CHAPTER 14

DISABILITIES, CARE AND THE HUMANITARIAN SOCIETY
STEPHEN WILLIAM HAWKING was born on 8 January 1942 in Oxford, England. He is renowned as one of the world's leading mathematicians and cosmologists, writing a worldwide best-selling book *A Brief History of Time* (1988). Since 1979 he has been the Lucasian Professor of Mathematics at Cambridge University. He studies the basic laws which govern the universe and is world renowned: he has twelve honorary degrees, was awarded the CBE in 1982, and was made a Companion of Honour in 1989. He is the recipient of many awards, medals and prizes and is a Fellow of the Royal Society and a Member of the US National Academy of Sciences. Professor Hawking has three children and one grandchild, and he continues his research with an extensive programme of travel and public lectures. He is a world success academic story.

He is also a person with motor neurone disease (or MND). He is severely physically impaired and has no voice. Although he was never especially active as a child or youth, he functioned reasonably well. But at 21, he went into hospital for tests and was eventually diagnosed. Over stages he became severely ‘disabled’ – he found his body poorly coordinated, had difficulty walking, couldn’t climb stairs. Bit by bit, he took to a wheelchair. Up to 1974, he was able to feed himself, and get in and out of bed. But then these became difficult – indeed, impossible. Community and private nurses looked after him for a few hours each day. But in 1985 he caught pneumonia and had to have a tracheotomy operation, which removed his ability to speak. After this, and to this day, he needed 24-hour nursing care. But all the time he continues to work and have a hugely successful career.

His voice has been aided by a technology which allows Hawking to select words from a series of menus on the screen, by pressing a switch in his hand. These can then be sent to a speech synthesizer and emerge as Stephen’s words. He can manage up to fifteen words a minute. As he says:

I can either speak what I have written, or save it to disk. I can then print it out, or call it back and speak it sentence by sentence. Using this system, I have written a book, and dozens of scientific papers. I have also given many scientific and popular talks. They have all been well received. I think that is in a large part due to the quality of the speech synthesizer. One’s voice is very important. If you have a slurred voice, people are likely to treat you as mentally deficient: Does he take sugar? This synthesiser is by far the best I have heard, because it varies the intonation, and doesn’t speak like a Dalek. The only trouble is that it gives me an American accent.

Disability is a difference that exists only to be undone.
Sharon L. Snyder and David T. Mitchell

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**KEY THEMES**

- What disability is and how to think about it
- Cultural, historical and contemporary responses to disability
- The disability movement and its features
- The globalisation of disability rights
- The growth of the compassionate temperament and the Humane Society

Motor neurone disease is comparatively rare – there are about 5,000 people in the UK living with MND. The mind continues to be active while the body starts to give up. It is a highly impaired experience that can happen at any age. There is no known cure at present.


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Pieter Breughel the Elder, *The Cripples*, sixteenth century
Source: To come

**Q** What does this painting say to you? Little is known of the artist’s politics or religion, so the exact nature of the moral is open to interpretation.
Stephen Hawking is an extraordinary celebrity of the ‘disability world’ – famous just because he combines such excellence of mind with such fraility of body. His image is known throughout the world, and his books are best sellers. In this chapter we delve a little into the wider social processes of disablement. The World Health Organisation (WHO) estimates that disabled people make up 10 per cent of the population – around 650 million. We go on to close this part by looking at the ways in which care and aid are being developed for the disabled and others.

First, who is and who should be called disabled? What does the term mean? Two strikingly different, but not necessarily incompatible, approaches can be recognised from the outset (though there is no reason that they cannot be linked). One is the concern with impairment. A person is blind, or deaf, physically or mentally ‘handicapped’. There may be physical or mental impairments, but they are features in which individual lives become incapacitated or impaired from their full functioning. Often these impairments can be directly linked to biology, genetics, and ‘medicine’. In contrast, another approach sees these impairments as differences surrounded by social reactions, which are usually forms of social discrimination that may well exclude people from normal life. These are usually called disabilities – they disable from society, rendering people less able than they are or could be, and they are social. It is disability rather than impairment that is the province of the sociologist.

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Although the two approaches are interconnected, they do seem to generate quite different ways of thinking about the issues. Table 14.1 suggests some of these contrasts. In reality, we blend both models.

Social workers and health providers have had a tendency to use the individual models in thinking about disability, while sociologists and disability activists (see below) have had a tendency to use the latter. But in fact the ‘social’ and the ‘individual’ model are only ways of thinking: they cannot be so clearly separated in practice. Everyday life combines elements of both. But as a thinking tool for sociologists, these distinctions can help show what some of the major issues may be for a sociology of disability.

### Clarifying disabilities and differences

<table>
<thead>
<tr>
<th>Individual model</th>
<th>Social model</th>
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<td>Impairment</td>
<td>Disability</td>
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<td>Personal tragedy</td>
<td>Social oppression</td>
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<td>Personal problem</td>
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<td>Expertise</td>
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<td>Control</td>
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<td>Policy</td>
<td>Politics</td>
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<td>Individual adjustment</td>
<td>Social change</td>
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Source: Oliver, 1996: 34.

In this chapter we discuss a wide variety of differences and impairments which come to be identified as ‘disabilities’. These can be seen as violations of some rules or expectations which then become social stigmas. Disabilities usually involve the social processes of norm violation, labelling and, often, dehumanisation.

### Types of ‘disablement’/‘impairment’

<table>
<thead>
<tr>
<th>Normative violations</th>
<th>Body stigmas</th>
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<tr>
<td>Body size</td>
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<td>Body weight</td>
<td>Anorexia, bulimia, obesity</td>
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<td>Body movement</td>
<td>Paraplegic/quadriplegic/wheelchair</td>
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<td>Body image</td>
<td>Disfigurement</td>
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<td>Senses</td>
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<td>visual</td>
<td>Blind – visually impaired</td>
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<tr>
<td>aural</td>
<td>Deaf – hard of hearing</td>
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<tr>
<td>speech</td>
<td>Stutterers</td>
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<td>Learning</td>
<td>‘Educationally sub-normals’, ‘learning difficulties’</td>
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<td>Emotional</td>
<td>‘Autism’</td>
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<td>Mind</td>
<td>‘The mentally ill’</td>
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<td>Wider health</td>
<td>AIDS and other illnesses</td>
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(see chapter 21)
Here we briefly re-introduce the three main traditional theoretical issues in sociology and link them to disability. We then take some of these ideas a little further.

**Functionalism and disability**

Functionalism examines the ways in which social orders function. It looks at the ways in which parts of societies function or fit (or not) into the wider social order. In this account, disability is examined as a social role – in this case, a ‘sick role’, which we discuss further in the chapter on medicine (Chapter 21). It could easily see disability as simply a dysfunction and consider the way it disrupts social life. But here it could also think about the ways in which the disabled perform crucial functions for society. One of these is the ways in which the existence of ‘disabled people’ in a society can help mark out the boundaries of the ‘disabled’ and the ‘normal’. Most commonly, disability becomes a role which serves a number of functions. Functionalism, in looking at the smooth running of society, often highlights social control.

This process has been discussed for a long time by sociologists. Indeed, one of our earliest sociologists, Emile Durkheim (see Chapters 1, 2 and 4), suggested that this kind of division – into the normal and the pathological – seems to be bound up with the conditions for social life. For him the simple classification of the normal and the pathological served to mark out moral boundaries, and unite people against common enemies. It establishes that there is a ‘we’ and the ‘other’, and it is hard to find instances of societies who do not do this. It could be that some societies need ‘others’ to know who they are, and hence to function well.

An interesting connection can be made to the theories of Mary Douglas. Disability here can be seen as a threat to the social order and responses to it help to mark out the boundaries of order (see box below).

**Interactionism and disability**

Interactionism looks at the processes through which meanings are constructed, and its close ally is labelling theory – which examines the role of social labels or...
categories in social life. In this account, disability appears as a social category and as an emerging meaning, and sociologists examine the ways in which it works in societies: how it emerges in situations and what it might do to people who are labelled as ‘disabled’. The key concerns here focus upon the meanings that are given to disabilities, and the ways in which many of these are stigmatising.

The sociologist Erving Goffman has been influential in understanding stigma. He suggests an array of problems that happen when people are confronted with stigmas. Stigmas break down normal and routine interaction. They challenge and threaten what we take for granted. Hence disabled people often come to find their disability as threatening routine order. The blind challenge the sighted world; the deaf challenge the world of hearing; the physically disabled challenge the ways in which we routinely move around the world. Disabilities generate interaction problems.

Conflicts theory and disability

Conflict theory looks at the different interests in a society and how frequently some interests come to dominate, oppress or exploit others. In this account, disability is located within a system of different conflicts and interests, and it is seen most commonly as an experience which is discriminated against and oppressed.

