

‘Emancipatory’ Disability Research: project or process?

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by

**Professor Colin Barnes
Centre for Disability Studies
Department of Sociology and Social Policy
University of Leeds**

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Introduction

It is now ten years since 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 about whether such an approach is a 'realistic goal' or an 'impossible dream' (Oliver, 1997). As someone who has been involved in doing disability research for the past fifteen years this presentation represents a personal reflection on key issues and concerns associated with the emancipatory research model.

The paper is divided into two main sections; the first provides a brief introduction to the notion of emancipatory disability research. The second part focuses on some core principles associated with this perspective. I shall conclude by suggesting that the emancipatory research paradigm is far more than an impossible dream but something that all those involved in disability research should be striving for.

Emancipatory disability research?

In many ways social scientists and sociologists in particular have been doing 'disability' research since at least the 1950s if not before. There are, for example, many studies dealing with 'doctor patient' relations (early examples include Parsons, 1951; Davis, 1963) stigma (Goffman, 1963; Scambler and Hopkins, 1982) institutional living (Goffman, 1961; Miller and Gwynne, 1972) as well as large scale studies chronicling the numbers of disabled people in the general population (Harris, 1971; Martin et al., 1988). All of

which have provided important insights into current thinking on disability and related issues.

However, the main problem with these studies and the numerous others that were, and in some cases are still being, produced is that by and large they are founded on the traditional assumption that people with accredited impairments are 'disabled' by their impairment whether physical, sensory or intellectual. It's worth noting here that some social scientists such as Thomas Szasz (1961), Thomas Scheff (1966) and Robert Edgerton (1967) had begun to question conventional explanations for society's treatment of people labelled 'mentally ill' or 'mentally retarded/handicapped' in the 1960s. These insights were not however extended to other sections of the disabled population; in particular people with physical or sensory conditions.

All of this began to change in the late 60s and early 1970s with the politicisation of disability by disabled people in America and Britain, the redefinition of disability by Britain's Union of the Physically Impaired Against Segregation (UPIAS) (1976) and the emergence of the social model of disability.

In the broadest sense the social model is nothing more or less dramatic than a concerted shift **away** from an emphasis on individual impairments as the cause of disability, but rather **onto** the way in which physical, cultural and social environments exclude or disadvantage certain categories of people; namely, people labelled disabled. In the wake of this insight has emerged several theories explaining societal responses to people with accredited impairments (see for example Priestley, 1998) and an alternative approach to

doing disability research generally referred to as 'emancipatory disability research' (DHS, 1992).

Again, it's important to remember here that the critique of mainstream disability research can be traced back to the early 1980s (Hunt, 1981). Moreover, as the decade drew to close several, mostly disabled, researchers began to draw on disabled people's experiences to illustrate the complexity of the process of disablement with reference to environmental and social forces. Examples include 'Walking into Darkness' (Oliver et al., 1989), 'Able Lives' (1989) and 'Cabbage Syndrome' (Barnes, 1990). Furthermore 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).

These developments were paralleled by a growing literature on 'critical social research' and/or 'action research' by researchers in the majority world, black writers, feminists and educationallists that positively allied itself with oppressed groups (Truman et al., 2000). All of which contributed to the thinking behind the emergence of the emancipatory disability research paradigm.

In 1991 the Joseph Rowntree Foundation (JRF) funded a series of seminars on researching disability that provided a forum for the development of this approach. This series of events brought together disabled and non-disabled researchers working in the disability field along with representatives of various research organisations. This initiative culminated with a national conference and a special

issue of the international journal 'Disability, Handicap and Society' (renamed 'Disability and Society' in 1993) on researching disability (DHS. 1992). Moreover, 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 Rioux and Bach, 1994: Stone and Priestley, 1996: Barnes and Mercer, 1997: Albrecht, Seelman and Bury, 2001).

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. Also, that this control should include both funding and the research agenda.

A decade ago such ideas seemed utopian to say the least. Then, the bulk of disability research 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). In many ways these bodies were dominated by traditional medical and academic concerns and interests and, of course, conventional assumptions about disability and disability related research.

