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Researching Disabling Barriers

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INTRODUCTION

This chapter provides a critical examination of research activities based on the social model of disability and, in particular, our current research on the definition and measurement of disabling barriers - the Measuring Disablement in Society[1] project - which is being carried out by the Policy Studies Institute (PSI) in association with the Disability Research Unit at the University of Leeds.

The project is intended to provide a model for undertaking large-scale participatory research based on the social model of disability. In practice there has been a number of significant problems in meeting this objective. Some of these problems have resulted from factors which it would have been all but impossible to predict. At the same time, some of the obstacles - particularly those relating to the structures for supporting the active participation of disabled people in the research -result from contradictions in both the social and material relations of research production and, as such, provide a salutary reminder that there is still a long way to go before the transformative potential of this kind of research can be fully realised. Nevertheless, there is still much encouragement to be drawn from the experience and important lessons to be learnt for the future development of disability research.

DEFINING THE GOALS FOR DISABILITY RESEARCH

Before describing the details of our research, and the practical issues which we have had to address, I would first like to outline some of the guiding principles which underpin both how we have tried to engage in the research and, most importantly, what we are trying to achieve.

The research we are currently engaged in is essentially concerned with investigating institutional social and economic structures and the extent to which these structures contribute to the specific forms of exclusion experienced by disabled people. However it is worth remembering that, as with any form of social activity, research does not operate outside of such institutional structures but is in fact deeply implicated in their construction. It is important therefore to try and retain a critical awareness about how our work can either contribute to or challenge the particular forms of exclusion we are researching. This in turn points to the important distinction between what have been termed the social and material relations of research production. As I have argued previously (Zarb, 1992), while researchers may have a degree of choice over how they engage with disabled people as part of their research activities (i.e. the social relations of research production), the extent to which either party can be said to be directing the overall research enterprise is constrained by the parameters set by funding institutions and policy makers who control the resources which enable them to undertake research in the first place:

> A critical appraisal of our research over the last few years indicates a clear relationship between the level of participation of disabled people in decision making about the research, the extent of consultation during and after the research, and who instigated and funded the research (i.e. disabled people or traditional funding institutions). In other words, the material relations of research production can be demonstrated as constraining the social relations of research production. This in turn has influenced how the objectives of the different projects were defined and operationalised, the kinds of questions we asked, and what happened to the products of the research - including the crucial question of whether or not there were any practical benefits to disabled people' (Zarb, 1992, p.129)

The question of whether or not research brings any practical benefits to disabled people points to one of the other guiding principles underpinning the development of the Measuring Disablement research project. A key objective for the research has been to develop methodologies which would enable us to identify and quantify disabling barriers. This was in part motivated by a need to address the conceptual and methodological criticisms of existing social model research from within the academic and research communities. In particular, the criticism that research based on the social model of disability has failed to provide 'a thought through alternative research strategy, or an adequate approach to the diverse views

and experiences of disabled people in different contexts' (Bury, 1996). While I would have a great deal of difficulty accepting the charge that the social model lacks conceptual clarity, the arguments relating to the perceived under-development of empirical research tools consistent with the social model do seem to have a certain justification. However it is important to recognise that this situation is itself largely the product of existing material relations of research production as, prior to the Measuring Disablement project, the vast majority of funding for large-scale primary research had been devoted to work based on the individual model of disability, thus denying researchers the opportunity to redress the perceived imbalance in the empirical knowledge base supporting these two approaches.

The development of methodologies to redress this imbalance is of more than academic interest however. As noted earlier, our overriding objective was to provide research tools which could lead to clearer identification of disabling barriers, thereby contributing to the process of highlighting the particular forms of exclusion they help to create and maintain. At the same time, any attempt to challenge the criticisms levelled at social model research by seeking to develop greater methodological rigour is a relatively 'risky' enterprise in that the distinctions between competing research paradigms can sometimes appear blurred. Great care is needed therefore to ensure that the orientation of the research to disabled people's exclusion is made explicit from the outset. This is particularly important in the context of expectations about how the products of the research are used and the extent to which our research activities could be said to have any transformative or emancipatory potential.