We return to the wider issues of class, ethnicity, gender and sexuality again here. Mark Hyde has reviewed some of these divisions and concluded:

Disabled people experience profound levels of economic disadvantage, resulting in intense deprivation, and ultimately, a poor quality of life ... they are particularly dependent on state social services and benefits ... are often segregated by welfare programmes ... are subject to a significant level of state regulation ... and experience considerable discrimination.

(Hyde, 2006: 270)

In the UK, 50 per cent of disabled people are economically inactive and disabled women are more than likely to be unemployed than men (Office for National Statistics, 2001). Mike Oliver’s *The Politics of Disablement* suggests that disability must be linked to the working of capitalism. The difficulties, subordination and conflicts of disabled people take on different patterns in different societies, and within capitalism they are often seen as threatening to the routine world of hard work and money making. In its earlier days, capitalism was a major tool for regulating people in general, but especially the disabled. These found themselves in prisons, asylums, workshops, industrial schools and colonies. It was a period when the disabled were seen as ‘less than human’ and placed under regulatory systems. While it may be helpful in examining the past, it does not help us see just how and why the current situation has been changing. Feminist
writers have also shown great concern for the differences of the disability experience for men and women. Private issues to do with marital relationships, housework, abuse, violence and care come more to the focus.

Labelling theory suggests the importance of categorising and labelling in social life. When people define situations as real, they become real in their consequences. We have met them before (in Chapter 7) and discuss some of these ideas further in Chapter 17. Here we just introduce a long history of words and practices that stigmatise, shame and exclude people from the normal world. Sociologists have taken a keen interest in this, asking just what these words and practices are, and why they have come about.

Let’s start with a sample of words. Throughout history, the experiences we are talking about in this chapter have been variously called:

Cripples. Idiocy, feeble mindedness, mental subnormality, cretins. Lepers, blind with canes, the deaf and dumb. A world of ‘freaks’ – giants, dwarfs, siamese twins, fat ladies and living skeletons (Fiedler, 1981:13). They are also lunatics, nut cases, wierdos, sad people. Sometimes they are monsters. They are the handicapped, the subnormal, the retarded ...

We are sure you can think of many others.

All of these images construct ideas of some people being ‘the other’. Whatever they are, they are not you. Over time, we may debate and change the words that we call ‘others’. But beneath terminology is still a sense that there are ‘others’ – people who are ‘out there’, who are something else, radically different from ‘us’. They are not ‘normal’ and often they are very dangerous.
It is important to see that our responses help to shape the very phenomenon we are looking at: the words help to bring into being particular kinds of realities for the ‘impaired’ and ‘disabled’. Labelling may be a key to understanding the process of disablement.

Sociologists find that stigmatising labels seem to function widely in most societies. They facilitate the hierarchy, division and ordering of society by making it clear that some people are most surely not in the society. They are excluded, and made to sit on their borders and boundaries.

Now some borders can be perfectly tame, harmless and useful. A garden fence can be a helpful marker. But they can also be harbingers of hatred. Many have commented upon this: Thomas Szasz, a social psychiatrist, once said: ‘the first law of the jungle is kill or be killed’, while ‘the first law of human society was stigmatize or be stigmatized’. It is precisely because the inside/outside debate so often leads to enemies – with all the mocking injury and terrorist exterminations they can bring – that it is especially potent. In many ways, as Beck (1997: 81) says, ‘enemy stereotypes empower’. The invention of the other galvanises animosity. In a telling phrase, Bauman remarks:

woman is the other of man, animal is the other of human, stranger is the other of native, abnormality the other of norm, deviation the other of law abiding, illness the other of health, insanity the other of reason, lay public the other of expert, foreigner the other of state subject, enemy the other of friend. (Bauman, 1991: 8)

A short history of responses to disabilities

We can trace the history of varying responses to what we now call disabilities from earliest links to religion and magic through to other responses where disabilities have been denied, mocked, excluded, institutionalised or even killed. A quick history of disablements would show our responses in the past have embraced religious demonisation, medical pathologisation and social discrimination. Consider:

• The slaughter of the innocents – the frequent killing at birth of deformed children.
• The entertainment of the freaks – amusement for the bored rich in many societies, found in the popularity of ‘circus freaks’ in the nineteenth century.
• The locking away and banishing from sight of the disabled – in workhouses, asylums and institutions.
• The applications of science – the categorisation of differences as disorders and dysfunctions.
• The perpetuation of ‘eugenic beliefs’ – the search for ideal people and the reductions of faults and others who display these faults (the racial hygiene of Nazi Germany led to mass death, of which some possible 275,000 were disabled).
• The medicalisation of the disabled – the search for treatments and cures.
• The growth of an ideology of benevolence – the creation of ‘charity systems’.
• The normalisation of disabilities – attempts to correct much of the above from the 1970s onwards through deinstitutionalisation, inclusion, normalisation.

Disablements are also to be found in art and literature and contemporary film (you might like to look again at the painting which starts this chapter). In ‘children’s books’ (also much read by adults) we see ‘disabilities’ in *Gulliver’s Travels* (with their Lilliputians and Brobingnagians), *Alice in Wonderland*, or even *The Wizard of Oz* with the little people of Munchkinland (and never mind the tale of what they get up to in the film version!). The adult world of literature is also full of somewhat scary deformed monsters (*Dracula*, *Mr Hyde*, *Wolf Man*, *King Kong* etc.)

In Western twentieth-century societies, one stream of ‘imagining/representing disabilities’ came to us from the mass media (see Chapter 22). In the modern film disabled people stagger around being mocked, scaring people and often even slashing, mutilating and engaging in cannibalism.

Several stages appear in the history of films representing disability. A first stage (roughly 1890s – 1930s) continued the ‘freak show’ tradition. Earlier films of interest here might include Quasimodo, the Hunchback of Notre Dame (Lon Chaney film, 1923) and Todd Browning’s *Freaks*, which shows a circus world of (actual) bearded ladies, human caterpillars and the dancing pinhead. Between the 1930s and the 1970s a more exploratory ‘personal tragedy’ approach was often taken. Often this was combined with some kind of mysterious intrigue or crime (*The Snake Pit*, *The Lost*...
Weekend etc.). Developing in parallel there is a ‘shock-horror’ tradition which appears with The Mummy, Dracula and Frankenstein films and is exemplified in more recent films like The Texas Chain Saw Massacre through to all the Halloween and Wes Craven films. Here, monsters are at work (cf. Norden, 1994).

While the older traditions may still continue, there has been a more recent tendency to incorporate – even ‘normalise’ – the disabled in mainstream films, such as Robert Zemecki’s Forest Gump (1994) or, more startlingly and controversially, David Cronberg’s Crash (1996).

This has also given rise to an alternative, radical representation – often in films made by the disabled themselves, or else by ‘radical film-makers’, such as Frederick Wiseman’s Blind, and Adjustment and Work (1986).
In recent years, and across the world, there have been major changes in the reactions to disabilities. In much the same way as there have also been major changes in social reactions to ‘women’, ‘gays’ or ‘blacks’, these new attitudes and policies have been generated largely by disabled people themselves. Of course, as with all change, these shifts have been limited and partial. But that said, there have been significant shifts in laws, policies and practices in many parts of the world. The castigating of the outsider disabled person becomes less and less acceptable; and new laws and planning help facilitate the environment for people with disabilities.

For example, in May 2001, WHO formally changed its official definition of disability and introduced the ICF – the International Classification of Functioning, Disability and Health. In this, it moved away from a purely physical model of impairment and adopted more of the social model (see above). They explain:

Functioning is an umbrella term encompassing all body function, activities and participation;

Joseph Merrick (often referred to as John Merrick and popularly called the Elephant Man) is a reasonably well documented nineteenth-century (Victorian) case study of a man with what is often called ‘neurofibromatosis’ (some think it was Proteus Syndrome). In any event, he was a hugely disfigured man, and this started in his childhood. Born into a middle-class family, his condition led to him being cast out of his home and being sent to the Leicester Union workhouse. Seriously ill, he would probably have died on the streets, had he not been ‘rescued’ by circus showmen who paid for his necessary surgery and then turned him into a successful museum freak show exhibit. He may have made a reasonable sum of money from this but it was later stolen from him by robbers and less scrupulous showmen. He eventually was taken to Whitechapel Hospital by a Dr Frederick Treves, where, after initially being cared for, he eventually became what could now be called a ‘medical freak’. He went before medical classes as a ‘case study’, subjected to humiliating public examinations (often naked), was visited by the rich and famous who wanted to see him, and was even taken out ‘to be seen’ in public life.

Here we can see a life that is turned into an object of derision and amusement, of benevolence and hate, of medical inspection and seemingly humanitarian compassion. We like to think these days that the many ‘physically different’ are treated much better than this. But are they?

