

MODELLING THE SOCIAL MODEL OF DISABILITY

Gerry Zarb, Senior Fellow, PSI, 1995

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INTRODUCTION

This paper sets out to illustrate some of the practical implications of carrying out research which is framed by the social model of disability. In particular, the paper will highlight how research can be used to investigate some of the key issues implied by the social model and to contrast this with research based on the individual or medical model of disability. Most of the discussion will draw on the work we are developing (in association with Colin Barnes at the Disability Research Unit, University of Leeds) as part of a major new ESRC funded project on *Measuring Disablement in Society*. This project sets out to investigate the various forms of disabled peoples' exclusion from key areas of social and economic activity and, most importantly, to demonstrate how the extent of their exclusion can actually be measured.

It is also important to recognise and acknowledge the ways in which the development of this research has been informed by disabled peoples' own agendas. As researchers we clearly have a choice - albeit within the boundaries set by certain pragmatic considerations such as funding criteria, social policy priorities, and so on - about the issues we are going to research; how we are going to operationalise them; and, most importantly, how we intend the products of research to be used. Further, even where there are partial limitations placed upon us by the relations of research production, we do still have a choice about the kind of research processes we engage in. In particular, we have a choice about the extent to which we try and ensure the active involvement of disabled people themselves, not only in carrying out the research, but - more fundamentally - in shaping (or reshaping) the research agenda.¹

Consequently, before moving on to outline what we are actually doing in our research, it is perhaps useful to discuss how and why we came to be doing such research in the first place and the influence which disabled people have had on this process.

PUTTING PARTICIPATORY RESEARCH INTO PRACTICE

Just like any other area of social research, disability research does not occur in a vacuum. The disability research agenda is clearly linked to both policy and - although less directly perhaps - to political agendas as well.

In the field of disability, there is currently the added dimension that disabled people and their organisations are engaged in trying to secure civil rights, while even the government - who were formerly opposed to this - have recently conceded that measures to tackle discrimination against disabled people are now required.

Growing acceptance of the validity of social model of disability has clearly played a part in these developments. At the same time, it has to be said that - until very recently - it was mostly only disabled researchers and disability organisations who actively pursued a research agenda which took the social model as its starting point. Further, one of the main reasons for this state of affairs was that they saw a need to develop alternative forms of participatory research which actively involved disabled people in the research process and, therefore, enabled them to influence the issues which needed to be addressed by research.

The development of a participatory framework for disability research is also closely tied to a wider set of issues relating to developing user involvement in the planning and delivery of services and other sources of support, the extension of citizenship, and a general trend towards consumer sovereignty and public participation. The field of health research, for example, has seen something not far short of an explosion of 'user orientated' research ranging from the relatively crude forms of patient satisfaction surveys, through quality circles, to the direct involvement of users in the evaluation of local health services.

However, there are some crucial yet often poorly understood differences between this kind of participatory research and a genuine emancipatory research framework which goes beyond simply involving disabled people in research over which they do not have any direct control. Essentially, the distinction between participatory and emancipatory research revolves around whether, and in what ways, research contributes to the empowerment of disabled people or other groups who are, or perceive themselves, as excluded from processes and institutions which impact on their day to day lives. At the same time, as Mike Oliver has pointed out, empowerment is not something which can be given but something that people must take for themselves. The key issue, he suggests: *'is not how to empower people but, once people have decided to empower themselves, precisely what research can do to facilitate this process.'*

This has two very important implications for researchers. The first is that, if research is to contribute anything to the empowerment of disabled people then it follows that disabled peoples' own agenda must be the starting point for defining what our research will be about.

The second is that the products of research must be framed in such a way as to allow disabled people to use them as tools in the process of their own individual and collective empowerment. So, in practical terms, the key to participatory research is in the influence this has on setting agendas; on what we will research; and, what we expect the research to achieve.

These considerations have had an important influence on framing the objectives for our current work on *Measuring Disablement in Society*. The aim for this research is not only to document and measure disabling barriers, but also to provide the tools for both disability organisations and statutory authorities to monitor the impact of measures aimed at removing such barriers.⁴

Consequently, it is absolutely essential that we ensure that the kind of barriers we set out to measure are in fact those which disabled people themselves define as the most important in terms of their own experiences. Further, we also need to try and ensure that the way in which we measure them will provide practical information that disability organisations and others will be able to use in their own work. When you also consider that we need to take account of the particular barriers faced by different groups of disabled people (e.g. black disabled people, people with physical and sensory impairments), it is obvious that the project calls for a high degree of consultation and feedback.

Consequently, we are spending the first six months of the project contacting local organisations of disabled people as well as national organisations in all parts of the country. We will also be meeting with all of those which wish to be actively involved in the project to discuss how they want to participate, and what we might be able to contribute to their own work.

THE MEDICAL AND SOCIAL MODELS OF DISABILITY

The objective of addressing the barriers which disabled people themselves see as most relevant to the levels of exclusion they experience also depends on being able to translate these into operational measures which can be subjected to empirical enquiry.

