

DISABILITY

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Polity

2003

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Disability: A Choice of Models

For most of the twentieth century in 'Western' societies, disability has been equated with 'flawed' minds and bodies. It spans people who are 'crippled', 'confined' to wheelchairs, 'victims' of conditions such as cerebral palsy, or 'suffering' from deafness, blindness, 'mental illness' or 'mental handicap'. The individual's impairment or 'abnormality' necessitates dependence on family, friends and welfare services, with many segregated in specialized institutions. In short, disability amounts to a 'personal tragedy' and a social problem or 'burden' for the rest of society.

However, from the late 1960s, this orthodoxy in thinking and practice became the target of campaigns across Europe and North America. Disabled people, particularly those forced to live in residential institutions, took the lead in calling for policy changes. Their demands highlighted the importance of much greater support for 'independent living' in the community (Hunt 1966a; Brattgard 1974), and in the United States also assumed a civil rights focus (DeJong 1979). Disabled activists and organizations of disabled people were united in condemning their status as 'second-class citizens' (Eisenberg et al. 1982). They redirected attention to the impact of social and environmental barriers, such as inaccessible buildings and transport, discriminatory attitudes and negative cultural stereotypes, in 'disabling' people with impairments (UPIAS 1976; Bowe 1978).

By contrast, the academic literature broadly accepted the 'orthodox' view that disability is an individual and medical issue. Although gender and 'race' were by the 1980s generally recognized as distinctive causes of social oppression, this was not true of disability. Disabled critics dismissed prevailing accounts in the social sciences as irrelevant, 'theoretically backward' (Abberley 1987: 5) and resolutely 'disablist' (Oliver 1996b). 'There were no disjunctures between the dominant cultural narrative of disability and the academic narrative. They supported and defended each other' (Linton 1998: 1).

In this introductory chapter, we begin by outlining social science approaches through the 1960s and 1970s that analysed disability as a form of social deviance and sickness. Next, we trace the gathering critique by disabled activists and academics and the development of an alternative, socio-political approach to disability. Finally, we identify key issues in disability theory and practice for more detailed discussion in later chapters.

Disability as a personal tragedy

Twentieth-century social theory typically followed medical judgements in identifying disabled people as those individuals with physical, sensory and cognitive impairments as 'less-than-whole' (Dartington et al. 1981: 126), and hence unable to fulfil valued social roles and obligations. This incapacity left them 'dependent on the productive able-bodied' (Safilios-Rothschild 1970: 12). These and other negative associations meant that disability was perceived as a 'personal tragedy' (Oliver 1983). This encompasses an individual and largely medicalized approach: first, disability is regarded as a problem at the individual (body-mind) level; second, it is equated with individual functional limitations or other 'defects'; and third, medical knowledge and practice determines treatment options. From a societal perspective, disability is dysfunctional:

the values which underpin society must be those which support the interests and activities of the majority, hence the

emphasis on vigorous independence and competitive achievement, particularly in the occupational sphere, with the unfortunate spin-off that it encourages a stigmatising and negative view of the disabilities which handicap individuals in these valued aspects of life (Topliss 1982: 112).

For most of the twentieth century, this personal tragedy approach was applied in a variety of educational and charitable institutions and through medical and psychological interventions. Indeed, large numbers of disabled people were 'put away' in segregated institutions on the grounds that it was for their own good and to stop them being a burden on others (Goffman 1961). Yet, in practice, institutional regimes were often harsh, and long-term residents were liable to be 'written off' as 'socially dead' while awaiting the ends of their lives (Miller and Gwynne 1972).

Disability and social deviance

The problematic aspects of disability from a societal viewpoint are vividly illustrated in functionalist analyses of health and sickness. As outlined by Talcott Parsons (1951), sickness is akin to social deviance, because it poses a threat to 'normal' role performance and wider economic productivity and efficiency. This leads to the establishment of a sick role that grants temporary and conditional legitimacy to the sick person. It seeks to achieve a balance between acknowledging 'incapacity' and preventing 'motivated deviance' or malingering. Society accepts that the sick person cannot get better simply by an 'act of will' and he or she is permitted to withdraw temporarily from 'normal' social roles. In return, the individual must obtain medical confirmation of their condition and follow the recommended treatment, while agreeing the importance of leaving the sick role behind as soon as possible.

However, the applicability of the sick role to those with a 'chronic illness and disability' attracted widespread criticism, because these conditions are defined as long-term if not irreversible. One response was to construct a separate 'disabled role' (Safilios-Rothschild 1970) characterized by adjustment to an extended but authorized dependency (Haber and Smith

1971). The individual is required to co-operate with rehabilitation professionals in order to achieve some degree of 'normality'. This describes a hierarchical relationship where the professional (helper) identifies the needs and capabilities of the lay (helped) person and prescribes appropriate individualized 'solutions' ranging from health and social care to special educational provision (Finkelstein 1983). Moreover, it adopts the profession's view of the 'ideal' patient as someone who defers to its knowledge and authority, and ignores the potential for contrary lay interests or expertise (Freidson 1970).

From a contrary theoretical perspective, symbolic interactionists stressed the social construction of what is perceived as deviance in everyday interaction:

social groups create deviance by making the rules whose infraction constitutes deviance, and by applying those rules to particular people and labelling them as outsiders. From this point of view, deviance is not a quality of the act the person commits, but rather a consequence of the application by others of rules and sanctions to an 'offender'. The deviant is one to whom the label has successfully been applied; deviant behaviour is behaviour that people so label. (Becker 1963: 8; - emphasis original)

A significant benchmark for studies of social reactions to difference was Charles Lemert's (1951) distinction between *primary* and *secondary* deviance. Primary deviance arises where social norms or rules are broken but there are no long-lasting consequences. In contrast, secondary deviance generates a more significant and enduring social reaction that is sufficient to produce a deviant identity and status. Generally, the attribution of deviance to people with impairments is associated with 'ascribed' (involuntary) rather than 'achieved' (purposive) rule breaking. Nevertheless, particular groups, including black people and women, disproportionately attract specific psychiatric labels such as 'schizophrenia' and 'depression' respectively (Scheff 1966; Busfield 1986). Once applied, a medical label such as 'mental illness' at least confirms and at most transforms the public perception of an individual. It is also difficult to challenge or remove a medical label (Freidson 1965, 1970).

As a further illustration of the social construction of deviance, the 'recipients' of deviant labels must be taught how to act out their ascribed role. Professionals and specialized organizations are central to this socializing process. Robert Scott, in *The Making of Blind Men* (1969), illustrates how agencies responsible for the education and training of people labelled as blind reorganize the personal identity of their clients so as to conform to the professionals' image of a 'blind person', even though 'there is nothing inherent in the condition of blindness that requires a person to be docile, dependent, melancholy, or helpless; nor is there anything about it that should lead him to be independent or assertive' (Scott 1969: 14). New entrants are rewarded for conforming to staff expectations. They are praised for being 'insightful' when they do what the rehabilitation team wants, and are criticized for 'blocking' or 'resisting' when they disregard agency aims. This regime generally brings about a profound change from recruitment to completion of training. Nevertheless, as Scott demonstrates with case studies of Sweden, England and America, there are significant national differences in the roles and expectations of blind people.

The preoccupation among service providers with appropriate adjustment on the part of those with an impairment is again vividly illustrated in the application of psychological 'loss' or bereavement models. One of the most widely cited studies contains a four-stage process of psychological adjustment and rehabilitation to a severe spinal cord injury (Weller and Miller 1977). The initial reaction of 'shock' and horror is followed by 'denial' or despair that any recovery is possible, leading to 'anger' at others, and finally to 'depression' as a necessary preliminary to coming to terms with diminished circumstances. This 'acceptance' or 'adjustment' may not be reached until one or two years later. A parallel response trajectory has been identified for children with impairments attending a residential school (Minde 1972). Its key phases are 'disorientation' (following the loss of links with home and the local community), 'depression' (as the permanency of their impairment is confirmed by older pupils), 'anger' (at their difference from non-disabled peers), and finally, 'acceptance' (of the limitations of the disabled role).

The determinism of these 'adjustment to loss' models effectively sets aside the subjective experiences of disabled people and the specific socio-cultural and economic context (Albrecht 1976). While there is widespread agreement that there are often significant psychological (and other) costs associated with impairment, such models impose a 'psychological imagination' based on able-bodied assumptions of what it is like to live with an impairment (Oliver 1983).