In 1980, David Lynch’s film The Elephant Man became a critical success and it is worth seeing. But ironically, the depiction of disabilities like this in film can also bring its own problems. On the one hand, such films may be seen as critically educational and designed to make us think about the different responses to disability. But on the other hand, there is a worry that it panders to some kind of lower interest in ‘the odd’. See www.phreeque.com for a series of photos and ‘stories’ about similar ‘freaks’ and perhaps monitor your own responses. See also: Robert Bogdan, Freak Show (1990); Michael Howard and Peter Ford, The Elephant Man (2001).

The Elephant Man: Joseph Carey Merrick (1862–1890)


Source: AP Photo/ho.
similarly disability serves as an umbrella terms for impairment, activity limitations or participation restrictions. ICF also lists environmental factors that interact with all these constructs. In this way it enables the user to record useful profiles of individuals functioning, disability and health in various domains.

WHO, 2001: 2

The ICF has two domains: classified body function and structure, along with activities and participation, within environmental and personal factors: it hence uses a multidimensional approach. You could say this is a little vague, and that it suggests the social model was only partially introduced. More recently, campaigners on disability issues have worked from a more developed social model, and yet others who once championed it (like Tom Shakespeare) have suggested the social model was too strong, and what was required was an interactionist model looking at the interaction between social and individual factors.

In the UK, the 1995 Disability Discrimination Act (DDA) 1995 made it illegal to discriminate against disabled persons in three areas: (a) employment; (b) access to goods, facilities and services; and (c) buying or renting land and property. A new legal definition of disability in the DDA is provided as any person who has a physical or mental impairment or long-term health condition, which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. Normalisation is a key guide, and it rejects refusal of employment on grounds of disability (Best, 2006: 85).

In 1999, a Disability Right Commission Act established a new body that would monitor the elimination of discrimination against disabled people and promote equal opportunities (a little like the Committee for Racial Equality set up in 1976 under the Race Relations Act). A little later, the Special Educational Needs and Disability Act 2001 enhanced the rights of parents of children with disabilities. If parents wish it, then Local Education Authorities now have a responsibility to educate children with special educational needs in mainstream schools.

But these laws are not just happening in the UK. Similar legislations, bodies and practices are now found around the world.

Despite all these developments, critics argue that they have amounted to very little. One says: ‘Despite major changes in legislation… the dominant picture remains one of discrimination, prejudice, injustice and poverty, often rationalised on the grounds of supposed progress for disabled people’ (Swain, et al., 2004: 1).

Contemporary disabling attitudes

Whatever recent legal changes may have occurred there is still substantial evidence that there remains a prejudice against disabled people today. In a recent study of British Social Attitudes (2007), for example, while only 25 per cent of the population think that there is a lot of prejudice towards the disabled, many survey respondents indicated the opposite. Around half, for example, would not be comfortable with a relative marrying a blind person and only 19 per cent say they would feel comfortable were a person with schizophrenia to marry a close relative of theirs. As is common with many prejudices, familiarity with disabled experiences usually reduces the levels of stigmatisation.

Although quite a small-scale study, one look in the UK at the attitudes of people to disability outlined five types of response:

1. Traditionalists (about 15 per cent) who had stereotyped views.
2. Followers (26 per cent) who were mainly non-disabled and have little interest in disability issues.
3. Progressives (36 per cent) mainly non-disabled, middle-class educated – normalising.
4. Transformers (9 per cent) younger, often disabled, who want normalisation.
5. Issue-driven respondents (14 per cent) – usually disabled or disabled identified – who were ‘vocal and active on behalf of disabled groups’ (Jane Sancho 2003).

The reactions from social science

The diagnostic social sciences have a long history of classifying, examining and suggesting responses (often treatments) to disabilities – which two authors have recently called ‘an obscene curiosity disguised beneath the neutral veil of empirical inquiry’ (Snyder and Mitchell, 2006: 193). They are critical of the rise of ‘people based research practices’ where disabled people start speaking back about their experiences – but often at their own expense of time, energy and liberty. They describe their own experiences, tell of their own stories (and subjectivities), and make public their interior worlds. This may have a dramatic policy function – to
make services better fit their needs. But it may also serve as tools which further exaggerate their differences and work to set them apart. Whether they are correct in this analysis remains to be seen.

How do human beings deal with their impairments, disabilities and stigmas? We could see four main patterns:

1. Denial: some try to deny their disabilities. Mild disabilities can simply be avoided – it does not seem serious enough to make an issue. Some impairments can be concealed, and even when they cannot, some try to pass as ‘normal’. A person with a speech defect, for example, may learn that they can hide their defect by not exposing themselves to certain situations (avoiding new people and strangers where they lack confidence) or not saying certain words or sounds (some sounds and words are often much harder to say than others). Sometimes they solicit the support of others. They adopt a cloak of competence. They avoid situations which would be threatening. They deny and disavow their stigma.

2. Normalisation: here the disability comes to be incorporated routinely into daily life. It becomes habitual, accepted. This does not mean the process is trying to make the disabled ‘normal’ – like everybody else. It means, rather, the means by which the disabled come to lead lives that are routine and normal for themselves, and that society in turn assists in this by providing the conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society.

Martha Nussbaum: Human capabilities and human rights

Martha Nussbaum (1947–) is a leading contemporary social philosopher. Originally a ‘classical scholar’ interested in the work of Aristotle, most of her recent work considers contemporary social issues where she is seen as a major champion of human rights. She has looked at disability rights along with many other issues: women in developing countries, the issues surrounding gays and lesbians, animal rights, the problem of shame in many cultures, and most recently social change and religious conflict in India. She argues from a position that we would call liberal, feminist, humanist and cosmopolitan. Her work seeks to develop ideas about the free, dignified and equal social human being, the ‘just society’, ‘well-being’ and a good quality of life. Many of her arguments lead her to the field of ‘human rights’.

Her core thesis centres around what she calls ‘human capabilities’, an idea she developed with the economist Amartya Sen. Human capabilities are ‘opportunities for functioning’ in the world. They are, in her view, basic human entitlements. We cannot flourish as human beings without these ‘entitlements’. The disabled cannot flourish without these capabilities being recognised and cultivated. One of her key questions concerns the activities which are central to a human life, so central that without them we could not consider this life ‘truly human’. ‘She suggests a number of human capabilities which include:

1. **Life**: being able to live to the end of a ‘normal human life’.
2. **Bodily health and integrity**: being able to have good health, be adequately nourished and have adequate shelter.
3. **Bodily integrity**: being secure and able to move from place to place in safety; and having opportunities for sexual satisfaction and for choice.
3 Disengagement: here the disabled withdraw from social groups and society. This can often be seen in the institutional response – not only when disabled people are placed in institutions and hence are made to withdraw from the wider society, but also when they become even more isolated and cut off within institutions.

4 Fighting back: here the response is to actively use their disability – in both their personal life and also for wider social change. This can be done in small personal ways (rebelling, resisting), but it can also be seen as part of a wider social movement – which is discussed below.

The Disability Movement is worldwide and plays an increasing role for disabled people. Some organisations are national; others are international like Disabled People’s International. Some are for specific groupings like the World Federation of Deaf, or the World Blind Movement. The movement gives a voice to disabled people, allowing them to challenge more traditional views and make their own decisions about their lives. No longer hidden away or patronised, the movement encourages a much more visible and active role.

They can be yet another example of the new social movements, which transform identities and society, creating new political awareness in the post-industrial society (we discuss this further in chapter 16).

Types of disability movements

Three main types of organisations stand out (adapting the work of Mike Oliver, 1990):

1 Umbrella/coordinating organisations of many groups. The United Kingdom’s Disabled People’s Council (UKDPC) is the UK’s national organisation of the worldwide Disabled People’s Movement. Set up in 1981 by disabled people to promote full equality and participation in UK society, it now represents some 70 groups run by disabled people in the UK at national level. Between them, member groups have a total membership of around 350,000 disabled people. It is run by disabled people, works on issues of human rights, and claims to have been the main body behind the changes which led to the Disability Discrimination Act (DDA) (see www.bcop.org.uk).

In general, these are the oldest and most established of organisations. In the past, they have been linked to charitable bodies and provided a range of services and consultations. However, they were often not very inclusive: grass-roots activism was not on their agenda. But this has changed a lot in recent years.

