Towards Emancipatory and Empowering Disability Research: Reflections on Three Participatory Action Research Projects

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Abstract

In this paper I consider recent debates in disability studies concerning how disability research should be conducted, who should conduct such research, and the ideology underlying research practice. Using data from in-depth interviews with thirty-five disabled people from Belfast and Dublin, I outline how they view disability research and how it is and should be conducted. I then detail three participatory action research (PAR) projects conducted in recent years – one concerning access to family planning clinics in Northern Ireland, one concerning access to school education in Kildare, and one creating an access map of Newbridge, Kildare - and reflect on their successes and failures in order to assess the developing an emancipatory and empowering research culture.

Note

The arguments and findings in this paper are an amalgam of previously published papers.[1]

Introduction

For the past decade, disability researchers have been involved in a debate about how disability research should be framed and conducted. This debate has centred on ideology (the uses and intent of research), research ethics and methodology. Mostly one-sided, and dominated by a group of mainly British sociologists, it has been argued that traditional research on disability issues is flawed and problematic in a number of respects (see Barnes, 1992; Oliver, 1992, 1999; Stone and Priestley, 1996; Zarb, 1992; also collections edited by Rioux and Bach, 1994 and Barnes and Mercer, 1997). Most crucially, these commentators have argued persuasively that disability research is not representative of disabled peoples' experiences and knowledge. This, they contend, is because disability discourse has been and to a large degree still is, overwhelmingly dominated by people who are not disabled and the vast majority of research is conducted by non-disabled researchers. They argue that it is only disabled people who can know what it is like to be disabled and so it is only disabled people, who can truly interpret and present data from other disabled people. Moreover, they note 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). Indeed, in an early paper expounding this view, Oliver (1992) argued that traditional research methodologies represent a 'rape model of research' which 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. In other words, existing research has largely been a source of exploitation rather than liberation (Barnes and Mercer, 1997). Drawing on work within feminism in particular, they argue that power-relations within the research process need to be destabilized and the research agenda wrestled free from academic researchers still using traditional research methodologies. As such, they called for the adoption of research strategies that are both emancipatory (seeking 'positive' societal change) and empowering (seeking 'positive' individual change through participation).

This view jars strongly with that traditionally adopted by disability researchers. This is not to say, however, that this research is not guided by ethical concerns. Indeed, ethical guidelines within research 'manuals' and those issued by representative bodies generally advocate a professional and ethical approach to disability research, focusing for example on issues such as privacy, confidentiality, and anonymity. These guidelines suggest that the researcher should carefully weigh the potential benefits of a project against the negative costs to individual participants. Such individual costs might include affronts to dignity, anxiety, embarrassment, loss of trust, loss of autonomy and self-determination, and lowered self-esteem (Kidder, 1986). As Table 1 illustrates, ethical decisions are framed within larger theories about what research seeks to achieve.

Table 1. Theories of Ethical Practice

Teleological	Judges actions according to primary ends (whether the research will result in good).
Utilitarian	Judges actions according to their benefits and costs to all parties.
Deontological	Judges actions according to whether the researcher would wish them upon herself/himself, and whether the participants are treated with the respect due to them.
Critical Theory	Judges actions according to whether the research has positive contributions to the researched.
Covenantal	Judges actions according to whether they agree with specific agreements made between the researchers and researched.

For those commentators most vocal in the debate, these traditional theories of ethical practice failed to consider the issues noted above, namely the imbalance of power within the research process and the privileged position of the researcher to set the agenda and control the project outcomes. They instead suggested a reformulation of traditional disability research, one that sought to destabilise the relationship between researchers and researched and to create new codes of research ethics. Stone and Priestley (1996:706) detail that the core principles of this new approach are:

- 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.

