

ONE

Introduction: *Global Disability Studies*

Introduction

Disability studies understand their subject matter as social, cultural and political phenomena. In defining terms, describing positions and laying foundations, we will interrogate the literature in ways that encourage us to think about where we sit/stand in relation to pan-national and cross-disciplinary perspectives on disability that have the potential to support the self-empowerment of disabled people. This first chapter sets the theoretical tone.

The global nature of disability

The word 'disability' hints at something missing either fiscally, physically, mentally or legally (Davis, 1995: xiii). To be disabled evokes a marginalised place in society, culture, economics and politics. It is concentrated in some parts of the globe more than others, caused by armed conflict and violence, malnutrition, rising populations, child labour and poverty. Paradoxically, it is increasingly found to be everywhere, due to the exponential rise in the number of psychiatric, administrative and educational labels over the last few decades. Disability affects us all, transcending class, nation and wealth. The notion of the TAB – Temporarily Able Bodied – recognises that many people will at some point become disabled (Marks, 1999a: 18). Most impairments are acquired (97%) rather than congenital (born with) and world estimates suggest a figure of around 500–650 million disabled people, or one in ten of the population (Disabled-World.com, 2009), with this expected to rise to around 800 million by the year 2015 (Peters et al., 2008). Currently, 150 million of these are children (Grech, 2008) and it is estimated that 386 million of the world's working-age population are disabled (Disabled-World.com, 2009). 88% live in the world's poorest countries and 90% of those in rural areas (Marks, 1999a). For example, India has a population of one billion and approximately 70 million are disabled (Ghai, 2002). A 1987 survey in China conservatively accounted for 51.64 million disabled people (Shen et al., 2008). In the USA, 19.3% or 49.7 million of the 'civilian non-institutionalised population of five years or older' are

disabled (Quinlan et al., 2008). This makes disabled people the largest minority grouping in an already crowded theatre of multiculturalism (Davis, 1995). We know that there are global discrepancies and intra-national differences. There are more disabled people in the Southern hemisphere (Stone, 1999) and you are more likely to be labelled as schizophrenic if you are black than if you are non-black in Britain (Beresford and Wilson, 2000a). Disabled people are more likely to be victims of rape and violence, less likely to receive legal protection, more likely to be excluded from mass education, be underrepresented in positions of power and more reliant on state benefits and/or charity (Meekosha, 2008). As children they remain underrepresented in mainstream schools, work, leisure and communities (McLaughlin et al., 2008). As adults, disabled people do not enjoy equitable access to human, economic and social capital resources (Priestley, 2001). If we accept Marx's view that charity is the perfume of the sewers of capitalism, then disabled people are subjected to the bitter/sweet interventions of charity. Of the 200 or so countries in the world, only a third have anti-discriminatory disability legislation and many of these laws are questionable in terms of their legislative potency (United Nations Department of Public Information, 2008).



Thinking point: Identify, via the Internet, disability-related social policy or anti-discriminatory legislation in your own country. What areas of public life are addressed by these documents?

Disabled people are likely to suffer socio-economic hardship. In rich countries, the expanse of the free market, the proliferation of human, welfare, social, educational services and professionals and the increasing need to be 'intellectually able' and 'physically fit' for work, makes disabled people economically vulnerable (Barnes and Roulstone, 2005). Impaired fetuses are eradicated everyday as a consequence of antenatal tests and reproductive technologies (Kittay, 2006). Alive, people with impairments are ignored, pitied, patronised, objectified and fetishised. Their very presence raises questions about the 'right to die' and 'assisted suicide' (Shakespeare, 2006a). And while impaired bodies and minds have always been part of everyday life, demeaning societal responses to impairment – which we can define as 'disablement' (Oliver, 1990) or 'disablism' (Thomas, 2007) – are historically and culturally relative. Disability studies aim to make sense of this relativity.

The politics of disability

Disabled people have challenged their social exclusion through their politics and disability studies have developed to accompany this politicisation: to assist disabled people in their fight for full equality (Thomas, 2004: 571). Pinpointing the exact origins of disabled people's politics is impossible (Shakespeare, 2006b). We know that over the nineteenth and twentieth centuries, disabled people's experiences of institutions, eugenics and the Holocaust galvanised many to organise collectively against the oppressive regimes of medicine, science and professional control (Wolfensberger, 1981; Barnes, 1991; Noll and Trent, 2004; Longman and Umansky, 2001; Snyder and Mitchell, 2006; Gabel and Danforth, 2008a). The rise of new social movements, such as feminist, queer, working-class and

black civil rights movements in the 1960s, enhanced the radicalisation of disabled people (Boggs, 1996). Disability studies developed, for Meekosha (2004: 724), in similar ways to Women's and Black Studies as a new interdisciplinary sphere of scholarly work. People with intellectual disabilities (previously 'mental retardation') demanded a rethink of their status through pioneering the self-advocacy movement (Goodley, 2000), while survivors of mental health hospitals and services (hitherto 'the mentally ill') demonstrated against psychiatric labelling (Sayce, 2000). Together, disabled people have exposed the material conditions of exclusion magnified through capitalism (Oliver, 1990), while also developing personal and political responses to normalising society (e.g. Morris, 1991, 1992, 1996; Shakespeare et al., 1996). The depth of activism is captured through reference to the (admittedly loose and Anglo-centric) typology adapted from Oliver and Zarb (1989) and Oliver (1990). Historically, disabled people were supported via *patronage* and *charity*, through organisations for disabled people which provide specialist services, consultation and advice from professional agencies (e.g. Royal National Institute for the Blind, Spastics Society). In time, *economic* and *parliamentarian* organisations for disabled people lobbied governments for changes in legislation to protect the rights of disabled people (e.g. Disablement Income Group, Disability Alliance, Disability Rights Commission). Such pressure was enhanced through the expanding *activist* network, where organisations of disabled people campaigned for collective action and consciousness raising (e.g. Direct Action Network, Sisters Against Disablement, Not Dead Yet). As these groups grew, so too did the number of *co-ordinating* organisations of disabled people at (inter)national levels (e.g. Disabled People's International). Disability politics, particularly activist and co-ordinating forms, have been felt by nation states and supranational organisations. The United Nations Department of Economic and Social Affairs (2009) reports how disability was placed on the radar of United Nations' policies and programmes by a raft of developments, including the 1981 International Year of Disabled Persons, the adoption of the United Nations World Programme of Action Concerning Disabled People (1982) and the release of the *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* (1993), all of which set in place systems for the regular collection and dissemination of information on disability and the promotion of disability-focused programmes. National responses are evidenced in the constitution of anti-discriminatory legislation, including the 1990 Americans with Disabilities Act, Disability Discrimination Acts of 1992 and 1995 (in Australia and the UK, respectively) and Malaysian Persons with Disabilities Act (2007). Over the last couple of years, (some) countries have ratified the UN Convention on the Rights of Persons with Disabilities. We have seen growing recognition of the need for inclusive forms of education (www.inclusion-international.org) and support for poorer countries in relation to their disabled members (www.worldbank.org/disability/gpdd). The Decade of Disabled Persons (1983–1992) was a fitting testimony, not simply to a widening participation agenda on the part of nations, but to the growing influence of disabled people's own organisations (Barnes, 2002).

