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## **DEFINING AND RESEARCHING DISABILITY: CHALLENGES AND RESPONSES**

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### **INTRODUCTION**

It is something of a cliché to say that we are living in a period of rapid social change. Yet it seems clear that a fundamental process of cultural as well as economic and social transformation is underway, and on a global scale. Arguments have proliferated as to the directions of such change. For some, the changes represent little more than cultural fragmentation, perhaps even degeneration, for others they represent renewal (Featherstone, 1992). What is less in doubt is that assumptions underpinning a range of social and intellectual activities are under strain. Nowhere is this more in evidence than in the health field. Not only is modern medicine being challenged on all sides, from managerialism to alternative medicine, but the very categories that have underpinned modern health and welfare systems are being severely scrutinised.

In this chapter, a preliminary sketch of change in one area of health and welfare is presented, namely that of disability. The chapter first examines the recent history of defining and researching disability, and identifies the emergence of a 'socio-medical' model, particularly in the British context. It then notes the development of a more explicit sociological view, which has emerged from these concerns and from more theoretical considerations. Second, the chapter examines recent arguments put forward by a number of 'disability theorists', that disability should be defined and researched primarily as a form of 'social oppression'. Critiques of the socio-medical model and sociological work which have been informed by these arguments will be examined. Finally, the chapter considers the impact this

controversy is having on the field of disability studies, and on the relationship between researchers and researched.

## **THE EMERGENCE OF DISABILITY**

In the immediate post-war world, at least in Britain, health care and social welfare in the disability area were characterised, in Topliss' terms, by a mixture of neglect and humanitarian concern (Topliss, 1979). The effects of war and industrial injury slowly gave way to the impact of chronic disease and disability in an ageing population. Though, of course, not all disability at this time was associated with chronic illness, and not all such illness involved disability, the relationship between the two was becoming increasingly evident (Taylor, 1976). In addition, disability in earlier stages of the life course, from the effects of congenital abnormalities, and from injuries caused by high risk sports and leisure activities was also becoming significant. The relationship between age, life course, disability and such factors as gender and ethnicity has subsequently received more attention, especially in social research (Arber and Evandrou, 1993).

During the same period medical specialties grew, and this has sometimes led to accusations, mentioned in more detail below, of the medicalisation of disability. Since then, areas such as rheumatology, stroke and rehabilitation services have grown rapidly, alongside the massive expansion of services for patients with a wide variety of other chronic disabling conditions. Specialist facilities for treating the effects of trauma, whether on the sports field or the roads have also grown. Medical research on these conditions and on the general profile of disability has also expanded at a rapid rate.

In Britain, research on the social dimensions of chronic illness and disability began in earnest in the 1960s, though it has to be said, within a less theoretical framework than in the U.S. (Bury, 1991). Collaboration between public health oriented rehabilitation specialists such as Michael Warren, and sociologists such as Margot Jefferys, focused on the definition and assessment of motor impairment in prevalence studies (Jefferys et al., 1969). As Donald Patrick has pointed out, such work was linked to the task of estimating medical

need and the possibility of developing preventive strategies (Patrick and Peach, 1989, p. 21).

This and other work culminated in the first OPCS national study of 'impairment and handicap' carried out by Amelia Harris and her colleagues, and published in 1971. This showed, for the first time, the extent of impairment in Britain, and suggested that just under 4% of the population aged 16-64 and just under 28% population over the age of 65 suffered from some form of impairment (Harris et al., 1971). Importantly, gender differences were noted, with twice the level of impairment in women compared with men (Patrick and Peach, 1989, p. 22). Comparable studies were carried out in the U.S. at this time (ibid.).

Subsequently, in Britain, Wood and his colleagues sought to clarify the terminology that was being used in this research, especially in the light of confusion, present even in the Harris survey, where different definitions (e.g. of impairment and handicap) were evident, with the terms sometimes being used synonymously. In 1980 the World Health Organisation published the results of this work in the form of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) which provided a more consistent definition of the terms involved (WHO, 1980). In this classification, impairment referred to abnormality in the structure of the functioning of the body, whether through disease or trauma; disability referred to the restriction in ability to perform tasks, especially those associated with everyday life and self care activities; and handicap referred to the social disadvantage that could be associated with either impairment and/or disability. The latter term was particularly emphasised as a means of revealing needs created as a consequence of chronic illness interacting with a sometimes hostile social environment.

