

Disability Definitions: the Politics of Meaning

The issue of meaning has been a central one in discussions of differences between the natural and social worlds and the generation of appropriate methodologies to understand these worlds. As far as the social sciences themselves are concerned, the debate around this issue has centred on the violation of meaning through the imposition of inappropriate theoretical perspectives or the ignoring of meaning through the collection of non-reflexive and abstracted data.

Many years ago Wright Mills (1970) criticised the work of social scientists for either being grand theory or abstracted empiricism. The subsequent case for a methodological middle way has had a profound effect on social scientific work ever since and there have been few areas, subjects or topics where theory and empiricism have not met. One exception however, has been the area of disability, to which little attention has been paid. There have been notable exceptions of course, including Topliss (1979), Blaxter (1980), Leonard (1984) and Borsay (1986a) who have approached the area from functionalist, interactionist, Marxist and Weberian positions. However Wright Mills' earlier indictment of social science in general is just as valid today in the area of disability as it was all those years ago.

Thus, while it cannot be claimed that there has been much grand theorising about disability, it can be argued that almost all studies of disability have a grand theory underpinning them. That grand theory can be characterised as 'the personal tragedy theory of disability'. It has fallen to disabled people themselves (Finkelstein, 1980; Oliver, 1983) to provide both critiques of this implicit

theory and to construct their own alternatives, which might be called 'social oppression theory'.

Abstracted empiricism has proceeded from the same implicit underpinning, firstly by seeing disability as a problem, and then by devising methodological strategies to measure the extent of these problems that disabled individuals have to face. Again it has fallen to disabled people to provide critiques of this (Sutherland, 1981; Oliver, 1987) and to begin to explore alternative methodological strategies.

A major focus for these debates has centred on the issue of definitions of disability and these, therefore have consequently undergone a number of changes and modifications. Starting from the work of Harris (1971) and her national survey of disabled people, a threefold distinction of impairment, disability and handicap was developed. Following various discussions and refinements, a more sophisticated scheme was advanced by Wood (1981) and this was accepted by the World Health Organisation as the basis for classifying illness, disease and disability. However, these definitions have not received universal acceptance, particularly amongst disabled people and their organisations. Before proceeding further, it is necessary to explain why definitions are important and to spell out the precise nature of the criticisms that have been made.

THE IMPORTANCE OF DEFINITIONS

The social world differs from the natural world in (at least) one fundamental respect; that is, human beings give meanings to objects in the social world and subsequently orientate their behaviour towards these objects in terms of the meanings given to them. W. I. Thomas (1966) succinctly puts it thus: 'if men define situations as real,

they are real in their consequences'. As far as disability is concerned, if it is seen as a tragedy, then disabled people will be treated as if they are the victims of some tragic happening or circumstance. This treatment will occur not just in everyday interactions but will also be translated into social policies which will attempt to compensate these victims for the tragedies that have befallen them.

Alternatively, it logically follows that if disability is defined as social oppression, then disabled people will be seen as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstance. Such a view will be translated into social policies geared towards alleviating oppression rather than compensating individuals. It almost goes without saying that at present, the individual and tragic view of disability dominates both social interactions and social policies.

A second reason why definitions are important historically centres on the need to identify and classify the growing numbers of the urban poor in modern industrial societies. In this process of identification and classification, disability has always been an important category, in that it offers a legitimate social status to those who can be defined as unable to work as opposed to those who may be classified as unwilling to do so (Stone, 1985). Throughout the twentieth century this process has become ever more sophisticated, requiring access to expert knowledge, usually residing in the ever-burgeoning medical and paramedical professions. Hence the simple dichotomy of the nineteenth century has given way to a whole new range of definitions based upon clinical criteria or functional limitation.

A third reason why definitions are important stems from what might be called 'the politics of minority groups'. From the 1950s onwards, though earlier in the case of

alcoholics, there was a growing realisation that if particular social problems were to be resolved, or at least ameliorated, then nothing more or less than a fundamental redefinition of the problem was necessary. Thus a number of groups including women, black people and homosexuals, set about challenging the prevailing definitions of what constituted these problems by attacking the sexist and racist biases in the language used to underpin these dominant definitions. They did this by creating, substituting or taking over terminology to provide more positive imagery (e.g. gay is good, black is beautiful, etc.). Disabled people too have realised that dominant definitions of disability pose problems for individual and group identity and have begun to challenge the use of disablist language. Whether it be offensive (cripple, spastic, mongol, etc.) or merely depersonalising (the handicapped, the blind, the deaf, and so on), such terminology has been attacked, and organisations of disabled people have fostered a growing group consciousness and identity.

