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The Researched Opinions on Research: disabled people and disability research

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ABSTRACT *Thirty-five disabled people with a range of physical, sensory and mental impairments were interviewed about (1) their experiences of research; (2) their general opinions concerning research; (3) whether they thought research had served/was serving disabled people well; (4) how research on disability should be conducted; (5) who should conduct research on disability; and, finally, (6) what they would like to be researched. In this paper, the results of aspects two to five are reported. It was found that the opinions of disabled people mirror quite strongly the recent arguments forwarded by disabled academics concerning the need for emancipatory and empowering research strategies. In particular, the respondents articulated a need for inclusive, action-based research strategies, where disabled people are involved as consultants and partners not just as research subjects, There were few arguments, however, for an exclusive approach, where disability research would be conducted solely by researchers who were themselves disabled.*

Introduction

In recent years there has been much discussion within the disability studies literature concerning how disability research should be conducted, who should conduct such research, and the ideology underlying research practice (see, for example, Rioux & Bach, 1994; Barnes & Mercer 1997a). Whilst these issues remain contested (see, for example, the debate between Barnes, Bury and Shakespeare [1]), there is no denying that disabled people have largely been excluded from disability discourse—excluded from academic and institutional research, political think tanks, charity and pressure groups, and marginalised within the political processes and the media structures that influence public and policy discussion (Oliver, 1992; Stone and Priestley 1996; Kitchin 1999a). Instead, disability discourse has been, and to a large degree still is, overwhelmingly dominated by people who are not disabled.

Many disabled academics, such as Oliver (1992), are unhappy at the widespread exclusion of disabled people from disability discourse and call for the adoption of research strategies that are both emancipatory (seeking 'positive' societal

change) and empowering (seeking ‘positive’ individual change through participation). They suggest that current research on disability issues is flawed and problematic in a number of respects. Most crucially, they argue that disability research is not representative of disabled peoples’ experiences and knowledges. This is because, as noted, the vast majority of research is conducted by non-disabled researchers. They contend that it is only disabled people who can know what it is like to be disabled and so only disabled people who can truly interpret and present data from other disabled people. Moreover, they argue that research concerning disability research is invariably researcher-orientated, based around the desires and agendas of the (non-disabled) researcher and able-bodied funding agencies, rather than subject(s) of the research (disabled people; Sample, 1996). Indeed, Oliver (1992) argues that the traditional ‘expert’ model of research represents a ‘rape model of research’ that is alienating, and disempowers and disenfranchises disabled research participants by placing their knowledge into the hands of the researcher to interpret and make recommendations on their behalf; that researchers are compounding the oppression of disabled respondents through exploitation for academic gain.

Often cited within these arguments is the critique of Hunt (1981) who describes the experiences of being a ‘victim of research’. He details how, as a resident of Le Court Cheshire Home, he and other residents became disillusioned with ‘unbiased social scientists’ who followed their own agenda and ignored the views of the people they consulted. This leads to the contention that continued academic ‘abuse’ by non-disabled researchers is leading to a growing dissatisfaction amongst those who they research. Indeed, some disabled activists and organisations have declared that existing research has largely been a source of exploitation rather than liberation (Barnes & Mercer 1997b), reproducing current social relationships, and perpetuating the dichotomy and unequal power relationships between non-disabled and disabled. As such, critically-formulated research (that with an emancipatory, political agenda) which adopts an expert model approach is paradoxically seeking change at one level (society), whilst at the same time reproducing unequal social relationships at another (within the research process; Kitchin, 1999a).

Drawing on feminist discourse, these disabled academics argue that power relationships within the research process need to be destabilised and the research agenda wrestled free from academic researchers still using traditional research methodologies. Indeed, Finkelstein (1985, cited in Barnes & Mercer 1997b) has called for ‘no participation without representation’. Such a reformulation, they argue, will close the emerging credibility gap between researchers and researched, provide a ‘truer’ picture of the experiences of disability, and strengthen policy-making formulation by initiating a move away from research practice that is currently defined by models of social engineering (Oliver, 1992; Sample, 1996). Stone & Priestley (1996, p. 706) suggest that the core principles of a reformulated research strategy should be:

- the adoption of a social model of disablement as the epistemological basis for research production;

- the surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation;
- the willingness to only undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers;
- the evolution of control over research production to ensure full accountability to disabled people and their organisations;
- giving voice to the personal as political, whilst endeavouring to collectivise the political commonality of individual experiences;
- the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.

In this paper, the representativeness of some of the arguments posed by academics such as Barnes, Finkelstein and Oliver are investigated through in-depth interviews with 35 disabled people with a variety of physical, sensory and mental impairments. In particular, the extent to which disabled people are dissatisfied with academic research, and their opinions on how and by whom disability research should be conducted, are gauged. The interviews were the first part of a two-part project. The second stage consisted of implementing two participatory action research (PAR) projects (one in Belfast, one in Dublin). In these projects, the disabled people involved decided on the topic to be researched, and how the data was to be generated and analysed, with the academic providing advice and labour. Data was collected and analysed jointly, as was the process of writing-up. These studies are reported elsewhere (Anderson & Kitchin, forthcoming; Kitchin, 1999b; Kitchin & Mulcahy, 1999c).

The Study

Thirty-five disabled people with a variety of physical, sensory and mental impairments were interviewed. The majority (26) of them were working in the disability field for a variety of organisations. The remainder were either attending a training course or day centre at the Irish Wheelchair Association, Clontarf. Seventeen of the interviewees either lived in the Belfast Urban Area or within 15 miles of Belfast city centre, and the other 18 either in Dublin or County Kildare. Interviewees in Belfast were sampled using a snowballing method, with initial contacts supplied by Disability Action. Interviewees in Dublin were arranged by the Irish Wheelchair Association and in County Kildare using a snowball sample. All the data were collected between March and November 1998 by the named author. Interviews lasted from 25 minutes to over 3 hours. Twenty-four of the respondents were interviewed separately, either in their home or place of work: two were interviewed as a pair, and the remaining nine in two focus groups of six and three (these were the training centre and day centre attendees). Interviews were taped, except in one case where notes were made by both interviewer and interviewee.

