter provides a reappraisal of his earlier work on stigma in which he identifies a 'hidden distress model' of epilepsy (Scambler 1989). He now maintains that this approach is at best '*partial and at worst deficient* in its failure to address sociologically a series of theoretical questions' (ibid. 2004: 29, emphasis in the original). Yet this critique does not reject or abandon the medically dominated perceptions of impairment as social deviance. Instead, the deviance perspective must be strengthened with the development of a 'new' research agenda based on the assertion that:

> Any appreciation of why and how epilepsy persists as a significant condition must be articulated against the background of the logics of capitalist accumulation (of the economy) and mode of regulation (of the state) and their respective relations of class and command.
>
> *(ibid.: 42)*

It is perhaps testament to the inward-looking practices of many medical sociologists, and academia generally (Barnes *et al.* 2002b), that Scambler chose to ignore the wealth of material already produced by disabled people and the organisations that represent them as well as by writers working from a social model perspective in the UK and elsewhere that deal with these very issues.

Indeed, the social model had become the 'big idea' (Hasler 1993) and a key factor in the mobilisation of disability activism during the 1980s and 1990s. Notable examples include the struggle for anti-discrimination legislation to outlaw discrimination against disabled people and the campaign to legalise direct payments to enable disabled people to employ their own support workers (Campbell and Oliver 1996). At its inception in 1981 BCODP had seven member organisations; its membership had increased to 80 by 1990 (Barnes 1991: 6). Disabled activists developed a range of innovative user-led initiatives, including a national network of telephone Disability Information and Advice Lines (DIAL) (Davis 1981), integrated accessible housing schemes for disabled and non-disabled residents (Davis and Woodward 1981) and direct payments to enable disabled people to employ personal assistants (HCIL 1981).

In a paper inspired by a 'social barriers model of disability', Ken Davis describes how the DCIL implemented a comprehensive 'operational framework' for service support based on seven needs and priorities formulated by disabled people. These included information, peer counselling and support, accessible housing, technical aids and equipment, personal assistance, accessible transport and access to the built environment (1990: 7). By the turn of the decade there were at least 85 user-led CIL-type organisations offering or aspiring to offer these and other services for disabled people and their families (Barnes and Mercer 2006).

The politicisation of disability also prompted the emergence of a burgeoning disability culture and arts movement. This includes disabled artists, musicians, poets and film-makers. The general aim is to give expression to the experience of living with impairment in a disabling society and to help to generate a celebration of difference and a positive disabled identity (Sutherland 1997, 2006; Peters 2000; Swain and French 2000). The social model was also central to the development of disability equality.

These activities generated an expanding literature produced mainly by disabled writers. A key factor was the establishment in 1986 of the first international journal devoted exclusively to disability issues, *Disability, Handicap and Society*, which was renamed *Disability & Society* in 1993. Disabled researchers inspired by social model thinking produced ethnographic accounts of coming to terms with impairment and disability. Examples include, Morris (1989) and Barnes (1990). Building on UPIAS's insights and Finkelstein's (1980) account of the link between capitalism and the emergence of the disability category, Oliver produced the first comprehensive materialist theory of disability in 1990 entitled *The Politics of Disablement*. The following year BCODP produced *Disabled People in Britain and Discrimination: A Case for Anti-Discrimination Legislation* (Barnes 1991) to bolster its campaign for an anti-discrimination law.

Social model thinking was instrumental to the development of Disability Equality Training courses devised and presented by disabled people. Primarily aimed at professionals and practitioners, these courses focus on environmental and social barriers to generate possible solutions (Gillespie-Sells and Campbell 1991). These courses differ from Disability Awareness Training, presented by non-disabled professionals, which tends to reaffirm disability as an individual problem through the use of simulation exercises (French 1996).

The year 1991 also heralded the emergence of a new approach to doing disability research founded on social model principles that placed disabled people and a social model approach at the centre of the research process – emancipator disability research (DHS 1992). Thereafter, a host of studies appeared focusing on a range of disability issues and conducted mainly by disabled researchers. Examples include disabling imagery and the media (Barnes 1992; Hevey 1992; Cumberbatch and Negrine 1992), ageing and disability (Zarb and Oliver 1993), direct payments and personal assistance (Oliver and Zarb 1992; Barnes 1993; Zarb and Nadash 1994), independent living (Morris 1993), ethnicity and 'race' (Begum 1992; Begum *et al.* 1994), sexuality (Shakespeare *et al.* 1996), parenting (Wates 1997) and employment (Roulstone 1998).

All of this has had a major influence on disability policy. In 1992 the British government acknowledged for the first time that disability discrimination was a major problem and three years later the Disability Discrimination Act became law. In 1996 the Community Care (Disabled Persons) Act allowed local authorities to offer direct payments to disabled people. Hitherto, this was technically illegal under the 1948 National Assistance Act (Zarb and Nadash 1994). The Disability Rights Commission (DRC) was established in 2000 and employed a social model definition of disability (DRC 2002). The government formally adopted a social model definition in its 2005 report entitled *Improving the Life Chances of Disabled People* (PMSU 2005). Social model rhetoric – if not policy – is now clearly evident in the publications of a host of agencies dealing with disability and related issues in both the statutory and voluntary sectors across the UK (Oliver and Barnes 2006; Shakespeare 2006; Barnes and Mercer 2010).

Social model thinking is also evident in policy statements and documents at the international level. In 1993 the UN produced the *Standard Rules on the Equalization of Opportunity for People with Disabilities*. This document outlines a radical programme for governments to follow in identifying and securing equality for disabled people (UN 2003/2004). The UN's Convention on the Rights of Persons with Disabilities and its Optional Protocol were adopted in December 2006. Negotiated over eight sessions attended by an ad hoc committee of the General Assembly, including representatives of disability organisations, it marks the first human rights treaty of the twenty-first century. With 50 articles, the Convention is the most comprehensive document ever to be produced on the rights of disabled people (UN Enable 2009). The European Union sanctioned the social model of disability in its policy Action Plan of 2003 (Commission of the European Communities 2003: 4).

A social model perspective played a key role in 'Rethinking Care from Disabled People's Perspectives', sponsored by WHO's Disability and Rehabilitation Team. This was a two-year project and conference supported by the Norwegian government that involved professionals, disabled people and their families from all over the world (WHO 2001). Furthermore, WHO's recent International Classification of Functioning and Health (ICF), which replaced the much maligned ICIDH, also claims to incorporate social model insights in its construction (WHO 2005). While there is not the space here to provide an extensive critique of the ICF, it suffices to point out that it is a three-tier construct, albeit with different terms for disability and handicap – 'activity' and 'participation', respectively – and founded on Western notions of 'scientific' medicine and normality. Furthermore, the ICF is presented as apolitical and acknowledges the role of the environment in shaping our understanding of disability. Yet the inference that impairment is the main cause of disablement is clearly retained in its title: the 'biopsychosocial' model of disability (Barnes and Mercer 2010).