Stigma: managing a spoiled identity

An associated feature of interactionist studies is their emphasis on individual coping or management strategies. Erving Goffman (1963) provides the classic study of responses to stigma, or a 'spoiled identity', including 'abominations of the body', with illustrations of those described as 'blind', 'deaf', 'crippled', 'deformed', 'disfigured', 'mentally ill' and 'stutterers'. He acknowledges that there is no necessary association between such attributes and their contemporary stereotype, but explores how the meaning of these marks of difference is negotiated through social interaction. In mid-twentieth-century America, he lists the benchmark 'identity norms' for a male as being 'a young, married, white, urban, northern heterosexual Protestant father of college education, fully employed, of good complexion, weight, and height, and a recent record in sports' (Goffman 1963: 128).

His characterization of 'abnormals' resonates with other social psychological writings on 'difference'. These highlight the 'liminality' of those on the margins of what society regards as 'normal':

The long-term physically impaired are neither sick nor well, neither dead nor alive, neither out of society nor wholly in it. They are human beings but their bodies are warped or malfunctioning, leaving their full humanity in doubt. . . . They are neither fish nor fowl; they exist in partial isolation from society as undefined, ambiguous people. (Murphy 1987: 112)

Goffman's interest in 'undesired differentness' (1963: 5) centres on how individuals manage their 'spoiled identity' in everyday social interaction – what one sociological text refers

to as the 'inevitable problems of living that confront the disabled as a result of their impairments' (Clinard and Meier 1989: 368). Encounters between 'normals' and 'stigmatized' people are characterized by immediate and often acute tensions for the visibly 'discredited', while for the 'discreditable' whose stigma is not immediately apparent the dilemma is whether or not to display their 'abnormality'. He documents a broad range of 'passing' (hiding the stigma) and 'covering' (reducing its significance) strategies to avoid embarrassment and social sanctions. These include repeated and often painful medical and surgical procedures to make the individual 'more normal' or less likely to attract a critical public gaze. The only other option for the stigmatized person is 'withdrawal' from social interaction.

Fred Davis, in a study of the social interaction between non-disabled people and those with a visible impairment, lists some of the points of tension: 'the guarded references, the common everyday words suddenly made taboo, the fixed stare elsewhere, the artificial levity, the compulsive loquaciousness, the awkward solemnity' (Davis 1961: 123). Nevertheless, he outlines a process of 'deviance disavowal' whereby the difficulties in social interaction are gradually 'normalized' over time. He identifies three main stages, starting with 'fictional acceptance', where interaction is kept to a minimum. A second 'breaking through' period begins when the stigmatized person encourages the 'normal' person to disregard their condition. The end-point is a 'normalized relationship' where difference is dissipated, leading to the seal of approval from a non-disabled person – 'I don't think of you as disabled' – so unthinkingly confirming the latter's tragic fate. The 'well-adjusted' disabled person is someone who lives up to non-disabled peoples' expectations as brave, cheerful and grateful when being helped. Conversely, they are quickly criticized if they act 'out of character' by being assertive and demanding.

The stigma label is further characterized by its potential to 'spread'. At the individual level, physical impairment is sometimes taken as an indication of a generalized incapacity – as typified by the 'Does he or she take sugar?' syndrome. In addition, negative attitudes and behaviour may be extended to other family members as a 'courtesy stigma' (Goffman 1963).

A general feature of this interactionist literature is its concentration on the defensive manoeuvrings of disabled people. This suggests that 'those stigmatised are apparently firmly wedded to the same identity norms as normals, the very norms that disqualify them' (Gussow and Tracey 1968: 317). However, there are exceptions: the treatment of disabled people is not always represented as benevolent, and not all disabled people take over the values of non-disabled people. In his study of life in a psychiatric institution, Goffman (1961) acknowledges that asylum inmates are 'colonized' and their supposed 'helpers' also act as jailers. He also outlines a continuum of potential responses to incarceration: from 'true believers' to 'resistors'. None the less, these examples are submerged beneath a general emphasis on achieving social acceptance and accommodating to the demands of 'normals'.

Deviance and social control

From a conflict perspective, studies of the social construction of disability took their cue from C. Wright Mills (1963), who argued that the definition of social problems must be located within wider material and political contexts, including the power relations and conflicts between dominant and subordinate classes. Historically, there was a trend away from judgements of social deviance rooted in religious criteria of 'badness' towards medical judgements of 'sickness'. The medicalization of disability confirmed the arrival of an orthodox medical profession, with State-legitimated authority in the delivery of health and illness services (Conrad and Schneider 1980). Over time, there has been a proliferation of other 'moral entrepreneurs' (Becker 1963), in education, psychology, counselling and social work, all seeking an enhanced role in services for people with accredited impairments.

The growing impact of professionals in general and medicine in particular on the lives of disabled people proceeded unevenly. It is most evident in studies of mental illness that include a full-blown critique of a self-serving profession (psychiatry) for exploiting its power of labelling and collaborating in a wider process of social control. From an 'anti-psychiatry' perspective, the concept of mental illness is

dismissed as a 'myth', or at least a socio-political construct, but there was little discussion of alternative support paths (Szasz 1971; Ingleby 1981). By comparison, the medicalization of physical and sensory impairments attracted little if any criticism, but rather confirmed the existence of a 'caring society'.

Challenging the disabling society

It was largely left to disabled people to develop their own critique of the conventional approaches to disability. A key contribution in Britain was Paul Hunt's edited collection entitled *Stigma: The Experience of Disability* (1966b). This challenged the standard preoccupation with the medical and personal 'suffering' experienced by individuals with an impairment. In his own essay, Hunt argued that 'the problem of disability lies not only in the impairment of function and its effects on us individually, but also, more importantly, in the area of our relationship with "normal" people' (Hunt 1966a: 146). A sharp dividing line is drawn between the social lives and interests of 'able-bodied' and disabled people. The latter are 'set apart from the ordinary' because they pose a direct 'challenge' to commonly held societal values: 'as unfortunate, useless, different, oppressed and sick' (p. 146).

Disabled people are viewed as 'unfortunate' because they are unable to enjoy the social and material benefits of contemporary society. These include the opportunity for marriage, parenthood and everyday social interaction. The few exceptions are lauded for their 'exceptional courage', but this simply confirms the 'tragic' plight of the vast majority. Indeed, it is overwhelmingly non-disabled people who like to celebrate such 'triumph over tragedy' heroics (Dartington et al. 1981).

The perception of disabled people as 'useless' flows from their lack of engagement in mainstream economic activities. As a consequence of their failure to conform to 'normality', whether in appearance or in control over their minds and bodies, they are set apart as 'different'. Moreover, 'People's shocked reactions to the "obvious deviant" stimulate their

own deepest fears and difficulties, their failure to accept themselves as they really are and the other person simply as “other” (Hunt 1966a: 152).

The level and form of prejudice against disabled people amounts to being ‘oppressed’. It is illustrated by the discrimination widely practised in the built environment, employment, leisure and personal relationships. Finally, disabled people clash with ‘able-bodied’ values in so far as they are defined as ‘sick, suffering, diseased, in pain’ (Hunt 1966a: 155). This represents everything that the ‘normal world’ most fears – ‘tragedy, loss, dark, and the unknown’ (p. 155). ‘Being seen as the object of medical treatment evokes the image of many ascribed traits, such as weakness, helplessness, dependency, regressiveness, abnormality of appearance and depreciation of every mode of physical and mental functioning’ (Zola 1993: 168).

What also now emerges is a contrast between the individual model’s ‘property’ approach that equates disability with an individual’s impairment and a ‘relational’ perspective that highlights how people with impairments are subjected to wide-ranging processes of social exclusion. Furthermore, the conventional absorption in ‘personal troubles’ gave way to a collective sense of injustice: ‘We are challenging society to take account of us, to listen to what we have to say, to acknowledge us as an integral part of society itself. We do not want ourselves, or anyone else, treated as second class citizens, and put away out of sight and mind’ (Hunt 1966a: 158).

