

# STRUGGLE, SUPPORT AND THE POLITICS OF POSSIBILITY

By Len Barton

*Abstract: Within this paper the nature and importance of a social model of disability will be examined. Particular attention will be given to the voices of disabled people in order that non-disabled people, including academics, can learn from them in terms of their thoughts, writings and actions (Branfield 1999). Conceptual, political and research issues will be raised in the concluding section of the paper and some implications for research will also be highlighted.*

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## Introduction

Disabled people and their organisations have been engaged in the development of a social model of disability, one in which disability is viewed as a major means of social differentiation in society, involving varying degrees of discrimination, exclusion and stigmatisation. This includes, being treated as less than human, being viewed as objects of charity, being excluded from the work force and living on or below the poverty line, being unable to experience the entitlements of citizenship resulting in a lack of real participation in social encounters and decisions over issues effecting their lives (Barnes 1991).

The language we use in our analysis of disability is very important in that it may contain disablist assumptions. Thus, in this paper, the term disabled people is used in order to reinforce a central proposition, that people are disabled by society's reaction to impairment. The disability movement,

including the British Council of Disabled People, prefer this politically more powerful term (Morris 1993).

How we define 'disability' is therefore crucial because it will influence both our expectations and the ways in which we interact with disabled people. Historically disabled people have experienced a range of responses in both official and common-sense discourses including, fear, hatred, pity, over-protection and patronisation. For example, in the later part of the last century and part of this century those individuals diagnosed as feeble-minded or mentally deficient were claimed to be sexually promiscuous and to procreate at an abnormal rate. This was seen as a mark of degeneration and a means of contamination to the quality of the genetic stock. Supported by the alleged scientific evidence of the relationship between disability, pauperism and criminal activities, custodial policy responses were introduced in a desire to both protect society and feeble-minded

girls in particular. These forms of segregated provision included social control as one of their basic treatment objectives. Activities within such institutions were often organised along gendered lines and females were placed in asylums for much longer periods than men on the basis of their being certified insane (Digby 1996). These conceptions received their strongest support from representatives of the new science of eugenics in several societies.

Recognising the centrality of institutional, ideological, structural and material disabling barriers within society is fundamental to a social theory of disability. This approach seeks to place the emphasis on those disabling barriers within society which exclude and discriminate against disabled children and adults. It is an unadaptive, unfriendly and hostile set of material conditions and social relations that cumulatively contribute to the marginalisation, disempowerment and exclusion of disabled people. This is where critical analysis has to focus and the changes have to take place.

The definitional support for the social model is to be found in the statement on Fundamental Principles of Disability which resulted from a discussion between The Union of the Physically Impaired Against Segregation (UPIAS) and The Disability Alliance. The UPIAS (1976) position is quite clear:

*In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairment by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (my emphasis).*

*Thus we define impairment as lacking part or all of a limb, organ or mechanism of the body; and disability as 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 participation in the mainstream of social activities (p.14) (my emphasis).*

This statement as Barnes (1997) notes, has since been broadened to include all impairments, physical, sensory and intellectual and is the official position of the British Council of Disabled People. This perspective is forcefully illustrated by Oliver (1990) in the following way:

*All disabled people experience disability as social restriction, whether these restrictions occur as a consequence of inaccessible built environments, questionable notions of intelligence and social competence, the inability of the general public to use sign*

*language, the lack of reading material in Braille or hostile public attitudes to people with non-visible disabilities (p.xiv. Introduction).*

The level of esteem and social standing of disabled people is derived from their position in relation to the wider social conditions and relations of a given society. This perspective challenges both professional and public perceptions of disability. It involves more than changes to access and resource issues. It is about the struggle for rights, citizenship and anti-discrimination legislation (Equality Studies Centre 1994).

