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UNDERSTANDING THE SOCIAL MODEL OF DISABILITY

Past, present and future

Colin Barnes

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 entered university to study disability. It summarized what I already knew about disability: that people with any form of accredited impairment are disabled by an unjust and uncaring society. It has influenced my work ever since. Subsequently, thinking inspired by the social model has had a major impact on policy circles and universities across 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 of social model 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

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 '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. Whilst 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 institutionalization of discriminatory policies and practices. Industrialization, urbanization, changing work patterns and accompanying ideologies: liberal utilitarianism, medicalization, eugenics and social Darwinism – all 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 then Nazi Government in the 1930s and 40s (Gallagher 1995; Burleigh 1994), there has been a general 'softening' of attitudes in policy circles in wealthy states such as the United Kingdom (UK), Europe and the United States of America (USA). 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 numbers of civilians and military personnel injured during the war. There was also an unprecedented growth in the numbers of disabled and elderly people due to increasing affluence and medical advances. All of this contributed to the politicization of disability by disabled people and their organizations in the latter half of the twentieth century in countries as diverse as Sweden (Hőjer 1951; Nordqvist 1972), the UK (Hunt 1966a; Campbell and Oliver 1996; Barton 2001), the USA (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 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 living in relative poverty and social isolation in the community. 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).

The 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 organizations 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 organization in the history of social model thinking, UPIAS functioned mainly through confidential correspondence and circulars distributed amongst its members. Drawing on personal experience and sociological insights, although none were trained sociologists, UPIAS members 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 (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 (emphasis added).
>
> *(Hunt 1966b: 146)*

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' (p. 146).

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 socio-political 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 therefore socially and politically divisive (Barnes 1996; Oliver and Barnes 1998).

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

Other important developments during the 1970s included increased disability activism in the USA 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 numbers of disabled Vietnam War veterans, to influence US disability legislation. During the 1960s, some American universities had 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 organizations 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 organizations providing 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 MP, 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, article 3)*

Growing interest in disability at the international level led to in 1980 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 (IYDP).

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 UPIAS definition, the stated aim of the ICIDH was to clarify concepts and terminology surrounding disability to facilitate accurate and comparable research and policy within and across nation states (Bury 1997). Designed to complement the 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 bio-physical assumptions of 'normality'. But '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 individualized and medicalized 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, minimized or 'cured'. But where 'cures' are ineffective, which is more often than not 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 comprised of 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 (2000–9), the European Year of People with Disabilities 2003, the Asian and Pacific Decade of Disabled Persons (2003–12) and the Arab Decade of Disabled Persons (2003–12) (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 organization composed of rehabilitation professionals (Driedger 1989: 18). DPI's first world congress was held in Singapore in the following year and attracted 400 delegates representing national organizations run by disabled people from around the world, including representatives of BCODP. As well as adopting a socio-political definition of disability, DPI's stated policy revolves around the promotion of grass roots organizations 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 organizations around the world (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 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 *et al.* 1999; 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 whilst 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*; and 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 degree. A key figure in the development of this course was Vic Finkelstein, a clinical psychologist and founder member of UPIAS. Initially aimed at professionals and voluntary workers, the course's primary objective was to help students improve their 'professional and social skills in order to assist handicapped people to achieve *maximum autonomy*' (emphasis added) (Finkelstein 1997: 41). From the outset the course was criticized for its 'sociological bias' (Finkelstein 1997: 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 re-titled '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 levels 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 America's Society for Disability Studies. At the turn of the 1980s, 12 disability studies courses at various levels were offered in 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 focused on women's experiences of living with impairment in the UK in the 1970s. Oliver's initial aim was to provide an accessible key to understanding the importance of the 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.
>
> *(Oliver 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, whether they be 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 *et al.* 1999; 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 in terms 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' (original emphasis) (Scambler 2004: 29). 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.
>
> *(Scambler 2004: 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 their organizations and 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 mobilization 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 legalize direct payments to enable disabled people to employ their own support workers (Campbell and Oliver 1996). At its inception in 1981, the BCODP had seven member organizations; 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 for disabled people to employ personal assistants (HCIL 1981).

In a paper inspired by a 'social barriers model of disability', Ken Davis describes how 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 (Davis 1990: 7). By the turn of the decade there were at least 85 user-led CIL-type organizations offering or aspiring to offer these and other services for disabled people and their families (Barnes and Mercer 2006).

The politicization 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 help 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*, 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 Oliver *et al.* (1988), 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: *The Politics of Disablement*. The following year the BCODP produced *Disabled People in Britain and Discrimination: A Case for Anti Discrimination Legislation* (Barnes 1991) to bolster their campaign for an anti-discrimination law.

Social model thinking was instrumental to the development of Disability Equality Training (DET) 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). This is in contrast to Disability Awareness Training, presented by non-disabled professionals, that tend to reaffirm disability as an individual problem with 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: emancipatory 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 employing a social model definition of disability (DRC 2002). The Government formally adopted a social model definition in its report of 2005 *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 Equalisation 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 2003/4). The UN's Convention on the Rights of Persons with Disabilities and its Optional Protocol were adopted in December 2006. Negotiated over eight sessions of an ad hoc committee of the General Assembly, including representatives of disability organizations, it marks the first human rights treaty of the twenty-first century. With 50 articles, the Convention is the most comprehensive document yet 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 the 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, the WHO's recent International Classification of Functioning and Health (ICF), which replaced the much maligned ICIDH, also claims to incorporate social model insights into its construction (WHO 2005). Whilst there is not the space here to provide an extensive critique of the ICF, it is sufficient 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 their organizations (Hurst and Albert 2006) and the appointment in 2004 of Judy Heumann, a key activist in America's disabled people's movement as principal advisor 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).

But, although this document focuses on the importance of disability rights and institutional change, the guidelines therein are not binding. Their impact depends on various factors including: the project or programme, local context and, most importantly, 'available resources' (p. 2). These must come from other sources such as international non-governmental organizations (INGOs), non-governmental organizations (NGOs) and charities. The Bank is neither a charity nor a human rights organization. Its policies are determined by a neo-liberal/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 the USA and China, have employed social model-type 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 which raises important issues for the growing numbers 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 amongst social scientists in universities and colleges across the world. This generated a growth 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 recognized academic discipline, with 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 seed-beds for tomorrow's politicians, policy makers and professionals. Perhaps inevitably with this heightened interest, a number of important challenges to social model thinking have 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 USA 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 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-radicalization of the social sciences generally and a retreat from radical theories which pose a direct challenge to a capitalist neo-liberal world view (Harvey 2010).

This finds expression in disability studies in America 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 toward a politically benign focus on culture, language and discourse. Whilst some studies acknowledge that cultural responses to impairment were transformed with the onset of industrialization 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 prioritized. 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 associate 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 theorizing (Morris 1991; Crow 1996), and that the removal of barriers would 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 in 2002:

> 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.
>
> *(Morris 2002: 1–3)*

Even so, the social model as advocated by UPIAS and evident in the writings of Finkelstein (1980) and Oliver (1990), amongst others, is criticized for generating a totalizing grand 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. Whilst 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 the social model impairment, disability dichotomy is a pragmatic one that 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 increasing numbers of people with impairments do not have access to these resources in both rich and poor nation states is due in large part to the globalization of a particular materialist world view that prioritizes 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 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 (1999) assertion that a critical realist approach runs 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' (Williams 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 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 over 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 be 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 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 disadvantage. 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 across 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 on-going struggle for change. To shy away from this task and focus instead on abstract and obscure theorizing 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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