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## Disability Studies: What's the Point?

### **Abstract**

[Excerpt] While the content of these courses had much to offer in terms of furthering our understanding of the experience of 'chronic illness' and the ensuing economic and social outcomes in terms of daily living for disabled people and their families, the central focus always seemed to be either on the physical and psychological consequences of the condition, or the complexity of the relationship between the disabled individual and their social environment. 'Disability', usually defined as 'functional limitation', was caused by either: chronic illness/impairment or the complex interaction between the limitations of the body and/or mind, and society at large. The dominant 'personal tragedy' theory of disability was never seriously questioned and, with one or two notable exceptions, meaningful explanations for society's responses to, and treatment of, people with impairments, whether real or ascribed, and 'labelled' disabled, were conspicuous by their absence.

### **Keywords**

disability, disability studies, education, personal tragedy, theory

### **Comments**

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# **Disability Studies: what's the point?**

**(This is a slightly amended version of a the plenary address at the 'Disability Studies: Theory. Policy and Practice' Conference; University of Lancaster, September 4<sup>th</sup>. 2003).**

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## Colin Barnes

This is something of an anniversary for me as it's now exactly twenty-one years since I entered University as an undergraduate, at the tender age of 35, and just over ten years since the phrase 'Disability Studies' appeared in an academic context in the UK. This is because although people had been studying 'disability' related issues both within and without British universities and colleges since at least the 1960s, if not before, under various guises, the phrase had not been used until I adopted it in 1992 for two new courses offered in the Department of Sociology and Social Policy at the University of Leeds.

These were a 20 credit module for second and third year undergraduates, entitled 'Disability Studies: an introduction', which started in October (1992) and a part time 'Post Graduate Diploma/MA in Disability Studies', open to graduates and people working in the disability field, that began operations one year later (1993).

Unlike previous courses dealing with 'disability' related concerns in Britain and elsewhere, the focus was and remains clustered around the re-definition of disability by disabled people and their organisations and, what is generally referred to as the 'social model of disability'. I'll come to that in a minute.

Hitherto 'disability' and related issues were covered at Leeds, as elsewhere, in a variety of courses within and without the areas of Sociology and Social Policy. An important example was 'The Sociology of Health and Illness'.

While the content of these courses had much to offer in terms of furthering our understanding of the experience of 'chronic illness' and the ensuing economic and social

outcomes in terms of daily living for disabled people and their families, the central focus always seemed to be either on the physical and psychological consequences of the condition, or the complexity of the relationship between the disabled individual and their social environment.

'Disability', usually defined as 'functional limitation', was caused by either: chronic illness/impairment or the complex interaction between the limitations of the body and/or mind, and society at large.

The dominant 'personal tragedy' theory of disability was never seriously questioned and, with one or two notable exceptions, meaningful explanations for society's responses to, and treatment of, people with impairments, whether real or ascribed, and 'labelled' disabled, were conspicuous by their absence (see for example, Bury, 1982, Anderson and Bury, 1989).

Key texts written by disabled academics and writers that provided a radical alternative to these conventions were, either, discussed only in passing and subsequently dismissed, or not mentioned at all.

In other words the profoundly disabling tendencies of modern society were downplayed and or over looked completely. The policy outcomes of these approaches allowed politicians, professionals and practitioners; either, to adopt an exclusively traditional individual approach to the problem of 'disability' or, to espouse a more liberal inter-relational agenda similar to what Miller and Gwynne termed an 'enlightened guardianship' perspective way back in 1972. Thus, allowing them to vacillate between individual and collective solutions to the 'disability' issue.

And, despite the on-going rhetoric to the contrary, in market led or capitalist economies they invariably gravitate toward the former. For recent examples of these 'all encompassing' policy formulations in practice with reference to disabled people and paid work see Roulstone, (2000), for the British experience, and the OECD (Organisation for Economic Co-operation and Development) Report 'Transforming Disability Into Ability: Policies to Promote Work and Income Security for Disabled People' (OECD, 2003), for a cross cultural account.