Frank Bowe, in *Handicapping America* (1978), pursues a similar theme when he lists six major barriers to the social inclusion of disabled people. These are architectural, attitudinal, educational, occupational, legal and personal (or everyday problems ranging from few material resources to the stigma of having an impairment). Common experiences of exclusion led to disabled people’s growing sense of themselves as an oppressed minority. Thus, the first national survey of disabled people in the United States in 1986 reported significant support for the proposition that disabled people are ‘a minority group in the same sense as are blacks and Hispanics’ (Harris 1986: 114). Disabled people were increasingly seeking to ‘take control of the definitional and interpretative

processes so that they can forge their own identities and manage their own lives’ (Albrecht 1992: 78).

Building a socio-political model of disability

The criticism of ‘able-bodied’ society was first codified into a radical, alternative to the individual model by the Union of the Physically Impaired Against Segregation (UPIAS) in Britain. Its manifesto, entitled *Fundamental Principles of Disability* (1976), contains the fundamental assertion that society disables people with impairments, thus directing attention to the impact of social and environmental barriers: ‘In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society’ (UPIAS 1976: 14).

UPIAS’s analysis of the disabling society is built on a clear distinction between impairment and disability (see box 1.1). A medical definition of physical impairment is adopted (and subsequently extended to include sensory and cognitive forms), in contrast to a definition of disability in socio-political terms, as ‘the outcome of an oppressive relationship between people with . . . impairments and the rest of society’ (Finkelstein 1980: 47).

Box 1.1 UPIAS definitions of impairment and disability

- **Impairment:** Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.
- **Disability:** The disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (UPIAS 1976: 3–4).

This distinction enables the construction of a ‘social model’ or a ‘social barriers model’ of disability (Finkelstein

1993b). The line of causation is redirected. In the individual model, 'disability' is attributed to individual pathology, whereas this social model interprets it as the outcome of social barriers and power relations, rather than an inescapable biological destiny. Thus,

an inability to walk is an impairment, whereas an inability to enter a building because the entrance is up a flight of steps is a disability. An inability to speak is an impairment but an inability to communicate because appropriate technical aids are not made available is a disability. An inability to move one's body is an impairment but an inability to get out of bed because appropriate physical help is not available is a disability. (Morris 1993b: p. x)

Moreover, instead of an individualistic regime of rehabilitation and personal care services, the 'disabling barriers' diagnosis suggests wide-ranging social changes coupled with alternative forms of service support and provision (Finkelstein 1993b). As Jenny Morris later argued: 'Our anger is not about having "a chip on your shoulder", our grief is not a "failure to come to terms with disability". Our dissatisfaction with our lives is not a personality defect but a sane response to the oppression we experience' (1991: 9).

The impact of socio-political analyses of disability can be dramatic:

I think I went through an almost evangelical conversion as I realised that my disability was not, in fact, the epilepsy, but the toxic drugs with their denied side-effects; the medical regime with its blaming of the victim; the judgement through distance and silence of bus-stop crowds, bar-room crowds and dinner-table friends; the fear; and, not least, the employment problems. (Hevey 1992: 2)

None the less, the social barriers *model* is only a stepping stone to building a 'social *theory* of disability' (Oliver 1996b: 41). This demands in-depth answers to such questions as: 'What is the nature of disability? What causes it? How is it experienced?' (Oliver 1996b: 29–30). As disability is socially produced, it follows that it displays contrasting forms, both historically and between societies. At the same time, theoretic-

cal analysis of the structures and processes that bring about the social exclusion and oppression of people with impairments also identifies the necessary targets for a new disability politics geared to overturning the 'disabling' society (Finkelstein 1980; Oliver 1983; Abberley 1987).

Nevertheless, the scope of this new approach to disability must not be exaggerated:

The social model is not about showing that every dysfunction in our bodies can be compensated for by a gadget, or good design, so that everybody can work an 8-hour day and play badminton in the evenings. It's a way of demonstrating that everyone – even someone who has no movement, no sensory function and who is going to die tomorrow – has the right to a certain standard of living and to be treated with respect. (Vasey 1992: 44)

Policy definitions and measures

In response to criticism that its approach to disability ignored social factors, including the disadvantages experienced by disabled people, the World Health Organization (WHO) produced its *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) (WHO 1980). It offered the definitions shown in box. 1.2.

Box 1.2 WHO definitions of impairment, disability and handicap

- **Impairment:** Any loss or abnormality of psychological, physiological or anatomical structure or function . . .
- **Disability:** Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being . . .
- **Handicap:** A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role (depending on age, sex, social and cultural factors) for that individual. (WHO 1980: 29)

In what disabled critics dismiss as a characteristically individual approach, 'impairment' refers to those parts or systems of the body-mind that do not function 'normally', while 'disability' covers those activities that the individual cannot perform as a result of the impairment. For example, blindness is a visual 'impairment' that causes 'disability' or difficulties in reading. The stress is on functional limitations in the performance of basic daily living tasks. These span locomotion, reaching and stretching, dexterity, seeing, hearing, personal care, continence, communication, behaviour and cognitive functioning.

Most of the novelty of the WHO schema lies in the interpretation of 'handicap'. This highlights the social consequences associated with an impairment and/or disability. It raises the difficulties in performing social roles, while acknowledging that these vary across social groups and cultural contexts.

The ICIDH definitions found immediate favour with many social scientists, but provoked considerable criticism from disabled people's organizations. First, the approach relies primarily on medical definitions and uses a bio-physiological definition of 'normality'. It disregards the impact of social criteria in informing judgements about whether body weight and shape, mental distress or cognitive functioning is 'normal' rather than 'pathological'. Moreover, the definition of 'handicap' ignores the social and cultural relativity in role allocation. For example, women might be rated as having a 'disability' but not be 'handicapped' because the society in which they live denies them the opportunity to engage in certain activities because these are not considered appropriate for females (Wendell 1996: 17).

Second, 'impairment' is identified as the cause of both 'disability' and 'handicap'. This privileges medical and allied rehabilitative and educational interventions in the treatment of social and economic disadvantages. It justifies the domination of disabled people's lives by health professionals. In contrast, disabled people increasingly argue that disability (as defined in a social perspective) is not a health issue, and therefore that health professionals are not the appropriate judges of their support needs.

This leads to a third criticism, that the ICIDH represents the environment as 'neutral', and ignores the extent to which disabling social, economic and cultural barriers are significant in the social exclusion of people with impairments. Even though social and environmental influences are recognized, these have little significance or credibility in the application of the ICIDH in service planning or provision. The overwhelming clinical focus dictates strategies for individual adjustment and coping. 'Unrealistic' hopes and ambitions are constrained. Whether a person is born with an impairment or acquires it later in life, the ICIDH reinforces socialization into a dependent role and identity, for lack of any other choice. Certainly, medical and allied interventions have had many positive outcomes for disabled people, but the ICIDH concentrates on diagnosing and treating the individual's 'limitation' rather than that person's social exclusion.

Widespread disenchantment among disabled people and their organizations, as well as criticism from mainstream medical researchers persuaded WHO to revise its classificatory scheme. This resulted in the *International Classification of Functioning and Disability* (WHO 1999), or, more 'popularly', ICIDH-2. It sought to incorporate the 'medical' and 'social' models into a new 'biopsychosocial' approach. The overall result is a 'multi-purpose' classification system that retains the concept of impairment in body function and structure, but replaces 'disability' with activities, and 'handicap' with participation. In addition, ICIDH-2 assumes that functioning, activity and participation are influenced by a myriad of environmental factors, both material and social. This opens up new possibilities for a socio-medical analysis of disablement, although it retains individualistic medical notions of disability and its causes (Hurst 2000).

Notwithstanding these developments, there is ample evidence internationally of the continued acceptance of the individual model of disability in policy circles. Thus, the 'functional limitations' approach is widely incorporated within anti-discrimination legislation (as in the USA and Britain), and it continues to inform surveys of the prevalence of 'disability' within the European Union (Barnes et al. 1999; European Commission 2001).

Issues and themes

C. Wright Mills (1970) argued that the sociological imagination has a particular contribution to make in helping us see how some seemingly 'personal troubles' are more appropriately understood as 'public issues' that link to the institutions of society as a whole (p. 14). The basic aim is 'to see the *social* in the *individual*, the *general* in the *particular*' (Bauman 1990: 10). The realization that apparently 'natural' features of society are both sustained and revised by human action allows for the possibility of 'alternative futures' (Giddens 1982: 26).