There is one final reason why this issue of definitions is important. From the late fifties onwards there was an upswing in the economy and an increasing concern to provide more services for disabled people out of an ever-growing national cake. But clearly, no government (of whatever persuasion) was going to commit itself to a whole range of services without some idea of what the financial consequences of such a commitment might be. Thus, after some pilot work, the Office of Population Censuses and Surveys (OPCS) was commissioned in the late sixties to carry out a national survey in Britain which was published in 1971 (Harris, 1971). Subsequent work in the international context (Wood, 1981) and more recently a further survey in this country, which has recently been published (Martin, Meltzer and Elliot, 1988), built on and extended this work. However, this work has proceeded

isolated from the direct experience of disability as experienced by disabled people themselves, and this has led to a number of wide-ranging and fundamental criticisms of it.

CRITICISMS OF OFFICIAL DEFINITIONS

This work attempts to operationalise a broadly similar conceptual framework and hence criticisms of one can be applied to them all. Specific criticisms of the WHO scheme have focused on the fact that it remains close to medical classifications of disease - disability - handicap. In so doing it conserves the notion of impairment as abnormality in function, disability as not being able to perform an activity considered normal for a human being and handicap as the inability to perform a normal social role. This reification of the idea of normality ignores the issue of what normality actually is, but even if the idea of normality is conceded, the failure to recognise the situational and cultural relativity of normality is a serious omission in an international scheme (Nordenfelt, quoted in OECD, 1987, p. 5). Similar criticism can be made of the OPCS schemes, in that they fail to recognise the influences of sub-cultures, gender or ethnicity on the idea of normality.

Further, the WHO and OPCS definitions take the environment for granted even though the handicap is no longer considered to be within the individual. As long as the environment consists of social roles that are considered to be normal, the inability of the individual to live up to the requirements of these roles puts him or her in a disadvantaged position and thus creates a handicap. In this way the medical approach is conserved since changes must be brought to bear on the individual rather than the environment (Soder, quoted in OECD, 1987, p.5).

At this point it is, perhaps, important to clarify what is wrong with the medical approach to disability and to emphasise the word disability. It is not being argued that the medical approach to illness or impairment is inappropriate, although some specific individual medical interventions may well be, but rather that

The problem ... is that medical people tend to see all difficulties solely from the perspective of proposed treatments for a 'patient', without recognising that the individual has to weigh up whether this treatment fits into the overall economy of their life. In the past especially, doctors have been too willing to suggest medical treatment and hospitalisation, even when this would not necessarily improve the quality of life for the person concerned. Indeed, questions about the quality of life have sometimes been portrayed as something of an intrusion upon the purely medical equation. (Brisenden, 1986, p. 176)

Hence this medical approach produces definitions of disability which are partial and limited and which fail to take into account wider aspects of disability.

A major reason for this has been the failure of the medical profession, and indeed all other professions, to involve disabled people in a meaningful way except as passive objects of intervention, treatment and rehabilitation. This has not just trapped professionals within the medical approach but has had oppressive consequences for disabled people.

Much of the work which has already been done on definitions has been carried out by people who do not themselves experience the daily problems of disability. This has directly affected the solutions, and in turn has often served to perpetuate discrimination

against us, as well as wasting resources on an enormous scale. (Davis, 1986a, p. 2)

A further criticism of both the WHO and OPCS schemes is that, in attempting to make concrete that which is not and can never be, they present disability as a static state and violate its situational and experiential components.