Today, the situation is somewhat different. Although the growing critique of disability research emanating from the disabled peoples' movement was undoubtedly a contributory factor, this transformation is almost certainly due to other factors too. Most notable is the growing emphasis of market forces within universities and other research agencies, the increased use or misuse of research data, both quantitative

and qualitative, by politicians, policy makers and the media, and the consequential and indeed understandable widespread disillusionment with anything that passes for social research amongst the general public.

As we enter the new millennium it is evident that a large number, if not the lion's share, of recent and current research projects focusing exclusively on disability and related issues in the UK are funded by charitable agencies and trusts such as the JRF and National Lottery's Community Fund. Both these organisations prioritise user led initiatives and concerns over those of the academy and professional researchers (www.jrf.org.uk).

Indeed, over the last decade or so there have been several pieces of research which I believe do conform to an emancipatory research model albeit implicitly rather than explicitly. Notable early examples include the BCODP research on institutional discrimination against disabled people, cited above, Mike Oliver and Gerry Zarb's (1992) analysis of personal assistance schemes in Greenwich and subsequent BCODP research on direct payments (Barnes, 1992; Zarb and Nadash, 1994). But more of that later.

Furthermore, 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 (see for example www.esrc.ac.uk). 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.

However, beyond the crucial issue of control the emancipatory disability research model may be characterised by six core principles. These centre on accountability, the role of the social model of disability, the question of objectivity, choice of methodology, the place of experience in the research process, and research outcomes (Stone and Priestley, 1996).

Core principles of an emancipatory research model

i. 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 an 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: Morgan et al., 2001). 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 problem is equally problematic for those working within university settings. Besides the vagaries of the market they are subject to the demands of a traditionally conservative academic community whose interests are often at odds with those of disabled people and their organisations (see. for example, Barnes, 1996: Bury, 1996: Shakespeare, 1996). All of which makes meaningful on going relations between disability researchers and disabled people's organisations difficult to maintain (Barnes, Oliver and Barton, 2002).

In my experience the standard for accountability was set with the BCODP discrimination project mentioned earlier. 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 a non-disabled person. The group met on a bi-monthly basis to comment on and review progress. Moreover, besides collecting data 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 analysis and drafts of chapters were periodically produced and circulated to the advisory group and representatives of disabled people's organisations along with requests for comments and recommendations. These were subsequently discussed at advisory group meetings before amendments were made. When the final report was completed a protracted process of dissemination was undertaken. I will return to this later.

Similar levels of accountability have been achieved by other BCODP research projects including the work on direct payments (Zarb and Nadash, 1996) and the more recent 'Creating Independent Futures' project (Barnes, Mercer and Morgan, 2000).

ii. The social model of disability

Emancipatory research should adhere to the social model of disability. I think it is useful here to remember what is actually meant by the social model. Mike Oliver first coined the phrase in 1983 to reflect the growing demand by disabled people for a more holistic approach to the problems they encountered

(Oliver, 1983). Since then much has been written about the social model by both activists and writers from within and without the disabled people's movement.

Hence the social model has been a, if not the, major catalyst for the increasing politicisation of large numbers of disabled people across the world. It has also provided a firm foundation for the development of a fully formed 'materialist' account of the social creation of disability within western society (Oliver, 1990), and one of the key elements in the emergence of the emancipatory research paradigm.

A decade ago adopting an overtly social model perspective may have been something of a novelty but this is no longer the case. In some respects the social model has almost become the new orthodoxy. For example, social model thinking underpins the work of the British Government initiated Disability Rights Commission (DRC) ([www,drc.uk.org](http://www.drc.uk.org)). Internationally, it has been incorporated into the World Health Organisation's (WHO) recently developed International Classification of Functioning (WHO, 1999) set to replace its overtly individualistic and discredited predecessor the WHO International Classification of Impairment, Disability and Handicap (Wood, 1981).

However, on a personal level adopting a social model perspective has never been a problem for me both ontologically and epistemologically. As someone with a congenital visual impairment and a 'special school' survivor, I have a lifetime's experience of disability. For me the insights of the 'social model' have never been in doubt. But this does not necessarily mean that I believe only disabled people can do disability research.