The Disabled People's Movement has revolutionised global understandings of disability. By raising the personal experience of disabled people as the primary source of knowledge and identifying disability as a social problem that should be addressed by socio-political interventions, the Disabled People's Movement has politicised disability (Vehmas, 2008: 21). We can trace many inter/national stories of disability politics. The first Disabled People's International (DPI) World Congress was held in Singapore

in 1981. Organisations came together from their national contexts to work towards a global political response. Since this time DPI has provided an essential hub for the sharing of campaign successes and the raising of transnational issues such as inclusive education and human rights. The historical legacy of the Disabled People's Movement can be found across the globe through the presence of Centres for Independent Living that offer not only services to disabled people, but also work with their struggles for equity (Charlton, 1998; Barnes and Mercer, 2006). We have seen the development of regional organisations such as Asia-Pacific Development Center on Disability (www.apcdproject.org) that responds to local issues facing disabled people in some of the poorest countries, such as community-based rehabilitation, basic literacy programmes and support for families. In rich parts of the world, such as the Nordic countries, Canada and the USA, the Disabled People's Movement has been heavily influenced by the self-advocacy movement organised by people with the label of intellectual disabilities (Williams and Shoultz, 1982). Organisations of the Blind were particularly strong in India, participating in hunger strikes to push for anti-discriminatory legislation (Chander, 2008). Britain saw the establishment of the United Kingdom's Disabled People's Council (formerly the British Council of Organisations of Disabled People), which has grown from the early political impact of organisations such as *UPIAS (Union of the Physically Impaired Against Segregation)* in the 1960s and 1970s (Campbell and Oliver, 1996). On the ground, disabled people's organisations have enacted institutional change through the delivery of disability equality training courses (Barnes, 2002), which seek to educate organisations to adopt more enabling philosophies and practices. This has created a new form of labour for disabled people.



Thinking point: Disabled trainers offer expert advice on eradicating the conditions of exclusion in areas such as education (www.diseed.org.uk; www.openroad.net.au/access/dakit/welcome.htm) and employment (www.breakthrough-uk.com; www.independentliving.org/indexen.html). On personal matters, disabled people have organised around inclusive play and leisure, social and sexual relationships (www.outsiders.org.uk/home). And culturally, disabled people have contributed immeasurably in the areas of arts, literature, music and performance (e.g. www.disabilityartsonline.org.uk/home). Visit these websites. How do you think these organisations have influenced wider ideas around disability?

While a plethora of helping professions have grown around disability, disabled people have themselves had a huge impact on professional, cultural and political life. Disabled people were specifically mentioned in Barack Obama's President-elect victory speech in 2008 and there is a growing historical awareness of their contribution to politics (e.g. Rosa Luxemburg, Antonio Gramsci, Woodrow Wilson) and culture (e.g. Frida Kahlo, Helen Keller, Christopher Nolan, Ian Dury, Kurt Cobain). This book is not the place for a detailed exposition of disability activism (for examples, see instead Chamberlin, 1990; Priestley, 1999; Meekosha, 2002; Barnes and Mercer, 2006; Gabel and Danforth, 2008). What is important to keep in mind is the breadth of disability activism that continues to influence debates within disability studies. The mantra 'Nothing about us, without us' (Charlton, 1998) asks pertinent questions about the ownership of disability studies. Across the globe, the priorities

of disabled people's organisations say much about their nation's (lack of) welfare system, view of the citizen (Dwyer, 2004), cultural ideas around disability (Watson et al., 2003) and the perceived importance of disability in comparison with other socio-economic inequalities (Armstrong et al., 2002).



Thinking point: Blackmore (2009) gathered information from the British Charity Commission for 2007–2008 financial years. All voluntary sector organisations have to complete and submit annual reports by law to the Commission. These annual reports are therefore legally binding and accurate. He found the following figures:

Organisations for disabled people (traditionally charities):

Leonard Cheshire = income £149,655,000; spending £146,046,000; surplus £3,609,000

Mencap = £183,456,000; spending £176,901,000; surplus £9,615,000

Organisation of disabled people (traditionally activist organisations):

UKDPC = income £167,920; spending £187,082; deficit –£19,162

People First = income £288,236; spending £274,197; surplus £14,039

What do these figures say to you about the contemporary status of charity and patronage in the lives of disabled people in Britain?

Defining disability: from pathology to politics

Official definitions of disability reflect the organisational requirements of governments, their institutions and key welfare professionals. In Britain, for example, the Disability Discrimination Act (DDA) (HMSO, 1995: section 1.1) describes a disabled person as 'anyone with a physical or mental impairment, which has a substantial and long-term adverse effect upon their ability to carry out normal day-to-day activities'. This includes *physical impairments* (weakening of a part of the body caused through illness, by accident or from birth, including blindness, deafness, heart disease or the paralysis of a limb); *mental impairment* (such as learning disabilities and all recognised mental illnesses); that the disability is *substantial* (does not have to be severe, but is more than minor or trivial), with a *long-term adverse effect* (more than 12 months) and influences normal *day-to-day activity* (your mobility; manual dexterity; physical co-ordination; continence; ability to lift, carry or otherwise move everyday objects; speech, hearing or eyesight; memory or ability to concentrate, learn or understand; or perception of the risk of physical danger). These administrative definitions allow nation states to identify those who qualify for welfare. Simultaneously, though, these definitions individualise the problems of disability. The DDA definition says something very simple: impairment, whether it be physical or 'of mind', results in and creates disability. Hence, impairment and disability are collapsed together as synonymous concepts.

Societies are predisposed to understand disability as a personal tragedy inflicting damage upon the mind and body, requiring treatment, rehabilitation or (at its most

logical extreme) cure (Barnes, 1990). Following this, impairments *lead to* a myriad of disabilities – disabled childhoods, disabled learning, disabled personal relationships, disabled sex lives, disabled parenting, disabled psychologies and so on. ‘The disabled’ are dependent on state and professional intervention (Morris, 1993b) and their only hope is to adjust to a lacking body or mind. Drawing on the work of Olkin and other disability scholars it is possible to identify two complementary worldviews that situate the predicament of disability firmly within the individual (Table 1.1).