French and Swain (1997:31) suggest that one way to approach these issues is for researchers to ask themselves three principal questions before undertaking work on disability:

1. Does the research promote disabled people's control over the decision-making processes, which shape their lives?
2. Does the research address concerns of disabled people themselves?
3. Does the research support disabled people in their struggle against oppression and the removal of barriers to equal opportunities and a full participatory democracy for all?

Building on these ideas two emancipatory and empowering approaches to research have been outlined within the literature. In the first approach, the professional model of research is adopted but is monitored by the research subjects who provide feedback at each stage of the research process (see Barnes, 1992; Oliver, 1992; Sample, 1996). The second approach seeks to more fully integrate research subjects into the research process so that they take on the role of co-researchers. Here, the research process is 'collectivised amongst its participants' (Priestley, 1997:89). A partnership approach is adopted where disabled people take 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 our co-researchers to help them make informed choices. Secondly, it is to provide a relatively privileged position through which the co-researchers can speak. Cocks and Cockram (1995:31) detail that emancipatory and empowering (participatory) research is premised upon five factors.

1. An acknowledgement that oppression within society creates oppressed groups and this leads to a need to engage in some transformation of the larger society to counter it.
2. Knowledge generation, control and application are central to the effort to emancipate and liberate people who are oppressed.
3. People have the capacity to work towards solutions to their own problems.
4. There is a vital link between knowledge generation, education, collective action and the empowerment of oppressed people.
5. Researchers should act in accordance with an explicit values position and should become actively involved in the process of liberation.

Commentators argue that involving disabled people in disability discourse as controllers or partners offers practical and social gains for disabled people. It is only with their active involvement that disability discussions will reflect their needs, concerns and interests. Through participation and partnership, research will become more reflexive, reciprocal and representative. It will provide 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. In short, research will become enabling and empowering. Inclusion acknowledges and signifies a respect, that the contributions of disabled co-researchers are valuable and worthwhile. Here the co-researcher's expertise is acknowledged as equal but from a different frame of reference than the academic (Elden and Levin,

1991):

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

Here, there is the development of a mutual sharing of knowledge and skills (Lloyd et al 1996). This is not to deny that an expert/lay-person relationship between researchers and co-researchers does not exist but rather that such a position can be re-worked into a more favourable, emancipatory position.

Many researchers might seek to reject inclusive, partnership-based research on scientific grounds (e.g. separation of researcher/researched). However, this collaboration does not necessarily 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. However, in contrast to the standard expert model of research where subjects have little opportunity to check facts, offer alternative explanations or verify researcher interpretations, inclusive approaches facilitate such interaction. As a result, inclusive approaches far from diminishing the academic rigour of research, enforces a rigorous approach that is crosschecked at all stages of the research process through the participant co-researchers. Consequently, Elden and Chisholm (1993) argue that inclusive approaches provide more valid data and useful interpretations. Greenwood *et al*. (1993) argue that this increase in validity is due to a democratisation of knowledge production giving the participants a stake in the quality of the results. As such, the usual barriers to disabled involvement such as inexperience, lack of expertise and lack of enthusiasm are revealed as red herrings erected by professionals too blinkered by their own 'expertise', tokenist gestures, and misreading to recognise disabled peoples' potential contributions to research about their lives.

This is not to say, however, that there is no role for the professional expert model of research. As Shakespeare (1996) argues there is a place for instrumental, theory-driven research, which although seeking emancipation for disabled people only includes them as data sources. He concludes that all socially based disability research is welcome research as long as it does not parasitise disabled people's experiences for the purpose of career development or further oppressive practices. However, it is contended here that *where beneficial and possible* a more empathetic approach to empirically based disability research should be adopted. While the debate has been hugely influential in re-shaping the landscape of disability research, much of the rhetoric used to support the arguments advanced was anecdotal and lacked detailed evidence to support the claims made. The research reported in the rest of the paper sought to fill this gap by asking disabled people their views on research and to experiment with operationalising a more emancipatory and empowering approach to disability research.

