An Ethical Agenda in Disability Research: rhetoric or reality?

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Introduction

Over recent years there has been a growing interest in the ethics of social research (Hammersley 1999). This is especially pertinent to studies that are considered overtly politically motivated and challenge conventional notions of objectivity, the elimination of bias and academic freedom (Humphries, Mertens and Truman, 2000: 3). A particular case in point is disability research.

Inspired by the writings of disabled activists and scholars in the 1980s and 90s the emancipatory turn in social research has had a particularly important influence on disability researchers in the UK. The emergent critique of conventional wisdom and ways of theorising disability was extended to mainstream social research. The shift from explaining disability solely in terms of individual pathology to the ways in which environmental and cultural barriers effectively exclude people with accredited impairments[1] from every day life was especially influential. Indeed, this socio-political, or social model of disability, approach has stimulated the adoption of a more justifiable emancipatory research paradigm that draws explicitly upon disabled people's collective experience and so challenges directly the widespread social oppression of disabled people.

This chapter will review key issues in the emergence of emancipatory disability research with particular reference to the British literature. It begins with a brief discussion of research ethics in relation to the emergent critique of traditional ways of researching disability, particularly its theoretical standpoint and the disempowering role of research experts. Second, attention centres on the key features of ethical or emancipatory disability research in line with a social model framework

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[1] The phrase 'accredited impairment' is used here in recognition that impairments are both biologically and culturally determined. Many impairments such as baldness in women, do not impede an individuals ability to function but result in social disadvantage or, from a social model perspective, disability.

(Oliver 1992). This stresses an avowed commitment to the empowerment of disabled people through a process of political and social change while also informing the process of doing disability research. The third section addresses claims that the emphasis on political partiality deflects attention away from important debates about the choice of methodology and data collection strategies, and their implementation when undertaking disability research.

I argue against recently expressed cynicism that openly partisan disability research has little or no meaningful emancipatory outcomes and therefore is little more than an 'impossible dream' (Oliver 1997). I suggest that research that adheres to emancipatory principles is a crucial element in the on going struggle for a less disabling society.

Ethics and the challenge to traditional disability research

Research ethics cover those questions about what ought and what not ought to be done by researchers when undertaking social research. For Martyn Hammersley a preoccupation with ethics, or 'ethicism', along with empiricism, instrumentalism and postmodernism has become a major concern in contemporary social research. He maintains that this tendency often results in a neglect of research technique - good as opposed poor research practice when doing social research, and the type of knowledge it generates. For Hammersley ethicism is the outcome of instrumentalism: the idea that research should have policy or practical implications, and the growing scepticism or 'irony' in social research commensurate with the emergence of postmodernism. This he maintains has led to a down playing of the importance of the detailed analysis of the complexity of knowledge (Hammersley 1999: 2000).

Whilst Hammersley's argument may have a considerable appeal amongst some sections of the research community concerned primarily with the generation and exploration of the nuances of knowledge production for its own sake, it has little resonance amongst the general population. It may also be responsible for the growing disillusionment with much social research over recent years as it inevitably generates the question what is the point of doing social research if it is of no practical use or benefit to those being researched. This is certainly the case with reference to the bulk of social research on disability until the 1990s as it rarely involved disabled people in the research process. Moreover, the knowledge generated was overly complex, generally couched in academic and technical language and, therefore, accessible

to research experts only. Hence it had little or no relevance to disabled people and their organisations. Moreover, as most of it was founded on individual medical or deficit explanations of disability, it also served to reaffirm traditional negative assumptions about disabled people and the causes of disablement. In so doing it helped compound disabled people's individual and collective disadvantage (Oliver 1992; Barnes 1996; Stone and Priestley 1996; Barnes and Mercer 1997; Barnes, Oliver and Barton 2002). The ethics of these approaches have been seriously questioned by disabled writers and critics.

