'Emancipatory' Disability Research and Special Educational Needs

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Introduction

Disability Studies is a relatively new and rapidly expanding field that offers radical challenges to conventional thinking about the education of disabled children, and thus often appears at odds with more traditional approaches to the study of 'special education' and 'special educational needs' (SEN). In the UK, Disability Studies examines 'inclusive education' not 'special education', unmet educational needs not 'special educational needs' and disabled children not children with 'SEN'. The disabled people's movement has organised around the premise that no one aspect of the disablement of people with impairments should be treated in isolation (UPIAS 1976). Disability Scholars then would argue that the inferior education received by disabled people cannot be separated from their inferior status in society and cannot therefore be examined in isolation. Despite these differences, this chapter will argue that the emerging discipline has much to offer the field of special education (Conway, 2004) - not least in its ongoing critique of 'disability' research.

It is over ten years since British researcher and disability activist Mike Oliver coined the term 'emancipatory disability research' to refer to a radical new approach to researching disability (Oliver, 1992). Since then there has been much discussion in the UK about whether such an approach is a 'realistic goal' or an 'impossible dream' (Oliver, 1997). This chapter is a reflection on key issues and concerns associated with the 'emancipatory' research model, and a consideration of its potential in the arena of 'SEN' research.

The chapter is divided into two main sections; the first provides a brief introduction to the reconceptualisation of disability by disabled activists in the UK and to the notion of 'emancipatory' disability research. The second part focuses on some core principles associated with this perspective, and the challenges it presents for those conducting research in the area of 'special' education. These core principles - were they enacted fully - might increase the chance that research would indeed be emancipatory, producing significant gains for disabled people at both micro and macro levels. In conclusion, it will be suggested that whilst the practice of 'emancipatory' disability research may remain an 'impossible dream', the process is something towards which all those involved in researching disability and 'SEN' could and should be striving.

The emergence of 'emancipatory' disability research

Here the social model of disability will be briefly described before the emergence and ethos of 'emancipatory' disability research are considered

The social model of disability

Whilst the predominant view of disability was once informed by religion, since the rise of scientific medicine in the eighteenth century, disability in industrialised countries has largely been understood in terms of health and illness, and viewed as a problem of individuals. The individual or medical model of disability - elaborated by non-disabled professionals and medical sociologists - focuses on disability as functional limitation, with disability commonly referring to 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' (Wood 1981: 27-29). According to the individual model then, people are disabled by their impairments, and it is the role of medicine and psychology to restore them to 'normality'. The problem of disability is thus located within the impaired individual.

These assumption began to be questioned in the latter part of the twentieth century, with the politicisation of disability by disabled people in America, Britain and elsewhere. In Britain, the disabled people's movement redefined disability as a form of oppression on a par with racism and sexism. The social model of disability thus emerged from disabled people's own critiques of the individual model, including its view of causality, its assumptions about the existence and nature of 'normality', and its failure to recognise disabled people as the experts on their own situation (Oliver, 1996). A two-fold definition of impairment and disability analogous to the sex/gender distinction, was elaborated by the Union of the Physically Impaired against Segregation (UPIAS), a collective of disabled people. Here, impairment is defined as 'lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body', whilst disability denotes 'the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have… impairments and thus excludes them from participation in the mainstream of social activities' (UPIAS 1976: 3-4). No causal link is assumed between impairment and disadvantage; rather disability is viewed purely as a social construction.

The insights of the social model of disability have been vitally important for disabled people, both personally and politically. They have instigated the development of Disability Studies as an academic discipline and prompted the elaboration of the 'emancipatory' research paradigm as an alternative to traditional ways of conducting disability research.

The emergence and ethos of 'emancipatory' disability research

It has long been argued that traditional research in the social sciences has mirrored and perpetuated the power relationships experienced by oppressed people in their day-to-day lives (Bourne 1980; Stanley and Wise 1993). Following

in this tradition, research is often said to be an alienating experience for disabled research participants - it is something that is done to them over which they have little or no control (Oliver 1992). The main benefit of research into disability is often to the researcher and their academic record - it does little to improve the position of disabled people and may even compound their problems (Oliver 1990).

