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USING EMANCIPATORY METHODOLOGIES IN DISABILITY RESEARCH

EMANCIPATORY RESEARCH: A VEHICLE FOR SOCIAL TRANSFORMATION OR POLICY DEVELOPMENT

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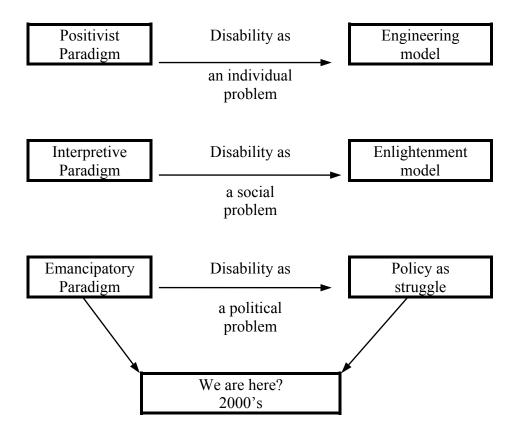
EMANCIPATORY RESEARCH: A VEHICLE FOR SOCIAL TRANSFORMATION OR POLICY DEVELOPMENT

In this paper I will attempt to provide a historical and contemporary framework for discussions about the development of emancipatory research. I will then look at the main ways in which emancipatory strategies have been developed, notably those using participatory and experiential approaches before considering the problems that they generate. I will then attempt to locate these in discussions of policy related research before finally, proposing an alternative framework which moves beyond methodological individualism and investigatory foundationalism.

Historical and contemporary framework

In looking at the history of research on disability, it is easy how it mirrors the history of social research more generally. Previously (1992) I have argued that research has essentially failed disabled people on at least three counts. Firstly, it has failed to accurately capture and reflect the experience of disability from the perspective of disabled people themselves. Secondly, it has failed to provide information that has been useful to the policy making process and has contributed little to improving the material conditions under which disabled people live. Thirdly, it has failed to acknowledge the struggles of disabled people themselves and to recognise that disability is not simply a medical or welfare issue, but a political one as well.

This situation can be summarised as follows:



The result of this situation is that many disabled people have become alienated from both the process and product of social research. In this I would suggest that they are not alone. In recent years other minority or oppressed groups from women, black people, the poor, gay men and lesbians and people from other parts of the world have all voiced similar criticisms in one way or another. While this situation has been recognised in some parts of the academy and by some researchers, it remains true that governments and funding

bodies still require research to be churned out in the old disabling ways. From the fetishism on methodology that still haunts the ESRC to government obsession with scientific validity, the positivistic approach to social research continues to dominate its funding. However, there have been some attempts to develop emancipatory methodologies and it is to these that I now turn (Oliver 1998).

Experiential and participatory accounts

The first of these prioritises and privileges individual experience above ethics, methodology, objectivity and even sometimes the funding body. While I have considerable sympathy with this approach, one problem is that it often assumes that providing faithful accounts of individual experience is enough. Of course it never is as many Chicago interactionists, medical sociologists and standpoint feminists could testify if they had been critically reflexive of their own work.

Another problem is a methodological one: the researching of collective as opposed to individual experience. Most of the research techniques involve one researcher and one research subject interacting with each other, the nature of the interaction being shaped by the research paradigm within which the researcher is operating. Even ethnographic approaches to collective phenomena like cultures or sub-cultures are still dependent upon one to one interactions with key informants. After nearly 200 years of social research we still do not have the faintest idea of how to produce collective accounts of collective experience.

A third problem is that the approach can be an exclusionary one which results in noses being bitten off spited faces because it focuses on a false problem; who is entitled to research experience? This debate about who can and should research experience is usually conducted as if it is the first time the issue has ever been raised and with such high emotions, that friends as well as enemies often end up being excluded. The final problem is that this approach often fails to tie itself to emancipatory theory or praxis, assuming standpoint epistemology is all that is necessary. As Denzin (1997.54) puts it, 'A politics of action or praxis, however, is seldom offered'.

The second approach calls for participatory strategies involving research subjects. It attempts to deal with the problem of emancipation by sharing or attempting to share responsibility and indeed blame with the research participants. The worst exemplar of this is the attempt to do participation by employing a few disabled people as researchers, often without much support or understanding of what that means. Next worse comes involving disability organisations (often non-representative ones) in the process of research production. Least worst involves commitment to involving organisations of disabled people at all stages in the research process, short of overall control over resources and agendas.