Until recently disability was equated almost exclusively with undesirable difference and individual functional limitations eased only by medical and professional rehabilitation. Hence, condemned as 'second class citizens' (Beckett 2007: 15) disabled people experienced wide-spread social exclusion from mainstream society, and were often segregated into residential institutions. Criticism of this conventional wisdom emerged in Europe and the USA in the 1960s. In the UK, the Union of the Physically Impaired Against Segregation (UPIAS) initiated a credible re-definition and socio-political analysis of disability (UPIAS 1976) that resonated around the world following its adoption by Disabled People's International (DPI) in 1981 (Driedger,1989). This approach highlights the impact of disabling social and environmental barriers on people with accredited impairments or long term health problems and, more specifically, non-disabled experts' roles in the disablement process.

The need to extend this critique to mainstream social researchers is evidenced by the experiences of disabled residents at the Le Court Cheshire Home in the South of England during the 1960s. A group of disabled residents at the Home asked academic researchers at the Tavistock Institute to investigate their living conditions stimulated by the anticipated benefits of applying social psychological insights into residential living (Miller and Gwynne 1972: ch.2). Little did the residents realise how severely their hopes would be dashed.

The trigger for the invitation was a dispute with management that began in the late 1950s over residents' attempts to counter the constraints of institutional living. Nursing staff in the home operated a fairly rigid regime in terms of resident's bedtimes, mealtimes and leisure activities. Consequently they wanted greater control over their lives. This included choosing their own bedtimes and TV programmes, whether they could go to the pub or enjoy sexual relationships in their rooms. Their attempts to introduce a more liberal regime that involved them in the running of Le Court, was repeatedly confounded by changes in senior staff (Mason

1990). Indeed, some staff and management committee members welcomed the restoration of discipline into the running of the home and a downgrading of regular consultation with the residents. The researchers were fascinated by the research issues raised in this clash of perspectives on residential life.

It was not until 1966 that funding from the Ministry of Health was obtained to conduct a pilot study. There followed an intensive investigation of attitudes and behaviour in 5 different residential institutions, with an action research component to follow through the implementation of changes of policy and practice (Miller and Gwynne 1972: 22). Le Court was placed at the centre of this phase, although the research was affected by periodic 'crises' with changes in senior staff and continuing concerns about consultation over how the home was run. The fieldwork at Le Court was completed at the end of 1967.

In concluding the project the researchers, Eric Miller and Geraldine Gwynne, stressed that their role as researchers was to maintain a balanced and objective outlook and to avoid being captured by a permanent bias that appeared to take sides in the conflicts between residents and management. Therefore whilst they recognised and sympathised with the aspirations of the residents these were considered unrealistic because of the assumed limitations of their impairments. Instead, they recommended that control within the homes should remain with the nursing staff, but that they should adopt an 'enlightened guardianship' approach that took greater account of the needs and ambitions of inmates (Miller and Gwynne 1972).

Perhaps unsurprisingly, the residents concluded that Miller and Gwynne had sided with their oppressors and were simply looking after their own professional and career interests. One of the inmates, Paul Hunt, a principal architect in the research initiative, and founder of the UPIAS, bitterly condemned the researchers describing them as 'parasite people'. They described the researchers' primary aim as to make repressive institutions 'work a little better' (Hunt 1981: 40). In short, the 'research experts' could not see beyond an individualistic medical approach to disability in which:

> The root cause of the whole problem is in our defective bodies and not in the social death sentence unnecessarily passed on us (Hunt 1981: 41).

This trenchant attack on academic research consultants for reinforcing existing prejudices and discrimination against disabled people became a central reference point for later writers exploring a new direction for disability research (Barnes and Mercer 2006). An approach which is considered more ethically justifiable emerged from a series of seminars funded by the Joseph Rowntree Foundation entitled Researching Disability in 1992 (DHS 1992). In order to counter the disabling tendencies of conventional disability research, emancipatory disability research requires researchers to fully involve disabled people and their representative organisations in all aspects of the research process. Its primary aim is to explore and de-construct widespread and commonsense assumptions that disablement is the inevitable outcome of physical, sensory or cognitive impairments.

