

Disability Studies Quarterly
Fall 2001, Volume 21, No. 4
pages 61-69 <www.cds.hawaii.edu>
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Using Participatory Action Research
Approaches in Geographical Studies
of Disability: Some Reflections

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Introducing current debates in disability research

In short, the challenge is to pursue a geography with disabled people which seeks the goals of material justice and political emancipation that are shared by contemporary movements. (Gleeson 1996: 395)

There have been several recent debates both within disability studies and geography about how disability issues should be researched and who should conduct such research. This debate has primarily centred on ideology and ethics, but has also focused on methodology per se.

The debate in disability studies has centred on the arguments of a group of mainly British sociologists, Barnes (1992), Oliver (1992, 1999), Stone and Priestley (1996), and Zarb (1992) (also see collections edited by Rioux and Bach 1994 and Barnes and Mercer 1997). These scholars argued that traditional research on disability issues is flawed and problematic in a number of respects. Most crucially, they suggested that disability research is not representative of disabled peoples' experiences and knowledges. This, they contended, was because a vast majority of research is conducted by non-disabled researchers. They argued 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 noted that research concerning disability 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, 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. Researchers are compounding the oppression of disabled respondents through exploitation for academic gain. Drawing on work within feminism in particular, they argued that power-relations within the research process needs 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).

In geography, the debate between the Reg Golledge (1993, 1995, 1996) on the one hand and his opponents, Ruth Butler (1995), Brendan Gleeson (1996), Rob Imrie (1996) and Hester Parr (1997), focused on conceptions of disability, understandings of space, ideology and methodology. Essentially, Golledge argued for the development of a geography of and for disabled people conceptualising disability as a function of impairment and conducting studies of (subjects of research) and on behalf of disabled people (beneficiaries of research). Within his position geographic research was cast as an objective, scientific pursuit, where space was conceived as an absolute entity with a fixed Euclidean geometry.

His detractors questioned the basis of such a geography, and instead advocated the search for a geography with disabled people which conceptualised disability as a function of social construction. Within their position geographic research was cast as a situated, political and ethical endeavour and space was conceived of as a social production. In other words, the two proposed approaches to geographical studies of disability were in direct opposition to one another: politically-neutral versus politically-charged; medical model versus social model; space as mere backdrop to life versus space as an active shaper of people's lives.

The upshot of the debate within geography is that despite Golledge's continued resistance to emancipatory and political approaches there is a broad agreement amongst geographers studying disability of the utility and need for such approaches (see Dyck 2000; Chouinard 1997, 2000; Gleeson 2000; Kitchin 1999a; Wilton 2000). How to successfully implement such an approach though is still being explored. The interviews and the three empirical projects reported here sought to determine whether the ideas developed (but largely unimplemented) by Barnes, Oliver, Stone and Priestley, and Zarb, might be a fruitful approach to developing emancipatory and empowering geographies of disability.

Methodology

The initial research project consisted of two phases. In the first phase, disabled people's opinions on disability research were solicited through in-depth interviews 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. All the data were collected between March and November 1998 by the author. 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 second stage consisted of implementing two participatory action research (PAR) projects (one in Belfast, Northern Ireland, and one in Dublin, Ireland). This second phase has subsequently been followed by another on-going PAR project in Newbridge, Ireland. 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 researcher and researched within social research. The philosophy behind PAR then is to try and facilitate a moral geography 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.

Findings from the Interviews

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. This is not to say that interviewees accepted research non-critically. Some warned that research needs to 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.'

When asked whether they felt that disability research as practised was serving/had served disabled people well the interviewees were divided. Some felt that research had/was serving disabled people well and was helping to dismantle disabling barriers and others thought research was helping to reproduce particular problems.

Many of the problems noted by the British sociologists as detailed above 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. Their opinions were based not only on their perceptions of research, but also 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.

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. 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. Others recognised that disability issues extend beyond disabled people to include carers, family members and service providers. 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. 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. The second, more popular approach, was a partnership approach where instead of merely advising the researchers disabled people were full partners in the project. 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).

The PAR Projects

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 accessibility of the clinics, 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 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 was an access mapping of Newbridge, County Kildare conducted with Newbridge Access Group. The project is divided into three parts. The first part was to map levels of access in the town (see Kitchin 1999b; Kitchin and Law 2001, see <http://www.may.ie/staff/rkitchin/newbridge.htm> for access maps). The second was a public

exhibition of the maps and photographs developed from the first part displayed in several places. The third part is to produce an accompanying guide including a list of the most pressing problems and a guide to good practice. The project as a whole will be used to lobby the local council and businesses in Newbridge to tackle existing problems and to adopt more disabled-friendly planning approaches in the future. One result so far has been that the Newbridge Access Group have spoken with a number of key people.

Experiences of using PAR

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 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).¹

Second, both projects were initially set-up to be run with the assistance 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 were 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 have been a series of hiccups that have delayed the project. Significantly, the group meets only periodically, every one to two months and not all members attend these meetings. Indeed, the meetings have clashed with my own commitments forcing me to miss attending. This inevitably delays the project further. Moreover the project has not received any significant funding and the group is run on a voluntary basis.

The Irish Council for People with Disabilities paid for the base maps and for two days work by a cartographic assistant. As such, there is a labour shortage that is hampering progress. This said the project has so far been 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 has largely been 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 to varying degrees been 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 and that the projects have had partially successful outcomes with articles in internationally refereed journals. The extent to which the research will change the `practical' conditions of disabled people 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 councilors in Newbridge, and the policies they draw up and implement.

Conclusion

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 more fully explored. It is clear from the analysis of the interview transcripts and my experiences of undertaking PAR projects that disabled people advocate the development and use of emancipatory and empowering research projects aimed at improving their lives in both practical and political ways. The paradox is, however, that despite the rhetoric most disabled people are unable or unwilling to actually contribute to full PAR projects.

It is my suggestion therefore that a different strategy be adopted, but one that still seeks to be emancipatory and empowering. This strategy would be one of consultation. Here, disabled people would help to formulate and monitor the research project, providing constructive criticism at all stages, but the actual processes of data generation, data analysis and writing-up be undertaken by a professional researcher. The academic then would largely retain control of the research process, but a panel of disabled people would get the opportunity to shape the research agenda and correct misinterpretations of the data.

Notes

1. Permission has been obtained to use people's real names.

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