A crucial but often poorly understood distinction between participatory and emancipatory research is that the former simply involves disabled people in research, while the latter means that the research is actually controlled by them as part of a broader process of empowerment (Zarb, 1992). The active participation of disabled people is therefore a necessary but not a sufficient condition for emancipatory research. Unless disabled people themselves are actively involved in determining the aims, methods and uses of the research then, clearly, it could not lay any claim to having any transformative potential. In this respect I certainly agree with Mike Oliver's argument that the participatory approach does not really go any further than allowing previously excluded groups to participate in the research 'game' whereas emancipatory research is concerned with 'conceptualising and creating a different game, where no one is excluded in the first place' (Oliver, 1997).

My main purpose in drawing the distinction between participatory and emancipatory research however was to offer a corrective to the idea that research carried out within existing material relations of research production could possibly contribute directly to any transformative action with respect to disabled people's position in society. I also wanted to emphasise that - even within these constraints - we are still able to exercise some meaningful choices about how we work with disabled people. In other words, we are still able to exercise some control over the social relations of research production. While accepting that this situation does not fundamentally alter existing power structures, it need not lead us to a completely negative conclusion about the value of the social relations we create or, for that matter, about what the products of our research can achieve.

WHAT CAN DISABILITY RESEARCH ACHIEVE?

As I have already suggested, disability research can only be said to be transformative to the extent that disabled people (and other groups or organisations with an interest in challenging social and material exclusion) are able to use such research as an aid to bringing about changes in the status quo. Indeed, as Barton (1996) has argued, this is (or should be) the litmus test for the whole sociological enterprise and is not in any way the exclusive concern of either disabled people or disability research.

Following the publication of the special issue of Disability and Society in 1992, there has been an ongoing debate about the nature of participatory and emancipatory research and some commentators have - quite rightly - continued to question whether any disability research to date could be said to have passed the test of contributing to the empowerment of disabled people (see chapter 2 by Mike Oliver in this volume). However, while sharing in much of this scepticism, I do not believe that the situation is entirely negative. Indeed, I would go further than this and argue that there are practical examples of research which has, and will continue to, contribute to the process of emancipation among both particular groups, and among disabled people as a whole.

The fact that these are still vastly outnumbered by research projects which have at best done nothing to contribute to the process of empowerment and, at worst, have often helped to shore up disablist social structures should not distract our attention from the transformative potential of the few exceptions to this rule. Similarly, while none of these examples are without their contradictions and limitations, this does not mean that they

should be rejected out of hand. Emancipation is not an event or series of events with a fixed beginning and end. Rather, it is an ongoing dialectical process of growth and development which, as the history of the disabled people's movement itself illustrates, is essentially characterised by conflict and resolution. It should not be surprising, therefore, that disability research is also characterised by contradictions which remain to be fully resolved.

The most important example of research which has contributed to the empowerment of disabled people is probably the work on disability and discrimination carried out by Colin Barnes for the British Council of Disabled People (BCODP) (Barnes, 1991). The subtitle for this research was 'the case for anti-discrimination legislation', reflecting one of the principal aims of the research which was to help bring about the introduction of civil rights for disabled people. While the disabled people's movement has not yet succeeded in its aim of securing comprehensive civil rights, it is undoubtedly the case that the evidence compiled by this research has provided a bedrock on which to base the campaign for achieving this goal and will continue to do so as the history of the campaign for civil rights unfolds. As Rachel Hurst (1995) has pointed out, the BCODP commissioned research on disability discrimination has been a major influence, not only in terms of reformulating disability as a rights issue, but also in terms of shaping the agenda for disability research:

> 'Within this country I would like to say that I think the disability movement has played a major role in the whole battle, this whole struggle at the international level, partly because we have been so marginalised here. As a result we have turned ourselves into thinkers and articulators and that articulation and that thinking about our oppression have been very useful tools. The book that BCODP[2] published in 1991 on disabled people and discrimination in the UK has been the basis for people's thought throughout Europe and in fact there is now going to be a research study throughout Europe based on the findings in that book. It is very important' (Hurst, 1995: 94-5).