Echoing the views of Howard Becker (1967) the disabled scholar Mike Oliver, in particular, expanded on this theme in specifying the following stark choice:

> do researchers wish to join with disabled people and use their expertise and skills in their struggles against oppression or do they wish to continue to use these skills and expertise in ways in which disabled people find oppressive? (Oliver 1992: 102)

Until the mid 1990s research on disability may be divided into two main areas. First, large-scale national surveys, conducted by the Office for Population Censuses and Surveys (OPCS) (Harris, Cox and Smith 1971; Martin, Meltzer and Elliot 1988), and as part of a study of poverty in the United Kingdom (Townsend 1979). These studies have documented the prevalence of impairments within the general population and the difficulties associated with such conditions in key areas of daily living. They were designed to inform discussions around possible policy changes, particularly in the social security system and social 'care'[2] services so as to reduce the number of people living in poverty. Second, there has been a considerable amount of small-scale, mostly academic research into chronic illness and disability by sociologists and psychologists. These concentrated on how individuals experience and cope with their illness or impairment and its symptoms and functional limitations (Bury 1997; Barnes, Mercer and Shakespeare 1999). In general, both approaches did not involved disabled people or representatives of their organisations, were based on individual deficit

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[2] The concept care is a contested concept within the disability studies literature in the UK as it implies social services users are somehow inadequate and dependent on the benevolence of non-disabled people and the state (see Banes and Mercer 2003).

models of disability, downplayed or ignored the impact of disabling physical and social environments, and their impact on policy has been negligible (Abberley 1991; Oliver 1992; Barnes and Mercer 1997).

There are exceptions though; examples include Mildred Blaxter's (1976) *The Meaning of Disability* and Peter Townsend's (1979) *Poverty in the United Kingdom.* Both studies highlight the link between impairment, poverty and the wholly inadequate service support for disabled people. It is notable however that the link between impairment and poverty was first brought to the nation's attention by the Disablement Incomes Group (DIG) formed in 1965 by two disabled women (Barnes and Mercer 2003). Also Townsend joined (DIG) in the late 1960s and was involved in detailed discussions with UPIAS concerning the root causes of disability in 1975 (UPIAS 1976). But disabled people were not involved in the gestation, development or dissemination of either of these projects, and there is scant reference in both studies of the activities of disabled people's organisations such as DIG and the UPIAS. The former is mentioned only once in the two reports and the latter not at all.

Furthermore, most of these projects affirmed their attachment to scientific ideals of objectivity and neutrality. All of which are contestable concepts (Barnes 1996). By contrast, disability writers took their lead from critical social theory (Oliver 1992; Rioux and Bach 1994). In the most widely cited contribution in Britain to establishing the credentials of an emancipatory paradigm for doing disability research, Mike Oliver (1992) locates it firmly within critical theory. This included anti-imperialist/racist and feminist attacks on positivist and, to a lesser degree, interpretive research on the grounds that these had failed to challenge orthodox wisdom on the causes of disability and the systematic exclusion of disabled people from everyday life.

Doing disability research from an emancipatory standpoint entails the adoption of a social model or sociological understanding of disability as a form of social oppression (Barnes, Mercer and Shakespeare 1999). Notwithstanding that given recent controversies surrounding the social model of disability (Shakespeare and Watson 2001; Shakespeare 2006) it is important to stress that the social model:

> 'involves nothing more fundamental than a switch away from the physical limitations of particular individuals to the way the physical and social environments impose limitations upon certain categories or groups of people' (Oliver 1981: 37).

Therefore it is not a theory but provides the starting point for several sociological theories of disability (Priestley 1998). Nor is the social model a rejection of appropriate medical or rehabilitative interventions. It is simply a tool which can be applied to the situation of all disabled people regardless of the nature of their impairment in order to further their empowerment (Oliver 2004).

Researchers are therefore openly committed to advancing disabled people's political struggles, by seeking to give voice to their experience and acting generally to eradicate disabling barriers in society. The early emphasis was on 'conscious partiality' (Mies 1983: 22) by the researcher and granting epistemological privilege to a specific social group. This praxis orientation requires researchers to become actively engaged in political struggles and function as a catalyst for exploring relations between theory, practice and action (Touraine 1981).