The shift away from the unquestioned dominance of the individual, medical model of disability has been accompanied by a shift in the way disability research is carried out. Disabled people have taken a lead from critical social science, feminism, and majority world writers like Freire (1972), and have produced critiques of both positivist and interpretative research methodologies (Oliver 1990; 1992; Ward and Flynn 1994). The new 'emancipatory' research paradigm now serves as an ideal towards which researchers working within a social model of disability can aspire - its aim - 'to make disability research more relevant to the lives of disabled people' (Oliver 1992: 109) and thus to make research part of the solution not part of the problem. The 'emancipatory' paradigm then is concerned with:

> the systematic demystification of the structures and processes which create disability and the establishment of a workable dialogue between the research community and disabled people in order to facilitate the latter's empowerment. (Barnes 1992: 122)

The emergence of the 'emancipatory' research model has stimulated considerable debate within the disability research community both in Britain and the rest of the world (see for example Albrecht *et al.*, 2001; Barnes and Mercer, 1997; Rioux and Bach, 1994; Stone and Priestley, 1996). Above all, the 'emancipatory' research agenda warrants the transformation of the material and social relations of research production. In short, this means that disabled people and their organisations, rather than professional academics and researchers, should have control of the research process. This control should include both funding and the research agenda. Both areas will now be briefly considered.

Controlling funding
A decade ago, the bulk of disability research in Britain was financed by large Government sponsored agencies such as the Department of Health (DoH), the Medical Research Council (MRC) and the Economic and Social Research Council (ESRC). These bodies were dominated by traditional medical and academic concerns; and conventional assumptions about disability and disability related research. Today however, the situation is somewhat different. A large number of recent research projects, focusing exclusively on disability and related issues, are funded by charitable agencies and trusts such as the Joseph Rowntree Foundation (JRF) and the National Lottery's Community Fund. Both

these organisations prioritise user led initiatives and concerns over those of the academy and professional researchers.

As a consequence in recent years there have been several pieces of research which arguably conform to an 'emancipatory' research model - albeit implicitly rather than explicitly. Perhaps most significantly, in 1989 the British Council of Disabled People (BCODP) - Britain's national umbrella for organisations controlled and run by disabled people - commissioned a large scale study of the discrimination encountered by disabled people in the United Kingdom in support of their campaign for anti discrimination legislation (Barnes, 1991). Other notable examples include Michael Oliver and Gerry Zarb's (1992) analysis of personal assistance schemes in Greenwich and subsequent BCODP research on direct payments (Zarb and Nadash, 1994).

Controlling the research agenda
Although the rhetoric has yet to be matched with meaningful outcomes, there is a growing emphasis on user participation, if not control, within the research programmes of the various research councils including the ESRC. Whilst these changes might not go as far as some might wish, and certainly their impact has yet to be comprehensively evaluated, they do mark something of a shift in the right direction. Whether this move towards user control will be extended to disabled children and young people remains to be seen however.

Recent innovative work has called for the incorporation of the social model into educational research, and its insights have begun to inform research into the barriers faced by children and young people categorised as possessing 'SEN' (eg: Clough and Barton, 1995a; 1998; Morris, 2003). As yet however, the potential of the 'emancipatory 'disability research model is largely untested in the context of 'SEN'. Indeed it is unlikely in today's world that disabled children - the 'users' of 'special' education - would ever be in a position to control both research funding and its agenda.

Transforming the relations of research production so that control lies with disabled people and their organisations is no easy task. Hence many researchers committed to emancipatory ideals settle instead for doing participatory or action research (Zarb 1992). Both of these have a concern with praxis - 'purposive action (including political action) to alter the material and social world' (Jary and Jary 1995: 517) - such that 'the intention to effect social practice stands shoulder to shoulder with the intention to understand it' (Kemmis 1982: 17). Control of the research does not however lie completely with the research participants.

Beyond the crucial issue of control, this new paradigm is more a set of loosely defined principles than a set of rules for doing disability research (Zarb 1992). The six core principles which are said to characterise the model centre on the

role of the social model of disability, accountability, the question of objectivity, choice of methodology, the place of experience in the research process, and research outcomes (Stone and Priestley, 1996). These core principles will now be examined, and the particular challenges they may present for those researching 'special' education considered.