As someone with a lifetime's experience of 'disability' who came to academia with the sole purpose of doing something on the discrimination experienced by disabled people this was both surprising and unacceptable.

It was especially so since as a student and researcher, working with and for disabled people and their organisations, I had come across a whole body of work produced by disabled activists and writers that identified 'disability' as a complex and pernicious form of social oppression or institutional discrimination that pervades every aspect of modern living.

Key influences included the re-definition of disability by UPIAS, the social model of disability, and various theoretical explanations for the social creation of the concept 'disability'.

In contrast to previous definitions UPIAS had re-defined 'disability' as something imposed on top of people with 'impairment's' lives, by a society that is intolerant of any form of biological flaw whether real or imagined (UPIAS, 1976).

In order to put this idea to practical use, Mike Oliver coined the phrase the 'social model of disability' in 1981. It was used initially for the training of social workers and professionals working in the disability field (Oliver, 2003) and, later, as the main mechanism for delivering Disability Equality Training (Gillespie Sells and Campbell, 1990: Rieser and Mason, 1990) as opposed to 'Disability Awareness Training which was usually constructed around traditional individualistic impairment specific considerations and concerns. .

It is important to remember here what the social model actually is. A model is what social scientists call a 'heuristic device' or an aid to understanding. Thus:

'A good model can enable us to see something which we do not understand because in the model it can be seen from different viewpoints... it is this multi-dimensional replica of reality that can trigger insights that we might not otherwise develop' (Finkelstein, 2002: 13).

Now, there are three main points that have been made repeatedly about the social model of disability.

- One, in contrast to the conventional individual medical model of disability, it is a deliberate attempt to switch the focus away from the functional limitations of impaired individuals onto the problems caused by disabling environments, barriers and cultures.
- Two, it is an holistic approach that explains specific problems experienced by disabled people in terms of the totality of disabling environments and cultures. This includes inaccessible education, information and communication systems, working environments,

inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media – films, television and newspapers.

- Three, a social model perspective does not deny the importance or value of appropriate individually based interventions in the lives of disabled people, whether they be medically, re/habilitative, educational or employment based, but draws attention to their limitations in terms of furthering their empowerment and inclusion in a society constructed by ‘non-disabled people’ for ‘non-disabled’ people.

In short, the social model of disability is a tool with which to gain an insight into the disabling tendencies of modern society in order to generate policies and practices to facilitate their eradication.

Subsequently, the phrase ‘the social model of disability’ has been used with reference to various theories explaining the social creation/construction of disability, but is generally linked to the materialist accounts of Finkelstein, (1980) Abberley (1987) Oliver (1990), and, more recently, Gleeson, (1999) and Thomas (1999) (see Priestley, 1998). .

Taken together these ideas underpinned the thinking behind the choice of the phrase ‘Disability Studies; which, for me is about the study of the various forces; economic, political, and cultural, that support and sustain ‘disability’, as defined by the disabled peoples movement, in order to generate meaningful and practical knowledge with which to further its eradication.



This is not to suggest that work that does not adhere to a social model perspective should be excluded from a disability studies agenda: far from it, to appreciate fully the significance of social model thinking it is necessary to have some knowledge of what has gone before.

Now, as we all know since 1992 there has been a considerable upsurge of academic interest from a variety of disciplines, both in the UK and overseas, not all of which goes by the name of 'disability studies', but the term is now firmly established on the academic agenda encompassing both teaching and research. And much welcome progress has been made too.

However, and perhaps inevitably with this heightened interest, several challenges have emerged that, in some ways, threaten to undermine a disability studies perspective, as defined above, or, more specifically, the social model of disability upon which it rests.

