

CHAPTER 6 (in 'Doing Disability Research' edited by Colin Barnes and Geof Mercer. Leeds, The Disability Press, pp. 88-107).

## Who's Research ?: A personal audit Mark Priestley

### INTRODUCTION

This chapter is based on my experience of 'doing' disability research in collaboration with the Derbyshire Coalition of Disabled People (DCDP) and Derbyshire Centre for Integrated Living (DCIL). I do not propose to discuss the organisations themselves in detail here. Suffice to say that DCDP was the first formal 'Coalition' of its kind in Britain and DCIL the first centre for independent/integrated living (Davis & Mullender, 1993, offer an excellent account of these developments). The project itself provided an empirical basis for my PhD thesis, a case study of quality issues in community care purchasing (Priestley, 1997). However, it also raised many fundamental issues about the very act of doing disability research.

The act of researching disability has become increasingly problematised as disabled people have begun to examine more critically the relationship between themselves and the researchers who have studied their situation. Such critiques have led to the development of an alternative 'emancipatory' paradigm for disability research which has much in common with feminist, anti-racist and anti-imperialist research methods. The key features of this model include a redefinition of the social relations of research production, a rebuttal of positivist and interpretative claims to 'objectivity' and assertions about the political position of the researcher (see Stone & Priestley, 1996).

With this in mind I was aware that the established social relations of research production give rise to inequalities of power between researcher and researched. One of the major challenges for me was then to redress the balance of 'vulnerability' in this process (see Stanley & Wise, 1983: 206). I wanted to find out whether it would be possible to produce an academically credible piece of disability research simply by placing my skills 'at the disposal' of the research participants (Barnes, 1992: 122). I wanted to see how far the research production process could be collectivised amongst its participants. I wanted to establish whether the radical agenda of emancipatory research could be realised in any

meaningful way. In order to show what happened I will begin with the theory and then examine the practicalities of 'doing' the research.

## THE POLITICAL POSITION OF THE RESEARCHER

Abberley (1987) argues that the sociology of disability has remained 'theoretically backward' because it:

'reproduces in the study of disability parallel deficiencies co chose found in what is now seen by many as racist and sexist sociology' (p.5).

These deficiencies are evident in the fact that the dominant discourses of disability research have tended to reproduce two sets of disabling social relations - first, between people who 'do' research and people who are 'being' researched and secondly, between disabled people and non-disabled people in the wider world. Thus, I believe that it is inappropriate for researchers to consider disability research production as an activity discrete from its social context.

Abberley (1987: 141), describes how disabled people have been treated predominantly as 'passive research subjects'. This has been true not only of large-scale quantitative surveys (such as those carried out by the Office of Population Censuses and Surveys - OPCS -in 1985) but also in approaches to research interviewing which accept rather than challenge the disempowerment of disabled research subjects - a tendency well-documented within the feminist research literature (see Oakley, 1981). In so doing, such research may easily reinforce existing feelings of passivity or exclusion amongst its participants.

This objectification (or subjectification) of disabled people through research production has been premised upon the maintenance and reproduction of disabling social relations and discourses within the production process itself (Oliver, 1992: 102). Problematizing the social relations of research production brings into question power relationships between the researcher and other participants. This in turn has profound implications for their respective roles in the research production process. In seeking to expose and redefine oppressive social relations in the wider world, new social movements (including the disabled people's movement) have de facto challenged many of the mores of social research. In this respect, feminist critiques of 'objectivity' have been among the most significant (Smith, 1988; Stanley, 1990). Similarly, claims to objectivity by disability researchers have been increasingly

characterised as methodological collusion with an oppressive discourse which marginalises or subordinates the experience and self-determination of disabled people (Zarb, 1992).

This process was most graphically exposed by Hunt (1981) writing about his experience of being researched as a resident of the Le Court Cheshire Home. Hunt condemned the researchers' self-imposed obsession with 'detachment'. For Hunt, such claims were inherently flawed because they were made within a context of oppression. Similar experiences have led many disabled writers to consider the notion of detached objectivity as a falsely premised, if not inherently oppressive, epistemological standpoint for disability research.

The realist challenge to positivism posed by emancipatory social movements is further accentuated when the subjects of the research are those same social movements. Thus, Touraine (1981: 29) argues that it is difficult for the student of social movements to arrive at an understanding of them other than by identifying with them. Touraine's approach to action research with social movements states openly that the purpose of the research is to 'contribute to the development of social movements' (p. 148) and envisages permanent change in the movement effected by the research. Thus, Touraine concludes (p. 198) that while participant observation can provide 'superficial information', a more productive approach is that of 'committed research'.