Core principles of an 'emancipatory' disability research model

The role of the social model of disability

> research itself creates - rather than merely studies - the phenomenon of special education/disability, and hence the constructs which researchers themselves bring to the work are important determinants not only of the success of the study itself but indeed also of the nature and direction of the field itself (Clough and Barton, 1995b: 3)

The initial question which any social researcher should ask themselves deals with ontological position: 'What is the nature of the phenomena or entities, or social 'reality' that I wish to investigate?' (Mason 1996: 11). Thus, a core principle of an 'emancipatory' research model is said to be: 'the adoption of a social model of disability as the ontological… basis for research production'. (Priestley 1997: 91). As described above, much disability research has assumed an individual model of disability as its ontological base. Disability is equated with lack of 'normal' functioning and its social and political realities are thus elided. Research that begins from such a premise cannot hope to further disabled people's self-emancipation. Instead, 'emancipatory' research *must* adhere to the social model of disability.

A decade ago adopting an overtly social model perspective may have been something of a novelty. This is no longer the case however. In Britain for example, social model thinking underpins the work of the Government initiated Disability Rights Commission (DRC). Internationally, it has been incorporated into the World Health Organisation's recently developed *International Classification of Functioning* (WHO, 1999), which replaces its overtly individualistic and discredited predecessor the *International Classification of Impairment, Disability and Handicap* (Wood, 1981). As yet however, the social model has made little impact on governmental thinking in the area of 'special educational needs'. Whilst lip service is now paid to the benefits of 'inclusive education' (eg: DfEE, 1997), it is doubtful how far this is carried through in practice. Whilst one of the features of such an approach is said to be the questioning of 'existing categories and language including, the validity of the discourse of "special needs" and "special educational needs"' (Barton, 2005: 3), such a critical stance is not, as yet, forthcoming from the UK Government.

The research community too needs to question its assumptions about 'SEN', since 'what we as researchers think and, importantly, where we are coming from, inevitable influences how we construct things' (Clough and Barton, 1995: 5). Sally Tomlinson (1982: 72) argues that uses of the term 'special needs' are 'more ideological than educational'. Hence, the ontology underpinning this social categorisation merits further consideration if research in this area is ever to conform to an 'emancipatory' paradigm. Like traditional notions of disability, hegemonic notions of 'SEN' as 'real (i.e. observable and objectively describable) phenomena in the world' (Dyson, 1998: 2) must also be rigorously questioned (Barton, 2005).

In the UK, the term 'special educational needs' first received official recognition in the 1978 Warnock Report. The report advocated the abolition of previous medical categories of 'handicap' - still in use in many parts of the world - in favour of the broader concept of 'SEN'. Arguable though, this apparent demedicalisation was little more than a 'cosmetic exercise'. Indeed the very concept of 'SEN':

> retains the assumption that people categorised in this way are somehow 'less than human'. The emphasis is still on the inadequacy of the individual: it is s/he who is different; it is s/he who is at fault; and, most importantly, it is s/he who must change (Barnes 1991: 33)

In reality then, little has changed with this shift from a categorical to non-categorical system. Take the 2001 *Special Educational Needs Code of Practice* definition for example. Here, we are told, children have 'special educational needs 'if they have a *learning difficulty* which calls for *special educational provision* to be made for them (DfES, 2001: 6). A learning difficulty, in turn 'may be the result of a physical or sensory disability, an emotional or behavioural problem, or developmental delay' (Cabinet Office, 2005: 26). Disability here is clearly defined *not* according to a social model perspective, but as individual functional limitation. The failure of the education system to provide for disabled children's needs is not questioned. This does not provide a sound starting point for research which strives to be emancipatory.

Furthermore, the ontological assumption that disabled people's needs are in some way 'special' is seen to be intensely problematic (Corbett, 1996), and indeed - to serve professional interest first and foremost. As Tomlinson argues:

> Needs are relative, historically, socially and politically. The important point is that some groups have the power to define the needs of others, and to decide what provision shall be made for these predetermined needs. The unproblematic acceptance of 'special need' in education rests upon the acceptance that there are foolproof assessment processes which will correctly diagnose and define the needs of children. But the rhetoric of special needs may have become more of a rationalisation by which people who have power to define and shape the system of special education and

who have vested interests in the assessment of, and provision of, more and more children as special, maintain their influence and interests. The rhetoric of special needs may be humanitarian, the practice is control and vested interests. (Tomlinson, 1982: 75)