Several of these criticisms are regularly repeated within and without the disability studies literature (see for example Shakespeare and Watson, 2002) without a qualified response. Since I believe this is a very worrying state of affairs I want to take this opportunity to address some of them here.

***First: it is argued that the conceptual division between impairment and disability upon which the social model rests is false (Shakespeare and Watson 2002).***

Now the UPIAS redefinition of impairment and disability was a deliberate attempt to separate the biological and the social. To suggest that such a distinction is false is like suggesting that the distinction between the individual and society is false.

Whilst such assertions may be of interest to philosophers and some social theorists, I believe that they have little, if any, practical value in terms of research, policy and practice.

This is not to say that the term 'impairment' is not problematic since it is generally understood to refer to damaged or weakened bodies. It may be relevant when used in relation to someone's reduced capabilities as a result of accident or illness, but is less so with reference to congenital conditions and those that do not affect people's capacity to do things. Those of us born with impairment only usually realise we are somehow 'different' when we come into contact with other 'non-disabled' people.

But it is important to remember here that although originally limited to physical impairments, shortly after its development, the UPIAS definition was adapted and adopted by the disabled people's movement, both nationally and internationally, to include all 'impairments': physical, sensory, intellectual.

Also integral to this re-assessment is the assertion that all physiological conditions have psychological implications and all psychological problems have physical consequences. It is therefore an inclusive concept that encompasses all sections of the disabled community including, for example, mental health systems users and survivors.

This is in recognition of the fact that labels are generally imposed rather than chosen, and, therefore, socially and politically divisive. It also encompasses, implicitly if not explicitly, the notion that like 'disability' the meaning of 'impairment' is a social construct too. Indeed, a key feature of 'social model' literature is that 'attitudes' toward

disabled people are historically, culturally and situationally determined.

Several writers from both sides of the Atlantic have subsequently centred on the cultural production of 'normality/normalcy' and the consequential interpretations of, and responses to 'impairment' (see for example, Finkelstein, 1980; Abberley, 1987: 1993; Davis, L. J.1996).

***Second: it is argued that the social model of disability neglects the everyday experience of 'impairment' and that as a result a major part of disabled people's lives is ignored and, consequentially, the 'disabled lobby' has sometimes opposed medical and rehabilitative interventions designed to 'maximise function' (Shakespeare and Watson 2002).***

With reference to the experience of 'impairment', as already mentioned social scientists and medical sociologists, in particular, have been documenting the everyday 'illness' experiences of disabled individuals for much of the last century.

As long ago as 1966 the disabled activist and writer Paul Hunt pointed out that much of the writing about 'disability' by people with accredited impairments 'is either sentimental biography, or else preoccupied with the medical and practical details of a particular affliction' (ix).

Advocates of the inclusion of such experiences in discussions about the exclusion of disabled people have yet to demonstrate how they would avoid such pitfalls, and equally importantly, those associated with the social science literature discussed earlier.

It is useful to remember too that the social model emerged from within the disabled people's movement and that, from the outset, organisations of disabled people had recognised the need for disabled people to talk about their experiences. Indeed, the need for 'peer counselling and support' was one of the 'seven needs' for independent living identified by the Derbyshire Coalition of Disabled People (DCODP) in the early 1980s (Davis, K. 1990).

Many of the user-controlled organisations that adhere to a social model perspective currently providing services for disabled people and their families in the UK, facilitate or support 'impairment specific' support groups (see, for example, Barnes, Mercer and Morgan, 2000).

Furthermore, the conceptual distinction between impairment and disability does not ignore the fact that it may be a 'personal tragedy' to have an 'impairment', and that this may have implications for the way we do things. And in order to identify the various barriers disabled people face, some knowledge of their impairment related needs is essential.

As a consequence, experiential or qualitative data have been used extensively in social model research advocating barrier removal, and/or the need for better services for disabled people (see for example Zarb and Nadash, 1995).