## TOWARDS A MODEL FOR DISABILITY RESEARCH

Disabled people and disability theorists have responded to the kind of issues I have discussed so far by seeking to formulate new methodologies commensurate with the emancipatory struggles of the disabled people's movement. Such moves have been consolidated in recent years with the articulation of an 'emancipatory' paradigm for disability research (see for example, the 1992 special edition of *Disability, Handicap & Society*, Rioux & Each's (1994) collection or indeed the contributions in this volume).

In a recent paper with Emma Stone (Stone & Priestley, 1996) we reviewed these developments and identified six core principles which we felt characterised the emancipatory research paradigm as follows:

1. the adoption of a social model of disability as the ontological and epistemological basis for research production;

2. the surrender of falsely-premised claims to objectivity through overt political commitment to the struggles of disabled people for self - emancipation;
3. the willingness only to undertake research where it will be of some practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers;
4. the devolution of control over research production to ensure full accountability to disabled people and their organisations;
5. the ability to give voice to the personal whilst endeavouring to collectivise the commonality of disabling experiences and barriers; and
6. the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.

In presenting these arguments, it was important for us to consider how we might address the social relations of our own research production *vis-à-vis* the disabled people with whom we sought to work. At the same time, we found it necessary to satisfy academic peers and examiners. For better or worse it is the academy, rather than disabled people at the grass roots, who pass judgement on a submitted thesis! It was often hard to conceive how this balancing act might be successfully achieved, to which end we prioritised those aspects of the emancipatory model which we saw as mitigating the potential 'tug-of-war' between academic-self and political-self. In problematising our role as non-disabled researchers we highlighted four areas where we anticipated methodological difficulties, namely:

1. the contradiction between surrendering control and maintaining integrity;
2. the tension between accepting our expertise as researchers whilst accepting disabled people's expertise as knowers;
3. the problem of collectivising analysis within a social model where that model is not necessarily part of the participants' own understanding of disability; and
4. a recognition that positive outcomes in individual lives need not be the sole criterion of 'good research' where a real contribution can be made in a wider context.

I have suggested (after Oliver and others) that the emancipatory research paradigm challenges the established social relations of research production. Thus, disabled writers have argued that the researcher needs to engage directly in the emancipatory struggles of disabled people by laying her/his research skills 'at the disposal of disabled people' (Barnes,

1992: 122), 'for them to use in whatever ways they choose' (Oliver, 1992: 111) and 'turning the researcher into a resource for their new employer' (Ramcharan and Grant, 1994: 237).

Zarb (1992) points out that simply increasing levels of participation does not necessarily challenge or alter the social relations of research production. The emancipatory model requires more. In my view it suggests a collectivisation of ownership over the means of research production and distribution to include all the research participants rather than just the 'researcher'. Since participation is not synonymous with emancipation, it was important for me to consider how I might translate participation into control during the course of my study.

In the remainder of this chapter I will focus on the form and content of my involvement with the research participants in order to show how we worked out this dialectic in practice. I have chosen to adopt a personal and reflexive narrative in order to do this, partly to facilitate the kind of methodological 'vulnerability' mentioned earlier and partly because it is the most direct way of illuminating the processes involved in 'doing' disability research.

## SETTING UP THE PROJECT

In the first part of this chapter I have set out the theoretical framework for my approach to disability research in a fairly aspirational way. The study was in this sense driven from the outset by my political and methodological commitment to engage directly with these issues. The purpose of the following discussion is then to illustrate how this framework influenced the way in which I set about the project. In particular I will examine the formulation of an appropriate research agenda, the choice of specific research questions, funding issues, epistemology and control. Later I will deal with the practicalities of data collection, analysis and dissemination.

## DETERMINING THE RESEARCH AGENDA

My initial interest in disability research was prompted both by my previous employment as a rehabilitation instructor (with visually impaired people) and by my academic interest in political theory. During the 1980s I had become increasingly aware of inherent contradictions between the ideology of 'care' and 'rehabilitation' within which I was professionally cultured and the ideology of self-empowerment advocated

by the emerging disabled people's movement. My increasing exposure to the self-organisation of disabled people at a local level and to work of social model writers such as Vic Finkelstein, Mike Oliver and Jenny Morris served to further illuminate these contradictions.

