

**CHAPTER 16 (In 'Disability Studies: Past Present and Future' edited by Len Barton and Mike Oliver (1997); Leeds: The Disability Press, pp. 248 - 253).**

## **Rules of Engagement: changing disability research**

***Tom Shakespeare (First published 1996)***

First, let me agree with many of the points raised by Colin Barnes, and share his concern at the danger of 'academic independence' being employed as a spurious cloak for research which reinforces, rather than challenges, the subordination of disabled people. However, I want to take issue with various points, and challenge the simplistic and reductionist analysis of the research process which I feel he is in danger of perpetuating. I think there is a risk of positivism within Barnes' stance, which reproduces the positivism of the so-called 'independent' researchers he criticises. I write this as a disability activist; as an academic trained in a traditional establishment context; as a researcher who believes that parallels with other movements can give us clues as to the development of Disability Studies; as a sociologist who finds the whole field under-theorised. I think there are particular questions about the types of research, the relationships to disabled people and organisations, the techniques of research and the roles of researchers. In this piece I will concentrate on a couple of these issues.

A key influence on my development as a sociologist has been the work of feminist theorists and researchers, and it is feminist models of the research relationship and the role of academic knowledge which have informed my approach. For example, Ann Oakley's work is important to me for several reasons. First, she departs from the traditional paradigm of 'objective' and 'positivist' social research, and develops an altogether more equal and balanced style of interviewing (Oakley, 1993). Secondly, she combines her academic publications with more accessible versions of the same research, intended to be used by the type of women who form her sample. These principles inform the best sociology currently being undertaken within the Disability Studies context, and underlined the special research issue of this journal (Various, 1992). Personally, I value my articles in *Coalition*, and *The Pink Paper* as much as those in *Disability & Society* or *The Times Higher Educational Supplement*.

However, within feminist work, it is clear that a variety of positions coexist and that numerous debates and disagreements have taken place: this is the mark of a mature and sophisticated discipline, and shows that it is unnecessary (and dangerous) for there only to be one voice. Sometimes, within Disability

Studies, there is a risk of an orthodoxy being established, or dissenting voices being marginalised, or challenging opinions being ignored. Additionally, the relationship between feminist academic work and the women's movement has been less formalised and unilinear than has sometimes been proposed in the case of disability. Arguments there have certainly been, but the expectation of accountability has been altogether more diffuse and generalised, and the notion of commitment has been rather more important. Within lesbian and gay studies, as Vance indicates, there has also been dissent from the orthodoxy of the lesbian and gay political movement (Vance, 1989).

I believe there is a difference between accountability to one's research subjects, and accountability to the disability movement or specific organisations within it. When I do qualitative research, I aim to represent fairly the experiences of my interviewees. I explain exactly what the research is about; I give them the opportunity to revise what they have said and I offer them the opportunity to ask me questions, either about the research or about myself. Equally, I do not use techniques which obscure the voice of participants, for example formal structured interviews or questionnaires. In these ways, I aim to equalise the research relationship, and give participants some control over the process, over their words and over their participation. I try to be accountable to research participants, and I am committed to representing interviewees and giving them a voice within my publications. At the end of the day, I am not naive enough to imagine I have completely equalised the relationship, because I believe this is ultimately impossible. I write the articles; I have the academic voice and authority; I have the education and the language which contributes to the acceptability of what I write.

These points, especially my espousal of 'experience' and 'authenticity', could be interpreted as suggesting that I am engaged on a search for truth. Often, researchers justify their own behaviour by reference to an external reality of this kind. However, feminist and especially post-structuralist theories have challenged the notion of a singular, unitary set of truths which are openly accessible to the researcher. I support this theoretical approach, which leads me to suggest that respondents views will themselves be subject to deconstruction and analysis. I acknowledge the tension between my espousal of accountability to respondents, and my epistemological anti-foundationalism, a dynamic which I am currently working through and exploring. My consolation is that I am not alone in this process:

S, I think my problem, and 'our' problem, is how to have simultaneously an account of radical historical contingency for all knowledge claims and knowing subjects... *and* a non-nonsense

commitment to faithful accounts of a 'real' world... (Haraway, 1988, p. 579).

## AGAINST ACCOUNTABILITY

In terms of the movement, I have a commitment, which is different from accountability. I support the cause of disability rights, I support the principle of self-organisation and I support the disability movement. This is an ethical or a political position, which informs everything I do, professionally and personally. I think it is clear from my published work that I am not a disinterested observer, but a participant in the processes I describe. I recognise that this could lead to criticism in sociological terms, because I might be perceived to be too close to processes which I seek to analyse. However, independent research is indeed ultimately a fiction, and my own engagement gives me insights which can be useful in the research, and enable me to get closer to the people and experiences which I try to analyse.

I do not feel I owe loyalty to BCODP to my local self-organised groups or to other organisations within the movement. As an academic, I have the luxury of reflection, and the possibility of looking in from outside. I believe it is sometimes my duty to be critical, to raise questions and consider issues which may have been overlooked in the heat of political debates. Sometimes, an organisation may become unrepresentative, or may act in ways which do not seem to be in the best interests of the disability community as a whole or sections of it. In that context, it is the right, indeed, possibly the duty of academics, to take an independent line. However, while I aim to be independent, I do not confuse this with being neutral or being objective.

