

## Rehabilitation for Disabled People: a 'sick' joke?

*(This is an amended version of an article that appeared in a special issue of the 'Scandinavian Journal of Disability Research', Volume 5. (1) 7-24: 2003).*

**Colin Barnes**

**Abstract:** This paper argues that the relationship between disability and rehabilitation is best explained in terms of three distinct but related definitions of disability. The first is the orthodox 'individualistic' medical definition; the second, is the more liberal 'inter-relational' account and; the third, is the 'radical' socio/political interpretation commonly referred to as the 'social model of disability'. By adopting the latter it is suggested that 'rehabilitation' for people with ascribed impairments and labelled 'disabled' is extremely limited in what it can achieve, due to the ongoing cultural bias against this increasingly large section of the population, and the effective de-politicisation of disability and related issues by politicians, policy makers and academics. It concludes with a brief focus on alternative strategies generated by disabled people and their organisations. . . .

## **Introduction**

When thinking about disability and rehabilitation it is important to remember that perceptions of disability are slowly changing. Since at least the 1960s there has been a gradual but increasing realisation amongst politicians, policy makers and, later, social scientists, across the world that the problem of disability can no longer be considered in purely individualistic medical terms (Barnes and Mercer, 2003). This is partly because people with any form of perceived physical or cognitive impairment or abnormality and labelled 'disabled' constitute an increasingly large section of the world's population and, partly because, the more technically and culturally sophisticated societies become the more impairment and disability they create (Oliver, 1990). Recent estimates suggest that there are around 8.2 million disabled people in Britain, 50 million in the European Union, and 500 million worldwide. And, these figures are set to rise dramatically in the coming decades both in the rich 'developed' countries of the minority world, and in the poorer 'underdeveloped' nations of the majority world (IDF, 1998). This is due to a variety of factors including medical advances, ageing populations, the intensifying pace of

technological and social change, military conflict and terrorism (Coleridge, 1993: Ingstad, 2001).

All of which has major financial, political and cultural implications for national governments and international bodies such as the European Union and the United Nations. A major concern is the seemingly ever-growing cost of 'rehabilitation' programmes widely regarded as 'scientifically' appropriate and socially acceptable solutions to the problems encountered by disabled people (Stone, 1985: Albrecht, 1992: Sandvin, 2002).

By adopting a socio-political analysis of disability, rooted mainly in the work of British disabled activists, this paper will argue that such solutions are counter productive and only serve to perpetuate and exacerbate the problems encountered by people with perceived impairments and labelled disabled. It is divided into two main sections. The first part will examine the various definitions of disability with reference to the concept 'rehabilitation'. The second section will address the various barriers; economic, political and cultural, to meaningful inclusion for disabled people in contemporary society. The paper will conclude by suggesting that the foundations for alternative strategies have been laid but have

yet to be fully explored by social scientists working in the disability studies field.

### **Three views of Disability and Rehabilitation**

The relationship between disability and rehabilitation can best be understood with regard to three distinct but related definitions of disability. The first is the orthodox 'individualistic' medical definition of disability. The second is the more liberal 'inter-relational' account, and the third is the 'radical' socio/political interpretation commonly referred to as the 'social model of disability'.

#### ***i. The traditional Individualistic approach.***

Although, historically, the individualistic medical approach to disability has in one way or another dominated western culture since at least the nineteenth century (Oliver, 1990: Gleeson, 1999) it is generally associated with the World Health Organization's (WHO) International Classification of Impairment Disability and Handicap (ICIDH) (WHO, 1980). In response to growing demands for clarification of meaning at the international level, and mounting criticism from disabled people and their allies that disability

involved more than purely medical concerns, the WHO commissioned a team of social scientists to develop the existing 'International Classification of Disease' to cover the consequences of 'long-term' or 'chronic illness'. The ICDH was published in 1980. Widely regarded as the most comprehensive catalogue of its kind, it has been used extensively as a basis for Government initiatives on disability in both rich countries of the minority world of Europe and North America, and poorer 'developing' nations of the 'majority' world of the South and East (Ustun, et al., 2001).

The ICDH employs a three-fold typology of 'impairment', 'disability' and 'handicap'. Impairment refers to 'any loss or abnormality of psychological, physiological or anatomical structure or **function**'. 'Disability' denotes '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', is the 'disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is **normal** (depending on age, sex and social and cultural factors) for that individual' (WHO, 1980, p. 29).

Evidently, this typology is based on notions of intellectual and physical 'normality', and that disability and handicap are caused by psychological or physiological 'abnormality' or impairment. Hence, the ICDH can be criticised on several levels. First, perceptions of 'impairment' and 'normality' are social phenomena that are not easily defined, and are subject to substantive temporal, cultural and situational variation (Hanks and Hanks, 1948: Scheer and Groce, 1988: Coleridge, 1993: Ingstad and Whyte, 1995).

'Dyslexia', for example, would not be viewed as a major problem in an agrarian society. Yet it is considered an important 'learning difficulty' in modern technically advanced societies such as Britain and the USA where literacy and numeracy are necessary prerequisites for economic and social participation. Second, implicit in the ICDH is the assertion that the human body is flexible and adaptable whilst the physical and/or social environments are not. This clearly flies in the face of reality since historically humans have always moulded the environment to suit their needs rather than the other way round (Barnes, 1991). Third, the ICDH definitions suggest that impairment, disability and handicap are static states. Apart from the fact that this is inaccurate, it creates distinctions and barriers between people with and without accredited impairments where there need not and should be none.