By trying to find strict measures of disability or focussing on 'severe' 'visible' handicaps we draw dividing lines and make distinctions where matters are very blurry and constantly changing. By agreeing that there are twenty million disabled or 36 million, or even that half the population are in some way affected by disability, we delude ourselves into thinking there is some finite, no matter how large, number of people. In this way, both in the defining and in the measuring, we try to make the reality of disease, disability and death problematic, and in this way make it at least potentially someone else's problem. (Zola, 1981, p. 242)

Because of these fundamental flaws, Disabled People's International has opposed the WHO scheme since its inception. Finkelstein, as the then Chair of its national counterpart, the British Council of Organisations of Disabled People, gives the following reasoning:

I remained convinced, however, that this classification system in its present form reinforces medical and administrative approaches towards us and that in this respect, it is not in our best interests to support it. (Finkelstein, 1985)

Not only do these definitions medicalise and individualise the problems of disability but they do the same to the solutions (policies) that are applied. Thus services too are

based upon an individualised and medicalised view of disability and are designed by able-bodied people through a process over which disabled people have had little or no control. Hence, we come to politics and the oppressive consequences that such definitions and the research based on them, can have for disabled people.

THE POLITICS OF MEANING

It could be argued that in polarising the tragic and oppressive views of disability, a conflict is being created where none necessarily exists. Disability has both individual and social dimensions and that is what official definitions from Harris (1971) through to WHO (Wood, 1981) have sought to recognise and to operationalise. The problem with this, is that these schemes, while acknowledging that there are social dimensions to disability, do not see disability as arising from social causes. Ultimately their rationale rests upon the impaired individual and the social dimensions of disability and handicap arise as a direct consequence of individual impairments.

This view of disability can and does have oppressive consequences for disabled people and can be quite clearly shown in the methodology adopted by the recent OPCS survey in Britain (Martin et al., 1988). The following is a list of questions drawn from the face-to-face interview schedule of this survey.

TABLE 1.1

Survey of disabled adults - OPCS, 1986

Can you tell me what is wrong with you?

What complaint causes your difficulty in holding, gripping or turning things?

Are your difficulties in understanding people mainly due to a hearing problem?

Do you have a scar, blemish or deformity which limits your daily activities?

Have you attended a special school because of a long-term health problem or disability?

Does your health problem/disability mean that you need to live with relatives or someone else who can help look after you?

Did you move here because of your health problem/disability?

How difficult is it for you to get about your immediate neighbourhood on your own?

Does your health problem/disability prevent you from going out as often or as far as you would like?

Does your health problem/disability make it difficult for you to travel by bus?

Does your health problem/disability affect your work in any way at present?

* * *

These questions clearly ultimately reduce the problems that disabled people face to their own personal inadequacies or functional limitations. It would have been perfectly possible to reformulate these questions to locate

the ultimate causes of disability as within the physical and social environments.

This reformulation is not only about methodology or semantics, it is also about oppression. In order to understand this, it is necessary to understand that, according to OPCS's own figures, 2231 disabled people were given face-to-face interviews (Martin et al., 1988, Table 5.2). In these interviews, the interviewer visits the disabled person at home and asks many structured questions in a structured way. It is in the nature of the interview process that the interviewer presents as expert and the disabled person as an isolated individual inexperienced in research, and thus unable to reformulate the questions in a more appropriate way. It is hardly surprising that, given the nature of the questions and their direction that, by the end of the interview, the disabled person has come to believe that his or her problems are caused by their own health/disability problems rather than by the organisation of society. It is in this sense that the process of the interview is oppressive, reinforcing on to isolated, individual disabled people the idea that the problems they experience in everyday living are a direct result of their own personal inadequacies or functional limitations.

TABLE 1.2

Alternative questions

Can you tell me what is wrong with society?

What defects in the design of everyday equipment like jars, bottles and tins causes you difficulty in holding, gripping or turning them?

Are your difficulties in understanding people mainly due to their inability to communicate with you?

Do other people's reactions to any scar, blemish or deformity you may have, limit your daily activities?

Have you attended a special school because of your education authority's policy of sending people with your health problem or disability to such places?

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?

What inadequacies in your housing caused you to move here?

What are the environmental constraints which make it difficult for you to get about in your immediate neighbourhood?

Are there any transport or financial problems which prevent you from going out as often or as far as you would like?

Do poorly-designed buses make it difficult for someone with your health problem/disability to use them?

Do you have problems at work because of the physical environment or the attitudes of others?

* * *

But research can have oppressive consequences not simply because disabled people are the passive recipients of the research process but also because such research has failed to improve the quality of life for them, while doing no harm to the career prospects of the researchers.

