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Involving Disabled People in Research: A study of inclusion in environmental activities

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INTRODUCTION

The need for research which gives disabled people as much control as possible over the questions it asks, the way these are investigated and over what happens to the eventual project outcomes, has been firmly established in recent years (Barnes 1996; Moore et al., 1998; Oliver, 1992; 1993). However, a range of difficulties face researchers who wish to hold on to these principles, and in this chapter we illustrate some of the practical dilemmas we have met in our own work. The notion of 'taking the lead from disabled people' has become extremely important in the context of political and theoretical debates surrounding disability research, but there are many problems in making this happen. This chapter addresses these issues by examining one of our own studies which ran into difficulties measuring up to the expectation that disabled people must have a central involvement in all aspects of research relating to their lives.

We would like to point out that our comments are not intended to judge individuals involved in the research being examined, but to make explicit the tensions which can permeate a research situation. There is invariably a problem with re-examination of research situations because other people implicated have no opportunity to have their say and we cannot be certain to protect personal or institutional anonymity. There are, however, many lessons to be learned from looking back and reviewing specific attempts to actively involve disabled people in research.

The aims of the chapter are:

- to illustrate the obstacles researchers may face in trying to maximise disabled people's involvement in research

- to examine interpersonal dynamics within research, with special reference to situations where communication is neither easy nor effective;
- to consider questions of researcher accountability for involvement of disabled people; and
- to prompt further consideration of how researchers can resist sidelining disabled people in the process of enquiry.

Discussion relates to the earliest stages of setting up a small project, funded by an agency concerned with environmental issues, to evaluate innovations for widening inclusion of disabled people in its schemes (Benzie et al, 1997). We have chosen to focus on preparatory research activity such as defining the potential agenda (or agendas) and getting the process of enquiry going. We illustrate how each part of the research act involves processes within a process and how recognition of structural, ideological and institutional barriers and differences of view is essential before the slow course of dismantling barriers to the involvement of disabled people in the research process can begin.

CONTEXT

The environmental agency wished to put research in place at short notice, and this obliged us to draw up proposals which would outline sensible plans for mounting a useful investigation while also leaving open the possibility of following alternative directions. Although the initial agency request was vague we wanted to respond positively for several reasons, and as others have said, it is incumbent upon researchers to acknowledge their personal purposes for becoming involved in a particular project (Shakespeare et al., 1993). First, we had been nominated as a disability research team by a service provider who had previously sub-contracted research to our team, and with whom we wished to keep good links. This person had already set up a number of joint ventures at branch level between his organisation and the environmental agency which had provided people with learning difficulties opportunities to join a walking club or go on courses in horticulture or conservation. It was felt that these projects needed to be evaluated. Secondly, we are under the same constant pressure as all academic researchers to bring funds into our University (Barnes, 1996). Thirdly, at a personal level we had various interests. One of our research team is disabled and would like greater opportunities and choice in environmental activities. One of us has a disabled sister, keen to be

outdoors and involved in the countryside, along with a background in Environmental Sciences which provided further affinity with this project.

These motivations are not intended to excuse our willingness to launch straight into disability research without subjecting the reasons behind a project to more rigorous scrutiny. They may however shed light on the reasons why we found ourselves, as no doubt other researchers do too, more than willing to assume a level of mutual agreement about disability issues in order that research might go ahead. Clearly, at the start of the collaboration we knew little about the nature of the work being done by the agency, nor about how they were including disabled people, and this was a risky point of departure. As Stone and Priestley (1996) have noted, researchers can find themselves in awkward situations if the work they carry out turns out to be at odds with the preferred approach of disabled people and their representative organisations. The research circumstances we were moving into were ambiguous, and so we committed ourselves to a fairly loose plan of research, specified only as :

a short-term intensive research project to monitor and evaluate access for disabled people to environmental activities with a view to (i) maximising the participation of disabled people in environmental activities and (ii) developing policy and practice in this area.

The project was to run over a five month period on a three days a week basis.

