

**Chapter 1 (in 'Exploring the Divide: illness and Disability', edited by Colin Barnes and Geof Mercer, Leeds: the Disability Press, 1996, pp.11-16).**

## **INTRODUCTION: EXPLORING THE DIVIDE**

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### **BACKGROUND**

The notion that disablement is a medical problem which affects only a small proportion of the population can no longer be sustained. In the 1980s, Government social survey figures suggested that 6.5 million people had at least one 'disability' (Martin, Meltzer and Elliot, 1988). A more recent study concludes that four out of every ten adult women and men have a 'long standing illness or disability' (CSO, 1996). Internationally, there are around 50 million disabled people in Europe (Daunt, 1991) and approximately 500 million world-wide (DPI, 1992). Although there are significantly more disabled people in the under-resourced, 'developing' nations of the world, the prevalence of disablement is greatest in wealthier, developed societies (Helander, 1993). Moreover, the combination of an ageing population and new medical interventions which prolong life will ensure that the number of people with an 'impairment' or 'chronic illness' will increase substantially over the next few years. The economic, political, and social implications will be far-ranging (Hills, 1993).

The impact of disablement has stimulated a growing literature, both personal and academic, on 'chronic illness' and disability. Since the 1960s, there has been an extraordinary expansion of self-help groups and organisations controlled and run by disabled people, on a world-wide basis (Driedger, 1989). In the UK, this mobilisation of disabled people led to the emergence in 1981 of the British Council of Disabled People (BCODP), which now represents 113 national and local organisations and has a membership of over 400,000 disabled individuals (BCODP, 1996). There has been a parallel emphasis on political campaigns and demonstrations. At the same time disabled

people have developed alternative perspectives to the traditional individualistic approaches to 'disability' which highlight the ways in which the medical condition constrains their daily lives. Through their actions, disabled people have sought to re-direct attention to the means by which individuals are 'disabled' by society. The focus is shifted to the level and character of social and economic disadvantage and discrimination experienced by disabled people.

Yet while there has been this politicisation of disabled people, an increasing division has emerged between 'disability theorists' and social scientists studying chronic illness, such as medical sociologists. The tendency has been to provide separate and competing, rather than joint, accounts of illness and disability. The tensions were amply illustrated in a panel discussion on chronic illness arranged during the British Sociological Association's Medical Sociology Annual Conference in 1992 (Bury, 1992). Considerable unease was expressed at the activities of disability theorists and their organisational allies, and the threat posed to the 'independence' of sociological researchers. Medical sociologists also voiced concern that disability theorists ignored complex issues in the interpretation and explanation of chronic illness and impairment in favour of political correctness and political campaigning. The trend was towards competing and more entrenched positions, whether in respect of language, theoretical approach, methods of inquiry or empirical conclusions.

It was against this background that the editors organised a conference in Leeds in April 1995 on the subject of Accounting for Illness and Disability. It is the participants in that event who provide the backbone to this volume. In order to contextualise these discussions, a brief review of the approaches to chronic illness and disability taken by medical sociology and disability theory will be provided together with an overview of the individual chapters.

## **MEDICAL SOCIOLOGY AND CHRONIC ILLNESS**

The sociological analysis of health and illness typically takes as its starting point a distinction between the medical concern with disease as an abnormal bio-physical condition and its own focus on sickness

as a social state. In sociological accounts, people's experience of ill-health encompasses much more than specific physiological symptoms. It extends to different levels of experience and the social meanings of illness. Two theoretical perspectives have dominated these studies: one functionalist, the other interpretative. In addition, a wide range of empirical investigations have been conducted, some influenced by a largely medical agenda, including work on the prevalence and character of chronic illness, and on patient compliance, and others interested in its associated social problems.