2 Consumerist/self-help. The ‘Independent Living Movement’ (De Jong, 1979) is a prime example of this. In the 1970s it signalled a major shift from the biomedical view of disability to a social concept model. The goals shifted from the cure, maintenance and safekeeping of the disabled – with disabled people being in a kind of childlike dependency – to goals of inclusion and full participation within society. The movement grew in North America along with other counter-cultural groups of the late 1960s (like the women’s, black, gay and student movements). It was developed in the Scandinavian countries during the 1970s.
With this approach, the disabled role and all the stereotypes associated with it are now rejected. Key ideas now become the normalisation of the disabled, their ‘mainstreaming’, and their deinstitutionalisation. Society should change to provide an environment for the disabled. Bit by bit, over the past forty years many of these arguments have become rather mainstream in themselves. Most Western governments now incorporate disability voices in their planning and programmes. Independent Living Centres are staffed by people with disabilities and usually entirely run by them. Hundreds of groups have been established. They argue for environmental change: accessible housing, curb cuts, audible pedestrian signals, accessible transportation and accessible public buildings. They work for rights and specific legislation. They change the wider culture – making an impact on transport systems, toilet facilities, recreation, shopping, education and employment (see: http://www.ilusa.com and http://www.ncil.org.uk).

3 

Populist/activist. In the UK, one of the major groups was UPIAS – the Union of Physically Impaired Against Segregation, established in 1974. Michael Oliver, in work with the Open University, produced a book, *Handicap in a Social World* (1981), which started to formulate a much clearer social model, distinguishing ‘personal tragedy theory’ from ‘social oppression theory’ (as outlined in Table 14.1). His main concern was neither with medical models nor social science models, but ones that came from the experiences of disabled people themselves.

Disability activism grew during the 1970s and it now plays a major role in shaping policies for the disabled. It engages in direct political action and consciousness-raising. In the UK, the Direct Action Network engages in some civil disobedience. It adopts a much more direct in-your-face approach:

Direct action is in your face. Disabled people are supposed to be invisible: they are not supposed to go out and be seen. Direct action has changed this. We are noticed!

(A disabled activist, cited by Hyde, 2006: 266)

The activist groups are the most radical of the groups. They usually provide a more complex analysis of ‘disability politics’ and generate heated debates about the future of disability. They offer a critique not just of the responses to disability but they also find the whole society lacking. Disability Identity Politics provides a new consciousness.

A recent development here has been the arrival of ‘crip theory’ (McRuer, 2006). This takes queer theory as its model of thinking (see Chapter 12) and uses the idea of ‘the cripple’ to threaten the general view of the normal body. They urge a radical rethinking of the ways we think about disability and disable people. Bodies and disabilities are fluid, ever changing. The enemy is the idea of ‘compulsory able-bodiness’ (McRuer, 2006)

Finding a voice

The importance of self-activism was highlighted in 1995 at the World Summit on Social Development, when the World Disability Movement presented their own position paper (*The Disability Movement: A Joint Statement*). They argued:

In any situation people find the best solution for themselves. And disabled people have come up with solutions, the solutions of advocacy, independent living, income generation and self help within our own organisations. All these solutions are based on the principles of integration and equalisation of opportunities and the implementation of human rights … These solutions are all effective, low-cost and do not require setting up tiers of professionals to run them. They do not include expensive building that has to be maintained and refurbished. They are the grass-roots solutions which can be employed everywhere – in rural and urban areas – which will benefit everybody and which include everybody. They are solutions that not only apply to all disabled people but to the rapidly growing numbers of elderly people, to children, to the poor, to refugees, to ethnic minorities …

(Hurst, 1999: 28).

Or:

We’ve begun to realize that the disabilities aren’t the problem that needs to be fixed. Just as some people are black or fat or short or tall or wear glasses, persons with disabilities have unique physical or mental characteristics which simply don’t meet (and often never can) society’s standard of normal. Experts trained in biomedical knowledge, and counsellors who understand the psycho-social dynamics of deviation, are not the ones who can solve the problems. Rather, it is other disabled persons who’ve lived, experienced, and found solutions on how to live with and manage disabilities in the so called ‘normal’
standardized world who are the ‘real’ experts who can best share the knowledge and experience required.  

(Disabled person)

**Disability sport**

Sports activities have, over the past few decades, provided a major worldwide arena where disabled people have been able to demonstrate to themselves and the wider world their functional abilities. The ‘Special Olympics’ started in 1968. It treated everyone who participated as a winner, and it now involves around 2.5 million children and adult athletes in more than 165 countries. The International Paralympics is more competitive. It started in England in 1948, being staged as an Olympic-style competition in Rome in 1960. The number of athletes participating in the Paralympics has increased from 400 athletes from 23 countries in Rome in 1960 to 3,806 athletes from 136 countries in Athens in 2004. From the 2012 bid process onwards, the host city chosen to host the Olympic Games will be obliged to also host the Paralympics.  

(On disability sport, see: the English Federation of Disability and Sport at http://www.efds.net; the International Paralympic Committee at http://www.paralympic.org/release; and the Special Olympics at http://www.specialolympics.org.)

Globally, the World Health Organisation (WHO) estimates that disabled people make up 10 per cent of the population – around 650 million people. 80 per cent of persons with disabilities live in developing countries. This figure is increasing through population growth, medical advances and the ageing process. On all our dimensions of inequality, the disabled feature prominently. Disabled people account for 15 to 20 per cent of the world’s poorest people. Women with disabilities are recognised to be multiply disadvantaged, experiencing exclusion on account of their gender and their disability. In Bangladesh, 97 per cent of disabled women are unemployed. They are also particularly vulnerable to abuse. A small 2004 survey in Orissa, India, found that virtually all of the women and girls with disabilities were beaten at home, 25 per cent of women with intellectual disabilities had been raped and 6 per cent of disabled women had been forcibly sterilised. According to UNICEF, 30 per cent of street youths are disabled. Disabled people of working age in developed and developing countries are three times
more likely to be unemployed and live in real poverty; 90 per cent of children with disabilities in developing countries do not attend school.

The disabled are also ‘excluded‘ from many key social institutions. In many countries, disabled people are unable to place their vote. While an estimated 386 million of the world’s working-age people are disabled, unemployment is as high as 80 per cent in some countries. Often employers assume that persons with disabilities are unable to work. Most low-income societies lack transport systems with accessibility; they usually have little or no free medical care or social protection services; and the idea of disability rights are only beginning to be placed on an agenda that often seems to have much more pressing needs. But disability levels are often very high in low-income countries – and not least because of many civil conflicts which can lead to severe disabilities. The UN suggests that for every child killed in warfare, three are injured and permanently disabled (see the brief discussion on child soldiers in Chapter 13). (The source for all these figures is a United Nations fact sheet on disabilities where you can find much more: www.un.org/disability/convention/facts. It is important to bear in mind that

The global politics of disability

The UN Convention on the Rights of Persons with Disabilities, 2007

Initially proposed by Mexico in 2001, the UN Convention on the Rights of Persons with Disabilities was signed by 102 countries in 2007. It aims ‘to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.’

People with disabilities are here seen to include ‘those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.

It is based on eight key principles:
1. Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons.
3. Full and effective participation and inclusion in society.
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.
5. Equality of opportunity.
6. Accessibility.
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The signatories will have to enact laws and other measures to improve disability rights and also agree to get rid of legislation, customs and practices that discriminate against disabled people. The thinking behind the convention is that welfare and charity should be replaced by new rights and freedoms. At the time of the Convention being passed, only 45 countries in the world had already passed disability legislation.


A Mexican example

Los Discapacitados of the City of Oaxaca, Mexico, is a grass-roots cosmopolitan advocacy group which campaigns for the rights, access and opportunities for people with disabilities in the city and region of Oaxaca. It is just one of thousands of such groups found all over the world.

Disabled people were in the recent past primarily dealt with by rehabilitation agencies. But now groups are creating a new culture for disabled people. Working with local and international groups, using the Internet creatively, they want the voices of the disabled to be heard.

German Lopez and his friend Pedro Flores (both had contracted polio in their infancy) set up major events for the local disabled. They spent numerous hours partying, often dancing the night away – some use their crutches while they dance, others dance in their chairs. They spent hours in sporting activities – basketball, tennis, track and swimming – leading to national and international tournaments.

In the past, the family was the core for looking after the disabled. Now there are many community groups which create strong identities for disabled people, as well as positive life styles.

facts are very hard to obtain as so many disabled people are hidden and anonymous with regard to official statistics.)

Disability World

One example of globalisation is the creation of the US webzine Disability World. Originally funded by the National Institute on Disability and Rehabilitation Research as the cornerstone of the IDEAS for the New Millennium Project (1999–2005), Disability World was managed by the World Institute on Disability (WID), based in Oakland, California, and conducted as a collaborative effort with the participation of three other US-based disability groups: The Independent Living Research Utilization Project, The Inter-American Institute on Disability (IID), and Rehabilitation International (RI).