Respondents were interviewed using an interview guide approach. Here, topics

and the issues to be covered are specified in advance in an outline form, but the interviewer can vary the wording of the questions and the sequence in which the questions are tackled (Kitchin & Tate 1999). As a result, the interviewer has much greater freedom to explore specific avenues of enquiry, and logical gaps within the data can be anticipated and closed. The interview also takes on a more conversational feel while ensuring that all the topics of interest are explored. In the present case, the issues to be covered in the course of the conversation centred on six themes: (1) whether respondents had taken part in research and their experiences; (2) their general opinions concerning research; (3) whether they thought research had served/was serving disabled people well; (4) how research on disability should be conducted; (5) who should conduct research on disability; and, finally, (6) what they would like to be researched. Here, themes two to five are reported.

All the interview data were transcribed, typed into plain ASCII files and imported and analysed using NUD-IST 4.0 (Non-numerical Unstructured Data Indexing Searching and Theorising). NUD-IST allows qualitative data to be easily managed, cross-referenced and analysed using simple Boolean operations to identify patterns. Using NUD-IST the data were analysed using the prescription detailed in Dey (1993) and Kitchin & Tate (1999). This prescription is structured and rigorous, consisting of three primary stages: description, classification and connection, that are operationalised through a sequence of standardised tasks. First, each discrete passage was annotated, detailing potential category allocation. Next, the data were sorted into categories of related material. Where relevant, data were assigned to more than one category. To aid the process of connection, the data categories were then split (divided into new discrete categories) or spliced (merged to form new more generalized categories) to create new sorted categories of related data. Where appropriate, links between sorted categories of data were then examined using the Boolean operations within NUD-IST. Finally, the interpretations drawn from the data within each sorted category were corroborated in relation to evidence within other sorted categories.

To allow the data to 'speak for itself' the following text is generously adorned with passages from the conversations between the interviewer and the respondents. Most respondent names have been changed to preserve anonymity (as requested by interviewees). The majority of the quotes and analysis centre on the data generated by the 26 respondents who worked in the disability field. These respondents were generally young, well-educated, had a knowledge of disability politics and disability literature (e.g. many were familiar with Oliver, 1990), and to varying degrees politically active (i.e. they campaigned for disability rights, some more vocally than others). As such, it should be noted that the knowledges reported here are situated and, as demonstrated in the text, far from universal. To structure the discussion, the reporting of the results has been split into three sections. In the first section, general opinions and experiences of research and its use are discussed. In the second section, opinions on how research on disability should be conducted and who should conduct research on disability are detailed. In the third section, opinions concerning specific research methodologies such as questionnaires and interviews are examined.

General Opinions Concerning Disability Research

Given that many respondents were familiar with research conducted within disability studies, it is perhaps unsurprising that the majority of them were of the opinion that research concerning disability issues is important and needed. As Frank (a prominent disability activist on the European stage) stated:

Research is absolutely vital because the more research that is done the better the argumentation that can be made.

This is not to say that interviewees accepted research non-critically. Frank, for example, continued with a warning that the research undertaken needs to be carefully selected, presented in a way that is unambiguous, have clear connections between theory and the lives of disabled people, and needs to be acted upon:

... there is so much being written and so much being researched, again, again, and again about disability. The whole thing is ludicrous. You could fill this hotel with reports and research studies and research papers that have been done in the past ten years—but what's the progress for people actually on the ground? It's very, very small And that's one of the most annoying things that all these studies, all of this research—where does it actually lead in the long term? And what use is it put to? Some of it can be used by governments to defend what they want to defend. A lot of it is written in such a way that it is very academic. I have problem with some of the academic work as I don't think it relates really to the what life is like for people on the ground. So, yeah, it can be interesting but reading some of the academic studies you wonder how the hell ... or who or where are they coming from?

He repeated several times during the interview a concern expressed by the majority of respondents: most research seemed to be ineffective at changing social relations 'on the ground'; that research remains in the academic realm failing to transfer to the 'real world'. As Susan (an activist with a pan-disability group operating across Northern Ireland) noted:

Susan: ... I would be cynical about what actually happens with research. The majority of times it just sits on a desk. May be it is referred to by academics or somebody actually doing a bit of study ...

A consequence of this lack of transference is that respondents felt, from experience, a frustration that academia was not aiding, as it might, the disability movement. Indeed, some respondents felt that research which is not acted upon is essentially worthless; that research concerning disability should not be for knowledge's sake, especially given the need to improve the quality of life for many disabled people, as illustrated by Ken (an undergraduate student, humanities) and Oonagh (a worker for a charity organisation):

Ken: There's no point doing research if no one is going to do anything about it. RK: So what sorts of action are you talking about? Ken: Well what

you find is implemented to improve the situation for disabled people. RK: So, you basically want whatever has been done ... Ken: ... to have an effect on my life and other peoples.

Oonagh: Yes, there has to be an outcome to it. There is no point doing research for the sake of research.

These sentiments led Jim (a worker for a local disability organisation) and Kevin (a committee member of a national pan-disability organisation) to question the logic in continuing to conduct research given that much of it is repetitive and remains unacted on. In both cases, these respondents felt, based on their knowledge of the literature and experiences of seeking to implement change, that the problems that disabled people face and their solutions are well documented but hidden, with the seemingly endless need for research being used to reproduce current social relationships:

Jim: (angrily) Everybody knows the problems—why are people conducting research, research, research? We should actually be out doing something about it.... 90% of research projects end up in the bin anyway!