As noted above the value free approach has been dismissed as 'politically naïve and methodologically problematic' (Back and Solomos 1993: 182). This view corresponds with the assertion that disability research should strive to produce a radical critique of the disabling society. However, this position invites criticism that politically committed researchers reveal or confirm little other than their existing perception of social reality and in so doing exclude from the outset, other perspectives, actions and beliefs (Silverman 1998; 2001). In response, disability researchers argue that the same could be said of all social research and acknowledge instead the significance of stating clearly their ontological (the character of social reality) and epistemological (how the social world is known) positions and strive to ensure that their choice of research methodology and data collection strategies are rigorous and open to scrutiny (Barnes and Mercer 2004). This is especially important as research projects that address politically sensitive issues are often subject to the most careful and intense scrutiny. Consequently any flaw in the research process may be used to undermine findings and policy implications.

This is not to suggest that they are unaware that 'objective partisanship' (Gouldner 1965, 1971) is not without difficulties or contradictions, but that they must address potentially counterfactual data or explanations as and when they appear within the research process. .

Doing Emancipatory Disability Research

Clearly then the social model of disability lies at the heart of emancipatory disability research. It focuses on the environmental, cultural and social barriers that exclude people with an accredited impairment from mainstream society, and prioritises disabled people's knowledge and experience (Oliver 1990).

Nonetheless, the social model has been criticised for over simplifying differences in the experience of oppression within the disabled population. Initially, a 'standpoint' position prevailed in which disabled people's experiences and knowledge claims were generalised across all groups but more recently the research spotlight has shifted to explore differences in the experience of oppression, particularly on the basis of age, gender, ethnicity and race. Thus undermining the notion of a homogeneous category of privileged knowers and turning the spotlight on to competing discourses, voices and experiences within the disabled population (Corker 1999). Additionally, the presumed commonality in experience and knowledge claims have been challenged by specific groups such as Deaf people, people with 'learning difficulties'[3] and mental health system users and survivors (Beresford and Wallcraft 1997). Here, capitalizing 'Deaf' refers to individuals with a 'severe' hearing impairment who self-define as a distinct linguistic and cultural group (Davis 1995). All of which is to be welcomed as it has served to enhance our understanding of the complexity and extent of the oppression encountered by different sections of the disabled population.

Further, the early focus on structural and cultural forces led to criticism that social model influenced disability research should widen its ontological gaze from 'public' barriers to incorporate the feminist maxim that the 'personal is political' to encompass private concerns including the experience of impairment (Morris 1992; Thomas 1999, 2007; Shakespeare 2006). Notwithstanding that any discussion of disabled people's experiences remains contentious where it does not concentrate on a critical analysis of the 'inner workings of the disabling society' (Finkelstein 1999: 861). This is because of the danger that they become entrapped in limited or restrictive service provider agendas that focus almost exclusively on cure or care solutions that implicitly if not explicitly reinforce a personal tragedy view of disability (Barnes and Mercer 2003: 2004: 2006).

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[3] The term 'learning difficulties' is the preferred term used by organisations controlled and run by people who have been diagnosed with cognitive or intellectual impairments or disabilities such as People First. However, the term is also widely used to refer to people with a diverse array of conditions to include people with Dyslexia and those with multiple impairments with complex support needs.

The impetus for emancipatory disability research is to expose disabling barriers as part of the wider politicisation and empowerment of disabled people (Finkelstein 1999), and the achievement of meaningful gain (Oliver 1997). Therefore political outcomes are elevated to centre-stage when judging disability research. Oliver specifically downgrades his own work on the experience of spinal cord injury: *Walking into Darkness* (Oliver, et al*.* 1988) precisely because of its lack of a definite impact on service provision. Yet the reasons why local and national policy makers accept research findings and recommendations are diverse and rarely within the control of the researchers (Maynard 1994). In practice, research may succeed or fail at different levels, or have an unintended impact, with any judgement liable to variation over time, or well after the research project has been completed (Barnes 2003: Barnes and Mercer 2004; 2006).

Emancipatory research should be judged upon whether it facilitates the self-empowerment of disabled people in terms of, 'individual self-assertion, upward mobility and the psychological experience of feeling powerful' (Lather 1991: 3). Here, empowerment and emancipation are used interchangeably and defined in terms of revealing social barriers, changing perceptions of disability, and generating political action. Alternatively a recent tendency amongst some disability researchers such as Mike Oliver (1997), for example, is to suggest that the chief beneficiaries of social research are researchers themselves. This is because social researchers are accorded a particular status and are often well paid in comparison to research participants. Vic Finkelstein (1999a: 863) referred to such confessions as 'Oliver's gibe'.

