

Competing Models and Approaches

THE individual, medicalized approach embedded in modern Western industrialized societies equates 'disability' with a professionally diagnosed condition characterized primarily by functional limitations. This underpins a policy emphasis on medical rehabilitation and allied service provision. An individual's 'disability', as viewed through the prism of a personal tragedy, is the fundamental reason for their social exclusion. Alternative interpretations attracted only occasional public or policy attention and had a minimal impact on public service provision. It was not until the 1960s, amidst wider social and economic upheavals, that campaigns organized by disabled people outlined a serious challenge to the orthodoxy surrounding disability.

This chapter begins by tracing the socio-historical origins of the established orthodoxy: the individual or medical approach to disability. What are its main contemporary features and why have disability theorists identified it with a 'personal tragedy' approach? The next section traces the development of alternative accounts by groups of disabled people. In America, the rise of the Independent Living Movement generated a new 'paradigm of disability' (DeJong, 1979a), while in the United Kingdom an emphasis on the social barriers to inclusion took root. A more detailed discussion then follows of the elaboration of this critique into a social model of disability (Finkelstein, 1980, 1991, 1993a; Oliver, 1983, 1990). The final section considers attempts to integrate specific aspects of the medical and social options, as illustrated by the World Health Organization's 'biopsychosocial' model (WHO, 2001a). Its 'environmental turn' is echoed in Nordic debates that stress a 'relational' approach to disability (Gustavsson, 2004).

Socio-historical perspectives

It has become commonplace to disavow early historical studies of disability. Most criticism highlights the lack of theoretical analysis

and adequate empirical grounding, as well as the pervasive claims of a steady, if uneven, growth of liberal and humanitarian policies and service provision with the rise of modern, industrial societies (Winzer, 1993; Gleeson, 1997; Bredberg, 1999). The literature is replete with examples of cruel and extraordinary attitudes and practices. Recent research has produced a much more complex picture of what was considered an impairment and how this was evaluated, and the identification of disabled people as a separate social group (Stiker, 1999). Studies document the considerable variation historically and cross-culturally in both patterns and perceptions of impairment and disability and appropriate local policy responses. Hence, it is important to locate attitudes and practices within a specific social context and to examine the interaction of diverse economic-material, cultural and political factors.

For so much of recorded history, the commonality of disease, infirmity and death, widespread poverty and violence has given a harsh reality to everyday life. Only a small privileged few were perhaps able to avoid their full impact. Thus, in ancient Greece and Rome: 'Most of the chronically deformed and disabled had to support themselves either by begging or by claiming the indulgence of a well-to-do relative' (Garland, 1995, p. 44), while people with perceived 'abnormalities' were widely devalued and openly derided (*ibid.*, pp. 73-86). On occasion, contemporaries justified discrimination on economic grounds, but more typically accounts drew on dominant cultural values, with practices such as infanticide attributed to the negative religious omens of the birth of an 'abnormal' child (Stiker, 1999). It was important to appease or deflect the possible threat to social order.

Even so, while religious beliefs were central to ancient societies, their prescriptions regarding impairment exhibited considerable diversity. Judaism regarded many impairments and diseases as a sign of wrongdoing, uncleanness and ungodliness that provided a justification for separating individuals from the rest of the society. Leviticus (21: 16-20), in the Old Testament of the Bible, catalogues a variety of impairments which precluded the possessor from participating in religious rituals - a crooked nose, sores, a missing limb, leprosy and skin diseases, and crushed testicles. Yet Judaism also prohibited infanticide of newborn children with an impairment and emphasized the importance of providing 'charity' for the 'sick' and less well-off. This ambivalence was replicated in the reactions of the early Christian Church, although again impairment and many other unexpected happenings were widely regarded as a punishment for sin or attributed to the 'forces of evil' (Stiker, 1999). Again, medieval society's 'astonishing sensibility' (Bloch, 1965, p. 73) to the supernatural extended to the potency of a range of demonic forces, revealed in the demise of

individuals with 'disordered' minds and the denunciation of visibly impaired infants as 'changelings' - the Devil's substitutes for human children, and the result of their mother's embrace of sorcery and witchcraft (Haffter, 1968). The disabled child became a shameful stigma in the eyes of society and a reason for isolation, ostracism and even persecution' (*ibid.*, p. 61). Similarly, in everyday social interaction, specific impairments were routine targets for popular jokes and denigration. Even so, poorer sections of the population and other marginal social groups, bore the brunt of such hostility towards 'abnormality'.

Notwithstanding such potential for public hostility, everyone, including those regarded as sick or infirm, was expected to contribute as much as possible to the household and local economy so that these were self-sufficient (Botelho, 2004). Those individuals not supported by their families had to rely on the haphazard benefits of charity and alms-giving for subsistence. By the sixteenth century in England, the combination of a decline in the wealth and power of the Church and a perception of a growing vagrant population as a result of plagues, poor harvests and immigration from Ireland and Wales threatened social stability, with a rising demand for charity and poor relief (Stone, 1985). The English Poor Law of 1601 sought to consolidate existing practices into a national system paid for by local rates. Yet there was considerable unevenness and arbitrariness in identifying those individuals regarded as legitimately unable to work and deemed part of the 'deserving' poor.

The possibilities of locating ideas and practices towards disability within broader socio-historical trends are illustrated by Norbert Elias's (1978) detailed analysis of the 'civilizing process' in which people learn to revise their perceptions of repugnance and shame and restraint in social relationships. His comparison of medieval and eighteenth-century European court societies illustrates how public manners and body control became targets for 'improvement', ranging from eating and drinking to farting, spitting, blowing one's nose, and urinating and defecating in public. Historically, the increasing emphasis on 'external' surveillance helped to transform self-control into a mark of social esteem. Yet, conversely, unruly bodies became a sign of animality and a rationale for the spatial segregation of increasing numbers of disabled people. This encompassed a general individualization of the body as a self-contained and controlled entity (Shilling, 1993).

Industrialized societies

Through the eighteenth century there was an intensification of the commercialization of land and agriculture and a marked rise

in industrialization and urbanization. These had significant consequences for community and family life and institutions. As far as disabled people were concerned, the speed of factory work, or working to the rhythms of machinery, often undertaking complex, dextrous tasks, coupled with its regimented discipline, formed 'a highly unfavourable change from the slower, more self-determined methods of work into which many handicapped people had been integrated' (Ryan and Thomas, 1980, p. 101). What might be ignored or tolerated in the slower and more flexible pattern of agricultural or domestic production became a source of friction and lost income, if not a threat to survival, within the new industrial system.

As yet, there was no distinct social group identified as comprising disabled people, just as there were competing cosmologies surveying the bases and possible remedies for disease, illness and impairment (Jewson, 1976). There was an increased categorization of 'sick and infirm' people as a social problem - marginalized by the economic system and socially dependent. In Britain, amidst concerns that the poor laws were not coping with the increased demand for assistance and considerable local variation in provision, legislative reforms in 1834 emphasized national standards, denial of relief outside an institution, and setting support at low levels to deter claimants. A variety of institutional 'solutions' were being promoted to contain the rising number of 'casualties' of the 'far-reaching changes in work and family life' (Ryan and Thomas, 1980, p. 101).