Disability studies are critical responses to these two cultural extremes, presented in Table 1.1, of supernatural vision and/or medical specimen (Snyder and Mitchell, 2001: 380). The moral position views disability as a sin (a punishment from God forgiven through divine intervention), while the medical perspective views disability as pathology (a physical, sensory or cognitive failing that tragically ‘handicaps’ those ‘afflicted’). Following Snyder and Mitchell (2001: 379), moral positions have included disability as a reflection of God’s dismay (ancient Greece), as evidence of an intimacy with God (medieval Europe) and a divine response to parental wrongdoing (Renaissance period). The medical model is a modern outlook (Christensen, 1996; Sachs, 2008). The church benefits from the moral position while the paramedical professions gain from the medical model. The eugenics movement of the early twentieth century, which accompanied the rise in the status of science and capitalism, located the burden of disability in the unproductive flawed individual (Fernald, 1912). Following Naidoo (2009), medicine has conceptualised disability as a distinct pathology (a pathogenic view) rather than a place on a continuum of dis/ease (a salutogenic position) or in terms of capacities and strengths (a fortigenic approach). The medical model becomes hegemonic – that is dominant – and encourages the disabled entity to be framed in terms of assisted suicide, euthanasia and antenatal termination. The human worth of disabled people is rendered highly questionable through the growing use of reproductive technologies. And as medicine intervenes so disabled bodies are made increasingly undesirable. For Oliver (1990), moral and medical approaches promote an *individual model of disability*, reducing the problem of disability to the flawed tragedy of individual personhood treatable through the interventions of charities and healthcare professionals.



Thinking point: The first Professor of Disability Studies in Britain, Mike Oliver, made the following observation about professionals:

The medical profession, because of its power and dominance, has spawned a whole range of pseudo-professions in its own image – physiotherapy, occupational therapy, speech therapy, clinical psychology – each one geared to the same aim – the restoration of normality. And each of these pseudo-professions develops its own knowledge base and set of skills to facilitate this, organising interventions and intrusions into disabled peoples’ lives on the basis of claims to discreet and limited knowledge and skills’. (Oliver, 1996: 37)

To what extent do you dis/agree with this observation?

Professionals and disability are clearly intertwined. McLaughlin et al. (2008) interviewed the parents of a one-year-old child, with the label of Down syndrome, who by that time had met with 124 professionals. Many bio-medical professions stipulate that impairment has such a traumatic physical or psychological impact upon the person that they will be unable to achieve a reasonable quality of life (Barnes, 1991: ix).

Table 1.1 Two dominant perspectives of disability (as) impairment

	Disability as a moral condition	Disability as a medical condition
Meaning	<i>Disability is a defect caused by moral lapse or sins.</i> The reification of sin or evil, failure or a test of faith. Includes myth that as one sense is impaired by disability another is heightened, i.e. the blind seer.	<i>Disability is a medical problem that resides in the individual</i> – a defect in or a failure of a bodily system that is inherently abnormal and pathological. Impairment and disability are conflated, i.e. the Down syndrome child.
Moral Implications	Shame to the person with the disability and their family. The family must address their immoral nature as evidenced through the presence of a disabled family member.	Repudiates the view of disability as a lesion on the soul but may blame person or family for healthcare habits (e.g. Type A personality leads to heart attack) and promulgates view of disability as a personal tragedy.
Sample Idea	God gives us only what we can bear. Example: (Gaelic plaque) 'May those who love us, love us. And those who don't love us, may God turn their hearts; and if he doesn't turn their hearts may he turn their ankles so we'll know them by their limping.'	Patients are described clinically (e.g. 'patient suffers from Trisomy 21/Down syndrome' or 'there is an incomplete lesion at the C4 level'). Isolation of body parts and view of people with disabilities (PWD) as atypical, abnormal and pathological.
Origins	Oldest of all disability models but, arguably, still the most prevalent worldwide.	Mid-1800s onwards. Underlies most rehabilitation facilities and most rehabilitation journals in rich countries.
Goals of Intervention	Spiritual or divine or acceptance. Increased faith and forbearance. Finding meaning and purpose in affliction.	Patients or clients are expected to avail themselves of services offered by trained professionals with the promise of cure (the amelioration of the physical condition to the greatest extent possible); rehabilitation (the adjustment of the person to their condition) or adjustment (adjust to live as a PWD).
Benefits of Model	Acceptance of being 'selected' to have a disability, feeling a relationship with God, having a sense of greater purpose. Some impairments understood as evidence of spiritual embodiment (e.g. pure simple child).	Promotes faith in medical intervention, a defined patient role and offers a label as explanation. Medical and technological advances in key services of the welfare state have improved the lives of PWD.
Negative Effects	Being ostracised from family and community, feeling profound shame, having to hide disability symptoms or the person with a disability. Disability exposes sinful (past and present) lives of family.	Paternalism, pathologisation and the promotion of benevolence. Interventions <i>on</i> PWD rather than <i>with</i> . Promotes research by outsiders and services for, but not by, disabled people.

Sources: Adapted from Oliver, 1996; Goodley, 2000; Olkin, 2001, 2002, 2009; Barnes and Mercer, 2003.

Linton (1998a) and Sherry (2006) suggest that this individual discourse creates a number of 'fault lines': disability is cast as an essentialist condition (with organic aetiologies); disabled people are treated as objects rather than as authors of their own lives; 'person fixing' rather than 'context changing' interventions are circulated; the power of health and social care professionals intensifies and the tyranny of normality is accentuated. Disabled people are infantilised, constructed as helpless and viewed as asexual (McRuer and Wilkerson, 2003: 10). For Abberley (1987: 18), presenting the disadvantage of disability as the consequence of a 'naturalised impairment' or 'biological flaw' lets exclusionary society off the hook.

For Greenop (2009), more and more people are being made aware that medicine makes promises it cannot keep, fails to fix 'the problem' of disability, creates dependency, denies individuals use of their own self-care strategies and may have iatrogenic consequences of side-effects and unforeseen complications (Greenop, 2009).¹ Indeed, across society, the growth in complementary therapies as alternatives to medicine and evidence of medical non-compliance of between 30% and 50% on the part of people in receipt of medical treatments (with £230 million worth of prescription drugs being incarcerated in the UK in 2002, due to non-usage), indicate that people are growing ever more critical of medicine (Greenop, 2009). Similarly, disabled people have offered their own criticisms of and alternatives to medicalisation. Key to these counter-views is the growing awareness of the social, cultural, historical, economic, relational and political factors that *dis*-able people. Disability studies dislodge disability from its medicalised and moral origins (Herndon, 2002: 122). 'Dis/ability' is not natural. Dis/ability is socially constructed. In Britain, the Union of the Physically Impaired Against Segregation (UPIAS, 1976: 3–4), devised the following definitions to acknowledge the role of society:

Impairment – lacking part of or all of a limb, or having a defective limb organism or mechanism of the body.

Disability – the disadvantage or restriction of activity caused by a contemporary social organisation which takes no account of people who have physical impairments and thus excludes them from mainstream social activities.

This was later adapted by the Disabled People's International (DPI) definition:

IMPAIRMENT: is the functional limitation within the individual caused by physical, mental or sensory impairment.