Further problems may arise with attempts to create a research balance sheet detailing the particular strengths and weaknesses of emancipatory disability research. Even for those pursuing a social barriers approach, the definition of oppressor and oppressed and their respective gains are not always clear cut. Consequently, it can never be a zero-sum contest with one winner and loser; while among the winners and losers some gain more than others. Again, oppressors and oppressed are not always easily distinguished and stable categories across different social contexts may change over time, and the former may include some disabled people in selected social situations (Barnes and Mercer 2006). Such difficulties might only be addressed through disability researchers' protracted involvement with research participants and or representatives of the disabled population.

Indeed, a key feature of emancipatory disability research is that it should be accountable to disabled people. The preferred option has been to ensure that control is vested in a small group led by representatives of disabled people's organisations. Thus, the emancipatory credentials of the British Council of Disabled People's (BCODP[4]) anti-discrimination project rested on its design within a social model approach and accountability to disabled people through an advisory group in which disabled people and members of organisations controlled by disabled people were in the majority. This group met every two months to review progress. The first five months were spent discussing the aims and objectives of the research with key figures in Britain's disabled people's movement, while data analysis and drafts of chapters were circulated to the advisory group and representatives of disabled people's organisations. Comments and recommendations for amendments were discussed at advisory group meetings and mutually agreed amendments included in the final draft (Barnes 1991: pp. xi–xix).

A further aspect to accountability is the wide-ranging dissemination of the research products in a variety of accessible formats to stimulate campaigns and legislative action. The BCODP project produced various articles in journals, magazines and the popular press and an eight-page summary leaflet - produced in Braille and on tape for people with visual impairments. In this way the research contributed to the further politicisation of disabled people. The distribution of this and similar material added considerable weight to the arguments for anti discrimination legislation at both the grass roots and national levels. Britain's first *Disability Discrimination Act* entered the statute books in 1995 (Barnes 2003). Similarly, research sponsored by the BCODP (Barnes 1993; Zarb and Nadash 1995) helped stimulate the clamour amongst disabled people for the legalisation of Direct Payments to enable them to purchase their own support services. The *Community Care (Direct Payments) Act* became law in 1996 empowering local authorities to provide funds to disabled individuals with which to employ personal assistants (Barnes and Mercer 2003; 2006).

Emancipatory disability researchers have stressed the significance of transforming the interactions between researcher and research participants, and the material relations of research production such as the reliance on external funding bodies (Oliver 1992, 1997; Zarb 1992; Lloyd, Preston-Shoot et al. 1996). All too often the expectations and constraints from funding agencies and academic orthodoxies reinforce

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[4] The British Council of Disabled People (BCODP) was renamed the United Kingdom's Disabled People's Council (UKDPC) at its annual general meeting in October 2006.

traditional research hierarchies and values (Barnes 1996; Moore, Beazley and Maelzer 1998).

The emancipatory potential of disability research is equated with disabled people being 'actively involved in determining the aims, methods and uses of the research' (Zarb 1997:52). This requires that researchers abandon traditional claims to autonomy. However, some disability writers have expressed alarm that there are signs of a new breed of disability research expert who adopts an approach similar to that of other disabling professionals (Finkelstein 1999). The fear is that some disability researchers claim to speak for disabled people without meaningful consultation or involvement with disabled people and their organisations. The aspiration to break down the established hierarchy and ensure researcher accountability to disabled participants raises a number of key questions about the nature of control and how it is implemented:

- Who controls what the research will be about and how it will be carried out?
- How far have we come in involving disabled people in the research process?
- What opportunities exist for disabled people to criticise the research and influence future directions?
- What happens to the products of the research? (Adapted from Zarb 1992:128).