Kevin: Ireland needs action not more research.

This use of research as a political tool, was also noted by Lisbeth (a co-ordinator of a local disability initiative). Drawing on her experiences of commissioning a feasibility study, she also questioned the value for money of some research projects in relation to the benefits gained from their undertaking:

Lisbeth: I suppose in a way that it was extremely useful but I felt our feasibility study was extremely expensive. It was an extremely expensive project of which most of the information was supplied from here. We sort of gave the information and they wrote it up.

These arguments concerning the application of knowledge follow those made by some academic themselves. For example, Mohan (1995) contends that not actively engaging with the oppressed group being researched in practical ways or with their respective politics is 'systematised selfishness'—the study of a subject without giving anything in return. He suggests that unapplied knowledge is knowledge shorn of its meaning. Oliver (1992) contends that this is the common model of disability research.

Many of the respondents outside of those working in the disability field found discussing the relative merits of research difficult because they had had little exposure to reports of research findings, and experienced difficulty in engaging with and interpreting that to which they had been exposed. For example, Catherine (a worker with a voluntary group) reported:

... I think in general as disabled people we don't always know what research is going on and sometimes it is totally academic—it is way, way away from the practical. Sometimes the bits you read in the journals are really obscure things that are done as a theoretical exercise rather than as something that is going to have any impact on our lives. And possibly,

sometimes the evidence is used against us to confine us or keep us in institutions or whatever, but in general people won't know what research is being done. If it is done in social science departments and academic institutions we won't know about it.

Here, the failure of academia to translate findings and recommendations into the public sphere is disenfranchising those whom the research seeks to represent. Compounding the problem of informing the wider, disabled community and organisations who can make very real differences to disabled people's lives, such as government health bodies, voluntary agencies and service providers, is the fact that the majority of reports are written in a certain style, and demand a certain level of literacy and time to invest in digesting the material. Even textbooks aimed at summarising a wide variety of ideas and research findings into a manageable form generally expect their audience to have an undergraduate standard of education. As is well reported in the disability literature, however, few disabled people reach university. As such, inaccessible academic texts are exclusionary and deny the disabled community the opportunity to act on the findings in a positive way,² as pointed out by Robert (a community worker and committee member of a civil rights group):

I think it can be useful but it depends upon how it is going to be used, how it is going to be put into practice. I think an awful lot of research tends to be ... we talked about Colin Barnes and Mike Oliver earlier—some of those books are very sociology orientated. And they are very hard to read and I think that is one of the things with academic research is that it is very jargonised.

Academic research then needs to utilise non-academic media to ensure that the ideas and conclusions they draw reaches an audience who can act upon it. Sean (an attendee of a sheltered workshop) thus argued that academics need to advertise their 'research when it is finished ... by making it public'. He suggested that this could be achieved by 'going to media with it—press, radio, television'.

Given their opinions on the value of research, respondents were then asked whether they felt that disability research as practised was serving/had served disabled people well. Whilst some respondents were unsure because they had little knowledge of current or past research, and how it was acted on, the others were divided between those who thought research had/was serving disabled people well, and those that thought it had not/was not. For example, Aisling (a nursing student) and Susan were reasonably positive, and argued that research although not ideal was helping to breakdown ableist social relations:

Aisling: It's keeping going forward. Obviously there are [...] things that are helping people and even research into things like accommodation has meant that there is more accommodation available for disabled people now. And also people are now more aware of certain needs such as access.... making people more aware ... and ignorance, stopping ignorance has helped.

Susan: I suppose it does to a certain extent, it can highlight things and people like me can actually use it. Take the PPRU³ report. We quoted from it continuously, 201,000 adults with disabilities in Northern Ireland, 118 are men—are women—83 are men, 16,000 are children.... it serves me well going out and quoting things and saying ‘research has shown, blah, blah, blah’.

In contrast, a number of respondents felt that on the whole research had not served/was not serving disabled people well. For example, Paul (a community worker for a self-help organisation) noted that research has been used to justify the institutionalisation of people with mental illness.

In the past that has happened—that is fact. That ... I know from own experience—that thirty years ago I would have been put into an asylum because I hear voices or whatever. And the research showed that that was the way it was treated.

Similarly, Simon (undergraduate student and committee member of a civil rights group) noted that some forms of research relating to disabled people still explicitly enforce ableist attitudes and practises by exploring and advocating ideas relating to eugenics:

I’ve read a lot of research and some of it is very good and impresses me. Especially research that comes from the social model of disability. However, research that comes from the medical model of disability quite frankly frightens disabled people because of eugenics, and people monitoring, and all the implications that they might have. So ... so you can understand disabled people being slightly sceptical of disability research.

Indeed, given that academic research has (and still) perpetuated, reproduced and legitimated the marginalisation of disabled people, justifying segregation, eugenics and the denial of civil rights, it is little wonder that disabled people are suspicious of research by non-disabled researchers, including those who claim to be allies (Rioux & Bach 1994). This suspicion is based, as described by respondents Eileen (a community worker with a disability charity) and Shane (a freelance journalist), upon the fact that academic researchers do not approach a project from a neutral, objective position, but are situated within constructed and historically-rooted, discourses of knowledge and power. As such, researchers come to a project with a ‘set of baggage’ and a pre-determined agenda (one that does not necessarily favour disabled people):

Eileen: On the whole I would probably say no. And I think—this is just my own opinion—I think it is because of society’s attitudes towards disability. Hopefully researchers try to be as neutral as they can be but they still have their baggage with them. And if they haven’t had much contact with disabled people, then you know ...

Shane: Most research will achieve something but some of it is just done so badly and so incompletely. In Hitler’s Germany a group of scientists would

just be bunged into a room and given a weird hypothesis and they wouldn't be allowed out until they had proven it. Which rather stretched the imagination sometimes. And I do feel that a lot of academic research sets off with not dissimilar attitudes. It is decided in advance that certain traits are present in the community and it seeks to prove it.