Such a situation is particularly ludicrous given that the ICIDH 'has a classification for every feature of human physicality' (Shakespeare, 1994: 104).

Finally, and most importantly here, besides reflecting a particularly narrow set of euro-centric values about what is and what is not biologically socially acceptable, the ICIDH presents impairment/s as the primary cause of disability and handicap. In this context, therefore, 'rehabilitation is both a philosophy and a practice' designed to eradicate or minimise the problem of impairment, and enable those with designated impairments 'to function at their highest possible physical, social and psychological levels' (Albrecht, 1992: 23). In other words disabled people become objects to be cured, treated, trained and changed and made 'normal' according to a particular set of cultural values. The limitations of such interventions have been well documented by disabled activists across the world since the 1960s (Hunt, 1966: Sutherland, 1981: Zola, 1982).

***ii. The 'liberal' or inter-relational approach.***

The 'liberal' inter-relational approach is best expressed in the WHO's latest attempt to redefine disability: namely, the International Classification of Functioning (ICF), previously known as ICIDH2 (WHO, 2002). This re-definition is a concerted attempt to bring together the traditional individualistic medical model of disability, referred to above, and the more radical socio-political interpretation discussed below; partly, as a result of its rejection by disabled people, their organisations and allies within and without the academy (Driedger, 1989: Oliver, 1990: Barnes, et al., 2002) and, partly, because, although widely used, its usage has been subject to various interpretations (Coleridge, 1993: Ingstad, 2001). In short, it has proved unacceptable to many and has not provided the clarity of meaning that was originally intended.

In common with its predecessor, the ICF retains a three-fold construct. The first level: Impairment, as in the original, relates to 'body function and structure'. The second level, what was 'disability', is now referred to as 'activity', and the third: 'handicap' is to be termed 'participation'. But despite the fierce debate over the meaning of the word 'disability' within the English-speaking world, discussed below, the term 'disability' is retained as an overall term 'for all three levels of functional difficulty'. And, in



contrast to the ICHD, the new formulation is presented as a 'universal classification' of human functioning. Advocates claim it offers a complete picture of the 'functional aspects of the health experience'. Within this framework disability remains a health rather than a political concern. It is an outcome of the inter-relationship between the 'features of the person, on the one hand, and social and physical environments, on the other'. Hence:

'rather than being a classification of persons with disabilities, or even of the problems that they may experience, the ICHD2 is a classification of functionality at three levels, ***understood in neutral terms***' (emphasis added) (Ustun, et al., 2001: 6-7).

In acknowledging the importance of the social and physical environment, the ICF can be said to be an improvement on its predecessor (Hurst, 2000). Notwithstanding, it is unlikely to be any more successful than its antecedent in generating a universal language of disability, because transforming cultural differences in conceptualising impairment and disability is notoriously difficult to achieve (Bury, 2000: Miles, 2001). This is especially so given that although the ICF recognises the cultural context of perceptions of

'disability', and by implication, 'normality', the actual classification system remains grounded firmly in 'western scientific concepts and formulations' (Finkelstein, 1998: Pfeiffer, 2000: Baylies, 2002).

Furthermore, whilst the ICF asserts that individuals are but one element in the analysis of disability, the 'biopsychosocial' approach is not that far removed from its forerunner in that it retains the individual as the starting point for the analysis of 'bodily function and activity'. The concept of participation is included but underdeveloped in the scheme and is still linked to individual circumstances rather than tied firmly to social and political inclusion. In addition, whilst the significance of context is emphasised in the ICF, strategies for its measurement are limited. Potential users are encouraged to classify environmental factors, but there are no effective tools with which to do so nor, indeed, to assess the disabling tendencies, or otherwise, of government policies and practices, physical environments and cultural contexts (Baylies, 2002).

This apparent retreat from overtly political concerns has characterised the bulk of mainstream social science since at least the nineteenth century. Indeed, the inter-relational definition of

disability and the ensuing de-politicisation of disability issues and concerns is characteristic of much of the 'disability studies' literature produced by academics and researchers during the latter half of the twentieth century. It has also recently re-surfaced in Britain in 'post-modernist' responses to the 'social model of disability' discussed later. This has prompted assertions that such accounts serve only to re-enforce rather than undermine the struggle for inclusion (Hunt, 1981: Germon, 1998: Linton, 1998: Gordon and Rosenblum, 2001).

With reference to rehabilitation this inter-relational approach is synonymous with the 'liberalisation' of social policy for disabled people in the late 1960s and 1970s; in particular, the shift from institutional to community 'care' type services and support. Here, the emphasis is on *integrating* disabled people into mainstream society. The 'United Nations (UN) Standard Rules on the Equalization of Persons with Disabilities' (1993), for example, maintains that all states should provide rehabilitation services. But these should go beyond 'initial medical care' to include 'a wide range of measures and activities from more basic and general rehabilitation to goal orientated activities (UN, 1993:11). Most importantly: all rehabilitation services:

‘should be available in the local community where the person with disabilities lives. However, in some instances in order to attain a certain training objective special time limited rehabilitation courses may be organised, where appropriate, in residential form (UN, 1993: 19).

Additionally, though the Standard Rules emphasise the importance of the involvement of disabled people and their organisations in the development of rehabilitation programmes, there is no clear statement that such strategies must be **controlled by** or **accountable** to them. There is therefore a tacit assumption that such services will be professionally led.