The opportunity to explore some of these issues in an academic context came in 1993 while I was studying for a Master's degree in Social and Public Policy at the University of Leeds. As a dissertation project, I was able to work closely with the Association of Blind Asians (ABA) in Leeds in order to witness, record and support their struggle to develop new modes of collective welfare provision based on self-advocacy and mutual support (Priestley, 1994b; 1995; 1996a). In particular, I became increasingly interested in determining how the new community care reforms might be exploited by disabled people's organisations in Britain to promote more participatory modes of welfare production.

The ABA study was conducted as far as possible within an emancipatory framework. For example, the research participants were encouraged to exercise a determinant influence over the design, conduct and dissemination of the study. Although this was a small-scale project it did demonstrate that accountability could be effectively widened in the research production process without compromising academic integrity. It was the success of this project above all that shaped my personal agenda for further study and I became increasingly interested in developing further the co-participatory methods which I had adopted.

## DEFINING THE QUESTION

Although I was developing my own research agenda, I also wanted to establish whether a credible piece of academic policy research could be conducted within an emancipatory paradigm. If this was to become any sort of reality then co-participation had to begin with the definition of a suitable research question. I wanted if possible to embark on a commitment to the new project without any pre-determined research question. Admittedly this is a somewhat unusual and rather vulnerable position for the would-be-researcher and later I would often question the logic of my approach. However, my hope was that by engaging with the participants at the very outset we could work together on defining a research proposal over which they could claim ownership.

At the suggestion of Colin Barnes I wrote, in December 1993, to the then chair of Derbyshire Coalition of Disabled People, Ken Davis, outlining

my interests and offering my services for any project that might be useful to the development of the movement. A meeting was arranged between myself, Ken and the research manager at Derbyshire Centre for Integrated Living (Dave Gibbs) during which we discussed the social policy issues facing disabled people's organisations and whether these might form the basis for a PhD. Not surprisingly, implementation of the NHS and Community Care Act earlier that year figured prominently in this discussion.

It was clear that the unfolding purchaser-provider reforms required DCDP and DCIL to re-evaluate their historical relationship with the agencies of the local state. There was much concern that unique support services developed by disabled people in partnership with the local authority might now be threatened by the new contracting criteria. Specifically, it was felt that new criteria for service quality measurement might fail to recognise the 'added value' of an integrated living approach. In view of this it was suggested that I might use my research opportunity to develop an approach to quality measurement which would give due credit to the kind of services developed by the integrated living movement in Britain.

It is important to acknowledge the significance of my organisational affiliation with Leeds University at this stage in the research process. My advances would no doubt have met with rather more scepticism without the backing of Colin Barnes in the Disability Research Unit. The fact that I was being supervised by people publicly committed to social models of disability, with a proven track record of co-participatory research and with directly accountable links to the British Council of Organisations of Disabled People was thus a critical factor in the gatekeeping process. There are few guarantees for disabled people engaging with would-be researchers but it is worth remembering that an institution's track record will invariably be an indicator of likely outcomes.

## GETTING FUNDING

Following the initial discussions I set about the task of forming the participants' ideas and concerns into a research proposal. This development was fed back and discussed with DDP/DCIL over a period of two or three months, resulting in agreement on a set of hypotheses and an outline method for the project (based initially on interviews with service users). The proposal was then consolidated into a funding

application and submitted as a PhD proposal to the Economic and Social Research Council (ESRC) in May 1994.

It is important to remember that disabled people do not generally control research funding (Zarb, 1992) and proposals which are not within established research paradigms may fail to gain access to limited funding resources. In this context, it is interesting to note that I was persuaded by a member of the faculty to modify the proposal agreed with DCDP /DCIL on the grounds that it might be regarded as too removed from the 'mainstream' (this included removing the word 'emancipatory'). It is impossible to know whether that decision was in the end justified. However, the fact that I felt obliged to make the changes illustrates the way in which academic discourse can generate a self-limiting influence on the radicalism of would-be disability researchers.

To secure funding from a major government research council for a project defined by representatives of disabled people's organisations was in itself a partial vindication of the emancipatory approach. It did at least demonstrate that disabled people (in collaboration with a 'committed' academic institution) could gain access to relatively scarce funding resources. It did not of course provide any guarantees to DCDP/DCIL that I would continue to devolve control over the subsequent use of those resources. The award was after all made to me and not to them. However, as I have already mentioned, there was some security in knowing that I would be supervised by a well-known ally within the Disability Research Unit.