DISABILITY: is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers. (DPI, 1982)

These definitions acknowledge impairment but politicise disability. Impairment is defined as a form of biological, cognitive, sensory or psychological difference that is defined often within a medical context and disability is the negative social reaction to those differences (Sherry, 2007: 10). Disability is understood as an act of exclusion: people are *disabled by* contemporary society. This concept is extended by Thomas (2007: 73), in her definition of *disablism* as 'a form of social oppression involving

the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being.' This is helpful because it permits disablism to sit alongside other forms of oppression, including hetero/sexism and racism. *Disability* is recognised as a phenomenon of cultural, political and socio-economic conditions (Abberley, 1987), disablism recognises the psychological, cultural and structural crimes against disabled people (Thomas, 2007) and *disablement* captures the practical consequences of disablism (Oliver, 1990).



Thinking point: The definitions of 'impairment', 'disability', 'disablism' and 'disablement' presented above are Anglocentric: they reflect the preferred terms of British disability studies scholars. In other English-speaking nations, terminology morphs and changes. 'Disabled people' (Britain) are referred to in terms of People First language in the USA as 'people with disabilities'. The North American preference for 'people with intellectual disabilities' (previously and now unacceptably 'the mentally retarded' or 'the mentally handicapped') are also related to other terms around the globe, including 'people with learning difficulties' (Britain) and 'people with developmental disabilities' (Australia). Individuals historically diagnosed as 'mentally ill', having 'psychiatric illnesses' or 'mental health problems' now more commonly use terms such as 'survivors of mental health systems'. And, while British scholars have addressed disablism, many North American writers have turned their attentions to ableism (see below). A helpful insight into some of the debates about disability language can be found in the publications coming out of Disability World (visit www.disabilityworld.org/aboutus.html#term) and Disabled Peoples' International (www.dpi.org). It is also worth reading the 'Editorial on Language Policy' of the leading international journal Disability & Society for a snapshot overview of the changes in terminology (available to download at www.tandf.co.uk/journals/authors/cdsolang.pdf). Whatever the preferred terminology, all disability studies scholars share an interest in appropriating language that does not demean, is culturally sensitive and recognises the humanity of disabled people before disability or impairment labels.

Disability is also a cultural concept. For Garland-Thomson (2002: 5), dis/ability is best understood as a sign system that, by differentiating and marking bodies and minds, produces dis/abled-bodies and maintains the ideal of the inherently stable non-disabled body or mind. Disability is a label, a signifier, that inaugurates consignment to an identity category, which signifies disadvantage and oppression (Jung, 2002: 179). The meaning and experience of impairment, disability and disablism morph over time, not simply because of the developments in 'scientific thinking' around the body and mind, but often because of changes in social policy, government guidelines and legislation. Disablism refers to those times when the relationship between the environment, body and psyche serves to exclude certain people from becoming full participants in interpersonal, social, cultural, economic and political affairs (Marks, 1999b: 611).



Thinking point: According to Ferguson et al. (1992), in 1973 the entire category of 'Borderline Retardation' was dropped from the Manual of Terminology of the American Association on Mental Deficiency, as the

manual was revised. What does this say about the biological or cultural nature of 'intellectual disability'?

Oliver (1990) records how the changes to the application criteria for mobility allowance in the UK in the 1980s significantly shifted and changed the population of those deemed eligible to qualify (and therefore defined as mobility impaired). A 'manipulative child' in the 1970s might get the label of Pathological Demand Avoidance Syndrome in the 2000s. Today's 'naughty boy' is more commonly known as a child with Attention Deficit Hyperactivity Disorder (ADHD) or Oppositional Defiance Disorder (ODD).

Disability breaks down when we start to scrutinise it (Davis, 1995). Disability speaks of society: being disabled is not simply a descriptor of an object – a person with a cane – but a social process that intimately involves everyone who has a body and lives in the world of senses (Davis, 1995: 2). For Ghai (2006: 147), disability refers to bodies that have become dis-embodied because of constructions around them, that create a total invisibility of the disabled individual. Society discriminates against disabled people when it becomes disablism. While disablism is negative, disability/impairment can be positive. Disability culture is rich in creativity and proud slogans of liberation, including 'Piss on Pity', 'Disabled and Proud' and 'People First'. A key task of disability studies is to tap into these affirmative understandings of the productive impaired body and mind, while examining how disablism is enacted at the level of psyche, culture and society. The psyche and the social are impossible to disconnect (Oliver and Edwin, 2002).

This book is written at an interesting time in the short history of disability studies. Analyses of disability have entered the curricula. This is evident in the USA in the founding of the Society for Disability Studies in 1982 (www.disstudies.org) and the constitution of special interest groups in Modern Language Association (MLA), the American Anthropological Association (AAA) and the American Educational Research Association in the 1990s (Gabel, 2006). The Nordic Network on Disability Research was established in Denmark in 1997 (www.nndr.no/index.php), the *New Zealand Journal of Disability Studies* was launched in the mid-1990s and the Canadian Disability Studies Association-Association Canadienne des Études sur L'Incapacité, held its first annual meeting at the University of Manitoba in Winnipeg in May 2004 (www.cdsa-acei.ca/about.html). The year 2003 saw the Inaugural Conference of the Disability Studies Association in Britain (www.disabilitystudies.net) and the establishment of the Japan Society for Disability Studies (www.jsds.org).

Disability studies perspectives

For Garland-Thomson (2002), disability studies is a matrix of theories, pedagogies and practices. Within this matrix are perspectives that should not be confused with theories (Oliver, 1996), nor constrain debate by masquerading as grand truths (Price, 2007), but viewed as particular knowledge positions (Goodley, 2001) from which to address and refute disablism (Thomas, 2007). Distinct responses have shot up in particular geographical locations. They have been viewed as oppositional (Barnes, 1999) and complementary (Linton, 1998b) though many have warned against exaggerating differences between them (L.J. Davis, 1997; Marks, 1999a; Barnes, 2004; Meekosha,

2004; Gabel, 2006; Thomas, 2007). As Marks (1999a: 9) suggests, concepts of dis/ability play a central, if latent, role in contemporary understandings of normality, the body and intelligence. It is therefore crucial to be respectful of the national contexts and historical times in which these new disability studies perspectives have emerged.

The social model: disability as a social barriers concern

A **social barriers approach** has led disability studies in Britain. Thomas (2007: 6) argues that the *social model*, as it is often referred to, remains *the* central theme around which disciplinary adherents coalesce. This is captured by Barnes and Mercer (1997a: 1–2) in the introduction to their text on disability studies research.

The significance of disability theory and practice lies in its radical challenge to the medical or individual model of disability. The latter is based on the assumption that the individual is ‘disabled’ by their impairment, whereas the social model of disability reverses the causal chain to explore how socially constructed barriers have disabled people with a perceived impairment.