Furthermore, since disability in the ICF is presented as a ‘health’ rather than a political issue, it is inevitable that rehabilitation workers will continue to be dominated by or ‘allied to’ medicine (Finkelstein, 1998). This is due to, first, the on-going and relentless subjugation of national governments by trans-national corporate interests and monetary organisations, and their ensuing prioritisation of profit over people and, second, the enormity of the barriers, economic, political and cultural, encountered by disabled

people in both rich and poor countries alike. In such an environment orthodox thinking on rehabilitation accords a convenient practical expedient for politicians, policy makers and professional institutions and organisations. As a result practitioners have invariably little choice but to opt for predominantly individual medical rather than collective political solutions in response to the problem of exclusion.

This is the very opposite of what is needed. Indeed, following the ground-breaking work of Talcott Parsons (1951) an extensive literature has emerged condemning the 'medicalisation' of everyday life from a variety of perspectives. For example, the Austrian philosopher, Ivan Illich pronounced the mid twentieth century 'the Age of Disabling Professionals' (1977: 11) for their misappropriation of knowledge, mystification of expertise, and the creation of a pervasive and persuasive culture of dependence. Whilst such critiques have been applicable mainly to the minority nations of the west, recent work suggests that though there is a chronic shortage of medical expertise and treatments in the poorly resourced 'underdeveloped' nations of the majority world, similar criticisms may be relevant here also (Stone, 1999: Ingstad, 2001: WHO, 2001).

### ***iii. The radical socio political approach.***

The radical socio/political interpretation of disability entered the arena in 1974; six years before the publication of the WHO ICIDH schema discussed earlier. Notwithstanding, there had been a groundswell of political activity amongst disabled people across the world during the 1960s and 70s (Scotch, 1988: Dreidger, 1989: Charlton, 1998), it was left to disabled people themselves to develop a sustained critique of orthodox explanations for the various deprivations experienced by people with accredited impairments and labelled disabled.

The critique of 'able-bodied' society was first codified into a radical, alternative to the individual medical model by Britain's Union of the Physically Impaired Against Segregation (UPIAS). Comprised exclusively of people with physical and sensory impairments, the UPIAS manifesto entitled *The Fundamental Principles of Disability* (1976) contains the profound assertion that it is society that disables people with impairments.

In our view it is society which disables physically impaired people. **Disability** (emphasis added) 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).

The UPIAS' analysis of the disabling society is built on a clear distinction between the biological (impairment) and the social (disability), and is contained in their Policy Statement of 1974.

Here Impairment denotes 'Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body' and disability is:

'The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities' (UPIAS 1976: 3-4) .

Clearly, the medical conceptualisation of physical impairment has been retained, in contrast to the definition of disability in socio-political terms. Such an approach renders the use of the phrase

'people with disabilities' problematic since it blurs the crucial conceptual and analytical distinction between the biological and the social. This has caused considerable confusion outside the United Kingdom since many non-English speaking countries have no equivalent, or are unhappy, with the term impairment. The confusion is further compounded by the tendency amongst academics and professionals to ignore the theoretical and investigative implications of the UPIAS construct.

Nonetheless, the UPIAS approach was later adopted and adapted by many organisations controlled and run by disabled people including, in 1981, the British Council of Organisations of Disabled People (BCODP) and Disabled People's International (DPI), to encompass all forms of impairment whether physical, sensory or cognitive (Driedger, 1989). The BCODP is Britain's national umbrella for organisations controlled and run by disabled people and DPI is the international equivalent for national agencies such as the BCODP. This holistic approach is based on the insight that in a society geared almost exclusively to the needs of a mythical non-disabled ideal, physical, sensory and cognitive impairments are inevitably interrelated. Also labels have little meaning beyond



the need for appropriate medical treatments and social supports; they are also socially and politically divisive.

Moreover, this re-interpretation of disability has facilitated the construction of a 'social model' (Oliver, 1983) or 'social barriers model' of disability (Finkelstein, 1991). This approach centres on the various barriers: economic, political and cultural, encountered by people with accredited impairments. Thus 'disability' is not a product of individual failings but is socially created; explanations for its changing character are found in the organization and structures of society. Therefore:

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 1993 ix).

Since its inception, however, the social model or barriers approach has been criticized for its apparent neglect of disabled people's experience, impairment related concerns, and the significance of culture. For example, drawing on recent feminist and postmodernist insights, Shakespeare and Watson argue that the social model distinction between impairment and disability is untenable, impractical, and represents an outmoded dogma that should be abandoned. For them disability is instead 'a complex dialectic of biological, psychological cultural and socio-political factors, which cannot be extricated except with imprecision'. This leads to the assertion that intervention at the physical, psychological, environmental and socio-political levels is the key to progressive change, and that one should not be a substitute for another. They also maintain that the disabled/non-disabled divide is no longer tenable and that 'everyone is impaired not just disabled people' and that this has far reaching implications for medical and social intervention in the twenty first century (Shakespeare and Watson, 2002).

It is important to reiterate here that the social model of disability is founded on disabled people's individual and collective experience, does not deny the significance of impairment related concerns,

appropriate medical interventions, nor the significance of culture (Finkelstein, 1986: Abberley, 1987: Lees, 1991: Barnes, 1992: Campbell and Oliver, 1996). It is a concerted attempt to **politicize** disability in order to provide a clear and unambiguous focus on the very real and multiple deprivations that are imposed on people whose biological conditions are deemed socially unacceptable in order to bring about radical structural and cultural change.