In addition, due to the critique of its activities from disabled people and the organisations that represent them (Hurst and Albert 2006) and the appointment in 2004 of Judy Heumann, a key activist in America's disabled people's movement as principal adviser on disability and development (Coleridge 2006), the World Bank has since adopted a policy of 'mainstreaming disability' in all its programmes. In 2007 it published its *Social Analysis and Disability: A Guidance Note*, which 'offers a practical guide to integrating social analysis and disability inclusive development into sector and thematic projects and programs of the World Bank' (p. 1).

However, although this document focuses on the importance of disability rights and institutional change, the guidelines presented therein are not binding. Their impact depends on various factors including the project or programme, local context and, most importantly, 'available resources' (World Bank 2007: 2). These must come from other sources such as international non-governmental organisations, non-governmental organisations and charities. The Bank is neither a charity nor a human rights organisation. Its policies are determined by a neoliberal/capitalist philosophy that strongly upholds the interests of big business and transnational corporations. Its primary function is to provide loans for economic development, which have to be repaid (Yeo 2005).

Moreover, many governments, as diverse as those of the United States and the People's Republic of China, have employed social model rhetoric to introduce policies to secure disabled people's rights (Doyle 2008). Yet these policies have had only a marginal impact on the growing numbers of people labelled disabled in both rich and poor countries alike (Charlton 1998; Albert 2006; Chen and Ravallion 2008; Inclusion Europe 2008; Sheldon 2010). All of the above raises important issues for the growing number of academics and researchers engaged in disability studies.

## The social model and its discontents

Since the 1980s there has been an unprecedented upsurge of interest in the general area of disability among social scientists in universities and colleges around the world. This has sparked an increase in the number of journals dealing with disability issues and networks of researchers studying disablement from a variety of academic disciplines. Disability studies is now an internationally recognised academic discipline, supported by courses, research centres and professorial chairs (Barnes *et al.* 2002a). This is to be welcomed as it raises the profile of disability issues in colleges and universities – the seedbeds for tomorrow's politicians, policymakers and professionals. Owing to this heightened interest, a number of important challenges to social model thinking have perhaps inevitably emerged which raise concerns about the discipline's future direction and role in society.

As indicated earlier, theoretical analyses of disability in the UK and the United States are rooted in the political activities of disabled people in the 1960s and 1970s. The American approach, however, differed from that of the UK in that it was dominated by professional academics and adhered to a conventional functionalist/deviance analysis commensurate with American ideology and culture – 'radical consumerism' and 'independent living' (De Jong 1979). By way of contrast, the foundations for a more comprehensive and radical social model-inspired materialist analysis were laid by disabled activists from outside the academy (Barnes *et al.* 2002a).

This perspective is still prominent within the disability studies agenda in the UK and elsewhere (Charlton 1998; Gleeson 1999; Hahn 2002). However, its significance has been seriously undermined over recent years by the emergence within the social sciences generally and disability studies in particular of postmodernist/structuralist perspectives. Since the coming to power of right-of-centre governments in America and in the UK in the 1980s and the collapse of Soviet-style communism, there has been a gradual but significant de-radicalisation of the social sciences generally and a retreat from radical theories which pose a direct challenge to a capitalist neoliberal world view (Harvey 2010).

This finds expression in disability studies in the United States and Canada in the work of Davis (1995), Mitchell and Snyder (1997), Thomson (1997, 2006) and Tremain (2002, 2005), and in the UK and Europe the writings of Corker and Shakespeare (2002), Shakespeare and Watson (2002), Shakespeare (2006), Kristiansen *et al.* (2009) and Goodley (2011).

In sum, these approaches shift attention away from the primacy of economic forces in the creation of disablement towards a politically benign focus on culture, language and discourse. While some studies acknowledge that cultural responses to impairment were transformed with the onset of industrialisation and non-disabled 'normalcy' (Davis 1995), the focus is on the role of discourse rather than the economy and associated ideologies. Constructions of the body rather than the economic and social relations of capitalism are prioritised. Standards of physical health, mental balance and moral soundness are closely linked, so that defective bodies and minds are associated with 'degeneracy' (Young 1990) and social anxieties (Thomson 1997, 2006). 'People with disabilities' are therefore recast as a disadvantaged minority in the tradition of American politics and writings (Hahn 2002).

The postmodernist rejection of a 'modernist' world view, 'grand theorising' and associated conceptual dualisms generated a critique of the social model and the impairment/disability distinction upon which it rests (Tremain 2002, 2005; Shakespeare and Watson 2002; Shakespeare 2006). These arguments are fuelled by disabled feminists' early assertions that impairment-related experiences must be included in disability theorising (Morris 1991; Crow 1996), and that the removal of barriers will not solve the problems encountered by all disabled people because of the complexity and severity of particular conditions (French 1993; Thomas 1999). All of these writers have subsequently acknowledged the importance of a social model analysis. For example, Jenny Morris stated that:

> The social model of disability gives us the words to describe our inequality. It separates out [disabling barriers] from impairment (not being able to walk or see or having difficulty learning). … Because the social model separates out disabling barriers and impairments, it enables us to focus on exactly what it is which denies us our human and civil rights and what action needs to be taken.
>
> *(2002: 1–3)*

Even so, the social model as advocated by UPIAS and as evidenced in the writings of Finkelstein (1980) and Oliver (1990), among others, is criticised for generating a grandiose theory that excludes important dimensions of disabled people's lived experience and knowledge. Critics and former advocates, such as Shakespeare and Watson (1997) for example, argue that the social model is an outdated ideology as the impairment/disability division upon which it rests is difficult to sustain and its emphasis on barrier removal is unrealistic.

However, to claim that the impairment/disability distinction is false is to suggest that the division between the biological and the social is false. While such assertions may be of interest to philosophers and some social theorists, they have little, if any, meaningful or practical value in terms of research, policy and practice. Besides helping to fuel further criticism of social model-inspired writings by medical sociologists (Bury 1996, 2000; Williams 2003), they serve only to re-enforce within policy circles the traditional bias for 'changing the person rather than changing the world' (Bickenbach 2009: 110).