It is our task to demonstrate the merits and potential of social analyses of disability. This entails addressing issues that arise at individual, social (group) and societal levels (Turner 1987; Layder 1997). Furthermore, as the disability studies literature has grown over the last two decades, the initial dominance of interactionist and minority group perspectives in the USA, and neo-Marxist analyses in the British literature, has been contested. A wide range of disciplinary perspectives and theoretical interpretations, including feminism, post-structuralism and post-modernism, now competes for attention in disability studies.

Most specifically in the chapters that follow, we review key issues and themes in analysing disability. In chapter 2, we equate a 'social model' approach within the analysis of disability as a changing form of social oppression and exclusion. It gives a specific stimulus to historical perspectives on impairment and disability, most notably with the growth of industrial capitalism. This highlights the establishment of professional (especially medical) dominance and the resort to institutional 'solutions'. These trends are exemplified by the emerging discourse around 'normalcy' and difference, including the scientific identification of 'defective' minds and bodies. Chapter 3 outlines more of the contemporary empirical detail required to substantiate claims about disabled people's social oppression. The discussion spans key areas across the 'public' and 'private' domains, including education, paid employment, the built environment, leisure and 'right to life' issues. It also explores how far other social divi-

sions such as gender and 'race' mediate disability as well as any life cycle patterns.

Recent calls to 'bring impairment in' to disability studies are addressed in chapter 4. These have generated intense debate about 'impairment effects', while overlapping with a considerable literature by medical sociologists on the experience and meaning of 'chronic illness and disability'. It merges with a burgeoning interest in difference and identity, and post-structuralist-inspired studies of changing discourses on the body. Cultural representation and the media are examined in chapter 5. This offers a counterweight to the structuralist focus in early social model debates by exploring the negative media images of disabled people that dominate (Western) cultures. We also examine attempts by disabled people to generate a more positive disability identity and culture(s).

Chapter 6 explores the exclusion of disabled people from mainstream political processes and institutions, and the policy responses adopted in liberal democracies, including equal opportunities and anti-discrimination legislation. It also illustrates the emergence of a new 'disability politics'. This raises important questions about how far impairment and/or disability can be the basis for a shared identity or political project, or the basis for a 'new social movement'. Finally, in chapter 7, we bring an important comparative and international dimension to the debates on disability.

Terminology

A critique of established definitions and language has been an understandable obsession for disabled people, given that disabled people's lives are so affected by 'official' definitions and meanings. In our view, widely used English words such as 'cripple', 'spastic' and 'idiot' have lost any semblance of 'technical' meaning and simply become terms of abuse or ridicule. Equally, common metaphors such as 'turn a blind eye' or 'deaf ear' to the world reinforce an impression of incapacity and abnormality. An alternative vocabulary has proved to be a source of endless debate, but here the phrase 'disabled people', rather than 'people with disabilities', is

used because it signals our emphasis on the ways in which social barriers affect life chances. Nevertheless, we concede that key terms, including 'disability' and 'disabled people', often defy easy translation into other languages. Moreover, different historical and cultural experiences often thwart agreement among those who speak a common language, as a cursory glance at the American and British literature confirms.

Review

Academic discussion of impairment and disability in the social sciences has been slow to undercut the prevailing 'personal tragedy' orthodoxy. Socio-political analyses of disability owe their momentum instead to the pioneering studies of disabled activists and the growing politicization of disabled people around the world. A new, vibrant disability studies literature is now building alternative perspectives to the established, individualistic approach to disability. This includes criticism of conventional policy responses to disability as well as mainstream service provision. It has also highlighted the contrasting form and character of disability across specific social, cultural, economic and political contexts. At the same time, the emergence of analyses of disability as a form of social oppression has triggered new demands for political action.

2

Disabling Societies: Domination and Oppression

The emergence of socio-political approaches to disability reflects disabled people's claims that they experience significant and entrenched social oppression. Our discussion starts from the premiss that oppression is a structural concept, and that it is evidenced by a highly unequal distribution of material resources and uneven power relations and opportunities to participate in everyday life, compared to those available to non-disabled people. We also assume that the form of dominance, and how it is maintained, may range from the overt force exercised by some ruling groups to the embedded assumptions and practices of everyday life that may also produce deep injustices – hence our interest in incorporating notions of 'ideological domination' and discursive power. As social oppression is interpreted in several ways, or contains distinct aspects, we begin this chapter by outlining the usage adopted here.

We conceptualize disability as a form of social oppression akin to sexism and racism, although it exhibits a distinctive form, with its own dynamics – hence our aim in the second part of the chapter to explore the social creation of disability as a historically and culturally specific form of social oppression. We review accounts of the emergence of a 'personal tragedy' approach to disability in Western societies, and its association with the growth of industrial capitalism. In the final part of the chapter we consider broad trends in

the social oppression of disabled people since the middle of the twentieth century.

Disability as a form of social oppression

In highlighting social oppression, disability writers have emulated anti-racist and feminist analyses by moving away from class-based accounts to explore historically specific relations of dominance between non-class groups (Brittan and Maynard 1984). Disability demonstrates its own distinctive set of dynamics, although these may on occasion interact with the processes of class oppression. Like sexism and racism, disablism expresses itself in exclusionary and oppressive practices at a wide range of levels: interpersonal, institutional, cultural and societal.

The identification of disablism as a specific form of social oppression stems from the subordination of people because of their impairment. People categorized in this way are marked apart as a distinct social group on the grounds of their perceived bodily deficiency or abnormality and treated differently: 'For disabled people the body is the site of oppression, both in form, and in what is done with it' (Abberley 1987: 14).

Historically, the oppression of other social categories, notably women and black people, has been justified in terms of their biological shortcomings and weaknesses. However, in the last quarter of the twentieth century these claims have been in general retreat. In stark contrast, there has been no such reversal in popular thinking or public policy with regard to people with impairments. There is a continuing and exclusive emphasis on the deficiencies of the disabled mind/body. Indeed, medical interventions such as surgery or 'mind-changing' medication remain acceptable ways of addressing disability – since the 'cause' is located in those with an impairment, rather than in the society or groups which discriminate against such individuals (Finkelstein 1993a).

The way in which contemporary analyses highlight oppression is indicative of a shift in the ways of theorizing political power and dominance. More traditional notions dwelt on the

uneven distribution of material resources and life chances. However, oppression is not just about being on the receiving end of a tyrannical power. It is also effected through apparently liberal and 'humane' practices, including medicine, education, bureaucracy, leisure and consumer goods (Foucault 1977). Thus, people in their everyday lives act and think in ways that are 'oppressive' to disabled people, but do not always recognize their actions as having this effect.

Iris Marion Young (1990) differentiates five main aspects of oppression: exploitation, marginalization, powerlessness, cultural imperialism and violence. *Marginalization* refers to the systematic removal of a social group from the mainstream of everyday life, and includes material disadvantages, exclusion from the division of labour, institutional segregation, and denial of citizenship rights. Countervailing social policies provide some recognition of disabled people's marginalization, but these 'solutions' may themselves facilitate economic and social dependency through enforced reliance on welfare benefits and services. This overlaps with *powerlessness* as the realization of oppression, which confirms that people have little control over or choice in what to do with their lives. It is verified by a sharp divide between those who exercise authority or power (as in the case of professionals) and those who simply 'take orders' and lack authority or status.

These two aspects of social oppression are contrasted with the Marxist concept of *exploitation*, which is reserved for the social relations between dominant and subordinate classes in the sphere of production, whereby the exploiting group extracts material gains from other workers. Of course, it is hardly possible to profit from the exploitation of another group's labour if, like disabled people, it is only marginally involved in the paid labour market. Alternatively, it is possible to emulate feminist arguments that men appropriate women's unpaid (domestic) labour as in sexual reproduction and child rearing and thus exploit them.

Cultural imperialism is a further aspect to social oppression. In recent centuries, a marked divide between 'able-bodied' and 'disabled' people has been established at the cultural level. 'Able-bodied normalcy' is embedded in everyday thinking and behaviour as a privileged or desirable state of being. The notion of 'able-bodied' assumes normative or

universal standards by which all other 'bodies' are judged. The disabled population is set apart, as 'Other', or as deviant in specific ways. 'In its identification of some groups with despised or ugly bodies, rationalistic culture contributes to the oppressions of cultural imperialism and violence' (Young 1990: 11).