On the contrary, understanding the process of disablement is not simply about having an accredited impairment. The range of physical, sensory and intellectual abilities within the disabled population is vast. People with congenital impairments experience a lifetime of disability. Those with acquired conditions only encounter it later in life. Having a designated impairment does not automatically give someone an affinity with people with similar conditions or disabled people generally, nor an inclination to do disability research. Indeed,

'Emancipatory research is about the demystification of the structures and processes which create disability, and the establishment of a workable dialogue between the research community and disabled people. To do this researchers must put their knowledge and skills at the disposal of disabled people. They do not have to have impairments themselves to do this' (Barnes, 1992: 122).

iii. The problem of objectivity

There are numerous debates about the question of objectivity within the social sciences and sciences generally. The idea that 'scientists' of whatever persuasion, social or otherwise, can interpret data without reference to personal values or interests is one that has been promulgated by philosophers, scientists, and later politicians, since at least the enlightenment.

The reality is that **all** data can be interpreted in several different ways and those charged with the responsibility of interpreting it are influenced by various forces, economic, political and cultural. If anyone is in any doubt about this contention consider the recent 'scientific' debates over the

causes of global warming, BSE (Bovine Spongiform Encephalopathy) in cattle, Britain's recent foot and mouth outbreak, and/or the value/dangers of the MMR (Measles, Mumps and Rubella) vaccine for children.

With reference to the social sciences, it is argued that all sociological judgements are coloured by personal experience and that all propositions are limited by the meanings, implicit or explicit, in the language used in their formulation. Furthermore, it is also suggested that all theories are produced by and limited to particular social groups, and that all observations are theory laden.

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

In response, all researchers can do is make our position clear at the outset. This means stating clearly our ontological and epistemological positions and ensuring that our choice of research methodology and data collection strategies are logical, rigorous and open to scrutiny. It is important to remember here that the more radical and/or controversial the findings of a particular piece of social research appear to be the more the methodology upon which they are based will be examined.

vi. The choice of methods

Since its inception the emancipatory disability research model has generally been associated with qualitative rather than quantitative data collection strategies. This is almost certainly due to the fact that hitherto large scale surveys and detailed quantitative analyses have been favoured by advocates of value freedom, that such approaches can never capture fully the complexity of the every day experiences of disabled people, and that they are easily subject to political manipulation (Abberley, 1991).

However, all data collection strategies have their strengths and weaknesses. It is not the research strategies themselves that are the problem it is the uses to which they are put. Throughout the modern epoch politicians and policy makers of all persuasions have used figures and statistics to add weight to their arguments and/or to justify particular actions or policy developments. Since its inception in the 1960s the disabled peoples' movement has used similar tactics to highlight the various deprivations encountered by people with accredited impairments and labelled disabled.

The BCODP research on discrimination mentioned above, for example, was heavily reliant on Government figures to underline the case for anti-discrimination legislation. Moreover, Gerry Zarb and Pamela Nadash utilised both quantitative and qualitative research methods to substantiate the argument for direct payments for disabled people to employ their own personal assistants. This research was commissioned by the BCODP Independent Living Committee and again funded by the JRF. Similarly, the Creating Independent Futures project employs a similar array of research strategies.

v. The role of experience

Some commentators have argued that social model research precludes research that documents the experiences of disabled people (Morris, 1991; Shakespeare, 1997). To say the least I think this is something of a misreading. The social model is founded on disabled peoples' individual and collective experiences. What is important is that discussions of disabled people's experiences, narrative s and stories 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.

Furthermore, I do not believe that a social model perspective cannot account for impairment related experiences or as Carol Thomas recently referred to them as 'impairment effects' or the 'psycho-social consequences of impairment' (Thomas, 1999). How we think about ourselves and our interactions with others, whether we have an impairment or not, is subject to a variety of structural and interpersonal forces and processes. Examination through a social model lense can and should illuminate those processes.

The great danger here is that by focusing on the experiences of disabled people we undermine or ignore the significance of the environment in which those experiences are shaped and, in so doing, simply re-emphasise, albeit possibly unintentionally, the personal tragedy theory of disability.

iv. Practical outcomes

Advocates argue that emancipatory disability research should have some meaningful practical outcome for disabled people. After all emancipation is about empowerment. But all research

produces data. The accumulation of data generates knowledge and knowledge is empowering or so the story goes.