The widespread use of this schema helped focus the socio-medical model that earlier work had been building, and provided the basis for both developments and debate in the years that followed. Community based studies, such as that in Lambeth, South London, provided the framework for the exploration of prevalence of impairment, health care and rehabilitation needs in disability and social aspects of handicap, such as material hardship and the role of social support. This kind of research helped to explore the mediating relationship

between the various planes of experience that the WHO schema described (Patrick and Peach, 1989).

National and local studies underlined, in particular, the economic dimensions of disability, and the hardship experienced by many, particularly in a period of growing recession. Though the Harris survey had been associated with the 1970 Chronically Sick and Disabled Persons Act, which for the first time obliged local authorities in Britain to estimate and meet the needs of the disabled, various research findings reinforced the view held by Mechanic and others in earlier U.S. work, that the consequences of disability were most obviously seen in financial hardship. In fact, a less well publicised volume of the Harris study revealed the extent of financial hardship among the disabled (Harris et al., 1971b). Townsend's compendious work on Poverty in the United Kingdom gave additional weight to the link between disability and inequality (Townsend, 1979).

Though the socio-medical model provided the grounds for identifying and drawing attention to the various needs of disabled people, many problems remained. At the research level, it had long been recognised that the definition of disability, unlike disease was less categorical and more 'relational' in character. It was pointed out that the term disability was conceptually 'slippery' and difficult to pin down (Topliss, 1979), and involved complex interactions between the individual and the social environment. Moreover, the boundaries between impairment, disability and handicap were recognised as less than clear cut in everyday settings, and difficult to operationalise in research, even though the distinctions remained important in directing attention to different planes of experience (Bury, 1987).

At the policy level, though the consequences of disability were being identified, financial compensation and greater emphasis on disabled people's own views was not much in evidence. In part this arose from the continuing part that medicine played, within administrative circles, in adjudicating access to benefits. In order to tackle this problem, and provide new estimates of disability based on a broader definition, a new national study was commissioned by the OPCS in 1984, and several surveys, including one on children, were carried out between 1985 and 1988. The main purpose of this new initiative was to inform a review of social security in the disability field, and pave the way for

such benefits to be based on a more systematic appreciation of the relational character of disability.

As a result of this orientation, the OPCS developed an approach to measuring disability which would be more sensitive to the difficulties encountered in earlier work. By combining judgements of professionals, researchers and disabled people themselves, and by using the basic definition of disability as laid down in the WHO classification, the OPCS was able to operationalise a new approach that gave a wider picture. Scales were developed on key areas of disability ranging from problems with locomotion, through seeing, hearing and personal care, to difficulties with communication (Martin et al., 1988, p. 10).

The development of these scales, at the pilot stage, was conducted in close co-operation with groups involved in disability at the time. A large number of people and organisations was invited to comment on the pilot interview-based questionnaires. A somewhat smaller number was involved in consultations in actually developing the scales, including, for example MIND, MENCAP, Royal National Institute for the Deaf (RNID), the Disablement Income Group (DIG) the Disability Alliance and the Royal National Institute for the Blind (RNIB) (Martin, 1995). By focusing directly on the nature and impact of disability on everyday life (but not on impairment) this approach shifted the centre of gravity of the socio-medical model towards defining the severity of disability in terms of its effects, including, again, employment and financial difficulties.

For present purposes, two main findings are of note. First, the association of disability with age was once more confirmed. This is of particular importance in the OPCS survey, which was innovatory in assessing the level of disability without, at the point of interview, an age reference; in other words, if a person could not perform a particular activity they were counted as disabled irrespective of age. However, when the data from the survey were analysed, they showed that of six million people living in Great Britain with at least one form of disability (based on the relatively low threshold used in the survey) almost 70% of disabled adults were aged 60 and over, and nearly half were aged 70 and over (Martin et al., 1988, p. 27). The very old emerged as those most likely to be affected, with 63% of

women and 53% of men over the age of 75 being disabled. When severity is taken into account, the very old again predominate, with 64% of adults in the two highest categories aged 70 or over, and 41% aged 80 or over (Martin et al., 1988). I will return to the significance of some of these findings later in the chapter.