GETTING STARTED

Once funding had been approved, a meeting was held with the service provider who had recommended us and the director of the local branch of the environmental agency commissioning the project. Whilst all such preliminary meetings are bound to be tentative, there was understandably some trepidation on all sides due to the unusual situation of having the funding in place before the different stakeholders could get to know each other or reach points of agreement about their priorities. Despite the common ground of the proposal, the director of the environmental agency knew little about our research reputation and further distanced himself by claiming little personal knowledge of disability issues. For our part, we had to seek clarification about the particular context to be investigated before we could begin to work out a way forward.

It emerged that the environmental agency branch director wanted several things from the project. As the agency was regularly seeking research funding there was an interest in defining a long-term research programme. Further aims included developing initiatives for disabled people, and opening up possibilities for working more closely alongside other service providers. Additional priorities for our team centred on ensuring that the views of disabled people were central and encouraging disabled service users to put forward their own ideas. At this early stage we agreed to focus on access to environmental activities created by a conservation course attended by disabled and non-disabled students and run at an urban parkland area used for practical involvement of people in the rejuvenation of city spaces. In addition, we agreed to draw together some strategies for seeking funding which would build on the findings from the course evaluation.

We had a plan of action now and arranged to meet the lead tutor on the course, who was employed by the environmental agency. The incidents which unfolded next go some way towards explaining the importance we attach to evolving crystal-clear strategies for facilitating disabled people's access to the research process. What we have found is that acceptance by service providers that service users should have opportunities to participate in research does not necessarily mean that participation will not be obstructed. Disabled people's rights to research involvement are often smothered by others who exercise strong and complex positions of power over their lives. Luck and good judgement alone will not ensure that researchers can effectively resist obstruction by various individuals who set themselves up as the gatekeepers of disabled people's well-being.

SELF-DETERMINATION OF ACCESS TO THE RESEARCH PROCESS

It was arranged that the research assistant should join the course for a period of time and thus get to know the context and also the students. The students would also become acquainted with the research assistant and his personal approach before deciding whether to participate in the project. After this 'getting to know you' phase, the students would be invited to group discussions. They would also have the opportunity of individual interviews at which they could contribute their views of the environmental course and what it meant for them generally and in relation to their future life and career plans. The information gathering settings were to be informal, the specific topics and mode of discussion to be defined by the students, and any involvement optional.

A phone call the following week brought the newly started project to an abrupt halt. It turned out that there were other agencies involved with the disabled students. These included a training agency associated with students with learning impairments and a voluntary project associated with some of the Deaf students, both of which asked for the research to be delayed. The agencies had only just found out about the project and whilst their representatives indicated they were willing to become involved, and did not seek to undermine our professionalism or the professional and ethical codes which we were operating under, it was argued that the research proposal would have to go through their own vetting procedures. In addition, the training agency independently set in motion a procedure for using support workers to secure agreement to the participation of the disabled students.

There are many frustrating issues for disability researchers here. The need to mediate consent through third parties was not mooted in relation to non-disabled students whose views we would be seeking; no agency was brought forward to determine (or ostensibly 'protect') their decision as to whether they were to participate. The disabled students were being singled out and denied their right to learn about the research first-hand. It seems to us that much of this problem stemmed from the newness of our link with collaborating service providers who appeared to have decided that issues regarding consent and the gaining of permission could not safely be left to the research team. Unfortunately, the service providers did not know that one of the researchers had concurrent experience as a communication support worker. This information might have added greatly to our credibility and skills. Equally, we had made certain assumptions about the link service providers, for example, that they would be aware of the sensitive politics of research situations, and were best placed to let key people know about the project. Progress was suddenly out of our control, and time, on such an intensive project, was very much against us.