It is essential that we do not underestimate the seriousness with which this task is viewed by disabled people. There are no quick, slick, easy answers to what are fundamental issues as Rachel Hurst (1996) vividly reminds us:

*For disabled people in particular, the interaction between our right to individual freedom and choice and control over our own lives and our rights to non-discrimination and inclusion measures is crucial. Our exclusion has been so systematic and rigorous that there is a need for fundamental changes to society in order to support our inclusion (no page numbers).*

Good will, charity and ad-hoc responses are insufficient to address the

profundity and stubbornness of the discriminatory factors involved (Glendinning 1991; Barnes 1991; Oliver 1993; Morris 1993; Oliver 1995).

For disabled scholars such as Barnes (1997); and Oliver (1996), understanding oppression necessitates engaging a historical perspective through which, on the one hand, the central value system underpinning Western culture and, on the other, the complex relationship between attitudes and the economy need to be carefully examined. This they argue, will contribute to the development of an informed understanding in which ignorance and discrimination will be effectively engaged with.

An awareness of history can provide us with significant insights into the diversity of human existence over time. History is both created and recreated by human action and as Giddens (1986) notes, this is "the double involvement of individuals and institutions" (p.11) in that such struggles also "produce outcomes that they neither intend nor foresee" (p.157). It should also remind us that Western civilisation is not superior to, nor a baseline from which to judge all other cultures. This is particularly important with the impact of globalisation and the demand for a more comparative understanding of disability. Undertaking an historical analysis is a complex task in that we cannot merely read off the present from the past. However, an historical

analysis of language-in-use "helps us to understand past values and social attitudes" (Digby 1996, p.3). Historical understanding cannot guarantee the development of a more socially just and equitable society but through an informed awareness of past conceptions, perspectives and practices, it will hopefully enable us to ensure that the struggle for change is a continuous one (Giddens, 1986).

A significant insight derived from such work is the recognition that disability is a social construction and has meant different things, in different historical periods and cultural contexts. This is reflected in the shift of official categories and their meaning including, 'moron', 'imbecile', 'idiot', 'insane', 'feeble-minded', 'mentally deficient', 'mentally retarded', 'subnormal', 'mentally handi-capped', 'people with learning disabilities' and 'learning difficulties'. These categories are themselves a reflection of particular socio-economic and cultural developments and the differential ways in which policy and service provision are associated with particular conceptions.

As a non-disabled person the social model of disability has raised several fundamental and challenging questions including:

- What do I understand by disability?
- What is required in order for me to listen to the voices of disabled people?

- How do relations of privilege and power influence my work and responsibilities with disabled people?
- How am I complicit in reproducing disabling images and discriminations?

### Struggle

Within this paper the appropriateness of the concept 'struggle' as a significant analytical construct, one which reflects the experience of disabled people, is contingent upon the meaning we attribute to disability. This is not a minor issue, nor merely a semantic one, especially if it is part of a critique of individualistic and medical approaches to this issue. Thus as Degener (1996) illustrates:

*Perceiving disability as a condition similar to illness and exclusively as a functional limitation means that disability is considered as an individual rather than a social problem, and that solutions are searched for in the individual sphere, through therapy and technical or personal support. Thus, neither the society nor the environment have to be changed. The awareness that individual abilities and problems of disabled persons very much depend on attitudinal, architectural and structural barriers of the environment, and on the willingness of society to include or exclude the needs of disabled*

*persons in every designing process, was the crucial factor which turned the disability movement into a civil rights movement (p.13).*

From a social model perspective disabled people are increasingly involved in oppositional politics and a serious challenge to the prevailing system of social relations. They are endeavouring to provide alternative definitions, understandings and insights to those based on exclusionary and demeaning conceptions. They refuse to accept the deficit and dependency role which has historically shaped policies and practices. Thus, they are involved in asymmetrical power-relations and the creation of appropriate strategies and alliances.

Disabled people are involved in a struggle to capture the power of naming difference itself. This involves challenging definitions which isolate and marginalise and replacing them with those which engender solidarity, dignity and inclusion. An emancipatory meaning of difference is one of the goals of social justice.