At a more fundamental level, some disabled people are worried that research currently being undertaken is not representative of their views and is conducted in such a manner that unless changed will continue to misrepresent them. These views are based not only on their perceptions of research but also their experiences of taking part in studies. Many of these experiences were negative, centred on the power inequality within the research relationship. Indeed, some interviewees felt they had been exploited—their knowledge and experiences 'mined' by the researcher(s), who were then never heard of again. The lack of post-study communication, not knowing the results or recommendations stemming from the study, was consistently articulated as one of the most annoying aspects of participating in research:

Lisbeth: The only thing I would have liked to know was the outcome of it. That would have been very, very helpful. I didn't actually know whether it was for her own benefit or for a project—I knew she was funded but I didn't know ... RK: So you got no feedback? Lisbeth: No, not at all.

Aisling: I think the research, and all the surveys that are actually carried out, they never get back to the person. And the person can't actually say—'yes I helped'. Or they don't see what actually happens in society as a result of the work that they have done with any of the research.

This is symptomatic of academia's lack of ability to communicate effectively with those who it seeks to represent, as discussed earlier, and is a situation that left some interviewees frustrated and wary of taking part in future studies.⁴ It is the relationship between researcher and researched to which we now turn.

Researchers and Researching Disability

Despite having varying levels of exposure to disability research, all the respondents (regardless of background) had strong opinions about how disability research should be conducted and by whom. It was widely appreciated, as with charity organisations and service providers, that disability research is dominated by non-disabled researchers. To the vast majority of respondents this created issues related to representativeness. First, and foremost, some respondents forwarded the argument that non-disabled researchers can potentially misrepresent and misinterpret disabled people's experiences and knowledge because they themselves have never experienced what it is like to be disabled. Traditional expert model approaches, when used by a non-disabled researcher, means that disabled persons' knowledge is placed into the hands of the researcher to interpret and make recommendations on their behalf. Such a situation means that there is greater potential to discount, deny or even fail

to acknowledge the lived experiences of disabled people who are under the analytical gaze (Imrie, 1996). For example, respondents Ken and Frank stated:

Ken: You don't know how a disabled persons life works. You can only imagine how it works. But you actually don't know.

Frank: I would love to see the day when disabled people are doing research about disability. Because it is much easier—no-one can ever say to me if I was doing a research project. 'look you've never gone through this, you've never been in that situation', because I use a wheelchair. It's quite easy to see that I can't get on the bus, I can't get into 60% of the shops, I can't get into most of the universities. So it's very difficult to say to me, 'well you don't know what it's like'. But it's quite easy for me—say your asking me about public transport or you know—you've never been in that situation. You've never sat at a bus stop and sat there ... you've been given a free bus pass but you can't blooming well use it. You've never been in a situation, like a blind person who has got on the wrong bus because there is no audible to tell them where it is going. Simple little things like that, that you can't empathise with, but someone like myself as a disabled person can. I think eventually it will come around to the fact that disabled people are doing research but to get people to that situation is going to need a lot of time and effort.

At a second level, some respondents suggested that disabled people will only tell partial stories to a non-disabled researcher for fear of embarrassment or lack of empathy or reporting things which may lead to a reassessment of benefits/services or that the researcher will not believe them. Moreover, they will, in the main, make situations seem better than they really are. As respondents Helen (a single parent who campaigns individually) and Frank report:

Helen: What I mean is people won't tell you [able-bodied researcher] the embarrassing stories.

Frank: ... because people will be more open with me ... when we asked whether they [disabled constituents] had ever brought this to the forefront in the past, or have you ever spoken to anyone, it was 'no, because no-one would ever listen to us, and at least you will have some idea about what your going through and we wanted to share that with you.' And that's why I'm saying that, that we will get a lot more than the normal researcher.

At a third level, Conor (a worker for a national disability organisation) argues that it is important that disabled people undertake and present research because it makes more of impact due to the fact that it is 'straight from the horse's mouth'. As such, research being presented by a non-disabled person potentially undermines the impact or significance of the research or point being made.

Conor: No disrespect to you, but when a disabled person voices it it comes out a lot better. Because they can get their point across and actually show

what they need. Actually show it in a physical form, rather than an able-bodied person trying to explain it. Which is difficult to do.

The discussion of representation and who should be conducting research on disability issues led in to a discussion of how research should be undertaken. Two sets of approaches, broadly categorised as exclusive and inclusive approaches were identified. Exclusive approaches are those where research is conducted solely by a (or team of) non-disabled *or* disabled researcher(s). Inclusive approaches are those where research is conducted by a team of disabled people (non-academic) *and* disabled/non-disabled (academic) researchers.

Exclusive Approach

Only three respondents expressed views concerning the adoption of exclusive approaches. Sean and Claire (a recent graduate, unemployed) initially suggested that research should be undertaken by a 'neutral', non-disabled outsider fearing that researchers with a specific disability may concentrate their efforts, and channel recommendations, towards themselves (a view based on their perceptions of how charity organisations compete with each other and often push their own agenda at the expense other groups):

Sean: I suppose if a disabled person was doing it themselves, then I suppose it would be with ... obviously the disability they have, it would lean towards their favour. I suppose an independent body would be the best. Someone like yourself who hasn't got a disability. Someone who can try and get to the root, to try and get to the understanding of the problems in regards to the disabled community.

Claire: ... basically I think the best approach would be if the government say appointed someone ... if they wanted research for a particular report or whatever that should really appoint somebody independently. I don't think really ... this is a personal opinion but organisations like Cheshire Homes or IWA [Irish Wheelchair Association] don't do it effectively because they push their own agenda. And I have seen them do it and I don't like the findings. I don't know whether that is a terrible thing to say but ...