Members of the research team endeavoured to make conciliatory phone calls. However, it emerged that those blocking progress were genuinely interested in pursuing the work but wanted to ensure that appropriate institutional protocol was followed. Nevertheless, this meant that the research was being determined more by the needs of non-disabled service providers than the needs of disabled service users. The importance of personal integrity became uppermost. For example, the person working with the Deaf students was conscious of the political nature of

disablement and rightly concerned only to proceed once matters of anonymity had been clarified. The key person at the training centre had concerns which we found less acceptable, commenting for example, that it was 'pretentious' to seek the views of people with learning difficulties and expressing the view that 'lots of care' rather than skill is needed to work with 'these people'. Our beliefs about which of the barriers to the research were reasonable could easily have started to displace our professional investment in retaining business-like relations with all participants. We kept quiet about our objections because we wanted to generate co-operation, but were thus engaged in reproducing disablement.

This highlights the diversity of personal understandings of disability which disabled people meet throughout their lives. For researchers, the broad range of philosophies held by different people drawn together in setting up a disability research project must be acknowledged and contextualised. Just how difficult these issues become in practice, how compromise in the name of co-operation can render the researcher part of the problem in the sense of perpetuating disablement through polite acquiescence, and how our responses to the diverse positions assumed by others, all deeply infuse the way in which we are dealt with by those who have power over a project. At this point, the issues of if, when and how researchers challenge disabling assumptions presented by others came to the fore. Roman (1991) has described how the role of gatekeepers is particularly questionable in relation to involvement of disabled people in research and we were now confronted with the enormity of ethical issues bound up with the freedom and rights of the students whose experiences we were hoping to uncover.

The time-scale for meeting our contractual obligations for project completion was being severely disrupted by individuals who were seeking to control disabled people's access to the research. This meant our original goals were looking distinctly unattainable and we had to consider urgently alternative ways forward. We wondered whether to conduct some interviews with professionals or with non-disabled students in the meantime, as there were fewer barriers to arranging this, but such a move would conflict with our commitment to having the directions of the research established by disabled students. The strong accountability we felt to disabled people may seem rather self-important and pretentious, but personal commitments to disabled family members and colleagues made it impossible to draw back from securing the adequate and primary inclusion of disabled people's own voices. We

acknowledge that we also feared losing the confidence of the service provider who had introduced us to this project and was funding other of our research activities. We decided against involving non-disabled before disabled participants but had to raise the time delay with the commissioning agency, while finding other ways of making up for lost time.

MOVING THE RESEARCH GOAL POSTS

It seemed a period of deferment was necessary, rather than a headlong dash to cram 'active research' of any available sort into the time vacuum that was looming. We needed to find alternative ways to fulfil our research obligations. Mid-way through the funded research period then, we decided to change tack and switch our focus more towards the interest of the environmental agency branch director in developing future bids for funding. We hoped this change of plan might open up new avenues for investigation in which we could hang on to our personal objective of evolving routes through which disabled people can influence research agendas and, at the same time, still respond to the needs of service providers. We wrote a progress report in order to clarify the change of direction and reframe our role. From here-on our aim was 'to act as facilitators and to elicit ideas from key stakeholders about what they feel should be explored in future projects looking at disabled people's access to the environment'.

Mid-project goal shifting is rarely countenanced within conventional academic research. Our own wide research experience suggests that disability researchers must be prepared to be very flexible in responding to the obstacles which are thrown in the way of disabled people's participation. We make no secret of the difficulty we encountered in trying to achieve this flexibility both when writing research proposals and in the fieldwork stage. In the case of the focal study, it was necessary and appropriate to revise the plan of activity in order to try and safeguard the central position of disabled people. Not until these changes had been settled did things start to feel comfortable again. But the problem of having to gain consent for disabled people to participate through third parties continued to cast a cloud over the issue of access.

RIGHTS TO KNOWING ABOUT THE RESEARCH PROCESS

We now hoped that, since the research could no longer be construed as evaluative, those preventing the participation of disabled students might

relent, but this did not happen. In discussions about who should receive the progress report, and/or be notified of the changes of direction, the disabled student's 'right to know' was denied. This placed us once more in the role of reinforcing the oppression of the disabled students. Relevant service providers seemed unconcerned about this and remained satisfied that we were doing our job in an acceptable manner. However, the function of the progress report, as we saw it, was to create a veneer which would make them and us feel comfortable about research progress, but which offered nothing at all for advancing the rights of disabled people to meaningful involvement in research.