In practical terms, one of the key contributions of the research was to refute the arguments that disabled people do not experience structural discrimination. As Richard Wood has pointed out, the research also helped to support a series of civil rights bills in the UK parliament and,

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[2] Barnes (1991)

despite the fact that none of these were successful, the evidence it presented has nevertheless been of fundamental importance in maintaining the disability rights campaign (Wood, 1996). Similarly, our current research on disabling barriers - which builds on this earlier work - is developing practical tools for measuring the extent of particular sources of discrimination which are intended for disabled people and others to use in their own efforts to monitor and challenge such exclusion. As noted in the extract from Rachel Hurst, the BCODP research on discrimination has also had a similar influence on other disability research projects which may, in turn, contribute to the ongoing struggles for comprehensive civil and human rights legislation, both nationally and internationally.

There have, in addition, been recent examples of research which has contributed directly to specific changes in policy or practice. More generally, there have been research projects which have contributed to making visible the experiences of particular groups of disabled people, thereby directly challenging the particular forms of exclusion and marginalisation which they face.[3] An example of the former was the work on direct payments which PSI carried out on behalf of BCODP (Zarb and Nadash, 1994) which effectively demonstrated the validity of the independent living movement's claims that direct payments were a more cost-effective solution to meeting disabled people's personal assistance needs than dependency creating services. As John Evans and Frances Hasler (1996) have pointed out, the research commissioned by BCODP has made a major contribution to the campaign for legislation to bring direct payments into the mainstream of social policy:

> 'Our research was the first study to combine the issues of cost and quality. It showed that on both counts direct payments are preferable, both cheaper and better. Information from our research was used by our allies in persuading the politicians to bring in direct payments. ... Interestingly enough, a week before the BCODP/PSI launch of the Direct Payment research findings, the Minister of Health announced that it was the Government's intention to bring about Direct Payments legislation in the next parliamentary year. We were ecstatic! After five years of campaigning vigorously, we had achieved the beginning of our main goal. We were more than pleased that the research and the lobbying had the impact that we were hoping for' (Evans and Hasler, 1996)

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[3] See for example Shakespeare *et al* (1996) and Vernon (1997)

A key feature of the particular examples noted above is that they were either commissioned directly by accountable organisations controlled by disabled people (i.e. BCODP) or, as with our current research on *Measuring Disablement in Society*, explicitly influenced by disabled people's agenda on the important issues which research should be addressing. Another important feature which they share is the active involvement of disabled people in both defining and carrying out the research. Colin Barnes' research on disability discrimination for example was one of the first of many projects carried out by the Disability Research Unit at Leeds. Similarly, the research proposal which led to the work on direct payments was drawn up by members of BCODP's Independent Living Committee prior to the research being commissioned, while nearly all of the interviewing for the project was carried out by disabled people who were themselves personal assistance users. Disabled people have also been actively involved in both the design and execution of our current work on disabling barriers.

ABOUT THE MEASURING DISABLEMENT IN SOCIETY RESEARCH

The Measuring Disablement in Society research project was started in summer 1994 and is now due to be completed by the end of 1997. The project is intended to provide empirical evidence on the physical, social and economic barriers faced by disabled people and attempts to demonstrate how such barriers can be measured. 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 (i.e. exclusion) they create.

In practical terms, the project is essentially a methodological one. As noted earlier, one of the main criticisms levelled against social model research has been that it has lacked fully developed methodologies which would allow some of the primary propositions contained in the model to be subjected to empirical analysis. By attempting to at least make a start on developing such methodologies it is hoped 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.

All of the data we are collecting is clearly focused on measuring deficits in society rather than in individuals, which is of course the primary focus for research based on the individual model of disability (Zarb, 1995a). So, for example, rather than asking questions like how far individuals with mobility impairments can walk unaided, we have carried 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 empirical analysis on the provision of accessible housing and the barriers to disabled people's access to public spaces and local amenities. We have also done work on developing tools for measuring the degree to which disabled people are able to influence local planning in areas such as the provision of social services and town planning. We are currently (summer 1997) carrying out an interview survey on disabled people's objective experiences of different forms of disablement such as educational disability, employment disability, information disability and so on, while the final part of the project will be focused on quantitative analysis of social and economic exclusion at national and regional levels.