From this perspective, therefore, rehabilitation for disabled people can be seen as little more than a 'sick' joke. It is 'sick' because both the individualistic and inter-relational approaches, discussed above, retain the traditional notion that disability is primarily a health, and consequentially a medical, concern rather than a political problem. Thus, the solution, whether institutional or community based, is on 'body fixing and repair' (Sandvin, 2002). It is a 'joke' because no matter how comprehensive the rhetoric to the contrary both disability and, indeed, health are unequivocally major political issues. For example, the main causes of disease, acute and chronic, and long-term impairments in both rich and poor nations alike are 'poverty, inadequate sanitation, poor diet, bad housing, environmental pollution, industrial and road traffic accidents, violence and war'. Moreover:

'Whilst there is a growing need for the most basic of medical treatments across the globe, and particularly in low-income countries, a disproportionate amount of resources, both financial and human, are increasingly being poured into the development of costly medical treatments which will benefit only a relatively small percentage of the world's population' (WHO, 2001: 16).

All of which require far reaching political rather than medical solutions.

Furthermore, as demonstrated below, there is overwhelming evidence that 'rehabilitation' and related interventions are extremely limited in what they can achieve in terms of enabling disabled individuals attain economic and social parity with non-disabled peers in societies organized almost exclusively around non-disabled lifestyles. Moreover, whether intentional or otherwise, academic debates about the epistemological relevance of the socio/political interpretation of disability encapsulated within the social model or barriers approach, serve only to re-affirm medical

hegemony within the rehabilitational field: again, the very opposite of what is needed.

### **Barriers to inclusion in the 21st Century**

Although there is some debate regarding causality (Barnes, 1997) there is a clearly discernable cultural bias against people with any form of assumed physical or intellectual 'abnormality' in western culture since the ancient world of Greece and Rome. It is evident in Greco/Roman philosophies, policies and practices, Judeo/Christian teachings, and medieval culture and art. It was institutionalised throughout Europe as a consequence of the economic, ideological and cultural upheavals that accompanied industrial development during the eighteenth and nineteenth centuries (Oliver, 1990: Gleeson, 1999: Stiker, 1999).

The growing importance of economic rationality, liberal utilitarianism, and medical science during this period contributed to and compounded ancient fears and prejudices and provided the intellectual justification for more extreme measures. These included the systematic removal of large numbers of people with any form of physical or cognitive abnormality from the mainstream

of every day life. This policy continued well into the twentieth century and reached its logical conclusion with the mass sterilization of people considered 'defective' in many western states, and the systematic murder of over 270,000 disabled people regarded as 'travesties of human form and spirit' (Burliegh 1994: 194) in the Nazi death camps of the 1930s and 40s

Moreover, despite the unprecedented growth of rehabilitation services in western societies, this cultural legacy remains with us today and is reflected extensively in classical and popular media (Hevey, 1992: Shakespeare, 1994). It finds expression in a variety of forms, but probably the most significant example can be found in current debates about abortion and euthanasia.

In many countries campaigns to legalise abortion explicitly reaffirm societal attitudes toward physical and cognitive abnormality.

Britain's 1967 Abortion Act, for instance, states that pregnancy may be legally terminated at any time if it threatens the health of the pregnant woman or if there is a 'substantial risk' that that the child 'would suffer from such physical and mental abnormalities as to be seriously handicapped'. Women are often put under enormous pressure by doctors and families to abort a pregnancy

once impairment is detected. Such pressure is justified on the grounds that a disabled child is an emotional and financial 'burden' on both the family and the state. Indeed, these views underpin the work of many 'scientists' involved in the development of genetic medicine. This is clearly reflected in the following statement from Professor Bob Edwards delivered at the European Conference on Human Reproduction and Embryology in 1999:

'Soon it will be a sin for parents to have a child that carries the heavy burden of genetic disease. We are entering a world where we have to consider the quality of our children' (Rogers, 1999: 28).

Despite the fact that the overwhelming majority of impairments are acquired rather than hereditary, there is little doubt that such assertions devalue the very existence of anyone with a recognised impairment and, at the same time undermines the legitimacy of their demands for meaningful change.

Furthermore, recent discussions around the legalisation of euthanasia also pose a direct threat to disabled people's existence. While the medical profession has been formally

opposed to 'mercy killing', in cases where there is agreement that the quality of life is unacceptable, a person's life may be terminated with medical approval, perhaps after prior discussion with the patient or the family. Once legalised, as now in the Netherlands, there will be growing pressure on people with 'severe' impairments to opt for euthanasia. (Disability Tribune, 2000).

Discrimination against disabled children is endemic to contemporary education and employment systems. Formal education is geared for two main activities. These are: first, the dissemination of dominant social values considered necessary for active citizenship and, second, the allocation and selection of people for participation in the labour market. Segregated 'special' education systems for disabled children are present in most western societies. Support for separate provision comes from a variety of sources including policy makers, professionals, parents and some sections of the disabled community. It is argued that mainstream schools are unable to provide the high levels of health and individualised educational support, and empathetic peer culture needed by children with 'special educational needs'. Advocates maintain that segregated schooling is more efficient



and effective because scarce and costly resources such as specialist teachers and equipment can be concentrated in special school environments (Corbett 1998).

Segregated schooling has long been the preferred option of Deaf people and their organisations as it is the only way to ensure the continuity of Deaf culture, non-aural communication systems, and that children with hearing impairments grow up with a positive self-identity and therefore able to participate effectively in a predominantly aural society. This has created a deep division between Deaf organisations and most other organisations of disabled people who argue that the special education system is deeply implicated in the oppression of people with impairments and should be abolished (Corker, 1998).