To reiterate: in the social model the impairment, disability dichotomy is a pragmatic one and does not deny that some impairments limit people's ability to function independently. Nor does it deny that disabled people have illnesses at various points in their lives and that appropriate medical interventions are sometimes necessary. Most people experience illness at various stages of the life course (Priestley 2003). Impairment is a common occurrence often due to environmental and social causes (WHO 1999, 2002). How people deal with impairment – whatever its cause and severity – is determined in many ways by their access to a range of social and material resources. The fact that an increasing number of people with impairments do not have access to these resources in both rich and poor nation-states alike is largely due to the globalisation of a particular materialist world view that prioritises the pursuit of profit over equality and social justice.

Whilst postmodernist accounts reaffirm the importance of the cultural in the process of disablement, they downplay the material reality of disabled people's lives. They provide no meaningful insight into how the problem of institutional disablism might be resolved in either policy or politics. Indeed, if the postmodernist denial of the impairment/disability distinction is accepted then disability activism and politics are rendered inconceivable and 'Impaired people might as well lie down to the discrimination and exclusion that disables their lives' (Hughes 2005: 90).

As the problems with postmodernism have become overt some disability theorists have turned to a critical realist perspective similar to that favoured by medical sociologists. Shakespeare, for instance, argues that this is 'the most helpful way of understanding the social world, because it allows for complexity' (2006: 55). This enables him to justify an allegiance to the ICF and to a 'relational' understanding of disability promoted by researchers in Nordic countries (see also Watson 2010 and Goodley 2011).

However, such arguments fail to address Williams's assertion that a critical realist approach stands in marked contrast to recent developments in disability theory, and postmodernist thinking in particular, as a basis upon which to fashion 'health care "fit" for the 21st century' (1999: 815). It is notable too that in Nordic states welfare and educational policies continue to rely on medical and psychological interpretations and labels. Research is essentially top-down, apolitical and often concerned with defining and measuring impairment with reference to impairment-specific groups such as those with 'learning disabilities', for example, rather than to oppression or discrimination (Tøssebro and Kittelsaa 2004; Soder 2009). Consequently, discrimination and oppression remain largely unchecked (Gustavsson 2004; Kristiansen and Traustadottier 2005; Inclusion Europe 2008).

Moreover, the shift in emphasis away from a social model focus on structural forces has important implications for disabled people, their families and indeed the general population in both wealthy and poor countries alike. Since the coming of capitalism, inequality within and across nation-states has escalated. This has been exacerbated in recent years by a succession of deepening global economic crises. These have fuelled long-standing concerns over environmental decay due to unregulated industrial development and its implications for a sustainable food supply in light of an unprecedented expanding global population (Harvey 2010). Consequently, as we move further into the new millennium economic and political stability in all countries is likely to become increasingly fragile and the struggle for a fairer and inclusive global society more difficult (Barnes and Sheldon 2010). Social model insights have provided a theoretical and practical framework with which to explore and address these concerns. To ignore these achievements is to usher in the demise of disability studies and its relevance to disabled people, their families and the population as a whole and the struggle for a fairer and just society.

## Final word

This chapter has focused on the various forces that have shaped what is generally referred to as the social model of disability. The combination of political activism and scholarship has helped to generate a shift in perceptions of disability both nationally and internationally. Disability is now regarded in policy circles as not simply a medical issue but also a human rights concern. A major catalyst for this development has been the social model emphasis on the material and structural causes of disabled people's disadvantages. This has led to the introduction of numerous legislative measures and policy initiatives to address the various economic and social deprivations encountered by disabled people around the world.

Yet these policies have had only a marginal impact on the everyday experience of disablement, and the majority of disabled people remain the poorest in all societies. And given the unprecedented economic, environmental and demographic challenges that lie ahead, this situation is likely to get worse before it gets better, if it does at all. Consequently, now more than ever we need to build on the insights of the social model and uncover the reasons why the policies to address disablism have been unsuccessful, and so contribute to the ongoing struggle for change. To shy away from this task and to focus instead on abstract and obscure theorising that has little or no relevance beyond the sterile confines of university lecture theatres and seminar rooms will almost certainly usher in the demise of disability studies as a credible and meaningful academic discipline (Sheldon 2006).

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# 3

# CRITICAL DISABILITY STUDIES

## Rethinking the conventions for the age of postmodernity

*Margrit Shildrick*

As one of the newer disciplines in academia, disability studies has seen a remarkable expansion and development in little more than two decades that has moved it decisively away from the rehabilitation studies that previously marked its effective limits to the status of an interdisciplinary subject that is as much at home with theory as with pragmatic solutions. It has become one of the fields in which new ideas have evolved most rapidly, suggesting the kind of changes in ways of thinking that can have significant material effects on the everyday reality of people with disabilities. In recent years, the powerful emergence of what has come to be called critical disability studies (CDS) has added new force to the theoretical impetus already at the heart of the social model, taking it in innovative directions that challenge not only existing *doxa* about the nature of disability, but questions of embodiment, identity and agency as they affect all living beings. As I understand it, CDS is of crucial importance to scholarship as a whole. Just as feminism, postcoloniality and queer theory have all successfully pushed out the theoretical boat, CDS is now the academic field to watch. What is exciting about each of those areas is that they have forced us to rethink everything. It is no longer a case of just 'adding on' women or ethnic minorities to a pre-existing syllabus; the task is to ask how that changes our understanding of society in general. In the same way, a course on the philosophy or sociology of the body, for example, cannot simply consign disability issues to week nine of an academic term, because any thoroughgoing consideration of the anomalous body introduces yet another arena of difference which once investigated has the capacity to change how we think about all sorts of other things. In short, our understanding of *all* bodies is affected once we take the difference of disability into account. CDS emphatically cannot be sidelined, then, as primarily the concern of those with disabilities. Insofar as each of us, however we are embodied, is complicit in the construction and maintenance of normative assumptions, CDS challenges every one of us to rethink the relations between disabled and non-disabled designations – not just ethically as has long been the demand, but ontologically, right at the heart of the whole question of self and other.