For the moment however, it is the predominance of chronic disease as the cause of disability, which is of particular note in the OPCS study. Many of the disorders associated with later life, especially arthritis, and hearing loss (the former helping to explain much of the gender difference in disability rates) were most frequently associated with disability, underlining the long term trend away from disabilities caused by trauma and medical conditions in early life, to disorders in later life.

Important though this study was in developing and improving the picture available from the Harris study, the role of chronic illness in the findings did expose one of the tensions to be found in work of this kind. For, no matter how justifiable the attempt is to influence the direction of the operation of welfare, and notably social security, away from medical adjudication, a full picture of disablement in contemporary populations inevitably exposes its health and illness dimensions. From the viewpoint of everyday experience, therefore, different aspects of health and welfare needs may be relevant. Moreover, these dimensions have implications for different forms of intervention on the impairment, disability, and handicap continuum. The presence of chronic illness as a causal factor in disability may highlight the need for greater attention to preventive measures, better delivery of health care and medical treatment, the provision of home adaptations, or the need for financial or social support.

Some needs may, therefore, be condition specific, depending upon the particular illness or impairment concerned. A follow up study by the RNIB, for example, involving further interviews with a sample of visually impaired people from the OPCS survey, and a more detailed analysis of the relevant OPCS material, was able to provide a more in depth picture of the special needs of people with visual impairments, including their health needs (Bruce et al., 1991). The relationship between the general profile of disability and the specific needs of groups within the population clearly needs to be appreciated.

This issue, for sociologists, at least, has underpinned their growing concern with the meaning of disability, and not simply its definition or prevalence. Alongside work on the socio-medical model, therefore, a more independent sociological voice began to emerge. This set out a more distinctive research approach, in comparison with the medical and policy agendas, which had dominated the field until then. This approach began to apply more explicitly sociological concepts to the area.

In Britain, Mildred Blaxter's book *The Meaning of Disability* (Blaxter, 1976), and in the U.S., Strauss and Glaser's book, *Chronic Illness and the Quality of Life* (Strauss and Glaser, 1975) captured the spirit of these concerns. Using different methods, both books explored the range of problems encountered by people with disabilities. In the case of Blaxter's book, she showed that over time the impact of disability on social life was particularly marked, even when other more practical problems had been resolved. She also showed how the complicated relationship between health and welfare systems hampered individuals and their families in adapting to disability. Strauss and his colleagues looked particularly at the balance people sought to strike between the demands of illness and treatment regimens and the need to maintain a normal everyday life.

Since these pioneering studies, more sociological work on specific disabling illnesses have now been undertaken, documenting both the problems people face and the active steps they take to overcome them. The emphasis on meaning in this work has revealed, in more depth, the issues that people find most difficult in adapting to in disabling illness. Such studies have also highlighted the constraints of societal responses and the availability or the lack of resources needed to tackle them (Bury, 1991). The exploration of the contextual and emergent nature of disability in sociological work of this kind has acted as a counter point to the more formal definitions and assessments in the socio-medical model, as described above.

However, despite, or perhaps because of this wider body of work, in both the U.S. and U.K., new challenges have developed, not least from among people with chronic disorders and disabilities themselves. As services and research have expanded so the

boundaries that have separated fields of activities, notably those between professionals and patients/clients have shifted. And as numerous sources of information have emerged these have inevitably provided grounds for more critical perspectives to develop. Indeed, under conditions of information explosion and media interest, as Anthony Giddens has pointed out in a more general cultural context, experts and expert knowledge become 'chronically contestable' (Giddens, 1991).

Though the field of chronic illness and disability has long contained a large number of lay charitable and self help groups, whose interests and views have often departed from those in the medical and academic establishments, new forms of organisation and outlook have recently emerged. While some groups, especially those linked to specific chronic diseases, continue to concentrate on supporting medical and, to a lesser extent, social research, others have begun to adopt and develop a more critical position with respect to both the definition and study of disability.

The emergence of the 'disability movement', characterised by an increasingly challenging attitude to the discrimination and 'exclusionary practices' which have historically affected the disabled in modern society, has gained considerable momentum. New forms of political, educational and professional activities have proliferated as expressions of these developments. In addition, help lines, lobbyists, and rights activists, have provided numerous opportunities for challenges to existing policies and practices to gain ground. Many of these activities have drawn on a range of writings that seek to confront current research. For example, a special issue of *Disability, Handicap and Society* was given over to the topic in 1992, following a conference supported by the Rowntree Foundation. It is to the main lines of the criticisms found here and elsewhere that the chapter now, therefore, turn. Following a brief outline of the definitional and theoretical issues addressed in these recent arguments, the implications for social research are then addressed.

