Breaking the Mould? An introduction to doing disability research

Colin Barnes and Geof Mercer

BACKGROUND

Over the last two decades disability activists have established the social model of disability as a comprehensive critique of mainstream academic theories and policy approaches. The disillusionment of disabled people and their organisations has also extended to research on disability. In a trenchant attack, Oliver (1992) condemns it as a 'rip-off that has done little, if anything, to confront the social oppression and isolation experienced by disabled people or initiate policies which have made a significant improvement in the quality of their lives.

The significance of disability theory and practice lies in its radical challenge to the medical or individual model of disability. The latter is based on the assumption that the individual is 'disabled' by their impairment, whereas the social model of disability reverses this causal chain to explore how socially constructed barriers (for example, in the design of buildings, modes of transport and communication, and discriminatory attitudes) have 'disabled' people with a perceived impairment (Barnes and Mercer, 1996).

While the social model suggests a way forward for a disability politics, its translation into specific forms of 'disability research' has been much debated. In this introductory chapter, we trace the background to the disenchantment with existing research and its replacement by an 'emancipatory' approach. There has been a significant expansion of research committed to these ideals within the present decade, and in the chapters that follow, a selection of the new disability researchers reflect on their work.

WHAT'S WRONG WITH SOCIAL RESEARCH ON DISABILITY?

The roots of the critique of social research on 'disability' can be traced back at least to the 1960s. In what has become a celebrated case in the

history of the disabled people's movement, disabled residents in the Le Court Cheshire Home asked 'experts' in 'group dynamics' to support their struggle against local managers and professionals for greater control over their everyday lives. Miller and Gwynne from the Tavistock Institute were funded to undertake a three-year in-depth study. However, the residents were soon alienated by the way in which 'unbiased social scientists' followed their own agenda. This was confirmed by the final report on the research which rejected the residents' complaints and recommended a re-working of traditional practice although they categorised institutional life as a 'living death' (Miller and Gwynne, 1972). The residents felt betrayed and denounced academic social scientists as 'parasites' (Hunt, 1981).

Several of the disabled people in the Le Court protest helped to form the Union of the Physically Impaired Against Segregation (UPIAS) in 1975. It was central to the development of what became known as the 'social model', and as part of its political statement delivered a comprehensive critique of the 'experts and professionals' who professed to speak on behalf of disabled people, but who in practice mainly pursued their own interests:

> 'We as a Union are not interested in descriptions of how awful it is to be disabled. What we are interested in is the ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our physical impairments by the way this society is organised to exclude us' (UPIAS, 1976, pp. 4-5).

Another illustration of how mainstream researchers have marginalised disabled people's concerns arose during discussions on the World Health Organization's (WHO) International Classification of Impairments, Disabilities and Handicaps (ICIDH) in the 1970s. Those responsible for updating the ICIDH decided on the following definitions of the key terms:

> impairment - 'any loss or abnormality of psychological, physiological, or anatomical structure or function';

> disability - 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'; and

handicap - 'a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual' (Wood, 1980, pp 27-29).

However, these definitions were strongly opposed by organisations controlled and run by disabled people -including the (then) British Council of Organisations of Disabled People (BCODP) and the Disabled Peoples , International (DPI) -exactly because they repeated the medical view that 'impairment' is the determining factor in explaining both 'disability' and 'handicap' (Oliver, 1996). BCODP and DSI reiterated their commitment to the social model, in which disability is defined as:

'the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities' (UPIAS, 1976, p. 14).

Subsequently, this definition was broadened to accommodate all impairments - physical, sensory, and intellectual -and adopted by national and international organisations including the BCODP and DPI.