In Britain, the 'aged and infirm' comprised one of the main categories in the new workhouse population. There was also an upward trend in incarcerating people defined as 'defectives', including people with visual, hearing or communication impairments and epilepsy. One of the most high-profile attempts to confine problem groups underscored the growth of asylums for those diagnosed as 'mad' (Scull, 1984). The institutionalized population rose substantially through the nineteenth century, from three to thirty per 10,000 (Scull, 1979). The inmate population in 'medical handicap' institutions also expanded significantly into the twentieth century. The rise of Social Darwinism offered fresh justification for 'intellectual' divisions and hierarchies based on the 'survival of the fittest'. Those categorized as 'subnormal' inspired fears of moral collapse, with resurrections of close links to sexual and criminal deviance (Ryan and Thomas, 1980). Additionally, the introduction of diagnostic labels such as 'Mongolian idiot' suggested that 'mental deficiency' constituted a potential racial threat to civilized society.

A notable development affecting notions of disability stemmed from the consolidation of an orthodox, state-legitimated medical profession, with a distinctive scientific knowledge and practice, based

in residential sites ranging from hospitals to asylums. Through the nineteenth century, the medical profession took the lead in colonizing impairment by providing a comprehensive system of regulation and surveillance from diagnosis to treatment, based on its claim to scientific knowledge. Medical knowledge determined the boundaries between 'normal' and 'abnormal' individuals, the sane and insane, healthy and sick people. These categories were continually being redrawn, with new diseases and impairments identified. There was an associated expansion in the number of medical specialisms, as in the fields of 'mental illness' and 'mental handicap', with a growing separation of the 'lunatic' and 'idiot' asylums. More recently, rehabilitative medicine has become more prominent, along with a growth in allied professional groups. Furthermore, there was a rise in activity by charitable organizations directed at the social problems associated with the dependency of particular groups of disabled people.

In the first half of the twentieth century, the growth of segregated, residential institutions continued apace. The live-in solution was particularly significant for the high number of children with impairments, with many common childhood diseases carrying a significant risk of impairment if not death. In a period of minimal social welfare provision, poorer families found it very difficult to meet the high medical costs and support required by a disabled child (Humphries and Gordon, 1992). There was also a widening impact of the medical profession's authority on policies towards disabled people, from the broad legitimization of an individual's claim to sickness and impairment. However, how far this translated into social and welfare benefits remained a contested area and, in general, a low priority for governments and public alike. The result was an uneasy trade-off between humanitarian and economic factors (Blaxter, 1976; Borsay, 2005).

The individual or medical model of 'disability'

By the late nineteenth century, the individual approach to disability located in medical knowledge was widely accepted in Western industrialized societies. It focused on bodily 'abnormality', disorder or deficiency and how this 'causes' functional limitation or 'disability'. For example, people with quadriplegia lack the use of their arms and are therefore unable to wash or dress without assistance. The foundations are laid by professional diagnosis, treatment and the measurement of recovery, although the distinctive character of 'chronic' conditions highlights rehabilitation rather than 'cure'. The authority of scientific medicine extends to allied health professionals,

such as physiotherapists and occupational therapists, as well as psychologists and educationalists. While also described as a medical model, more strictly it is 'an individual model of disability of which medicalization is one significant component' (Oliver, 1996a, p. 31).

It was not until the mid-twentieth century that legislation used the generic term 'disabled' - defined in the 1948 National Assistance Act as covering 'the blind, the partially sighted, the deaf, the hard of hearing, and the general classes of the physically handicapped'. The administrative task of setting precise (impairment) eligibility criteria for welfare benefits and social services concentrated on the extent of an individual's physical 'abnormality' or 'loss' and its translation into a specific level of incapacity. Even in the 1960s, the British National Insurance Benefit Regulations advised that the loss of fingers and a leg amputated below the knee constituted a 50 per cent disability, while that of three fingers and the amputation of a foot or the loss of an eye translated into a 30 per cent rating (Sainsbury, 1973, pp. 26-7). However, this largely mechanistic approach to the effects of impairment was attracting growing censure from policy-makers, social researchers and disabled people alike.

This prompted a shift to more explicit assessment and measurement of an individual's functional limitations in performing everyday tasks (Jefferys et al., 1969). The first national survey was undertaken by the Office of Population Censuses and Surveys (OPCS) in the late 1960s (Harris et al., 1971a, 1971b). It utilized a threefold distinction between

- *impairment*: 'lacking part or all of a limb, or having a defective limb, organ or mechanism of the body'
- *disability*: 'the loss or reduction of functional ability'
- *handicap*: 'the disadvantage or restriction of activity caused by disability' (Harris et al., 1971a, p. 2).

The measurement of the level of handicap was based on a series of questions about an individual's ability to undertake key personal activities such as toileting, eating and drinking, and doing up zips and buttons.

Over time, the definition of *impairment* ('disability') has been widened to encompass 'anatomical, physiological or psychological abnormality or loss', such as those without an arm or a leg, or who are 'blind, or deaf or paralysed', as well as chronic conditions that interfere with 'physiological or psychological' processes, such as arthritis, epilepsy and schizophrenia (Townsend, 1979, p. 686). There were continuing efforts to produce more valid and reliable measures of an individual's ability to perform key personal activities. The early focus on physical capacity was complemented by research into the service

requirements of people with perceived 'mental' and 'intellectual' impairments (Herz et al., 1977; Meltzer et al., 2000).

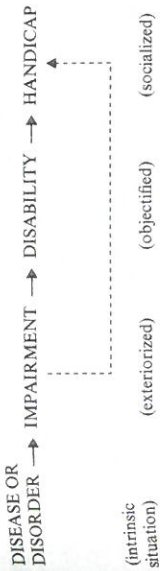
Internationally, the most influential contribution has been the World Health Organization's *International Classification of Impairments, Disabilities and Handicaps (ICIDH)* (WHO, 1980). This taxonomy was designed to complement the *International Classification of Disease* (WHO, 1976) by moving beyond acute conditions and the simple causal sequence (etiology → pathology → manifestation) (WHO, 1980, p. 10, where the last stage consisted of an outcome measure of degree of recovery following medical treatment. It demonstrates many similarities with the OPCS scheme in the definition of its central components:

- *impairment*: 'any loss or abnormality of psychological, physiological or anatomical structure or function' (ibid., p. 27)
- *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' (ibid., p. 28)
- *handicap*: 'a disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual' (ibid., p. 29).

Impairment covers those parts or systems of the body that do not work properly, and 'disability' centres on the (functional) activities that an individual cannot accomplish. The *ICIDH* represented a break from the traditional medical model by its inclusion of social 'handicap'. The first OPCS survey demonstrated the growing attention of social researchers to the impact of impairment/disability on valued social roles and relationships (Harris et al., 1971a, 1971b). This is substantially extended in the *ICIDH* coding classification to encompass, for example, socio-economic disadvantages or 'economic self-sufficiency' (Bury, 2000a, p. 1074). Consequently, exponents of the *ICIDH* asserted its distinctive credentials as a 'socio-medical model' (Bury, 1996, 1997).

The overall disablement process is represented in terms of a causal chain between separate but linked linear states (figure 2.1). These discussions leading to the *ICIDH* also influenced the second OPCS national study of disability in Britain in the 1980s. It examined functional limitations in nine fields:

- reaching and stretching
- dexterity
- seeing
- hearing
- personal care.
- continence
- communication
- locomotion behaviour
- intellectual functioning



Source: WHO (1980, p. 30).