Both, however, backed the adoption of partnership approaches when discussed at the end of the interview.

Lisbeth, in contrast, continued the theme of representation, arguing that it is only disabled researchers people that can truly understand and represent disabled people. This viewpoint draws on her experiences of setting up a local scheme for disabled people and the misperceptions as to what was needed articulated by non-disabled professionals who ultimately made decisions regarding funding and so on.

Lisbeth: People with disabilities.... I think it is—I feel very, very strongly not only about research but also in giving disability awareness. This is a

very in-thing at the present. It would be like you, with all respect, standing up in front of a lot of women and giving them awareness on what it feels like to be a woman. You can give the theory and you can give what you have been taught but you cannot get inside the skin and know exactly what it feels like.... I think it should be given by disabled people because they have the insight. They know what it feels like and the empathy is probably something that can't be taught.

Inclusive Approaches

The vast majority of disabled people interviewed were of the opinion (for reasons stated above) that disability research should involve disabled people beyond the subject source. However, the majority of the respondents argued that the way forward was a collaboration of disabled people and (non-disabled) academics through consultation and partnerships (see below). The role of non-disabled researchers was seen as important for a variety of reasons. For some interviewees, the disabled status of the researcher was simply not an issue as long as the researcher was approaching the research from a 'disabled-friendly' position:

Eileen: Some people would argue that for credibility's sake its better coming from a disabled person. I wouldn't necessarily agree with that but I think that whoever is doing the research has to do it with disability as their focus and not coming from a non-disabled perspective.

Nuala (a worker for a local disability organisation): I don't see it as a uniquely disabled initiative or as a uniquely able-bodied initiative—I really think there has to be a true partnership that has to emerge.

Simon, similarly drawing on his reading of the disability and feminist literature, argued for the need for researchers committed to disabled emancipation but continued that any exclusion of non-disabled researchers reproduces forms of discrimination, and thus perpetuates the duality of abled/disabled and the maintenance of dualistic power relationships, albeit with disabled people in power, that much emancipatory and empowering research seeks to challenge:

Simon: Quite simply people who are committed to the social model of disability. And people who are committed to productive research that is based upon helping people fulfil the expectations that they have ... people who are committed to the principles of disability equality would be my preferred researchers ... if we as a movement put that stipulation on people [need to be disabled to do research on disability] we would be discriminating against them the way they are discriminating against us now ... I don't think that we can progress unless we are inclusive. And for me to adopt the attitude of 'oh, he hasn't got a disability, why should I be talking to him?' is wrong.

Others recognised that disability issues extend beyond disabled people to include

carers, family members and service providers. As such, the disability movement consists of a variety of individuals and groups who work separately and collectively to fight ableist discrimination. Part of this movement are researchers who study disability issues. To many of the interviewees in this study, alienating researchers who are non-disabled allies is counter-productive and does not aid the disability movement's cause.

Other respondents were concerned that the removal or discrediting of non-disabled researchers from disability studies would leave the fledgling field in the hands of a small number of disabled academics, who are already seen as having their own agenda. Keeping non-disabled people involved allows the field to develop whilst the base of disabled academics grows, and also provides another perspective. As Patrick (a postgraduate student and journalist) and Michael (a worker for a national state agency serving for disabled people) stated:

Patrick: I am quite concerned that there is the development of a disability elite who are centered around certain universities in England ... who are trying to control everything that is going on but bending it to serve their own purposes ... I am a freelance journalist for papers like Disability Now and I find that the reaction of the real disabled people, i.e. people living in dire straits is actually markedly different from these people in the rarefied atmosphere of these universities. I think the elite have caught themselves up in this ideology and it is spiralling out of control. The real disabled people tend to look at it and ... think that they are all in denial. And you know, it's probably not true but you know, it's an impression that is hard to shift.

Michael: No, I don't buy that argument at all because you can be an arsehole with a disability. And I know people in the movement who would say 'we are the experts'. To a certain extent that is true, but that doesn't mean that you don't have blind spots, you know. And I mean coming at things from a totally different perspective, it all depends on how you approach it. I think that if your coming at it from an expert view, or expert position, no matter who you are, whether you're a disabled person or not, I still consider that to be a bit dodgy. Er ... and what pisses me off about some people in the movement is that they consider themselves to be the sole expert in the area and ... they go on and on as if their word is gospel and only they can do stuff ... or even talk to a person with a disability—'Well I have a disability and I'm the only person who does understand it', but that only ghettosises it further.

As their quotes illustrate, these two interviewees had encountered disabled activists with differing opinions which had left them sceptical of disabled-only representation.

One respondent, Karen, felt that she could be equalled misrepresented by a disabled person, and that non-disabled researchers could undertake sound research as long as approached in a 'positive' and appropriate manner:

Karen: I think it has to be in conjunction with a disabled person and

abled-bodied because there are disabled people out there who I wouldn't want representing me. A lot of people. And I resent the fact that everybody else with a disability thinks they understand me because they don't. We are all individual. I think it doesn't really matter as long as they [non-disabled researchers] aren't out just for themselves, that it's going to be worked on, and that they do get feedback from the person with a disability and they do work hand-in-hand with someone who has a disability. I don't think it matters as long as it's done in a positive way.

Other arguments for research involving disabled and non-disabled people are discussed in relation to the inclusive approaches recommended by the interviewees.

Disabled People as Consultants

A few respondents suggested that studies by non-disabled researchers could be enhanced and made more representative by employing disabled people as consultants. For example, Rebecca (a project worker on a community scheme) stated:

Rebecca: May be they could have some sort of advisory group they could go back to once they know what it is they want to research and the areas they want to research and why they want to research ... They should have an advisory group of disabled people that they can show a layout of their research and they will give you a more of an insight into problems areas that need to be looked at and the things that have been missed and that sort of thing.