My own involvement, working in and writing on disability studies on and off for about the last 15 years, has largely deployed what I term a postconventional analytic, which may seem somewhat unfamiliar to those who understand disability in terms of issues like rights, or who use the social model of disability as a starting point. The move towards postmodernism in CDS is often met with external scepticism, but just recently it has felt as though this is now the area in which some of the most exciting new theoretical work is being done. The point is to deliberately shake up some of our assumptions about disability and its historical antecedents by employing critique, not just as a way of challenging external forces, but as a method that contests the apparent verities of disability studies itself. It is Judith Butler, I think, who best captures the exciting opportunities that are mobilised by the use of critique in disability studies:

> What [critique is] really about is opening up the possibility of questioning what our assumptions are and somehow encouraging us to live in the anxiety of that questioning without closing it down too quickly. Of course, it's not for the sake of anxiety that one should do it … but because anxiety accompanies something like the witnessing of new possibilities.
>
> *(Quoted in Salih and Butler 2004: 331)*

Butler, of course, has a reputation of being too difficult – too postmodernist, too abstract – to be of much use in the substantive field of disability, but what I want to suggest is that her approach, and that of other postconventional thinkers like her, offers a new productive way of thinking that has significant material application. We ignore the developments of postconventional theory and the changing environment of postmodernity at our peril – not because older models of understanding (notably the social model of disability) are wrong and should be replaced, but because we need to maximise the ways in which we can confidently develop our own agenda for CDS. In moving away from practice-based rehabilitation studies, disability studies – together with disability activism – has already made huge advances. But the issue I want to consider is whether sociopolitical gains and an increased understanding of the history and material conditions of disability are sufficient to the extent that it could be said that there is nothing more to be done. My claim is not that the postmodernist enquiry of CDS could ever provide final answers, but that, as Butler indicates, the work of critique is to keep alive the very process in which questioning itself generates new potential.

The initial question that must concern all those engaged with disability issues is why in the era of postmodernity, when multiple geopolitical insecurities are writ large and our individual expectations of the future are at best ambivalent, the societies of the global north should be so unsettled by non-normative forms of embodiment. As I put it elsewhere, '[f]or such anxieties to persist in the face of apparently more weighty global concerns speaks not to an over-investment in the local and individual, a kind of displaced anxiety even … but to the extraordinary significance of human corporeality' (Shildrick 2009: 1). What is striking in such societies is that the continuing discursive and material exclusion of disability coexists with concerted – and often effective – programmes of change that move towards the *formal* integration of disabled people into the standard rights, obligations and expectations of normative citizenship. To be perceived as differently embodied, however, is still to occupy a place defined as exceptional, rather than to simply be part of a multiplicity of possibilities. Despite the endlessly differential forms of human embodiment, the dominant discourse continues to mark some people – but not others – as inherently excessive to normative boundaries. Rather than simply continuing to base interventions on exploring *how* this happens, we should try to understand *why* – what it is that underlies and motivates the move to exclude others – and that will entail utilising and, where necessary, pushing to new limits all sorts of theoretical resources that take apart discourse as well as practice.

My contention is that disabled people[1] continue to be the targets of widespread discrimination, oppression and alienation, not so much for their differences (both visible and hidden), but because their performativity of embodied selfhood lays bare the psychosocial imaginary that sustains modernist understandings of what it is to be properly human.[2] Perhaps the very notion of 'properly human' alone should give pause for thought, for that designation is precisely one that is increasingly contested in the era of postmodernity. Nonetheless, given the challenged but enduring influence of the modernist logos, we should note that the valued attributes of personhood are autonomy, agency – which includes both a grasp of rationality and control over one's own body – and a clear distinction between self and other. Clearly, then, any compromise of mental or physical organisation or stability, any indication of interdependency and material connectivity, grounds – for the normative majority – a deep-seated anxiety. The consequence, as we see in substantive effects every day in the lives of those who are anomalously embodied, is that difference is made other, rejected and devalued by those who are able to broadly align themselves with the illusory standards of the psychosocial imaginary. As such it is easier to see that the conventional demands for an extension and solidification of rights for disabled people, and for a more inclusive culture, fall short of a more radical move that would shake up not just law, policy and sociocultural relations, but would contest the very nature of the standards that underpin their normative operation. In order to move forward, it is necessary to investigate more deeply what it is that continues to impede the evolution of equitable conditions of possibility.

Such a mode of thinking marks what is often termed critical disability studies, a relatively recent development that is broadly aligned with a postconventional theoretical approach.[3] Its purpose is both to extend into new territory the existing achievements of more modernist paradigms of disability like the social model, and where necessary to productively critique the limitations of such models. While CDS should never lose sight of its own history, it must consciously engage with all the theoretical resources available to it, whether drawn from feminism, postmodernism, queer theory, critical race theory or long-established perspectives like the phenomenology of the body and psychoanalysis. Such committed interdisciplinarity in a postconventional vein is still relatively unexplored in published work, particularly in the United Kingdom, where the social model has long held sway. However, there are signs that it is beginning to open up. The way forward was partly evident in Corker and Shakespeare's edited collection *Disability/Postmodernism* (2002), which consciously set out to introduce new ways of thinking about the disabled body. Although not fully transdisciplinary, the book offered a whole-hearted endorsement of the value of, at least, a soft postmodernist lens in understanding the status, meaning and practices of disability. In the preceding years, many individual scholars had been developing their own contestation of the modernist paradigms that underlay disability studies, but the new collection represented a radical shift that greatly increased the range of critique while enthusiastically engaging with new theoretical models more suited, perhaps, to the fast-changing landscape of the twenty-first century. More recently, Dan Goodley's book *Disability Studies* (2011), which provides an introductory overview of the whole field that takes on board a much broader critique than usual, has made the case for non-specialists, while my own work – and especially *Dangerous Discourses* (Shildrick 2009) – attempts to stir up the interlinked issues of sexuality and subjectivity in the terms of such discourses as Lacanian psychoanalysis and Deleuzian assemblages. In turning to what I class as postconventional approaches, the elements to stress are a new focus on the significance of embodiment; an awareness of the workings of the cultural imaginary; a deconstruction of binary thought in favour of the fluidity of all categories; and a recognition that emotion and affect are as important as the material aspects of life.

Before looking into those aspects more closely, it is instructive to ask what comprises the category of disability, which marks out one major contemporary location of what I have referred to as anomalous embodiment (Shildrick 2002). Although some form of definitive answer is often called for, and is given, it is one that those working within a postconventional framework are particularly reluctant to provide. The setting out of any fixed parameters or definitional boundaries has long been resisted by disability scholarship as unnecessarily reductive – and perhaps only the medical model has attempted such a categorisation – but for recent theorists, the demand appears to speak to a desire to close down and thus normalise what otherwise remains a shifting nexus of both physical and mental states that resists final domestication.[4] What qualifies as a disability in any case varies greatly according to the sociohistorical and geopolitical context, and even in a single location the designation remains stubbornly multifaceted and resistant to definition in terms of both its boundaries and meanings. As is clear from Rosemarie Garland Thomson's summary of just some of the considerations, conventional binary thinking – either this or that – cannot capture the rich interweaving of bodily states that constitute a more nuanced approach to the question of difference:

> Disability is an overarching and in some ways artificial category that encompasses congenital and acquired physical differences, mental illnesses and retardation, chronic and acute illnesses, fatal and progressive diseases, temporary and permanent injuries, and a wide range of bodily characteristics considered disfiguring, such as scars, birthmarks, unusual proportions, or obesity. … The physical impairments that render someone 'disabled' are almost never absolute or static; they are dynamic, contingent conditions affected by many external factors and usually fluctuating over time.
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> *(1997: 13)*

For all its complexity, Garland Thomson's list outlines solely physical as opposed to cognitive developmental disabilities. Moreover, what further and necessarily complicates the picture are the many other intersectional concerns – such as those of ethnicity, age, class, sexuality, gender and more – that impact on the experience and significance of any disabled state.