Disability World covers seven key areas: independent living; employment; arts and media; technology and accessibility; governance and legislation; women; children and youth. It focuses on ten countries each year, holds international meetings on specific themes (like independent living, employment, media and disability governance), and is developing a portrait of the status of people with disabilities in each of the countries targeted for coverage. The first 23 issues were published in both English and Spanish. It houses a literature database of more than 800 abstracts of articles primarily covering employment, independent living, governance, disabled women, disabled children, technology and appropriate technology, community-based rehabilitation and rehabilitation in developing countries, all searchable by topic or country. It is all accessible on its website: http://www.wid.org/publications.

The growth of the ‘compassionate temperament’

Natan Sznaider has characterised the development of modernity (and into postmodern times) as one which sees the growth of ‘the compassionate temperament’. For Sznaider, ‘compassion is the moral organization of society’. It is about pain – ‘about sensing other people’s pain, about understanding pain, about trying to do something about it’ (Sznaider, 2001: 25). And this has not always been the case. As he says:

It is the first moral campaign not organized by the church or the state. The structures of modernity are what make this self organization possible. And the moral sentiments that result from this process constitute qualitatively new social bonds.

(Sznaider, 2001: 1)

Sznaider, rather boldly, suggests that it is exactly the modern world which fosters ‘compassion’. It was not present before. And by compassion, he means the development of ‘moral sentiments’. Usually sociologists say almost the opposite: that modern society has corroded moralities and fostered breakdown. But Sznaider takes an alternative stance, which he tries to document through recent history. Of course, he agrees with sociologists who say major changes are taking place, but he interprets the many changes in a different way. He says:

What they see as discipline, I see as compassion. Where they see power, I see moral sentiments. And where they see social control as the state’s control over society, I see social control as society’s control over itself – a kind of control explicitly different from state control or religious control.

(Sznaider, 2001: 2)

This is a radically different statement about society to that which has informed much ‘critical sociology’. In this view, a ‘humanitarian consciousness’ developed during the eighteenth and nineteenth centuries. Cruelty and pain came to be seen as social evils, and compassion becomes organised to protest against it. It is not shaped by divine will but through an abstract
and rational idea of ‘humanity’. Prior to modern times, cruelty and suffering were more likely to just be accepted. In modern times, cruelty and suffering became – to put it bluntly – acceptable.

Public compassion involves the ability to sense and imaginatively reconstruct others’ sufferings, along with a desire to do something about it. Modern humanitarianism implies universal sympathy, an equality of sentiment and a striving for universal happiness. The past did not. Medieval charity and its precursors lacked this empathy and moral sentiment.

Of course, Sznaider does not deny that modern times have also been times of unspeakable cruelty, holocausts and other horrors. But as he says: ‘this has been the century of cruelty, and it has also been the century of compassion’ (Sznaider, 2001: 99).

### Looking for the signs of an emerging compassionate society

Much of sociology has looked at the sufferings of people in humanly constructed social worlds – of how, in a way, they make ‘hell on earth’ for each other. If you read this introductory book carefully you will find a long list of troubles: genocides, wars, environmental crises, suicide, inequalities of many kinds, and world and local poverty. No wonder that the social sciences (especially economics) are called the dismal and the sad sciences!

Recently, however, some social scientists are starting to look more for the signs of a better society – taking a more positive interpretation. They look for ‘well-being’ across the world; at their most extreme they try to measure ‘happiness’(Layard, 2007). Sometimes, this kind of work is ridiculed by more critical social science as utopian and, indeed, for closing its eyes to the terrible things that are going on in the world. But, of course, this approach is not denying the existence of terrible things happening in society – it just wants to redress the balance a little, and show signs of betterment.

To close this part of the book, then, you might like to consider the following issues as ‘signs of an emerging compassionate society’.

### 1 Welfare states and social protection

Over the past hundred years, many societies have come to accept that the state has a major role to play in the well-being of its members. It cannot just leave them and their lives to their own disasters. It needs policies for welfare – to fight the problems of poverty, ignorance, poor health and others. It needs to provide money that will facilitate the protection of its more vulnerable societal members – the child, the elderly, the disabled and others. It needs to establish legislative frameworks in which this can be done. Hence we have seen the growth of the welfare state, social protection, and the rise of health services and education systems. The big issue, of course, is whether this should be the final responsibility of the government or whether it should be placed in a system of capitalist markets.

**Social protection** is the help available to people who are in need or are at risk of hardship for reasons such as illness, low income, family circumstance or age. The most basic aim is to provide healthcare and income security for all. To this end, central governments, local authorities and private bodies (commercial and voluntary) can provide help and support in four major areas:

- Direct cash payments – social security, benefits.
- Payments in kind – bus passes, free prescriptions.
- Provision of service.
- Unpaid care. *(Social Trends, 2007: 102)*

In the UK in 2004/5, the total government expenditure on social protection was £294 billion – equivalent to 25 per cent of the gross domestic product at market prices. For 2003, it was calculated out at £4,710 per person (which was higher than the EU average). Luxembourg, Sweden and Denmark spend the most (at around £5,000–£6,000 per head); Spain and Portugal spent the least (at around £3,000). In other words, we spend a great deal on these acts of benevolence and are willing to be taxed to support them.

In the UK, social security benefits cost around £130 billion in 2005–6 (65 per cent was for people of pension age). The personal social services (social work) cost £18.2 billion (2004–5) – 44 per cent (£8 billion) on people aged 65 or over.

Table 14.4 suggests some of the key ways in which the UK government spent money on public services in 2006/7. Although it is never ‘enough’, many governments now spend vast sums of money on caring for and protecting their members.
2 Social care

In recent years, and especially because of the works and research of feminist writers, there has been a growing recognition of the importance of ‘care’ as a feature of social life. The nature of social care and its provision is now a ‘hot topic’ in sociology, and governments increasingly take it into account as a major organising principle of society.

In the latter decades of the twentieth century, some sociologists have become more and more interested in ‘care’. An early example was the study by Janet Finch, who looked directly at the ways in which daughters often look after – ‘care’ for – their elderly parents. Why was it daughters that mainly did this? What did they actually do? What did it do to them?

Care can mean two things, but they are often linked. Care (as in caring person) can mean a kind of mental state, usually viewed positively. We say ‘they are such a caring person’. But it can also mean an act of labour (see Chapter 15), a practice, in which a person does certain things to assist others. We say ‘she’ is a ‘carer’. These two ideas often hang together, and they may even be a sequence: from a caring thought comes a caring action. Hilary Graham (1983) suggests there is also a caring about, which suggests a more general concern for others, and a caring for, which concerns the more specific work employed in looking after someone. The former tendency can lead to an interest in ‘an ethics of care’; the latter has been neatly called ‘a labour of love’ (1983)

Joan Tronto, in developing her ideas of care, does, however, note just how much ideas of care are often devalued in society. ‘Carers’ tend to be at the bottom of the hierarchy. Care workers are unpaid, underpaid, devalued and often marginalised. Put like this, ironically it comes to appear that ‘care’ really may not be one of the core assumptions on which we can agree – who cares about the shit workers? Who cares about the carers?

Australian sociologist Michael D. Fine has provided us with a very nuanced account of care in the twentieth century. His concern is with care in all its forms, but notably the distinction between private care and formal care. He sketches a basic model, as shown in Table 14.5.

3 Rights and equality frameworks

Many contemporary societies have come to take for granted that people have rights and that they should be treated, roughly, equally. Much contemporary legislation, for instance, seeks to provide frameworks that will facilitate:

Table 14.5 Modes of care provision: a basic schema

<table>
<thead>
<tr>
<th>Informal</th>
<th>Formal</th>
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</thead>
<tbody>
<tr>
<td>Care of particular individuals</td>
<td>Care of strangers</td>
</tr>
<tr>
<td>Unpaid</td>
<td>Volunteers</td>
</tr>
<tr>
<td>Paid</td>
<td>Human service facilities and institutions.</td>
</tr>
<tr>
<td>Family care (at home)</td>
<td>Care professionals</td>
</tr>
<tr>
<td>Paid domestic help (private)</td>
<td></td>
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</tbody>
</table>

• A broad equality of people before the law.
• The idea of people having human rights.
• The idea of what it is to be a good citizen.

These ideas have been debated for centuries (Ishay, 2004) but have come to prominence in the modern world. The human rights movement is worldwide; and the debate over citizenship is currently ubiquitous (Isin and Turner, 2004).

4 Self-care and global activism

One of the most striking developments in the late twentieth century, with roots back into Samuel Smiles Self Help etc., has been the widespread growth of self-help groups and global social movements of care which aim to promote the health and well-being of their members. They range from patient and patient support groups to radical action groups. These days they often have to be media aware in order to bring their concerns to a wider public.