## DEVOLVING CONTROL

Having secured funding for the project, the next problem was to determine how control over its production could be devolved to the participants. In August 1994 we discussed the proposal again in order to develop a strategy by which DCDP/DCIL could direct the research. The outcome of this was the suggestion that I could be 'commissioned' (without remuneration) to do 'my' research for DCDE. An initial contract was drawn up and agreed in order to coincide with my registration as a PhD student at the University of Leeds.

In practice, it is fair to say that my contractual obligation to DCDP/DCIL was not evoked by them at any time during the conduct of the research and its primary function had more to do with setting the tone of our relationship rather than governing it. However, it was certainly intended



to be much more than a purely symbolic representation of the idea that this research would 'belong' in some way to its primary participants.

In general terms the use of contracts by disabled people's organisations to control researchers seems to me to be a useful one. However, it is relevant to note that, while the transfer of formal control was possible in this case, it might well be incompatible with the contracting criteria of some major research funders. For example, British government research contracts commonly prohibit the researcher from engaging in secondary contracts for the same work. This clearly has implications for the feasibility of using our approach for other projects within the mainstream of academic research.

## KNOWLEDGE AND EXPERTISE

Academics working within positivist and interpretative paradigms have often cast themselves in the role of 'expert' or 'knower' - a role which implicitly ( and, on occasion, explicitly) maintains that the knowledge and experience of disabled people counts for little (Hunt, 1981; Finkelstein, 1980; Abberley, 1992). Conversely, researchers working within an emancipatory approach have increasingly sought to prioritise that knowledge and experience over and above that of rehabilitation professionals or indeed researchers.

Most criticisms of this approach emanate from outside the radical research community, predominantly in defence of academic research traditions (see Bury, 1992) although they have also come from 'inside' (see Glucksmann, 1994:151). Kelly et al.(1994) develop the debate by acknowledging the positive elements of researchers' expertise:

'It is we who have the time, resources and skills to conduct methodical work, to make sense of experience and locate individuals in historic and social contexts' (p. 37).

My initial decision to undertake the study was motivated by my view of disability as a form of social oppression and by my decision to adopt a research agenda defined by the disabled people's movement. The selection of a specific research question was determined by establishing the common ground between my expertise (social policy analysis and research skills) and the knowledge of disabled people's organisations in Derbyshire ( derived from service provision and political struggle). The

decision on a particular research issue was theirs; the decision to locate it within a broader socio- economic analysis was largely mine.

Later on in the data collection it was important for me to accept that disabled people would be invariably best placed to identify the form and content of disabling barriers in service provision. For the purposes of my study the primary knowers were the people who designed, managed and used DCIL's support services. However, I also had to value knowledge produced by policy makers, other academics and those in the 'caring' professions. Where these knowledges conflicted it was impossible to prioritise one above the other without also considering the relationship between knowledge and power.

## CASE STUDY METHODS

Representatives of DCDP and DCIL had selected the topic for my research because it was a pressing organisational issue for them at the time. Thus, it was not surprising that the organisation's own activities frequently coincided with my agenda, providing important and relevant research opportunities. The difficulty for me (as someone hoping to write a PhD) was to forge coherent links between the sometimes disparate opportunities for data collection. I have found it helpful to consider the evolving data collection as a set of three semi-discrete projects guided by the needs and priorities of the research participants. This rationalisation is post hoc and, at the time, it is fair to say that I was often unclear where the research was 'going'.

## AN ACTION RESEARCH PROJECT ON USER INVOLVEMENT

In July 1994, DCIL's General Council considered a proposal to host a Joint Focus Group project on 'Improving User Participation in Service Monitoring' in collaboration with the Living Options Partnership (LOP). Since this initiative coincided directly with my interests in quality and user controlled services, it was suggested that I could be 'employed' to facilitate the project for DCIL.

DCIL' s General Council asked its member organisations to nominate representatives for the group and an initial meeting was convened in November 1994. This meeting was attended by representatives of DCDP the social services department and two local NHS Trusts. LOP's Network Co-ordinator was also present. At this meeting, each representative was asked to prioritise a user involvement issue in Derbyshire. It was decided

that these contributions should form the basis for a series of four workshops to be held at DCIL over a period of several weeks.