The self-evident reality of such complex variations, nonetheless, has not prevented the kind of reductive universalising approach that speaks of disability as a single classification, although to a certain extent – where the simplification is internal to disability politics rather than imposed from the outside – there might be some strategic justification. In order to make the strong point that those with disabilities are 'othered', reference must clearly be made to the binary structures that support all modern societies in the global north. For that reason, 'the contestation of ableist attitudes, values and politics will often set aside intricate differential considerations in the face of strategic necessity' (Shildrick 2009: 3). The apparent strength to mount a sociopolitical challenge to existing normativities often resides in the extent to which an identity politics is adopted, signalling a self-defined and unified group identity and the capacity to voice a common cause, even at the expense of marginalising actual internal differences. A period of identity politics is heavily associated with most movements that stand up against the mainstream, and real changes are often procured; the drawback is that minority interests within – unconventional forms of sexual expression for example – are once again silenced. As Donna Haraway reminded feminists facing similar problems, the 'dream of a common language … of perfectly faithful naming of experience, is a totalizing and imperialist one' (1991: 173). What she recommended in place of identity politics was the pursuit of temporary and partial affinities, ad hoc alliances that would give leverage to sociopolitical claims without solidifying and policing the reductive coils of sameness and difference. The very diversity of disabilities demands a similarly sensitive temporal approach that recognises broad overlapping interests but refuses the putative safety of naming oneself as a member of a fixed and bounded category. Speaking of disability in theoretical terms, then, must both respond to, and critique, the power and simplicity of binary thinking. To postmodernist thinkers, the dominance of the binary may be based on an illusion, but its operation is all too real. What matters is that we recognise that the essential challenge to the damaging *effects* of oppositional binaries is not the limit of what is either possible or necessary. Indeed, Haraway herself, although not writing about disability as such, indicates an alternative way forward based precisely on the extravagance of corporeal possibility. She writes:

> How can our 'natural' bodies be reimagined – and relived – in ways that transform the relations of same and different, self and other, inner and outer, recognition and misrecognition into guiding maps for inappropriate/d others? And inescapably, these refigurings must acknowledge the permanent condition of our fragility, mortality, and finitude.
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> *(Ibid.: 3–4)*

The issues at stake here are twofold and are ultimately related. The first is that while most of us who are concerned with disability studies may already have an enriched understanding of the multiple subdivisions of human morphology, the further point is that the parameters around all and any types of embodiment – and not just disabling conditions – are in any case uncertain. In the postconventional approach, all putative categories are slippery, unfixed, permeable, deeply intersectional, intrinsically hybrid and resistant to definition. Second, while recognising that what exactly constitutes the 'otherness' of those assigned to the category of disability is hard to identify, we should remember that the binary distinction between disabled and non-disabled is itself vulnerable to deconstruction. Lennard Davis (2002), for example, catches one highly significant aspect of the issue when he points to the instability of disability as 'a subset' of the wider instability of all identities in the era of postmodernity, while Henri-Jacques Stiker points out that the disabled 'are the tear in our being that reveals its open-endedness, its incompleteness, its precariousness' (1999: 10). In short, although the boundary that separates those who count as able-bodied from those who are marked as disabled is deeply influential and taken for granted in modernist thought, neither of those terms is as self-evident as it appears. Indeed, I would argue that the separation and distinction between diverse forms of embodiment is at best an expediency, and at worst a violent imposition of epistemic and/or material power. The challenge of such a view is that it undermines the seductive lure of identity politics that has seemed to offer the most socio-political impact, not least to disability activism. By complicating the liberal humanist claim that, like other identifiable oppressed groups, disabled people should simply be afforded the same rights and benefits enjoyed by mainstream members of their society, critical theorists acknowledge the notion of multiple irreducible differences, as well as the indistinction of boundaries in a way that problematises the whole notion of categorical clarity. In other words, the status of both disabled and able-bodied designations is at best provisional rather than marking a fixed identity.

At a superficial level, it is a truism that any individual may experience unexpected accidental trauma, the loss of capacity through illness, or simply the processes of ageing that can result in any one of us crossing the boundary between one category and another and acquiring the label of disability. The use of the term 'temporarily able-bodied' to express this insight has become ubiquitous in disability discourse. Nonetheless, I find such an explanation of the limits of the central binary of disabled and non-disabled deeply inadequate, and scarcely likely to shake the epistemic certainty with which that binary is habitually deployed. It is more important to uncover the imbrication *within* difference that destabilises the normative notion that there is a clear distinction between forms of embodiment. The issue, for me, is not only that the mainstream model of temporarily able-bodied can only envisage an individual *falling away* from what remains a dominant, normative standard, but that it shows no recognition of either the material or psychic intercorporeality that underlies our relations with others. If we ask why disability should be so unsettling, so productive of anxiety, it is surely because it speaks not to some absolute difference between the experience of disabled and non-disabled forms of embodiment, but rather to a deeply disconcerting insinuation of commonality. Stiker puts it at its most provocative and personal when he comments that 'Each of us has a disabled other who cannot be acknowledged' (1999: 8). Or as Thomas Couser notes, 'Part of what makes disability so threatening to the non-disabled then may be precisely the indistinctness and permeability of its boundaries' (1997: 178). As poststructuralism has made clear, the modernist confidence in the separation of self and other cannot hold.