Up until the 1990s, disability was broadly conceived in terms of rehabilitation, medicine, psychology, special educational needs and social work. Sociologists tended to be medical sociologists (Barnes, 2004). From the 1990s, British disability studies grew and enjoyed disciplinary residencies in sociology, social policy and education. The social model was a ‘paradigmatic leap’ (Olkin, 2009: 12), offering a new vision of disability which, according to Barnes et al. (1999: 213), could not be dismissed as a ‘minority concern’ (see also Barnes et al., 2002; Barnes and Mercer, 2003). The social model followed the pioneering work of UPIAS (1976), adopted their distinction between impairment and disability and put forward an analysis of disabling barriers. The first major working up of the social model is to be found in Oliver’s (1990) seminal text.² This built on Britain’s Open University course (Breachin et al., 1981) Campling’s (1981) influential collection by disabled women and the emergence of international journals such as *Disability & Society*. Social model scholars turned attention away from a preoccupation with people’s impairments to a focus on the causes of exclusion through social, economic, political, cultural, relational and psychological barriers (see also Oliver and Zarb, 1989; Barton, 2001).



Thinking point: Vic Finkelstein (1981a) illustrated the disablement of modern culture by describing an imaginary community where wheelchair users were the majority and the environment was designed accordingly. In this ‘disability culture’ (as opposed to a ‘disablist culture’) able-bodied people were marked by bruises from banging their heads on lowered entrances (made for wheelchair users) and suffered backache from stooping down. They were helped by able-bodied equipment such as helmets, neck braces and, ‘best of all’, limb amputation, and money was collected for them in up-turned helmets with, ‘Help the able-bodied’, imprinted upon them.

To what extent does Finkelstein’s imaginary community shed light on the cultural construction of ‘disability’ and the ‘able-bodied’?

The social model has been debated as much by activists as academics. To observers outside Britain, these debates are seen as overly aggressive, exclusionary and in some cases anti-intellectual (e.g. Traustadóttir, 2006a; Vehmas, 2008), but might be better seen as testimony to the political roots of the social model. This model was, and remains, the British disabled people's movement's 'big idea' (Hasler, 1993). As Abberley (1987) argued, the social model originated in analyses of the political economy of disablement by disabled people's organisations.

One development of the social model has been the *affirmation model* (Swain and French, 2000). This approach, well summarised by Brandon (2008), celebrates the positive impacts of the disability community. Affirmation is most readily found in the Disabled People's Movement, disability arts and in Deaf culture (Corker, 1998). Social and affirmation models are best understood as platforms on which to develop theories (Thomas, 2008). To further complicate matters, a social model perspective has been developed by a group of psychologists in the USA (Nagi, 1976; Olkin, 2001, 2002, 2003, 2008; Olkin and Pledger, 2003; Pledger, 2003, 2004), who have worked within and against rehabilitative psychology. Nagi (1976), for example, pioneered a view of disability in which functional limitation was viewed as an expression of failure of environments to accommodate disability characteristics (Pledger, 2003: 282). What is apparent, according to Barnes (1998) and Davis (2006b), is that there is now a generation of second-wave social model theorists. For some, this has meant looking elsewhere for theoretical and political inspiration.

The minority model

While the social model was gathering momentum in Britain, North American activists and scholars were developing their own culturally applicable analyses. According to Gabel (2006), this work revolved around a social interpretation approach that coined the *minority group model*.



Thinking point: Why might the notion of a minority approach to the framing of disability be in keeping with a North American perspective?

Clearly influenced by American Black civil rights and queer politics demands for raised social status, alongside thousands of returning Vietnam veterans (Meekosha and Jakubowicz, 1996), a number of key writers (Zola, 1982; Hahn, 1988a, 1998b; Rioux and Bach, 1994; Longman and Umansky, 2001) and disabled people's organisations in the USA (including American Coalition of Citizens with Disabilities, Not Dead Yet), asserted a positive minority identity (McRuer, 2002: 223–224). This was an identity forged under an American 'ethic of individuality and achievement' (Davis, 2002: 11). Underpinning this model, for Davis (2002) and Gabel (2006), was a clear challenge to *ableism*: social biases against people whose bodies function differently from those bodies considered to be 'normal' and beliefs and practices resulting from and interacting with these biases to serve discrimination (Wendell, 1996). The minority model demanded cultural redefinition in opposition to 'the cutthroat individualism' of the dominant North American and Canadian societies (McRuer and Wilkerson, 2003: 4). The People First language of 'people with disabilities' was coined to recognise humanity before the label (Linton, 1998b; Gabel and Peters, 2004).³ For Gabel (2006), while the social model boasted neo-Marxist leanings, which addressed socio-structural barriers,

the minority model took a more eclectic approach to the socio-cultural formations of disability (see also; Albrecht et al., 2001; Shakespeare and Watson, 2001a). By illuminating the common marginalised experiences of disabled people, African, Native and Hispanic American groups, the minority model addresses the importance of race and ethnicity in North American politics and the emergence of new activism from minority bodies, behaviours and abilities (McRuer and Wilkerson, 2003: 6).

Table 1.2. summarises the social and minority model approaches to disability studies described above and captured by writers such as Olkin and others.

Table 1.2 The minority and social barrier approach (incorporating the affirmation model) to disability studies (adapted from Oliver, 1996; Olkin, 2001, 2002, 2009; Gabel, 2006; Brandon, 2008)

	Disability as minority politics (USA and Canada)	Disability as social barriers (UK)
Meaning	<i>People with disabilities (PWD) constitute a minority position in society, like people of colour, who are devalued, stigmatised, discredited and discounted. PWD comprise a minority group that has been denied its civil rights, equal access and protection.</i>	<i>Disability is a social construct. People with impairments are oppressed/ disabled by society: they are disabled people (DP). Primary impediments are discrimination, social isolation, economic dependence, high unemployment, inaccessible housing and institutionalisation.</i>
Moral Implications	Society has devalued and marginalised disabled people to confer minority status. PWD are only offered peripheral membership of society.	Society has failed DP and oppressed them through barriers that prevent access, integration and inclusion to all walks of life, including work, education and leisure.
Sample Idea	The politics of PWD. 'Nothing about us without us', 'Not Dead Yet', 'Access Now', 'You gave us your dimes, now give us our rights', campaigning for anti-discriminatory legislation. 'PWD and proud'.	The politics of DP. 'Nothing about us without us', 'Piss on Pity', 'Civil rights, not charity', campaigning for anti-discriminatory legislation. 'DP and proud'.
Origins	Early 1900s, disappeared until 1975 protests in Washington DC and San Francisco, demanding that the 1973 Rehabilitation Act was signed. Intellectuals with disabilities (e.g. Charlton, 1998; Hahn, 1988a) followed impact of Goffman (1963) and Black civil rights movement.	Post-Second World War, DP's organisations. Disabled intellectuals (e.g. Hunt, 1966; UPIAS, 1976; DPI, 1982; Oliver, 1990; Barnes, 1991; Morris, 1993a) with strong adherence to (Neo-Marxist) materialist accounts of disability.
Goals of Intervention	Political, policy, economic, educational and social systems; increased accessibility of places and services; broad systemic change; development of Centres for Independent Living; disability arts. Promote positive sense of disabled self.	Political, policy, economic, educational and social systems; increased accessibility of places and services; broad systemic change; development of Centres for Independent Living; disability arts. Promote positive sense of disabled self.