The workshops were chaired by me and the representatives invited disabled service users from their organisations to attend. The meetings were tape-recorded and notes were made of the main contributions. The notes and tapes were analysed after each meeting and summaries of the main points were collated. These summaries were copied and circulated to the participants for feedback. After the fourth workshop a summary report and key point checklist was compiled in collaboration with DCIL's research officer. These were circulated to the participants for validation. A final meeting was convened at which the participants discussed the report and decided collectively on its dissemination.

The object of the workshops was twofold. First, we anticipated that each organisation would learn something about the process of user involvement in its own and other agencies. Second, we hoped to produce some draft guidelines for evaluating user participation in purchaser and provider organisations. To this end, the outputs of the project (a short report and an evaluation tool for assessing the quality of user involvement) were widely disseminated among disabled people and service commissioners/providers.

In March 1995 DCIL's General Council formerly adopted the measurement tool as a basis for advocating user involvement in all disability services and agreed to promote the summary report with their constituent organisations at chief executive level. In September 1995 we were able to present a version of the report and recommendations to the Disabled Peoples' International, European Symposium (Gibbs & Priestley, 1996). This prompted much discussion and enabled me to validate the initial work with a wider range of disabled activists. Later, I was able to use the outcomes of the project as the basis for a presentation to an NHS Executive Seminar organised by DCIL in Derby (Priestley, 1996b). This provided an opportunity to disseminate the group's work to a wider constituency of service commissioners and practitioners.

The Living Options project was productive in enabling me to become familiar with current debates about the role of disabled people in Derbyshire's main service provider agencies. It also provided an opportunity for some initial action research addressing the apparent conflict of values between DCIL and its major funders. It was of direct benefit to DCIL in two ways: by making available my time and skills as a

facilitator/recorder for the group sessions and by producing a widely disseminated and validated tool for evaluating user involvement in disability services.

## A STUDY OF CONTRACTING

Our agreed agenda for research focused attention on the definition and measurement of service quality. However, it was apparent that DCIL perceived the contractual relationship with the local authority as the most immediate barrier to implementing quality services within an integrated living approach. During 1995 we discussed the possibility of using my resources to facilitate further action research with the purchasing authority aimed at resolving some of these conflicts. For this reason it was important to understand as much as possible about the impact of community care implementation on the organisation.

In order to achieve this, DCIL provided me with complete and unrestricted access to their records. I was able to analyse the full text of internal minutes, supporting documents, reports and accounts for the period before and after community care implementation (1991-1996). This enabled me to study in detail the impact of contracting on DCIL's ability to provide participative integrated living services to disabled people in the locality. I was also able to talk at length with DCIL managers about the operational pressures of contracting for services.

Ultimately, there were no tangible outcomes for DCIL from this part of the study. The relationship between DCIL and the social services department was becoming increasingly strained and some of the issues targeted for my research moved onto a more political plane ( via DCIL' s management committee) .In view of this, the opportunities for social services participation in the research design became increasingly limited and it was necessary to re-focus my efforts on the primary research participants.

By this stage I had written up a fairly detailed analysis of DCIL's situation as a draft 'academic' paper but much of the material was politically sensitive and I felt that it would not have been appropriate for me to disseminate my analysis widely at that time. This in itself was a useful lesson, illustrating the potential conflict between 'academic' self and 'committed' self (Stone & Priestley, 1996). To devolve control over the dissemination of research findings to the research participants is to accept that there may well be constraints on the researcher's ability to

'publish'. I am not necessarily advocating the participants' right of 'veto' over research outputs but I do believe that a sincere commitment to collective responsibility requires us to reject our absolute privilege to 'independence'.

## AN EVALUATION PROJECT WITH SERVICE USERS

I had discussed for some time with DCIL the most appropriate way of incorporating service user participation into the project. The need for service user input was emphasised as a priority both by DCIL's director and by my academic supervisor. In early 1996 I wrote to DCIL's Personal Support Service Manager asking whether any of the service users might be interested in talking to me and how I might go about this.

On a personal level, I was keen to 'get some interviews' for my PhD; on a methodological level I was concerned (as were DCIL) that there was no point in bothering service users unless this would be relevant and useful to all concerned. There was in fact a delay of some months during which we were unable to clarify how user involvement could be best targeted. However, by early June an opportunity for relevant contact began to present itself.