Some are geared towards research and education, some are fund raising organisations, some are politically active – from lobbying governments to challenging general perceptions – some provide general mutual support for their members, some offer treatment: many offer all or most of these things. They can be looked at as social movements, pressure groups, resistance to professional power, charities, philanthropic groups and as models of new selves. In general, they divide between those which are assimilationsist (i.e. those that want improvements and support within the terms of the existing society) and radical (i.e. those that see the need for fundamental changes before the issues around the problem can be resolved) (Robinson and Henry, 1977).

Movements that ‘care’ about rights, illness, education, the environment and health are widespread. Just as we have seen, in this chapter, the rise of...
disability activism, so we can find—elsewhere in this book—an environmental movement (Chapter 25), a women’s movement (Chapter 12), gay and lesbian rights movements (Chapter 12), a health movement (Chapter 21), a minority rights movement (Chapter 11), AIDS activism (Chapter 21) and many others. These days they are more and more facilitated in their organising through websites.

5 Charity and philanthropy

In the early twenty-first century there are some signs that charity and the ‘not for profit sector’ is growing. UK registered charities doubled in thirty years with 76,000 in 1970 and some 187,000 by 2002. In 2005/6, the UK population donated some £8.9 billion to charities. The average annual donation per UK adult was £183.36, and the average monthly amount given per person was £15.28. Their total annual income was around £30 billion per annum—half of which comes from government funding. About a third of UK households give to charities. Some studies suggest that relatively little of this charitable money from big spenders actually goes to low-income groups (CAF, www.cafonline.org and charity-commission.gov.uk) (see also the Center on Philanthropy www.philanthropy.iupui.edu).

The ‘rich’ pledged or gave around £1.2 billion in 2007. Some were major and international charitable organisations (AIDS, worldwide humanitarian relief, helping Africa feed itself). Many see it as social investment rather than charity. Some find their names in the newspapers for their acts—Elton John gave around £25 million to AIDS causes in 2006, JK Rowling some £22 million. Often the celebrities are deeply involved in their charities. In the US, Bill Gates has given some £30 billion to health and education causes. The Top 10 box below suggests that high-level donors seem more likely to give money to religious and artistic causes than to those charities that support low-income groups (see Sunday Times Giving Index, 2007).

The continuing development of ‘charity’ and philanthropy is often given bad press by social science—charity and benevolence are often seen as masks of self-interest and as sops for the conscience of the rich. When Madonna adopts a child from Africa, she is wide open to attack! Nevertheless, charity and philanthropy are widespread social practices which do help large numbers of people. Nowhere can this be seen more clearly than in the assistance given to many low-income societies. Critically there are major debates about the giving of aid to poor societies (as we have seen in Chapter 9), but should we stop all such activity? Doesn’t it seem so deeply embedded in the contemporary social structures that we should at least try to help when we are better off?

6 International governance

It is possible that societies have always dreamed of living in global harmony. At the start of the twenty-first century, there are now major international organisations firmly in place to provide global governance and care. One hundred years ago we had neither the United Nations nor the thousands of international non-governmental bodies that strive for the care and protection of citizens on a global scale. These movements monitor progress in the world, set major targets for social improvements, galvanise actions for change. Already in this textbook, for example, we have met measurement devices like the Human Development Index and the gender gap. For all their problems (see Chapter 9), these are useful in trying to see ‘the state of the world’ (see Chapter 26). Likewise, the millennium development goals attempt to provide goals for eliminating world poverty (see Chapter 9), while the
Kyoto agreement establishes international agreements of carbon emissions (see Chapter 25). Table 14.6 shows the number and range of major human rights protocols the UN has established to date. Engaged in all of these activities are hundreds of thousands of people from across the world who are fighting to make the world a better and more equal place. These organisations can be criticised on many grounds; but that this is a start on the development of major worldwide institutions of care and compassion cannot easily be denied. Sociologists need to study their workings.

### 7 The compassionate temperament and the cosmopolitan attitude

Finally, accompanying all this has not just been a compassionate temperament, but also a growing cosmopolitan attitude. Again, this is not a new idea – the history of cosmopolitanism is long. But it has become a major talking point in recent times. As Appiah (2006) puts it, cosmopolitanism means a ‘universal concern and respect for legitimate difference’.

<table>
<thead>
<tr>
<th>Table 14.6</th>
<th>Global human rights conventions</th>
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<tbody>
<tr>
<td>The core United Nations Human Rights Conventions are:</td>
<td></td>
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<tr>
<td>- International Covenant on Civil and Political Rights</td>
<td></td>
</tr>
<tr>
<td>- International Covenant on Economic, Social and Cultural Rights</td>
<td></td>
</tr>
<tr>
<td>- Convention on the Elimination of all Forms of Racial Discrimination</td>
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<tr>
<td>- Convention on the Elimination of all Forms of Discrimination against Women</td>
<td></td>
</tr>
<tr>
<td>- Convention against Torture and other Cruel, Inhuman and Degrading Treatment or Punishment</td>
<td></td>
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<tr>
<td>- Convention on the Rights of the Child</td>
<td></td>
</tr>
<tr>
<td>- International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families</td>
<td></td>
</tr>
<tr>
<td>- Convention on the Rights of Persons with Disabilities</td>
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</tbody>
</table>

All can be consulted on the web at the Office for the Commissioner of Human Rights at: http://www.unhchr.ch/html/menu.

Falklands veteran Simon Weston addresses the Conservative Party Conference defence debate in Bournemouth, where he received a standing ovation

Source: To come.
Differences and disabilities have been responded to throughout history in a multitude of fashions. For much of the twentieth century, many differences – including people with disabilities – were stigmatised, medicalised, regarded as ‘victims’ of their condition and a ‘burden’ on society. But what we have also started to see in this chapter is the ways in which people of difference have started to change the conditions in which they live. More and more, and across the world, there is a growing ‘disability awareness’ and a rejecting of the old discrimination. It is part of a more general trend towards rights and care. Disabilities are now increasingly seen as distinctive forms of social inequality, discrimination and social exclusion which require social changes in order to be rectified.

We have seen (Chapter 4) that the idea of progress is a difficult one. Over the past few chapters you have read a lot about exclusion, discrimination and inequality. The bad news is that it pervades all of social life and that, in some of its forms, inequalities are growing wider and the potential for conflicts is growing. But the good news is that over the century or so we have experienced new social structures of compassion which argue for change and bring about new practice of care. The notion of the growth of a compassionate, caring society does give some room for hope in a world that is so often seen as being interminable decline.
We need to distinguish between impairments and disabilities and social and medical models. Disability rather than impairment, and social models rather than medicine, is the province of the sociologist.

Main social theories of disability include the functionalist, interactionist and conflict theories. The first examines the social role of disability. The second looks at the social meanings of disability. And the third looks at the inequalities that surround disablement.

The category of disabled often functions to mark out the normal and the outsider in society.

There is a long history of stigmatising the disabled. They have been demonised, medicalised, and turned into objects of fun. Looking at both literature and film shows shifts in the ways the disabled are being portrayed in contemporary societies.

The disabled can deal with their impairments in four ways: as denial, as ‘normalisation’, through disengagement and in resisting and fighting back.

Disability movements divide into (a) coordinating (b) self-help and (c) activist.

Disability movements and the rights around disability have now become global issues.

The ‘humane society’ is one that tries to reduce inequalities and divisions and to foster humane responses to social life.

The modern world has strands of development that seem to foster ‘compassion’ and the development of ‘moral sentiments’.

Signs of this emerging society include: welfare states, social protection, social care, rights and equality frameworks, self-care and global activism, charity and philanthropy, international governance and the cosmopolitan attitude.
Suggestions for going further

A Review the chapter

Briefly summarise (in about five sentences or one paragraph) just what this chapter has been about. Consider:

1. What you have learned from this chapter.
3. How would you develop all this? How could you get more detail on matters that interest you?

B Pose questions

1. Trace the history of changing attitudes to disabilities and impairments. Could you argue that the twenty-first century has shown some signs of progress?
2. 'The first law of the jungle is kill or be killed', while 'the first law of human society was stigmatize or be stigmatized' (Szasz). In what ways are the disabled at the forefront of the stigma process? Analyse the work of disability activist movements as part of a wave of new global social movements.
3. In what ways, if at all, can the twenty-first century be seen as a 'compassionate' and 'caring' society?

C Enhance key words

Many concepts have been introduced in this chapter. You can review them from the website or from the listing at the back of this book. You might like to give special attention to just five words and think them through – how would you define them, what are they dealing with, and do they help you see the social world more clearly or not?

D Search the web

When you net search, make sure you have your critical faculties with you. What is the source of your site? Is it reliable authority, a pressure group, or one that is known to be a little bit shaky (like Wikipedia)? If it has weaknesses, what are they and are you taking them on board? Is it up to date? How will you cite it?

Some useful sources for this chapter are:

- Disability Alliance
  http://www.disabilityalliance.org
  Produces the very useful annual Disability Rights Handbook, and works to break the link between poverty and disability.