The point arising from such an analysis is that, while there may be a strategic necessity to do so, it cannot suffice to put in place formal structures of equality in order to ameliorate the discrimination and oppression that disabled people face worldwide. This is not to deny that many pragmatic aspects of living with a disability can and do benefit from an approach focused on changes in law and social policy, but rather to draw attention to the limits of the equality model in terms of both the embodiment of difference and the anxiety that disability is so clearly capable of generating.[5] In consequence, I have reservations about the efficacy of the social constructionist model of disability (SMD), and believe that an investigation into both the phenomenological experience of the disabled body and into the psychosocial dimensions of what mobilises normative exclusions would yield a deeper understanding of the issues at stake. To summarise briefly, what the SMD importantly insists on is that the major 'problem' of disability is located not in the marginalised individual but within the normative structures of mainstream society. In relatively recent years, the North American and the UK disability movements have decisively rejected the biomedical discourse of disability as an individual pathology of physical or cognitive development and have embraced an understanding that the condition is socially constructed. The determined promotion of the SMD has resulted in considerable material gains for disabled people insofar as many countries have passed dedicated legislation that undercuts discrimination and undoubtedly leads to a more inclusive organisation of social life. While grounding a revalorisation of people with disabilities, however, the changes do not necessarily contest the underlying attitudes, values and subconscious prejudices and fears that are the basis of a persistent, albeit often unspoken, intolerance. In other words, in the psychosocial imaginary, morphological imperfection is still disavowed. The response, then, must go beyond simply extending the *formal* framework in which disabled people can maximise their status as good citizens of the neoliberal polity, but must seek ways of first critiquing and then transforming the nature of those entrenched in it and scarcely acknowledged obstacles to fundamental change. Insofar as each of us – whatever our individual form of embodiment – is complicit in the maintenance of the psychosocial imaginary, what is required is both a recognition of just why disability appears so threatening to the normative majority, and a re-imagining of the potentialities of bodily difference. Whether we choose to focus on who is to count as a subject or on something like the experience of sexuality, the ethical task is to mobilise both discursive analysis and substantive intervention, each of which can demonstrate the capacity of disabled embodiment to perform a radical queering of normative paradigms.

What, then, are the implications of such a perspective? The identification of any disruption to the perceived stability of normative expectations both mounts a direct challenge to the attitudes and values of mainstream society *and* constitutes a critique of the model of disability politics that primarily sets out to reform what is identified as an oppressive external social structure. What CDS intends is to unsettle entrenched ways of thinking on both sides of the putative divide between disabled and non-disabled, and to offer an analysis of how and why certain definitions are constructed and maintained. Given that none of us stand outside the discursive conventions of our specific time and place, this is no simple task; whatever our relation to disability, we are all deeply influenced at both the conscious and subconscious level by a characteristically modernist conception of the world. It is as though all knowledge and experience were grounded in binary opposites that would unproblematically figure a sociopolitics of inclusion or exclusion, and that identification with one category rather than the other is an inevitable step that requires no further analysis. To be aligned with normative forms of embodiment automatically and *naturally* entitles one to a range of external goods, benefits and advantages, while to be named as disabled signals a marginalisation that can only be countered by the strength of unified resistance and a claim to access that which is denied. The struggle for equal opportunities in jobs, education, transport, and so on, may be stubbornly resisted, but it is one in which the participants on either side of the have/have not divide 'know their place' in the binary hierarchy and can speak and act from it as though the problematic were wholly resolvable at the structural level. The losses and gains from any confrontation may entail some reformulation of categorical assumptions, but the fundamental binary of disabled/non-disabled is undisturbed. As Wendy Brown points out, 'rights are never deployed "freely", but always within a discursive, hence normative context' (2002: 422).

When it comes to experiential and affective issues like subjectivity and sexuality, moreover, it is even less possible to see the problematic in such clear-cut terms. Both areas are highly productive of anxiety precisely because they disorder normative assumptions and generate demands, not so much for structural reform as for a transformation in the meaning of selfhood, not only for those who are anomalously embodied but, by extension, for every one of us. As soon as the other moves beyond simple binary opposition and refuses to stay in place, the implications of change affect the whole relation. By and large, in seeing the negative status of disability as externally based in the discriminatory social procedures, the SMD has been unconcerned with subjectivity, and slow to put sexuality on the agenda. A social constructionist understanding of disability simply assumes that there is some core pre-given subject waiting to be empowered. The argument is where disabled people have been treated in the past as passive objects of concern, rather than as autonomous subjects, the sociopolitical approach will be effective in demanding the recognition of independent agency. But just as feminism has painfully learned to question its own founding assumptions about equality, disability studies also needs to ask whether demands for recognition within the existing system – as though the problem were no more than one of material exclusion – is an adequate response. For poststructuralists, in any case, the subject is no longer seen as a stable, grounding category that can be taken for granted, but as a discursive construction, which indicates that all sorts of epistemic, ontological and ethical claims must be rethought (Shildrick 1997). In similar ways, the notion of sexuality has been problematised by critical cultural and queer theory to the extent that CDS acknowledges the need to complicate the sociopolitical assertion that disabled people have the same rights as others to sexual identity and expression. Given that unmanaged sexuality already has the propensity to threaten the efficient organisation of social relations – a threat greatly amplified in the context of the anxiety-provoking disabled body – then we need to uncover which psychosocial factors are in play and what is the nature of the boundaries that are vulnerable to transgression.

My argument is that all of us – regardless of our own individual morphology – are participants in the sociocultural imaginary that pervasively shapes the disposition of everyday attitudes and values – and we all therefore have a responsibility to interrogate it. The implication is that the view that only disabled people themselves have a right to speak authoritatively with regard to disability must be rethought. The attraction of standpoint theory is that it openly privileges the lived experience and knowledge of those at the centre of a specific problematic, and gives a voice to those who may previously have been unheard, be they women, black people or people with disabilities. What standpoint theory promotes is a hierarchy of truth telling in which the oppressed uncover a suppressed reality while those who are dominant – effectively historic oppressors of all kinds – speak only a limited discourse that reflects their own ideological interests. This interpretation is partly supported by Foucault's assertion that power does indeed construct a very biased and incomplete form of knowledge but, as he also makes plain (1980), the partiality of discourse does not imply the existence of some absolute truth that could, under the right conditions, be accessed. In contemporary feminist thinking, the implausibilities of standpoint theory have largely led to its demise as a mode of analysis, only for it to reappear in disability theory and practice. Clearly the promotion of voices that have been historically subjugated – what Foucault calls 'the great anonymous murmur of discourses' (1989: 27) – is a good thing, but not to the extent of claiming a categorical authority that puts in question the validity of any account proposed by those who are defined as non-disabled. Indeed, I would argue strongly that they are the ones – and I include myself here – who have the weightiest responsibility in the matter, not to speak on behalf of, or to pre-empt the experience of, others unlike themselves, but to interrogate precisely their own cultural and psychosocial location as non-disabled (Marks 1999; Shildrick 2009).