As the end of the first year of DCIL's contract for the Personal Support Service approached it became evident that there would need to be some evaluation of service quality by the purchasing authority. Managers at DCIL were becoming increasingly concerned that any evaluation conducted by the social services department might be limited in its scope and therefore fail to recognise the 'added value' of an integrated living approach. There was also some concern that it might not be conducted with full user participation.

In view of this situation it was suggested that I might conduct the evaluation as an 'independent' outsider and, in June 1996, DCIL wrote to social services asking for an independent appraisal (to be conducted by me). The social services department declined this offer, preferring to conduct the evaluation themselves. This caused further concern to DCIL, who now felt even more strongly that they needed to 'commission' me for an independent study focused on outcomes for users. By early July, DCIL had identified nine service users as potential participants (some of whom were also participating in the social services review) and DCIL's service manager wrote to each of these people indicating that I would be in touch.

In accordance with the emancipatory research principles outlined earlier, I wanted to maximise participant control over the conduct of the interviews. My plan was to adopt a similar model to Barnes' (1992) 'three stage' strategy for interviewing. Within this approach the first stage would be critical. In particular, I wanted to ensure that the people concerned were able to make informed decisions about their participation before any interviews took place. To this end, I drafted a set of potential interview questions, a statement of good practice and a covering letter. In the letter, I outlined the purpose of the research, my role as a researcher, an explanation of the accompanying documents and a suggested time-scale for the interviews. The statement of good practice gave a concise account of what participants should expect from their contact with me. The list of questions gave a speculative agenda for the interview but provided an opportunity to amend or veto its form and content. These documents were discussed in draft with DCIL, amended, clarified and sent out to the participants at the end of July.

Two people declined to be interviewed (one due to lack of time and one because he had nothing to say other than that DCIL's service was 'excellent'). In consultation with DCIL a schedule of visits was arranged for early August to meet the remaining seven people. The meetings were arranged so as to give the participants several days notice to think about the questions in advance. The interviews themselves were semi-structured and lasted for between forty minutes and an hour and half. Each interview was tape-recorded and typed transcripts were made. The transcripts were reviewed and the major points summarised in note form.

The main points, together with supporting quotes were written up as a draft report and a one page summary. These were circulated back to all the participants (including those who were not interviewed) for comment and amendment. The intention was to encourage the participants to use the interviews not only to give voice to their views and experiences but also to facilitate their greater influence over the development of DCIL's service provision. The final report (Priestley, 1996c) was submitted to DCIL for them to disseminate and the summary was tabled at their September AGM.

## ADDITIONAL DATA COLLECTION

In addition to the three 'projects' outlined above I was able to participate in many DCDP/DCIL activities including working parties and

discussions directly relevant to the study. During these ongoing contacts the issues raised were fed back to the organisation and discussed. Thus, data from the focus groups, documentation and interviews was supplemented by numerous 'field notes'. Finally, the research data included a wide reading of relevant literature and related studies directed by the changing research priorities of the participants and by my own interests.

Central government data was drawn from legislative documents (Green Papers, White Papers, Bills and Acts); from policy guidance documents (Department of Health circulars etc.) and from Parliamentary debates and Committee Reports. The implementation of the community care reforms during the course of the study produced an enormous amount of such data and it was necessary to prioritise those publications which dealt most directly with the issues raised by participants at DCDP and DCIL.

In all, about twenty documents were used directly for detailed content analysis (although a much larger number were consulted as background reading).

It was possible to gain much information about the form and content of the contracting process by a detailed analysis of the general service level agreement and the contract/service specification for the Personal Support Service issued by the County Council. These documents were available in a number of drafts illustrating the changing position of the contracting parties over time. Several attempts were made to engage Derbyshire social services' direct participation in the study at a managerial level but these were unsuccessful and the primary data available from the purchasing authority was therefore limited to textual analysis of a relatively small number of documents.

The operational management of DCIL is made accountable through its Management Committee and General Council. I was able to study the complete minutes of these bodies for the period in question (1991-1996). DCIL's Director and Liaison Group (a working party of key function managers) submit monthly reports to Management Committee on the Centre's activity and strategy. A review of these reports yielded much factual data about the changing nature of DCIL's financial and organisational structure. The management reports, together with various internal papers, also provided important insights into the level of collective consciousness about DCIL's organisational values and mission. This documentary data was supplemented, validated and clarified by

ongoing discussions with DCIL's director, research manager and the manager of the Personal Support Service.