The defining feature of *violence* and harassment in the oppression of disabled people is that it is systematic and widespread. Irrespective of whether it takes the form of physical or sexual attacks, eugenic policies or verbal ridicule, it is directed at specific individuals because they belong to a particular social category – the 'disabled'. Moreover, even the threat of violence is a source of considerable fear and restrictions on life activities of the group targeted.

In the discussion that follows, we assess the specific pattern and intensity of these several dimensions of the oppression of disabled people, and consider claims that disabled people experience a specific form of social oppression and exclusion that rests on the following foundations:

At an empirical level, it is to argue that on significant dimensions disabled people can be regarded as a group whose members are in an inferior position to other members of society because they are disabled people. It is also to argue that these disadvantages are dialectically related to an ideology or group of ideologies that justify and perpetuate this situation. Beyond this it is to make the claim that such disadvantages and their supporting ideologies are neither natural nor inevitable. Finally it involves the identification of some beneficiary of this state of affairs. (Abberley 1987: 7)

Historical patterns and perspectives

Until recently, there have been few historical studies of disability, and existing contributions have been criticized as lacking theoretical sophistication or extensive empirical grounding (Bredberg 1999). Most stress the continuity of negative attitudes and practices towards those with perceived impairments, although some identify signs of more liberal and humanitarian attitudes and policies towards disabled

people, at least in modern times. The latter concentrate primarily on improvements brought about by philanthropy, scientific medicine, social welfare and educational policies (Winzer 1993).

Histories of disability often start their journey in ancient Greece with its idealization of body shape and fitness linked to acceptance of infanticide for those born with visible impairments. The dread of impairment is reinforced by examples drawn from the Bible suggesting that it is a punishment for past sins. The negative picture gathers further corroboration in the denunciation of newly born children with impairments as 'changelings', or inhuman beings substituted by the Devil, by a continuous line of medieval clerics from St Augustine to Martin Luther. There is also ample evidence that everyday life and popular culture were permeated with views that associated impairment with evil and wrongdoing and as a source of ridicule, fear and pity (Ryan with Thomas 1980; Thomas 1982; C. Barnes 1997). A more nuanced picture is occasionally available, as in Henri-Jacques Stiker's (1999) grand historical journey, which provides enough evidence to convince that oppression is not a universal or consistent experience for people with impairments. While the force of 'cultural imperialism' is abundantly evident, a major shortcoming is that there are very few attempts to explore a material basis to this changing historical detail.

Industrial capitalism and disability

In one of the first attempts to advance such a theoretical framework, Vic Finkelstein, in *Attitudes and Disabled People* (1980), outlines a historical materialist account. This relates qualitative changes in social responses to impairment to three main economic-technological 'phases': pre-industrial (feudal society), industrial capitalism, and post-industrial society.

In the pre-industrial phase, activity is agrarian, or cottage-based. While most people with impairments occupy the lower ranks of the social hierarchy, they are expected to participate in economic life. Other writers on disability, such as Brendan Gleeson, agree that, 'whilst impairment was probably a prosaic feature of feudal England, disablement was not'

(1997: 194). Feudal social relations focused more on subsistence than wealth generation and accumulation, so that 'disabled people were regarded as individually unfortunate and not segregated from the rest of society' (Oliver 1990: 27). At the same time, 'peasant households could not afford to consider any bodies as unproductive' (Gleeson 1999: 83). It was accepted that differences in individual economic performance might force people to change work to accommodate their impairment, rely on begging and charity alms, or in the case of older disabled people unable to work, they might provide shelter to others in return for personal support (Pelling 1998).

Little evidence has been provided to substantiate claims that people with impairments were readily integrated into social life in feudal societies. Certainly, sickness and impairment were constant features of everyday life, although the high mortality rate among people with impairments greatly reduced the numbers otherwise reliant on community support. As always, impairments varied in how far they led to marginalization. Certainly, there are studies, particularly that of the island of Martha's Vineyard in Massachusetts, that illustrate how this small-scale, isolated, rural community in the nineteenth century acted in inclusive ways to the relatively high proportion of people with hereditary deafness. Most notably, substantial numbers of the local hearing population learned sign language (Groce 1985).

Finkelstein's second phase relates to the establishment of industrial capitalism in nineteenth-century Europe and North America. His suggestion of a qualitative shift in responses to impairment is replicated in what Mike Oliver (1990) terms the 'social creation' of disability as a personal tragedy with the rise and entrenchment of capitalism. Both writers highlight the spread of a free market economy, wage labour, and the change to mechanized systems of production. 'The speed of factory work, the enforced discipline, the time-keeping and production norms – all these were a highly unfavourable change from the slower, more self-determined and flexible methods of work into which many handicapped people had been integrated' (Ryan with Thomas 1980: 101).

This build-up of constraints on the employment of people with impairments led to the increased displacement of 'unproductive' disabled workers from the work-place,

although this process was uneven and drawn out, rather than sudden. The person with an impairment was at a disadvantage because of the decline of traditional, local community and family-based support systems and values, and the rising importance of geographical mobility to find employment. By contrast, the rapidly expanding industrial towns and cities appear far less accommodating to disabled people. A case study of nineteenth-century Melbourne in Australia demonstrates a growing 'socio-spatial marginalization' of disability (Gleeson 1999). This encompassed the segregation of disabled workers into a diminishing number of specialized activities such as home working, handicraft production and street trading.

Disability as a personal tragedy

Finkelstein's primary aim was to explain the development of an ideology of disability that stressed 'personal tragedy, passivity and dependence' (Finkelstein 1980: 1). This was extended by Mike Oliver in *The Politics of Disablement* (1990), where he draws on the neo-Marxist literature to highlight the crucial role of a reinforcing ideology or 'mode of thought' – that is, a set of values and beliefs underpinning social practice, in sustaining social oppression: 'the disabled individual is an ideological construction related to the core ideology of individualism and the peripheral ideologies related to medicalisation and normality' (Oliver 1990: 58).

A key inspiration within these debates in the 1970s and 1980s was Antonio Gramsci (1971, 1985), with his analyses of the way in which dominant interests do not simply rely on force or coercion. Instead, they seek to win the 'willing consent' of the subordinate population and achieve a 'hegemony' in the ideological domain through their involvement in cultural production and consumption. Their success is evident when one way of looking at the world is accepted at a common-sense level as 'natural'. Gramsci also presumed a more complex relationship between material and cultural factors. Whereas other Marxists had described a single, all-enveloping dominant ideology, he allowed for the 'relative autonomy' of 'hegemonic' culture from dominant economic

interests, and recognized the existence of 'subaltern' cultures and their potential for generating political resistance and change.

With the rise of industrial capitalism, the hegemony of 'able-bodied' normality became the yardstick for judging people with impairments as 'less than human' (Oliver 1990: 89). This view pervaded education, religion and the law. Most particularly, the negative representation of disabled people in Victorian literature, by eminent novelists such as Charles Dickens, impressed itself on the popular imagination. It is replicated in the twentieth century by film and television images of disability (Hahn 1989). A further crucial aspect of cultural imperialism is the importance of charity in the lives of disabled people across Europe and North America. It provides an enduring cultural message that helps perpetuate an image of helplessness and dependency.

A further crucial issue in European and North American countries has been the increased profile of the (local and central) state in addressing disability issues, particularly since the seventeenth century. Mildred Blaxter (1976) reviews this interplay between economic and humanitarian factors in the development of social policies. Deborah Stone further elaborates this argument in *The Disabled State* (1985), suggesting that industrializing societies (such as the USA, Britain and Germany) faced a dilemma over how to distribute goods, services and other rewards. Although the main criterion is employment status, not everyone is able or willing to work, hence a second system emerges geared to resource distribution on the basis of perceived needs. The dilemma for those administering policy has been how to determine who is a deserving case and properly part of the needs-based system.

The state has played a key role in establishing administrative categories that expressed a 'culturally legitimate rationale for nonparticipation in the labor system' (Stone 1985: 22). The English Poor Law of 1601 offered an early example, with its distinction between the deserving and undeserving poor, with disabled people generally categorized as 'deserving' cases. Over the next two centuries, the disabled element was refined to include the 'sick, insane, "defectives" and "aged and infirm"' (Stone 1985: 40). The last two centuries have witnessed a further 'widening and loosening' of the definition

of disability (Blaxter 1976). Nineteenth-century target groups were supplemented by those with war-time injuries, while eligibility gradually extended to some industrial injuries, and then more widely to cover individuals with a range of 'chronic illnesses and disabilities'. The growing numbers entitled to disability benefits raised cost concerns, but there was also a clash in occupational perspectives, with 'unavoidable incompatibilities between medical definition systems, which ideally are individual, qualified and provisional and administrative categories which are necessarily rigid, dichotomous and designed for large groups of people' (Blaxter 1976: 10).