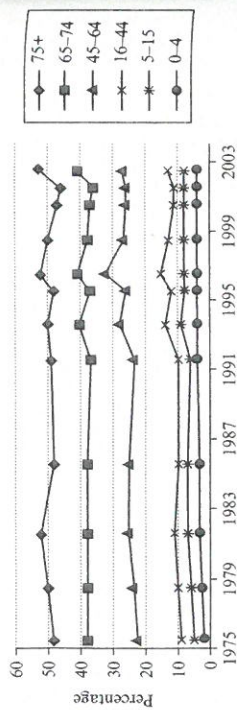
Figure 2.1 The process of disablement

On the basis of performance across these areas, the OPCS researchers constructed an overall measure of 'disability' with ten levels of severity. This echoes policy approaches in other Western societies. For instance, the Americans with Disabilities Act of 1990 defines 'disability' as an 'impairment that substantially limits one or more of the major life activities', with 'normal' functioning again the yardstick.

The OPCS surveys in the 1980s were undertaken with a sample of disabled adults and children who lived in either 'communal establishments' or private households. The 'entry criteria' were widened in comparison with its earlier study (Harris et al., 1971a) to take in people with a 'mental illness and handicap' and those with 'less severe' impairments (Martin et al., 1988). As a consequence, the estimated number of disabled adults in Great Britain (England, Scotland and Wales) doubled to 6.2 million, equivalent to 14.2 per cent of the total population. More consistently, both surveys reported that a majority of this disabled population was over sixty years of age and contained a higher proportion of women than men. Increasing age was also closely associated with 'severity of disability'. Overall, almost a third of the disabled population was ranked in the two 'least severe' categories.

More recent data from the General Household Survey (figure 2.2), based on a different measure – a self-classifying head count of people with a 'limiting long-standing' condition – indicate an increase to nearly 12 million people, or around 19 per cent of the total population (Cabinet Office, 2005). The United States Census Bureau (Brault, 2008) identifies a similar proportion, 18.7 per cent, of the population in 2005, although this represented a slight decline from 1992, when 19.4 per cent of Americans reported a 'disability'. Additionally, both national surveys relate impairment to a wide range of social disadvantages, for example, in employment and transport.

However, the diverse ways in which these surveys are designed and implemented internationally suggest considerable caution when comparing data on the size and composition of the disabled population, as well as trends over time. Measures change, while the collection



Source: Cabinet Office (2005, p. 55).

Figure 2.2 Percentage of the UK population who reported limiting long-standing illness or disability, by age

and presentation of information on impairment/disability also vary between countries. These contrasts weaken, if not undermine, the reliability of historical and international comparisons (Fujiura and Rutkowski-Kmitta, 2001; Mbogoni, 2003; Eide and Loeb, 2006).

The attempts to operationalize the individual/medical model highlight major difficulties in its underlying theoretical basis and policy implications. Key tenets of the medical model include (1) the definition of disease as deviation from normal biological functioning; (2) the doctrine of specific etiology; (3) the concept of generic diseases, that is, the universality of a disease taxonomy; and (4) the scientific neutrality of medicine' (Mishler, 1981, p. 3). Yet each of these has been disputed by social scientists. For example, the definition of disease (and impairment) as a deviation from a 'normal' biological state raises the question: 'Does normal refer to an ideal standard or to the average value of a population characteristic?' (ibid., p. 4). Spectacles are a necessary aid for many with a visual impairment, but they have become so widely used that few regard them as a mark of 'abnormality'. Furthermore, the apparently objective designation of an individual as 'not normal' may contain a value judgement on that person's social worth, most obviously with labels such as 'mental illness' and 'mental handicap'.

Additionally, there has been growing recognition within medicine of the impact of social factors and relationships on the origins and trajectory of impairment and illness (Armstrong, 1983). This diverges from the traditional assumption, illustrated in the OPCS and ICIDH definitions, that 'impairment' is the underlying cause of 'disability' and/or 'handicap'. The orthodox assumption has been that the primary solution to 'chronic illness and disability' rests with medical intervention and allied (physical and psychological) rehabilitation. Conversely, the environment is represented as 'neutral', with little elaboration of alternative explanations for social 'handicap'. This

downplays the potential of social policy reforms and of legislation to guarantee disabled people full citizenship rights. The disabled person is expected to make the best of their diminished circumstances and concentrate their expectations on individual adjustment and coping strategies, with appropriate professional direction (Finkelstein, 1993a, 1993b).

The individualistic approach is further exemplified by psychological studies of the individual adaptation and adjustment to impairment (perhaps following a stroke) and the 'loss' of bodily function, such as a limb amputation (Parkes, 1975). In the case of a severe spinal injury, a staged process of personal adaptation and accommodation, akin to the grieving process of bereavement, is suggested (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 their diminished circumstances. This fifth stage, termed 'acceptance' or 'adjustment', may not be reached until one or two years later. This psychosocial journey has been widely applied, for example, in counselling those who acquire a hearing impairment (Wilson, 2003) and in charting the experiences of disabled children forced into a segregated 'special' school (Minde et al., 1972), as well as to parents coming to terms with having a disabled child (Sapey, 2004).

Critics complain that this representation of the accommodation to loss is 'too facile' and 'idealized' (Albrecht, 1992, p. 74). The stages are not always evident or followed sequentially. Again, progress is defined and measured by professionally determined criteria and interests. Those who stray from this prescribed script – for example, by not being as depressed as predicted – run the risk of being regarded as in a state of denial and in need of further psychological guidance and counselling (Oliver, 1995; Reeve, 2000; S. Wilson, 2003). The individual's own experiences and priorities are given short shrift, and 'unrealistic' hopes and ambitions are constrained (Alaszewski et al., 2004; Sapey, 2004). In the case of individuals with a spinal cord injury, rehabilitation professionals persist with the goal of helping them to walk again (Seymour, 1998), although individuals may prioritize the inclusive opportunities provided by technological aids and equipment such as wheelchairs (Tremblay, 1996).

Too often, psychological approaches individualize disability and are barely distinguishable from a standard medical approach (Finkelstein and French, 1993; Shakespeare and Watson, 1997). They downgrade the lived experience of disabled people and fail to locate the individual-professional encounter within a wider social context. However, there is a well-established socio-psychological interest in adjustment to physical and mental impairment (Hamilton, 1950;

Barker et al., 1953) that distances itself from an overly medicalized approach. Beatrice Wright's text on the psychology of 'physical disability' emphasizes the influence of the social environment, or 'the ways of behaving prescribed by society' (1960, p. 3), and argues that 'impairment' is not a sufficient condition for social 'handicap' (ibid., p. 9). More recent contributions indicate a growing polarization within psychology of individual and social (psychological) models of disability (Olkin and Pledger, 2003). Dan Goodley and Rebecca Lawthom, for example, advocate a 'community psychology' perspective that owes more to sociology than psychology insofar as it entails 'a counter hegemony to mainstream psychology's individualism; an inter-disciplinary context that brings together politics, sociology, social policy, health and social welfare' (2006, p. 8).

However, disability theorists derided the dominant approach as the 'product of the "psychological imagination" constructed on a bedrock of "non-disabled" assumptions of what it is like to experience impairment' (Oliver, 1996b, p. 21). In a similar vein, psychological contributions are criticized for ignoring the existence of professional stereotypes, 'prejudice and discrimination (physical and social barriers) while pursuing a 'normalizing and pathologizing perspective' (Shakespeare and Watson, 1997, p. 296). A contrast is drawn with feminist analyses of sexism that identify the individual consequences of collective oppression but look beyond the individual in seeking to understand 'the mechanisms of that oppression' (Abberley, 1993, p. 108).

In summary, the central thrust of the individual models to cast disability as a personal tragedy where the person with an impairment has a health or social problem that must be prevented, treated or cured: 'the assumption is, in health terms, that disability is a pathology and, in welfare terms, that disability is a social problem... To have a disability is to have "something wrong with you"' (Oliver, 1996b, p. 30).