The opposition expressed by disabled people to the WHO Classification was in complete contrast to its broad acceptance by those social scientists studying chronic illness and 'disability'. They proclaimed that it represented a significant advance because, for the first time, social factors (i.e. 'handicap') were included in what had been an exclusively medical model (see Anderson & Bury, 1988; Bury, 1996). Yet important statements by disabled people that social factors as much as biological ones are the source of their social disadvantages were ignored by academic social researchers. Witness the lack of impact of the collection of essays by disabled women and men entitled Stigma: The Experience of Disability (Hunt, 1966), or Campling's (1981) volume on disabled women. In contrast, the 'socio/medical model of disability' has been dominated by interpretative studies of the experience of 'illness', which focus on individual coping mechanisms, including the management of 'stigma', and other perceived threats to 'self and 'identity' (Bury, 1996).

For their part, disability theorists have criticised this socio/medical model for not breaking the causal link with impairment, or at most, providing a 'social model of impairment'. The latter reinforces the view that disability

is studied as a 'personal tragedy' rather than as social oppression. In Paul Hunt's (1966) words those with an impairment are treated as 'unfortunate, useless, different, oppressed and sick' .They represent everything that the 'normal world' most fears - 'tragedy, loss, dark, and the unknown' (p. 155).

The impact of the ICIDH/individual model is also very evident in policy-oriented research, most notably in the national disability survey conducted by OPCS in the 1980s (Martin et al., 1988; Martin and White, 1988). Although officially presented as the most comprehensive account of the social conditions and needs of disabled people, its reception by disabled people has been highly critical. If anything, the study has become synonymous with a lack of consultation with organisations of disabled people, a denial of the social model, a reduction of disability to simplistic, 'objective' measures, the dissemination of disputed findings, and few positive policy outcomes (Abberley, 1991; Oliver, 1992).

As the 1980s drew to a close, some disability researchers undertook studies which turned the spotlight on the experience of disablement and away from individualistic explanations. Examples include: Mike Oliver et al's (1988) Walking into Darkness; Jenny Morris' (1989) Able Lives; and Colin Barnes' (1990) Cabbage Syndrome. The disabled people's movement (through BCODP) also commissioned research in support of its campaign for anti- discrimination legislation which led to the publication of Disabled People in Britain and Discrimination (Barnes, 1991).

At the same time, there was a burgeoning literature on the possibilities of 'critical social research', including work by feminists, Black writers and educationalists, which positively allied itself with oppressed groups. This complemented charges by disabled activists and their organisations that existing research had been a greater source of exploitation than liberation. The scene was set for disability research to break completely with mainstream approaches.

DOING EMANCIPATORY RESEARCH

Although not a unitary body of thought, 'critical social research' has achieved a pre-eminent influence on disability researchers, at least in its emphasis on emancipatory goals, and its calls for openly partisan and politically committed research. It became an 'article of faith' that social researchers adopting a critical perspective should take the side of the oppressed (Becker, 1967). Traditional claims to be 'objective' and 'neutral'

were dismissed on the grounds that all knowledge is socially constructed and culturally relative (Kuhn, 1961).

A crucial opportunity for disabled people to debate the possibilities of developing new ways of' doing disability research' was provided by a series of seminars funded by the Joseph Rowntree Foundation in the late 1980s and early 1990s. These brought together a variety of interested individuals and organisations and resulted in a national conference and a special issue of the journal Disability, Handicap and Society in 1992 (Ward and Flynn, 1994) Probably the most influential contribution was Mike Oliver's call for disability research to follow 'what has variously been called critical inquiry, praxis or emancipatory research' (1992: 107). At its heart is a political commitment to confront disability by changing: the social relations of research production, including the role of funding bodies; the relationship between researchers and those being researched; and the links between research and policy initiatives.