The new millennium is said to be the information age, but it is also the age of information overload. Too much information can often lead to confusion and uncertainty and so be disempowering. In turn, this can lead to a reliance on those who generate that information: namely, researchers. Indeed, it has been argued that the principal beneficiaries of social research are the researchers themselves (Oliver, 1999).

Whilst this may be true for some sections of the research community, and I include myself here, I'm not sure that this is the case for the vast majority of social researchers. Due to the insidious but seemingly relentless encroachment of market forces into the organisations that control research production, a career in social research is more often than not characterised by financial and social uncertainty. For most researchers employment is linked to the length of the research contract.

It is however the case that historically many social researchers have undertaken research on sensitive social issues without serious reference to the interests and needs of those being researched, and critics have argued that this is especially evident within the context of disability research (Hunt, 1981; Oliver, 1992).

But can emancipatory disability research offer anything different? I would argue that it can and has. Partly because of all the reasons already mentioned but also because of the high priority placed in dissemination by researchers who

adhere to this perspective. The findings from each of the projects discussed above have been disseminated widely in various ways throughout the disabled community. For example, the data from the BCODP research on institutional discrimination were disseminated in a variety of formats. This included presentation by all those involved in the research project at various locations during 1992/3, the production of various articles in journals, magazines and the popular press and an eight page summary leaflet (some of the printed material is now available on the internet via the disability archive UK (www.leeds.ac.uk/disability-studies/archiveuk/index)). Two thousand leaflets were produced and distributed free of charge to all BCODP groups during 1992/3. In this way the research made an important contribution to the further politicisation of disabled people both in the UK and across Europe.

'The book that BCODP produced in 1991 on disabled people and discrimination in the UK has been the basis for people's thought throughout Europe..... It is a very important book' (Hurst, 1995: 95).

I would argue that this particular piece of research played a crucial role in getting anti-discrimination legislation on to the statute books in the UK. I also think that the production and dissemination of the numerous projects on direct payments and personal assistance schemes, only some of which are cited above, have 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, but they did provide some substance to the arguments for changes in

policy put forward by disabled activists and their allies. And in so doing they did contribute to the further mobilisation of the disabled peoples' movement. However, whether the policy outcomes in terms of the changes to the law will live up to disabled people's expectations is another matter. If they do not then it may generate a demand for further research; but that is something that disabled people and their organisations must decide for themselves.

Conclusion

By definition emancipatory disability research should be judged mainly by its ability to empower disabled people through the research process, but whether this is achievable is a highly contentious issue. It would be impossible to imagine that any one piece of research, no matter how comprehensive or rigorous, could empower all disabled people at the same time. Disabled people like their non-disabled peers are not an homogeneous group. And of course to eradicate disability and, therefore, empower the disabled population emancipatory research must resonate with non-disabled people too.

With this in mind the emancipatory research paradigm must be seen not in terms of one single project or projects but as a process. 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 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 but no one said that it would be. Nonetheless, it is a task that all of us involved in doing disability research should be aiming for. If we aren't then, for my money, there's little point in doing it.

References

Abberley, P. 1992: Counting us Out: a discussion of the OPCS Disability Surveys. In *Disability, Handicap and Society*, 7 (2) 139-155.

Albrecht, G. L. Seelman, K. Bury. M. eds. 2001: *Handbook of Disability Studies*, London: Sage.

Barnes, C. 1990: *Cabbage Syndrome: The Social Construction of Dependence*, Lewes: Falmer.

Barnes, C. 1991: *Disabled People in Britain and Discrimination: A Case for Anti-discrimination Legislation*, London: Hurst and Co.

Barnes, C. (ed.) 1992: *Making Our Own Choices*, Belper: The British Council of Disabled People. Available on the Disability Archive UK www.leeds.ac.uk/disability-studies/archiveuk/index..

Barnes, C. 1992: Qualitative Research: valuable or irrelevant. In *Disability, Handicap and Society*, 7 (2) 115-124.

Barnes, C. 1996: Disability and the Myth of the Independent Researcher. In *Disability and Society*, 11 (2) 107-110.

Barnes, C. and Mercer, G. (eds) 1997: *Doing Disability Research*, Leeds: The Disability Press.

Barnes, C. Mercer, G. and Morgan, H. 2000: *Creating independent Futures, Stage One Report*, Leeds: The Disability Press.