## **DISABILITY AS A FORM OF SOCIAL OPPRESSION**



Perhaps the sharpest challenge to existing ideas about disability is the argument that disability should be seen as a form of 'social oppression' (Oliver, 1990; 1992). Although this term is not clearly defined, the basic position is clear. In contrast to existing notions of disability, which, it is argued, portray it as a characteristic of individuals, 'disability' is seen, instead, as a wholly social phenomenon. Mike Oliver, whose writing may act as an exemplar in this context, states, for example, that 'disability as a category can only be understood within a framework, which suggests that it is culturally produced and socially constructed' (Oliver, 1990, p. 22). 'Disability' is seen to be a function of those practices and perceptions linked to certain bodily mental or behavioural states which are so designated. Here the ICIDH definition of 'disability' is rejected, in favour of an approach which at times is similar to that of the ICIDH definition of 'handicap', that is, the social disadvantage experienced by disabled people.

From the 'social oppression' viewpoint, disability is not the resulting limitations caused by chronic illness, impairment or trauma, but the way such matters are responded to and categorised by the wider society. Disability is the product of definitions and practices that seek to exclude individuals who might be seen to deviate from the socially constructed norms of the 'able bodied'. In short, 'disability' is what a 'disablist' society decides so to call. The links with labelling theory developed by sociologists in the 1960s are immediately apparent in such an argument. It is not the 'inherent' nature of disability that matters, but the labelling process, which categorises people by virtue of their position in relation to the dominant structures and values of the society.

The important starting point for 'oppression theory', is that 'disability' should not be conceptualised as an individual attribute, but as the result of 'exclusionary practices'. In a capitalistic society, these designate which attributes are seen as productive and acceptable and which are abnormal or deviant. Definitional questions, according to this argument, therefore flow not from the 'personal tragedy' of disability, but from the needs of the social system to distinguish between people in industrial and educational environments, and the need to decide who is to be excluded or segregated (Oliver, 1990, p.28).

State involvement in people's lives, throughout the modern period, is seen to be preoccupied with the sorting and segregating of individuals, especially in terms of their abilities to meet the dictates of the work place, and, in general, to ensure that social order is maintained by regulating exclusions in matters such as eligibility for state benefits. Thus disability turns out to be a central rather than peripheral matter to the development and maintenance of modern welfare states (Stone, 1984; Albrecht, 1992).

In addition to the 'exclusionary practices' that result from this process, the tendency to portray disability as a feature of the individual, it is held, reinforces an 'ideology of individualism'. This, to stay with Oliver's argument, is held to be at the heart of our current concepts. In extending his 'political economy' view of disability, to cover this point, Oliver argues:

'It is not the ideological construction of property owning, self interested or rational individuals that is important (in discussing disability). Rather it is the construction of "able bodied" and "able minded" individuals which is significant' (Oliver, 1990, pp.45-46).

The 'theory of medicalisation' is then added to this approach in order to explain the role of medicine in regulating and managing disability. Rather than accepting medicine as a means of meeting the needs of individuals, Oliver, again, casts medicine's role as essentially the handmaiden to the capitalist order. Referring to Zola's (1972) theory of medicalisation and social control, Oliver argues that medical labels 'stick to some groups and not others'. This process is held to be a function of the ideological and material needs of the system, rather than the health and welfare needs of individuals. Indeed the latter act as a screen behind which discriminatory practices take place. In this sense, the argument that medical knowledge is 'socially constructed' (Bury, 1986) is also invoked.

Given the apparent lack of effective treatment for many chronic disorders, the only explanation Oliver can find for medicine's involvement in disability is a regulatory and 'imperialistic' one. Though the expanding role of medicine, including surgery, in treating

a variety of different 'impairments' is left unclear, Oliver echoes Finkelstein's employment of the idea of 'medical dominance' of disability to account for the development of specialisms such as rehabilitation medicine (Finkelstein, 1980). In so doing such writers draw on a range of medical sociology writings from the nineteen seventies which, as Gerhardt (1989) has noted, portrayed medicine as the result of the (largely arbitrary) artful practices of the medical profession, rather than as the application of objective knowledge to the patient's condition. In an attempt to turn the tables on this process Oliver asks, 'who should be in charge of the rehabilitation process, disabled people or the professionals?' (Oliver, 1993, p. 61).