However, this emphasis on the objective and measurable dimensions of social exclusion may, in itself, leave the project open to the counter-criticism that the research ignores the subjective or experiential aspects of discrimination. Honesty requires an admission that this was not considered to be a major concern at the outset. However, recent debates about the social model of disability among disabled people and researchers do raise important questions about the extent to which our emphasis on structural issues might disguise and/or distort these experiential dimensions of disablement. Indeed, this issue has been the subject of debate with some of the organisations of disabled people who have been closely involved in the project's development and this has resulted in modifications being made to certain aspects of the research methodology. The parts of the research dealing with access barriers, for example, have undergone considerable modification from the design originally planned. While the original focus was on attempting to quantify particular physical features of buildings and places, this has now been supplemented by an experiential design which focuses on the ways in which disabled people actually use buildings and public spaces in the course of carrying out their day-to-day activities.

HOW THE PROJECT HAS BEEN CARRIED OUT

The first six months of the project were taken up with wide-ranging consultation between the researchers and numerous local and regional organisations of disabled people, government departments and other groups with an interest in different types of disabling barriers. While this process has, to a certain extent, been on-going, the main wave of consultation was used to inform the methodological design of the project and to identify ways of defining and measuring the different types of

disabling barriers to be covered by the research. These initial plans are subsequently being refined in consultation with local organisations of disabled people and other organisations in the two case study areas in which the main stage of field work is located.

We also organised a major two-day conference on the theme of 'Removing Disabling Barriers' which was held at the Policy Studies Institute in September 1994. Papers presented at the conference -mostly by leading disabled academics and activists - drew together the evidence on the extent and causes of discrimination and disadvantage faced by disabled people and examined the policy options for removing the barriers to disabled people's participation in social and economic life (Zarb, 1995b). The conference has also made a very useful input into the development of the project and, perhaps more importantly, provided an important platform for generating interest in the ideas on which it was originally based. The fact that the conference was held at a time when the campaign for civil rights legislation was in full-swing certainly added an edge to the proceedings. The energy generated by participants during those two days probably did more to contribute to the empowerment of disabled people than anything else the project has done since.

The research team has also been working with local authorities and local organisations of disabled people in two case study areas - Manchester and Leicester - where the second stage of the research is located. Local disabled people are also being recruited to carry out some of the fieldwork in these areas, including the access surveys mentioned earlier. This part of the research involves a more detailed investigation of barriers at a local level and provides an opportunity to develop and test different ways of measuring levels of inclusion and exclusion which, hopefully, local authorities and local disability organisations might be able to adapt for their own use after the project has finished. Consultation with local organisations of disabled people has been undertaken at each stage and will continue up to and including the production of the final set of findings from the research.

BARRIERS TO DEVELOPING INCLUSIVE RESEARCH PRACTICE

As discussed earlier, it has always been the intention that disabled people should be actively and closely involved with both the design and execution of the project. In practice this involvement has taken a variety of forms including the recruitment of disabled researchers, the involvement of local organisations of disabled people as paid consultants to the project, and the canvassing of comments on our proposed research

plans from a number of local and regional organisations in both the case study areas and elsewhere. In terms of the scale of disabled people's involvement, this aspect of the project has been relatively successful. However, there have also been some significant practical problems along the way which have created obstacles to disabled people being as fully involved as we had intended.

Three main areas of difficulty have been encountered: the employment of disabled researchers; the resources required to facilitate the maximum involvement of local disabled people; and conflicts between the need for such involvement and the institutional constraints posed by the material relations of research production.