Researchers and other professionals then, determine inclusion in the category 'children with special educational needs'. It is not an objective category, but a category based on 'unacceptable assumptions that legitimate and maintain existing exclusionary, discriminatory policies and practices' (Barton, 2005: 3). Clearly then, the notion of 'SEN' does not sit comfortably alongside a social model perspective. 'Emancipatory' disability research *cannot* be built upon ontological foundations that construct disabled children and young people as having needs that are 'special'. Instead, it must be recognised that they are children like any others, but their needs are not currently met by our education system. Research might then seek to facilitate a 'fundamental restructuring' of that system (Triano, 2000: 13).

Accountability

Accountability to the disabled community is a key component of the 'emancipatory' research model. This poses particular problems for all researchers working within a market-led environment where continued employment and future career prospects are all too often determined by the ability to secure lucrative and long-term research contracts. Most of the organisations led by disabled people are local, hand to mouth operations with very limited resources (Barnes *et al.*, 2000). In such organisations funding for research is usually accorded a low priority and when it is needed, the demand is usually for small-scale, locally-based projects that are relatively short-term in character.

The standard for accountability was set however with the BCODP discrimination project (Barnes, 1991). The research was conceived by representatives of the BCODP, with funding from the JRF and Charity projects. It began in 1990 and was co-ordinated throughout by a research advisory group of five people, only one of whom was non-disabled. The group met on a bi-monthly basis to comment on and review progress. The first five months of 1990 were spent discussing the aims and objectives of the research with key figures in Britain's disabled people's movement. Data analyses and drafts of chapters were circulated to the advisory group and representatives of disabled people's organisations, along with requests for comments and recommendations which were then discussed at advisory group meetings. When the final report was completed a protracted process of dissemination was undertaken (see below). Similar levels of accountability have been achieved by other BCODP research

projects including the work on direct payments (Zarb and Nadash, 1994) and the more recent *Creating Independent Futures* project (Barnes *et al.*, 2000).

Ensuring accountability becomes a particular challenge when the views and participation of disabled children and young people are sought. Children are assumed incapable of finding solutions to their own problems. Instead, adults are deemed to be the 'experts', who 'know what is best for children' (Davis, 2004: 144) and frequently make decisions about children's lives without consulting them. However, participatory research with disabled children and young adults has successfully challenged stereotypical assumptions of 'disabled childhood as static, vulnerable and dependent, and disabled children as lacking agency, imagination and creativity' (Davis and Hogan, 2004: 185).

Jenny Morris for example (2003) documents her involvement in three research projects, all of which set out to involve disabled children and young people. Each project had a reference group comprising disabled young people who had similar experiences to the research participants. These reference groups had an input into the research at various points: deciding what information should be gathered, designing the information schedule and advising on how best to elicit information from disabled children and young people; commenting on a preliminary analysis of the data generated and identifying key themes; and making suggestions for disseminating the research findings.

Whilst young disabled people are without doubt 'critical social actors' (Davis and Watson, 2001: 672), they face various barriers however to attending meetings and having meaningful involvement in such reference groups. This necessitates incredible attention to detail on the behalf of researchers, including the physical environment of meeting venues, the quality of assistance provided and the way in which meetings are run. It also involves negotiating with adult gatekeepers, who frequently act to disempower young people, yet may need to consent for their participation (Morris 2003). There are enormous challenges then in making research accountable to disabled children, which further work in this area may help to highlight. As Jenny Morris (2003: 23) suggests, it is vitally important that details of what does and does not work are shared, and that 'we are brave enough to share our experiences of not getting it right.'

The problem of objectivity

Historically, disability research has been dominated by medical and academic interests. These have generally been seen as *objective* whilst alternate views, such as a social model perspective, have been viewed as politically biased and/or subjective. As indicated above in many ways this is no longer the case. Nonetheless, all social scientists, particularly those who endorse a politically sensitive or minority group perspective, are vulnerable to accusations of bias.

Disability activist Paul Hunt (1981: 42) suggests that research can never be detached and impartial:

> Faced with any socially oppressed group, social scientists have a choice of only two alternatives: either a firm commitment to serve the interests of the oppressed group to end their oppression, or a commitment to serve the interests of the oppressors to continue their oppressive practices... There is no middle way.