## **RESEARCHING DISABILITY**

As has been stated, one of the purposes of this chapter is to trace how these critical ideas about disability are being applied to the area of research. Perhaps one of the first questions that arises, in this connection, is why 'disability theorists' should be particularly concerned with research in the first place. If disability, from a 'social oppression' viewpoint, is self evidently entirely 'social' and therefore 'political' in character (Oliver, 1992) a social movement espousing such a position might well be expected to concern itself primarily with political action against a 'disablist society' and use social research findings, wherever possible, for these purposes, rather than focus on the activities of research and researchers as such. Indeed, Oliver has done precisely that, using the OPCS study and its estimates (which, as I will show, has been severely criticised elsewhere by 'disability theorists') in support of disability rights (Barnes and Oliver, 1995).

In fact, disability groups have long adopted this approach, in their campaigning as the reference to the RNIB earlier in this chapter indicates. Others, such as the Disability Alliance, have long used the research findings of Townsend and others in pamphleteering, campaigning and advancing their case. Recent campaigns for 'disability rights' legislation in the British parliament have employed similar tactics. It could be argued that in such activity, challenging definitions and research approaches has not been a high priority. The majority of those arguing for disability rights seem more concerned

with other, more substantive issues. The position of 'disabled people' has been advanced without the need for a radical 'deconstruction' of the term, as defined, for example, by WHO/ OPCS. These 'second order' constructs have not been the focus of concern. It seems that appeals to generally accepted definitions of disability, rather than 'social oppression' theory, have been more than adequate for the political tasks in hand.

However, the role that medical and social research has played in the recent history of disability is often held by others, especially the 'disability theorists', to be negative and part of the problem to be addressed, rather than a potential (if limited) part of its solution.

As a result, 'disability theorists' have developed critiques both of the putative effects of recent research, and the research process itself. In so doing they have drawn links between their general critiques of the variety of professional discourses on disability, and recent research activities. Here, both medical and social research have become the focus of 'struggle', because they have been seen, like other professional activities, as largely self serving. As Oliver has stated:

'The idea that small groups of "experts" can get together and set a research agenda for disability, is again, fundamentally flawed' (Oliver, 1992, p. 102).

This suggests that 'disability theorists' should extend their arguments to fashion a different research agenda and possibly a new methodology. Whilst this immediately opens up the possible counter charge that 'disability theorists' may be making a similar play to establish themselves as a groups of 'experts' - especially as many now hold university posts, and run research projects and units - the main thrust is to argue a strong case against the activities of the present research community.

Current research on disability, it is held, is grossly unsatisfactory for two main reasons. First, it is alleged that most, if not all, research in the area is an alienating experience for disabled people. Though, as far as I can see, this charge is not supported by any systematic empirical evidence, it is forcibly argued from first principles that, as the disabled are the object of research rather than its authors, 'almost

all social research has been alienating' (Oliver, 1992, p. 103, quoting Rowan, 1981). Because, it is held, the disabled themselves have not carried out the research, this is taken to mean that its execution is wholly negative. Though it would be difficult to know, in most cases, of course, whether individual researchers were or were not impaired or disabled (Oliver and others write as if they know that all previous research was carried out by the 'able bodied') this is held, importantly, by 'disability theorists' to add to the sense of exclusion and oppression, identified in the general critique of disability as it is currently defined. Although it is not at all clear what this might mean, from here it is a short step to argue that research on disability should only be carried out or controlled by disabled people themselves (Zarb, 1992).

Second, the effects of research in terms of its impact on policy is also seen as largely or wholly negative. The WHO and OPCS approaches have attracted particular opprobrium, from broadsides by Finkelstein (1980) onwards. According, to Oliver, for example, in discussing the OPCS study:

'despite promises to the contrary, the Government has failed to take any coherent policy initiatives based upon it (i.e. the OPCS survey)' (Oliver, 1992, p. 103).