To recap, what I understand by CDS is an approach marked by a true transdisciplinarity and an openness to a plethora of resources that are not commonly seen as being relevant to the concerns of mainstream disability studies. Although to simply conflate our specific parameters of inquiry with other categories of difference, like those of race or gender, would be damagingly reductive, there is, I believe, a sufficient overlap in the respective discursive constructions to justify some corresponding strategic responses. If the aim is critique, then it calls for the utilisation – and sometimes deliberate deformation – of multiple elements of feminist, queer, poststructuralist and postmodernist theory in order to disrupt the conventional meanings of the terms associated with disability, including those of subjectivity and sexuality. Underlying each of those inherently resistant discourses is a retheorisation of the question of difference that entails a radical shift from the modernist privileging of an autonomous and stable self to the postmodernist contention that the self is always embodied, dependent on its others, unsettled, and always in process. To mobilise such a critique signifies not the search for some successor theory, but a way of holding open theoretical conjunctions that are potentially contradictory in meaning and original intent. The goal is not to construct a universal theory, but to position disability as figuring an irreducible provocation to the normative desire, evident in the psychosocial imaginary, for stability and certainty about what it means to be human. The far from modest question that underlies the enterprise of CDS is: what it would mean, ontologically and ethically, to reimagine dis/ability as the very condition of human becoming? The task at the level of embodiment is to explore how and why the disabled *body* – the body that falls outside modernist conventions – already disorders the power of prevailing sociocultural normativities. In place of modernist stereotypes that construct an insidious devaluation of bodily difference, and of disabled people, postconventional theories of embodiment expose the uncertain and vulnerable nature of all forms of embodied selfhood. Where once the post-Enlightenment sovereign subject, who relies on the exclusionary strategies of separation and distinction, seemed secure, the emergence of first Merleau-Ponty's phenomenology and later the theory of performativity have been prominent in showing how the privileging of some forms of embodiment to the detriment of others might be productively disturbed.

My purpose is not to suggest that such disruption is a unique feature of postmodernity, although the particular theoretical framework of postmodernism embraces such disturbance as central to ontological and epistemological knowledge. As both Foucault (2003) and Stiker (1999) have shown, a genealogy of the disabled body will always disrupt the notion of a progressive and sequential development of ideas, and uncover instead a series of contradictory, splintered and non-teleological discourses firmly embedded in particular socio-historical locations. Where mainstream disability studies has relied on a narrative of progressive transformations of meaning – from early Judaic Biblical models of impurity to a dominant biomedical approach that pathologises the disabled body, and more recently to the SMD analysis that has politicised the problematic – CDS works with a far more messy, disorganised and insecure set of indicators. As Stiker shows, we can identify a thoroughgoing governmentality at the heart of policy initiatives – as with rehabilitation programmes or the use of prosthetics – that indicate that they are never as positively progressive as they claim or may seem to be. Like the critical legal theory of Wendy Brown which shows how rights-based claims to equality arising from a liberal recognition of the exclusionary nature of the modernist model of sovereign selfhood are double-edged, holding out material gains only at the cost of assimilation to normative standards, Stiker is fully cognisant of the danger of normalisation strategies that cover over difference. As he notes, 'Paradoxically, [disabled people] are designated in order to be made to disappear, they are spoken in order to be silenced' (1999: 134). His warning has direct relevance to the recent claims to 'sexual citizenship', which have been strongly promoted within disability politics (Shakespeare et al. 1996; Siebers 2008; Rogers 2009). The issue of who counts as a sexual subject is highly cogent insofar as the sexuality of disabled people is both highly regulated *and* invalidated or silenced completely (Shildrick 2009), but it remains to ask whether sexual citizenship is an effective objective. As I understand it, the move neither radically contests nor transforms the current neoliberal understanding of sexuality, but simply attempts to buy into the normative order and thus fails to break with the devaluation of difference.[6]

We must not forget that beyond the insistent operations of governmentality that mark contemporary society, there is also a level of interior, even subconscious meaning given to disability. Where a Foucauldian analysis speaks to the ubiquitous forms of the self/other binary, a more specifically deconstructive approach reveals the other to be an interior element of the embodied self. Consequently, a more nuanced understanding of the materialisation of normative constructions of disability supplements the Foucauldian approach by engaging with the psychosocial elements that constitute the Western imaginary. With specific regard to the pleasure and danger of sexuality and erotic desire, for example, a psychoanalytic approach would ask what part the links between desire, lack and anxiety play in frustrating a positive model of disability and sexuality. Although many disability theorists have been justifiably wary of psychoanalysis and its use as a tool of oppression, others are increasingly turning to it in recognition that the perspective may offer an important and resistant mode of understanding (Wilton 2003; Shildrick 2009; Goodley 2011). At its heart is the conviction that our apparent psychic and bodily integrity is never given, but is an ongoing process, constantly open to disruptions from within in terms of both stable body image and self-identity, and is always risking the irruption of anxiety, especially with regard to sexuality. Building in particular on Lacan's rereading of Freud, which traces the gradual emergence in the Symbolic of a putatively coherent (sexual) subject, we need to ask what has been repressed in order to achieve the illusion of unity and order, and which forms of embodied subjectivity cannot come into being because their antecedents in the Real are already too disruptive? The psychoanalytic approach offers some powerful insights into the sociocultural denial of desire and sexual identity to people with disabilities, and more generally it provides a convincing account of the normative anxiety that surrounds the whole subject of disabled embodiment. As a tool for further understanding normative responses, psychoanalysis is extremely valuable and signals where resistance might lie, but what it cannot fully do is provide a positive model of disability in all its aspects. In that respect, queer theory, and particularly its extension into Deleuzian theory, is considerably more productive.