For Oliver, emancipatory research must be located in the social model of disability. It must reject the individual or medical model view that impairment is the root cause of disabled people's problems. This includes giving proper recognition to disability and disabled people in social research (e.g. in studies of the family, employment, sexuality, education and the like) but more ambitiously, it is suggested that disability research presents a radical alternative to mainstream research theory and methods. The idea that research should be about changing the world, not simply describing it, goes back at least to Marx. Contemporary critical theorists have argued that research is inherently 'political' (rather than 'objective'), and must be guided by the 'purpose of emancipation' (Gitlin et al., 1989). Needless to say, the political challenge must have particular targets in the research process. Uppermost in the minds of most disability writers has been the need to transform the' social and material relations of research production' .With respect to the latter, it is argued that the main funders of disability research have a considerable potential to influence its direction and character. Similar concerns have been expressed about the role of the large research institutes and units which dominate 'contract' policy research. The primary issue for those who have focused on 'social relations' has been the asymmetrical relationship between researcher and researched. This is seen as a major reason for the alienation of disabled people from the research process. The power of the researcher-experts is enshrined in their control over the design, implementation, analysis and dissemination of research findings. As a consequence, the 'subjects' of research are treated as 'objects', with little positive input to the overall research process. The emancipatory paradigm rejects this notion of researcher-experts moving between projects like 'academic tourists', and

using disability as a commodity to exchange for advancing their own status and interests. The response of disabled people is quite simple: 'no participation without representation' (Finkelstein, 1985).

The role of the non-disabled researchers has raised similar questions. For some, their lack of personal experience of disabling barriers means that their contribution lacks authenticity; for others, disabled and non-disabled researchers live in a disablist society and can both contribute to disability theory and research.

A striking feature of the call for a new approach in disability research has been the lack of alignment with particular research methods or techniques, although this may now be changing. Oliver suggests that the new paradigm should highlight 'reciprocity, gain and empowerment' (1992: 111), but there has been relatively little discussion on what these entail or how they should be achieved. In contrast, feminist criticism of 'malestream' research has prioritised the validity of personal experience as opposed to 'scientific methods'. This has been translated into an enthusiasm for unstructured research methods (Morris, 1996).

This is highlighted in the emphasis on reciprocity in the relationship between researcher and researched as an attempt to give due recognition to those being researched as 'expert-knowers'. It also means that the 'expert- researchers' place their skills and knowledge at the disposal of those being researched. However, this objective has proven difficult to translate into practice. Is the elimination of power differences always necessary or feasible? Is the relationship to be reversed or equalised in some way? In addition, the presumption that the social world is divided neatly between oppressors and oppressed has been challenged. Studies with black people, for example, have pointed to the cross-cutting sources of oppression -such as gender, 'race' and disability. The designation of oppressors and oppressed varies across social contexts.

There is a parallel dilemma for researchers who try to convey the experience of disability if the 'oppressed' group resists non-hierarchical research relationships or alternatively takes contrary lines by explaining their 'disability' in terms of their impairments. At the same time, there are concerns that research findings are misrepresented or used to reinforce disablist notions, for example by describing disabled people as helpless 'victims'. One solution is to distinguish between the structural position of disabled people and their own experiences. According to one feminist researcher:

> 'This enabled me to see that evidence of women successfully accommodating to various structural features of their lives in no way alters the essentially exploitative character of the structures in which they are located' (Finch, 1984: 84).

An associated issue is the significance that should be attached to people's subjective experiences of disability and impairment. As described by Finkelstein (1996), the choice is between an 'outside in' or an 'inside out' approach. In the former, disability research and political activity concentrates on the barriers 'out there' (e.g. Oliver, 1996), while the latter adds an emphasis on disabled people's subjective reality - their experience of physical pain, fatigue and depression - (Morris, 1991; 1996; Shakespeare et al., 1996; Crow, 1996).

In summary, emancipatory research in the disability context should be enabling not disabling. It must be 'reflexive' and self-critical lest a new orthodoxy is established which turns 'doing disability research' into a technical routine. Disability research must not deteriorate into propaganda: it must be politically committed but rigorous.

REFLECTIONS ON DOING DISABILITY RESEARCH

Mainstream social research has long recognised the potential divergence between 'theory' and 'practice': as is illustrated by such volumes as Doing Sociological Research (Bell and New by, 1977), and Doing Feminist Research (Roberts, 1981). Following these examples, the contributors to this volume have been encouraged to explore the promise and possibilities of 'doing disability research', as well as its problems and pitfalls. This collection includes established writers on disability as well as 'new recruits'. The chapters span the theory and practice of disability research, from the preparatory stages through to dissemination of findings.

