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DEFINING IMPAIRMENT AND DISABILITY: ISSUES AT STAKE

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INTRODUCTION

For the past fifteen years the social model of disability has been the foundation upon which disabled people have chosen to organise themselves collectively. This has resulted in unparalleled success in changing the discourses around disability, in promoting disability as a civil rights issue and in developing schemes to give disabled people autonomy and control in their own lives. Despite these successes, in recent years the social model has come under increasing scrutiny both from disabled people and from others working in the field of chronic illness.

What I want to explore in this chapter are some of the issues that are at stake in these emerging criticisms and suggest that there is still a great deal of mileage to be gained from the social model and that we weaken it at our peril. I will do this by briefly outlining the two alternative schemas which have emerged in the articulation of conflicting definitions of chronic illness, impairment and disability. I will then discuss six issues that, I suggest, go to the heart of the debate as far as external criticisms from medical sociologists are concerned. These are: the issue of causality; the question of conceptual consistency; the role of language; the normalising tendencies contained in both schemas; the problem of experience; and finally, the politicisation of the definitional process.

Having identified the issues at stake externally, I will discuss a number of internal criticisms that have emerged from disabled people themselves around the place of impairment, the incorporation of other oppressions and the use and explanatory power of the social model

of disability. While remaining sceptical about these criticisms, I will finally suggest that a start can be made towards resolving some of them by focusing on what disabled people would call impairment and medical sociologists would call chronic illness.

THE PROBLEM OF DEFINITIONS

Since the 1960s there have been various attempts to provide and develop a conceptual schema to describe and explain the complex relationships between illness, impairment, disability and handicap. This has led to the adoption of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) by the World Health Organisation (WHO) (Wood, 1980) which has been used as the basis for two national studies of disability in Britain (Harris, 1971; Martin, Meltzer and Elliot, 1988).

Not everyone has accepted the validity of this schema nor the assumptions underpinning it. Disabled people's organisations themselves have been in the forefront of the rejection of the schema itself (Driedger, 1988), others have rejected the assumptions which underpin it (Oliver, 1990) and the adequacy of it as a basis for empirical work has also been questioned (Abberley, 1993). This is not the place to discuss these issues in detail; rather I intend to look at some of the dimensions of the debate that is currently taking place. In order to facilitate this, I reproduce the two alternative schemas below for those who are not familiar with either or both:

The WHO International Classification of Impairment, Disability and Handicap:

IMPAIRMENT: In the context of health experience, an impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function ...

DISABILITY: In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being ...

HANDICAP: In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual' (Wood, 1980, pp 27-29).

The Disabled People's International (DPI) definition:

IMPAIRMENT: is the functional limitation within the individual caused by physical, mental or sensory impairment.

DISABILITY: is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' (DPI, 1982).

THE ISSUE OF CAUSALITY

The search for causality has been a major feature of both the scientific and the social scientific enterprise. What is at stake for the disability schemas described above is how to explain negative social experiences and the inferior conditions under which disabled people live out their lives. For those committed to the WHO schema, what they call chronic illness is causally related to the disadvantages disabled people experience. For those committed to the DPI schema however, there is no such causal link; for them disability is wholly and exclusively social. Hence each side accuses the other of being incorrect in causal terms.

Causality in the two schemas

WHO Model

Impairment

i

Disability

i

Handicap

DPI Model

Impairment

Disability

These schemas appear to be incompatible and have led one medical sociologist critically to suggest:

`Sometimes, in seeking to reject the reductionism of the medical model and its institutional contexts, proponents of independent living have tended to discuss disablement as if it had nothing to do with the physical body' (Williams, 1991, p. 521).

Ironically that is precisely what the DPI definition insists, disablement is nothing to do with the body. It is a consequence of the failure of social organisation to take account of the differing needs of disabled people and remove the barriers they encounter. The schema does not, however, deny the reality of impairment nor that it is closely related to the physical body. Under this schema impairment is, in fact, nothing less than a description of the physical body.

The appearance of incompatibility however, may be precisely that: appearance. It may well be that this debate is in reality, the result of terminological confusion; that real similarities exist between chronic illness and impairment and that there is much scope for collaboration between supporters of both schemas if this confusion can be sorted out.

THE QUESTION OF CONCEPTUAL CONSISTENCY

This terminological confusion is not just a matter of agreeing to use the same words in the same way. It is also about understanding and appeared when a policy analyst attempted to relate her own experience to policy issues in the area of disability.