Interviews

To discover disabled people's opinions on disability research, in-depth interviews were undertaken with 35 disabled people with a variety of physical, sensory and mental impairments. 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. I collected the data between March and November 1998. Interviews lasted from twenty-five minutes to over three 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 (see Kitchin and Tate, 1999).

The issues covered in the course of the interview included: whether respondents had taken part in research and their experiences; their general opinions concerning research; whether they thought research had served/was serving disabled people well; how research on disability should be conducted; who should conduct research on disability; and finally what they would like to be researched. The interviews revealed a number of interesting themes about how disabled people themselves view research concerned with disability issues (see Kitchin, 2000 for a full account). The majority of interviewees were of the opinion that research concerning disability issues is important and needed. *Research is absolutely vital because the more research that is done the better the argumentation that can be made* (Frank).

This is not to say that interviewees accepted research non-critically. Some warned that research should be carefully selected, presented in a way that is unambiguous, has clear connections between theory and the lives of disabled people, and needs to be acted upon. In their opinion, most research seemed to be ineffective at changing social relations 'on the ground', failing to transfer from academic realm to the 'real world'. … *I would be cynical about what actually happens with research. The majority of times it just sits on a desk* (Susan). When asked whether they felt that disability research as practised was serving or had served disabled people well the interviewees were divided. Some felt that research had or was serving disabled people well and was helping to dismantle disabling barriers and others thought research was helping to reproduce particular problems.

> 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 *(Robert)*.

> 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 ... you can understand disabled people being slightly sceptical of disability research *(Simon)*.

Many of the problems noted by advocates of emancipatory and empowering research were articulated. For example, some interviewees worried that much research was not representative of their views because it was conducted by people who did not know what it was like to be disabled. *You don't know how a disabled person's life works. You can only imagine how it works. But you*

actually don't know (Ken). Their opinions were based not only on their perceptions of research but also on their experiences of taking part in studies. Many of these experiences were negative and some interviewees felt they had been exploited - their knowledge and experiences 'mined' by the researcher(s), who were then never heard of again, and whose research had made no or little perceivable impact on their daily living.

> 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 *(Aisling).*

All but three of the interviewees were of the opinion that disability research should involve disabled people beyond the subject source. Rather than research being conducted solely by disabled people however, it was argued that the way forward was a collaboration of disabled people and (non-disabled) academics through consultation and partnerships. *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* (Nuala).

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.

> I think it has to be in conjunction with a disabled person and able-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's 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 *(Karen).*

Others recognised that disability issues extend beyond disabled people to include carers, family members and service providers. To many of the interviewees, alienating researchers who are non-disabled allies is counter-productive and does not aid the disability movement's cause. Some 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. Interviewees suggested two potential approaches to combat some of the issues described above. The first was a consultant approach. Here, 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.

> Maybe 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 canshow a layout of their research to and they will give you a more of an insight into problem areas that need to be looked at and the things that have been missed and that sort of thing *(Rebecca).*

The second, more popular approach was a partnership approach where instead of merely advising the researchers, disabled people were full partners in the project.

> 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 maybe 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 *(Lisbeth).*

In every case, respondents expressed enthusiasm at the prospect of PAR projects being undertaken in their local area, but when offered the opportunity to take part in this research, without fail, the interviewees (including strong advocates of inclusion) declined, 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). 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.

Three PAR Projects

In order to explore the merits of a more inclusive research strategy to date three participatory action research (PAR) projects have been conducted (one in Belfast, Northern Ireland, one in Dublin, and one in Newbridge, County Kildare). Simply stated, PAR aims to re-negotiate the position of 'the researched' to one of co-researchers, involving participants in every stage of the research process from the design stage to the writing of the research results. As such, PAR is an attempt to address the problems of representiveness and unequal power arrangements between researchers and researched within social research. The philosophy behind PAR is to try and facilitate a moral programme of social action through the facilitation of studies *with and by* research subjects. Here, the role of the academic becomes enabler or facilitator: the academic takes a supportive position and seeks to inform and impart knowledge and skills to the research subjects who co-direct the project.