The classic example of this was the often quoted study A LIFE APART (Miller and Gwynne, 1972) which has been savagely attacked by one such 'passive' recipient.

It was clear that Miller and Gwynne were definitely not on our side. They were not really on the side of the staff either. They were, in fact, basically on their own side, that is the side of supposedly 'detached', 'balanced', 'unbiased' social scientists, concerned above all with presenting themselves to the powers that be as indispensable in training 'practitioners' to manage the problem of disabled people in institutions. Thus the fundamental relationship between them and the residents was that of exploiters and exploited. (Hunt, 1981, p. 5)

Finally, the theoretical underpinnings of much research on disability have usually been so divorced from the everyday experience of disabled people that

they have felt victimised by professionals who write articles about the reactions to disability that are based more upon theory than fact. (Trieschmann, 1980, p. xii)

For these reasons more and more disabled people are refusing to participate in research over which they have no control and which they regard as likely to further their oppression.

A WAY FORWARD

This debate over the nature of disability (whether it is ultimately reducible to the functional limitations of disabled individuals or the structural features and social forces of society), is symptomatic of a more general debate that has occurred throughout the history of the social sciences and

has centred on the notion of methodological individualism. This can be defined in the following way:

Methodological individualism is a doctrine about explanation which asserts that all attempts to explain social (or individual) phenomena are to be rejected (or, according to a current, more sophisticated version, rejected as 'rock-bottom' explanations) unless they are couched wholly in terms of facts about individuals. (Lukes, 1973, p.110)

Clearly, neither the WHO nor the OPCS's schemes have been able to shake off the shackles of methodological individualism which has been criticised thus;

Methodological individualism is thus an exclusivist, prescriptive doctrine about what explanations are to look like ... it excludes explanations which appeal to social forces, structural features of society, institutional factors and so on. (Lukes, 1973, p. 122)

As has already been suggested, the social sciences do not have a very good track-record in critically examining dominant definitions of disability nor the policies and practices to which they give rise. This is somewhat surprising, for there is a tradition within the social sciences which has examined some of the definitions, policies and practices based upon methodological individualism and underpinning a whole range of other social problems. What is urgently needed therefore is a social theory of disability, for

A social theory of disability should be integrated into, rather than separate from, existing social theories. It has to be remembered, however, that personal tragedy theory itself has performed a particular ideological function of its own.

Like deficit theory as an explanation of poor educational attainment, like sickness as an explanation of criminal behaviour, like character weakness as an explanation of poverty and unemployment, and like all other victim blaming theories (Ryan, 1971), personal tragedy theory has served to individualise the problems of disability and hence leave social and economic structures untouched. Social science in general and social policy in particular have moved far in rejecting individualistic theories and constructing a range of alternative social ones - let us hope that personal tragedy theory, the last in the line, will soon disappear also, to be replaced by a much more adequate social (oppression) theory of disability. (Oliver, 1986, p. 16)

The purpose of this book, therefore, is to attempt to develop a social theory of disability. A social theory of disability, however, must be located within the experience of disabled people themselves and their attempts, not only to redefine disability but also to construct a political movement amongst themselves and to develop services commensurate with their own self-defined needs. This process of re-definition has already been begun by disabled people who have dispensed with the intricacies and complexities of the definitions discussed earlier and instead propose the following twofold classification.

IMPAIRMENT lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body;

DISABILITY the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the

mainstream of social activities. (UPIAS, 1976, pp. 3-4)

What is at stake here is the issue of causation, and whereas previous definitions were ultimately reducible to the individual and attributable to biological pathology, the above definition locates the causes of disability squarely within society and social organisation.

The rest of the book, therefore, will concentrate disability within the context of society and social organisation. It will be argued that the kind of society that one lives in will have a crucial effect on the way the experience of disability is structured. The focus will then shift to consider the ways in which disability is 'produced' as an individual and medical problem within capitalist society. The individual experience of disability within capitalism is itself constrained by some of the structural features of capitalism including ideology, culture and the influence of race and gender as well as by the activities of key groups and institutions (professionals and professions). These influences will be discussed before, finally, issues of social policy, change and politics will be considered as part of broader developments within late capitalism.