Looking beyond individual solutions

The rise of disabled people's campaigns in America and Europe contained common elements, such as challenging their social and economic exclusion and exposing the ways in which medical rehabilitation and social welfare professionals stressed their functional and other limitations and general dependency, leading to widespread segregation in residential settings. In the United States, protest action was encouraged by a general political context that stressed civil rights and equal opportunities, as well as specific factors such as the return of a significant number of disabled veterans from the

Vietnam War (Safilios-Rothschild, 1976; DeJong, 1979b). In contrast, in Western European and Scandinavian countries, the emphasis was less on civil rights and more on campaigns to influence political parties and policy-makers to enhance state welfare entitlements and service support.

The Independent Living Movement (ILM)

The few academic accounts of the ILM in America stressed the novelty of disabled people's critique. Most notably, it was characterized as akin to a new 'paradigm of disability', epitomized by its campaigns for self-help, consumerism, de-medicalization, de-institutionalization, 'mainstreaming' and 'normalization' (DeJong, 1979b, 1981). This placed the ILM squarely within central political and philosophical traditions and values of capitalist America, namely, 'consumer sovereignty, individualism, self-reliance, economic and political freedom' (Williams, 1984b, p. 1004). The 'free-market pluralist ideology' stressed the enhanced opportunities to pursue a radical consumerist agenda. Notwithstanding disabled people's general experience of structural disadvantage in the economic and political marketplace, the ILM espoused the ambitions of those who wanted to be part of the 'American economic-political system' (DeJong, 1979a, p. 46).

The reliance on medical rehabilitation to the exclusion of change in other areas attracted considerable criticism. This underscored a central aim of the ILM to overturn professional dominance and bureaucratic inertia, which militated against radical policy change. The ILM sought innovative ways of countering the impact of professional dominance and institutionalization in disabled people's lives. This was reinforced by antagonism towards the 'monopolistic stranglehold of state controlled human service organizations' (DeJong, 1979a, p. 47). The new paradigm of independent living also placed a high emphasis on locating disabled people's social exclusion not in their bodies but in negative environmental influences.

The radical programme of the ILM made a great impression on disabled people around the world, not least among disabled activists in Europe (Evans, 1993). However, it was recognized that the ILM philosophy and analysis did not necessarily translate easily from the individualist culture of the United States to those countries where disadvantaged groups looked to state-sponsored welfare systems to address manifest economic and social inequalities. Some social scientists, such as Gareth Williams, argued that the ILM analysis is based on a dubious sociological and political conception of 'an abstract individual battling against a sanitised environment' (1984b, p. 1009). Thus, in practice, liberal market capitalism encourages a bidding war

for scarce resources. Action by disadvantaged groups will favour at best a relatively small minority. Indeed, the ILM gained more support among young, well-educated, middle-class white Americans with physical impairments, rather than among the mass of poorer and often retired disabled people. Additionally, while DeJong (1979a, p. 56) accepts the ILM goal of a de-regulated 'attendant care' (personal assistant) market as a progressive move, others echoed C. Wright Mills's (1970, p. 37) trepidation that hopes for free and equal access to economic opportunities in a capitalist society are a 'fairy tale'.

European commentators on the ILM paradigm of disability also expressed reservations about its attachment to a 'behavioural ecology' that risks reducing social actors from active agents to a mere 'cultural dupe' (Williams, 1984b, p. 1006). It underplays issues of power, 'social structure and human agency' (ibid., p. 1008), as well as the 'mediating effects of the symbols and contexts of social life' (ibid., p. 1009), which may be enabling or constraining. In contrast, Williams commends a 'move from an individualist to a relational model that posits an autonomous but social being in a political context rather than an abstract individual battling against a sanitised environment' (ibid.).

Yet, the politicization of disability also fed into an established line of analysis in American politics, with disabled people conceptualized as a 'disadvantaged' or 'minority' group akin to black and minority ethnic people (Albrecht, 1976; Safilios-Rothschild, 1976). Membership signifies an imposed second-class, or deviant, position and a denial of 'majority status' rights, but also a sense of common identity and grievance that sustains political protest. The American political scientist Harlan Hahn (1986, 2002) argues that the growing perception of disabled people as a 'new minority group' confronting prejudice and discrimination heralded a direct challenge to the individual model or 'functional limitations' approach that underpins traditional medical rehabilitation and social policies.

Medical definitions of 'disability' identified 'authoritative' criteria for distinguishing between the 'deserving' and 'undeserving' poor in industrializing societies (Stone, 1985). In America, they were integral to late eighteenth- and nineteenth-century compensation programmes directed at disabled ex-soldiers and workers. Nevertheless, for Hahn, the medical preoccupation with the functional consequences of impairment amounted to a 'cultural invention' (1986, p. 131), whereby individually based 'deficiencies' are accentuated and then used to justify professionally orchestrated 'rehabilitation' programmes. It ignored broader economic policies that created and sustained higher levels of unemployment among disabled people, as well as employer bias against the recruitment of workers with impairments. Hahn suggests such policies contain

specific disadvantages for disabled workers while failing to address the general needs of a 'post-industrial society'. They place an exaggerated emphasis on training for low-grade, 'entry level' jobs and manual labour. This inhibits disabled people from 'upgrading their skills' for the type of work increasingly available in a technically advanced service sector economy (Hahn, 1986, 2002).

The implication is that minority group politics encourages radical policy options to overcome the social inequalities experienced by disabled people. While all minorities are 'striving to improve their status in society', disabled people, unlike other groups are still experiencing 'the residual effects of medical concepts' (Hahn, 2002, p. 137). Most noticeably, despite protest action and the introduction of successive legislative measures such as the 1990 Americans with Disabilities Act to secure equal rights for disabled people, US courts still adhere to a traditional 'functional limitations' perspective. Nevertheless, Hahn argues that disabled people have little alternative but to continue the active struggle for civil rights.

Critics of the minority group approach have expressed concerns that disabled people risk becoming one more special interest group competing for attention in a pluralist system of political bargaining. Others have questioned whether their campaigns go far enough in confronting the major organizing structures and values of a disabling society (Liggett, 1988). Hahn maintains that, 'in a fundamental sense, the ultimate origins of the problems facing disabled citizens probably can be traced to the nature of economic systems' (1986, p. 133). However, the minority group approach may militate against detailed analysis of the changing and contrasting forms of disability across industrial capitalist societies, or of the interrelationship between disability and other lines of social division.

Challenging the 'disabling society' - a British perspective

The new ways of thinking about disability in Britain, as in America, had their roots in the climate of social and political protest that emerged in the 1960s. These translated into specific campaigns for greater autonomy and control by disabled people in residential institutions (Finkelstein, 1991) and for a comprehensive disability income and new living options (Oliver and Zarb, 1989).

One of the first books to challenge the 'able-bodied' orthodoxy on disability in the UK was *Stigma: The experience of disability*, edited by Paul Hunt (1966a), a disabled activist. It comprises twelve personal accounts of disability from six disabled women and six disabled men, none of whom was an academic. They were chosen by Hunt from over sixty responses to a letter published in several national newspapers

and magazines requesting contributions. His aim was to avoid 'sentimental autobiography' or 'preoccupation with the medical and practical details of a particular affliction'. In his chapter, Hunt argues that 'the problem of disability lies not only in the impairment of function and its effects on us individually but more importantly in our relationship with "normal" people' (1966b, p.146). Disabled people 'are set apart from the ordinary' in ways which see them as posing a direct 'challenge' to commonly held social values by appearing 'unfortunate, useless, different, oppressed and sick' (ibid.).