Talcott Parsons provided the primary stimulus to sociological theorising with his application of a functionalist analysis to a study of health and sickness (Parsons, 1951). He treated individual 'health' as central to effective task performance and the overall well-being of contemporary American society. In general terms, it was necessary for society to control those who deviated markedly from its central values and social structure. Hence, the functional significance of dealing with sickness in such a way as to eliminate any 'unconscious motivation' by individuals to avoid recovery and a resumption of their regular social obligations (Gerhardt, 1987). To obviate this particular possibility for social deviance, a special and conditionally legitimate status or 'sick role' is established, where individuals are temporarily located. As formulated by Parsons, the sick role includes both responsibilities and privileges. Thus, the sick person is not held responsible for their condition, and is granted exemption from fulfilling their 'normal' social obligations. In return, the sick person is required to take all appropriate steps to ensure their recovery, including consulting a medical practitioner.

The Parsonian approach has attracted considerable criticism within sociology (Freidson, 1970; Gerhardt, 1989). The notion of a universal role available to all sick people has been widely disputed. It has been demonstrated that access to, and granting of, the rights and privileges of the sick role are mediated by the social status and structural location of the sick person, including their gender, 'race'-ethnicity and social class. Moreover, exemption from normal social obligations is sometimes partial rather than general. A considerable literature has also developed from suggestions that some illnesses are stigmatised - perhaps the individual is 'blamed' for their condition, or the disease instils a generalised fear and dread (Goffman, 1968).

Whatever the reason, the rights and privileges of the sick role are not, or only partially, granted (Freidson, 1970). A further criticism has been that Parsons wrongly narrowed the application of the sick role to 'patient' behaviour rather than the overall illness experience. Following the latter route, particular significance is accorded to studies of lay beliefs and networks (Zola, 1973). And, not least, the very notion of chronic illness runs counter to the temporary status of the sick role.

While attempts have been made to refurbish role theory, most recent studies of chronic illness have drawn inspiration instead from other sociological frameworks. The attack has been led by those located in an interpretative tradition, in particular phenomenology, which highlights the experiential aspects of illness and its underlying assumptions (Strauss & Glaser, 1975; Bury, 1982). Research has documented the ways in which chronic illness influences daily living, social relationships, and people's sense of self and identity. Analysis has centred on how individuals balance the demands and uncertainties of chronic illness and its associated treatment regimes with the attempt to maintain everyday social routines. The focus has been on the meaning and experiences of chronic illness, and how far, and in what ways, people adapt to, and cope with, these constraints. In contrast to the socio-medical model, which concentrated on formal definitions and the assessment of needs, interpretative accounts have highlighted the emergent and contextual dimensions of chronic illness. The research interest has been on the ways in which the individual makes sense of their illness, and how their understandings influence social action (Anderson & Bury, 1988; Bury, 1991).

In order to understand the meanings people attribute to chronic illness, its trajectory and consequences, interpretative studies have sought to examine how these experiences are woven into individual biographies. From this standpoint, chronic illness is represented as not simply a physical challenge, but as having a more far-reaching potential for 'biographical disruption':

'First, there is the disruption of taken-for-granted assumptions and behaviours....Second, there are more profound disruptions in explanatory systems normally used by people such that a fundamental re-thinking of a person's biography and self-

concept is involved. Third, there is the response to disruption involving the mobilisation of resources in facing an altered situation' (Bury, 1982, pp. 169-70).

The reference to individual biography implies a close link between meaning and context. Following this line of analysis, Bury (1988) distinguishes between meaning as 'consequence' and as 'significance'. The former is concerned with the 'problems which chronic illness and disability create for the individual' (p.91), such as difficulties in employment, with money, and in self-care. In an early illustration of this approach, Mildred Blaxter (1976) explored the meaning of 'disability' and its impact on social life, as well as the ways in which health and welfare systems constrain individuals. In contrast, 'meaning as significance' refers to the cultural representation of different conditions, and how the imputed stigma or other perceptions impact on individuals. Nevertheless, these meanings are not fixed or guaranteed, but are periodically 'put at risk' and perhaps revised as they are 'tested' in everyday interaction.