Table 1.2 (Continued)

	Disability as minority politics (USA and Canada)	Disability as social barriers (UK)
Benefits of Model	Promotes integration of disability into self. Focus on how world disadvantages PWD. Sense of belonging and involvement in a disability community. Disability pride.	Promotes integration of disability into self. Focus on how world disadvantages DP. Sense of belonging and involvement in a disability community; disability pride. Clear distinction between social barriers (which can be changed) and impairment (which cannot).
Negative Effects	Feeling powerless in the face of political and economic odds. Need for strong self-advocacy skills. Blurring of impairment and disability.	Feeling powerless in the face of political and economic odds. Need for strong self-advocacy skills. Lack of acknowledgement of the effect of impairment on everyday life.

Sources: Adapted from Oliver, 1996; Olkin, 2001, 2008, 2009; Gabel, 2006; and Brandon, 2008

Unlike the two dominant individualising perspectives of ‘disability as impairment’ outlined in Table 1.1, social and minority models break the ‘impairment → disability’ causal link and, turn attention to the socio-political, structural and economic minoritisation and exclusion of people with impairments. Each developed in direct response to, and were developed by, the Disabled People’s Movement. Through the rise of these perspectives, disability studies were born.

The cultural model

A distinguishing feature of North American – including Canadian – disability studies has been its interdisciplinary dispersion across the social sciences and humanities. Writers such as L.J. Davis (1995, 1997, 2002, 2006a); Garland-Thomson (1996, 1997, 2002, 2005); Wendell (1996); Mitchell and Snyder (1997, 2006); Linton (1998a, 1998b); Kittay (1999a, 1999b, 2001, 2006); Albrecht et al. (2001); Longman and Umansky (2001); Snyder and Mitchell (2001, 2006); Tremain (2001, 2002, 2005a); McRuer (2002, 2003, 2006); Michalko, (2002, 2008) and Titchkosky (2003, 2008), brought to bear cultural and literary analyses. Their work has been keen to connect analyses of disability studies with transformative ideas from feminism, queer and critical race studies (as we shall see in Chapter 3). Humanities scholars came to the study of disability with these critical lens already honed to put forward a **cultural model of disability**. An overview is provided by Garland-Thomson (2002: 2), who posits that disability is a cultural trope and historical community that raises questions about the materiality of the body and the social formulations that are used to interpret bodily and cognitive differences. Affiliated scholars reject a firm distinction between impairment and disability because they view biology and culture as impinging upon one another. The cultural stance is read by Ware (2009) as a shift in thinking from ‘viewing bodies as bad’ (biological determinism and medicalisation) to ‘thinking about bodies’ (socio-cultural analyses). For Meekosha and Jakubowicz (1996), this allows us to attend to cultural empowerment and the saturation of bodies with cultural meaning. Disability pervades

all aspects of culture. Burke (2009) and Bolt (2009) dismiss the (social scientific) view of cultural studies as ‘decorative discipline’, and point instead to a substantive corpus of literature around disability that deconstructs societal texts, critiques ideology and destabilises biological imperatives. Representations of disability and impairment are manufactured by charities, science and popular culture in ways that *dis-locate* disabled people (Snyder and Mitchell, 2006: 19). Key sites of analysis include novels, film, performance, art and drama. These cultural artefacts act as cultural vents. One strong analytical theme is disability as metaphor (Mitchell and Snyder, 1997; Snyder and Mitchell, 2001, 2006; Danforth, 2008). Far from being excluded by popular culture, the disabled person is ubiquitous, used as a metaphor for sinister, evil, ungodly, lacking, brave, fragmented and unviable. Disabled people have a perpetual place in cultural representations, reflecting deep-seated cultural conflicts (Snyder and Mitchell, 2001: 376–377). Mitchell and Snyder (2006) term this *narrative prosthesis*: disabled people are everywhere, functioning in literary (and other) discourses as a stock feature of characterisation or opportunistic device to signal social or individual collapse and disruption. Disability is used by popular culture to uphold dominant ideas as the crutch upon which narratives (and cultural practices) lean for representational power.



Thinking point: List five movies in which disability is portrayed. Now visit www.disabilityhistory.org/dwa/edge/curriculum/cult_contenta3.htm. Following Barnes (1993), to what extent do films portray disabled characters as ‘to be pitied’, ‘tragic’, ‘sinister’ or ‘super-human’?

Cultural critique overturns disabling modes of cultural production (Barker, 2008). The work of Mitchell and Snyder, Davis and Garland-Thomson has been especially influential in exposing the myth of the ‘disabled/abnormal body’ – and its needed opposite ‘the able/normal body’. The cultural analyst turns her gaze on to ‘normal society’ and considers how it promulgates its own precarious position through demonising dis/abled bodies. Cultural analysts explore how today’s treatment of disabled people reflect the phantoms of the past, including eugenics, institutionalisation and science. For Mallett (2007), such theorists add a necessary cultural mix to the barriers and minority politics analyses of other disability studies thinkers. The maintenance of ‘normate culture’ relies heavily on its relationship with disabled people, a cultural reality defined as *dismodernism* by Davis (2002) and cultural *dislocation* by Snyder and Mitchell (2006), ideas we will revisit in this text.

The relational model

While Anglo-American disability studies have developed in the social sciences and humanities, Thomas (2007: 7) observes that interdisciplinarity is more overtly felt in the Nordic countries. Disability researchers such as Bjarnason (2002, 2004), Tøssebro (2002, 2004), Gustavsson (2004), Kristiansen and Traustadóttir (2004), Traustadóttir (2004a, 2006a), Kristiansen et al. (2008), and Björnsdóttir (2009) (see also *Scandinavian Journal of Disability Research*, 6 (1), 2004) from Denmark, Finland, Iceland, Norway and Sweden counter the dominance of Anglo-North-American theories through the development of the **Nordic relational model of disability**. Through ‘writing back’ from their own contexts, they have highlighted the positive influence of services and professionals on the

lives of disabled people. Traustadóttir (2004a, 2006a) draws on the work of writers such as Gustavsson (2004) and Tøssebro (2002, 2004) to map out the theoretical terrain in relation to Nordic disability studies. Since the 1950s, Nordic countries have expanded disability services in ways that have been championed as some of the world's best. A strong welfare state functions in the same way as a good home (Nes, 2004). Unlike social and minority perspectives, Nordic disability studies are less connected to the Disabled People's Movement, with leadership often being found in the academy (Vehmas, 2008). Instead, disability studies developed in the context of welfare and, specifically, were influenced by the principles of normalisation (Stromstad, 2004). This philosophy originated in Denmark (with the work of Bank-Mikkelsen), Sweden (with Nirje), Britain (with O'Brien) and the USA (following Wolfensberger), and aimed to promote the community participation of disabled people. Early normalisation principles informed the beginnings of self-advocacy, and this movement remains a strong component of Nordic disability activism to this day. Being more of a guiding philosophy than a service technique, normalisation (later renamed social role valorisation) marked a radical departure in terms of professional and policy values with respect to disabled people, particularly people with intellectual disabilities (Brown and Smith, 1992). Wolfensberger (1972a, 1972b, 1987) and O'Brien (1987) set out to make ordinary available patterns of everyday living that were as close as possible to the regular circumstances of life in society.