The perception of disabled people as 'unfortunate' arises because they are unable to 'enjoy' the social and material benefits of modern living. These include the opportunity for marriage, parenthood, social status, independence and freedom, employment, 'a house and a car - these things and plenty more may be denied us' (Hunt, 1966b, p. 147). When, despite these deprivations, disabled individuals appear happy, they are lauded for their 'exceptional courage'. Apart from devaluing other disabled people who may not have the same response to their situation, this encourages non-disabled people to see disablement as a 'personal tragedy'.

The description of disabled people as 'useless' arises because they are deemed unable to contribute to the 'economic good of the community'. This marks them out as 'abnormal' and 'different' or as members of a 'minority group' analogous to other oppressed groups, such as black or gay people. Moreover, 'people's shocked reactions to the "obvious deviant" stimulates their own deepest fears and difficulties, their failure to accept themselves as they really are, and the other person simply as "other"' (Hunt, 1966b, p. 152). This underpins the 'prejudice which expresses itself in discrimination and even *oppression*' (ibid., *emphasis in original*), akin, for example, to those minorities who experience racism. The last element in disabled people's 'challenge' to 'able bodied' values is that they are 'sick, suffering, diseased, in pain' - in short, they represent everything that the 'normal world' most fears: 'tragedy, loss, dark, and the unknown' (ibid., pp. 155-6).

Hunt acknowledges the 'vast differences' between disabled people and other 'downtrodden' groups (1966b, p. 156), with the conscious and unconscious association of a 'sick' body and mind with a sense of evil. Nevertheless, disabled people are 'becoming presumptuous' and rejecting 'all the myths and superstitions that have surrounded us' (ibid., p. 157). He detects the beginnings of a growing collective consciousness: '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' (ibid., p. 158).

As Peter Townsend argues in his foreword to Hunt's volume, the inequalities experienced by disabled people 'reflect a much deeper problem of a distortion of the structure and value-system of society' (1966, p. vi). With disabled people set apart by their 'incapacity' and 'unproductiveness', they are relegated to the bottom of the social hierarchy. Townsend wonders about the appropriate political response: 'Is it possible to secure real gains for those who are disabled without calling for a reconstruction of society and schooling new attitudes in the entire population?' (ibid.). For Hunt and his co-contributors, the aim was to break free from a system 'dominated by condescension and patronage on the one hand and inferiority or deference on the other' (ibid., p. viii). These arguments underpin the demand for a new approach to social equality, one that sustains 'more equal and less discriminatory social relationships' (ibid.).

In the UK, a number of groups of disabled people were formed to explore an alternative approach. Among these was the Liberation Network of Disabled People (LNDP), which produced its own magazine, *In From the Cold*, containing political commentary and personal experiences of exclusion and discrimination (Campbell and Oliver, 1996). Another small group of disabled activists, including Paul Hunt and Vic Finkelstein, established the Union of the Physically Impaired Against Segregation (UPIAS) in 1974. The designation as a 'union' announced its political intentions. Their 'manifesto' - *Fundamental Principles of Disability* (UPIAS, 1976a) - criticized organizations controlled by non-disabled 'experts' for their failure to address the social barriers central to disabled people's exclusion from mainstream economic and social activity and their lack of accountability to the disabled community. This has exerted a major influence on the disabled people's movement and disability theorizing in the UK (Oliver, 1983, 1996a).

The social model of disability

During the 1970s and 1980s, disabled activists and their organizations in Europe and North America became increasingly vocal in their dismissal of the individual, medicalized model of disability and its psychological and social welfare implications. Reflecting on their experiences of discrimination, disabled people focused on the organization of society rather than individual functional limitations or differences. Modern society failed to recognize or accommodate the human diversity associated with impairment (Oliver, 1983; Zola, 1983).

UPIAS made a fundamental distinction between impairment and

real cause of disability, i.e. discrimination and prejudice. To mention biology, to admit pain, to confront our impairments, has been to risk the oppressors seizing on evidence that disability is 'really' about the physical limitation after all. (Shakespeare, 1992, p. 40)

The rationale for the social model separation of impairment and disability was 'pragmatic' (Oliver, 1996a, p. 38), and this 'does not deny that some illnesses may have disabling consequences and many disabled people have illnesses at various points in their lives' (ibid., pp. 35-6). However, this points to major difficulties in disentangling the circumstances under which specific illnesses are 'disabling' or not (Thomas, 1999).

Nevertheless, the architects of the social model mostly resisted studies of the experience and impact of impairment on the grounds that these would not advance the understanding of disability, but were more likely to reinforce a personal tragedy orientation and so undermine a radical disability politics (Finkelstein, 1996, 2002). The UPIAS view was that, 'at the personal level we may talk about acquiring an impairment being a personal tragedy, but at the social level we should talk about the restrictions that we face are, and should be interpreted as, a crime' (Finkelstein, 2001a, p. 2). UPIAS reserved some of its most scathing remarks for the ways in which non-disabled experts exercised a harmful influence over the everyday lives of disabled people:

We reject also the whole idea of 'experts' and professionals holding forth on how we should accept our disabilities, or giving learned lectures about the 'psychology' of impairment. We already know what it feels like to be poor, isolated, segregated, done good to, stared at, and talked down to - far better than any able bodied expert. We as a Union are not interested in descriptions of how awful it is to be disabled. What we are interested in is the ways of changing our conditions of life. (UPIAS, 1976b, pp. 4-5, emphasis in original)

As an illustration, Finkelstein (1999) explored ways of emulating initiatives by user-led organizations to build alternative service support to institutional 'care'. He bemoaned the descent of professions allied to medicine into performing bureaucratic, task-oriented activities that undermine the basic aim of providing services that empower clients. He argues instead for a new type of professional to support disabled people's efforts to achieve independent lives - what he terms 'Professions Allied to the Community' (PACs). Others have stressed the value of recruiting more disabled people into professional ranks, as well as extending existing initiatives to generate 'anti-oppressive' practice (French and Swain, 2001).

In his codification of UPIAS's (1976a, 1976b) statements on disability, Mike Oliver differentiated 'personal tragedy' from 'social

disability. The medical definition of impairment is broadly accepted as an individual attribute, but the meaning of disability is radically reinterpreted:

- *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, 1976a, p. 14).

Subsequently, the restriction to 'physical impairments' was dropped to incorporate all impairments: 'In the broadest sense, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment - whether physical, mental or intellectual' (Oliver, 2004, p. 21).

This social model approach breaks the traditional causal link between impairment and disability. The 'reality' of impairment is not denied, but it is not necessarily a sufficient condition of disability. Instead, the spotlight shifts to how far, and in what ways, society restricts opportunities to engage in mainstream economic and social activities and renders people with impairments more or less dependent. In what has become the defining statement, *Fundamental Principles* argues that: '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, 1976a, p. 14). Overall, disability is 'the outcome of an oppressive relationship between people with ... impairments and the rest of society' (Finkelstein, 1980, p. 47). This asserted the significance of common interests and experiences of oppression and concentrated on those areas that might be changed by collective political action and social change.

The clear distinction drawn between impairment and disability replicates a division between the biological and social domains. On that basis, Oliver asserts that 'disablement has nothing to do with the body' (1990, p. 45) and that the 'social model is not an attempt to deal with the personal restrictions of impairment but the social barriers of disability' (1996a, p. 38).