Critics maintain that removing disabled children from family, peers and the local community has wide-ranging negative implications (Morris 1997). Residential and segregated institutions inhibit disabled children's ability to make friends with non-disabled peers. In special schools impairment considerations often take priority over educational ones. Lower expectations amongst educationalists and teachers often means that disabled children

are exposed to a limited curriculum consequently the academic achievements of pupils in these environments is well below that of non-disabled peers.

In Britain, disabled children from 'special' schools leave with fewer qualifications and marketable skills than non-disabled contemporaries. Working age disabled people are 'more than twice as likely on average than non-disabled people to have no formal qualifications' (Christie 1999: 89). While Government documents proclaim their broad commitment to deliver 'excellence for all children' (DfEE, 1998), the education system is geared increasingly to competition, choice, and selection. Strategies include a national curriculum, and published league tables with performance indicators of educational attainment and exam results. In this policy environment disabled pupils are perceived as a liability. Similar patterns of lower educational achievement among disabled children compared with non-disabled peers exist around the world. In Canada and Australia, this is widely documented at both secondary and university levels (Gleeson 1999: NIDDR, 2000).

In most modern societies paid work is arguably the most important criterion for categorising people in terms of class, status and power. Consequently, those on the margins of the labour market encounter a variety of economic, political and social deprivations. Although unemployment rates vary over time and place, except in times of war, this is a common experience for disabled workers. In 1999 'disabled people are seven times as likely as non-disabled people to be out of work and claiming (welfare) benefits' (Christie 1999: 89). The unemployment rate for disabled Americans in the mid 1990s stood at 13.4 percent, or more than twice the level for non-disabled peers (LaPlant et al., 1996). The figures for Australia tell a similar story (Gleeson, 1999).

Disabled people are particularly under-represented in the professions and management, where there are higher earnings, job security and opportunities for promotion. Conversely, disabled people are over-represented in low skilled, poorly paid, less secure jobs. In Britain disabled men working full time earned on average 25 percent less than their non-disabled counterparts while the wages of disabled women were only two thirds that of disabled men (Burchardt 2000). In Australia disabled employees earn around 30 percent less than their non-disabled equivalents

(Gleeson 1999). In the USA disabled workers earn only 64 percent of the average non-disabled income, often due to lower hourly wages and fewer hours worked (LaPlante *et al.* 1996). Within the disabled population, those identified as people with learning difficulties or with a 'mental illness' experience much greater work disadvantages.

This can be attributed to several factors. In Britain, for example, there is consistent and persuasive evidence of negative practices and attitudes towards the employment of disabled workers among both employers and workmates. Inaccessible transport and workplaces, inflexible working conditions provide significant barriers. The increasing emphasis on formal qualifications, marketable skills, medical screening, and a 'socially acceptable' appearance by employers further contribute to the discrimination against groups within the disabled population (Barnes 1991: Burchardt, 2000). Similar patterns have been identified across Europe and North America (Thornton *et al.* 1997: NIDRR 2000).

An important outcome of this situation is that the majority of disabled people in western countries experience higher levels of poverty, and are more reliant on state welfare payments or charity

for financial support. In Britain, state welfare benefits are the sole source of income for three-quarters of all disabled adults. Indeed, around 45 percent of disabled Britons live below the official poverty line (Barnes and Mercer, 2003), while in the USA 30 per-cent of disabled people of working age are classified as living in poverty. The rate is even higher amongst specific sections of the disabled community, rising to 72 percent for disabled women with children under 6 years (LaPlante *et al.* 1996: 2). At the same time, people with impairment/s have higher costs simply because society is geared to the needs of non-disabled people. This is reinforced by expenditure on impairment related items such as specialised equipment, personal clothing, heating, transport and housing adaptations (Berthoud, 1998).

Social and economic inequalities are also reflected in the consumption of services. In those countries with significant public and private welfare sectors the reliance on public rather than private sector provision in such areas as housing, transport and education) has been an important mark of social status. In practice, most disabled people remain disproportionately reliant on the state, and voluntary, sectors while they are further

differentiated as a result of their segregation in special schools and housing (Barnes and Mercer, 2003).

Institutional discrimination against disabled people is perhaps never more apparent than in the built environment – housing, transport and public space. Examples include:

- ‘physical barriers to movement for disabled people, including broken surfaces on thoroughfares (streets, guttering, paving) that reduce or annul the effectiveness of mobility aids (e.g. wheelchairs, walking frames);
- building architecture which excludes the entry of anyone unable to use stairs and hand-operated doors;
- public and private transport modes which assume that drivers and passengers are non-impaired; and
- public information (e.g. signage) presented in forms that assume a common level of visual and aural ability’  
(Gleeson 1999: 137).

Until recently urban infrastructures were designed with little or no thought for the needs of people with recognised impairments. An inaccessible built environment has a knock-on effect for a wide

range of activities, including the choice about where and when to work, type and location of housing, and participation in leisure activities. This in turn inhibits earning and shopping opportunities while also leading to higher travel costs and investment of more time in making the necessary, alternative arrangements. .

Although most western societies now have some form of legislative framework with which to address inaccessible built environments, these policies have been slow to make an impact on discriminatory urban design. For example, Britain's 1970 Chronically Sick and Disabled Persons (CSDP) Act instructed local authorities to address the access needs of disabled people in terms of housing, public buildings, schools and universities. In the early 1970s local authorities' 'completions' of wheelchair adaptable dwellings rose substantially, but thereafter declined dramatically to a handful in the 1990s. Moreover, despite the rhetoric of 'social inclusion' that pervades recent official publications, segregated 'special needs' housing remains central to Government plans for 'community care'. In Britain, homelessness among the disabled population is relatively high and particularly so among mental health system users and 'survivors' (Sayce, 2000). Economic and

social participation is inhibited by inaccessible public transport systems including: buses, trains, coaches and planes.