Researchers also have to consider many issues of accountability. There is obviously no blue-print for knowing exactly to whom disability researchers are accountable in situ. There are many hazy areas, such as the one we were now in the middle of, over who should be consulted about shifts in research focus and direction, especially if these consultations further exclude disabled people. Critics might regard us as naive for not knowing whose permission would be needed for reports {including progress reports) to be produced and disseminated. It was only in retrospect that we began to recognise how far these issues are critically entwined with the ethical considerations of 'informed ' consent and gaining of permission. There is clearly an argument that researchers should know the precise answers to these questions before research plans are agreed. In the focal study, one of the service providers working with Deaf students was especially anxious about anonymity because many of those to whom the report would be circulated - not least those who commissioned the project - might recognise the identities of agencies and individuals. This illustrates how spending time to lay down ground-rules in advance would have made for greater effectiveness in the long run. We ended up having to provide assurances that circulation of the report would be limited, but this of course, contravened the rights of many significant others to know what was (or was not) going on. In any event, confidentiality never could be total. What is at issue is the denial of disabled people's right to know about the existence of research activity concerning them.

EVOLVING RESEARCH RELATIONS

Eventually, after a long period of negotiation, the research assistant was permitted to join the students on the course, doing some digging and hedge planting. He attended the conservation course over a period of a month, taking part in day-to-day activities, with a view to building

relationships with prospective participants. Immediately, another difficult set of issues arose about the involvement of disabled people in research. Some of those who were prospective participants were disabled in social contexts because of communication barriers and through long experience of exclusion. Our problem was in knowing when and how the researcher/researched relationship could be deemed 'good enough' for meaningful conversations to take place. Although the researcher became friendly with all of the students met on the course, the short time period involved meant that the researcher could not establish relationships of sufficient familiarity and skill to allow easy and effective communication. This was made more difficult because the research assistant did not have qualifications in British Sign Language (BSL), or training for communicating with people experiencing mental illness. Such barriers placed a heavy constraint on the opportunity for self-expression among disabled participants (Booth et al, 1990). Moreover, one of the service providers felt that, given these obstacles, it would be inappropriate for the research assistant to hold project-related discussions with the disabled students. Once again, students were not given the chance to give their views on what should happen. In the end, a manager of one of the voluntary agencies involved undertook to talk to some of the disabled students along with their communication support worker, herself a Deaf person. The voluntary group manager spent some time gathering relevant information about the aims of the research. Unfortunately, things went from bad to worse, however, when this person then became ill and was off work for the duration of the study.

We had no alternative but to contact the communication support worker to ask if she could find out the views of the disabled students. We recognised that accessing disabled people through third parties was hazardous, but had little option. Given that the communication support worker was Deaf and no textphone was available, contact was made by fax rather than telephone, but this limited the exchange of information. However, it was suggested that the communication support worker was well acquainted with the goals of the project and could be further assisted in addressing the students by having access to a preliminary set of questions which we were in the process of putting together to guide eventual discussions with service providers. We wanted to reduce barriers between ourselves and the communication support worker and provided this provisional list of questions. However, what was intended as a starting point for discussion was used instead as a questionnaire. The responses thus obtained by the communication support worker, being

structured, were constrained, and respondents had not been invited to exercise their prerogative of establishing the agenda in any way.

The effect of conducting the research by proxy was that our methodological aspirations could not be realised and this is a source of difficulty for the research team. The complexity of technical difficulties is evident in relation to factors such as phrasing, or the amount of time dedicated to posing a question, which in turn influence the response obtained. For example, the communication support worker reported in response to the question 'what hobbies/activities do/would you like?' (taken literally from the written draft of possible prompts) that 3 students answered 'private'. This might, of course, legitimately comprise the view of the respondents, but their replies could also be a product of BSL/English mismatch. For example, a signer might, if attempting to simplify the vocabulary, ask 'what do you like to do in your own time?', or 'what do you like to do yourself at home?' No researchers were present to observe or monitor the discussion sessions. Perhaps in hindsight, video-recording would have been useful, though we suspect that gaining permission for this might well have proved difficult. The point is that disabled people's involvement in research may not necessarily be maximised by placing the methodological and conceptual tools of research in the hands of disabled people. Even where disability researchers meet with very little active political resistance, the process of handing over the tools of research can, in reality, be tainted by a lack of commitment or ambivalence. Certainly our attempts to ensure that any third party presentations of the research maximised the interests of disabled people were hampered because we were obliged to hand over part of the process which, through illness of a key player, was then handed on again.