The problem with all of these is that they do not confront the objective structures of oppression and despite personal intentions in many cases, disabled people are still positioned in oppressive ways. Whether we like it or not, failing to give disabled people through their own representative organisations complete control over research resources and agendas inevitably positions disabled people as inferior to those who are in control. To

preview what I am coming on to say, we produce disabled people as inferior by our actions, regardless of our intentions.

When we set up research programmes, persuade our organisations to take a specific interest in disability issues and bid into funded initiatives (and I have done all these things myself) we are instrumental in the production of a particular set of social relations. In settling my final accounts with myself, I can no longer pretend that adopting any of the above strategies are the best we can do in current circumstances or that its better than doing nothing. Because of the oppressive structures in which we are located, such actions inevitably keep that oppression in place.

The politics of policy related research

Certainly the most comprehensive and expensive attempt to provide a universal framework for undertaking disability research has been the work done by the World Health Organisation (WHO) to produce a classification system which became the International Classification of Impairments, Disabilities and Handicaps (ICIDH). However since its inception it has been widely criticised as being unusable, confused, confusing and even disablist. Partly as a result of criticisms like these and partly because disability organisations, notably DPI have forced the issue, the WHO has recently commissioned a review of its scheme and this has now been completed. In the Introduction to ICIDH-2 it claims

"ICIDH-2 has moved away from a 'consequence of disease' classification (1980 version) to a 'components of health' classification. 'Components of health' defines what constitutes health, whereas 'consequences' focus on the impacts of diseases or other health conditions that may follow as a result. In this way,

ICIDH-2 takes a neutral stand with regard to etiology and allows researchers to arrive at causal inferences using appropriate scientific methods. Similarly, this approach is also different from 'determinants' of health or 'risk factors'. To allow for the study of determinants or risk factors, ICIDH-2 encompasses a list of environmental factors that describes the context in which individuals live.

(http://www.who.int/icidh/intro.htm)

It is clear from the passage that the authors of the new scheme are distancing themselves from the issue of causality by leaving it open to researchers and by adding the fourth, environmental component, they are seeking to remedy some of the weaknesses of the earlier scheme. Additionally, by shifting the focus away from disease and onto health, they have tidied up some of the disablist and disabling language that appeared in the original. They also claim elsewhere that the scheme is based upon universalism in order to facilitate the development of universal policy.

Universal, disability policy, in other words, merely expands the range of human normality to more realistically include empirically grounded human normality.

(Bickenbach J Chatterji J Badley E and Ustin T 1999, 1183)

But, of course, empirically grounded human normality is code for biologically and medically based classification systems at just the point when social theory is attempting to come to terms with the universality of difference rather than the universality of expanded categories of normality.

What is at stake here is not just social theory but the usefulness or otherwise of ICIDH-2 as tool to facilitate the development of social policy, universal or not, in order to improve the lives of disabled people all over the world. There are a number of different opinions on this matter. Bury (2000) who was involved in the development of the original scheme, argues that much of the criticism of it was unfounded. While he welcomes ICIDH-2 he does suggest that attempts

to use positive rather than negative terminology may make it more difficult to identify and tackle the very real disadvantages that disabled people face. On the other hand, Pfeiffer (2000) remains a trenchant critic of all such schemes and argues that the very existence of disabled people is at stake.

As long as the white, able-bodied, middle-class, Western, male values govern the discussion of public policy, the ICIDH and similar schemes will be used to support them. And in the presence of these values the disability community worldwide faces extinction. Simply revising the details is not sufficient.

(Pfeiffer, 2000, 1082)

Hurst (2000) takes a middle way between the two positions. While she points to many flaws that remain in ICIDH-2, she suggests that

The environmental context covers all areas of life and experience, including attitudes and belief systems, the natural world, services, legislation and policy. If used properly and disabled people involved in the classification, these factors will build up a considerable body of evidence for major social to change to ensure the inclusion of disabled people.

(Hurst, 2000, 1086)

She makes the point that any classification scheme is only as good as the way it is used and that disabled people must be fully involved in its utilisation.

However, for me, the new scheme has failed to shake of the shackles of 'methodological individualism' which underpins almost all medical and social research and so its usefulness remains doubtful. Additionally such research is based upon what I shall call 'investigatory foundationalism'; an approach which assumes that there is a real world out there independent of our conceptions of it, which we can, indeed, investigate. As we move into a different kind of world we need a different kind of research enterprise to enable us to understand it and it is to this that I shall now turn.