There is a direct link here with the work of medical sociologists in facilitating and applying the World Health Organisation's International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980). This scheme provides a framework for exploring how the effects of impairment or chronic illness 'create both activity restriction (disability) and social disadvantage (handicap)' (Bury, 1988, p. 91). The intention was to conceptualise the consequences of chronic illness in such a way that practical and policy issues would be more easily identified. In practice, the widespread adoption of the WHO classification by medical sociologists stands in sharp contrast with its rejection by disability theorists. While sociologists believed that the ICIDH gave a clearer conceptual focus to the social disadvantages experienced by those with chronic illness, their disabled critics dismissed it as exhibiting little significant difference from the medical model. At the centre of the dispute was the question of how far sociological accounts elevated impairment to the determining 'cause' of disablement.

The portrayal of chronic illness by medical sociologists has also been criticised by disabled people as all too often a one-dimensional catalogue of negative consequences and meanings - the stigma,

`loss of self' and dependence - and the generally defensive coping strategies and manoeuvring. Studies which suggest a more diverse experience, or which report a positive sense of self and creative involvement in the lives of disabled people are far less in evidence. At the same time, medical sociology has tended to investigate all impairments, including stable visual or hearing impairments, from an illness perspective.

The impact and dominance of the interpretative approach in studies of chronic illness is a further source of disagreement. It is a matter of debate within medical sociology whether such research gives undue weight to subjective meanings and too little attention to wider structural forces. But it is noteworthy that non-interpretative theoretical perspectives have not made anything like the same significant or enduring contribution to the study of chronic illness. This particularly applies to studies of chronic illness and impairment in a broader political and economic context. For example, the analysis of medicine as an institution of social control, and the medicalisation of social problems, has obvious application to the study of disability and disabled people. Similar comments apply to the power and authority exercised by professionals. The Parsonian notion of a benign medical authority has been widely challenged in respect of doctor-patient relations, but sociologists have been slow to explore the potentially conflictual relations between disabled people and the professionals and other `helpers' attached to them. This has led to a perceived disinterest in, and denial of, disability by medical sociology which has provided a powerful spur to the development of disability theory.

## **DISABILITY THEORY AND PRACTICE**

In recent years the sociological approach to chronic illness and disability has been seriously challenged by a radical socio-political perspective that has advanced the `social model of disability'. This was initially developed by a small but influential group of disabled activists during the late 1960s and early 70s (UPIAS, 1975, 1976). An early illustration of this socio-political approach to disability is contained in Paul Hunt's book, `Stigma: The Experience of Disability'; which appeared in 1966. This collection of essays by six disabled

men and six disabled women was one of the first to call for a focus on social rather than biological factors in understanding disability.

It was through such interventions by disabled people, that the grounds for rejecting the dominant 'medical' approach to disability were formulated. Their contention was that disablement should not be attributed to biomedical causes, and that medical or other health professional action was not the appropriate 'treatment' for a social problem. Initially, the social model focused on those with physical impairments, but it has subsequently been extended to include intellectual and sensory impairments. The main thrust of disability theory has been its analysis of the ways in which material and cultural forces have effectively 'disabled' people. Where disability had been treated as if an individual problem that stemmed inevitably from a person's impairment, this is reinterpreted as a socio-political issue. The central concern is the impact of disabling barriers and hostile social environments. The way forward has been to reconceptualise disability as a complex system of social oppression (Abberley, 1987) or institutional discrimination (Barnes, 1991):

'In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation, in every area of life, such as education, work, mobility, housing, etc.' (UPIAS, 1976, pp 3-4).

Disablism enters the political vocabulary on a par with racism and sexism. The further effect of re-defining disability as a social problem is to highlight the significance of developing organisational forms, tactics and strategies in order to advance the interests of disabled people through political struggles. The early inspiration was derived from the civil rights struggles of other oppressed groups, while the mobilisation of disabled people into more overt campaigning activity took off in the 1970s. This pressure from disabled people and their organisations has continued through the 1980s and 1990s, with the recent passing of the 1995 Disability Discrimination Act a sign of the disabled people's movement's continuing vitality (Barnes and Oliver, 1995) .