`I found myself puzzled by arguments that held that disability had nothing to do with illness or that belief in a need for some form of personal adaptation to impairment was essentially a form of false consciousness. I knew that disabled people argue that they should not be treated as if they were ill, but could see that many people who had impairments as a result of ongoing illness were also disabled. My unease increased as I watched my parents coming to terms with my mother's increasing

impairments (and disability) related to arterial disease which left her tired and in almost continual pain. I could see that people can be disabled by their physical, economic and social environment but I could also see that people who became disabled (rather than being born with impairments) might have to renegotiate their sense of themselves both with themselves and with those closest to them' (Parker, 1993, p.2).

The DPI schema does not deny that some illnesses may have disabling consequences and many disabled people have illnesses at various points in their lives. Further, it may be entirely appropriate for doctors to treat illnesses of all kinds, though even here, the record of the medical profession is increasingly coming under critical scrutiny. Leaving this aside, however, doctors can have a role to play in the lives of disabled people: stabilising their initial condition, treating any illnesses which may arise and which may or may not be disability related.

The conceptual issue underpinning this dimension of the debate, therefore, is about determining which aspects of disabled people's lives need medical or therapeutic interventions, which aspects require policy developments and which require political action. Failure to distinguish between these up to now has resulted in the medicalisation of disability and the colonisation of disabled peoples lives by a vast army of professionals when perhaps, political action (i.e. civil rights legislation) would be a more appropriate response.

THE ROLE OF LANGUAGE

Despite recent attempts to denigrate those who believe in the importance of language in shaping reality, largely through criticisms of what has come to be called 'political correctness', few would argue that language is unimportant or disagree that attempts to eradicate terminology such as cripple, spastic, wobbler and mongol are anything other than a good thing.

This role of language, however, is more complex than simply the removal of offensive words. There is greater concern over the way language is used to shape meanings and even create realities. For

example, the language used in much medical discourse including medical sociology is replete with words and meanings which many disabled people find offensive or feel that it distorts their experiences. In particular the term chronic illness is for many people an unnecessarily negative term, and discussions of suffering in many studies have the effect of casting disabled people in the role of victim.

The disabling effects of language is not something that is unique to disabled people. Other groups have faced similar struggles around language. Altman in his study of collective responses to AIDS points out:

‘... in particular the Denver Principles stressed the use of the term "PWA" as distinct from "victims" or "patients", and the need for representation at all levels of AIDS policy-making "to share their own experiences and knowledge" ’ (Altman, 1994, p.59).

The struggles around language are not merely semantic. A major bone of contention is the continued use of the term ‘handicap’ by the WHO schema. This is an anathema to many disabled people because of its connections to ‘cap in hand’ and the degrading role that charity and charitable institutions play in our lives.

THE NORMALISING TENDENCIES OF BOTH SCHEMAS

Underpinning both schemas is the concept of normality and the assumption that disabled people want to achieve this normality. In the WHO schema it is normal social roles and in the DPI schema it is the normal life of the community. The problem with both of these is that increasingly the disability movement throughout the world is rejecting approaches based upon the restoration of normality and insisting on approaches based upon the celebration of difference.

From rejections of the ‘cure’, through critiques of supposedly therapeutic interventions such as conductive education, cochlea implants and the like, and onto attempts to build a culture of disability based upon pride, the idea of normality is increasingly coming under attack. Ironically it is only the definition advanced by the Union of the

Physically Impaired Against Segregation (UPIAS) that can accommodate the development of a politics of difference. While its definition of impairment is similar to that of DPI, its definition of disability is radically different:

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).

Again, this is not just a matter of semantics but a concerted attempt to reject the normalising society. That some organisations of disabled people have not fully succeeded cannot be explained only as a matter of dispute between different political positions within the disability movement but also as evidence of just how ingrained and deep-rooted the ideology of normality is within social consciousness more generally.

THE PROBLEM OF EXPERIENCE

Recently, a number of sociologists working in the general area of medical sociology and chronic illness have expressed concern over the growing importance of the 'social oppression theory' of disability, associated research methodologies, and their implications for doing research in the 'chronic illness and disability fields' (Bury, 1992).

Whilst these writers feel the need to 'positively debate' these developments, the basis of their concern is similar to that expressed by Hammersley with respect to some aspects of feminist research, i.e. the tendency to 'privilege experience over sociological research methodology' (Hammersley, 1992). In short, this privileging of experience is perceived as a threat; firstly, to 'non-disabled' researchers doing disability research; secondly, to the traditional role of the sociologist giving 'voice to the voiceless' - in this case 'older' disabled people whose interests are said to be poorly served by 'social oppression theory'; and, thirdly, to the 'independence' of sociological activities within the 'medical sociology world'.