A serious emerging concern is that of the representation and expression of their voice. This interest in the perspective of disabled people is motivated by a recognition that both as individuals and groups they have been **excluded** from decision-making over a range of issues affecting their lives.

Historically, a major disabling barrier has been that of the role of charity organisations and their contribution to the development of disempowering stereotypes of disabled people. Such organisations maintaining to work on **behalf** of disabled people have been the subject of some of the strongest criticisms by disabled analysts and organisations of disabled people. Historically, these charitable bodies have encouraged the dissemination of impairment imagery that is oppressive and which overwhelmingly presents the disabled person as pitiable, pathetic and overly dependent (Rieser & Mason 1990, and Barnes 1991). In their demonstrations against such activities as Telephon, disabled people have carried placards with the deeply felt slogans of 'Piss on Pity' and 'It is Rights not Charity that we want'.

I wish to contend therefore that the concept 'struggle' is a valuable concept linking personal and political issues and is important because it reminds us that the issues involved are complex and gravely serious. That there are no quick, easy, slick answers to what are fundamental issues. That we must never underestimate the forces to be struggled against. The issues are more than mere resource concerns. They are to do with citizenship, equity and human rights.

### **Support**

Having argued for a social model of disability in which discrimination

and oppression are fundamental features of the disabling barriers within society, it is important to emphasise that this is not just an individual struggle but one in which increasing numbers of disabled people and their allies are engaging in. We need, therefore, to resist portraying disabled people as passive, incomplete, unfortunate recipients of overwhelming constraints and controls, in that this underplays the active agency of disabled people in their struggle for change. Alternatively, portraying disabled people as heroines, or heroes minimises the very real costs of oppression and gives an impression that they can do it alone. Both of these perspectives are unacceptable and counter-productive to the realisation of a social model.

Campbell and Oliver (1996) explore the social and political contexts within which, over a relatively brief period of time, disabled people have gained in strength against enormous odds. These include, chronic underfunding, a lack of faith in the viability of the new movement by many professionals, policy makers and politicians, active opposition on the part of traditional voluntary organisations and finally, because of the general disabling environment problems of disabled people meeting, communicating and organising.

Some analysts view the disability movement as an example of a new social movement in modern societies

(Oliver 1990; Hasler 1993; and Shakespeare 1993). Certainly the membership and influence of The British Council of Disabled People continues to increase. The latter involves the struggle to engender collective solidarity, campaigning for anti-discrimination legislation, independent living and a barrier-free society.

Collective support has been an essential element in the engagement for change, as Evans (1996) notes:

*One of the successes is the pride disabled people find in their organisation. I think that's a great success as well as our sense of identity, our sense of meaning in life. These are important things to me because that's what disabled people's lives are about. It's not living in isolation (p.122).*

This emphasis upon collective solidarity, political consciousness and positive identity is echoed by Wood (1996):

*Discovering our identity as disabled people is very, very important. It's still important today, otherwise people won't value themselves. I think this is probably the biggest success that the movement has been able to point to. It is our movement, nobody else owns it. We know who we are (p.124).*

Nor must such a development be overly romanticised. There are, as with any social movement, serious internal conflicts, dissatisfactions and crucial tasks still to be tackled. There is no room for complacency. The position of disabled black people, gay and lesbian, and people with learning difficulties, in terms of their effective participation within the movement are examples of such difficulties.

The significance of developing support networks of disabled people is contingent upon the degree to which oppression and change are of such an ultimate magnitude that they necessitate collective effort. Support as an organising conceptual tool, reminds us that establishing such networks takes time and effort and includes the development of policies and strategies for the removal of disabling barriers. Collective pride and motivation provide a vitally important antidote to excessive individualism.

### **The Politics of Possibility**

In this paper I have argued that disability must be viewed as a form of oppression and as such it needs to be understood as part of a wider set of inequalities and oppressions. The socio-political perspective adopted is important because it provides a framework in which the voices of disabled people can be heard and engaged with. It also reminds us that current conceptions, policies and practices are neither natural nor neutral.