In consequence, a continuum spanning weak to strong involvement is evident. Indeed, instances of disabled participants assuming full control of research projects are rare but increasing, and this is evident in research studies involving groups of mental health users and survivors (Chamberlain 1988), and people with learning difficulties (Goodley and Hove 2005). A useful example is the Strategies for Living project, a user led programme of work supported by the Mental Health Foundation which produced six local user led research projects between 1998 and 2000. The main concern of many of these projects 'is on alternative and self help approaches to mental health'. This focus developed out of extensive nationwide consultation with 'mental health' system user groups complemented by a UK-wide Strategies for Living study in which 71 key informants were interviewed about their experiences of dealing with emotional distress. Each of the six reports demonstrates an innovative example of 'mental health' research that is articulated, designed and carried out by mental health systems user and survivors.

'The projects distributed around England and Wales were supported through small grants (for costs), training in research skills and ongoing support to the researchers during the main period of the research. The combination of topics and research approaches has been highly innovative and had the advantage of being independent of existing statutory mental health services and thus the particular agenda attached to those services (Nicholls 2001: 3).

Examples of the projects undertaken include 'An investigation into Auricular Acupuncture' by Carol Miller (2001) and 'Research Project into User Groups and Empowerment' by Sharon Matthew (2001).

Another notable example is the work conducted by Shaping Our Lives, a national research and development project run by service users, including disabled people, older people, people with 'learning difficulties', 'mental health' systems users and survivors, and support services. Formed in 1996, Shaping Our Lives has conducted extensive user led research on service users' experiences of 'social care' services (for example, Turner 2003).

Moreover, other work has developed around 'co-researchers and co-subjects' cooperation (Reason 1988: 1; 1994), indicating a reflective dialogue with neither side dominating the other (Lloyd, Preston-Shoot et al. 1996). Some believe that participatory options are the most realistic aspiration in the present political and economic context (Ward 1997; Zarb 1997) but these offer something far less than full control by disabled people (Oliver 1992).

It is important however to remember that not all lay participants have the time or inclination, even if politically aware, to take control of research production. John Swain illustrates the more general experience of many researchers whereby participants tend to defer to the 'research experts'. This is especially so where technical matters such as devising research questions, collecting and analysing data are concerned. For Swain, rather than seeking a reversal of the social relations of research production, disabled participants sought to build a 'working partnership' that would generate 'mutually beneficial outcomes' (Swain 1995: 104-105).

Nonetheless, greater participant or user involvement has been given a major boost by the active support of the Joseph Rowntree Foundation, which has been a long-term major supporter of social and disability

research (examples include, Barnes 1991; Morris 1993; Zarb and Nadash 1994). More recently, the Big Lottery's Health and Social Research Fund has also prioritised user participation in its research programme and a similar focus has been developed in NHS (National Health Service) funded research programmes (Barnes and Mercer 2006). Nonetheless, the structural constraints and inequalities between researcher and researched are not easily eliminated, particularly if the researchers are not used to having their authority challenged (Lloyd, Preston-Shoot et al. 1996; Moore, Beazley and Maelzer 1998). Furthermore, some disability researchers have been reticent to acknowledge power relations and hierarchies within research teams, mostly by assuming that a consensus position is inevitable (Barnes and Mercer 2006).

Moreover, whilst the use of Braille, large print and computer disks for people with sensory impairments has become widespread, equivalent support for people with learning difficulties has been far less widely recognised (Ward 1997; Goodley and Moore 2000). This has been raised by studies involving people from this section of the disabled population where some of the most
Imaginative attempts to develop collaborative approaches have been implemented. Indeed, research has moved a considerable distance since the early 1990s towards recognising informant's reliability as the 'best authority on their own lives, experiences, feelings and views' (Stalker 1998: 5). This has generated a number of innovative methodological approaches, often adopting 'advocacy' models, with people with learning difficulties acting as research advisers through to conducting their own research with researcher support. Recent examples include Chappell (2000) Walmsley and Johnson (2003) and Williams, Simons and Swindon People First Research Team (2005).

Methodology and methods

Here methodology refers to a theory of how research should be conducted: positivist, interactionist, participatory and emancipatory, and methods comprise the specific techniques for data collection, such as surveys or participant observation, and analysis (Harding 1987). Early explorations of emancipatory disability research tended to conflate methodology and data collection strategies and treat both as subsidiary, technical matters. In view of the complexity of the research process, whether emancipatory or otherwise, it is useful to recognise that discussions of 'methodology matters' (Stanley 1997) and warrants more

than a vague commitment to pluralism, whether of methodologies or methods.