The first contributor is Mike Oliver who has been central to debates about the character and objectives of disability research. He delivers a 'critical reflection' on his recent research on the history of disability politics which he undertook with Jane Campbell (Campbell and Oliver, 1996), as well as making general observations on the state of disability research. Oliver expresses grave doubts about the extent to which the social and material relations of research production have been changed, and highlights the impact of major research funders. He concludes that, in seeking to make a contribution to the emancipation of disabled people, disability researchers

must be more explicit about the ideological position which they are adopting. A less pessimistic perspective on what has been achieved this far is provided by Linda Ward, based on her experience working with the Joseph Rowntree Foundation (JRF) and the Norah Fry Research Centre. She argues that JRF has become committed to the social model of disability and has supported very innovative research that has made significant advances in involving people with learning difficulties and disabled children in the research process from interviewing to dissemination. Ward contends that an organisation which is idealistic in its goals, and open to persuasion about new ways of doing research, has been a catalyst for change in shifting the balance of power between researchers and those being researched. She concludes that a constructive dialogue between funders and disability researchers is possible and has had a positive impact on disability research.

One obvious research project suggested by the social model of disability is to measure disability by investigating disabling barriers. This is now the subject of an ESRC-funded study entitled Measuring Disablement in Society.

Its director, Gerry Zarb, outlines the steps it has taken to change the social and material forces of research production. The project has been particularly ambitious in the significance attached to enabling disabled people to guide the research agenda. A further commitment has been to the recruitment and role of disabled researchers. Zarb examines various problems encountered in the course of the research, including the constraints imposed by research funders and employers that do not always take into account the particular circumstances of disabled researchers.

In their chapter, Beresford and Wallcraft consider the applicability of disability research to the survivors' movement- those with experience of the psychiatric system. Not all survivors consider themselves 'disabled' despite the similarities in social disadvantage and social oppression. This in part explains why the survivors' movement has been far less united on its theoretical and research agenda. In research terms, there has been a slower movement down the emancipatory path and survivors have been used more as a resource for experiential data rather than the 'creators of our own analysis and theory' .However, the authors detail the gathering tradition of survivor-led research which is seeking alternatives to the medical control of definitions of mental illness and of psychiatric treatments and institutions.

Mark Priestley's discussion of doing disability research centres on a collaborative project with Derbyshire Coalition of Disabled People and Derbyshire Centre for Integrated Living. The discussion spans issues associated with being a non-disabled researcher, setting up the project, agreeing the research questions, and devolving control to those being researched. All parties were committed to breaking down the traditional researcher- researched hierarchy, but found that compromises had to be made. Not least, Priestley's position as a postgraduate student provided considerable potential for conflicts of interest between his' academic' and 'political' self. Indeed-issues of power and control are central to his discussion. Not that disabled people always wanted to take the research over, rather their concern was to equalise the relationship and ensure researcher accountability.

Lunt and Thornton's chapter on disability and employment policies in different countries diverges significantly from most others in the book in that it relies on secondary analysis of published literature. The research also took its cue from national governments, rather than disabled people. However, its focus on the policy establishment allows discussion of the social and material relations of contract research production. The authors argue that they were not constrained by their funders as much as disability theorists might suspect. Indeed, funders were not always clear what they wanted and on occasions did not speak with one voice. Nevertheless, time and resource pressures meant that the research was very reliant on official sources for information and policy evaluation.

Tim and Wendy Booth have an established reputation for conducting research with people with learning difficulties. Their contribution identifies a range of technical, ethical and conceptual difficulties encountered in a recently completed project on parenting. Innovative data collection methods were employed which stemmed from a narrative method of 'life review'. They describe how they sought to ensure that the processes of data collection were determined by the respondent's subjective interpretation of their own experience and development of their storyline. Various devices were employed to generate the necessary rapport, including writing stories, and shared interviews between siblings. The overall goal was to facilitate the interviewee taking control of the interview. The study throws new light on taken-for-granted assumptions about parenting by focusing on those who 'break the rules', but in so doing, the Booths illuminate parenting processes in general.

