

**THE EMERGING FIELD OF
DISABILITY STUDIES:
A VIEW FROM BRITAIN**

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Introduction

We approach this presentation with a mixture of excitement and apprehension. When we established the journal Disability, Handicap and Society, later to become Disability and Society, in 1986 we did not imagine that less than 15 years later that we would be attending a major international conference in Washington to launch disability studies into the global world. Nor did we expect to see the proliferation of books, articles, teaching courses, conferences and seminars all devoted to the topic of disability. More importantly we did not expect to see the political struggles of disabled people for emancipation make such remarkable progress within local, national and international contexts. Hence our excitement, but why, you might ask, our apprehension?

Our first concern is epistemological. The very notion that this veritable ragbag of ideas about oppression, emancipation, representation, struggle, inclusion, independence, discrimination, rights, genocide and so on, and the ratpack of sociologists, educationalists, psychologists, linguists, historians, literary theorists, disabled people and others who have made a contribution to all this could somehow all be codified and encapsulated into a single discipline called disability studies is itself perplexing. But because such attempts at codification and encapsulation are linked to some of the

dominant social institutions of our time, we are not merely perplexed but concerned about whose interests might ultimately be served.

Following on from this our second concern is political. Not only are we concerned with the links between what Foucault would have called knowledge/power and his refusal to separate the two, but also with another link; between disabled people and the academy. In Britain at least and in our version of the story of the emergence of disability studies disabled people have been absolutely crucial, providing the main ideas and shaping the academic agenda throughout. Given that the academy is not as accessible (in its broadest sense) as it might be to disabled people, how might such links be maintained?

Linking these two aspects of the political together, we cannot help but note that the very point at which women's studies was accepted as a legitimate academic discipline in its own right was precisely the point at which it seemed to lose its radical, cutting edge. Of course, as we teach our own research students, 'correlation does not prove causation', but if the price to pay for the codification and encapsulation of disability studies is the loss of its cutting edge, then perhaps the price is too high.

Part of our brief for this panel is to consider some of the tensions within the field. It is this which we will now do, bearing in mind that what we are about to present is our version of a contested story and that we are drawing specifically on our experiences in Britain. The tensions we are going to consider are those within the academy and those between disability studies and disabled people.

Tensions within the field

Until 1975 disability was studied within the academy largely within medicine and its allied disciplines but in that year the Open University introduced an undergraduate course entitled “The Handicapped Person in the Community”. It continued in various guises for more than 15 years and the first postgraduate programme emerged in 1979 at the University of Kent. Various other initiatives were established in the 1980s but it was not until the 1990s that disability studies began to emerge with an academic identity of its own. This emergence has largely been ignored by medicine and its allied disciplines but has caused some major concerns within that sub-branch of sociology called the sociology of health and illness. There is not the time here to review all of these tensions save to point out that, as with all contested knowledge, there are issues of territoriality, representation, legitimacy, validity and politics at stake.

From the perspective of disability studies we would however wish to argue that a major basis of this tension continues to be the way in which sociologists of health and illness have consistently misrepresented what disability studies is really about. In order to do this we propose to concentrate on a paper by Simon Williams published last year in their flagship journal The Sociology of Health and Illness. We are using this as an exemplar and whether our concern with misrepresentation arises in other disciplines and other parts of the world is something we wait to hear about during the rest of these proceedings.

The first area of misrepresentation comes when Williams suggests that the disability movement (and by implication, disability studies) has ‘written the body out ‘ (p803) of all consideration. Quite how he comes to this conclusion when one of the central planks of the disability movement since Berkeley 1961 has been independent living is a mystery. Independent living is of course about nothing more or less than rescuing the body from the hands of medics, other professionals and welfare administrators. What’s more these are real issues about control over when to open ones bladder or bowels, what times to go to bed or get up, indeed who to go to bed with and so on. For a non-disabled university academic to ignore or be ignorant of all this is insulting to all those disabled people who have been involved in the struggle to live independently, some of whom have died in the process.

The second area of misrepresentation concerns the relationship between impairment and disability. Williams claims that disability studies only sees disability as a form of social oppression (p803) but the only evidence he cites for this is a book written by one of us (Oliver M [1990] The Politics of Disablement). While the book is, of course, about oppression but it is also about many other things, one chapter being devoted entirely to the cultural production of impairment. He also ignores or is ignorant of most of the other writing on impairment that has emerged from disabled people over the last 15 years.

Williams then goes on (p810) to advocate a new framework in which he sees the links between impairment and disability as emergent and relational. Again he ignores or is ignorant of one of the seminal texts in the emergent disability studies, notably Vic

Finkelstein's Attitudes and Disabled People (1980), which proposes just such a relational framework in much more detail and with much greater clarity than Williams manages in his article.

The third area of misrepresentation concerns the way in which disability studies fails to represent diversity or difference. This claim has two dimensions; (a) that the movement does not represent all disabled people and (b) that it assumes heterogeneity when in fact impairments give rise to 'a diverse array of symptoms and their own disease specific trajectories' (p810). In respect of the former he cites no evidence for his claim and we know of none; in our experience the disability movement has only ever claimed to represent its members. As far as the latter is concerned, diversity and difference have been considered in great detail but not in respect of impairment, but race, gender, sexuality, ageing and the like; whereas much work in the sociology of health and illness merely reduces people to their symptoms.