As a social researcher, I have some sympathy for these concerns but the problem is that most social research has tended to privilege methodology above experience and, as a consequence, does not have a very good track record in faithfully documenting that experience; whether it be the black experience, the experience of women, the experience of disability and so on. Additionally, scientific social research has done little to improve the quality of life of disabled people. Finally, it is difficult to demonstrate that so called 'independent research' has had much effect on policy, legislation or social change (Oliver 1992).

THE POLITICISATION OF THE DEFINITIONAL PROCESS

By now it should be clear that defining impairment or disability or illness or anything else for that matter is not simply a matter of language or science; it is also a matter of politics. Altman captures this in respect of the definitional battles surrounding AIDS:

'How AIDS was conceptualised was an essential tool in a sometimes very bitter struggle; was it to be understood as a primarily bio-medical problem, in which case its control should be under that of the medical establishment, or was it rather, as most community-based groups argued, a social and political issue, which required a much greater variety of expertise?' (Altman, 1994, p.26).

This battle is related to two political processes; exclusion and inclusion as far as disabled people and disability definitions are concerned. The ways in which disabled people have been systematically excluded from the definitional process has recently been described in one incident which captures the nature of this exclusion more generally.

'It is a hot summer day in London in the late 1980's. Gathered together in one of the capital's most venerable colleges is a large number of academics, researchers and representatives of research funding bodies. Their purpose? A symposium on researching disability comprising presentations on a variety of

different methodological and other themes, given and chaired by a panel of experienced disability researchers.

Those convening the seminar are proud that it will shine a spotlight on a usually neglected area of social science research. But some in the audience (and one or two others who have chosen not to attend) hold a different view. What credibility can such a seminar muster, they ask, when none of those chairing or presenting papers are themselves disabled? What does it say about current understanding of disability research issues that such an event has been allowed to go ahead in this form, when a symposium on researching gender issues given entirely by men, or race relations research given entirely by white people, would have been laughed out of court?' (Ward and Flynn, 1994, p.29).

It should be pointed out that this exclusion has been systematic and disabled people have not been properly consulted by organisations such as WHO and the Office of Population Censuses and Surveys who have been most heavily funded in Britain to undertake such work. Where claims that this is not the case have been made, the reality is that research organisations have demonstrated that they don't even understand the difference between organisations for and organisations of disabled people and while they may have consulted the former, they have not consulted the latter.

However, disabled people have begun to resist this situation by producing their own research based upon their own definitions (Barnes, 1991; 1992), the British Council of Disabled People (BCODP) has established its own research sub-committee and in Canada disabled people have produced their own guidelines on what is acceptable and not acceptable research for disability organisations to be involved in (Woodhill, 1993).

These initiatives have begun to have some impact on not only the research community but on Government as well. Altman discusses the role of people with AIDS (PWAs) in AIDS research and argues that it is in everyone's interest to encourage such developments:

`. CRI (Community Research Initiative) has proved that a community model of research, involving PWAs themselves in

decision making, could run effective trials - partly because it was able to successfully access suitable patients and encourage them to participate - and could resolve the complex ethical questions of such research successfully' (Altman, 1994, p.70).

At a recent meeting of disabled people from all over Europe, the group decided to reaffirm their own definition of disability and to spell out the implications of this for the WHO schema.

`A Disabled Person is an individual in their own right, placed in a disabling situation, brought about by environmental, economic and social barriers that the person, because of their impairment(s), cannot overcome in the same way as other citizens. These barriers are all too often reinforced by the marginalising attitudes of society. It is up to society to eliminate, reduce or compensate for these barriers in order to enable each individual to enjoy full citizenship, respecting the rights and duties of each individual'.

`By supporting this resolution this meeting on human rights expresses its non-support for the current classification of impairment, disability and handicap operated by the World Health Organisation. We call upon the WHO to enter into a dialogue with disabled people's organisations to adopt a new definition in line with the above resolution' (DPI, 1994).

DEVELOPING A SOCIAL MODEL OF IMPAIRMENT?

Whatever happens to this call for a dialogue between organisations of disabled people and the World Health Organisation, disabled people have begun their own internal dialogue around the social model of disability. It is to some of the dimensions of this dialogue that I now turn before considering some of the implications.

A major criticism that some disabled people have made of the social model concerns the way it connects, or rather doesn't connect with the experience of impairment. French (1993), for example, argues that her visual impairment imposes some social restrictions which

cannot be resolved by the application of the principles of social model. She cites as examples her inability to recognise people and read or emit non-verbal cues in social interactions.