The establishment of DCIL arose from the conscious political organisation of disabled people in Derbyshire (through DCDP) in conjunction with the local authority (DCC). This conscious political action and discourse was relatively well recorded in both published and unpublished documentation emanating from all three organisations. It was thus possible to learn much about the historical development of DCIL, its organisational goals and operational dilemmas directly from these accounts. The content analysis of these documents was supplemented by personal discussions and tape-recorded interviews with key informants in DCIL/DCDP who were able to shed additional light on their relevance and accuracy.

In 1993 DCDP produced an historical account of its activity to mark the tenth anniversary of the organisation (Davis & Mullender, 1993) which provided much of the historical background. This account was supplemented by other published accounts emanating from prominent individuals within the Coalition and the wider disabled people's movement. DCDP also publishes a regular newsletter (Info: the voice of disabled people in Derbyshire). An examination of contributions to this periodical provided many additional insights.

As I have illustrated there was a good deal of reciprocity between the data collection and analysis. A large amount of non-uniform qualitative data was collected for the study from a variety of sources. The collection of this data was shaped by the changing priorities of the primary participants, by my shifting analysis of those priorities and by the bureaucratic politics of the organisations involved. Moreover, the analysis was not mine alone. My key informants were also highly analytical and the categories they used to order their actions were necessarily a primary influence on the collection and analysis of data. For this reason it is important to recognise that co-participatory research brings into question the dualist assumption that only the researcher analyses.

## SUMMARY AND CONCLUSIONS

In this chapter I have outlined the methodological context for my work with DCDP/DCIL and sought to illustrate the kind of choices which I made. It is important to understand that the project was driven from the



outset by my attempts to work within an emancipatory research paradigm. This was not easy nor indeed always possible and the process resulted in some less than ideal corn promises (particularly in presenting the research as a coherent PhD thesis). As I have outlined, it was not possible to achieve some of the original action research goals due to considerations of diplomacy and organisational politics. This is undoubtedly the 'price' for conducting such research.

It is important to remember that disabled people are more likely to be concerned with enabling action research outcomes than with the production of 'learned' journal articles or doctoral theses. These publications are of course vital to the career patterns of academic researchers and to the research profiles of university departments. However, as my experience shows, devolving control over dissemination means giving up the 'right' to determine what gets published and how. Ultimately, the most stressful period for me was waiting to find out how DCDP /DCIL would respond to the proposed content of my thesis. It is quite conceivable that if they had expressed major concerns I might have failed to submit on time. However, this is perhaps how it should be when 'the boot is on the other foot'.

In practice, when we finally met in February 1997 to discuss issues of content and dissemination, no such fears were expressed. Indeed, there was much resistance to the idea that emancipatory research should involve a reversal of the social relations of research production. Rather, they felt it necessary to stress the importance of a working partnership towards mutually beneficial outcomes. For us the goal became one of equalising power rather than devolving it. In the final analysis the responsibility for what I had written could not and should not be devolved to anyone.

DCIL were able to use my research skills to develop, articulate and disseminate aspects of their own thinking in order to influence local policy makers. My involvement as an 'independent' person was felt to be particularly useful in validating this work. They were also able to draw directly on my writing to inform and supplement their own reports. On a very practical level my involvement in data collection, chairing meetings, recording, writing reports, presenting papers and so on enabled DCIL to engage in developmental and advocacy work for which funds would not have otherwise been available.

The research was specifically helpful to the service user participants in helping them to communicate their views and experiences to the service provider and to purchasers. In particular, the research process provided a mechanism for them to think and act collectively where they would not otherwise have been facilitated to do so. It provided the space and resources for them to articulate personal views and opinions which might not have been 'heard' had they expressed them solely as individuals.

It is fair to say that, at the time of writing, the research was more personally empowering to me than to anyone else. I was enabled to learn an enormous amount about the implementation of integrated living services and about the self-empowerment of disabled people. I was enabled to add to my publications list and to write a PhD thesis. I was enabled to generate a modest income for three years and to establish considerable skills and experience for future academic employment. In the final analysis I would not claim to have accomplished a truly 'emancipatory' piece of work but it was certainly fun trying.