Taken together these barriers have potentially profoundly negative psychological and emotional implications for disabled individuals (Thomas, 1999) and their families (Parker, 1993; Read, 1999). All of which makes the practice of rehabilitation even more problematic and the philosophy upon which it is based even more implausible.

### **Concluding remarks and a glimmer of hope?**

Hitherto, this paper has argued that societal understandings of disability are currently in the process of transition. This is clearly reflected in recent developments in official documents regarding definitions of disability and rehabilitation. Although economic and demographic factors are increasingly relevant, it is evident that the driving force behind this phenomenon was the unprecedented politicisation of disability by disabled activists, their allies, and the growing demand for equity of opportunity for people with ascribed impairments. However, despite the conceptual and analytical utility of the ensuing socio/political interpretation of disability, progress



has been limited. This is due mainly to the on going tendency amongst politicians, policy makers, and academics to link disability to health and in so doing, whether intentionally or otherwise, propagate the misguided illusion that 'poor health' and the disadvantages experienced by people with ascribed impairments can be overcome with medical rather than political solutions.

Consequentially rehabilitation philosophies and practices remain locked into person centred approaches. But whilst medical interventions and treatments are important, and much needed in the poorer nations of the majority world, they can have only a limited impact in a cultural environment that is geared almost exclusively to non-disabled living. It is evident therefore that public health and the problems encountered by disabled people are political issues that can only be resolved by deep-rooted structural and cultural change involving the systematic re-distribution of resources and the development of a culture that celebrates rather than denigrates the realities of human diversity.

Moreover, as the boundaries between what is and what is not considered a socially acceptable condition becomes ever-more blurred, as they most surely will if only because of the changing demography of European society and recent developments in

genetic medicine, changes which are evident throughout much of the 'western' world, the significance of this insight will become evermore significant.

It is important therefore not to overlook the fact that the foundations for meaningful change have already been laid with the emergence of the international disabled people's movement. Besides a socio/political analysis of disability, the full implications of which have yet to be fully explored by academics (Germon, 1998; Barnes et al., 2002), this has generated a whole host of policy initiatives that confront either implicitly or explicitly traditional wisdom on the subject of disability and concomitant policy responses. The international network of user led initiatives, often referred to as Centres for Independent, Integrated or Inclusive Living (CILs) is an important example. In addition to stimulating a long overdue recognition in official circles of the importance of user involvement in service development, as exemplified in the UN's Standard Rules, mentioned above, these organisations have developed and provide a whole range of services for disabled people, professionals and other disadvantaged groups within an overtly socio/political (Charlton, 1998) or 'social model' framework (Barnes et al., 2001).

In the UK, for instance, these services include user led information providers, peer support networks, user controlled personal assistance schemes, and consciousness raising programmes in direct opposition to the traditional medically influenced 'disability awareness' schemes, known as Disability Equality Training (DET) (Gillespie-Sells and Campbell, 1991). A further corollary of these developments has been the coming of the disability arts movement and the generation of a whole range of cultural activities involving both disabled and non disabled individuals which, taken together, constitute meaningful alternatives to the various 'non disabled' cultures and conventional perceptions of a 'disabled', or passive dependent, identity that continue to permeate late capitalist society. Furthermore, such initiatives have also precipitated the demand for a new breed of professionals who, rather than being allied to medicine and accountable to medical institutions and associate ideologies and professional organisations, are allied and accountable to the disabled community (Finkelstein, 1999).

All of which offers a fragile but nonetheless significant glimmer of hope for the future creation of a truly meaningful and inclusive society. The task now for academics and researchers working in

the general area of disability studies, is to find appropriate and non-oppressive ways of working with disabled activists and their organisations in order to nurture and encourage their further development.

## References

Abberley, P. 1987: The Concept of Oppression and the Development of a Social Theory of Disability, reproduced in L. Barton, and M. Oliver eds, 1997: ***Disability Studies: Past Present and Future***, Leeds: The Disability Press (Also available on: [www.leeds.ac.uk/disability-studies/archiveuk/index.](http://www.leeds.ac.uk/disability-studies/archiveuk/index.))

Albrecht, G. L. 1992: ***The Disability Business***. London: Sage.

Barnes, C. 1991: ***Disabled People in Britain and Discrimination***. London: Hurst and Co., in association with the British Council of Organisations of Disabled People.

Barnes, C. 1992: ***Disabling Imagery: An Exploration of Media Portrayals of Disabled People***, Derby: The British Council of

Organizations of Disabled People (Also available on:

[www.leeds.ac.uk/disability-studies/archiveuk/index.](http://www.leeds.ac.uk/disability-studies/archiveuk/index.))

Barnes, C. 1997: A legacy of oppression: a history of disability in Western culture. In L. Barton and M. Oliver (eds), **Disability**

**Studies: Past, Present and Future**. Leeds: The Disability Press, 3-24 (Also available on: [www.leeds.ac.uk/disability-studies/archiveuk/index.](http://www.leeds.ac.uk/disability-studies/archiveuk/index.))