One reading of this comment could be that it suggests that the government could have taken policy initiatives, and that it is the politicians who are at fault. It appears that broken promises rather than poor research are the problem here. Moreover, it would also seem to follow from this, that in such a political climate, a more 'radical' style of research might run into even more difficulties at the political level. In either case, criticism of the research and of the researchers would not seem to be, in principle, the key issue, but the lack of action by governments, on the evidence they have paid to be collected. In fact, the OPCS survey did have an impact on policy in the U.K., especially in the formulation and implementation of the Disability Living Allowance (DLA) and the Disability Working Allowance (DWA). The DLA has increased the number eligible for benefit on the lower threshold set by the survey, and medical tests for the DWA now use functional scales and everyday language; only in extreme cases is reference made to medical conditions.

However, the OPCS survey, in particular, has continued to come in for intense criticism from 'disability theorists', and, it should be noted, other lobbying groups in the field, including some of those who were not just 'the object' of enquiry, but participated in it. Even though, as argued earlier, the survey was based on a more detailed appreciation of the perceptions of disabled people themselves, in comparison with any previous equivalent study, this has not been accepted by the critics as a sign of progress. Thus, research of this kind has been held to be at best useless and at worst a further source of 'oppression'.

The background to this takes us back to the underlying conception of disability discussed earlier. While critics such as Finkelstein and Oliver recognise that research endeavours such as Harris's 1971 survey, Wood's WHO classification and the OPCS survey contain a social component, they remain dismissive of them because, they argue, such 'research is based on the idea that disability and handicap arise as a direct consequence of individual impairments' (Oliver, 1990, p.7). This argument is advanced despite the fact that the WHO approach expressly underlined the complexities of the relationships between the different dimensions, and that the disability movement's own conception of disability also begins with some form of underlying impairment, whether through disease or trauma. French (1993), for example, has made the point that though she agrees with:

'the basic tenets of the ('disability theorists') model', she believes, 'that some of the most profound problems experienced by people with certain impairments are difficult, if not impossible, to solve by social manipulation' (French, 1993, p.17).

Here, French seems to recognise the dangers of an 'oversocialised' view of disability, creating a reductionist perspective in its zeal to exclude the role that different factors plays.

In fact, the idea that impairment and disability are closely related, but distinct proves difficult to reject. Without some underlying initial problem, social responses would, so to speak, have nothing to respond to. If labelling theory is invoked, some form of 'primary

deviation' is necessary, if societal reactions are to have any meaning. Labels have to be attached to a restricted range of phenomena if they are to be effective (positively or negatively) as labels at all. Moreover, while the role of impairment (especially as the result of chronic illness) was clearly conceptualised in the WHO approach, this was not the most important aspect of the schema. It was the emphasis on handicap which mattered most, in its attempt to point to the social disadvantage which may result from the social reactions and conditions within which disability is experienced.

As mentioned earlier, as a result of the 'relational' character of the processes at work, the distinctions between disability and handicap are inevitably problematic (Bury, 1987). Both disability and handicap can be seen as a product, from this viewpoint, of the interaction of the individual and the social environment. The distinction between them is simply designed to direct attention to the different dimensions of experience, that is, the difference between restricted activity (which, following French's comment, may be more or less 'social produced' in character) and related social disadvantage. Without such a distinction, the ability to know that disadvantage has increased or reduced would be difficult indeed to establish. The 'disability theorists' critique, however, rejects this distinction and asserts that disability is wholly a product of social circumstances.

Once this uni-dimensional view of disability is adopted, the next step in their critique of research is fairly easily taken. If research is based on an unacceptable definition of disability, all research which fails to adopt the 'disability theorists' conception becomes a target as part of the 'oppression' of disabled people. This reinforces the argument that research should be a field of struggle in which 'disability as oppression' can be produced or resisted.

Oliver states:

'This view (the WHO approach to research) can and does have oppressive consequences for disabled people and can be quite clearly in the methodology adopted by the recent OPCS survey in Britain' (Oliver, 1990, p.7).

In order to develop this argument, Oliver then goes on to examine in some detail the questionnaire items from the OPCS survey. It may be helpful at this point to follow his line of attack. The questionnaire, he contends, contains items such as:

- Can you tell me what is wrong with you?
- How difficult is it for you to get about your immediate neighbourhood on your own?
- Does your health problem/disability make it difficult for you to travel by bus?

Oliver comments:

'These questions clearly ultimately reduce the problems that disabled people face to their own personal inadequacies or functional limitations' (Oliver, 1990, p.7; see, also Abberley, 1992, p. 140).

