Researching Disability: setting the agenda for change
National Conference - 1 June, 1992

Setting Future Agendas
Vic Finkelstein

Introduction

Len Barton (1992, page 99) introduced the publication of selected papers from the 1991 series of seminars on 'Researching Physical Disability' with these words:

> 'Part of the motivation behind the series was an increasing disenchantment with many research projects. Criticisms of such research included their misunderstanding of the nature of disability, their distortion of the experience of disability, their failure to involve disabled people and the lack of any real improvements in the quality of life of disabled people that they have produced.'

If true I do not think there can be a more devastating criticism of work with disabled people, particularly if you bear in mind that a major justification for research is the greater insight it is supposed to bring. If incorrect these accusations are a remarkable collective misunderstanding from leading figures in the movement of disabled people; and that would warrant a research project in its own right.

Mike Oliver and I have both argued over many years that disability is socially created and that interventions which are not based on this understanding are bound to become inappropriate over a period of time. In the early 1970s those of us who were just becoming active in the new and growing disability movement were increasingly disillusioned with social scientists. Although sometimes active in the forefront of campaigns, like the campaign for a National Disability Income, their research seemed to go nowhere; at least no further than to document the poverty and deprived conditions under which disabled people were living. As this information was something most disabled people knew from their direct personal experiences research results often seemed particularly ineffectual. What was needed was a way out of the piecemeal campaigns against piecemeal government policies of that period.

Final recognition that we were on our own was provided by the appalling outcome of Miller and Gwynne's (1972) research. Invited by Paul Hunt on behalf of residents of the Le Court Cheshire Home to investigate the way they were being denied the elementary right to organise their own lives the researchers concluded that disabled residents in institutional homes were 'socially dead' and that the function of the home was to manage the transition from social to actual death. They concluded that staff needed training so that this process could be managed as humanely as possible.

It was clear that if there was to be a social interpretation of disability we would have to produce it ourselves. In 1976, Paul Hunt wrote on behalf of the *Union of the Physically Impaired Against Segregation* (UPIAS, 1976, page 3):

> 'Our own position on disability is quite clear ... In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.'

I added to this a criticism of social scientists for their reluctance to analyse the nature of disability while not being shy in advocating their own pet solutions; I wrote on behalf of the *Union of the Physically Impaired Against Segregation* (UPIAS, 1976, page 13):

'Any scientist, seeking to deal effectively with a problem, knows that the cause must first be identified. Therefore, if disability is a social condition then an analysis of the ways in which society actually disables physically impaired people is obviously required before the condition can be eliminated. To persist in concentrating on the effects, on the other hand, is to divert attention from the real problems; and in fact it entrenches disability even further by seeking its remedy in the opposite direction from the social cause by concentrating on the assessment of the individual.'

Of course, since then the analysis has been expanded, some issues clarified and new issues raised. Mike Oliver (1992, page 101), for example, puts the argument very clearly. He points out that most researchers have operated within the same intellectual straight-jacket that attributes the social restrictions faced by disabled people to personal failings. He says:

'Disability cannot be abstracted from the social world which produces it; it does not exist outside the social structure in which it is located and independent of the meanings given to it. In other words, disability is socially produced. In the past 100 years or so, industrial societies have produced disability first as a medical problem requiring medical intervention and second as a social problem requiring social provision. Research on the whole, has operated within these frameworks and sought to classify, clarify, map and measure their dimensions.'

The objectivity of the subjective

In our society the predominant view is that disabled people are incapable of functioning independently in the community. From this point of view they are regarded (in Miller and Gwynne's terms) as 'socially dead'. This means that if disabled people are not to be left to starve or beg on the streets others have to administer to their needs. Where the family cannot cope, or to ease the 'burden', charities and the state intervene. In the first instance, as Mike Oliver has noted, this involves medical interventions, followed by social provision.

Working with people who are regarded as dysfunctional has a particularly powerful logic. If disabled people are assumed to be incapable of managing their own lives then those planning for their care have to be the experts in what is appropriate for them. Mike Oliver (1992, page 102) puts it this way:

'These social relations are built upon a firm distinction between the researcher and researched; upon the belief that it is the researchers who have specialist knowledge and skills; and it is they who should decide what topics should be researched and be in control of the whole process of research production.'

Quite aside from the fact that all this does is to give an overwhelming able-bodied bias to understanding disability issues it also discourages disabled people from taking an active role in their own affairs.