They are a social creation and as such are subject to change. Finally, this approach gives particular critical attention to the position and responsibilities of government and the political-will required for the development and implementation of appropriate legislation and support.

By breaking out of a subordinate role, refusing to acquiesce to a stigmatised social identity and asserting pride in oneself coupled with the pursuit of solidarity, the disability movement is mounting a serious challenge to discrimination, prejudice and disablist images. Disabled people have a dream, a hope of a future society which, as Morris (1992) advocates:

*.....celebrates difference, a society which does not react to physical, sensory or intellectual impairments, or emotional distress, with fear and prejudice. We want a society that recognises the difficulties we face, but also values us for what we are (p.28).*

The pursuit of such a society needs to be based on an informed *historical* view of *hope*. We, as Apple (1996) contends, "need to recapture our past to see what is possible" (p.177). Hope is essential in the struggle for change in that: It arises from within the context of inequalities and discriminatory social conditions and relations. It is based on the strong conviction that

current situations are not natural, proper or eternal. They can be changed. It emphasises the significance of a vision as a means of motivation and inspiration. It emphasises the importance of understanding the world in order to change it.

However, it is crucial that we should not, as Simon (1987) reminds us:

*....romanticise all dreams about the future. Not all fantasy is benign. The basis of what many people view as a "better tomorrow" sometimes includes the unjust and oppressive disparagement or control over others. Not all dreams are dreams of hope (p. 382).*

Finally, the struggle for change, support, and the politics of possibility involves moral indignation, passion and an openness that does not prevent but encourages critical self reflection, debate over ideas, strategies and intentions.

## Conclusion

In presenting this brief paper I am aware of the dangers of essentialism in relation to the notion of disability, thereby giving the impression of sameness. Disabled people are not a homogeneous group. The difficulties and responses to being disabled are influenced by class, race, gender and age factors. These can cushion or compound the experience of discrimination and oppression. Some individuals experience

simultaneous oppression thereby experiencing differential impact on internal oppression, self-pride and collective identification. Not all disabled people are politically engaged in the way in which the authors referred to in this paper are. Some are prepared to work within the system and seek the minimal of change.

A further related outcome of the analysis offered in this paper is the reminder that the struggle for participatory citizenship, equity and non-discrimination, is essentially **political**. Engaging with injustice, exclusion and inclusion and thereby overcoming policies and practices of regulation and control, requires an identification of the ways in which oppression is structured and legitimated in the taken-for-granted norms, habits and rules of institutions. Thus we urgently need to develop a theory of political action (Eagleton 1996) and difference that is not in conflict with a politics of solidarity.

This also necessitates an engagement with the question of **power** and the role of labels in the legitimation and continuance of exclusionary policies and practices. So for example, the idea of 'normality' is concerned with issues of what is being seen as desirable, or included within a cultural context. When applied to disabled people it can be viewed as tyrannical in that they are always found to be wanting or inadequate. It is this which



Morris (1991) had in mind when she argued that:

*...the non-disabled world assumes that we wish to be normal or treated as if we were. From this follows the view that it is progressive and liberating to ignore our differences because these differences have such negative meanings for disabled people. But we are different (pp. 16/17).*

Disabled people experience anger, frustration, offence because of the ways in which viewing them as 'other' entails varying degrees of isolation, humiliation and marginalisation.

Research itself is subject to serious critique and is often part of the disablist vested interests of non-disabled researchers. The social model of disability encourages us to re-examine the whole question of research, its purpose, practice and outcomes. This includes asking such serious questions as What is the purpose of research? Whose interests is it serving? What right have researchers to undertake such investigations? What responsibilities arise from the privileges we have as a result of our social position? and Does my writing or speaking reproduce a system of domination or challenge it?

Finally, for all of us the following questions remain with regard

to our own societies - What is our hope? What is our vision? How passionate are we over such concerns? Engaging with these questions in societies based on inequalities and exclusionary policies and practices, will involve us in a serious struggle in which the necessity of support will also be increasingly evident.

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