In fact, the first of the above 'questions' was not actually part of the survey proper, and was not coded, being used only to establish the terms in which individual respondents normally talked about their disability. However, though it is hard to see how the construction of 'personal inadequacy' can simply be read off from the other questions about transport and work difficulties, specifically designed to elicit people's problems in working and moving around, a critical view of the precise nature of the questions and the assumptions on which they are based is, of course, a justifiable exercise. However, instead of analysing these questions in any detail, especially in relation to the aims of the survey, Oliver goes on to put forward an alternative set of questions, based on the 'social oppression' approach. These, Oliver argues, would include such questions as the following:

- Can you tell me what is wrong with society?
- 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? (Oliver, 1990, p.8).

While we might wonder just what sort of answer a researcher might expect to the first (presumably ironic) question; 'What is wrong with society?', and how this might help in a study of disability, the other examples do offer a more persuasive alternative to the OPCS approach. But these questions, in turn, raise similar difficulties to those they replace. The second alternative question about transport, for example, could be asked of anyone and therefore loses its value as a question about disability. In order for the question to work, the respondent would need to have a prior and identified 'health problem/disability' in order to be the focus of research in the first place. If this is not accepted, then the idea that 'the disabled' should have control over the research process evaporates. If it is, then some prior question about what is 'wrong' with the person seems inescapable. In both contexts 'disability' must have some degree of independence from the social consequences associated with it.

The recognition of the role of impairment, alone, does not circumvent these dilemmas. Without a working and restricted definition of disability involving activity restriction, the strong form of relativism in the 'social oppression' approach threatens to negate any meaningful form of enquiry, as it seems to refer to any form of difficulty that the 'disability theorists' wish to include. Asking people in the general population about transport problems, for example, is hardly likely to form the basis of effective, let alone radical action to reduce 'disabling barriers'.

Moreover, there is not much point asking such people about specific issues, such as the design of buses, or other environmental barriers if they present no problem. Indeed the third example alternative question on bus design, given above, has to mention, if it is to make sense at all, the person's 'health problem or disability'. The inadequacy of buses can only be judged (and, indeed campaigned against) if there is good evidence of what they are inadequate for, and this inevitably takes us back to disability among people in specific contexts. Poorly designed buses do not in this sense create or construct disability. If a person has difficulty climbing steps as a result of paraplegia or arthritis, for example, the presence of steps on buses

has not created the person's disability, in the sense of reduced mobility. What it means is that these technologies have not been designed to help the disabled person have access and overcome mobility restriction.

I think it also has to be recognised that while `struggles' over which barriers need to be tackled and to what extent they can be overcome or removed is the understandable focus of political arguments and action, they raise all manner of problems about the different needs, interests and values in different social groups, including those among the disabled. The removal of some barriers might be at the expense of tackling others, as one group may articulate their needs more effectively. For example, the elderly chronically sick and disabled have traditionally had less of a voice than younger people. For older people, resources spent on removing some barriers may be of less importance than resources for care in the home. Rolling up the different aspects of disability into the one dimension of `oppression' fails to recognise these potential differences, which carefully conducted research is likely to reveal.

This also suggests that the alternative form of questioning in survey research, advocated by Oliver, may make sense to some disabled people but not to others. Diversity in experience arguably cuts across an approach to research methodology directed by an ideological argument about `oppression'. From this viewpoint the alternative approach advocated by Oliver and others, in opposition to survey work such as that of the OPCS, all too often reads like a list of somewhat confused `politically correct' statements about the position of disabled people. Challenging though these may at first sight seem, the present discussion suggests that they do not provide a thought through alternative research strategy, or an adequate approach to the diverse views and experiences of disabled people in different contexts.

The idea of research as a field of `struggle' becomes even more complicated as attacks on qualitative social research are added to the campaign of `disability theorists'. Survey work, such as the OPCS study, carried out by epidemiologists and government departments is in one sense a readily identifiable target, partly because it exemplifies a `positivist' approach, and can be seen as part of official medical and

state responses to disability (Abberley, 1992). Qualitative research however, carried out largely by sociologists, presents a slightly different challenge to 'disability theorists', and has received separate attention because of the difficulty identifying, 'which side is it on?' (Becker, 1963; Oliver, 1992).