It is vital then for researchers to overtly serve the interests of disabled people in challenging their oppression. Hence, a core principle of 'emancipatory' research is said to be: 'the surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self emancipation' (Stone and Priestley 1996: 706). As disabled researchers and activists, the authors of this chapter make no claims to be detached or impartial. Disablist oppression however exists not just in 'the thoughts and actions of individuals or groups', but is 'objectively structured by the social and material relations of capitalism' (Oliver, 1999: 184). It can be examined then as an objective reality, and 'science can be placed at the service of the oppressed group to help them free themselves' (Hunt, 1981: 42). It is thus difficult to support the notion that those involved in disability research should put aside any claims to objectivity. One *can* be objective about oppression, even whilst experiencing it oneself. Indeed, as Hunt (1981: 43) suggests, it is 'precisely those who try to take a detached view of oppression who <u>cannot be objective</u>'.

In response, all that researchers can do is make their position clear at the outset. This means stating clearly their ontological and epistemological positions and ensuring that their choice of research methodology and data collection strategies are logical, rigorous and open to scrutiny. Information such as this is vitally important in helping disabled children make a decision about whether they want to participate in research (Morris, 2003).

The choice of methods

Since its inception the 'emancipatory' disability research model has generally been associated with qualitative rather than quantitative data collection strategies, in part because such strategies allow more scope for participants to take control over their words and thus affect the direction of the research (Shakespeare 1996). In contrast, 'special' educational needs research has traditionally relied on positivist research strategies. Whilst educational researchers have also recognised the benefits of qualitative research, there are as yet 'relatively few published qualitative research studies on the theme of special educational needs' (Vulliamy and Webb, 1995: 265). Perhaps such studies pose a particular challenge when disabled children/young people are involved as research participants. Traditional methods such face-to-face

interviews may not be appropriate, and more creativity may be needed on behalf of researchers. A wide variety of innovative alternative methods have been utilised when working with children, including drawing, role play, using toys to tell a story and participating in children's games (Davis, 1998). It is important then to look beyond tried and tested orthodoxies. As one researcher has suggested:

> There are no rules for research with children! When apparent 'formal methods do not work, it is important to acknowledge 'just hanging out' time with groups of children as valuable data in itself. It's OK to bin the questionnaires or work-sheets and follow your instinct, or the children's lead... (Smith, in Gallagher, 2005: 5)

Quantitative research methods have been somewhat discredited within Disability Studies in the wake of various large-scale surveys conducted in Britain. The infamous OPCS disability surveys for example (Martin *et al.* 1988) adhered to an individual model of disability and were used to count and classify disabled individuals. Whilst their findings are still cited by those working in the field of Disability Studies, they stand accused of disempowering their disabled research participants and producing little in the way of positive change (Abberley, 1992). Politicians and policy makers however make use of figures and statistics to add weight to their arguments and to justify particular actions or policy developments. Surely then quantitative research must also have some potential?

The disabled people's movement has used quantitative data not to research individual disabled people, but to highlight the various deprivations encountered by people with accredited impairments, and to research disabling barriers in society. The BCODP research on discrimination mentioned above, for example, was heavily reliant on Government figures to underline the case for anti-discrimination legislation. Gerry Zarb and Pamela Nadash (1994) utilised both quantitative and qualitative research methods to substantiate their argument. The *Creating Independent Futures* project (Barnes *et al.*, 2000) employed a similar array of research strategies. Similarly, Vulliamy and Webb (1995: 265) have outlined recent calls for a 'judicious blending of quantitative and qualitative approaches' when conducting research in 'special' education. All data collection strategies then may have their strengths and weaknesses when researching disability/'SEN'. What is most important is that the choice of research methods be determined by the needs of the research participants and/or disabled people generally.

The role of experience

The place of individual experience within 'emancipatory' disability research, and Disability Studies generally, is hotly contested. On the one hand, it is argued that disabled people are the experts on their own situations and should have their

long-silenced voices heard. On the other, it is argued that disabled individuals should not be the subjects of research - rather it is the disabling society that should be examined.