Thinking point: Visit www.socialrolevalorization.com and outline five key components of social role valorisation. What positive effects could this approach have on the ways in which communities and professionals respond to disabled people? With reference to Table 1.2 above, how does normalisation fit with minority and social perspectives?

Normalisation was adopted as a method for assessing services, the practice of professionals and the impact of social policy.⁴ For example, in the Icelandic context, Björnsdóttir (2009) argues that the 1979 Act on Support to Individuals with Intellectual Disabilities, which enforced the rights of individuals with intellectual disabilities to lead normal lives, created an 'integrated generation' of disabled people. The focus on community has led Nordic scholars to embrace feminism (see, for example, Bjarnason, 2002, 2004, 2008; Kristiansen and Traustadóttir, 2004; Traustadóttir, 1991, 1995, 1999, 2004b, 2006b) and this work has been highly influential in other countries (e.g. Read, 2000; McLaughlin et al., 2008). Traustadóttir (2004a, 2006a) informs us that the lack of unity within the Nordic languages means that the distinction between 'disability' and 'impairment' does not translate. A relational understanding of disability/impairment had to be devised through empirically-driven work and multiple approaches in order to speak across the Nordic countries. The Nordic relational model approaches the study of disability with three main assumptions: (1) disability is a person-environment mismatch; (2) disability is situational or contextual; and (3) disability is relative (Tøssebro, 2002, 2004). For Campbell (2009: 95), a relational model understands disability as a phenomenon emerging out of interactivity between impairment and disabling modes of socio-economic organisation.

Table 1.3 captures some of the nuances of the cultural and relational approaches. The former has the deconstruction of normalcy and ableism in its line of fire and celebrates the emergence of counter-cultures, including disability arts. The latter excavates the interactions of bodies, minds and environments with particular focus on the dis/empowering contributions of services and their practitioners.

Table 1.3 The cultural and relational models of disability (adapted from Davis, 1995, 1997, 2002, 2006a; Garland-Thomson, 1997; Mitchell and Snyder, 1997; Tøssebro, 2002, 2004; Traustadóttir, 2004a, 2006a; Snyder and Mitchell, 2006)

	Disability as cultural construction (USA and Canada)	Disability as relational (Nordic)
Meaning	<i>Disability is a construction of culture and modes of production, in ways that provide a metaphorical crutch for the constitution of 'abled'. Disability can only be understood in relation to 'the normate', normalcy and ableism.</i>	<i>People with disabilities are disabled through dynamic relationships of body/mind and the environment. Disability is created through three relational processes: (i) the person-environment mis/match (relationship/relational); (ii) disability is a situational or contextual phenomenon; and (iii) Disability is a relative construct.</i>
Moral Implications	Cultural re/production constitutes disabled people as mere carriers of information and passive recipients of hegemony that is founded on the ambitions of 'able' people.	Disabled people are excluded from communities, services and professional practices because of a mismatch of expectations, biological needs and environmental opportunities.
Sample Idea	Deconstruction and ideology critique of film, novel and media. Reconstructing disability histories, identifying disability fantasies and offering 'crip' alternatives.	Slogans, services and practices associated with 'Empowerment now', 'Label Jars not People', 'Community-based workplaces not segregated employment'.
Origins	1960s onwards, emerging out of minority group and social models through dialogue with cultural and literary critiques and the areas of feminism, queer and postcolonial critique. Key writers include Davis (1995), Garland-Thomson (1997), Mitchell and Snyder (1995).	1960s roots in normalisation principles – the community resettlement of disabled people outside institutions and the development of expansive, responsive forms of welfare. Open minded to pan-national models of disability studies. (e.g. <i>Scandinavian Journal of Disability Research</i> , 6(1), 2004).
Goals of Intervention	Destabilise cultural performances of dis/ability and ab/normality; promotion of disability arts and subculture; subvert liberal arts agenda which often excludes disabled people. Disability is renamed as a site of resistance that critiques 'the normate' and 'the abled'.	Political, policy, economic and social systems; increased accessibility of places and services; broad systemic change; development of Centres for Independent Living; normalisation and inclusive community living; an ordinary life.
Benefits of Model	Sense of belonging and involvement in a disability community; disability pride; promotion of critical faculties in relation to the normate culture. Disability is a site of phenomenological value not purely synonymous with the process of social disablement.	Sense of belonging and involvement in a disability community; disability pride. Promotion of empowering professionals and self-advocacy informed services.

(Continued)

Table 1.3 (Continued)

	Disability as cultural construction (USA and Canada)	Disability as relational (Nordic)
Negative Effects	Feeling powerless in the face of cultural hegemony. Lack of explicit engagement with disability activism, professional practice and service delivery. Over-emphasis on cultural construction rather than political marginalisation.	Lack of distinction between impairment and disability might re-insert a medicalised view of the disabled body and mind. Over-emphasis on professional practice and service delivery and lack of engagement with disabled people's organisations.

Sources: Adapted from Davis, 1995, 1997, 2002, 2006a; Garland-Thomson, 1997; Mitchell and Snyder, 1997; Olkin, 2001, 2002, 2009; Tøssebro, 2002, 2004; Traustadóttir, 2004a, 2006a; and Snyder and Mitchell, 2006

In and Outside Anglo-Nordic-North-American orthodoxies

As disability studies mature the ensuing analyses become increasingly eclectic. Herdon (2002) characterises the work of American scholars Linton (1998a, 1998b) and Wendell (1996) in terms of the former being more in keeping with the British social model and the latter more in tune with the Nordic relational approach. Linton's early work has also been aligned with a minority perspective (see Barnes, 2004; Roach, 2004), though later on, her writing can be viewed as more in keeping with a cultural stance (e.g. Linton, 2006a, 2006b). The boundary busting continues. The North American scholar Charlton (1998, 2006), whose work is often assigned a minority model position, draws heavily on Marxism and ideological critique, sharing much with social modellers. While Mallett (2007) draws attention to the definition offered by Pfeiffer and Yoshida (1995: 480) of (US) Disability Studies as a discipline that 'reframes the study of disability by focusing on it as a social phenomenon, social construct, metaphor and culture utilising a minority group model'; clearly blurring minority and cultural perspectives. Recently, cultural theorists Mitchell and Snyder (2006: x) have proposed an analysis of the cultural locations of disability 'to evoke sites of violence, restriction, confinement and absence of liberty for disabled people', harking back to the early priorities of the minority model. More and more collections of disability studies transcend perspectives and transnational contexts (e.g. Albrecht et al., 2001; Barnes et al., 2002). Increasingly, researchers work across disciplines, such as the social sciences and humanities (e.g. Barnes, 1993; Watson et al., 2003), as evidenced in initiatives such as the British Cultural Disability Studies Research Network (www.cdsrn.org.uk), the International Network of Literary Disability Scholars (www.journalofliterarydisability.com/index.htm) and the *Journal of Literary & Cultural Disability Studies* (www.jlcds.lupjournals.org).⁵ Right across the globe disability studies have developed in 'glocal' ways, reflecting distinct regional contexts such as, to name but a few, Australia (Gleeson, 1999a; Meekosha, 2004; Campbell, 2009), Malaysia (Yeo, 2006; Kuno et al., 2008), France (Armstrong et al., 2002), India (Mohit, 2000; Ghai, 2006; Gabel and Chander, 2008), Greece (Vlachou, 1997; Vlachou-Balafoutis and Zoniou-Sideris, 2002), New Zealand (O'Brien and Sullivan, 1997, 2005), Zimbabwe (Chataika, 2007; Badza et al., 2008; Chimedza et al., 2008), Malta (Azzopardi, 2000, 2003, 2007, 2008),