The generation of the social model of disability and the politicisation of disabled people has been achieved despite what many in the disabled people's movement regard as little support, and often opposition and obstruction, from social scientists and other 'experts'. For example, in Britain, the relationship between poverty and disability was first placed on the political agenda by two disabled women, Megan du Bosson and Berit Moore, when they formed the Disablement Incomes Group (DIG) in 1965. The DIG campaign for a disability income was later joined by a host of other organisations - both 'of' and 'for' disabled people. These came together in 1972 under the umbrella of the Disability Alliance. However, the mobilisation of disabled people exacerbated tensions between disabled activists and non-disabled social scientists. These conflicts surfaced in UPIAS' critique of the Disability Alliance and its dominance by non-disabled academics (UPIAS, 1976). The Alliance was regarded as a forum where others speak on behalf of disabled people, whereas UPIAS aimed for mass participation of the disabled community:

'We reject also the whole idea of "experts" and professionals holding forth on how we should accept our disabilities, or giving learned lectures about the "psychology" of disablement. We already know what it feels like to be poor, isolated, segregated, done good to, stared at, and talked down to - far better than any able-bodied expert. We as a Union are not interested in descriptions of how awful it is to be disabled. What we are interested in, are ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our physical impairments by the way this society is organised to exclude us. In our view, it is only the actual impairment which we must accept; the additional and totally unnecessary problems caused by the way we are treated are essentially to be overcome and not accepted. We look forward to the day when the army of "experts" on our social and psychological problems can find more productive work' (UPIAS, 1976, pp 4-5).

Other signs of the perceived paternalism, if not suspect 'support', were evident in the 1960s. Paul Hunt was again involved: on this occasion in a dispute with the staff of a Cheshire Home over the residents' demands for greater control of their lives (Miller & Gwynne,



1972). Researchers from the Tavistock Institute were called in to investigate conditions in the home. Their proposals for an 'enlightened guardian' approach to disability management provoked considerable opposition among the disabled residents:

'The half concealed assumption that our severe impairments actually cause our social problems is essential for Miller and Gwynne's attempt to justify their concentrating on the task of reconciling us to the inevitability of our social death, and for legitimising their research into how that sentence may most humanely be carried out' (Hunt, 1981, p. 42).

In like fashion, medical sociologists, who had long represented their starting point as a critique of the medical model of health and disease, found that their contribution was downgraded. There was a growing polarisation between social researchers and disabled activists and theorists who identified academic social science as part of the problem rather than part of the solution. The emphasis given to subjectivity and the presumed disregard for structural factors were raised as primary weaknesses in the medical sociology approach. There was little sympathy with the phenomenological interest in the complex contextual negotiation of everyday life, of identity and interaction, and the importance of treating the relationship between impairment and 'disability' as problematic and variable. It was argued that such studies deflected attention away from disablement and made no impression on removing 'disabling barriers'. This left little common ground with disability theorists and their concentration on the social exclusion and oppression of disabled people. The expanding division between disability theorists and medical sociologists included: the role of language, the causal link between impairment and disability, and the relevance of experience (Abberley, 1987; Finkelstein, 1993; Oliver, 1990; Davis, 1993).

Nevertheless, the formulation of the social model of disability has been challenged recently from within the ranks of the disabled people's movement. Two issues predominate. Firstly, there are those who wish to include 'impairment' in the account of disability. Whereas the 'orthodox' position has been that this will undermine the political force of the social model, there have been increasingly vocal claims that the individual experience of disabled people runs counter to the exclusion of the pain, fatigue and depression that often goes with

impairment and chronic illness (Crow, 1992; French, 1993). A second criticism of the social model has been that it has been exclusionary to the extent that it has ignored or downplayed the significance of other structural divisions and disadvantages that affect disabled, as well as non-disabled, people. Attention is particularly drawn to the impact of sexism and racism and how these produce contrasting experiences within the disabled population (Begum, Hill and Stevens, 1994; Killin, 1993; Morris, 1991; Stuart, 1992). These debates assume considerable significance for attempts to build a positive disabled identity which incorporates and celebrates social and cultural differences.