Further, a social model perspective does not preclude the analysis of disabled people's accounts of interpersonal barriers within the context of personal and family relationships. Nor does it exclude discussion of the psycho-emotional consequences of being perceived as 'impaired', abnormal and or somehow less than human, by the rest of society: what disabled writers have sometimes referred to as 'internal oppression' (Rieser, 1990).

It would however warrant that these discussions be grounded firmly within a social model framework in order to avoid misinterpretation and misuse. Indeed, Donna Reeve (2003) and Carol Thomas (2003) are currently conducting important work along these lines at this University.

With regard to the opposition to medical and rehabilitation interventions, as mentioned above the social model is not opposed to appropriate medical treatments and interventions.

But advocates along with disabled people and their organisations have rightly drawn attention to the psychologically debilitating consequences for disabled individuals, that result from unrealistic and raised expectations following the promise of miraculous treatments and cures by medical and rehabilitation professionals and the media.

A well-known example is that of Philip Olds; an ex-policeman with an acquired spinal cord injury who died in the 1980s. After a lengthy period of 'rehabilitation', Olds committed suicide once he realised that a 'revolutionary' new technique to enable him to walk would not work, and so return him to his former 'non-disabled' status.

Furthermore, the 'disability' lobby and, indeed, many other sections of society including social scientists, some medical professionals, various voluntary agencies not associated with disability, as well as large elements of the lay public, are justifiably sceptical about the supposed benefits of certain medical and re/habilitative interventions.

For instance, long standing concerns have rightly been voiced over the effectiveness or otherwise of various drug therapies and electric shock treatments for 'mental health systems users and survivors' by many people and groups not generally associated with the social model or 'disability' organisations.

More recent concerns revolve around developments in genetic medicine and MMR vaccines and autism,

Given that such interventions have particular significance for disabled people and that these and similar concerns are widespread throughout the social sciences and society at large, I think it is perfectly understandable that disabled people and their organisations have reservations about their use.

***Third: it is often said that barrier removal will not solve all the problems associated with 'disability' as some of the problems encountered by disabled people are caused by impairment and not by society (Shakespeare and Watson 2002).***

Again it is important to remember here that within a social model framework there is a conceptual distinction between the biological and the social, and that advocates have never claimed that barrier removal will eliminate all the problems associated with 'impairment'.

However, there is a wealth of literature from a variety of sources showing that how people deal with physiologically debilitating conditions is not only about the nature of the condition itself, but also about their access to resources: medical, material and social.

A social model analysis is not simply about the identification and removal of the barriers to economic and social activity, it also about identifying and removing the barriers that prevent access to such resources.

Whilst access to better resources may not eliminate all the problems associated with physiologically based 'impairments' it would certainly make a difference as to how people are empowered to cope with them.

Additionally, a social model outlook is about the removal of cultural barriers and the struggle for a cultural environment free from prejudice, stigma and the discrimination associated with 'impairment' or 'difference'.

Surely in such a context the psycho-emotional implications currently linked to living with 'impairment' and a conventional 'disabled' (devalued/dependent) identity would be greatly reduced if not eliminated altogether?

***Fourth, it is claimed that the social model of disability is inadequate because many people with accredited impairments do not choose to adopt the label 'disabled' as they do not consider themselves ill enough, or because the concept is too limited to encompass the complexity of identity in the twenty first century (Shakespeare and Watson 2002).***

Well I'm sure that this news will be welcomed by Gordon Brown, the treasury and all the other welfare agencies, including the OECD, around the world concerned about the escalating costs of disability benefits?.

On a more serious note, this is hardly surprising given that in an increasingly competitive and unequal society the

label 'disabled' is still widely associated with abnormality, social and psychological inadequacy and incompetence, and that, in one way or another, all of us are socialised into the view that to admit to such things is a sign of weakness and failure.

To be 'ill' is far more socially acceptable than it is being 'disabled'.