Turning first to the issue of employing disabled researchers. In one of the keynote presentations at the national conference held to mark the end of the 1991-92 Disability Research seminar series, Vic Finkelstein outlined an agenda for change in the way research is carried out. One of the key issues highlighted in his presentation related to the active involvement of disabled people through their employment and development as researchers. This is not only important in terms of utilising disabled people's experience and expertise to inform the content of research, but also in terms of directly challenging social and economic exclusion:

> '...as long as disabled people avoid, or are discouraged from, participation in research into their own affairs they will remain passive and dependent upon others. This means that the "subjectivity" of disabled people should be regarded as an "objective" asset, to be cultivated in the research setting' (Finkelstein, 1992)

This was certainly one of the guiding principles informing the organisation of the Measuring Disablement research. In addition to involving local organisations of disabled people in the project's development, we were also keen that new researchers recruited to work on the study should be disabled people. Indeed at the outset, both research posts which we needed to fill were advertised on the basis that priority would be given to disabled applicants and this intention had also been specified in the original funding application made to the Economic and Social Research Council (ESRC). In taking this step we were aware that, as a result of the limited opportunities available to disabled people wishing to develop research careers, we were not certain to receive a large number of applications from people able to offer both a range of practical research experience and a detailed understanding of the

application of the social model to research on social and material exclusion. While the former obviously offers practical benefits, this can - as Vic Finkelstein suggests - be developed through training and on-the-job experience. Consequently, we were much more concerned to ensure that researchers employed to work on the project were able to demonstrate an awareness of some of the fundamental research issues around disabling barriers.

However, in practice, we soon found that there were considerable obstacles to achieving this seemingly straightforward objective. The problems started more or less straightaway as the first round of recruitment failed to produce any applications at all from disabled researchers. Consequently, the post had to be re-advertised, with the result that the start of the project was delayed for three months. The fact that we were initially unable to shortlist any disabled applicants also led to questions being raised within the Institute about whether or not we should be insisting on the post being filled by a disabled researcher. It was suggested that we needed to be sure that this would offer a particular kind of expertise which we could not have accessed by other means.

Other questions were raised - both on that occasion and in subsequent recruitment rounds - about the potential difficulty in managing the tensions between the 'subjective' and/or 'political' dimensions of disabled researchers experiences and the 'objectivity' of the research - particularly if they were, or had been, directly involved in the disability movement. This was not so much an internal concern but, rather, reflected our awareness of how the organisation and direction of the project might be viewed by those seeking to detract from the validity of social model research. As Finkelstein (1992) has argued, disabled people who become involved in this kind of work:

> '...often do so as a result of personal experience and this brings the subjective element out into the open. This subjectivity is immediately identified as a danger (while the able-bodied subjectivity goes unrecognised) and the applicant for the job can then be regarded as unsuitable' (Finkelstein, 1992)

While we were of course aware of the potential tensions in the relationship which a politically conscious disabled researcher might have to the research, it was understood that this was, in a sense, 'part of the deal'. Indeed, given that we were actively seeking researchers with an appropriate level of understanding of issues around social and material exclusion it would have been unrealistic to expect anything else. Rather,

this subjectivity can be regarded as an asset in the context of disability research. This does not mean that any tensions and contradictions which do arise should be swept under the carpet, nor that we never have to face some difficult choices about the positions we adopt in a public setting. However, the primary aim in managing this relationship has always been simply to try and ensure that the subjective consciousness which disabled researchers bring to the project remains analytically focused.

The main difficulties in practice arise when we engage with the external world as there are always those who seek to challenge the validity of research which is suspected of diverging from the canons of 'scientific objectivity'. Our main 'weapon' in trying to deal with this kind of opposition has been to focus on the methodological rigour of the research through the adaptation of conventional research methods and through development of alternative methodologies informed by the social model. However, there is a sense in which this approach can be interpreted as a subordination of disability research to the ideological version of 'objectivity'. Further, while we did already have some awareness of this potential contradiction at the outset, it is certainly the case that the involvement of disabled researchers in the project has contributed to a heightened consciousness of the compromises which this involves. As a result there have been occasions when, because of the questions raised by disabled researchers, certain aspects of the project's methodology have been re-examined and/or altered in an attempt to make them more experientially grounded. The fact remains however that the project is still essentially seeking to meet head-on the methodological criticisms of social model research on the grounds that this is the best way to refute them. Only time will tell if this pragmatism has been successful and whether the compromises which have had to be made along the way have been worthwhile.