Barnes, C. Mercer, G. and Morgan, H. 2000: **Creating Independent Futures: Stage One Report**, Leeds: The Disability Press (Also available on: [www.leeds.ac.uk/disability-studies/archiveuk/index.](http://www.leeds.ac.uk/disability-studies/archiveuk/index.))

Barnes, C. and Mercer, G. 2003: **Disability**. Cambridge: Polity.

Barnes, C. Oliver, M. Barton, L. eds. 2002: **Disability Studies Today**, Cambridge, Polity.

Baylies, C. 2002: 'Disability and the Notion of Human Development: questions of rights and responsibilities', in **Disability and Society**, 17 (7) 725-740.

Berthoud, R. 1998: ***Benefits: a review of the issues and options for reform***, York: York Publishing Services.

Burleigh, M. 1994: ***Death and Deliverance Euthanasia in Germany 1900-1945***, Cambridge: Cambridge University Press.

Burchardt, T. 2000: ***Enduring Economic Exclusion: Disabled People, Income and Work***. York: Joseph Rowntree Foundation.

Bury, M. 2000: 'A Comment on the ICDH2', in ***Disability and Society***, 15 (7) 1073-1078.

Campbell, J. and Oliver, M. 1996: ***Disability Politics: Understanding our Past, Changing our Future***. London: Routledge.

Charlton, J. I. 1998: ***Nothing About Us Without Us: Disability Oppression and Empowerment***. Berkeley: University of California Press.

Christie, I. with Mensah-Coker, G. 1999: ***An Inclusive Future? Disability, social change and opportunities for greater inclusion by 2010.*** London: Demos.

Corbett, J. 1998: ***Special Educational Needs in the Twentieth Century: a cultural analysis,*** London: Cassell.

Corker, M. 1998: ***Deaf and Disabled: or Deafness Disabled?,*** Milton Keynes: Open University Press.

Coleridge, P. 1993: ***Disability, Liberation and Development.*** Oxford: Oxfam Publications.

DfEE. 1998: ***Excellence for all Children: Meeting Special Educational Needs*** London: Department of Education and Employment.

Disability Tribune. 2000: ***Lives Not Worth Living.*** London: Disability Awareness in Action, August, 1-2.

Driedger, D. 1989: ***The Last Civil Rights Movement. Disabled People's International.*** London: Hurst and Company.

Finkelstein, V. 1986: ***Supporting the Cultural Expression of Disabled People Through the Arts***, (Also available on [www.leeds.ac.uk/disability-tudies/archiveuk/index](http://www.leeds.ac.uk/disability-tudies/archiveuk/index).)

Finkelstein, V. 1991: 'Disability: An Administrative Challenge (the Health and Welfare Challenge)' ***Social Work, Disabled People and Disabling Environments***, London: Jessica Kingsley (Also available on [www.leeds.ac.uk/disability-tudies/archiveuk/index](http://www.leeds.ac.uk/disability-tudies/archiveuk/index).)

Finkelstein, V. 1998: The ***Biodynamics of Disablement***, Paper presented at the Disability and Rehabilitation Research Workshop in Harare, Zimbabwe, 29 June (Also available on: [www.leeds.ac.uk/disability-studies/archiveuk/index](http://www.leeds.ac.uk/disability-studies/archiveuk/index).)

Finkelstein, V. 1999: ***Professionals Allied to the Community, (PACs)*** [www.leeds.ac.uk/disability-tudies/archiveuk/index](http://www.leeds.ac.uk/disability-tudies/archiveuk/index)

Germon, P. 1998: 'Activists and Academics: part of the same or a world apart' in T. Shakespeare, ed. ***The Disability Reader: social science perspectives***, London: Cassell, 245-255.



Gillespie-Sells, K. and Campbell, J. 1991: ***Disability Equality Training***, London: Central Council for the Education and Training of Social Work (Also available on: [www.leeds.ac.uk/disability-studies/archiveuk/index](http://www.leeds.ac.uk/disability-studies/archiveuk/index).)

Gleeson, B. 1999: ***Geographies of Disability***. London: Routledge.

Gordon, B. O., and Rosenblum, K. E. 2001: 'Bringing Disability into the Sociological Frame; in ***Disability and Society***, 16 (1) 6-20.

Hanks, J. and Hanks, L. 1948: The physically handicapped in certain non-Occidental societies. ***Journal of Social Issues***, 4 (4), 11-20.

Hevey, D. 1992: ***The Creatures that Time Forgot: Photography and Disability Imagery***. London: Routledge.

Hunt, P. (ed.) 1966: ***Stigma: The Experience of Disability***, London: Geoffrey Chapman.

Hunt, P. 1981: 'Settling Accounts with the Parasite People', In *Disability Challenge*, 2, 37-50. Available on the Disability Archive UK [www.leeds.ac.uk/disability-studies/archiveuk/index](http://www.leeds.ac.uk/disability-studies/archiveuk/index).

Hurst, R. 2000: To revise or not to revise. *Disability and Society*, 15 (7), 1083-7.

IDF. 1998: *World Disability Report*, Geneva: International Disability Forum.

Illich, I. 1977: Disabling professions. In I. Illich *et al.*, *Disabling Professions*. London: Marion Boyars, 11-39.

Ingstad, B. 2001: Disability in the Developing World. In G. L. Albrecht, K.D. Seelman, and M. Bury (eds), *Handbook of Disability Studies*. London: Sage, 772-92.

Ingstad, B. and Whyte, S.R. (eds) 1995: *Disability and Culture*. Berkeley: University of California Press.