Clearly, most disabled people can come up with similar examples. As a wheelchair user when I go to parties I am more restricted than some other people from interacting with everyone else and what's more, it is difficult to see a solution - houses are usually crowded with people during parties and that makes circulation difficult for a wheelchair user. But other people may find circulation difficult as well but for other reasons; they may simply be shy. The point that I am making is that the social model is not an attempt to deal with the personal restrictions of impairment but the social barriers of disability as defined earlier by DPI and UPIAS.

Other disabled people have criticised the social model for its assumed denial of 'the pain of impairment', both physical and psychological. In many ways some of these criticisms mirror those made from without although they are not beset by the same terminological confusion between illness and impairment.

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

This denial of the pain of impairment has not, in reality been a denial at all. Rather it has been a pragmatic attempt to identify and address issues that can be changed through collective action rather than medical or other professional treatment.

'If a person's physical pain is the reason they are unhappy then there is nothing the disability movement can do about it. All that BCODP can do is facilitate the politicisation of people around these issues. Of course this politicisation is fairly difficult to make practical progress with - much easier to achieve anti-

discrimination legislation than a total review of how society regards death and dying, I imagine. This might explain why these subjects haven't been made a priority, but their day will come' (Vasey, 1992, p.43).

These criticisms are taken further by Crow (1992) who argues that the way forward for the social model of disability is to fully integrate the experience of impairment with the experience of disability. However, up to now and for very important reasons, the social model has insisted that there is no causal relationship between impairment and disability.

`The achievement of the disability movement has been to break the link between our bodies and our social situation, and to focus on the real cause of disability, i.e. discrimination and prejudice. To mention biology, to admit pain, to confront our impairments, has been to risk the oppressors seizing on evidence that disability is "really" about physical limitation after all' (Shakespeare, 1992, p.40).

Finally the social model of disability is criticised because it was written (if it ever was?) by healthy wheelchair users. According to one recent commentator:

`The social model of disability appears to have been constructed for healthy quadriplegics. The social model avoids mention of pain, medication or ill-health' (Humphrey, 1994, p.66).

The social model of disability does indeed avoid mention of such things, not because it was written by healthy quadriplegics, but because pain, medication and ill-health properly belong within either the individual model of disability or the social model of impairment.

OTHER INTERNAL CRITICISMS OF THE SOCIAL MODEL OF DISABILITY

A further internal criticism comes from other oppressed groups who feel that these other oppressions such as racism (Hill, 1994), sexism

(Morris, 1991) and homophobia (Hearn, 1991) have not been incorporated into the social model. Again, it is certainly true that the social model of disability has not explicitly addressed the issue of multiple or simultaneous oppression but then such issues are only just beginning to be explored in respect of both impairment and disability (Begum, Hill and Stevens, 1994; Zarb and Oliver, 1993; Priestley, 1995).

This dissatisfaction has been expressed not simply because the social model does not adequately reflect experience of oppression of all disabled people but also because it may 'oversimplify' some of the issues raised in Disability Equality Training (DET).

'For some time I have been dissatisfied with the oversimplified "social model" of disability we are obliged to use in Disability Equality Training and have read with interest the recent arguments re-introducing "impairment" into that model.

'Although the "social model" has for some time served us well as a way of directing attention away from the personal to the political, I feel now that the debate has been hampered by the rather rigid genealogy of disability thinking. My own literary, linguistic and therapeutic background led me to post-modernist thinkers such as Foucault, Derrida, Barthes and Lacan in an attempt to make sense of the personal and political aspects of the disability debate' (Cashling, 1993, pp.199-200).

While it is undeniably true that some DET trainers may have used the social model in an over rigid way, those like myself who draw on Marxist rather than post-modernist thinking call this reification; that is, the elevation of a concept into a thing, a social construction into reality. And it remains to be seen whether post-modernist explanations of the oppression of disabled people as simply a manifestation of society's hatred of us, will take us as far as the social model of disability in challenging that oppression. Cashling suggests they might but I have my doubts. For me our oppression is ultimately due to our continued exclusion from the processes of production, and not because of society's hatred (real or imagined) of us.

Such criticism, however, raises questions about the way the model is used, rather than the model itself. If we expect models to explain, rather than aid understanding, then they are bound to be found wanting. Many of those arguing for the incorporation of impairment have confused models and theories. I suggest that the continuing use and refinement of the social model of disability can contribute to rather than be a substitute for the development of an adequate social theory of disability. As both Abberley (1987) and myself (Oliver 1990) have argued, an adequate social theory of disability must contain a theory of impairment.