Though sociologists may have thought that they were dealing with chronic illness and disability from the patient or person viewpoint, and especially, as argued earlier, addressed its meaning in a social context, these assumptions are also now being challenged by the 'theorists'. Far from bringing new perspectives to bear, it is argued, qualitative research has not addressed which side it is on; the world of the disabled or the world of the expert. Although interpretive or qualitative research in this area is recognised as a possible improvement on the 'dominant' positivistic paradigm, all is, unfortunately, not well here either. According, again, to Oliver:

'Interpretive research has still a relatively small group of powerful experts doing work on a larger number of relatively powerless research subjects. To put the matter succinctly, interpretative research is just as alienating as positivistic research because what might be called the "social relations of production" have not changed one iota' (Oliver, 1992, p. 106).

While many sociologists may be surprised to see themselves regarded as 'powerful experts' the intention is clear. In order to bring about a change in research activity and method, a new kind of research is called for; 'what has variously been called critical enquiry, praxis or emancipatory research' (Oliver, 1992, p.107). Because, it is held, previous research has made no difference to the position of disabled people, and brought about no beneficial results, a new 'emancipatory' approach is called for which:

'is about the facilitating of the politics of the possible by confronting social oppression wherever it occurs. Central to the project is a recognition of and confrontation with power which structures the social relations of research' (Oliver, 1992, p. 110).

Qualitative social research as much as survey work is now being exhorted, therefore, to abandon its existing orientation and join the struggle against 'social oppression'. Definitional and research issues are now being linked together in a common endeavour, in which researchers of any hue are being asked to put themselves and their skills at the disposal of the 'theorists' and their particular approach to disability politics.

## **THE FUTURE OF RESEARCHING DISABILITY**

The scene is set, therefore, for a lively period in both 'official' research and sociological work. It appears that this may involve a struggle for influence, and possibly control over the direction and funding of research in disability. Quoting Gollop (cited in Oliver, 1992), Oliver has argued that the new emancipatory paradigm should be based on 'reciprocity, gain and empowerment'. In effect this means that, 'researchers have to learn how to put their knowledge and skills at the disposal of their research subjects' (Oliver, 1992, p.111). In this way a new research agenda will, apparently be fashioned. Moreover, research relationships, as expressed in traditional social research methods, are likely to be the focus of considerable critical debate.

Partly as a result of these developing arguments and criticisms (though also for other reasons) researchers are already coming under greater pressure to examine their assumptions and methods. In many respects this is to be welcomed, and is already having the effects of bringing 'client' and patient groups into the research process. However, this chapter has said enough to suggest that there are also grounds for concern with the alternatives being argued. Two main reservations about their implications for research relationships may act as an appropriate conclusion to the present discussion.

First, this chapter has tried to show that the 'social oppression' approach to disability is open to the criticism of reductionism, especially as an 'over socialised' conceptualisation of the processes at work. If this is accepted, the models it seeks to replace may be of continuing use, both in research, and in the policy process. There is a danger, in adopting the 'social oppression' approach of caricaturing

alternatives, and generating hostility where collaboration and rational debate would be of greater value. While the relationship between researchers and the researched is always a sensitive issue, and needs to be approached with care, it is difficult to sustain the argument, that either survey methods or qualitative research in themselves are inherently 'alienating'.

Second, the idea that research should become a site for 'struggle' suggests a politicisation of research that may have a number of unintended consequences. While it may be taken as axiomatic that individuals have a unique insight into their own experiences, it does not logically follow that they are qualified or able to undertake research. Moreover, such a view also runs the risk that the status of being disabled should be the main criteria for carrying out research on the subject. This sits uneasily in an argument in which the very idea of 'disability', as a defining characteristic of individuals, is being challenged.

Taken to its logical conclusion this could also mean a direct threat to the independence of research. Given the political climate in which we now live, this argument needs to be approached with caution. The independence of research has long been guarded by researchers, and others, including the disabled. Independence in this context does not mean a lack of engagement with social issues, or a naive view of 'value free' research, or most importantly an unwillingness to work closely with those being researched (Bury, 1996). What it does mean, though, is that research findings need to be based on the use of 'publicly available methods' (Hammersley, 1992) if they are to withstand hostile scrutiny, especially by governments. Threats from neo-conservative sources to social research have seriously reduced this independence throughout the 1980s and 90s. Margaret Thatcher, in particular, was associated with a view that research should serve political interests. It would be an irony indeed if 'disability theorists' in emphasising empowerment and autonomy of people with disabilities were to add to this trend. Instead, a process of open debate and mutual tolerance would seem to offer a more productive way forward.

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