- Disability World
  http://www.disabilityworld.org
  Produced by the World Institute of Disability, it provides a wealth of worldwide information on all aspects of disability. Strongly recommended.

- Disability Now
  http://www.disabilitynow.org.uk
  Published regularly online by Scope. Very useful for up-to-date information.

International websites

- World Health Statistics 2007

- Disability Tables
  http://www.icdi.wvu.edu/disability/pages/World_Contents.htm

- International Disability Alliance
  http://www.internationaldisabilityalliance.org

- Human functioning and disability – statistical definitions and guidelines

UK websites

- Arthritis Care
  http://www.arthritiscare.org.uk/Home

- British Polio Fellowship
  http://www.britishpolio.org.uk

- Scope – about Cerebral Palsy
  http://www.scope.org.uk

- Multiple Sclerosis Society
  http://www.mssociety.org.uk

- Cystic Fibrosis Trust
  http://www.cftrust.org.uk
Learning Disability Statistics
http://www.learningdisabilities.org.uk/information/learning-disabilities-statistics
Mental distress statistics: Mind
http://www.mind.org.uk

Watch a DVD

- Peter Bogdanovich’s Mask (1985): mother, played by Cher, fights for rights of a badly disfigured boy.
- Mike Nichol’s Regarding Henry (1991): tough lawyer is seriously injured and makes a slow recovery.
- David Lynch’s The Elephant Man (1980).

See also:

- Shapiro and Rubin’s Murderball (2004): follows teams of paraplegics to the 20004 Paralympics. Much of the film is shot via the wheelchair, and there’s no preaching.
- The Life and Death of Bob Flanegan, Supermasochist (1997): an example of ‘crip theory’ at work as a man with cystic fibrosis performs dramatic sexual acts!

Think and read

Jo Campbell and Mike Oliver, Disability Politics (1996) and Tom Shakespeare, Disability Rights and Wrongs (2006). Important critical reviews of the state of disability studies which promote new agendas.
Erving Goffman, Stigma (1962). This is the classic and field-shaping text. Short and fairly easy to read. It helped change the way the world sees disabilities.
Paul Higgins, Outsider in a Hearing World (1980) Sage; and Robert Edgerton’s The Cloak of Competence (1972) are two early field work studies of disabilities.

Relax with a novel

- Blake Morrison, And When Did You Last See Your Father?
- John Gayley, Iris.
- C.S. Lewis, A Grief Observed.

Connect to other chapters

- Link to Chapter 17 on theories of labelling and deviance
- Link to Chapter 21 on health and medicine
- Link to Chapter 16 on social movements
- Link to Chapter 26 on the state of the world

The big debate

Bio-ethics and disability rights

As we shall see in Chapter 21, medicine plays a major role in contemporary social life. And as this chapter suggests, in the modern world it has played a significant role in the cultural response to all kinds of disabilities. Differences are often medicalised.

Recent trends have looked more and more to moral, ethical and ultimately political debate about differences. This is not to reduce the significance of medicine, but simply to note that many of the decisions around lives are moral ones. And in a society that is called ‘reflexive modernity’ (see Chapter 4), people are more and more reflecting on the nature of their differences and disabilities.

Medical ethics have been around for a long time. The Hippocratic oath (from the Greek physician Hippocrates) is famously cited – even though nowadays this is much disputed – as a key source for what became ‘medical ethics’ in the seventeenth century. (The first code of medical ethics appears to have been adopted by a professional organisation was written by English physician Thomas Percival)
Modern bio-ethics is mainly a response to, and product of, concerns around the new technologies. Bio-ethics grew from the 1970s and is now a huge specialism with major journals, books and conferences covering a vast field of issues. Among these are:

- Long-term and end-of-life care, cloning, life support, surrogacy, medical torture, euthanasia, cryonics, contraception, eugenics and medical research(!), abortion, animal rights, artificial insemination, assisted suicide, body modifications, circumcision, female genital mutilation, gene therapy, genetically modified foods, human cloning, genetic engineering, population control, drug use, life extension...

On all of these significant issues, there are important case studies, wide philosophical debates, ‘world expert’ pressure groups campaigning around the issues, books, leaflets, publications, conferences and significant social worlds organised around them. There are charters of rights, research centres, ethics committees, websites and international organisation. Bio-ethics is now a major industry.

Several values guide much debate, including:

2. Minimal harm: ‘first, do no harm’
3. Rights: the patient has the right to refuse or choose their treatment.
4. Dignity and respect: the patient (and the person treating the patient) have the right to dignity and respect.
5. Truthfulness and honesty: there should be informed consent, and people must be fully informed of their situation.
6. Justice: this concerns the distribution of scarce health resources, and the decision of who gets what treatment. People should be treated fairly.

Values such as these do not give answers as to how to handle a particular situation, but provide a useful framework for understanding conflicts.

**The disability debate**

Ethics appears at three critical junctures for the disabled. New ethical issues are raised by disability and disability activists which often go against the grain of much contemporary ethical trends. They centre on the ethics of living a disabled life. So much research, policy and law-making seems to work from the view that in some ways ‘disability’ is not good, and needs to be cured or removed. But behind this is a coded message to all who live with disabilities: in some ways your life is not really worth living. Many ethical issues bring to the fore the devaluation of disabled lives. These are thorny issues. Tom Shakespeare, a disabled activist and researcher, suggests three main areas for scrutiny.

The first concerns prenatal diagnosis (PND). It raises the question: if you learnt in advance that your child is likely to be born with a serious impairment, would it be right to abort this child? This re-raises the issue that the eugenics movement was confronted with some 100 years ago. It also raises key issues for those concerned more generally with the abortion debate.

The second concerns the new cures and remedies that are fast becoming available for the disabled. The Human Genome Project, gene therapy and stem cell research (see Chapter 23) are now key features of medical research. But they all work with ideas about the ‘perfect’ or ‘better’ body. Their research will lead to a decline of bodily impairments of all kinds. With an eye on the future, this may be very good news. But for those living with disabilities in the present, it can serve to reinforce their problems. Medicine can never solve all problems.

The third concerns the wider issue of death and the autonomy of the end of life (which we discuss in Chapter 21). These issues of disability rights at the end of life are dramatically portrayed in films like *Million Dollar Baby* (2004) and *The Sea Inside* (2004). Increasingly, there are many issues to confront at the end of a life: living wills, assisted suicide, voluntary euthanasia, and resuscitation. One danger for the disabled in much of this is that their lives may be prematurely ended.

On all these issues, Shakespeare (2006: 131) concludes that:

Listening to the voices of disabled people and those directly affected is an important principle in bio-ethics. It is dangerous for non-disabled people to project their own fears and misconceptions as to what it might be like to be impaired.

With this comment in mind, discuss each of the three debates above. Gather data from disability rights groups on their position and try to hear their voice on these issues.

Social divisions and global youth

Here are two films that became popular in the first years of the twenty-first century. They are worth seeing.

First is the award winning film City of God, by Katia Lund and Fernando Meirelles and released worldwide in 2003, which takes us into the world of two young people living in Rio de Janeiro over a ten-year period. It tells us the story of being young and growing up in a lower-class slum (favella), Cidade de Deus (Portugese for City of God). This is not an easy life – far from it; and it is a far cry from the ‘youth cultures’ of the West, which sociologists more commonly have studied. It is full of violence, drug use and deep poverty. Both the film and the book are based on a true story, the war between Rocket (Knockout Ned) and Li’l Dice (characters it is based on their real-life counterparts).

Rocket comes from a fishmonger’s home, where his family sold fish in the quarter, while Li’l Dice grows up in a gang of hoodlums who kill and steal. The film begins close to the end of the story and moves back a decade. The whole story is told against a background of violence, despair and drugs. As the kids grow up in this environment, they take different paths and go through many changes. Li’l Dice becomes a violent gangster with his own gang, killing his rivals. Rocket wants to escape all this – though he witnesses it. He develops an interest in photography and wishes to use it to escape the violence of his environment. The tagline of the film is: ‘Fight and you’ll never survive ... Run and you’ll never escape.’

A few years later, a second film, Favella Rising (by Jeff Zimbalist and Matt Mochary, 2006) returned to similar favellas of the poor in Rio de Janiero. And, again, this film vividly tells another (real) story of the gang life of the young in the Brazilian city. This time we are told the story of Anderson, a drug dealer who turns good citizen, But not without a lot of trouble on the street. The young here live amidst street violence, shootings, gun running, drugs and street crime. The police are under-trained, underpaid and corrupt. The documentary tracks a number of street deaths (proclaiming at the start that over 1,000 children were killed in just one year!). But, and this seems to be the film’s point, there is an escape: many young people who are surrounded by this life do not want it. In this story, they actively trace a new life through the styles and culture of music – in this instance, Afro-Reggae. They dance away in large concerts and the film turns from a story of despair to a story of hope. It is here in the music, the film seems to suggest, that utterly marginalised youth find their own systems of respect.