Beazley, Moore and Benzie began their study determined to provide as much control as possible to their disabled subjects. However, the lack of

time and resources, the involvement of other 'stakeholders' with differing interests and commitments, plus other unforeseen interruptions, represent not untypical complications. The researchers describe how their attempts to maintain the direction and progress of the project were frustrated in various ways and by different people and groups. Even the involvement of other disabled people did not mean 'emancipatory' research objectives were easily sustained. There were further tensions to be sorted out in terms of different interest within the research team. The path of disability research requires considerable skills as well as the commitment to emancipatory goals!

Ayesha Vernon provides an 'insider's perspective' on researching the oppression experienced by disabled Black women. She placed particular significance on devising ways to break down the researcher- researched hierarchy. Her discussion explores a wide range of issues confronting the researcher committed to achieving respondent control and researcher accountability. These include: setting the research focus; getting the researcher-researcher relationship 'right' before interviews began; involving interviewees in checking/changing their answers; and commenting on the researcher's commentary on their experiences. The dilemmas posed extended from practical constraints of time and resources through to differences of interpretation: how does the disability researcher respond to 'disablist' views from disabled respondents? Her emphasis on reciprocity reinforced the importance of interviewees taking something positive from the research experience, but 'intent is no guarantee of outcome'.

Tom Shakespeare's chapter draws on research which led to the jointly-authored book The Sexual Politics of Disability (Shakespeare et al., 1996). He raises many issues about the approach to researching people's experiences of disability and sexuality, which he sets within the twin considerations of intellectual and political commitment. He notes the diverse reasons which underpin disability projects by academics: personal ambition and advancement; intellectual curiosity, political commitment and perceived need; and a dose of pragmatism. So is it emancipatory research? 'To be honest, I don't know and I don't care' is Tom's response. He espouses a 'free spirit' view of the researcher. 'I don't follow recipes when I cook'. He also distances himself from the 'stronger' claims for emancipatory research, and argues that the tension between researching disability and researching disabled people's lives must be recognised.

Marcia Rioux and her colleagues discuss their research into inequality, citizenship and human" rights, through the specific prism of the abuse and

violence experienced by disabled people in Canada. The authors outline the limitations in existing theory and methodology in this area. They argue for both a re-interpretation of 'violence and abuse' as well as more appropriate research methods. The emphasis is on creating the right climate for interviewees. Although using disabled researchers was not a priority, careful training in interviewing the research subjects was. Indeed, the study relied heavily on an enhanced role for the interviewers in interpreting the experience of interviewees. (British readers will note that the editors have resisted the temptation to change the authors' use of terms such as 'people with disabilities' which prevail North America.) Emma Stone brings the volume to a close with an account of her experiences as a postgraduate research student embarking on a disability research project in China. As a non-disabled researcher and a 'foreign devil' researching a contentious subject, she was confronted by searching questions from her hosts. Compromises had to be made. The social model did not travel easily: at times it seemed culturally and linguistically untranslatable. Chinese views of doing research also conflicted with the emancipatory paradigm. Stone was obliged to devise strategies to satisfy these different research and political sensibilities. She concludes that emancipatory research must relinquish some of its wider claims: for example, in her experience, participatory and action research does not necessarily mean acting as an oppressor.

REVIEW

One aim of this book is to explore what 'doing disability research' really means. The contributors to this volume take us down this path. By adopting a 'confessional' and 'reflexive' approach, they help to put flesh on the bones of the emancipatory model. They convey a sense of the vitality and diversity of disability research, and what is possible with commitment and perseverance. They provide a picture of innovative disability research that encourages optimism about the way forward, while also recognising that much more work needs to be done.

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