The achievement of the disability movement has been to break the link between our bodies and our social situation, and to focus on the

UPIAS - VALUE OF IMPAIRMENT AND OPPRESSIVE SEGREGATION
impairment
disability
social model of disability
social model of disability

oppression' theory - that is, an individual/medical from a social model approach. Quite simply, 'personal tragedy theory has served to individualize the problems of disability and hence to leave social and economic structures untouched' (Oliver, 1986, p. 16). This parallels sociological criticism of the extension of professional intervention into areas not hitherto regarded as relevant to its knowledge base (Zola, 1972; Strong, 1979b) (see chapter 3). The medicalization of disability raises immediate concerns, because 'disability is not measles' (Rioux and Bach, 1994). Nevertheless, the social model emphasis on overcoming social barriers to inclusion does not extend to blanket opposition to medical treatment for impairment or long-term illness.

The ways in which the social model approach differs from that of the individual model are illustrated by Mike Oliver (1990, pp 7-8). He compares questions devised by OPCS from an individual perspective in the 1980s with his own reinterpretations based on a social barriers perspective - as the following selection illustrates:

- OPCS: 'Are your difficulties in understanding people mainly due to a hearing problem?'
- Oliver: 'Are your difficulties in understanding people mainly due to their inability to communicate with you?'
- OPCS: 'Does your health problem/disability prevent you from going out as often or as far as you would like?'
- Oliver: 'What is it about the local environment that makes it difficult for you to get about in your neighbourhood?'
- OPCS: 'Does your health problem/disability affect your work in any way at present?'
- Oliver: 'Do you have problems at work because of the physical environment or the attitudes of others?'
- OPCS: 'Does your health problem/disability mean that you need to live with relatives or someone else who can help or look after you?'
- Oliver: 'Are community services so poor that you need to rely on relatives or someone else to provide you with the right level of personal assistance?'
- OPCS: 'Does your present accommodation have any adaptations because of your health problem/disability?'
- Oliver: 'Did the poor design of your house mean that you had to have it adapted to suit your needs?'

Oliver's suggestion is that the OPCS items, as with the ICIDH, do not allow those questioned to consider or indicate how far, if at all, social and environmental barriers are part of their everyday experience.

This reinforces the near total reliance on a functional limitations

approach to disability in the collection of official statistics and governmental research. Indeed, it is only since the 1990s that research funding agencies (including government departments) have responded to calls from disabled people's organizations to sponsor studies of disability (instead of the consequences of impairment). The task of critical disability research is to examine the character and extent of social exclusion and disadvantages facing disabled people, and across different social contexts, as well as the impact of shifts in disability policy towards social barriers - for example, from rehabilitation to an integrated living support system (Finkelstein, 1991, 1993b).

Social modelists further stress the close links between theorizing and researching disability and associated political action. They call for openly partisan and politically committed research that promotes citizenship rights, equal opportunities and inclusion. The central objective is phrased in terms of striving for social justice, to enhance disabled people's autonomy over their lives rather than out of a compassionate concern for their 'personal tragedy' (Rioux and Bach, 1994). This extended to wider claims about the ways in which participatory and, more particularly, emancipatory research methodologies embody a radical alternative to mainstream contributions - not simply in their political goals but also in their procedures by placing disabled people in control (Oliver, 1992; Barnes and Mercer, 1997). The aim is to draw disabled people into the process of designing, conducting and disseminating disability research so as to facilitate debate on the personal tragedy approach and possible alternatives.

The importance of the social model of disability is that, as a model providing an alternative understanding of the experience and reality of disability, it has given disabled people a basis on which to organize themselves collectively. Using the social model as a basis for explanation, disabled people have been drawing attention to the real problems of disability: the barriers they face; the patronizing attitude they have to deal with; the low expectations that are invested in them; and the limited options available to them. (Swain et al., 2003, p. 24)

Notwithstanding these ambitions, the social model is a simplified representation of a complex social reality, distinguished by its fundamental separation of impairment and disability. It is not a substitute for social theory. The social model does not explain what disability is. For an explanation we would need a social theory of disability' (Finkelstein, 2001b, p. 11). It offers a fundamental alternative to the individual model that poses a very different set of research questions, most particularly: 'What is the nature of disability? What causes it? How is it experienced?' (Oliver, 1996b, p. 29). This includes reflection on other social approaches to disability. Precisely because it is a model, it should be judged on its capacity to stimulate a more

comprehensive social theory (explanations and understandings) of disability and to facilitate socio-political changes that enhance the life chances of disabled people.

Early disability research inspired by a social model account concentrated on structural explanations of the social and material conditions experienced by disabled people in the family, education, income and financial support, employment, housing, transport and the built environment (Barnes, 1991). This was considered central both to building explanations of how far, and in what ways, 'society disables' people with impairments and to analysing the structures and processes associated with social oppression and discrimination, whether at the level of social policy and the state or in everyday social interaction. Key contributors to the development of a social model approach strongly favoured a 'materialist' or 'social creation' strategy over an 'idealist' account that prioritized cultural values and representations (Finkelstein, 1980; Oliver, 1990). Notwithstanding this emphasis on the social oppression of disabled people, an associated priority is to examine the circumstances in which disabled people resist and challenge orthodox ideas and practices.

While the social model, as elaborated by UPIAS, has been proclaimed as 'the big idea' of the disabled people's movement in Britain, it has been subjected to a range of criticism from service providers, policy-makers and academic social scientists, as well as from some disabled people who are perhaps otherwise generally supportive of the new disability politics. At this juncture, we briefly outline some of the main areas of debate among writers on disability, while leaving more detailed discussion to subsequent chapters.

The significance of separating impairment and disability in *Fundamental Principles* triggered a variety of questions on the grounds that it wrongly diminishes the significance of impairment, whether in terms of theorizing disability or as a reflection of disabled people's everyday lives. The social model was further questioned for its own form of reductionism, based on what Carol Thomas argues is a misreading of the original UPIAS formulation, that 'all restrictions of activity experienced by people with impairment are caused by social barriers' (1999, p. 42).

Disabled feminists in particular led calls to 'bring impairment back in' to theorizing disability on the grounds that disabled people do not typically differentiate impairment and disability, and that the 'personal is political', in contrast to the public domain assumptions that permeate the social model (Morris, 1991; Crow, 1996). It appeared that the social model disregard for the personal experience of impairment replicated the general 'malestream' dismissal of private compared to public life.

there is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability - and do indeed disable us - to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying. (Morris, 1991, p. 10; emphasis in original)

it is these experiences of impairment and disability that distinguish a disabled from a non-disabled person.

Moreover, some argue that it is wrong to presume that all activity restrictions experienced by individuals with an impairment have a social basis and are therefore amenable to eradication by social changes. Hence, specific impairments will continue to exclude some individuals from some areas of life (Crow, 1992; French, 1993; Shakespeare, 2006). This means it is not possible in the foreseeable future to eliminate all activity restrictions by social intervention.

I believe that some of the most profound problems experienced by people with certain impairments are difficult, if not impossible, to solve by social manipulation. Viewing a mobility problem as caused by the presence of steps rather than by the inability to walk is easy to comprehend. . . . However, various profound social problems that I encounter as a visually impaired person, which impinge upon my life far more than indecipherable notices or the lack of bleeper crossings, are more difficult to regard as entirely socially produced or amenable to social action. (French, 1993, p. 17)

Sally French cites as examples her inability to recognize people only a short distance away, being 'nearly blinded' in sunlight, and not always being able to understand non-verbal cues in social interaction. Similar points are raised in the (medical) sociology literature on 'chronic illness and disability' and the social body (Barnes and Mercer, 1996; Thomas, 2007).