This, in turn, is dependent on a clear understanding of the conceptual distinction between the medical and social models of disability and the practical implications of this distinction for defining what needs to be researched and how.

The distinctions between the medical and social models of disability have been well rehearsed by a number of writers such as Mike Oliver, Jenny Morris, Vic Finkelstein, Paul Abberley, and Colin Barnes. Consequently, there is little need to spend too much time on a detailed discussion of the definition of the two models here. Rather, the main purpose of this paper is to focus on the practical application of these models in the field of research on disability issues. It is, nevertheless, important to be clear about the essential features of the two models as the differences are crucial to understanding why we need to develop different types of methodologies for researching disability.

First, while the medical model sees disability almost purely in terms of individuals and their impairments, the social model sees it as a product of social organisation. The medical model is focused on individuals and their impairments, while the social model is focused on the barriers which disabled people face in their day to day lives - both individually and collectively. In other words, the first crucial distinction is based on where the 'problem' of disability is located - i.e. in the individual or in society.

Second, the difference between where the problem of disability is located logically leads on to a further distinction between the nature of disability. According to the medical model, the nature of disability is essentially about physical, sensory, or intellectual deficits. In other words, a disabled person is disabled by what they cannot do; although it is important to keep in mind that what they cannot do is measured against the normative concepts of the able-bodied world. According to the social model, on the other hand, the nature of disability is essentially about barriers which prevent disabled people participating in social, cultural and economic life. These barriers can be related to societies attitudes to disabled people (e.g. seeing them as objects of pity); economic barriers such as poverty and discrimination in the labour market; physical barriers (e.g. the lack of accessible transport systems); or, political barriers relating to the lack of civil rights to counter discrimination.

Third, the differences in the how the nature of disability is defined lead, in turn, to further distinctions between the proposed solutions for overcoming the difficulties which disabled people face. And, it is in this area where the type of research we undertake becomes most relevant.

As the medical model views the nature of disability only in terms of impairment and impaired individuals, the solutions it proposes - implicitly or explicitly - do not go beyond trying to find ways of trying to 'help' disabled people to accommodate themselves to living with disadvantage.

For example, therapeutic research such as studies on rehabilitation, counselling, or medical treatments concerns itself with evaluating the best ways of helping disabled people to come to terms with their impairments - either physically or emotionally - or with trying to evaluate ways in which some of the effects of impairments can be partially alleviated.

Similarly, research on social security and employment policies has tended to focus on evaluating issues such as the adequacy of benefits or the effectiveness of sheltered employment schemes. Again, this kind of research is primarily about helping disabled people to live with economic disadvantage rather than the ways in which such disadvantage could be removed.

In contrast to this, research which is framed by the social model of disability focuses on investigating the institutions, structures, and forms of social organisation which create the disadvantages which disabled people face. So, for example, rather than seeking to evaluate which is the best way to rehabilitate people with mobility impairments so that they can try and cope with a largely inaccessible environment, research based on the social model would seek to identify why the environment is inaccessible, and how it could be changed to accommodate people who have impairments.

Similarly, although no-one would deny the validity of examining the adequacy of the social security benefits for disabled people, research based on the social model would seek to go beyond this and investigate why so many disabled people are poor in the first place, and what could be done to enable them to become economically independent. For example, research on barriers to employment can focus on what employers can do, either in terms of changes in working practices or investing in appropriate technology, to enable disabled people to compete for jobs on equal terms with non-disabled people. At a broader level, there is also a place for research which investigates how the costs of such investment compare to the benefits in terms of reducing the need for social security benefits and the additional tax revenues associated with greater numbers of disabled people participating in employment.

So, in essence, the medical model of disability is really about impairment and the characteristics of impaired individuals - it is not about disability at all. The social model, on the other hand, is about disablement. In other words, the social model is all about investigating the way in which society disables people who have impairments by failing to accommodate their differences. The main priority for research, then, is to examine the characteristics of a disabling society rather than impaired individuals.

ATTEMPTING TO MEASURE DISABLEMENT IN SOCIETY

The practical consequences of the conceptual distinction between the medical and social models are clearly illustrated by the aims and methodology of the *Measuring Disablement in Society* project.

As noted earlier, one of the most important criticisms made of most existing disability research is that it focuses on disabled individuals and their physical impairments. Numerous 'disability' and 'severity of disability' measures are employed to categorise disabled people and their needs (the OPCS disability surveys for example).¹¹ Similar categorisation is typically employed in making assessments for eligibility for support services and/or social security benefits. This kind of research, which is grounded in the individual model of disability, fails to address the ways in which unsupportive social and physical environments actually cause disability by creating barriers, not only to physical mobility but, more fundamentally, to the full participation of disabled people in social, cultural, economic and political life.