Each of the PAR projects focused on a different aspect of disability. The first project investigated disabled people's access to family planning clinics, sex education and sexual health in Northern Ireland (see Anderson and Kitchin, in press, for full results). The chosen method of data generation was a short questionnaire that was mailed to all family planning clinics in the Province in August 1998. The survey consisted of two sections. In the first section, the clinic staff were asked to assess the overall accessibility of the clinic and conduct an access audit of their building. In the second section, the clinic staff were asked about information access and specific services. The questionnaire was anonymous to encourage responses without fear of undue publicity. The aim was to assess the state of play, not to make scapegoats of particular clinics.

The second project investigated disabled children's access to schools in County Kildare, Ireland, in light of the Irish Education Act 1998 (see Kitchin and Mulcahy, 2000 for full results). The chosen method of data generation was a questionnaire survey that was mailed to all first level (age 5-11) and second level (age 12-18) schools in the county. The survey comprised of six short sections: (1) school details, (2) a census of numbers of pupils, including those with different disabilities, (3)

school policy, (4) access and provision, (5) plans for the future, (6) further comments. To complement the survey data, a random selection of 10 school principals, who indicated that they would be willing to discuss further issues raised in the survey, were interviewed. Interviews were conducted over the telephone and were recorded and transcribed in full. The third project undertook an access audit and produced an access map of Newbridge, County Kildare and was conducted with Newbridge Access Group. Formed in 1997, NAG is a pan-disability organisation that has campaigned with some success for better access in Newbridge, County Kildare (population 13,363, OCPS 1996). The project had a number of aims (1) to undertake a detailed access audit of the town, (2) to produce an access map that residents and visitors could use to help effectively navigate and enjoy the town, (3) to lobby local politicians for change, and (4) to create a knowledge and skills base so that the disabled participants could repeat the exercise with other access groups helping them set up their own mapping projects. The project consisted of eight phases, each aimed to adhere to the principles of inclusive participation: that the planning, execution, and control of the project were agreed collectively:

1. Planning the remit and scope of the audit.
2. Planning the specific and structural details of the audit
    - Developing a symbol set that would be sufficient to represent all situations and impediments that a disabled person (with either a physical or sensory impairment) might encounter while moving through the environment
    - Deciding which areas of the town would be surveyed, and possible strategies for dividing the work between the group's members.
3. Pilot study to assess the effectiveness of the symbol set.
4. Training session to teach the members of NAG basic map reading, to illustrate how to recognize all environmental impediments, and how to apply symbols to the field map
5. The actual field survey itself followed by a de-briefing session to make sure the survey was complete, and to compare notes about how well the survey had gone and to identify any problems encountered.
6. Producing high quality access maps suitable for distribution Survey maps checked against the final access map, and then a field check of the access maps in the environment itself
7. Publishing the access map and its symbol set on the Internet via a series of Web pages. In addition, a large poster showing the entire map and a sample of the photographs was produced, and has been displayed at several locations around the town, and displayed at different community events.

Experiences of Participatory Research

It is fair to say that none of the three projects ran smoothly. The two initial projects were hampered by four principal factors. The first was each project only consisted of a partnership between myself and one other person. As discussed earlier, whilst enthusiastic, the disabled people interviewed were very reluctant to commit themselves to a project. This was due to a number of factors such as the time involved, a lack of confidence, and, as explained below a lack of familiarity with myself. Both the individuals who did take part worked full-time, Paul worked at the Family Planning Association in Belfast and Frank as a disability activist (secretary of both the European Union's Disability Forum, and Disabled People's International). Second, both projects were initially set-up to be run with the assistant of Disability Action in Belfast and the Irish Wheelchair Association in Dublin. By the time funding had been secured, contacts in both establishments had left and both groups claimed