Belgium (Devlieger et al., 2003, 2006a, 2006b; Roets et al., 2004, 2007, 2008; Van Hove et al., 2005), Japan (*Disability Studies Quarterly, Special Issue*, 28 (3), 2008), Israel/Palestine (*Disability Studies Quarterly, Special Issue*, 27 (3), 2007; *Women's Asia*, 21; *Voices from Japan*, 22, April 2009), Germany (*Disability Studies Quarterly, Special Issue*, 26 (2), 2006), Russia (Phillips, 2009). Meekosha's (2004) work in Australia combines Anglocentric social model analyses of class with North American cultural studies of colonial settler communities but finds neither suitable for explaining disability in indigenous Australian Aboriginal people and Torres Strait Islanders communities. Countries at the periphery of the English-speaking world, such as Australia, India, South Africa and Asia-Pacific rim nations, require analyses of disability that reflect their own specific colonial-settler histories (Meekosha, 2004: 725). This raises questions about how the cultural specificity and local relevance of disability studies can develop in light of attempts to cultivate a supranational universal model of disability: the *International Classification of Functioning, Disability and Health (ICFDH-2)* or the *ICF model*. As Grech (2009a: 38) argues:

with the ambitious aim of becoming a unified universal framework for defining and quantifying disability in a culturally neutral way, the ICF attempts to bridge the medical and social models by providing a bio-psy-chosocial model, motivated by the effort 'to achieve a synthesis' and 'provide a coherent view of different perspectives of health from a biological, individual and social perspective'. (World Health Organization, 2001: 20)

In this case, disability is an umbrella term for considering the interaction of impairment, body functions and structure, activity, participation against the wider context of personal and environmental factors (see Figure 1.1).

The ICF is upheld as a universal model that captures the complexity of disability. Barnes (2006), Pledger (2004) and Snyder and Mitchell (2006) have criticised the

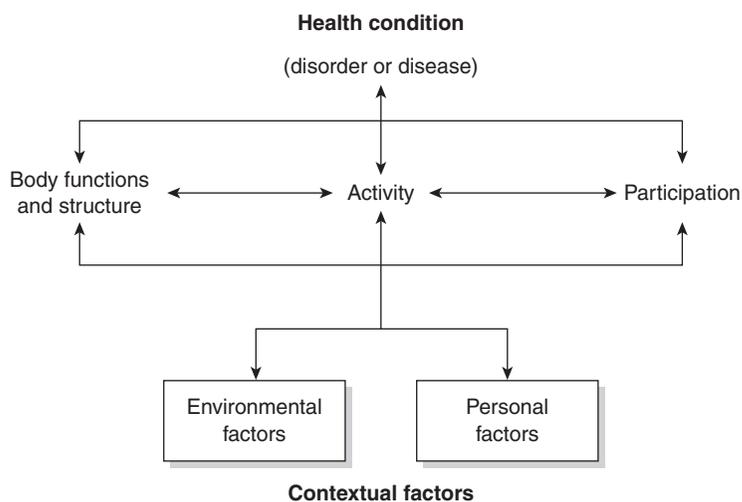


Figure 1.1 The ICF model (World Health Organization, 2001; adapted from Grech, 2009a)

ICF for being a vague catch-all model that fails to capture the complex meanings of 'impairment',⁶ simplistically placing it alongside social and relational factors like participation and ignoring definitions developed by disabled people's organisations. Wendell (1996: 14) is sceptical about universal definitions:

Failure to recognise that standards of structure, function, ability and participation are socially relative could be dangerous to disabled people. If the standards employed are generated by people in highly industrialised societies, many people in less industrialised societies and rural areas where there are fewer technological resources will be considered non-disabled when they are in fact in need of special assistance to survive and participate where they are.

In searching for universalism, definitions such as the ICF are in danger of ignoring the culturally-specific foundations on which impairment, disability and disablism are created. Similarly, disability studies devised in Anglo-Nordic-North-American contexts may have limited value in the rest of the world.

Conclusion

This book poses a challenge: How can disability provide *the* focus for a consideration of citizenship, rights, personhood, difference and diversity at the start of the twenty-first century? This book will demonstrate that disability provides a central core around which to organise considerations of theory, methodology, politics and practice.

Further reading

Campbell and Oliver (1996). Draws on interviews with some of the key founding figures in the British Disabled People's Movement.

Gabel (2006). An accessible introduction to the development of disability studies in America.

Longman and Umansky (2001). A renowned historical text in disability studies.

Meekosha (2004). An Australian perspective on minority, cultural and social models of disability.

Mitchell and Snyder (2006). A brief though informative introduction to a key area of analysis in cultural approaches to disability: the metaphor.

Olkin (2002). An accessible introduction into social, minority and medical approaches to disability.

Tøssebro (2004). Introduces Nordic responses to disability and models of disability.

Notes

- 1 A recent example of the waning trust in medicine (and the values we attached to impairment fetuses) is proffered by the front-page headline '146 healthy babies lost every year due to poor Down's syndrome test' (The *Guardian*, 15 May 2009: 1), due to a test giving a 'false positive' result: assessing women as 'at risk' of having a Down syndrome when they were, in fact, carrying children without this label.
- 2 Though, as we shall see later in Chapter 6, it is also possible to see early ideas around the social model in Oliver et al. (1988) and early thoughts on models in Oliver (1983).
- 3 Such definitions paralleled the affirmative identities of Black civil rights groups as well as Gay and Lesbian groups, of which the latter offered more productive identities to the pathological labels of the medicalisation of homosexuality (Richardson, 2005).
- 4 For a reflection of the debates for and against normalisation, see Meekosha and Jakubowicz (1996: 81), who consider it 'paternalistic reform clothed in the language of liberation', and Race et al. (2005), who offer a more sympathetic reading.
- 5 An excellent overview of the emergence of cultural and literary disability studies analyses is offered by Bolt (2009).
- 6 Indeed, as McKenzie (2009) shows, the World Health Organisation's ICD-10 *International Classification of Diseases*, which is used by health professionals as a complementary guide to the ICF, provides a definition of intellectual disabilities which is unambiguously individualistic by definition: 'a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities. Retardation can occur with or without any other mental or physical condition.'