In practice this approach would consist of feedback (empathetic) loops being inserted into the research process so that whole process is monitored by the subjects of research who provide constructive criticism at all stages (see Barnes 1992; Oliver 1992; Chouinard 1997). As such, the academic would retain control of the research process and the questions being asked, but the participants get the opportunity to correct misinterpretations and influence the direction of the research. To Rebecca, this approach was sensible as it was a practice common in her workplace, used to successfully guide the organisation's activities. This approach would allow her to input her ideas into a research project given that she did not have the time to act as a full time research partner due to her work commitments.

Disabled People as Partners

In the main, however, interviewees favoured a partnership approach where instead of merely advising the researchers, disabled partners have a degree of control over the research process which is not tokenistic. As Lisbeth and Paul stated:

Lisbeth: At the end of the day you have to live in the world so I suppose teams. For example, I would be ... my assistant would have to compliment me. There are things I can't do, so may be research could be done that way. That, together, partnerships between people who have disabilities

with people who don't. But equal partners. That people with disabilities are not going to be there as a token. They have to know and they have to feel their true worth.

Paul: I've always wanted a like, sort of, a 50/50 democracy because I have respect for the person who is not disabled and his point of view is as valid as mine but he might not have the insight that I have ... I want to be together, both the researcher and the researched on an equal level instead of the way it is really—the way society has it at the minute.

Such partnership approaches seek a democracy between (non-disabled) researcher(s) and disabled co-researchers that is based upon recognising that both parties have expertise but from differing frames of reference (Kitchin, 1999a):

- Disabled people occupy insider positions. Their knowledge on a particular subject is often individual, tacit, practical led, from first hand experience.
- Academics occupy outsider positions. They have specialised skill, systematic knowledge, are theory led, based upon second-hand experience.

To the interviewees in this study, a partnership allows research to become more representative and reflexive by addressing the issue of unequal power arrangements within the research process and recognising the 'expertise' of disabled people in their own circumstances. Inclusion acknowledges and signifies a respect that the contributions of disabled co-researchers are valuable and worthwhile and leads to the development of a mutual sharing of knowledge and skills (Lloyd *et al*, 1996). Indeed, it is only with their active involvement that disability discussions will reflect their needs, concerns and interests. As articulated by the respondents, inclusion provides a platform from where disabled people can speak for themselves, to seek the services and support they want, to explicitly influence social policy and fight for disabled rights. As such, the shared benefits to researchers, policy makers and disabled co-researchers potentially outweigh costs in terms of time and organisation.

As already noted, being a disabled researcher does not preclude the use of inclusive approaches. Indeed, what is really being advocated here is the movement of some of the subjects of research to a inclusive position. As such, academics who are themselves disabled do not occupy privileged positions where they can speak on behalf of their fellow disabled people. Rather, they too must develop a partnership with non-academic participants to allow the research to become more representative of wider views and thoughts. Admittedly, this partnership may be more 'comfortable' as the disabled academic will have the benefit of insider and outsider knowledge. However, as the recent debate between geographers who research disability issues (see Gollidge, 1993, 1996; Butler, 1994; Gleeson, 1996; Imrie 1996), and the views of interviewees in this study (see Claire's, Patrick's and Michael's statements above concerning 'elitist cliques' and not being represented by disabled academics), demonstrates, not all disabled academics adopt a critical, emancipatory position or all disabled people agree with disabled academics.

As discussed in Kitchin (1999a), many researchers might reject such inclusive, partnership-based research out-of-hand because scientific principles (e.g. separation

of researcher/researched) are clearly being compromised. However, collaboration does not mean a radical departure from the procedures of conventional positivistic or interpretative science, just that such science is carried out with and by the participants. In other words, there is a re-negotiation of the relationship between the researcher and researched, rather than a radical overhaul of the scientific procedures underlying the research: the study still aims to be professionally administered (indeed, this was how both the PAR studies that accompanied these interviews were undertaken). However, in contrast to the standard expert model of research where research subjects have little opportunity to check facts, offer alternative explanations or verify researcher interpretations, inclusive approaches facilitates such interaction. As a result, inclusive approaches far from diminishing the academic rigour of research, enforces a rigorous approach that is cross-checked at all stages of the research process through the participant co-researchers. Consequently, Elden & Chisholm (1993) argue that inclusive approaches provide more valid data and useful interpretations and Greenwood *et al.* (1993) contend that this increase in validity is due to a democratisation of knowledge production giving the participants a stake in the quality of the results.

One particular partnership approach, participatory action research (PAR), was detailed at the end of every interview and respondents invited to comment. PAR consists of a research process that is 'collectivized amongst its participants' (Priestley, 1997, p. 89) with (non-academic) disabled people taking an active role in the whole research process from ideas, to hypotheses, to data generation, to analysis and interpretation, to writing the final report. In this approach, the role of the academic is not as expert, but as enabler or facilitator. As such, the academic takes an emancipatory position which seeks to inform and impart her/his knowledge and skills to the disabled people who are co-researchers in the project, and provide an outlet to inform the policy makers. The academic's role is primarily to provide specific technical advice to co-researchers to help them make informed choices. The approach is action-led in that it explicitly aims to use the research to change social relationships.

In every case, respondents expressed enthusiasm for the proposed PAR approach. There were, however, a couple of queries concerning how the project would work in practice and who the disabled co-researchers would be:

Catherine: As long as the people involved at [local scheme] feel that it is them that is taking the lead. That it is something that they want to do rather than they are pushed into.

Frank: It's brilliant as long as you get the right people involved. Because, you see again ... certain self-interest groups within the disability field ... would have a number of disabled people active within an organisation. And it [would be] a way for them to build their own empire.