The second main area of difficulty associated with recruiting disabled researchers to work on the project relates to the organisation of the research and the structural barriers to accommodating the individual needs of the researchers involved. For two of the three disabled researchers who have worked on the project, this was either their first job since becoming disabled, or their first after an extended period out of employment. In both cases, therefore, the individuals concerned viewed their employment as 'experimental' in the sense that neither they nor the Institute could be sure either about how they would cope with the demands of the job, or exactly what accommodations might need to be made in terms of working arrangements. In the event, these turned out to be quite substantial.

For example, all of the disabled researchers recruited to work on the project requested, either at the outset, or not long after joining the project that they work on a part-time basis and/or work mostly from home.

Although this is not a major problem in itself, it did require a fair amount of re-organisation in terms of team working, as well as the arrangements which needed to be made in order to try and avoid researchers becoming isolated from their colleagues. The restrictions on availability, combined with the considerable difficulties which two of the three researchers experienced with trying to use inaccessible transport systems, also meant that fieldwork (e.g. meetings with local organisations of disabled people, research interviews and so on) often needed to be re-allocated to other members of the research team or, in some instances, involved extra expenditure on providing accessible overnight accommodation so that the researchers did not have to undertake long journeys all on the same day.

All of these employment related issues were of course largely under our own control in the sense that, financial considerations aside, we were able to exercise choice over the accommodations which needed to be made. However, on this particular project we have also had to deal with the consequences of unforeseen problems relating to extended periods of sick leave and the impact which certain aspects of the work (particularly travel) have had on the researchers involved. While it would be inappropriate to go into any detail about the personal circumstances involved, it is the case that for reasons relating to either impairment or sickness, all three researchers found it necessary to leave the project after less than a year in post. It is also the case that the difficulties faced by these workers were added to by the very long delays in obtaining suitable equipment such as an adapted workstation, voice controlled computer software, and an electric wheelchair through the Access to Work scheme. (In fact, some of this equipment only arrived after the researcher concerned had already left!) The delays created by the necessity of readvertising the post each time, and the work lost due to ill-health, were detrimental to the project.

Statistically, the chances of three consecutive post-holders having to leave their jobs in this way must be viewed as pretty remote. We know from our contacts that other organisations employing disabled workers have had nothing approaching this level of sickness and staff turnover. To say that both the project and the workers involved have been unlucky would therefore be something of an understatement. The main purpose for recounting this sorry tale, however, is to examine the practical consequences which such eventualities have had for the project and, in

particular, what our experiences can tell us about the social and material relations of research production.

The first point to note is that any research organisation faced with this set of circumstances will have to deal with some difficult choices about how to respond and about the extent to which they are able to support the researchers involved. I would like to think that we have been as flexible as possible in terms of trying to enable the individuals concerned to carry on working by making changes to working arrangements, accommodating periods of reduced productivity and - in one case - being prepared to hold the job open indefinitely rather than looking to terminate the contract after six months sick leave (as often happens elsewhere). In one sense these were not difficult choices as it was of course in our own interests to try to retain the services of able and talented researchers who we had been keen to recruit in the first place. At the same time, we were also aware of the practical difficulties this can create in terms of keeping the project on schedule (which we have failed to do) and the negative impact on the project's financial resources (the equivalent of at least 60 working days were lost as a result of these problems).

The most significant consequences of these staffing problems however were those relating to the relationship between ourselves and other organisations involved with the research, particularly the project's funders.

First, the protracted delays in progressing the research have had a negative impact on relationships between the research team and some (but, fortunately, not all) of the local organisations of disabled people with whom we have been working. Not surprisingly, the fact that we have not been able to deliver all that was promised from the research has meant that the considerable enthusiasm about the project which they expressed at the outset has gradually been replaced by varying degrees of cynicism, frustration and apathy. While it is to their great credit that the organisations concerned have not abandoned the project altogether, a considerable amount of effort is having to be spent on repairing this damage so that we can move forward together towards bringing the research to a satisfactory conclusion.