An alternative framework

No matter what the new scheme may say, the medical and social research enterprises will continue to be based upon methodological individualism underpinned by an investigatory foundationalism. The best definition of the former remains the one provided by Lukes.

Methodological individualism is a doctrine about explanation which asserts that all attempts to explain social (or individual) phenomena are to be rejected (or, according to a current, more sophisticated version, rejected as 'rock-bottom' explanations) unless they are couched wholly in terms of facts about individuals. (Lukes, 1973, p. 110).

He goes on

Methodological individualism is thus an exclusivist, prescriptive doctrine about what explanations are to look like ... it excludes explanations which appeal to social forces, structural features of society, institutional factors and so on. (Lukes, 1973, p. 122)

Foundationalism is a term used by Hammersley (2001) in his recent defence of objective social research undertaken by the academy. He suggests

"In its most extreme form, foundationalism presents research, when it is properly executed, as producing conclusions whose validity follows automatically from the 'givenness' of the data on which they are based.

(Hammersley 2001,154)

While he claims to be distancing himself from such an extreme position, it remains true that almost all social research continues to proceed on the foundational assumption that there is a real world out there and that by using appropriate methods we can investigate it and hence produce worthwhile and workable knowledge about it (Oliver 2001).

Hence the ICIDH-2 will continue to be used to count, classify and control disabled people all over the world rather than to ensure their emancipation because it remains based upon the twin pillars of methodological individualism and investigatory foundationalism. Hurst, however, has recently suggested that disabled people can prevent this from happening.

Perceptions will not change without our input. We must influence people to understand that the ICF, if properly used, supports the rights model of disability and will help us collect the evidence to show what our lives are really like.

(Hurst, 2001.11)

There are a number of problems with this position, of course. To begin with, the evidence that the vast majority of disabled people throughout the world live deplorable lives (Despouy 1993) already exists and Hurst's own organisation, Disability Awareness in Action has been in the forefront of drawing international attention to this. Additionally, it is by no means certain that WHO will continue to involve disabled people now the scheme has been revised. It may return to type and regard its operationalisation at a matter of science not politics, as an issue for experts, not 'disabled people'. Further, there is no guaranteee that the international disability movement will see continued involvement with WHO and ICIDH-2 as high on its list of priorities. Finally, the history of social research in general and disability research in particular is not notable for its success in resolving the problems it has investigated.

Changing the social relations of research production

There are no simple or magic bullet solutions however and even some of the suggestions from oppressed groups themselves border on the naïve. For example, standpoint theorists who suggest that all that is needed is for researchers to identify with their research subjects in order to produce accurate accounts of experience. The harder version of this position goes further and argues that shared experience is essential; in other words only women can research

women's experience, black people the black experience, disabled people the disability experience and so on. But as Norman Denzin has recently pointed out

"The standpoint theorist presumes a privileged but problematic place in her own textuality. ... a romantic, utopian impulse organises this work: the belief that if lived experience is recovered, somehow something good will happen in the world. A politics of action or praxis is seldom offered".

(Denzin 1997.54)

My own view is that the crucial issue in developing more useful and less alienating research is that of control, not that of experience. Not all research based on experience accurately reflects that experience and not all 'objective' research fails to accurately capture experience even if the general criticism has some validity. This is not to deny the value of research which gives voice to those previously denied it, but to question whether, by itself, giving voice can ever be enough. If it were, then the work of Mayhew and Engels, let alone Townsend and Abel-Smith, would have resulted in the disappearance of the poor.

If such research is ever to be useful, it must not only faithfully capture the experience of the group being researched but also be available and accessible to them in their struggles to improve the conditions of their existence. This isn't just about making researchers more accountable but of giving over ultimate control to the research subjects. Elsewhere I have referred to this as the 'changing of the social relations of research production' (Oliver 1992). This does not mean that researchers have to give up researching but that they have to put their knowledge and skills in the hands of research subjects themselves. It also implies that we need to develop a language (or discourse) which does not continue to maintain the artificial distinction between researcher and

researched. We do not, as yet, have a language which enables us to talk about research not premised upon the researcher/researched distinction.

Politics and praxis in research

My argument however is not intended to replace one naïve solution with another – away with experience and on with control, so to speak. The world (of research) is far more complex than that (Oliver 1997): indeed it is far more complex than many researchers recognise when they reflect on the relationship between their own politics and their research practice. David Silverman, for example, has recently suggested that researchers can choose one of two roles in relation to their own work; what he calls the scholar or the partisan.