Both these films have a focus on poor ‘black’ male youths in the city. These environment are found all over the world. And always we can view them through the lenses of class, gender, sexuality and ethnicity. The films act as ethnographies of urban life in low-income societies. And in them we see the social divisions of a society at work. Here you can start to apply these ideas to a specific group.

Parallels can be found in many of the cities of high-income cities. For example, sociologists have studied similar experiences in the United States. In Philadelphia, for instance, and many inner cities in North America, a pervasive street violence exists. Many young people come to live tormented lives in the midst of drugs, death and a decaying environment. Discount stores appear, along with graffiti and very run-down buildings – many no longer inhabited. It is here that groups of black youths start to appear, hanging around on street corners, outside stores, in the street and at...
These are major complexes. The air is thick with danger and potential violence. It is the world of *Boyz’n the Hood* and, indeed, *Favella Rising*. Street families seem to show a lack of consideration for others. And at the heart of the problem is the issue of respect – being treated ‘right’ or being granted one’s ‘props’ (or proper due) or the deference one deserves.

**Youth in low-income societies**

As we might expect, the issue of youth in low-income societies takes on different dimensions to those in the richer West. In much of the world, young people live in severe poverty, experience unemployment on a mass scale, are illiterate, and get bound up with drugs, youth crime and sexuality. Of course, these issues are found in high-income societies too – the news is constantly full of the horror stories of the young. But in low-income societies we are talking on a different scale. Consider some findings from *The United Nations World Youth Report*, 2005. It claimed:

- Over 200 million young people (18 per cent of all youth) lived in poverty (that is, on less than one dollar a day); and 515 million lived on less than two dollars a day. That is getting on for an eighth of the world’s population.
- World youth unemployment is high and, at a total of 88 million, it is highest in western Asia, North Africa and sub-Saharan Africa.
- As in the Western world, young people are reaching adolescence at earlier ages and marrying later, with premarital sex increasing.
- There are growing problems of drug use, youth crime and sexuality (with HIV/AIDS being a prime cause of mortality – 10 million young people were living with HIV/AIDS –mostly in Africa and Asia).
- More: 130 million young people are illiterate. And while ICT’s have proliferated, the digital divide between the young of the rich world and the poor world is (fairly obviously!) huge.
- And in the midst of all this a great many young people – especially in African states – are disproportionately involved in conflicts – local and national. They become young soliders, fighters, guerrilla activists. Violence and injuries are a common form of death. This is more common for young men than young women: but they also have their ‘problems. Women in low-income societies have a much higher likelihood of being drawn into sexual trafficking (UN (2005), un.org/youth).

**Back to the rich kid’s world**

Although all societies have age grades which must include the young, the recognition of a category called youth is relatively new. ‘Youth’ as a distinct social category seems to have appeared alongside the Industrial Revolution.

(Musgrove, 1968). In the chaos of mass urbanisation in the nineteenth century (brilliantly depicted in the writings of Charles Dickens, and the more academic writings of Mayhew and Booth), young people were often found to be ‘in trouble’. There were street gangs in New York, Fagin’s pickpockets in the London of *Oliver Twist*, Parisian hoodlums known as Apaches, and regular battles between street gangs in England. Indeed, a number of studies have shown how we can find ‘Hooligans’ throughout recent history (Pearson 1980; Humphreys, 1981). By the late nineteenth century, poverty and lack of education were soon recognised by many early social researchers like G Stanley Hall in the United States, and John Barron Mays in Liverpool in the United Kingdom to play a key role in the lives of the young. In 1889, Hall named a new life stage ‘adolescence’ which he saw as characterised by paternal conflict, moodiness and risk taking (Savage, 2007). So, in some ways, ‘youth’ came to exist because of the rise of the modern world. They are part of it. And in it they often come to signify ‘trouble’.

But even more specifically, ‘teenagers’ started to appear in the post-Second World War of the United States, and was transported rapidly around the ‘Western world’ – linked to the rise of a new music and commercial /consumer market. New styles, dress and fashion, accessories, magazines and music became more and more important until now, in the Western world, youth culture is almost dominated by the notions of ‘music’ and styles (Savage, 2007). These styles have largely been read by sociologists as indicating both class locations and class problems. The styles of ‘mods’ in the 1960s set up a mode of aspiring working-class youth, whereas the ‘rocker’ style set up a mode for traditional working-class youth. And today there are a multitude of youth styles – but most have some class link. Music, fashion, language, style: all differ significantly across class and gender lines. Chapter 5 has shown a little of this diversity (Muggleton and Weinzierl, 2003; Hebdidge, 1977).

In all of this, young people – often willingly – are separated out as a distinct and separate group. Some sociologists claim that youth has become a major scapegoat, and is frequently socially excluded and stereotyped.

**Disconnected youth in the UK**

In the UK, the sociology of youth is usually divided into two major concerns. One – which we have already met – is concerned with youth styles and cultures. It delights in studying punks, Goths, chavs and scammers, ‘emo skaters?, ‘indie bohos’ and skinheads – along with older styles that keep reworking themselves. It is a world of postmodern cultures and shows how class, gender and ethnicity intersect in ‘style’. Much research about youth looks at their leisure...
and consumer lifestyles – centering on music, sport, ‘the youth market’, dress, leisure drugs and style (Thornton, 2006; Muggleton and Weinzierl, 2003).

But a second strand of study has been concerned more with the last years of education and the passage into work. How kids get, or do not get, jobs. These researchers often find a great deal of ‘leisure poverty’. A real lack of money prohibits (much, if any) participation in night clubs, drinking, dressing up or going to the movies. As a 17-year-old said in a study of Teesside Youth in England: ‘We just sit in watching the TV, or if it’s pay day [i.e. benefit payment day] we get a few cans and a video’ (Louise, seventeen, unemployed). Disengaged young men and single mothers have even less opportunities. ‘Hanging around’ can become a major life activity, and trying to fill up time becomes a major problem (MacDonald and Marsh, 2005).

Global youth

Finally, some sociologists are talking about ‘Generation Global’. Gathering in ‘global cities’ throughout the world where work and lifestyles are available in plenty – Dublin, Cape Town, Prague, Saigon, Shanghai, Tel Aviv, London and New York – they find a world of young people travelling and going overseas in record numbers. Here, middle class and relatively rich kids find themselves on gap years abroad; travelling through international corporations; or simply surfing in cyberspace. Their social networks become global. They makes friends all over the world. But once again we can speak of a global divide being created. Most youth of the world cannot even begin to aspire to this.

Still, Western influences have frequently created major concerns for young people in much of the world. Youth in many non-Western cultures nevertheless may well gain knowledge about the lifestyles of ‘Western youth’, and can often gain access to some of the artefacts of western youth culture – music, dress, film. Growing numbers can communicate via some access to ICT. DVD, music, dance and the Internet set up a kind of international youth culture. Witnessing global mass media and some migrating (sometimes in exile) from their own countries, young people become more and more exposed to the consumerism and ‘lifestyle’ issues of young people in the West. But all of this sets up major tensions.

For example, one examination of youth in Teran found growing numbers of young Iranians were gaining access to all kinds of modern commodities. Everything from DVDs and CDs to large-scale use of the Internet – often illegally – are part of Iranian youth life. But at the same time, much of it involves risking jail for things their counterparts in the West take for granted: everything from wearing make-up to slow dancing at parties can be seen as ‘moral crimes’, and anxious parents have to bail their children out of courts (Basmenji, 2005).

Likewise, ever since the break-up of the old Soviet Union, people in central Asia (or Eastern Europe) – those in Tajikistan, Kazakhstan, Kyrgyzstan, Turkmenistan and Uzbekistan – have experienced Western influences that stress individualism at the expense of central Asian traditions of family and communalism. As we have seen in Chapter 5, Islam has historically played a powerful force in their lives. When anthropologist Collette Harris looked at the lives of Muslim youth in Tajikistan, she found that the dominant Islam culture still framed the lives of the young, but beneath the surface youth often modified, shifted and resisted it. Young central Asians today confront a complex mixture of the old and the new that strains personal relations, especially within the family, between generations and between spouses. For many ‘global youth’, the old worlds of tradition become increasingly unsettled (Harris, 2006).

Look at:


The web is flooded with youth scenes. You may not have seen:

www.un.org/youth

The United Nations website on youth which provides a great deal of information across the world.

www.unicef.org/voy/
The ‘Voices of Youth’ page of the UNICEF website.

Finally, a controversial film about kids in downtown USA released in the 1990s was Larry Clark’s Kids (1995). This is now over a decade old. Has life changed much since then?