## REFERENCES

- ABBERLEY, P. (1987) 'The Concept of Oppression and the Development of a Social Theory of Disability', *Disability, Handicap & Society*, 2(1):5-19.
- ABBERLEY, P. (1992) 'Counting Us Out: a discussion of the OPCS disability surveys', *Disability, Handicap & Society*, 7:139-155.
- BARNES, C. (1992) 'Qualitative Research: valuable or irrelevant?', *Disability, Handicap & Society*, 7(2):139-155.
- BURY, M. (1992) 'Medical Sociology and Chronic Illness: A comment on the Panel Discussion', *Medical Sociology News*, 18(1): 29-33.
- DAVIS, K. and MULLENDER, A. (1993) *Ten Turbulent Years: a review of the work of the Derbyshire Coalition of Disabled People*. Nottingham: Centre for Social Action, School of Social Studies, University of Nottingham.
- FINKELSTEIN, V. (1980) *Attitudes and Disabled People: issues for discussion*. New York: World Rehabilitation Fund -monograph 5.
- GIBBS, D. and PRIESTLEY, M. (1996) 'The Social Movement and User Involvement', in B. Walker, ed. ( 1996) *Disability Rights: A Symposium of the European Regions*. Headley, Hampshire: Hampshire Coalition of Disabled People.
- GLUCKSMANN, M. (1994) 'The Work of Knowledge and the Knowledge of Women's Work', in M. Maynard and J. Purvis, (1994)

- Researching Women's Lives from a Feminist Perspective. London: Taylor & Francis.
- HUNT, P (1981) 'Settling Accounts with the parasite people: a critique of "A Life part" by E. J. Miller and G: V. Gwynn', *Disability Challenge*, 1:37-50.
- KELLY, L., BURTON, S. and REGAN , L. (1994) 'Researching Women's Lives or Studying Women's Oppression? Reflections on What Constitutes Feminist Research', in M. Maynard and J. Purvis, eds. (1994) *Researching Women's Lives from a Feminist Perspective*. London: Taylor & Francis Ltd.
- OAKLEY, A. (1981) *Subject Women*. London: Fontana.
- OLIVER, M. (1992) 'Changing the Social Relations of Research Production?', *Disability, Handicap & Society*, 7(2):101-114.
- PRIESTLEY, M. (1994a) 'Blind Prejudice', *Community Care*, 3:28-29.
- PRIESTLEY, M. (1994b) *Organising for Change: ABA (Leeds) Research Paper*,  
Leeds: Association of Blind Asians Leeds City Council Health Unit.
- PRIESTLEY, M. (1995) 'Commonality and Difference in the Movement: an Association of Blind Asians in Leeds', *Disability & Society*, 10:157-169.
- PRIESTLEY, M. (1996a) *From Strength to Strength: a report on the recent development of ABA (Leeds) 1995-1996*. Leeds: Association of Blind Asians Leeds City Council Health Unit.
- PRIESTLEY, M. (1996b) *Making Effective Use of User Inputs*, paper presented at the DCIUNHS Executive Seminar, Midland Hotel, Derby, 23-24 July 1996.
- PRIESTLEY, M. (1996c) *Perceptions of Quality: user views on DCILs Personal Support Service*, Ripley: Disability Research Unit, University of Leeds/Derbyshire Centre for Integrated Living.
- PRIESTLEY, M. (1997) *Disability, Values and Quality: a case study in Derbyshire*. Leeds: PhD thesis, University of Leeds.
- RAMCHARAN, P. and GRANT, G. (1994) 'Setting one agenda for empowering persons with a disadvantage within the research process', in M. Rioux and M. Each, eds. (1994) *Disability Is Not Measles: New Research Paradigms in Disability*. North York, Ontario: L'Institut Roehrer.
- RIOUX, M. and EACH, M. (1994) *Disability Is Not Measles: New Paradigms in Disability*. North York, Ontario: L'Institut Roehrer.
- SMITH, D. (1988) *The Everyday World as Problematic: a feminist sociology*. Milton Keynes: Open University Press.
- STANLEY, L. (1990) *Feminist Praxis: Research, Theory and Epistemology in Feminist Sociology*. London: Routledge.

STANLEY, L. and WISE, S. (1983) *Breaking Out: Feminist Consciousness and Feminist Research*. London: Routledge.

STONE, E. and PRIESTLEY, M. (1996) 'Parasites, Pawns and Partners: disability research and the role of non-disabled researchers', *British Journal of Sociology*, 47(4):699-716.

TOURAINÉ, A. (1985) 'An Introduction to the study of social movements', *Social Research*, 52:749-87.

ZARE, G. (1992) 'On the Road to Damascus: first steps towards changing the relations of disability research production', *Disability, Handicap & Society*, 7(2):125-138.