Reliance on a medical interpretation of impairment has also generated strong objections. For example, a significant proportion of those designated as having a hearing impairment and whose first language is sign language reject this biomedical categorization and identify instead as Deaf people, who are members of a unique linguistic and cultural group (Ladd, 1988). Similar dissent has been expressed by people with the label of learning difficulties (Goodley, 2000) and mental health system users or survivors (Beresford, 2000, 2002). How far who 'qualifies' as having a specific impairment and as a disabled person remains a contentious issue. Again the different social locations, experiences and support requirements of specific groups are not fully recognized in social model debates, as Peter

Beresford (2005) suggests when outlining a 'social model of madness and distress'. An associated criticism is that specific groups are marginalized within the disabled people's movement by the social model's accentuation of disability as an influence on an individual's status and self-identity over other social locations such as social class, gender and ethnicity.

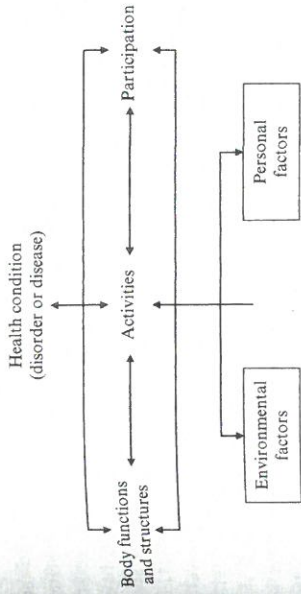
Debates on disability now routinely acknowledge the influence of social model thinking. What is particularly striking is its impact on current policies across a diverse range of organizations, including central to local governments, charities and voluntary agencies. Indeed, some disabled activists and disability theorists have been unsure whether this has always been a positive development (Oliver, 2004). At the same time, attacks by social scientists on the social model have multiplied (Bury, 1997; Williams, 1999; G. Williams, 2001), with additional criticism 'from within' (Shakespeare and Watson, 2001; Shakespeare, 2006). This highlights the importance of exploring the very contrasting interpretations of the social model. A strong dose of caution is obligatory: 'Sadly a lot of people have come to think of the social model of disability as if it were an explanation, definition or theory and many people use the model in a rather sterile formalistic way' (Finkelstein, 2001b, p. 6). Again, the social model must not be overloaded with unrealistic expectations:

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, 1992a, p. 44)

The biopsychosocial model of disability

Continuing censure of the ICDH (WHO, 1980), on both conceptual and practical grounds, by mainstream researchers, policy-makers and organizations of disabled people led the WHO to plan its revision. The team responsible began their discussions in 1993, and ICDH2, or the *International Classification of Functioning, Disability and Health (ICF)* (WHO, 2001a), as it became known, was finally endorsed by WHO member states in 2001. It was also adopted by the United Nations and incorporated in *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (UN, 1993).

The WHO development team confirmed the Western scientific medical model as the foundation for classifying, measuring and



Source: WHO (2001a, p. 18).

Figure 2.3 Interaction between the components of ICF

treating biophysiological conditions. However, they accepted dissent with the ICDH's 'consequences of disease' orientation and its linear (causal) sequence from impairments through 'disabilities' to social 'handicaps'. They agreed with critics from disabled people's organizations that this diverted interest away from examining 'environmental influences or 'social barriers' (Bickenbach et al., 1999, p. 1176). At the same time, the social model was condemned as neither 'operationalizable' nor amenable to empirical research and validation (ibid., p. 1178).

The team's discussions led to an attempted 'synthesis' of the medical and social approaches in a 'biopsychosocial model'. The ICF comprised a classification of 'components of health' (WHO, 2001a, p. 4) rather than of disease, with the aim of establishing 'a coherent view of different perspectives of health from a biological, individual and social perspective' (ibid., p. 20). It confirmed the ambition of universal application, and promised 'a unified and standard language and framework for the description of health and health-related states' (ibid., p. 3).

Similar to the ICDH, the ICF identifies three levels of human functioning: 'at the level of the body or body part, the whole person, and the whole person in a social context' (WHO, 2002, p. 10). It distinguishes (see figure 2.3) body functions and structures (impairments), both 'physical' and 'mental'; activities and participation; and 'contextual factors', which comprise 'environmental' and 'personal' factors. The coding scheme allows either positive/facilitating or negative/barrier outcomes, thus generating a large number of potential categories for data classification.

'Activity' is defined as the execution of a task (based on a clinical assessment in a standardized environment), while 'participation'

Structure

1992a, p. 44

1993

covers a more 'social' aspect equated with capacity and actual performance (in real-life situations). In practice, this distinction between 'individual' versus 'social' perspectives deviates relatively little from the *ICIDH* formulation, and raises similar doubts because of competing interpretations of these terms by key 'players' such as professionals and disabled people, as well as across societies. Extra qualifiers of 'capacity' and 'performance' differentiate between an individual's ability to undertake a task or action, with or without 'assistive devices or personal assistance' (WHO, 2001a, p. 15).

The contextual (environmental and personal) factors refer to the 'complete background of an individual's life and living'. Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives' (WHO, 2001a, p. 16). They span the individual (e.g. home, workplace and school) and societal levels (formal and informal social structures and services, such as climate and terrain, transportation systems, government policies, and ideologies). How far these indicators act as barriers or facilitators is based on individual self-reports. Again, different theoretical and methodological concerns will influence the choice of coding options of key dimensions such as 'support and relationships' (ibid., pp. 187-88) and attitudes that 'influence behaviour and social life at all levels' (ibid., p. 190).

Another feature of the *ICF* is the range of 'personal factors' enumerated, which indicates the scale of the task facing researchers and policy-makers:

gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behaviour pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level. (WHO, 2001a, p. 17)

However, 'assessment is left to the user, if needed' (ibid., p. 19). Aside from the contentious definition of the 'personal' domain, the exclusion of such factors would undermine the broad-based ambitions of the biopsychosocial model.

Despite changes in terminology, the *ICF* retains some obvious similarities with the *ICIDH*. Its association of impairment with a 'significant variation from the statistical norm' (WHO, 2001a, p. 221), raises similar criticism to that directed at its predecessor because it ignores the extent to which identifying and labelling deviations as illness or impairment are social processes, liable to vary between social groups and societies and over time. Again, an individual's capacity and performance are assessed against those of an individual

without a similar health condition (disease, disorder or injury, etc.) (ibid., p. 15). The *ICF* also employs a much broader definition of disability that includes restrictions at the level of the body (impairment) as well as in social participation more generally.

The WHO team stresses the novelty of the *ICF* definition of disability as the outcome of a 'complex relationship between an individual's health condition and personal factors, and the external factors that represent the circumstances in which the individual lives' (WHO, 2001a, p. 17; Schneidert et al., 2003). This aligns with extensive research literature in the social sciences on the significance of psychosocial factors on health and illness, as well as 'person-environment interactions' in such fields as public health. While the *ICF* recapitulates social model suggestions that the form of disability (and impairment) varies across societal contexts, it ignores interaction between activities and participation, environmental and personal factors. Overall, there is too little discussion of the level and character of cross-level relationships.

The emphasis throughout the *ICF* is on a 'scientific' approach, and its taxonomy is firmly grounded in Western concepts and theories (Finkelstein, 1998; Pfeiffer, 2000; Baylies, 2002). This underscores its universalism, with expectations that concepts and measures are 'transculturally and linguistically applicable' (Bickenbach et al., 1999, p. 1185). While it anticipates a long-term research programme to validate the required measurement tools, ample evidence already exists of significant cultural differences in a 'normal' health status and ascribed 'deviations'. Moreover, the adoption of a standard quantifying approach, with its emphasis on establishing causal relationships between discrete variables, sits uneasily with recent trends towards more qualitative research in health and disability.