LaPlante, M. P., Kennedy, J., Kaye, H. S. and Wenger, B. L. 1996: *Disability and Employment*. Abstract 11, January. University of

California: Disability Statistics Centre.

<http://dsc.uesf.edu./abs/ab11txt.htm>.

Lees, S. 1992: ed. ***Disability Arts and Culture Papers***, London: Shape Publications (Also available on: [www.leeds.ac.uk/disability-studies/archiveuk/index](http://www.leeds.ac.uk/disability-studies/archiveuk/index).)

Linton, S. 1998: ***Claiming Disability: knowledge and identity***. New York: New York University Press.

Morris, J. 1993: ***Independent Lives***, Basingstoke: Macmillan.

Morris, J. 1997: ***Gone Missing***, York: The Joseph Rowntree Foundation.

Miles, M. 2001: 'ICIDH, Meets Postmodernity, or "incredulity towards meta-terminology" in ***Disability World*** 7 (March-April). Available at: [http://www.disabilityworld.org/03-04\\_01/resources/icidh.shtml](http://www.disabilityworld.org/03-04_01/resources/icidh.shtml) (Accessed 24th February 2003).

NIDDR. 2000: **Long Range Plan**, Washington DC.: Department of Education, National Institute on Disability and Rehabilitation Research.

Oliver, M. 1983: **Social Work with Disabled People**. Basingstoke: Macmillan.

Oliver, M. 1990: **The Politics of Disablement**. Basingstoke: Macmillan.

Parker, G. 1993: **With this Body**, Buckingham: Open University Press.

Parsons, T. 1951: **The Social System**. New York: The Free Press.

Pfeiffer, D. 2000: 'The Devils are in the Detail' the ICDH2 and the Disability Movement' in **Disability and Society**, 15 (7) 1079-1082). .

Read, J. 2000: **Disability, the Family and Society: listening the mothers**, Buckingham: The Open University Press.

Rogers, L. 1999: 'Disabled children will be a "sin", says scientist', ***Sunday Times***, July 4<sup>th</sup>. 28.

Sandvin, J. 2002: 'Rehabilitation: A Norwegian expert asks if it's still a useful concept', in ***Disability World***, 15 September/October, unpagged (Available on [http://www.disabilityworld.org/09-10\\_02/il/useful.shtml](http://www.disabilityworld.org/09-10_02/il/useful.shtml)) (Accessed 24th February 2003).

Sayce, M. 2000: ***From Psychiatric Patient to Citizen*** Tavistock, Macmillan

Scheer, J. and Groce, N. 1988: Impairment as a Human Constant: Cross-Cultural and Historical Perspectives on Variation. ***Journal of Social Issues***. 44 (1), 23-37.

Scotch, R. 1988: Disability as the Basis for a Social Movement: Advocacy and the Politics of Definition. ***Journal of Social Issues***, 44 (1), 159-72.

Shakespeare, T. 1994: Cultural representation of disabled people: dustbins for disavowal? ***Disability and Society***, 9 (3), 283-99.

Shakespeare, T. and Watson, N. 2002: 'The Social Model for Disability: an Outdated Ideology' in ***Research in Social Science and Disability***, 2 9-28 (Also available on: [www.leeds.ac.uk/disability-studies/archiveuk/index.](http://www.leeds.ac.uk/disability-studies/archiveuk/index.))

Stiker, H-J. 1999: ***A History of Disability***, trans. W.Sayers. Ann Arbor: University of Michigan Press.

Stone, D. 1985: ***The Disabled State***, Basingstoke: Macmillan.

Stone, E. 1999: Disability and development in the majority world. In E.Stone (ed.), ***Disability and Development***. Leeds: The Disability Press, 1-18.

Sutherland, A. T. 1981: ***Disabled We Stand***, London: Souvenir Press (Also available on [www.leeds.ac.uk/disability-studies/archiveuk/index.](http://www.leeds.ac.uk/disability-studies/archiveuk/index.)).

Thomas, C. 1999: ***Female Forms: Experiencing and Understanding Disability***, Milton Keynes: Open University Press.

Thornton, P. Sainsbury, R, and Barnes, H. 1997: ***Helping Disabled People in Work: a cross national study of social security and employment provision***, London: The Stationary Office.

UN. 1993: ***Standard Rules on the Equalization of Opportunities for Persons with Disabilities***. New York: United Nations

UPIAS. 1976: ***Fundamental Principles of Disability***. London: Union of the Physically Impaired Against Segregation (Also available on: [www.leeds.ac.uk/disability-studies/archiveuk/index.](http://www.leeds.ac.uk/disability-studies/archiveuk/index.))

Ústún, T. B. et al., 2001: ***Disability and Culture: Universalism and Diversity***, Seattle: World Health Organisation in a association with Hogrefe and Huber Publishers.

WHO. 1980: ***International Classification of Impairments, Disabilities and Handicaps***. Geneva: World Health Organization.

WHO. 2001: ***International Classification of Functioning and Disability, Beta-2 draft, Short Version***. Geneva: World Health Organization

<http://www3.who.int/icf/icftemplate.cfm?myurl=inytroduction.html>

(Accessed 24th February 2003).

WHO. 2001: ***Rethinking Care from Disabled People's Perspectives***. Geneva: World Health Organization (Also available on: [www.leeds.ac.uk/disability-studies/archiveuk/index.](http://www.leeds.ac.uk/disability-studies/archiveuk/index.))

Zola, I. K 1982; ***Missing Pieces, A Chronicle of Living with a Disability***, Philadelphia: Temple University Press.