Second, the delays resulting from long-term staffing problems on the project have had very serious consequences for our relations with the organisation funding this research. As noted earlier, we have done our best to accommodate an unusual and unfortunate set of circumstances. However, the impact which this has on a research organisation's ability to

cope with this kind of situation is obviously affected by the existing material relations of research production. As Barnes (1996) has pointed out, some disabled workers (particularly if they have 'unpredictable' or intermittent impairments) are always likely to experience a need for 'a more flexible and less demanding work schedule' from time to time and that this needs to be taken into account by funders:

> 'Clearly, if we are serious about encouraging disabled people to enter the research field then these concerns must be accounted for in all future research prop9sals and research agendas. Moreover, funding agencies must also recognise that these are legitimate considerations and they must be encouraged not to discriminate against research organisations and researchers who adopt such a policy when awarding research contracts' (Barnes, 1996).

Unfortunately, in this particular case, the research funding body has not been able to accommodate the difficulties we have experienced as the regulations covering the funding for this project include specific and strictly enforced sanctions against failure to complete projects within the agreed timescale. This has resulted in the balance of the funding for the research being withheld. Together with the resources which we have already lost through extended periods of sick leave, this has created a shortfall in excess of £20,000. Commitment to the project is such that some members of the research team have volunteered to take unpaid leave in order to finish the work on the project. This will still leave some funds to be found from PSI's reserves. This has also meant that we have had to scale down some aspects of the consultation process, thereby reducing the extent of disabled people's involvement in the final stages of the research.

Again, this is in some ways an atypical situation. Nevertheless, our experience does also highlight some wider issues relating to the economics of doing disability research as some of the problems we have encountered are clearly endemic to the way in which the material relations of research production are organised.

The intense competition for research funding over recent years has led to many elements of research budgets being 'squeezed' in order to meet the increasing demands for 'value for money' from sponsors. There are a number of negative consequences of this trend which, as Colin Barnes has pointed out:

'has important and worrying implications for those of us trying to develop a more emancipatory research agenda... particularly with reference to disabled researchers' (Barnes, 1996).

This has certainly been the case with the Measuring Disablement research as several items of expenditure relating to both the employment of disabled researchers (e.g. expenses for facilitation and/or personal assistance), and the involvement of organisations of disabled people in the research (e.g. consultation fees) were declined at the time the research grant was awarded on the grounds that these were 'exceptional items' which the funding body was unable to support. Further, while a proportion of this additional expenditure could be offset by support offered though the Employment Service Access to Work scheme, in practice, this only applied to certain items of equipment and a partial contribution to travel expenses which has resulted in the costs having to be met from our own resources.

Similar comments apply to the costs of facilitating the involvement of local disabled people in the two case study areas. Again, some of these expenses - particularly consultation fees for the local organisation of disabled people advising the project on the design of the research -had to be met from our own resources by transferring funds which should have been used to pay for our own research time. In one case there have been additional expenses associated with the fact that many members of the local organisation of disabled people are Asian and require translation and interpreting services to facilitate their participation. Fortunately, these costs have subsequently been met by additional funding from the City Council concerned (Leicester). Altogether, the costs of facilitating the involvement of local disabled people in the two case study areas have amounted to around £10,000 yet none of these items was considered eligible for funding through the research grant mechanism.

CONCLUSIONS

Even without the additional staffing problems which have dogged the project all the way through, it is clear that the material relations of research production are far from ideal in terms of supporting the model of participatory research which we have been trying to follow. Nevertheless, I hope that the experience of the Measuring Disablement project, and other research projects based on similar principles, has demonstrated at least some of the possibilities for progressing the development of participatory research -despite the obstacles which exist. Whether or not such research can deliver anything beyond this in terms of contributing to

the transformative process required by the emancipatory paradigm remains an open question. However, this is really a question which only disabled people themselves can answer and one which, ultimately, depends on the uses (if any) they and others find for the products of research. I remain optimistic that at least some of the products of our research will - eventually - pass this test but, as ever, only time will tell.

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