The final area of misrepresentation concerns the idea that disability studies is anti-medicine. Williams seems unable to recognise the difference between critiques of medical imperialism and criticisms of medicine per se and lashes out at those who see disability as social oppression as an 'erroneous option for only those spared the ravages of chronic illness' (p812). His assumptions that the disabled academics he castigates as erroneous are also spared his so-called ravages are unsubstantiated and personally insulting. What's more does he really think that those disabled people he calls erroneous are unable to distinguish between the personally life enhancing effects of surgery,

rehabilitation, drugs and therapy and the potentially death making threats of gene therapy, abortion, do not resuscitate policies and euthanasia?

We have used the paper by Williams as an exemplar of what we believe is a much wider problem because it is not simply the fact that an individual like Williams can hold such views but also that they can be published in one of the leading academic journals. When discussing how such a paper came to be published with a leading professor of medical sociology, his response was that it was not surprising because the paper merely reflected what most medical sociologists believed about disability studies anyway. However we would contend that it is impossible for anyone who has bothered to keep up with all the literature that has emerged within disability studies within recent years to sustain such a position.

For this reason in our critique of Williams we have left open the issue of whether he has ignored or is ignorant of all this work. The former implies a deliberate attempt to misrepresent disability studies, the latter bad scholarship. As a new kid on the academic block so to speak, disability studies is bound to tread on the toes of established academic disciplines and indeed some of the wannabe sub-branches of these disciplines and as a consequence suffer the butt of deliberate misrepresentation and bad scholarship. One of the crucial issues for emergent disability studies is how it responds; does it continue to develop its own ideas and work to its own agendas or does it divert some of its energies to responding to sabotage and bad scholarship?

The other major tension we wish to discuss here is the one between disability studies and disabled people. As we have already suggested in Britain at least disabled people have played an absolutely central role in the development of disability studies providing the main ideas and shaping the academic agenda. But as disability studies becomes codified and encapsulated and buoyed by its own success it spawns conferences like this one, so these links become increasingly difficult to maintain. Again there are several dimensions of this tension which we need to discuss separately.

The first aspect of this tension concerns the emerging gap in the lifestyles of those who have built academic careers out of the emergence of disability studies and the rest of disabled people. It is an inescapable fact that the relationship between disability studies and disabled people is essentially a parasitic one and there are real concerns about abuse, exploitation and colonisation. This is not completely one sided however and academics have increasingly come under fire as more and more disabled people empower themselves individually and collectively and accuse academics of careerism and selling out.

A second aspect of this tension concerns the issue of access. In trying to speak to two communities, the academy and disabled people, disability studies faces the difficult task of producing work that the disabled person on the street will understand as well as trying to satisfy the academy of its academic credentials. Writing for two such diverse audiences is not always easy and disability studies has not always succeeded. To understand the complexities of the process of disablement in society is difficult enough; to write clearly

about them is even more so. But it is not only that disability studies has sometimes failed in this task but also that disabled people have not always been prepared to put in the necessary intellectual work to understand their own situations. The gradual establishing of teaching programmes in disability studies, especially where they actively encourage disabled people to participate fully has begun, at least to address this issue.

A third aspect of this tension centres on the need to ensure that disability studies continues to focus on issues that are important to disabled people and not on issues that are intellectually challenging or academically rewarding for disability studies scholars themselves. Currently fashionable issues like postmodernism, representation and embodiment may well turn on disability studies scholars but their immediate relevance to the struggles of disabled people to lead a decent life are hard to justify. Disability researchers sometimes feel trapped between a rock and a hard place as there is often a big gap between what funding bodies are prepared to fund and the priorities that disabled people see in their lives.

We see these tensions that we have discussed as growing in the next few years and we remain apprehensive about the future of disability studies. However our excitement about the achievements of disability studies over the past twenty years or more and the possibilities and potential it offers for the future outweigh these concerns. It is to these that we now turn.

Potential and possibilities for disability studies

Again we wish to emphasise that the points we now wish to raise relating to the issue of advancing Disability Studies reflect our own personal perspectives with regard to the needs of the current British situation in higher education. They arise from our experience and understanding of the development of such courses.

Firstly, it is our contention that the future quality and effectiveness of Disability Studies will be fundamentally contingent upon the extent to which such courses draw upon and critically engage with the writings, poetry and songs of disabled scholars, writers and activists from within the disability movement. This material will provide a wealth of very important ideas, insights, understandings and questions that course teams and their students need to seriously engage with. This critical engagement will involve exploring such material in terms of conceptual, theoretical and explanatory value.