Current debates are centred around the disability as a particular form of social exclusion and the emerging redefinition of disability as a civil rights issue. There is a growing consensus about the need for a social model of disability as the most appropriate tool for analysis of forms of exclusion. However, the social model of disability is largely based on a set of assumptions which, although consistent with existing evidence, has not been subjected to critical scrutiny. Consequently, there is a need for methodological tools which would facilitate empirical research on disabling barriers which underpin such exclusion.

Further, there is also still a significant imbalance between the empirical knowledge base for the social and individual models of disability. Given that the only large scale disability surveys undertaken to date have all been based on the individual model, there has been very limited scope for carrying out alternative kinds of analysis suggested by the social model of disability. In particular, while some of the existing data can be re-examined through secondary analysis, there are no comprehensive sources of primary data on disabling barriers. Consequently, the *Measuring Disablement* project aims to try and redress some of this imbalance by making a start on a systematic analysis of disabling barriers and by developing and testing quantitative and qualitative measures of disablement in society.

In contrast to research based on the individual model of disability, the study is evaluating key areas of social life and organisation in terms of the degree of disablement (ie. exclusion) they create. The particular areas the research is focused on are:

- i) Physical environments (e.g. housing, transport systems, access to public spaces);
- ii) Social and political environments (e.g. the availability of services to promote independent living; opportunities for and barriers to participation in local planning; the extent to which the operation of policies extend or deny the rights of disabled people);
- iii) Economic environments (e.g. levels of participation in employment, social mobility, the distribution of income between disabled and non-disabled people).

All of the data we are collecting is clearly focused on measuring deficits in society rather than in individuals. So, for example, rather than asking questions like how far an individual with a mobility impairment can walk unaided, we are carrying out a national survey designed to measure how much of the existing rail and bus network is accessible to people with different types of impairments. Similarly, we are carrying out surveys on the provision of accessible housing and the degree of access which disabled people have to public spaces and local amenities. We will also be working on the development of tools for measuring the degree to which disabled people are able to influence local planning in areas such as the provision of social services, town planning, building projects and so on.

An important feature of these different research activities is that disabled people themselves will be actively involved both in the design of the research and, most importantly, in testing the research tools in practice. The practical significance of such involvement is clearly illustrated in the area of access. As part of the project we will be carrying out a series of access audits in selected towns and cities. While the design of and planning of these access audits is going through the 'traditional' stages of background research, operationalisation and so on, the audits themselves will be carried out by disabled people who actually live in these towns and cities. This is not only important in terms of developing a participatory framework for the research but, given that disabled people themselves are obviously particularly well qualified to make a direct assessment of any access barriers encountered,

it is also essential for ensuring production of the kind of measures we require. In other words, this approach will actually enhance the validity of the data collected.

Similar considerations apply to the research on barriers to inclusion in the area of social and political environments. Part of the research is concerned with measuring the extent to which local authorities and others are actively seeking to promote and enable the inclusion of disabled people.

In the area of social services, for example, we are collecting evidence on the extent to which local authorities actively promote independent living by looking at levels of expenditure on residential care and other forms of institutional support structures and how these compare with expenditure on self-operated personal assistance and other types of independent living schemes. Similarly, in area of involvement in local planning we are collecting data on the kinds of practical assistance provided to support involvement of disabled people in planning (e.g. transport, facilitation, interpreters), the relative level of local authority expenditure which goes towards supporting organisations 'of' and 'for' disabled people, the extent to which local authority staff are involved with disability equality training, and so on.

All of these kinds of measures will give some indication of the extent to which local authorities are actively seeking to facilitate and promote independent living and the inclusion of disabled people in the planning of policies and services which affect their lives. At the same time, it is essential that we go beyond these measures of processes to look at the impact of such policies on extending equal opportunities and rights for local disabled people. In the context of local planning, for example, we will be carrying out surveys of local disabled people to collect information on levels of awareness about local planning (e.g. how it works, how to access information etc), and - most importantly - whether or not they feel that they are actually able to have any say in decisions which affect their own lives.

Finally, in the area of economic environments we will also be looking at some of the wider structural issues around disabled peoples' position in society and, in particular, the extent to which it is possible to monitor the effects of discrimination and (in the future) the impact of measures aimed at removing discrimination. We are, for example, carrying out a detailed analysis of levels of participation in the workforce in different parts of the country. Closely related to this, we will also be looking at the distribution of wealth between disabled people and other groups in society,

and the impact this has on either maintaining or removing barriers to social mobility.

By these means we hope that the research will help to demonstrate that it is possible to carry out sound 'objective' and empirical research within the framework of the social model of disability. By ensuring that disabled people are fully involved in all stages of the project's development we can also try and ensure that the research addresses some of the issues which are of most relevance to the reality of disabled peoples' lives.

Most importantly, we hope that the products of the research will also be of practical benefit, not only to disabled people themselves, but to all parties with an interest in removing the barriers to disabled peoples' full participation in society. At the end of the day, however good the research is, this will be the most vital criterion for judging whether or not the project has been a success.

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Policy Studies Institute
100 Park Village East
London NW1 3SR