Further concerns arose in relation to the role of communication support workers in our study. It was standard practice on the conservation course for some of the disabled students to use communication support workers to facilitate dialogue with unfamiliar people. Several points are worth making. First, communication support workers can facilitate better access for disabled people to the research process by enabling them to choose their preferred interactive medium and language. Second, both disabled research participants and researchers have to trust the judgement and skill of the communication support worker and vice-versa. Subtle changes of meaning frequently occur in the process of moving from one language to another. There is conspicuous powerlessness on all sides in such mediated interactions (Moorehead, 1997). The third point is really

an extension of the first two in terms of self-determination in research. When using communication support workers, researchers have restricted access to disabled people's own articulations. Those acting as communication support workers may, subconsciously or consciously, introduce shifts linked to their own value systems and beliefs or to a desire to represent one or other of the parties in a certain light. There is inevitably a level of dependency which will influence proceedings and it is important for researchers to be prepared for such pitfalls when communication is indirect. Finally, there are hazards if either party wishes to discuss things which may unsettle relations either with the communication support worker, or within relevant social groups.

We were left wondering just how effective any communications in the course of a shared research process can be, and unclear about how critical it is that they are. Is the process of handing over research design and implementation essential to ensure power is properly devolved, and does the handing over guarantee that disabled people's rights will be adequately respected? When sharing control over research what are the risks of a project becoming so 'designed by committee' that it loses direction? Who needs control of disability research to ensure it will generate outcomes in sympathy with the human rights agenda as defined by contemporary disability rights movement? And to what extent are researchers bound to impose this agenda upon disabled people who are as yet untouched by it -or perhaps even disagree with it? Whilst the demands are for disability research to be enabling and empowering and take its lead from disabled people, this is plainly not a soft option.

RELATIONS WITHIN THE RESEARCH TEAM

Another category of relations within the research community concerns those between members of the research team, and in particular, the relative positions of those who are disabled and those who are not. The researchers in our own team can be placed on a continuum ranging from personal acquaintance with impairment to indirect experience through disability in the family. The disabled/non-disabled divide is one we experience as blurred and indeterminate and is a source of vulnerability and unease. We have had to look carefully at what this means in practice and how the distinction impacts upon the way we do things. The project under discussion involved some difficulties in this respect.

It will be obvious by now that the environmental activity project was fraught with problems and that our team was fearful that failure to

resolve these might mean that people who valued us as researchers might begin to think twice about continuing their support. There were internal, as well as external pressures, which culminated in an uncomfortable decision that the person with most research experience in the team, who happened to be non-disabled, would have to take the reins and steer the project efficiently towards a specific set of pre-determined tangible outcomes. This conclusion is clearly not in accord with recommendations that disabled people should have ultimate control over the research process. We knew full well that the reason why non-disabled people so often occupy the most powerful positions within research teams is because of the long years of disablement experienced by colleagues who have impairments, but were compelled to take realistic account of where the buck should stop in our own setting. We have had to discuss at length whether we could have dealt with things differently or better. It should not be thought that the research team was ducking proper recognition of the call for disabled people to be at the helm of disability research projects and others too have heeded the difficulties of making each and every disability research endeavour wholly collective (Campbell and Oliver, 1996; Oliver, 1996; 1997). The reallocation of tasks came about as the result of an ordinary everyday management problem which meant that the input of the disabled researcher from the environmental access project was even more crucially required on another of our disability studies (Skelton et al., 1997).