Also, not only should the content of the curriculum reflect the perspectives of disabled people in their multiple forms, but also the construction of such courses and where possible the teaching of them should involve disabled people. Thus, in order to enrich and increase the significance of such courses disabled people need to be actively involved in all aspects of their development. In advocating this we are aware that the dangers of tokenism on the one hand and the academicisation of programmes on the other, need to be carefully monitored and, where necessary, critiqued. A motivational factor informing this whole set of concerns is to be found in the expression relating to the history and

philosophy of the disability rights movement; ‘Nothing About Us Without Us’ (Charlton, 1998).

Secondly, within Disability Studies much more serious work needs to be undertaken in relation to methodological issues, questions and practices. In particular, the question of ‘emancipatory’ research, its nature, purpose and outcomes, needs much more rigorous and critical exploration. In a series of seminars we ran in London nearly ten years ago, which were funded by the Joseph Rowntree Foundation, we attempted to provide an innovatory and serious critique of the institutionalisation of research activities and the disablist assumptions informing them (Oliver 1992). We maintain, that much of what constitutes research including the position and role of the researcher, serves interests other than those of disabled people. Several significant questions emerge from his analysis including: What is the purpose of research? How far is research part of the disabling barriers that need to be challenged and changed? Who should undertake disability research?

Whilst these and other important questions have been the subject of some serious critical examination on the part of disabled and non-disabled researchers, much more needs to be undertaken (Barnes & Mercer, 1997; Moore et al, 1998; Davis, 2000). For example, what does emancipatory research mean and how is it being operationalised in specific studies? What are the relationships and difference between existing research traditions/analysts who use the term ‘emancipatory’ and those within disability studies? What can disability research learn from and contribute to developments within research

generally? To what extent are some methods being viewed as more suitable for undertaking 'emancipatory' research than others and why?

A further set of issues concerns the question of who controls the research agenda, process and implementation? How is 'power' being understood and engaged with in specific research projects? In what ways is disability research providing a serious critique of institutionalised barriers including the position and role of Government in shaping research intentions and outcomes? As well as, of course, the crucial issue of determining who and what gets funded in the first place.

These are some examples of the extent and seriousness of the task we face within disability studies relating to the issue of 'emancipatory research'. One of the most pressing concerns is the development of programmes of research training for new scholars and professionals, that will enhance the development of more open, reflective and effective forms of research practice. At the moment, in Britain at least and we suspect in most other parts of the world as well, the trend in research training is to produce all round methodologists rather than emancipatory researchers.

Thirdly, one of the most seriously under-examined areas of work within Disability Studies relates to establishing an informed understanding of the relationship between class, race, gender, sexuality, age and disability. It is essential that Disability Studies courses examine, for example, issues of equity, social justice, citizenship, exclusion and inclusion and thus with factors that are beyond the question of disablement. Thus, the

ultimate concern is with the establishment of a non-oppressive, inclusive society. This requires the development of a dialogue with members of staff working on related issues in other departments. This will, hopefully, result in reciprocal, beneficial, learning experiences involving theoretical, practical understandings and struggles.

Developing a constructive, collaborative working relationship with a range of colleagues resulting in co-operation over teaching and research, will be an extremely demanding task. Part of the relationship needs to be about clarifying values and providing insights into not only a theory of social change, but also how that can be brought about in practice. The generation of an ethos of mutual respect, lively and constructive debate and the establishing of realisable goals will all contribute to a more inclusive approach to research, teaching and learning outcomes. The dangers of compartmentalisation in terms of disciplines, ideas and practice must be challenged and changed if Disability Studies is to go forward and offer an alternative, effective perspective. This development will take time, serious effort, a willingness to listen and learn and an ability to deal with conflict constructively at the level of ideas and values.

Finally, and no less importantly, the advancement of Disability Studies in terms of conceptual, theoretical and research developments and agendas, requires not only a much greater integration of cross-cultural insights and understandings but also of the whole globalisation process and how that impacts on the lives of disabled people. By exploring the interests, values and practices at work in other societies, the barriers of ignorance, prejudice and ethnocentrism will become a serious dimension of the learning process. A

cross-cultural and global approach will endeavour to take into account both the cultural and political legacies of historical change and the underlying processes and values within different contemporary national and international contexts.

It can powerfully counter the view that dominant values, practices and taken-for-granted power-relations in particular societies are universal or natural. It can reveal the specific, contingent and culturally constructed nature of social phenomena which have traditionally been regarded as fixed (Barton & Armstrong, 2000). Learning about other societies' engagement with disability issues will hopefully provide an informed basis for a critical reflection on our own assumptions, understandings and practices. The readings, intentions and discussions within Disability Studies need to reflect these cross-cultural and global dimensions.

Conclusions

In this paper we have attempted to articulate and share some of our concerns and excitement about the future of disability studies. As the future remains before us pregnant with all kinds of possibilities, we do not feel it is appropriate to end this with anything other than a series of questions which have emerged from our own reflexive encounters with that which has come to be called disability studies.

- How does disability studies respond to attacks within the academy?
- How can links with disabled people be maintained and strengthened?
- How can we continue to develop non-disabling forms of research?
- How do we deal with difference and diversity?

- How do we foster multi-disciplinary co-operation and collaboration?
- How do we include other cultures and the processes of globalisation in our work?

We look forward to discussing these and other questions over the next two days.

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