## **ORGANISATION OF THE BOOK**

The papers delivered at the Leeds conference on illness and disability were organised around three broad inter-related themes: definitions, identity, and environment. In practice, issues raised under one heading tended to spill-over into other areas. Therefore, it was thought inappropriate to divide the book into separate sections. Moreover, additional contributions were sought from other participants at the conference which explore key themes in detailed case studies. Just as those attending came from a wide range of backgrounds, so too the contributors to this volume include disabled activists and academics, medical sociologists, policy researchers, and people working in social services.

In chapter 2, Mike Bury surveys changes and challenges to sociological approaches to chronic illness. He traces the move from a socio-medical approach to a more explicitly sociological focus which takes an interpretative view of the individual's experience of chronic illness. Bury promotes a 'relational' approach to 'disability' which focuses on the interactions between the individual and their social location, while also noting that sociological studies have influenced policy makers away from a narrowly medical viewpoint. His review includes a robust critique of the 'social oppression' theory of disability, and maintains that disability theory is following a path which leads to an 'over-socialised' view of disability. He also takes issue with disability theorists' characterisation of the 'politics' of disability

research and he concludes with a defence of the independent social researcher.

Mike Oliver provides a disability theorist's perspective on the significance of definitions in chapter 3. He identifies six main areas of contention: causality; conceptual consistency; the role of language; the normalising tendencies in both approaches; the issue of experience; and the politicisation of the definition process itself. The World Health Organisation's International Classification of Impairments, Disabilities and Handicaps (WHO, 1980) is criticised because it elevates impairment as a determining force in the lives of disabled people and acts as a spur to the medicalisation of disability. He contrasts it with definitions advanced by disabled people. Oliver also addresses challenges to the social model of disability from within the disabled people's movement. He argues for a concentration on the 'social barriers of disability' and those aspects of a disabled person's life which can be resolved by collective political intervention.

An alternative formulation of the relationship of impairment to the social model of disability is provided by Liz Crow in chapter 4. She emphasises the merits of the social model of disability while also arguing for its refurbishment. She contends that it runs counter to the personal experience of so many disabled people because it excludes the negative experiences associated with impairment. Her concern is that such an important part of disabled people's experience must be fully integrated into the account of disability and she calls for proper recognition of this subjective interpretation of impairment. For Crow, this does not go against the interests of disabled people in confronting disabling barriers, nor does it drive disability theory into accepting the position that all of the disadvantages experienced by disabled people are determined by their impairments.

In chapter 5, Mike Kelly draws on phenomenological perspectives to elaborate a theory of social identity which takes issue with early sociological role theory. He uses data from a study of people who have undergone total colectomy and ileostomy surgery to explore concerns about identity change and 'maintenance of self'. Kelly illustrates ways in which this illness and associated surgery are a source of potentially profound effects on the individual's self-identity and social interaction, although their salience varies across different

contexts. His account highlights the significance of cultural stereotypes and self-imposed negative attributions associated with this form of radical abdominal surgery, and the tensions and difficulties in confronting and overcoming these perceived threats to self-presentation and identity construction in social relationships, most particularly in intimate, and potentially sexual, encounters.

A contrasting journey through disability, identity and difference is provided by Tom Shakespeare in chapter 6. He argues that disability theorists' critique of the medical model has not gone far enough in creating space for a positive disabled identity to take root and flourish. He explores disability identity options at the personal, cultural and political levels, and draws parallels with struggles by feminists, black people, gays and lesbians. Disabled people need to break out of the psychological prison of 'personal woes' and engage with the liberating feminist maxim that the personal is political. Shakespeare also draws on post-structuralist writings to explore how disabled people can actively engage in constructing their own narratives and 'stories'. It is by these means that disabled people have a chance of constructing a new persona for themselves.