The involvement of the medical profession in disability has been central to the legitimation of a personal tragedy approach. Medicalization (or the application of medical knowledge to an increasing range of social problems) emerged as a key aspect in the social control of disabled people. It supplanted more religious and traditional approaches. While people in early modern societies consulted a range of lay and 'medical' practitioners about their health and general well-being (Pelling 1998), by the nineteenth century an orthodox medical profession had overturned this pluralism in healing practice. Its ascendancy was not only justified in terms of theories of disease and healing grounded in scientific knowledge claims, but reinforced by its location in specialized sites (hospitals and asylums). These established a further distance and hierarchy between professional experts and lay patients, with control over the recruitment, education and training of new practitioners. Equally crucial, the medical monopoly of health care was legitimated by the state (Jewson 1976; Larson 1977).

More generally, the late eighteenth and nineteenth centuries witnessed a wide-ranging institutional system of social control that extended beyond hospitals and asylums to include prisons, workhouses, industrial schools and colonies (Cohen and Scull 1983). Specific impairment groups who became identified as social problems, notably those designated as having a mental illness, became significant targets for incarceration. Andrew Scull (1979, 1984) provides a detailed picture of this symbiotic relationship between state policy and the achievement of a medical monopoly over mental illness allied to 'manufactories of madness'. He

contends that the medicalization of 'madness' and its institutional regime proved 'functional' to the capitalist state in terms of both economic efficiency and social order. While industrialism and urbanism led to physical and 'mental' harm among the mass of the population, the rise of institutions, particularly where it was allied to medicine, offered reassurance that something positive and humane was being done for the 'deserving poor'. Nevertheless, the scale of confinement demonstrated considerable international variation: less evident in Britain than in its European neighbours such as France.

As far as disabled people were concerned, another key aspect to their institutionalization emerged with the development of segregated schooling for disabled children. The origins of 'special education' lie in the late eighteenth and early nineteenth centuries, initially for deaf children and then for those with visual impairments, followed by those labelled as 'feeble-minded'. There were successive waves of expansion into the early decades of the twentieth century, leading to 'special schools' for 'crippled' and 'physically defective' children and for those categorized as 'educationally backward' (S. Tomlinson 1982; Humphries and Gordon 1992; Winzer 1993). The training provided confirmed public expectations of disabled adults as capable of only minimal social and economic participation.

The medicalization of disability and the growing emphasis on the education and training of disabled children and adults also signalled a crucial professionalization of disability that continued apace through the twentieth century. To many writers on disability, professionals have proved to be 'disabling' and self-serving, always looking to extend their influence to new areas and groups (Illich et al. 1977). Certainly, disability was not long in becoming an occupational territory reserved for professional 'experts' who laid claim to specialized, esoteric knowledge (Freidson 1970). Moreover, with the growth in disability services, an increasingly complex division of labour was established. This encompassed a marked expansion in the professions allied to medicine, such as occupational therapists and physiotherapists, as well as in the educational and social welfare fields. The end result for disabled children and adults was a widening

professional involvement in their lives, over educational provision, entry to paid employment, eligibility for welfare payments, and provision of technical aids and equipment.

While following a broadly materialist perspective in tracing the emergence of a personal tragedy approach to disability, it is important not to overstate the case. It is important to reject 'explanations' that resort to the 'logic of capitalism' or undercut detailed examination of the actions of key interests such as medicine by claims that they operate 'inevitably' as the 'agents' of capitalism (Giddens 1981). This denies any autonomy to the struggles between competing groups and interests, including what were on occasion clashes between different capitalist interests. The outcome of these struggles is neither pre-determined nor so easily categorized.

Discourses and bio-politics

Another perspective on medicalization and the growth of institutions was advanced by Michel Foucault. His writings have exerted a growing influence in disability studies, and offer a counter to accounts that interpret disability as a direct reflection of capitalist/ruling class interests (Finkelstein 1980; Abberley 1987; Oliver 1990).

By contrast, Foucault (1980) highlights power/knowledge struggles, with the body placed centre stage. He concentrates on the way in which knowledge and meaning are produced through discourse or ways of organizing claims and assumptions. The operation of power/knowledge is explored in relation to specific institutional settings and 'technologies' or techniques, in ways that historicize discourse, knowledge and 'truth' (Foucault 1982). Scientific (rather than juridical or religious) categories, as produced in medical discourse, become the focus of analysis. He identifies a new technology of the body or disciplinary power. This new 'bio-politics' encompasses a shift from sovereign to disciplinary power (Armstrong 1983). Whereas the body had previously been physically or externally controlled, the emphasis now moved to mechanisms of self-discipline. The aim was a docile body that 'may be subjected, used, transformed, and improved' (Foucault 1977: 136).

This discursive approach displaced the individual as an independent, authentic source of meaning and action (Hall 1997). Moreover, the new medical 'scientific' discourse on 'normality' served both a clinical and a moral function: 'it claimed to ensure the physical vigour and the moral cleanliness of the social body; it promised to eliminate defective individuals, degenerate and bastardised populations. In the name of biological and historical urgency, it justified the racisms of the state... It grounded them in "truth"' (Foucault 1979: 54).

Lennard Davis illustrates the Foucauldian project in *Enforcing Normalcy* (1995) when he argues that 'the social processes of disabling arrived with industrialisation' as a new set of discourses and practices (p. 24). These centred on the distance between 'normalcy' and the 'disabled body', with a particular influence exerted by statistics on medical knowledge and practice. What had been the dominant discourses around notions of the 'grotesque' and the ideal body in the Middle Ages were completely overturned by the normalizing gaze of modern science. This established a hierarchical standard for pronouncing some bodies and minds as abnormal and inferior – in terms of appearance and performance. Standards of physical health, mental balance and moral soundness became closely linked, so that defective bodies and minds were also associated with 'degeneracy' (Young 1990).

In the case of mental illness, the professional take-over has long attracted condemnation from social scientists, on the grounds that the growth of psychiatry has been self-serving. Thus, its dominance of mental health was 'neither warranted nor desirable', and ignored the social origins, if not also the social construction, of mental illness (Ingleby 1983: 143). In terms of psychiatric discourses, by the mid-nineteenth century, 'mental illness' was accepted as a generic term covering very different conditions. Entering the twentieth century, psychiatry extended its gaze from the psychoses to the neuroses (Armstrong 1983). It also moved outside the asylum into families, schools and work-places. A growing army of mental health workers in psychology, counselling, social work and education gained legitimacy, and the basis for social regulation shifted from 'dangerousness' to 'risk'

(Castel 1983; Miller and Rose 1988). This legitimated professional interventions around prevention and rehabilitation.

Davis (1995) provides a further detailed illustration of the transformation in discourse in a historical review of deaf people's emergence from their isolation in an overwhelmingly aural society and culture. He suggests that eighteenth-century Europe witnessed the 'invention' of deafness, in the sense that a novel philosophical-scientific discourse was established. The hearing world perceived the 'deaf and dumb' as particularly tragic, because of their inability to communicate and to think rationally. This was also a period when literacy and reading emerged as marks of distinction. The pursuit of enlightenment was a spur to establishing residential schools for deaf children. However, these became a discursive battleground between the advocates of sign language ('manualism') and those promoting lip-reading and speech ('oralism'), with 'Deaf people' stressing the importance of linguistic and cultural identification and solidarity, and critics underscoring assimilation rather than linguistic difference (Lane 1989; Baynton 1992). (For the purposes of this discussion, the use of the capital "D" denotes membership and recognition of a distinctive Deaf culture.)

Overall, professional discourses around impairment/disability targeted unruly or defective bodies as evidence of a lack of humanity. There was an emphasis on regulating the body, through socializing (controlling and self-disciplining), rationalizing (with a clear separation between natural impulses and rational behaviour) and individualizing (as a self-contained entity) (Shilling 1993).