Contemporary disability scholars such as Tremain (2000), Sherry (2004) and McRuer (2006) increasingly deploy queer theory with the aim of opening up the question of how anomalous embodiment in all its forms can be seen as inherently transgressive. In place of a Foucauldian model of governmentality, or an alternative psychoanalytic model based on the notion of lack – each of which adds to our understanding of the challenge disability makes to normativity – a queer reading of the performativity of desire, especially in a Deleuzian sense, offers an affirmative account of disability. For Deleuze and Guattari (1984, 1987), the concept of desire is greatly extended to encompass its meaning, not just as a component of specifically sexual being, but as an element of *self-becoming* that permeates all aspects of what it means to live in the world. Desire enables a productive positivity that leaves behind the normal/abnormal binary to mobilise instead the ungovernable energies and intensities that emanate from a series of unrestrained and often unpredictable conjunctions. Where other models are engaged with the contested boundaries of self and other, the Deleuzian toolbox facilitates a move beyond conventional distinctions and separations between whole and 'broken' bodies, or between the organic and non-organic. The conditions of possibility are transformed, and one immediate outcome is that neither the disabled body in general nor the prostheticised body are excluded from discourses of pleasure and desire. Rather, the disabled body could be seen as paradigmatic, not of the autonomous subject at the heart of modernist discourse, but of the profound interconnectivity of all embodied social relations. In Deleuzian terms, we are all interdependent, and come together and break apart in unpredictable energies and flows of desire (Grosz 1995; Gibson 2006). To rely on a wheelchair for mobility, a prosthetic limb for balance, or a human assistant for daily tasks, is to be engaged in assemblages that always exceed the individual and his or her capacities. In the era of postmodernity, where the liberal humanist subject is displaced by the posthuman, corporeal variation is an unlikely justification for devaluation or exclusion. The overriding point, however, is that indeterminacy and instability are not unique to the anomalous body but stand as the conditions of *all* corporeality in as much as the finality and integrity of the normative subject are merely features of a phantasmatic structure. As such, the 'disabled' body signals not some exceptional lack or failure, but simply one mode among multiple ways of becoming. Once corporeal integrity loses its privilege in the era of postmodernity, and is seen as no more than a provisional mode of embodiment, then modernist anxieties about non-normative morphology become signs of a pointless nostalgia.

In conclusion, I want to set out some ambitious claims for critical disability theory that highlight its efficacy and even its inevitability. Where feminism, postcolonial studies and queer theory have in the recent past all helped us to think and therefore to act differently, I believe that CDS can now take up that task. Given the widespread oppression of disabled people perpetuated in many societies globally, it is clear that disability poses probing questions about the nature of those societies, not only with regard to their overt organisation but also in terms of their psychosocial imaginaries. The responsibility for enquiry and analysis falls on all those who participate in the relevant structures, and just as racism has been identified as a problem of whiteness, so too must (dis)ableism be addressed both by those who are identified with normative standards, and by those who are excessive to them. By taking on a range of contemporary critical theories and asking what difference they can make to the othering of disabled people, no single perspective is privileged above others. At the same time, whole new areas, like that of sexuality, which had been previously sidelined as politically inessential, have been opened up to scrutiny, and deconstructive inquiry has been directed inward as well as engaging with external realities. As I indicated at the beginning of the chapter, the key to the new scholarship is critique, not in the sense of the destruction of old certainties, but as a bold and risky enterprise that subjects all the conventions to potentially disruptive analyses. This is no empty scholarly game, but a necessary move that recognises that in cases at the limit certain bodies – monstrous bodies and disabled bodies – clearly demonstrate the inadequacy of conventional models of embodied selfhood as self-sufficient and in control. To take the path of CDS and to rethink the operative conditions under the gaze of postconventional critique is bound to generate controversy, but ultimately it is a move of high ethical responsibility.

We are left, then, with an important ethical question: how can we engage with morphological difference that is not reducible to the binary of either sameness or difference?[7] What should be the response to those who cannot be assigned to either the category of those others who are absolutely not like us, or to the category of those who can be reclaimed or normalised, or made more like us. As long as the anomalous body remains the absolute other, it is so distanced by its difference, its not-me-ness, that it poses no threat. However, once it begins to resemble those who lay claim to the primary term of identity, or to reflect back aspects of ourselves that we do not usually acknowledge, then its indeterminate status – as neither wholly self nor absolutely other – becomes deeply disturbing. If we are to have an ethically responsible encounter with corporeal difference, we need, then, a strategy of queering the norms of embodiment, a commitment to deconstruct the apparent stability of distinct and bounded categories. We need to remind ourselves that the embodied self is always vulnerable, and that the normative parameters of the embodied subject as defined within modernist discourse are based on an illusion. Perhaps if there was greater recognition that there is no single acceptable mode of embodiment, and that all bodies are unstable and vulnerable, then rather than being labelled as deficient, the bodies that are further from normative standards could be revalued as simply being different. The way forward is far from clear, but my hope and expectation is that, in its commitment to deepening conceptual frameworks, CDS has begun to engage with just the kind of critical thinking that throws new ontological, epistemological and ethical questions into relief.

## Notes

1 Disability terminology is highly contested, not least regarding the naming of those who putatively occupy the category. The current preference within both CDS, and some but no means all activist circles, is for ‘disabled people’ rather than ‘people with disabilities’, although even then practice may vary between the UK and the United States. The term ‘people with disabilities’ was initially promoted to signal a break with older and more evidently stigmatising terms such as handicapped, retarded, crippled, and so on. Other supposedly more positive designations such as differently abled, physically challenged or special needs have fallen out of favour, and the use of so-called *people-first* language forms is now seen as failing to encompass the significance of disability (Overboe 1999; Titchkosky 2006), treating it as more as a contingent add-on than a fundamental element in the production of identities. Nonetheless, ‘people with disabilities’ remains in widespread use among disabled and non-disabled people alike, and some academic journals make it mandatory. On either side such policing seems unnecessarily divisive, and in any case chases after the illusion of perfect terminology that will not in time become marked by ongoing prejudices and anxieties. Accordingly, although I prefer ‘disabled

person' as more adequate to denoting the process of embodiment, I use its alternative wherever it seems contextually more appropriate.

2 The imaginary is the fictive (non)location where multiple projections and identifications work to shape dominant corporeal, categorical and sociocultural formations. It is the locus in which the so-called normal and abnormal are held apart.

3 See Meekosha and Shuttleworth (2009) for their assessment of the significance of the term 'critical'. It is not entirely clear when the discipline of *critical* disability studies first appeared as such, but certainly York University, Canada, established an MA – and subsequently a PhD – programme in it in 2003.

4 At the time of writing, the UK coalition government was attempting to reverse the gains of recent years and reimpose simple binary – and broadly medicalised – definitions of disability that would better allow its management within a welfare system. In the neoliberal state, the desire to domesticate – and thus eliminate the troublesome excessiveness of morphological anomaly – is reinvigorated in the service of socio-economic governance.

5 See Shildrick (1997) for a fuller analysis of the shortcomings of claiming equality in relation to any oppressed grouping.

6 This critique is more fully developed in Shildrick (forthcoming).

7 Given the hierarchies of difference that operate within disability, where those with physical conditions may feel superior to those with developmental and intellectual disabilities – not to mention the myriad subtle nuances within each form – the question concerns all of us, and not just the normative majority.

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