Rather than retreat into a relativist stance, the methodological criteria advocated for evaluating disability, or indeed, all social, research varies considerably between paradigms. For positivists the emphasis is on:

> internal validity (isomorphism of findings with reality), external validity (generalisability), reliability (in the sense of stability), and objectivity (distanced and neutral observer)... (while those within the interpretive paradigm stress)... the trustworthiness criteria of credibility (paralleling internal validity), transferability (paralleling external validity), dependability (paralleling reliability), and confirmability (paralleling objectivity) (Guba and Lincoln 1994: 114).

More recently, the same authors have supplemented their account by noting the recent concern with achieving 'authenticity' in both interpretive and post-structuralist accounts (Lincoln and Guba 2000).

This warrants a commitment to make the entire research process transparent from design through data collection, analysis, disseminations and recommendations. The aim is to produce an accessible and convincing account of the research procedure that is understandable to research participants and lay audiences (Mies 1983; Stanley and Wise 1993; Maynard 1994). However, the use of formal tests of quality control promoted by mainstream social researchers has often hidden disablist assumptions that rarely acknowledge the specific circumstances of researching disability (Sample 1996; Stalker 1998).

By contrast, advocates of emancipatory disability research have concentrated on participant validation. That is, the involvement of disabled people in identifying research questions, collecting data, analysing and disseminating findings. The notion of taking fieldwork data back to respondents for verification is generally regarded as a key criterion, whereas collectivising the whole process of data collection and analysis, except perhaps to a small advisory group, is infrequently practised. Not least, achieving full participation requires additional time and resources if it is to prove effective. Only two of the thirty key activists who provided in-depth interviews for Campbell and Oliver's (1996) study of disability politics took up the offer to 'validate' interview transcripts or read the draft manuscript. Oliver candidly admits that, 'we neither had the time, energy or money to make it a wholly collective production'

(Oliver 1997: 19). This option may result in substantial changes in the research agenda and possibly its funding, something institutions are reluctant to sanction (Mercer 2002: Barnes and Mercer 2004: 2006).

A further measure is the feminist assertion that the validity of their research methods can be judged effectively by the quality of their relations with research participants. Friendliness, openness, and general close rapport with participants have acquired a confirmatory status. Researchers record how their disabled participants expressed their appreciation that their views were taken seriously and they were encouraged to express their 'real' feelings (Mercer 2002). However, such narratives cannot be considered an adequate indication of quality assurance. Also, exploiting an individual's willingness to discuss their private thoughts and or relationships in order to enhance the quality of research raises important ethical considerations that are not easily resolved. This suggests much greater sensitivity to how researchers directly and indirectly influence the research process (Lloyd *et al.* 1996; Davies 2000). But the problems arsing from how to balance methodological concerns and political goals are rarely discussed in depth in much of the disability literature.

Conversely, researchers adhering to emancipatory principles have been keen to devise new ways of collecting, processing and analysing their data (Mercer 2002), including innovative studies with disabled children (Ward 1997: Watson et al., 1999). Some disability researchers have particularly stressed the importance of choosing a disabled person as interviewer or the equivalent (Vernon 1997), but what little discussion has taken place has not reached agreement about how far this matching process should be extended to cover, for example, age, social class and type of impairment. Hence it is useful to note that:

> 'Having an impairment does not automatically give someone an affinity with disabled people, nor an inclination to do disability research. The cultural gulf between researchers and researched has as much to do with social indicators like class, education, employment and general life experiences as with impairments (Barnes 1992: 121-22).