But as I pointed out earlier, labels are generally imposed and rarely chosen. Surely whether people with accredited impairments choose to identify as 'disabled' is not the issue, what is at stake is how people are perceived and treated by society at large.

Moreover, given the various deprivations generally associated with disability it is a miracle that anyone would want to adopt the label. The fact that they do can only be attributed to the politicisation of disability by disabled people and their organisations: alas, I don't have the space to deal with that here. .

But there is another inference implicit in this claim and that is that the concept 'disabled' cannot accommodate other social indicators such as age, class, sexual preference, gender and ethnicity and so on, that shape our identity and, therefore, that social model thinking and disability politics are somehow inadequate.

Now it's important to remember here that throughout recorded history all forms of inequality, injustice and oppression have been sanctioned in one way or another on the basis of assumptions of biological inferiority.

And that social model advocates have often pointed out that the politics of disablement is about far more than disabled people, it is about challenging oppression in all



its forms as 'Impairment' is not something that is peculiar to a small section of the population; it is fundamental to the human experience.

But 'disability' as defined by the disabled people's movement, is not. Like racism sexism and all other forms of social oppression it is a human creation and that.

'It is therefore impossible to confront one form of oppression without confronting them all' (Barnes, 1996: xii).

***And, finally, it has been claimed that the social model of disability is no longer relevant as it has had little real impact beyond the UK (Shakespeare and Watson 2002).***

As mentioned above, the UPIAS re-definition of 'disability' was adopted by the international disabled people's movement, as represented by Disabled People's International, in 1981; albeit the terms 'disability' and 'handicap' were initially substituted for the words 'impairment' and 'disability' because of concern over the term 'impairment' amongst some DPI delegates. However, DPI Europe subsequently reversed this substitution because of concern over the term 'handicap'.

The issue here is not necessarily the terms used but the meanings to which they are attached; in particular, the redefinition of disability/handicap as social oppression, and the adoption of a 'social model' or social/political analysis of its origins, continuity and abolition.

DPI's influence at the international level, particularly, within the UN is indisputable. A social model perspective is implicit if not explicit in various UN documents. The UN (1993) 'Standard Rules on the Equalisation of

Opportunities for People with Disabilities' is but one example.

A social model perspective played a key role in the recent 'Rethinking Care from Disabled People's Perspectives' sponsored by the WHO's Disability and Rehabilitation Team; a two year project and conference that involved professionals, disabled people, and their families from all over the world (WHO, 2001).

In terms of European Policy, in a recent study entitled 'Disability Policies in European Countries' (2001) Vim van Ooscrhot and Bjorn Hvinden stated:

'(T)he thinking about disability associated with the 'Social Model (of disability) appears to have become more widely accepted' (Oorshot and Hvinden, 2001: 9).

At the academic level the conceptual distinction between the biological and the social and a social model outlook is now evident in much of the writing on disability in other parts of the world. See, for example, in Australia, Gleeson, 1999: Canada, Rioux and Bach, 1994: Michalko, 2002: Titchkosky, 2003: and, the USA, Davis, L. J. 2000: Linton, 1998.

To summarise, the key issue here is that the re-conceptualisation of disability, the social model, and social model theorising, have played a crucial role in the development of a disability studies agenda in terms of clarity, meaning and purpose.

Yet although substantive progress has been made, much of the last decade seems to have been spent going over well-trodden ground, without due rigour and qualification (see for example Shakespeare and Watson 2002: and

more recently Shakespeare, 2006). This for me has been a major disappointment as it has in many ways stifled further and meaningful development of the disability studies agenda. .

This is not to suggest that the principles upon which disability studies, as defined above, are based should not be subject to scrutiny or constant re-evaluation; on the contrary, in my view, they can and will only benefit from such examination.

But surely, the point is to build on what's gone before rather than simply tear it down without having anything of substance with which to replace it. If this is not what disability studies is all about then in my view its future is limited and justifiably so.

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