Within Disability Studies it is widely acknowledged that an 'essential element in the politicisation of disability has been the recognition that the personal is political' (Barton and Oliver, 1997, p. xii). For disabled feminists particularly, an engagement with personal experience is viewed as 'an essential part of developing an understanding of disability' (Thomas, 2001: 54). Others argue compelling that:

> Seeking out the constructions of the oppressed... is a political act which critiques the constructions of the oppressors and makes possible emancipatory action which will transform the oppressive relationships of the groups involved. Dyson (1998: 6)

The question of 'voice' is also said to be crucial in relation to educational research that strives to be non-oppressive (see for example Clifton, 2004; Garth, 2004). Children's voices are seldom sought or heard, let alone taken seriously. This is particularly the case with disabled children and young people, to whom multiple assumptions of incompetency are ascribed. According to the UN Convention on the Rights of the Child however: 'Disabled children have the human right to express their views and for these to be taken into account' (Morris, 1999: 1). It is said to be *essential* then that these views are not discounted. Giving priority to the voices of disabled children in the research process not only upholds their human rights, it also provides a 'more accurate evidence base for informing improvements in policy' (Garth and Aromi, 2003: 573). Arguably then, there is 'considerable urgency attached to the agenda of raising the voices of young disabled people' (Garth, 2004: 107).

This of course presents enormous challenges for researchers, especially when children have communication or cognitive impairments (Morris, 2003). It must be assumed however that *all* children and young people are capable of expressing their views. Furthermore, they must be enabled to 'challenge the structural, cultural and individual conditions which create disability.' (Davis and Watson, 2001: 671). Researchers simply have to make the effort to learn the different ways in which they communicate and find ways of understanding their experiences (Davis, 2004; Morris, 2003).

However, as stated above, the place of 'experience' is much debated amongst disability activists and researchers (Finkelstein, 1996; Sheldon, 1999). We are warned about extolling the virtues of 'giving voice', and urged to beware of the

> sloppy and sentimental view that what is often described as 'giving disabled people a voice', suggesting an act of generosity, automatically improves the quality of their lives (Riddell *et al.*, 1998: 79).

As with disabled adults, by focusing on the individual experiences of children labelled as having SEN, we may undermine or ignore the significance of the environment in which those experiences are shaped - both inside and outside the educational context. In so doing, we may run the risk of reverting to an individual model framework. As Jenny Bourne (1980: 339) famously argued of research into black people's disadvantage: 'It was not black people who should be examined, but white society'. Similarly it could be argued that it is not those deemed to have 'special educational needs' that should be examined, but the system that creates and sustains the SEN category.

There is indeed a very real danger that the use of personal experience as the only analytical tool 'can obscure the collective nature of disablement as a form of social oppression' (Stone and Priestley, 1996: 705). Whilst experience may be 'a necessary starting point', it should not be viewed as 'an end in itself' (Kelly *et al.*, 1994: 29). Instead, it is vital that researchers 'locate individual's narratives in the wider socio-cultural context, and explore narratives principally, though not exclusively, for what they tell us about disablism and other sources of oppression' (Thomas, 1999: 151).

If is suggested that in order to facilitate the removal of inequality in education, solutions must be sought at various levels - at the macro level 'through legislation, policy and guidance'; and at the micro level, because 'individuals, both staff and pupils can make significant differences to young people's lives' (Clifton 2004: 89). It is at this micro-level that listening to the insider perspective becomes most important. At the macro-level however, it may be that such accounts have little or no value. By no means *all* research which incorporates 'emancipatory' principles is concerned with disabled people's individual experiences. Barnes (1991) for example did not set out to 'give voice' to disabled people. They were not the focus of study. Instead the attention was turned on the oppressive society in which disabled people are forced to live their lives. If disabled people's experiences *are* discussed, it is vital that they are couched firmly within an environmental and cultural context in order to highlight the disabling consequences of a society that is increasingly organised around the needs of a mythical, affluent non-disabled majority. This is equally true in relation to research in SEN. As Sally Tomlinson (1982: 73) has argued, the rhetoric of 'special needs' involves 'seeing children outside a social context'. Thus,

> It is essential when considering the question of 'voice' in relation to educational research that we are aware of, and seek to learn from, the struggles disabled people have been and still are involved in outside the educational context. (Barton, 1998: 29)