to know nothing about the project. Third, there was a set of personal factors that made setting-up the projects difficult. I moved to Northern Ireland as the initial funding bid was being formulated. Whilst I certainly made a lot of contacts through the interviews I conducted, I was previously unknown to all the interviewees. Therefore there was little basis upon which interviewees could decide whether to commit time to working on a joint project. PAR projects it seems are only really suitable in cases where all members are already well known to each other and who know they can work together. As it happens, both initial projects were highly personable and a working trust developed very quickly. Moreover, I moved to Dublin mid-way through the project running in Northern Ireland, making it difficult to sustain. On moving, I once again encountered the problem of forming a new network of contacts. Fourth, the project funding was minimal and did not permit either project to hire any personal or professional assistance, although it did pay some transport costs.

The third PAR project was formed through existing contacts. However, the project has suffered from other problems. The Newbridge Access Group is undoubtedly very dedicated to access issues, but there were a series of hiccups that delayed the project. Significantly, the group met only periodically, once every one to two months, and not all members attended these meetings. Indeed, the meetings clashed with my own commitments forcing me to miss attending some meetings. This inevitably delayed the project, stretching it out over a considerable period of time. Moreover the project did not receive any significant funding and the group is run on a voluntary basis. The Irish Council for People with Disabilities (now PWDI) paid for the base maps and for two days work by a cartographic assistant. As such, there was a labour shortage that hampered progress. That said the project was very rewarding to work on. All three projects then slipped from being full PAR projects to a semi-PAR status. The disabled people were involved in setting up the projects, and did share the task of data collection, but analysis and writing-up was largely left to myself. Almost inevitably, given my familiarity with various literatures and professional research experience, the projects have reflected and been shaped by my opinions. As a consequence, whilst the projects alluded towards equal partnership, they have been to varying degrees, directed by myself.

Despite these difficulties, I would argue however, that a 'third-space' (Routledge, 1996) between researcher and researched, academic and activist, was occupied by myself, that the disabled people who took part learnt new skills and contributed to wider debates, and that the projects have had partially successful outcomes, with articles in internationally refereed academic journals and other outlets. The extent to which the research will change the 'practical' conditions of disabled people more broadly has yet to be assessed. At the least, it is hoped that the findings will influence health board officials in Northern Ireland, the Department of Education in Ireland and the local councillors in Newbridge, and the policies they draw up and implement.

Conclusions

The wider disabled population holds many of the arguments forwarded by critics of traditional disability research. Perhaps given that 'scientific' research has perpetuated, reproduced and legitimated the marginalisation of disabled people, justifying segregation, eugenics, and the denial of civil rights, it should be of little wonder that disabled people are suspicious of disability research, especially by non-disabled researchers (Rioux and Bach, 1994). New ways of undertaking disability research are being developed that hold considerable promise for creating inclusive, emancipatory and empowering research, without undermining the 'scientific' and policy credentials of the research produced. These new approaches – five of which are outlined in the National Disability Authority's

'Guidelines for Including People with Disabilities in Research' – are still in their teething phase. Significantly, most of the problems lie not with the principles of inclusive research but with practicalities such as time, skills, resources, and reward. In time then their impact will lessen as responses to particular issues become standardised. Of crucial import in the Irish context is the National Disability Authority's policy of fostering inclusive research as the preferred mode of investigating and addressing disability issues and the detailed guidance its 'Guidelines' outlines to those wishing to undertake inclusive modes of disability research. This provides an important message concerning the politics of disability research and of disability issues more generally. Consequently, I am sure that over time, inclusive research in Ireland will transform disability research and help empower those that undertake the research and the wider disabled community.

Notes

1. See Kitchin (1999, 2000, 2001, in press), Kitchin and Mulcahy (1999), Anderson and Kitchin (2000), Kitchin and Law (2001), Kitchin and Wilton (2000)

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