The paradox within the current research project was that when offered the opportunity to conduct research on whatever aspect of disability and society they wished almost without fail the interviewees (including strong advocates of inclusion) de-

clined, bar three (these were the three most prominent and politically active interviewees who were keen to explore any avenue that would aid the cause of the disability movement). They wanted inclusive research to be conducted but were unprepared to undertake such research, as the quotes by Ken and Karen illustrate:

Ken: I think that you have to get disabled people to carry it out and get as involved as possible, and be involved in all aspects of it.

RK: How would you feel about doing something like that?

Ken: I don't really know I'd get involved now. I'm quite happy to give these ideas, now, but getting involved is a different story.

RK: You wouldn't want to do it yourself?

Karen: No, God no! I want to be out of here at five o'clock and have a life. That sounds awful, but I'm like a lot of other people in that way. I'm selfish, I have to say. I've got my life together now and, it took me a long time, you know, I fought every inch of the way and I don't want to ... do it anymore. There will be people who love that, who relish it, but I don't. But it is still a good way, but it wouldn't be everyone's cup of tea, you know what I mean?

In general, time was cited as the main reason for not wanting to take part, although there were in some cases issues of confidence (particularly amongst those who were not in full-time employment) linked to conducting a project funded by an academic funding agency and administered by a university lecturer. As such, if partnerships projects are to be successful, then locating potential partners is an issue that will have to be addressed. Given time constraints, especially on large projects which need concerted effort over a long period of time, a strategy of partnership-based consultancy (still have decision making powers but most of the labour undertaken by research assistants) may be a viable alternative. This approach is currently being used in a new project, initiated by a local access group.⁵

Training for Researchers

Whether adopting a consultancy or partnership approach some interviewees thought that non-disabled researchers should have to undergo a process of disability awareness training that would ensure that were approaching the research using an appropriate frame of reference. This perception is based on experiences of non-disabled people who hold misconceptions about what it is like to be disabled:

Eileen: Well I would like researchers to have training in that particular field. If they are going to go into disability research they should have some sort of training in that particular area. How or in what format it would have to be decided after a process of consultation.... It could well be that they would have to work with disabled people in different environments for a time or whatever, or have structured training sessions.... I think they have to know where disabled people are coming from.

Helen: My strongest opinion is that whoever is doing it should be put into a wheelchair for a day, I'll lend them my wheelchair and let them see what it is actually like. Or if your doing it for the blind then put glasses on you and be led around for a day and see what it is like to be ... not to know where you are going. To be blindfolded.... it's the only way you would get an insight.

The politics of the second suggestion are not straightforward. There is a danger that by giving non-disabled researchers a 'snap-shot' experience of disability for a day it provides a site from which they can claim to 'know' what it is like to be disabled. This is clearly not the case given that the experiences of disability are complex, and go beyond the removal of bodily functioning or senses. A better strategy might therefore be to use the inclusive approach to allow disabled people to fully articulate their experiences.

Methods to Generate Data

The final aspect to be considered in brief here is how data relating to disability issues should be generated. Interviewees were invited to discuss some of the shortcomings of data generation methods employed in studies they had previously participated in or just to comment generally on how they think data should be generated.

In general, respondents were wary of questionnaires and statistics. Questionnaires they felt were often poorly presented, poorly conceived, limited their responses, and lead to a limited understanding of the subject which they seek to address. As Nuala stated:

Nuala: Well there are times when you are cornered into doing it. There are times when I have felt that I am answering questions that I don't really want to answer because I feel it does not really apply to me. Sometimes I feel restricted by the questions. That, the questions you're asked, or rather the response you're forced to give doesn't always give you the opportunity to say what you want to say.... someone asking you pre-set questions where you need to—even if the answer is meant to be yes or no you really need to qualify it sometimes. It doesn't always give you the opportunity to do that.

Similarly, Michael contended, based on his own experiences of conducting research, that quantitative data and statistics are limited and potentially deceptive. He suggested the use of qualitative data as an alternative:

Michael: I can never get to remember the term but qualitative stuff is much better than the quantitative stuff. I've done stuff with both of them ... with numbers where you produce frequency tables and *t*-tests and all that sort of stuff and I've done the more narrative stuff where it's more chunks of text and transcribe from tapes and ... er, the later is much more meaningful.... You can manipulate numbers. I would have done a fair bit of statistics in my time and for one, nobody can understand them, ... you can bullshit people away and they really haven't got a clue what your talking

about it... the feeling comes through [in interviews] and the injustices come through and you wouldn't get that out of '56,500 people interviewed 46 were dissatisfied with their situation ...'. You know you aren't going to get that.

In general, there was strong support for qualitative methods of research, particularly interviews because they allow respondents to express and contextualise their true feelings, rather than having them pigeon-hold into boxes with no or little opportunity for contextual explanation. As Nuala stated:

Nuala: Well I think the way that you doing it at the minute is quite good. Your going and you're meeting people. People who you don't know and you're prepared to meet them and talk to them and you are prepared to listen to them.

Karen suggested that in-depth discussion-based focus groups might be advantageous as they provide supporting structures for a group who might be intimidated by the researcher:

Karen: I think it's better to talk to people and I think it's more positive because you can say more than a list of questions.... You get more feedback face-to-face with a person. And not in a huge group may be. If it was two or three of us in a group may be.... There are times when we can feel intimidated. And especially I feel, many disabled people, they get intimidated by able-bodied people and by institutions that do all this research, because they feel like that they are being ... I'm not sure what it is really ...

Eileen also noted that within the interview framework there has to be flexibility to allow the respondent the freedom to express themselves as they wished:

Eileen: Whatever suits that particular interview. Because if you try to access information from an individual in a format that does not suit them you would not get the best out of them and it's highly unlikely that you would get a true picture of what's going on, because they are feeling uncomfortable about it or whatever—they just won't be forthcoming.

Discussion

Simon: And very often, whether we like it or not, academics take the lead and we need to have as a movement, as a disabled people's movement, our academics.