The first item on the agenda for future change, then, is acceptance of the principle that as long as disabled people avoid, or are discouraged from, participation in research into their own affairs they will remain passive and dependent upon others. Sixteen years ago Paul Hunt drafted a response to approaches which in any way discouraged disabled people from participating in their own affairs. He wrote this as one of the fundamental principles for the *Union of the Physically Impaired Against Segregation* (UPIAS, 1976, page 3):

'disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over

their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people.'

This principle means no less than giving the experiences of disabled people the dominant role in determining any analysis of the meaning of disability and the route to solving the problems that we face.

In my view this is another way of saying that the shared experiences of disabled people (the subjective side) provides a better objective foundation for generating an understanding of the reality of disability than the 'objective' distinction researchers make between themselves and the researched. Once disabled people are distanced from actions of the researcher the researcher has already taken a major step in adopting the predominant view of disabled people as fundamentally dysfunctional in their own affairs. The experiences of disabled people can no longer be understood because it is no longer active within the research process. The research process, then, classically transforms disabled subjects into flawed images of the researchers - as impaired able-bodied people or, what is the same thing, as people with disabilities.

Changing the agenda for change

As can be seen I subscribe to the views developed by Paul Hunt, that disabled people have to be in the forefront of action for change. In the words of Gerry Zarb (1992, page 128):

'... there are a number of important questions which can be used as a starting point for a critical evaluation of existing research. (i) Who controls what research will be about and how it will be carried out? (ii) How far have we come in involving disabled people in the research process? (iii) What opportunities exist for disabled people to criticise the research and influence future directions? (iv) What happens to the products of research?'

However, there is also one missing consideration. Most of the discussion in the research seminar papers are concerned with involving disabled people in research in order to ensure more appropriate outcomes. I think there is another consideration which is far more important in promoting emancipatory outcomes, rather than in just making a piece of research follow an emancipatory paradigm. Gerry, it seems to me touches on this when he says (1992, page 129):

'Also, bearing in mind the earlier assertion that, participatory research practice is only a step on the way towards the development of a paradigm for emancipatory research, there are also more searching questions which could be asked about the transformative potential of disability research; for example, what opportunities exist for self-reflection and mutual sharing of experience between researchers and disabled people? How alienating are research practices, and how can alienated research be transformed? and, what does or could research contribute to the empowerment of disabled people?'

In my view this raises the heart of the matter. Research is an active process and those that engage most vigorously in the process gain most substantially from the experience. In fact, we can argue that making sense of the world is one of the most important components of being human. All that research does, when we strip it of its grand pretensions that lead to the kind of criticisms raised by Len Barton at the beginning of this paper, is to try to carry out this sense-making function of being human in a more systematic way. Taking part in the research process, then, is *more important* than ensuring that a particular outcome will emerge. It is the involvement in the processes of research, participating as a researcher, that can transform passive, dependent people into thinking decision-makers, whether or not 'good' solutions emerge. My view, then, is that the objective of research should be to engage

disabled people in the processes of research. The findings are secondary. This is not just to set a new agenda for change but to question the rules for setting agendas for change. Certainly looking at research as a vehicle for involvement rather than as a tool for understanding cannot do any worse than has been done so far.

Given this approach to recruiting disabled people into the research process there are two issues on the agenda for immediate change:

- Firstly, to increase general awareness about the importance of disabled people becoming involved in the processes of research as part of the emancipatory experience.

- Secondly, to bring home the unique contribution that disabled people's experiences can make to disability related research when projects are based upon their perspectives.

I believe the involvement of disabled people in research will prove an important stepping stone in the link between he struggle for emancipation and the role of research in supporting this. In the words of Jenny Morris (1992, page 162):

'If disability research is to be emancipatory research then it must be part of disabled people's struggle to take over ownership of the definition of oppression, of the translation of their subjective reality.'

REFERENCES

BARTON, L (1992) *Introduction*. Disability, Handicap and Society (1992) 7(2), page 99.

MILLER E J and GWYNNE G V (1972) *A life apart*. London: Tavistock Publications.

MORRIS, J (1992) *Personal and political: a feminist perspective on researching physical disability*. Disability, Handicap and Society (1992) 7(2), pages 157-166.

OLIVER, M (1992) *Changing the social relations of research production*. Disability, Handicap and Society (1992) 7(2), pages 101-114.

UPIAS (1976) *Fundamental principles of disability*. Union of the Physically Impaired Against Segregation.

ZARB, G (1992) *On the road to Damascus: first steps towards changing the relations of disability research production*. Disability, Handicap and Society (1992) 7(2), pages 125-138.