"The partisan is often condemned to ignore features of the world which do not fit his or her preconceived moral or political position. The scholar goes too far in the other direction, wrongly denying that research has any kind of involvement with existing forms of social organisation. Both positions are too extreme and thus fail to cope with the exigencies of the actual relationship between social researchers and society".

(Silverman 1998.93)

It is not simply a matter of researchers choosing whether to adopt partisan or scholarly positions because researchers themselves are not free to make such simple choices. Researchers, I have suggested elsewhere (Oliver 1997), are trapped between the material and social relations of research production; between the way research is organised and funded and the way it is actually carried out precisely because the only research that attracts funding is that based upon

methodological individualism and investigatory foundationalism.

Research as production

We can only maintain the position that these wider issues are beyond our control if we remain committed to the idea that social research is an act of scientific investigation of the social world. Increasingly this position is coming under attack from a variety of post-modernist and post-structuralist positions to the point where a view of research as production is becoming increasingly influential. Norman Denzin, in his recent book, puts the moderate version of this position

"...the worlds we study are created, in part, through the texts that we write and perform about them".

(Denzin 1997.xiii)

In my own research career I am conscious that I have now made that transition from seeing research as an attempt to investigate the world into seeing research as action involved in producing the world. I began the recent study of the disability movement (Campbell and Oliver 1996) believing that we were investigating the self organisation of disabled people in Britain but I can now only make sense of that experience by seeing it as an act of production, not one of investigation. Once one takes that cognitive leap, not only is research never the same again but neither is the world itself.

A new epistemology for research praxis is necessary. For me this epistemology must reject the discourse that sustains investigatory research and replace it with a discourse that suggests that research produces the world. This is not new, of course; Marx argued that the class that owned the means of material production was also responsible for 'mental production' and Gramsci suggested that under certain conditions, ideas themselves could be material forces. And finally Foucault refused to separate knowledge/power arguing that the structures that maintain one also sustain the other. But, on the whole, research, no matter how radical, committed or emancipatory, has continued to be based upon the investigatory discourse.

As researchers then, we labour to produce ourselves and our worlds. We do not investigate something out there, we do not merely deconstruct and reconstruct discourses about our world. Research as production requires us to engage with the world, not distance ourselves from it for ultimately we are responsible for the product of our labours and as such we must struggle to produce a world in which we can all live as truly human beings. Thus the research act is not an attempt to change the world through the process of investigation but an attempt to change the world by producing ourselves and others in differing ways from those we have produced before, intentionally or not.

Conclusion

Increasingly as oppressed groups such as disabled people continue the political process of collectively empowering themselves, research practice based upon the investigatory discourse and utilising 'tourist' approaches by 'tarmac' professors and researchers will find it increasingly difficult to find sites and experiences ripe for colonization. Disabled people and other oppressed groups will

no longer be prepared to tolerate exploitative investigatory research based upon exclusionary social relations of research production.

Indeed, one could go further and suggest that the production of all knowledge needs itself to become increasingly a socially distributed process by taking much more seriously the experiential knowledge that oppressed groups produce about themselves and research based upon the discourse of production will have an increasingly important role to play in this. And who knows this may eventually lead to the fusion of knowledge and research production into a single coherent activity in which we produce ourselves and our worlds in ways which will make us all truly human.

However it is clear that disability research continues to remain locked into methodological individualism and investigatory foundationalism for as Hurst points out in respect of the continued classification of disabled people.

There is no other group of individuals who have been subjected to this analysis of individual characteristics. Women and indigenous people as discreet groups have been analysed, but only in relation to their social, cultural and economic status. An in-depth classification of their individual characteristics has never been seen as necessary as an analysis of their status or for the provision of services or the implementation of policies to implement rights.

(Hurst 2000, 1084)

Indeed, any attempt so to do would almost certainly be seen as racist or sexist.

However I would not like to leave you with the impression that I have abandoned materialism for the cultural and methodological relativity of postmodernism for as Oakley correctly points out "If there are really no such things as 'facts' about the way people are treated, then there is no such thing as discrimination or oppression. Post-modernism is inherently political. It drives the enforced injustices of social inequality into the personal cupboard of privately experienced suffering"

(Oakley 2000.298)

The real challenge therefore for research in the 21st century is how to build an enterprise that exposes the real oppression and discrimination that people experience in their everyday lives without merely contributing to the classification and control of marginalised groups who seek nothing more than their full inclusion into the societies in which they live.

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