In chapter 7, Marian Barnes and Polly Shardlow explore the rarely documented attempts by 'users' or 'survivors' of mental health systems to achieve a positive identity. They explore one of the most fundamental objectives of such groups which is the right of 'survivors' to define their own needs, problems and solutions - rather than have this done by others. For the authors, their study of mental health user groups provides evidence of the formation of a 'new social movement'. They examine how far, and in what ways, the presumed 'passive and dependent recipients of welfare' are regaining some control over their own lives, for example, by contributing to the organisation and delivery of services. By the same token, such actions help them achieve a more positive sense of identity.

The emphasis given by medical sociologists to understanding the experience of chronic illness is illustrated in chapter 8 by Ruth Pinder. She uses two detailed case studies to point to the dilemmas and difficulties for people with arthritis in differentiating sickness and health in the labour market. She takes issue with the proponents of the social model of disability, and also rejects most attempts to 'bring

impairment back in' because they do not go far enough. What is particularly lacking, she argues, is attention to the relational aspects of disability and impairment within their wider economic and socio-cultural contexts. Pinder's account examines the interplay between the body in its individual, social and political forms, and how body symbolism works at different levels, in shaping peoples' working lives.

In chapter 9, Nasa Begum, taking her lead from the social model of disability, explores the social control exercised by General Practitioners (GPs) over disabled women. Using survey data, she illustrates the ways in which doctors so often relied on stereotypes in their interactions with disabled women. Those interviewed resented the ways in which medical control operated. They felt that GPs could not see past their impairment. The disabled womens' relationship with their GPs was further complicated because the latter acted as gatekeepers to a range of non-medical resources and activities. In addition, the experiences of respondents were compounded by structural divisions located in class, and `race'. Begum concludes by re-iterating her support for the social model of disability, while also arguing that disability theory considers further the relationship between illness, impairment and disability.

The new climate created by a reformed NHS and an internal market with purchasers and providers raises important questions about the extent to which disabled people have been meaningfully involved in decisions about their service needs and priorities. In chapter 10, Judith Emanuel and David Ackroyd report on one such initiative: the North West Regional Health Authority's development of guidelines on services for disabled people for purchasers, Health Authorities and GP Fundholders. The authors focus on a number of key questions, such as: What are the needs of disabled people? What influences the decisions taken by purchasers? How were providers to be made responsive to purchasers? The chapter elaborates how the guidelines were developed and the associated actions identified, as well as the difficulties encountered.

An exploration of the main issues in exploring the experience of impairment, disability and the environment is undertaken in chapter 11 by Gareth Williams. He identifies contrasting characterisations in rehabilitation, medical sociology and disability theory. The medical

model's basic project is to deal with impairment, to which the environment is uneasily 'added on'. In medical sociology, the typical focus is on the interaction between symptoms and situation or external environment. Such accounts have been concerned primarily with subjective experience and the negotiation and re-negotiation of identity through talk. He acknowledges criticism that such studies can lose sight of the structures which shape experience. In contrast, disability theory's pre-occupation with 'social oppression' has excluded the variable social experience of chronic illness. Williams concludes by arguing for an approach which draws from both disability theory and medical sociology.

## **REVIEW**

The impetus behind the Leeds conference, and of this volume, has been a desire to bring disability activists and theorists together with medical sociologists in order to explore areas of common concern. Over recent years there has been a widening gap, although the suggestion of protagonists lining up on opposing sides ignores the different emphases and approaches among medical sociologists and disability theorists and activists. The aim was to re-build a more positive dialogue on the key issues and concerns articulated by disability theorists and medical sociologists - and it is in this spirit that we decided to keep the editorial function to a minimum and, not least, leave the choice of terminology to participants.

We feel that the contributors in their different ways make the case for sustaining and developing such contact between the two 'disciplines' in order to generate a better understanding of the issues at stake or in dispute. Certainly, there is ample evidence that contributors remain suspicious and critical of each other's accounts of chronic illness and disability, but it is also important to highlight the common interests of disability theory and medical sociology in making the connections between the world of policy and politics and the realm of personal experiences. We hope that this volume will encourage theorists and activists to maintain the momentum towards constructive debate.

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