Part of the problem for us, related to the fact that the key disabled member of our team felt they had little professional experience with learning disabled and/or Deaf people who were the focus of the study, whereas the non-disabled researchers have more. We were agreed that the distance between researchers and those disabled people who were to be the researched was most appropriately reduced by recognition of the nearness of experience to those in the specific community being examined and this need not be impairment-led. We feel that the role of disabled people in research teams is a broad one bringing both personal and political dimensions to the team's understanding, but it is misleading to assume that individual disabled researchers can be, or wish to be, representative of and answerable to disabled people in every circumstance.

Our concern is that in making the decision for a non-disabled person to take charge, even for straightforward time-management reasons, commitment to placing disabled people firmly in the driving seat of research is jeopardised. This highlights the wide gulf between the

rhetoric of commitment and practical issues facing the disability researcher.

Critics of non-disabled disability researchers may suggest that our account reveals yet another example of disabling and oppressive research. We hope, however, to have shed some light on the practical difficulties which can sometimes explain the origins of such shortcomings in everyday disability projects. Disability researchers often have to take account of their own needs and roles. There is considerable variability with regard to what we are doing, and whether what we are doing is what we ought to be doing. This points to the urgency for coalitions between both disabled people and researchers, and between research teams as well. Even as we seek to close our reflections on disabling barriers in this one example of our work, we are left with many questions which must similarly trouble other researchers.

A particular concern of this chapter has been to explore the role of disability researchers. If we are to act simply as facilitators, taking up ideas from key stakeholders and providing a vehicle for the collection and dissemination of information they prioritise, we must explore the implications for keeping the interests of disabled people clearly in view. What position are researchers in if initiatives for disability research do not stem from disabled people in the first place, or if oppressive dimensions slowly unfold once a project is under way? Do we refuse to participate in such enquiries or become involved on a best-efforts basis, hoping to be part of a drip-drip process which will stimulate less oppressive activity? How much personal political commitment can be usefully exposed? In what circumstances does it become imperative to disclose the disability research principles which we hold dear, and to whom must we communicate these principles? What about funding bodies, service providers, disabled people or their representative family members? How should our research commitments be articulated? What is practical and what is necessary? It may be tempting to gloss over the finer considerations raised in answer to these questions when setting up a research contract, but they all invest disability researchers with critical obligations, which, as the preceding discussion aims to show, usually need facing up to sooner rather than later.

CONCLUDING REMARKS

We have acknowledged elsewhere that disability research involves debate, listening and earning the respect of others, particularly in relation

to the voices of disabled people (Moore et al., 1998). Nevertheless, in this chapter we have had to describe how even well-intentioned research acts can leave disabled people outside of, and alienated from the research process. Our account shows that there is no room for complacency on the part of disability researchers and that we are ever and always embroiled in, and required to openly resist, the politics of oppression.

Within our own research teams we are agreed that there is no turning back on the issue of maximising the role of disabled people in research. Yet the conditions in which disability research originates and later takes place can, as we hope to have illustrated, quickly swamp prospects for securing a central role for disabled people. We agree with Oliver (1997) that researchers must be mindful of the damage their work can do to disabled people's lives and recognise and support the role of research in resistance. But carving out a pivotal role for disabled people at all levels in a disability research project is a task which should not be oversimplified. Barriers to maximising the involvement of disabled people are many and far-reaching as we have tried to show.

It is also important to admit that agitation for changes in the way disability research is done can imbue researchers with an intense sense of powerlessness. Our activities are caught up in seemingly immovable institutional and structural factors. Recognition of the barriers to greater involvement of disabled people, both as researchers and those whose lives are being researched, does not necessarily lead to resistance to those barriers. Disability research must challenge oppression, but it is not easy to engage with such lofty obligations in the political world of everyday research. What we hope to have reinforced is the need for critical attention to, and personal resistance of, those attitudes, situations, events and behaviours which continually threaten to undermine the rights of disabled people. Important as resistance by individual researchers and research teams will be, it is only through collective resistance that platforms for change will eventually emerge.

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