Practical outcomes

Much research involving disabled research participants has been criticised for failing to have 'any serious effect on services for disabled people and their quality of life'. Instead, the chief beneficiaries are said to be the researchers themselves (Oliver 1992: 109). Similarly, critiques of educational research often centre on its 'lack of relevance to schools and classrooms' (Barton, 1998: 32). Here At least the two disciplines are in accord:

> There are clear parallels between the criticisms leveled at disability research and those made of educational research by classteachers regarding its irrelevance to those researched, the distorted representation of their experience and the failure to bring about change. (Vulliamy and Webb, 1995: 269)

Within Disability Studies then, we are urged 'only to undertake research where it will be of some practical benefit to the self empowerment of disabled people and/or the removal of disabling barriers' (Stone and Priestley 1996: 706). The same is argued of research and consultation with children and young people: 'don't involve them unless there is really something in it for them' (Duffy, in Gallagher, 2005: 4).

A disabled woman interviewed by (Kitchin, 2000: 29) is quoted as saying: 'I would be cynical about what actually happens with research. The majority of times it just sits on a desk'. Research which seeks to make changes cannot simply sit on a desk. It must share knowledge and ideas with disabled people. It must influence policy makers. It must also highlight the inherent contradictions of such short-term reformist solutions. It is vital then that research findings are disseminated appropriately, in a variety of formats, since 'even good research is wasted if it does not reach those who need to be reached' (Ward and Flynn 1994: 44). It is not enough simply to write academic journal articles or book chapters to be read by fellow academics and researchers. Findings must not only be read by fellow researchers, they must also be disseminated widely, in accessible, ways throughout the disabled community. As Penny Germon argues, it makes little sense to promote an 'emancipatory' research model 'when the findings are inevitable inaccessible to an audience of disabled activists' (Germon 1998: 251).

The data from the BCODP research on institutional discrimination were disseminated in a variety of formats. This included presentations by those involved in the research project at various locations; the production of various articles in journals, magazines and the popular press; a book; and an eight page summary leaflet. Two thousand leaflets were produced and distributed free of charge to all BCODP member groups, so that the research made an important contribution to the further politicisation of disabled people both in the UK and across Europe (Hurst, 1995). The research played a crucial role in getting anti-discrimination legislation on to the statute books in the UK. Similarly, the production and dissemination of the projects on direct payments and personal

assistance schemes made a significant contribution to the argument for the introduction of the 1996 Community Care (Direct Payments) Act. This is not to suggest that these projects in themselves are responsible for these outcomes. They are not. They did however provide some substance to the arguments for changes in policy put forward by disabled activists and their allies. In so doing they also contributed to the further mobilisation of the disabled people's movement.

Dissemination of research findings to disabled children and young people requires innovative approaches. Dan Goodley and Michelle Moore (2000: 876) have successfully used cartoons and pictures to disseminate research findings to people with the label of learning difficulties, a strategy that might be equally useful for disabled young people. Ideally though, those young people with a direct interest in the research should be consulted about how the findings would best be disseminated (Morris, 2003). Goodley and Moore (2000: 876) caution however that:

> academic researchers find their careers obstructed if they attach greater precedence to research outputs valued by disabled people than to the blueprint laid down within academic departments. This turns out to be especially true when it comes to dissemination.

Whilst there have been definitive moves forward then, it is clear that the 'emancipatory' research paradigm is still not fully supported in the current market-led academic environment. This perhaps presents the greatest challenge of all.

Conclusion

This chapter has described the emergence of a radical new approach to researching disability, and highlighted both its potential and the challenges it poses for research in 'special' education. By definition 'emancipatory' disability research should be judged by its ability to empower disabled people - both inside and outside the actual research process. Whether this is achievable is highly debatable however. The 'emancipatory' research paradigm then must be seen not in terms of one single project or projects but as a process. This process is still in its early stages, especially in the context of 'special' education where the principles of user-led 'emancipatory' research have yet to be fully explored. Each piece of research must build on and develop what has gone before. It must seek to make a further contribution to our understanding and our ability to erode the various forces - economic, political and cultural - which continue to create and sustain disability at both the macro and micro levels. This is not an easy task. Neither however is it an 'impossible dream'. It a goal for which everyone involved in doing disability research - both within and without the 'special' educational setting - should be aiming. If we aren't, then what's the point in doing it?

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