Therefore it may not be a necessary prerequisite for researchers to have an impairment to do emancipatory disability research. Neither Gerry Zarb nor Pamela Nadash were disabled people when working on the BCODP sponsored *Cash for Care* project mentioned earlier. Nonetheless the merits of employing non-disabled researchers are

disputed. It is rare though for anyone to contend, like Humphrey (2000), that research knowledge may be improved by their involvement. ,

There have also been few attempts to involve research participants, beyond a small advisory committee, in collectivising the processing and analysis of data. The exceptions are mainly restricted to small-scale, interview-based studies but it remains unclear how far participants defer to researcher expertise (Vernon 1997). More generally, disciplinary and theoretical perspectives exacerbate the division between participants and researchers by influencing what the researcher records and how it is interpreted. This includes a decision about how far researchers will go in re-presenting or re-authoring lay accounts by making inferences, selecting, abstracting, and reformulating what people said or really meant (Shakespeare *et al.* 1996; Vernon 1997; Corker 1999).

Initially, exponents of emancipatory disability research expressed uncertainty about the relative merits of different quantitative and qualitative research methods.

> 'I am not sure whether interviews, questionnaires, participant observation, transcript analysis, etc., are compatible or incompatible with emancipatory research (Oliver 1997: 21).

Subsequently, the majority has emulated the general trend in social research by utilising more qualitative procedures and data. This is justified on the grounds that quantitative methods are inherently exploitative of research participants and produce less authentic data, in comparison with the qualitative emphasis on inter-subjectivity and non-hierarchical relationships. Even though there are some notable counter examples, including Miller and Gwynne's (1972) much derided study of life in a residential home, a generally dismissive attitude to the quantifying method has prevailed. It was forcibly expressed by critics of the OPCS surveys who charged that reliance on postal questionnaires and structured interviews reinforced the division between research experts and lay disabled respondent (Oliver 1990; Abberley 1992).

Nevertheless, mainstream quantitative research has been widely exploited by emancipatory researchers to expose the extent of disabling barriers (Barnes 1991). Furthermore large scale surveys were employed in the Zarb and Nadash (1994) study on direct payments and more recently on research into user led disability service providers sponsored and sanctioned by national agencies controlled and run by disabled people; the BCODP and the National Centre for Independent Living

(Barnes and Mercer 2006). Moreover, even within feminism, there have been growing claims that experiential studies have done much less than quantitative studies to document women's social oppression (Oakley 2000). Indeed, the 'qualitative turn' in social research generally and disability research in particular, has tended to discourage researchers from devising participant-centred structured interviews and surveys that could facilitate resistance to disabling barriers and attitudes. Again, specific methodological issues such as sampling, data processing and constructing concepts and explanations have generated little serious debate (Mercer 2002).

As many advocates have demonstrated (Stone and Priestley 1996; Moore, Beazley and Maesler 1998; Mercer 2002; Barnes and Mercer 2004) the process of doing emancipatory disability research throws up many unexpected issues. One of the most significant is the degree to which presumptions of objectivity and detachment remain common within the academy, whilst the alternative assertions of emancipatory disability research are largely unknown or contested (Barnes, Oliver and Barton 2002).

Conclusion

This Chapter has chronicled how an ethical or emancipatory research paradigm has been adopted as a distinctive approach to doing disability research by researchers in the UK. It is an approach that is rooted in the redefinition of the cause of disabled people's individual and collective disadvantage by disabled people themselves, generally known as the social model of disability, a broad based accountability to disabled people and their representative organisations, and a commitment to social research that challenges the social exclusion of disabled people from mainstream society. Inevitably, however, its emergence has generated a range of criticisms from the increasingly diverse theoretical traditions that now engage with disability and disability research; many of which arise from the problems associated with the often difficult and controversial task of transforming these broad principles into research policy and practice. As a consequence recent debates on data collection strategies within the disability research literature are limited and sometimes contradictory. All of which has given rise to concerns that doing emancipatory disability research is proving to be an 'impossible dream' (Oliver 1997).

Nevertheless, if such rhetoric is not to become an unwelcome reality, disability research must be judged by its capacity to facilitate the empowerment of disabled people. This is not an easy option as there are no universally agreed epistemological or methodological guidelines. In addition, the disabling tendencies of post millennium environments and cultures will not succumb easily to individual emancipatory projects. However, the argument presented here suggests that when directly linked to disabled people's ongoing struggle for change, doing emancipatory disability research can have a meaningful impact on their empowerment, the policies that affect their lives, and the on going struggle for a more equitable and just society.

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