A final criticism comes from one of the founding fathers of the social model, Vic Finkelstein, who is also critical of the adequacy of the social model's explanatory power. Recently he has questioned the ability of the social model to explain fully the social position of disabled people in modern society, and suggests that there are at least two variants: the social death model and the social barriers model (Finkelstein, 1993). He then goes on to suggest that the administrative model is the only one which has sufficient scope to fully explain societal responses to disabled people.

`In my view administrative approaches dominate all forms of helping services for disabled people in the UK, whether these are provided by statutory agencies or voluntary bodies, or demanded by pressure group organisations. The cure or care forms of intervention are administered within the rehabilitation and personal-care services respectively' (Finkelstein, 1993, p.37).

For me, the administrative model is similar to the position I took in trying to locate disability historically within the rise of capitalist society.

`As the conditions of capitalist production changed in the twentieth century, so the labour needs of capital shifted from a mass of unskilled workers to a more limited need of skilled ones. As a result of this, the Welfare State arose as a means of ensuring the supply of skill, and in order to "pacify" the ever increasing army of the unemployed, the under-employed and the unemployable' (Manning and Oliver, 1985, p.102).

While I think Finkelstein and I are basically saying the same thing, for me it is important not to stretch the explanatory power of models further than they are able to go. For me the social model of disability is concerned with the personal and collective experiences of disabling social barriers and how its application might influence professional practice and shape political action. It is not a substitute for social theory, it is not an attempt to provide a materialist history of disability and it is not an explanation of the failure of welfare state in respect of services to disabled people.

THE SOCIAL MODEL OF DISABILITY IS ALIVE AND WELL

These are some of the major internal debates going on around the social model. One of the things they have in common is their concern to somehow integrate impairment into the social model of disability. Personally I have no interest in such attempts because, as Vasey (1992) has already pointed out, the collectivising of experiences of impairment is a much more difficult task than collectivising the experience of disability. Our own history has taught us this in the way in which we have been classified and segregated by our impairments and the way in which single impairment organisations have failed to provide an adequate basis for collective self-organisation amongst disabled people in the past (Campbell and Oliver, 1996).

Additionally there is still much mileage in the social model of disability. It has the power to transform consciousness in a way that a social model of impairment never will. David Hevey describes his own transformation:

‘The second flash on this road to Damascus as a disabled person came when I encountered the disability movement. I had learnt to live with my private fear and to feel that I was the only one involved in this fight. I had internalised my oppression. As a working class son of Irish immigrants, I had experienced other struggles but, in retrospect, I evidently saw epilepsy as my hidden cross. I cannot explain how significantly all this was turned around when I came into contact with the notion of the

social model of disability, rather than the medical model which I had hitherto lived with. Over a matter of months, my discomfort with this secret beast of burden called epilepsy, and my festering hatred at the silencing of myself as a disabled person, "because I didn't look it", completely changed. I think I went through an almost evangelical conversion as I realised that my disability was not, in fact, the epilepsy, but the toxic drugs with their denied side-effects; the medical regime with its blaming of the victim; the judgement through distance and silence of bus-stop crowds, bar-room crowds and dinner-table friends; the fear; and, not least, the employment problems. All this was the oppression, not the epileptic seizure at which I was hardly (consciously) present' (Hevey, 1992, pp.1-2).

While it has the power to transform consciousness in the way described above, its demise is surely premature.

Finally, the hegemony of the individual model of disability may have begun to be challenged by the social model, but it has not yet replaced it. Hence, engaging in public criticism may not broaden and refine the social model; it may instead breathe new life in the individual model with all that means in terms of increasing medical and therapeutic interventions into areas of our lives where they do not belong.

Despite my reservations about the project, the development of a social model of impairment to stand alongside a social model of disability appears inevitable. This being the case, those disabled people concerned may wish to develop a dialogue with medical sociologists working on the experience of chronic illness. In so doing, the issues identified earlier in this chapter may well help the dialogue to develop. In any case, our understandings of the experience of impairment may well be enhanced and the enterprise of medical sociology enriched.

CONCLUSIONS

In this chapter I have looked at some of the definitional issues involved in impairment and disability. Subsequently, my argument

has centred on three key points. Firstly, we must not assume that models in general and the social model of disability in particular can do everything; that it can explain disability in totality. It is not a social theory of disability and it cannot do the work of social theory. Secondly, because it cannot explain everything, we should neither seek to expose inadequacies, which are more a product of the way we use it, nor abandon it before its usefulness has been fully exploited. Finally, if a social model of impairment is to be developed, a dialogue between disabled people and medical sociologists may enrich the process.

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