It is clear from the analysis of the interview transcripts and the actions of disabled people in society (e.g. growth, politicisation and radicalisation of disabled people's movements over the past two decades) that disabled people want (1) disabled people to be more involved in disability discourse (including the research process); (2) academics to be engaged in emancipatory and empowering research projects aimed at improving the lives of disabled people in both practical and political ways. As

academics (disabled and non-disabled), the engagement with the emancipation of disabled people can take one of two forms. Both forms consist of engaging with disabled people in a common struggle against ableism. The first form is merely the adoption of an inclusive research approach. The second form takes the inclusive approach one stage further so that it becomes action- and politically-led. As such, the second form seeks the formation of strong links between academic theorists, disabled people and ‘on-the-ground’ activists. Here, it is recognised that for academia and research to become truly emancipatory and empowering it has to actively seek change rather than hoping that the ‘right people’ read the work and act upon it. As the interviewees in this study argued strongly, research needs to be acted upon rather than gathering dust on a library shelf. This means ensuring that the results reach their audience and that academics engage with what Touraine (1985) has termed ‘committed research’, Katz (1992) a ‘politics of engagement’, and hooks (1994) described as an ‘ethics of struggle’ both within the academy and beyond. As Chouinard (1994, p. 5) argues:

This means putting ourselves ‘on the line’ as academics who will not go along with the latest ‘fashion’ simply because it sells, and who take seriously the notion that ‘knowledge is power’. It means as well personal decisions to put one’s abilities at the disposal of groups at the margins of and outside academia. This is not taking the ‘moral high ground’ but simply saying that if you want to help in struggles against oppression you have to ‘connect’ with the trenches.

Such links are not as yet well developed, and where they are developed they are often partial and not research-based.

Given the views of the disabled respondents in this study [e.g. the enthusiastic endorsement of the participatory action research (PAR) strategy] it seems that the viability of partnership-based, action-led research needs to be investigated. The second part of the study did seek to explore the experiences of conducting action-led, partnership-research and the findings from these studies are documented elsewhere. It is suffice to say that whilst challenging to undertake and not without its difficulties, that a ‘third-space’ (Routledge, 1996) between researcher and researched, academic and activist, can be occupied. Given, however, the paradox that the vast majority of disabled people approached turned down the opportunity to conduct a small research project (for a variety of reasons—time being the main concern), and the general problems of literacy and lack of third-level education amongst the disabled population, a route of consultation may be the most appropriate to follow. Clearly not all researchers will agree (e.g. Shakespeare, 1996). As Patrick stated:

Patrick: Are you talking about the sort of argument about disability circles that you are only allowed to academic research that they have agreed before hand what you should do? My point is that you should do it. Academic research ... research is the researchers agenda, you know. I don’t think you should necessarily pay attention to anybody else.

Whilst having sympathy for the researchers right to choose, one also has to consider the position of the researched. Therefore, whilst not denying that there has been, and will no doubt continue to be, high-quality, rigorous, scholarly, and critical studies of and for disabled people, the route of critical studies *with* disabled people needs to be fully explored. This is because as argued, emancipatory and empowering research (whichever strategy is chosen—consultancy or partnership) potentially represents another step towards independence, self-advocacy and self-determination. Involvement provides a rational and democratic basis for disability discourse shifting discussions and policy from tolerance, charity and common humanity to diversity, difference and rights (Beresford & Croft, 1995). This provides a more effective basis for the campaign for civil rights and the fight for self-organisation, independent living and anti-discrimination legislation (Beresford & Wallcraft, 1997).

Conclusions

Lisbeth: We have to teach everyone to change attitudes—which we do—we also have to let ourselves be used to change attitudes.

In this paper, the results from 35 interviews with disabled people concerning their general opinions of disability research, how disability research should be conducted and by whom has been reported. There is much support for the arguments advanced by academics such as Barnes, Finkelstein and Oliver, that disability research is alienating and disempowering. Such feelings are generated because disabled respondents feel that their knowledges and experiences are being ‘mined’ and suspect that little action is being taken on the basis of findings. Moreover, many interviewees felt that research conducted by non-disabled people may be unrepresentative and may not be serving the interests of those participating. However, the majority of respondents recognised that research can play a vital role in the emancipation of disabled people. This can be fully realised if research is modified radically. The ideal model forwarded by the respondents was one of inclusivity: an equal-based, democratic, partnership between disabled people and disabled/non-disabled academics. The model did not preclude non-disabled researchers, but positively welcomed them. Such a model would be action- and politically-led, seeking to explicitly change social relationships. This model, because it seeks to balance the concerns and power of researcher and researched, interviewees felt would address their concerns of focus, lack of action, the inaccessibility of disability studies literature and levels of representativeness. As such, the viability of using inclusive models of research to examine disability in society needs further investigation.

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NOTES

- [1] Originally in *Disability and Society* (1996) and reproduced in Barton & Oliver (1997).
- [2] The language of this paper is academically orientated. That is because it is aimed at informing an academic audience of the need to change their relationship with the researched. There is no denying that texts need to be written to suit different audiences. However, the same texts can be written to suit different audiences. Papers presenting the results of empirical research from this project will be published in academic/non-academic forms and be available in a variety of formats.
- [3] Policy Planning and Research Unit, Surveys of Disability, five reports concerning prevalence of disability in Northern Ireland. Available from Statistics and Social Division, Department of Finance, Stormont, Belfast, BT4 3SW.
- [4] All respondents in this study were sent the transcripts of their interviews and drafts of all papers based upon their interview material. Respondents were invited to clarify/change their statements and to comment/critique the arguments within the paper.
- [5] This project is a joint venture between Newbridge Access Group and myself and aims to produce an access map and guide to the town which will be used to raise awareness of disabled access and to lobby local councillors for better access. The project was conceived by the group who contacted me for help in designing and administering the research.

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