Eugenics

With the spread of Darwinian ideas about evolution and 'the survival of the fittest', impairment became identified as a threat to social progress.

We civilised men, on the other hand, do our utmost to check the process of elimination; we build asylums for the imbecile, the maimed, and the sick; we institute poor-laws; and our medical men exert their utmost to save the life of everyone to the last moment... Thus the weak members of society

propagate their kind. No one who has attended to the breeding of domestic animals will doubt that this must be highly injurious to the race of man. (Darwin 1922: 136)

Several of the early, eminent statisticians – Galton, Pearson and Fisher – promoted the eugenic applications of statistics for ‘improving the human race’. Initially, the merger between statistics and biology promised a science of the average effects of the laws of heredity (Abrams 1968: 89), but this interpretation of ‘normality’ gave way to the idea of ranking, with those deviating from the norm located on a continuum from higher to lower scores.

This is vividly illustrated in the case of Intelligence Quotient (IQ) scores. They quickly acquired a moral connotation of superior and inferior ‘intellectual’ functioning. Early scientific interest concentrated on distinguishing between ‘mental deficiency’ and ‘normality’, but the application of a normal distribution curve and new tests, such as the Binet–Simon, led to the identification of ‘mildly retarded’ and ‘moron’ categories. Statistical theories reinforced a deterministic account of intelligence, ‘race’ and human evolution. Social Darwinists classified disabled people with ‘severe’ impairments as ‘mutants’ (Radford 1994). The spectre of ‘race degeneration’ was fostered by John Langdon Down’s 1866 classification of the ‘mongolian idiot’ as a throwback to a non-Caucasian type (Gould 1980). Defective bodies and minds were perceived as ‘dangerous’ and ‘threatening’ to the rest of society.

Eugenicists further highlighted links between intellectual and physical deficiency and a range of social evils, including crime, vagrancy, alcoholism, prostitution and unemployment (Kevles 1985). Across Europe and North America, policies espousing ‘social hygiene’ gained ground, ranging from segregation in institutions to State and medically sponsored schemes for sterilization and abortion. In 1938, thirty-three American states had a law allowing the forced sterilization of women with intellectual impairments, but in Nazi Germany during the 1930s and 1940s an altogether more systematic and extensive extermination programme was introduced against the ‘unworthy’. This led to the murder of more than 270,000 disabled people on the grounds that

they were ‘travesties of human form and spirit’ (Burleigh 1994: 194).

Late twentieth-century trends

‘Phase Three’ in Finkelstein’s (1980) account corresponds to mainstream accounts of the emergence of a post-industrial society in the second half of the twentieth century, with the new, computerized, information technology identified as the harbinger of significant social and economic changes. He interprets this as bringing altogether more positive opportunities for the inclusion of people with impairments in paid employment, so allowing ‘the most severely physically impaired people . . . to live relatively independently in the community’ (1980: 11).

In the 1990s, fresh momentum was given to claims about significant changes in late twentieth-century capitalism. Manuel Castells (1996) is one of those who argues that there has been a notable shift away from manufacturing and service industries towards ‘informationalization’ and an increasing global economy. However, most writers on disability are less sure than Finkelstein about the impact of these trends on the social inclusion of disabled people (Albrecht 1992; Roulstone 1998; Sapey 2000). Some believe that the replacement of the spoken by the written word, through changing forms of communication technology, and speech translation software will facilitate the inclusion of those with sensory and some physical impairments (cost considerations notwithstanding). Conversely, people with learning difficulties, mental health system survivors, and older disabled people may be further marginalized and excluded. Finkelstein’s optimism notwithstanding, the consequences of the new informational economy seem far from clear, offering both an enabling and a disabling potential, and likely to divide disabled people in new ways.

From a non-Marxist perspective, Gary Albrecht (1992) also draws links between economic and technological changes and historical shifts in disability. He categorizes societies according to their technological subsistence base into hunting and gathering, pastoral, horticultural, agrarian and

industrial (with post-industrial and post-modern stages). Each societal type is characterized by a distinctive set of relations between its biological, physical and cultural environments. This includes a unique 'type, incidence, and prevalence of impairment and disability and of social responses to them' (p. 39).

Albrecht's illustration of the American experience of industrialism provides a valuable corrective to accounts that focus exclusively on Western Europe. While there are significant similarities, the parts played by key interests, including the State, the medical profession, and private corporate interests demonstrate important differences, at least in emphasis (Berkowitz 1987). He acknowledges the significance of the medicalization of impairment and disability, but stresses how in a private insurance-dominated health care system people with impairments have become a huge market for the services and products of health and social care agencies and professions. These include aids and equipment, drugs and insurance, training and rehabilitation. 'The disability business focuses on both treating persons with disabilities as raw materials and by commodifying disabilities and rehabilitation goods and services, making them objects of commerce' (Albrecht 1992: 68).

The profit potential of the disability business has led to considerable competition between different factions of capital or groups within the dominant class. Marta Russell illustrates how, in what she terms the 'Money Model of disability' (1998: 96), the recent expansion of rehabilitation medicine and services, including the massive growth in residential (nursing) homes for disabled people, has turned 'entrepreneurial medicine' into a multi-million-dollar business. Throughout this period, the American state has played a facilitating role for private and professional interests without prioritizing public sector or publicly funded services to the same extent as in many European countries.

Notwithstanding these differences, disability policy has become an increasingly significant item for political debate. It was in the second half of the twentieth century that separate disability policies and growing numbers of disabled people dependent on services and benefits became established features of social welfare systems. However, disability

policies became a primary target when governments across Europe and North America began to advocate a retrenchment in state expenditure in the late 1970s. These constraints rekindled administrative battles over where to draw the boundary lines around eligibility and support needs. Capitalist states were caught between balancing financial interests and constraints with the maintenance of their political legitimacy and social order.

Disablement makes an important contribution to the ideological crisis surrounding health and welfare in capitalist societies. This is because disabled people, being both deserving and expensive, pose a crisis of legitimacy for the State in those capitalist societies which seek to be both profitable and civilised at the same time. (G. Williams 1991: 517)

While restricting eligibility for, and cutting expenditure on, disability benefits and services provides a strategy for reduced spending, it is constrained by expectations among disabled people of continued social welfare support and general public willingness to continue to support policies for disabled people as just and reasonable. Equally, the corporate groups with a vested interest in the 'disability business' will strive to ensure that expenditure on disability policies expands.

Changing practices

From the late 1950s, segregated institutions attracted growing criticism, both from disabled people and their organizations and from mainstream providers, academics and politicians. In Britain, as in many other European and North American countries, inquiries documented the shortcomings in support and 'care' provided in old people's homes, psychiatric and 'mental handicap' hospitals (Townsend 1967; Martin 1985). Standards of residential care were very basic, with many examples of institutional abuse and harassment: 'There are staff who bully those who can't complain, who dictate what clothes people should wear, who switch the television off in the middle of a programme, and will take away "privileges" (like getting up for the day) when they choose' (Hunt 1966a: 154).

For Goffman (1961), the psychiatric asylum represented one form of 'total institution' characterized by long-term incarceration. Life within such institutions is strictly regimented and geared towards organizational goals. A strict demarcation line is drawn between the inmates and the staff, with mutually hostile and negative stereotypes characterizing their relations. On first entering the institution, inmates are subjected to various 'degradation' ceremonies amounting to a 'mortification of self'. The individual's former identity and clothes are removed, and replaced by an impersonal institutional identity (Humphries and Gordon 1992). Privacy is denied, and constant surveillance and regulation become standard routines.

British residential institutions studied by Eric Miller and Geraldine Gwynne (1972) in the 1960s confirmed this grim picture. They identified two contrasting value positions: one 'humanitarian' and the other 'liberal'. These correspond to distinctive styles of care: warehousing and horticultural. Humanitarian regimes stress maintaining life as long as possible, but in a minimalist, 'keep the residents cheerful' sense. In liberal regimes the goal is to attain 'normality', no matter how desperate the individual's circumstances (although the staff conception keeps inmates from expecting too much). Humanitarian approaches to warehousing regard the residents' lives as beyond improvement and akin to 'social death', so they are largely passive and dependent on care staff. By contrast, liberal horticulturalism stresses the potential for rehabilitation and satisfying an inmate's unmet needs. Miller and Gwynne (1972) expressed their preference for a positive regime of 'enlightened guardianship' that did not raise false expectations among residents about what can be achieved.