Overall, the *ICF* provides a detailed taxonomy to structure data collection but lacks a coherent theory of social action as a new basis for understanding disability. Significantly, its architects promote it as 'an essential tool for identifying and measuring the efficacy and effectiveness of rehabilitation services' (Üstün et al., 2003, p. 567) rather than of wider social exclusion. They incorporate key elements in the medical and social model approaches to disability without presenting a convincing case that the promised synthesis will progress a deeper understanding of disability. Moreover, one of the principal architects of the *ICF*, Jerome E. Bickenbach, has recently cast doubt on its usefulness.

So, how do we answer questions about who is disabled or the prevalence of disability in a country or region? As a multi-domain, multi-dimensional, interactive and continuous phenomenon (as it is characterized in the *ICF*), we must specify which impairment domains

qualify, to which degree of severity. Different prevalence rates flow from different decisions. If we are interested in any impairment domain, to any degree of severity, then prevalence is roughly universal – a conclusion of no use to policy makers whatsoever, if we restrict our scope to specific domains and severity levels, then our prevalence results will differ accordingly. But these decisions cannot be made conceptually or scientifically, they are political. The scientific approach in a word, does not solve the problem the policy analyst needs to solve. (Bickenbach, 2009, p. 120, emphasis added).

Nonetheless the aim of the ICF team to produce an alternative to the individual and social model accounts is mirrored by debates across the social sciences. Most notably, academics in the Nordic countries have championed a 'relational' approach to disability that aligns with policy aims to modify the environment to accommodate people with impairments. Its advocates view disability as 'situational rather than an always present essence of the person' (Tøssebro, 2004, p. 4).

'First, disability is a person-environment mismatch or "poor fit" between the individual's capabilities and the demands of the broader societal environment . . . an individual is defined as disabled if a limitation, disease or loss (impairment) causes him or her to experience significant barriers in everyday life. . . . Second, disability is situational or contextual. . . . Third, disability is relative' (Traustadóttir and Kristiansen, 2004, p. 33). This is the basis for a continuum from 'weak' to 'strong' versions of the relational approach (Tøssebro and Kittelsaa, 2004). Its 'weaker' forms comprise variations on the 'human-ecology model' (Tøssebro, 2004, p. 5), while the social model promoted by activists in Britain is described as a 'strong' approach. This presumes – incorrectly, according to some writers (Thomas, 1999, 2007) – that social modelists claim that impairment is a necessary and sufficient condition for disability and disavows situational or relational aspects. However, Jan Tøssebro reiterates criticism of the social model, that it 'overestimates what can be accomplished by environmental changes', particularly in the case of people with 'severe cognitive disabilities' (2004, p. 5).

More widely, the Nordic literature raises important issues for a social theory of disability. An early influence stemmed from Martin Söder's classification of 'essentialist' theoretical approaches into two main strands: individual (clinical/medical model) and contextual (social model) (1999, cited in Gustavsson, 2004). Söder condemns the reductionism of biomedicine along with the 'determinist' character of the social model, whether in its materialist emphasis on disability as 'caused by contemporary social organization' or in constructionist guises that stress language and culture.

This leaves interactionism as the primary stimulus to the

'environmental turn' underpinning the Nordic relational approach. It comprises four distinct sub-types (Gustavsson, 2004). The first adopts a realist perspective towards disability, as with the ICIDH and, even more closely, the ICF. A second 'relative interactionist' group emulates critical realism, allied to a 'weak' form of constructionism. This treats social reality as multi-levelled, with interaction at each level explained in terms of its own internal mechanisms while recognizing inter-level relationships. A third approach understands interaction in terms of phenomenological systems theory (Michailakis, 2002) and distances itself from the 'naïve realism' (Gustavsson, 2004, p. 65) of the WHO schema. A fourth 'critical interpretation' approach examines disability at different analytical levels, with an emphasis on 'the life world perspective of human meaning-making' (ibid.).

This account helpfully identifies competing social science currents in theorizing and researching disability. Yet broad references to an 'environmental turn', a 'relational' or even a 'human ecology' approach contain an all-embracing positional statement but lack specificity about their theorization or empirical elaboration. There has been little inclination to incorporate either power relations in theorizing disability or a political economy of disability (Tøssebro, 2004, p. 6). Closer analysis of the interaction between individuals with impairments (accepting the contentious character of these terms) and the precise influence of the physical environment, embodied individuals, and psychological, political, legal, cultural and societal factors are important ingredients in theorizing and researching disability. This is a challenge that extends across theoretical approaches not only for adherents of a social model of disability.

Review

The rise of an orthodox, state-legitimated medical profession in Western societies in the nineteenth century confirmed and medicalized an individual or personal tragedy approach to disability. It focused on an individual's functional limitations: how these led to social restrictions. Hence, the primary policy response rested on individual medical treatment and rehabilitation. This approach was subsequently revised, with the introduction of the *International Classification of Impairments, Disabilities and Handicaps* (WHO, 1980), to allow for 'handicapping' social conditions, although the basic causal link to impairment remained intact.

As disabled people embarked on concerted campaigns against their general marginalization and exclusion from mainstream society, they developed an alternative socio-political approach that directed

attention to the social and environmental barriers to inclusion. In Britain, the social model of disability offered an incisive alternative to the individual approach. It drew a basic distinction between impairment, defined largely in medical terms, and disability, which represented any exclusionary relationship between people with impairments and the wider society. Most recently, the WHO produced a biopsychosocial approach that is a synthesis of the individual and social models.

This review of competing models demonstrates some of the key issues and themes that will inform a sociological analysis of impairment and disability. A considerable literature already exists in the area of what medical sociologists call 'chronic illness and disability', and this will be examined in more detail in the following chapter.

CHAPTER 3

Sociological Approaches to Chronic Illness and Disability

EARLY exponents of the social barriers model of disability condemned the failure of sociological approaches to health and illness (medical sociology) either 'to challenge the individualization and medicalization of disability' (Oliver, 1996b, p. 18) or to analyse it as a form of social oppression. Mike Oliver attributed this silence to 'the undoubted influence of American sociological theorists such as Parsons, Becker and Goffman' (ibid., p. 19). This chapter argues for recognition of the diversity of theoretical and empirical debates within medical sociology and their potential relevance for critical analyses of disability (and of impairment).

We begin by tracing studies of illness as a social state, particularly as a form of social deviance, starting with Talcott Parsons's (1951) functionalist analysis of the medical system and, more specifically, the sick role. The discussion then considers contributions from contrasting sociological perspectives, starting with labelling and interactionism and the rise to pre-eminence of interpretive accounts in examining the links between the illness experience, social relations and self-identity. A further literature drawing on conflict and neo-Marxist studies concentrated on a political economy of health and sickness, including medical and professional power. Lastly, we review post-structuralist analyses of the embodied character of social theory and competing discourses around 'chronic illness and disability' in an increasingly 'somatic society'.

Functionalism, Parsons and the sick role

Until the 1950s there was little interest in analysing medicine sociologically. Talcott Parsons's *The Social System* (1951) signalled a change in direction in its chapter on modern medicine. His functionalist analysis of social order presumes that the effective operation of the social system rests on individual performance of necessary social roles. Health is defined as a 'normal' and stable state that underpins