- Barnes, C. Oliver, M. Barton, L. 2002: Conclusion. In *Disability Studies Today*, Oxford: Polity (In Press).
- Bury, M. 1996: Disability and the Myth of the Independent Researcher: A Reply. In *Disability and Society*, 11 (2) 111-113.
- Davis, F. 1963: *Passage Through Crisis: Polio Victims and Their Families*, Indianapolis: Bobbs Merrill.
- DHS. 1992: 'Special Issue: Researching Disability', *Disability Handicap and Society*, 7, (2).
- Goffman, E. 1968: *Stigma*, Harmondsworth: Penguin.
- Goffman, E. 1961: *Asylums*, Harmondsworth: Penguin.
- Edgerton, R. 1967: *The Cloak of Competence: Stigma in the Lives of the Mentally Retarded*, Berkeley: University of California Press.
- Harris, A. 1971: *Handicapped and Impaired in Great Britain*, London: Her Majesty's Stationary Office.
- Hunt, P. 1981: Settling Accounts with the Parasite People, In *Disability Challenge*, 2, 37-50. Available on the Disability Archive UK www.leeds.ac.uk/disability-studies/archiveuk/index..
- Hurst, R. 1995: International Perspectives and Solutions. In G. Zarb *Removing Disabling Barriers*, London: Policy Studies Institute.

Martin, J. *et al.*, 1988: *The Prevalence of Disability Among Adults*, London: Her Majesty's Stationary Office.

Miller, E. J. and Gwynne, G. V. 1971: *A Life Apart*, London: Tavistock.

Morris, J. 1991: *Pride Against Prejudice*, London The Women's Press.

Morris, J. 1989: *Able Lives*, London: The Women's Press.

Oliver, M. 1998: Final Accounts with the Parasite People. In M. Corker and S. French (eds), *Disability Discourse*, Milton Keynes: Open University Press.

Oliver, M. 1990: *The Politics of Disablement*, Tavistock: Macmillan.

Oliver, M. 1983: *Social Work with Disabled People*, Tavistock: Macmillan

Oliver, M. and Zarb, G. 1992: *Personal Assistance Schemes in Greenwich: An Evaluation*, London: University of Greenwich.

Oliver, M. *et al.*, 1988: *Walking Into Darkness: The Experience of Spinal Cord Injury*, Tavistock: Macmillan.

Oliver, M. 1983: *Social Work with Disabled People*, Tavistock: Macmillan.

Parsons, T. 1951: *The Social System* London: Routledge and Kegan Paul.

Rioux, M. H. and Bach, M. 1994: *Disability is Not Measles*, Ontario: York University, Roeher Institute.

Scambler, G. and Hopkins, s. 1986: Being Epileptic: Coming to Terms with Stigma. In *Sociology of Health and Illness*, 8, 26-43.

Scheff, T. 1966: *Being Mentally Ill: a sociological theory* London: Weidenfield and Nicolson.

Shakespeare, T. 1996: Rules of Engagement: Doing Disability Research. In *Disability and Society*, 11 (2) 115-119

Stone, E. and Priestley, M. 1996: Parasites, Pawns and Partners: disability Research and the role of non-disabled researchers. In *British Journal of Sociology*, 47 (4) 699-716.

Szasz, T. S. 1961: *The Myth of Mental Illness: foundations of a theory of personal conduct*, New York, Dell

Thomas, C. 1999: ***Female Forms: Experiencing and Understanding Disability***, Milton Keynes: Open University Press.

Truman, C. Mertens, D. M. and Humphries, B. 2000: *Research and Inequality*, London: UCL Press

WHO, 1999: *International Classification of Functioning, Disability and Health*, Geneva: World Health Organisation, Available on www.who.int/icidh/index.htm.

Wood, 1981: *International Classification of Impairment, Disability and Handicap*, Geneva: World Health Organization.

UPIAS. 1976: *Fundamental Principles of Disability*, London: Union of Physically Impaired Against Segregation. Available on the Disability Archive UK www.leeds.ac.uk/disability-studies/archiveuk/index..

Zarb, G. and Nadash, P. 1994: *Cashing in on Independence*, Derby: The British Council of Disabled People.

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