Nevertheless, there was a general shift in public policy in the second half of the twentieth century towards closing large, residential institutions. As a result, more disabled people were transferred to living 'in the community'. The number of places in British institutions registered under the Mental Deficiency Act of 1913 rose six-fold to 32,000 through the inter-war years. The association with social deviancy was such that having an illegitimate child might constitute grounds for confinement (Ryan with Thomas

1980). Large psychiatric institutions for the mentally ill demonstrated a similar trajectory in North America and many European countries. By 1955, the inmate population in county and state mental hospitals in the USA had risen to 558,000 (Conrad and Schneider 1980), but then a sharp decline occurred with the state mental hospital inmate population falling by 78 per cent by 1981. In Europe, the psychiatric hospital population was halved in Italy from 100,000 to 50,000 between 1968 and 1978, compared with a less dramatic decline in England and Wales from 148,000 in 1954 to fewer than 96,000 in the early 1980s.

The policy shift was thought a cheaper option by governments, and attractive for that reason alone. In addition, professional discourse argued that pharmacological innovations now enabled medical control of inmates outside the institution, while psychiatric professionals looked to greater integration with their medical counterparts (Scull 1984; Busfield 1986). The transition to living in the community was also accompanied by a reassertion of rehabilitation and caring goals by those working in the 'human care industries'. Yet, according to Wolf Wolfensberger, whatever the stated aims, their latent function has been to create and sustain large numbers of dependent and devalued people in order to secure employment for health and social care staff and profits for private companies. His review of the Dutch welfare system suggests that, instead of supporting independent living for 'people with learning difficulties', it actually 'discriminates against independence, communality, and non-congregate and non-institutional living' (Wolfensberger 1989: 37).

The search for alternative support for disabled people underpinned the introduction of 'normalization' policies. These emerged in Scandinavia in the late 1960s (Bank-Mikkelsen 1980). The service goal was to decarcerate people with learning difficulties in long-stay institutions so as to enable them to lead more 'normal' lives by integrating them as far as possible into the mainstream. The philosophy and practice of normalization stressed the aim of assisting individuals into 'socially valued life conditions and socially valued roles' (Wolfensberger and Thomas 1983: 24). Yet critics have argued that normalization policies are professionally led in decisions about what constituted culturally

valued and appropriate services (Brown and Smith 1992; Chappell 1992). Even policies invested with ideas of empowerment and anti-discrimination have been downplayed as an exercise of professional control by more subtle means (Chappell 1998; Stalker et al. 1999). This denotes the very thin line between enabling and disabling discourses and practices that applies more widely across such areas as counselling, advocacy and special needs education.

While the move away from living in large institutions continued, there was a corresponding growth in less formal, small-scale units and support networks (Russell 1998). However, these did not deliver the promised reworking of helper-helped relationships. Day centres and small group 'homes' or hostels 'in the community' still demonstrated an 'institutional' atmosphere (Barnes 1990), and concentrated on helping individuals cope with their personal tragedy.

Further criticism poured down on community care policies. The ideology of 'care' was castigated as integral to the individual approach to disability. Moreover, the overwhelming contribution is made by women, whether as informal carers in the family or friends or in the personal services. This attracted feminist charges that care policies were exploiting women's labour and time. Disabled feminists replied that this ignored the contribution of disabled women (in particular) as 'carers', besides portraying disabled people as a 'burden' or liable to exploit their children as unpaid helpers (Morris 1991). For disabled people, 'care' is the opposite of what they want from government policy or service providers, and misrepresents what people need to live 'independently' in the community. There has been a slow liberalization of social care policies, but there remains too little choice for disabled clients, and professional dominance of their needs and priorities is resistant to change.

There remains considerable debate regarding where care should be provided (in homes, institutions or something in between), who the providers of care should be, and what forms such 'care' might take (M. Barnes 1997). There have been renewed public campaigns, particularly from parents' groups, advocating the value of enlightened institutional regimes for some disabled children and adults. Yet, there has also been heightened policy support for service user 'partici-

pation' (Croft and Beresford 1992). The desired form and level of user involvement remain uncertain, but have demonstrated the existence of very different philosophies and strategies. On the one hand, there are user-led movements seeking autonomy, control and power, and on the other hand, there is an agency-led view of consulting with consumers about their preferences, in line with a market economy of welfare approach (see chapter 6).

Disabling professionals

In characteristic polemical vein, Ivan Illich (1977b) condemned the 'medicalization of life', and castigated medicine as 'a major threat to health' by misappropriating knowledge, mystifying its expertise, and creating a dependence on doctors, while ignoring medicine's deleterious consequences on individuals and society. 'I propose that we name the mid-twentieth century The Age of Disabling Professions, an age when people had "problems", experts had "solutions" and scientists measured imponderables such as "abilities" and "needs"' (Illich 1977a: 11). There is more than a hint of such criticism in the disability studies literature. Professionals are distinguished by their capacity and inclination to overcome lay opposition in deciding what is in the disabled person's 'best interests' (Gliedman and Roth 1980).

The link between the rise of professional dominance and institutional solutions to the 'problem' of disability has already been noted. With the moves towards decarceration in the second half of the twentieth century, there was a further transition in professional discourse. Attention now focused on a range of 'talking therapies', as a veritable 'psy complex' began to take root in advanced industrial societies (Ingleby 1983).

Through self-inspection, self-problematisation, self-monitoring, and confession, we evaluate ourselves according to the criteria provided for use by others. Through self-reformation, therapy, techniques of body alteration, and the calculated reshaping of speech and emotion, we adjust ourselves by means of the techniques propounded by the experts of the soul. (Rose 1990: 10)

In addition, rehabilitation medicine occupied an even more prominent place in the lives of disabled people. It highlights the importance of taking the opportunities for a 'second chance' by working with appropriate professional experts. Eugenic thinking has also been revitalized by developments in biotechnology and genetic medicine. These raise the spectre that a 'new genetics' may stimulate a 'geneticization' of explanations of human behaviour and human values (Steinberg 1997).

There are examples where medical imperialism has not been successful and apparent opportunities for extension of professional interests have not been pursued. There are also instances of de-medicalization in which lay or State interests have pressed for medicalization in the face of a reluctant profession (Strong 1979). The enduring impression, however, is of the dominance of 'able-bodied' experts, particularly in the 'human service' professions (Wolfensberger 1989). Attempts to develop more enabling services have encountered considerable opposition from professionals and policy makers (Finkelstein and Stuart 1996). It is professional discourse on the 'special needs' of disabled people that prevails even over clearly expressed user 'demands' for support or 'quality of life' (Doyal and Gough 1991).

The enduring impression, from the perspective of disabled people, on both sides of the Atlantic (UPIAS 1976; DeJong 1979; Zola 1982), is that lay-professional relations are characterized as hierarchical, encouraging helplessness and dependence. They encapsulate the dependence and powerlessness of disabled people. Professionals are immersed in an individual approach, and regard disability as a health issue. The ideas, values and interests that permeate the helper-helped relationship are of 'able-bodied normalcy' (Finkelstein 1980: 17).

Review

Location on the wrong side of the 'oppression' divide characterizes the lives of disabled people from the more public through to the more personal domains. It is this combination

of material disadvantages, powerlessness and demeaning cultural stereotyping that marks out disabled people's experience of social oppression. Their marginalization acquired a new intensity with the maturation of industrial capitalism, which also came to colonize disabled people's lives in new ways. Even where disabled people's support needs were identified, this led to renewed medicalization and control of their lives by charities and professionals in ways that continue to instil dependence and frustrate attempts to live more autonomous lives.

In summary, people with impairments have been 'isolated, incarcerated, observed, written about, operated on, instructed, implanted, regulated, treated, institutionalized, and controlled to a degree probably unequal to that experienced by any other minority group' (L. J. Davis 1997b: 1). The main beneficiaries are invariably represented as self-serving professionals, although their links with capitalism are not explored in detail. Again, attempts to link changes in the social oppression of disabled people with broader changes in productive forces, and in social and power relations remain unproved. At most, the impact of any changes is uncertain but probably uneven.

The next task is to turn from this broad socio-historical perspective to examine some of the empirical detail regarding contemporary patterns of social exclusion and oppression, including social divisions within the disabled population.