Incidentally, the tension that has existed between disabled academics and disabled activists, and which perhaps contributes to a certain defensiveness on my part, can be compared to an issue which seems to me to be more problematic. As an academic, one is subject, not just to the institutional and financial constraints which Colin outlines, but also to peer review and evaluation. The intellectual work one performs is scrutinised for its accuracy, effectiveness and consistency, in a process which is meant to ensure quality and integrity. Disabled academics are thus subject to at least two monitoring processes: academic colleagues and movement comrades. Compare this to the legions of self-employed, self-appointed consultants who now operate in the disability field. Some are also leading members of the disability movement, many are not. The latter may be more obviously feathering their own nests, but even the former have conflicts of interest and may, indeed, be profiting personally from the collective endeavours of disabled people. As a disabled academic, I do not depend on disability for my career and I do not exploit the

disability movement for advancement. I research disability, but equally I teach and research on a number of other social issues.

## ACCESSIBILITY AND ADEQUACY

This all relates to a broader point, which was an underlying issue at the Leeds University seminar to which Colin refers. Academic work on disability may not always be accessible. I believe writers should use plain language, but this does not equal a duty to be immediately comprehensible. Theories and concepts, and social reality itself, will often be complex, nuanced and difficult. If Disability Studies is to capture this richness, it will have to be able to use ideas and develop analyses which may not be transparent and simple. Mike Oliver has spoken of the dangers of a 'Noddy Guide' to disability, and elsewhere I have quoted Einstein, who said 'Make everything as simple as possible. But not simpler'. This was in the context of reviewing a book by a disability arts practitioner, not a professional sociologist which highlights the point that the autodidact may be more obscure than the academic.

Within sociology, the distinction between 'common sense' and sociology is absolutely central, and refers to the greater rigour, the formalised language and the urge to deconstruct and uncover which is central to academic social science. Sociology has to be adequate, and accurate, and precise. Disabled people certainly need access to sociology and we need more disabled sociologists, but Disability Studies is an academic investigation of the social world, and as such is more than simply common sense (Giddens, 1989). Sociological discourse is a critical discourse but also a reflexive discourse, because it is critical upon itself. In this, it differs from political language.

I have major reservations with the concept of emancipatory research, even while admiring the motivation and commitment of those engaged in it. I am cynical about the possibility of research achieving major change, whether it be radical and emancipatory, or traditional social policy research. Ideas clearly have a role, but actions decide the day, and while it is possible to make the research process more balanced, grandiose claims for its revolutionary potential seem to me to be over-optimistic. Furthermore, while few would now argue in terms of objectivity, a notional independence and balance is still seen as critical to the academic endeavour. Given the political context, there is little point in developing progressive research which is rejected out of hand by government and media alike as being contaminated by ideological prejudice. That is not to say that research is ever uncontaminated by politics, but merely to highlight the reality that academics cannot be perceived to have axes to grind. Neither is it to support the current arrangements for funding (or not

funding) research in this country, which Colin is right to characterise as unfair and misguided.

My current research concerns sexuality and disability, and is not emancipatory research. I hope it is research which reflects the reality of disabled people, and which acts as validation and affirmation for disabled people who read the book. It may have some indirect policy outcomes, but I do not think it should be judged on instrumental grounds, and I defend the right of researchers to undertake research and develop theory for its own sake. This is not the same as offering researchers *carte blanche* to parasitise disabled people's experience and develop careers on the back of disabled people's lives.

## PARTNERSHIP OR PRAXIS

Many of the points I have made here may not sit easily with the prevailing orthodoxy of Disability Studies. It may be that my persona as an academic, and my academic socialisation, is outweighing my activist persona. However, in my view, it is necessary for there to be a division of labour between academics and activists: notions of accountability and representation are relevant in the political context, while notions of engagement and commitment are more relevant in the sociological context.

Ultimately, political action achieves change. Intellectual activity contributes to a climate in which change becomes possible and offers theoretical support to practical debates. Clearly, this dichotomy is not as clear cut as this statement implies, especially when many academics are also activists, and other academics are actually in opposition to the disability movement. Politics is often about pragmatism, instrumentalism, and rhetoric: sociology must be about different things, and sociologists must have the space and the integrity to tell it how it is. Gramsci's concept of praxis, the dialectical relationship of theory and practice, is an important principle in this context (Gramsci, 1985, p. 365). However, I find equally useful the approach of Michel Foucault:

I dream of the intellectual who destroys evidence and generalities, the one who, in the interstices and constraints of the present time, locates and marks the weak points, the openings, the lines of force, who is incessantly on the move, doesn't know exactly where he (sic) is heading nor what he will think tomorrow, for he is too attentive to the present; who, wherever he moves, contributes to posing the question of knowing whether the revolution is worth the trouble and what kind (I mean, what revolution and what trouble), it being understood that the question can be answered

only by those who are willing to risk their lives to bring it about  
(Foucault, 1990, p. 124)

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