

Disability Studies and the Quest for Inclusivity: Some Observations.

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Abstract

This paper seeks to provide some personal reflections on the emergence and development of Disability Studies in England. The paper contends that underpinning this process of development is a conception of disability as a form of social oppression, in which the nature of discrimination and exclusion in their complex and varied forms, are viewed as fundamentally significant. The identification, challenge and removal of disabling barriers is seen as a serious and urgent task. Disability Studies is perceived to be a critical process of enquiry, in which engaging with the voices of disabled people, the conceptual, theoretical, explanatory and practical dimensions involved, are perceived to be of central importance.

The paper also argues that the struggle for inclusivity entails a serious and perennial exploration of conceptions, issues and questions concerning equity, social justice, exclusion and citizenship. The motivation for this engagement is a desire for transformative change. This goes beyond the issue of disablement in the pursuit of a non-discriminatory, non-oppressive social and material world.

Highlighting particular insights from Disability Studies, attention is focused on their impact on the development and teaching of postgraduate courses in Inclusive Education in two Universities which the author and other colleagues have been responsible for. Three insights are identified and discussed, and they are: the social creation of categories; the social model and its implications for the nature and purpose of research, and finally, the issue of transformative change.

In the Conclusion, a series of questions are highlighted which have emerged from this particular engagement and which continue to be a challenge for future changes. Finally, the account is set within a broader framework in which cross-cultural issues, globalisation, the importance of encouraging critical reflections on personal assumptions, understandings and practices are foregrounded. The overall intention is to stimulate further discussion and analysis.

Key words: disability studies; social model, rights; inclusivity, exclusion, disabling barriers, equidad, transformative change.

Introduction

This paper will seek to identify and examine some of the key developments of Disability Studies in higher education in England, and its implications for the pursuit of inclusion. The paper will draw on the experience and knowledge derived from both research and teaching. In seeking to undertake this task, I wish to acknowledge the benefits I have received in terms of my own learning and development in this field from my engagement and friendships with disabled people, academic colleagues and students.

Disability Studies

Until 1975 disability was primarily studied within the academy largely within medicine and its allied disciplines, but in that year the Open University, mainly through the efforts of Vic Finklestein, introduced an undergraduate course entitled *The Handicapped Person in the Community*. Since that time, there has been a steady growth of various undergraduate and postgraduate courses within, for example, the fields of sociology, health studies, cultural studies and education. More recently there has been a developing interest in disability issues in social geography and political science.

The substantive evidence of the development and importance of disability studies within higher education can be found in the following combined elements: the significant growth of courses at initial and postgraduate levels; the position and work of disabled scholars within higher education; the increasing number of research centres and groupings specialising in disability research; the increasing support for funding disability studies research by Research Councils; the status and impact of the journal *Disability and Society* which now publishes 7 issues a year and is recognised as the world's leading journal in the field; the increasing support for national and international conferences in the UK and the position of the UK Disability Studies Association in this process and the rapid growth of publications covering a wide range of disability concerns including, specially Commissioned Book Series published by international publishers. (Barnes, C., Mercer, G. & Shakespeare, T. (1999); Barton, L. (1996), Thomas, C. (2007).

Nor should these impressive developments mask the extent of the work that still needs to be undertaken especially in relation to the ways in which disability issues are still often overlooked within the academy, or can best be viewed, as a bolt on factor in relation to what are seen as the main concerns of class gender, race and sexuality.

In an earlier unpublished paper, Oliver & Barton (2000) outlined some of the emerging challenges and tensions within the field of disability studies. This included an identification and critique of what they claimed were some of the misrepresentations of sociologists of health and illness over how they defined disability studies. They challenged such claims as: disability studies has «written the body» out of all consideration; that it failed to represent diversity or difference and that it is anti-medicine. They also highlighted tensions between scholars working in the field of disability studies and disabled people generally. These included: the increasing gap of the life-styles of those who have built academic careers out of the emergence of disability studies and the position and experience of disabled people generally; the tensions of satisfying the demands of membership of the academic community, including particular forms of publishing and maintaining access to, and credibility with, disabled people and their organisations in their everyday struggles. Finally, the additional pressures that academic life involves for disabled scholars in terms of seeking to achieve and maintain status in a world, which is far from inclusive in terms of conditions, relations and values. Whilst this analysis was almost a decade ago, it is still applicable to the current situation.

In some recent interviews I have undertaken with disabled scholars who have been influential in the development of Disability Studies, I asked them: What constitutes Disability Studies? and received such responses as:

One is that it is an academic studies course. It is not a professional training course... That means, that you do not necessarily do disability studies if you work with disabled people... The other thing is, that it is social model based. It is about the society in which we live. It is not about impairments. Impairments come into it naturally but it is not what is wrong with people, it is about society in which we live. It is the academic study of the society in which we live and within that, disabled people's experience and the treatments that they face and the discrimination that they face within our society.

Or again:

Those groups of academics and researchers who operate around the idea of the social model of disability. That's what I perceive to be disability studies in the universities in the UK.

Or finally:

Disability studies.... The virtue of it is, that it uses a range of social sciences to understand the lives of disabled people, and if it is good disability studies, it engages with the voices of disabled people and their organisations.

Several important points can be identified from these responses with regard to how these disabled scholars understand the nature of disability studies in England. Firstly, the subject is seen as unashamedly and fundamentally concerned with the position, experience, future possibilities of disabled people and their organisations in the struggle for rights, citizenship and independent living. Secondly, the social model of disability is at the centre of disability studies and it is this which links it with the grassroots disabled people's movements. In summary the social model which has been developed by disabled people serves several functions:

- It provides a framework and language through which disabled people can *describe* their experiences. Discrimination, exclusion and inequality can be named and challenged.
- It offers a means through which the question of disability can be *explained* and understood in terms of wider socio-economic conditions and relations.
- It provides a basis for *support* and collective engagement of disabled people.
- Finally, it is a means through which the non-disabled world can be provided with an alternative and positive view of disability. Thus it has a very important *educative* function.

Lastly, this form of understanding and commitment underpinning such courses, has significant implications for the nature of research itself, in terms of the purpose, process and outcomes of such investigations.

In the remainder of this paper, a further analysis will be presented with regard to these identified factors and the impact they can have on the struggles for inclusivity. Whilst the term social model can be attributed to the work of Oliver (2004) a disabled scholar, the definitional support for the model is to be found in the statement on Fundamental Principles of Disability which resulted from a discussion between The Union of the Physically Impaired Against Segregation and The Disability Alliance. The UPIAS (1976) position is quite clear:

In our view, it is society which disables physically impaired people. Disability is something *imposed* on top of our impairment by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (my emphasis).

This statement as Barnes (1997) notes, has since been broadened to include all impairments, physical, sensory and intellectual and is the official position of the British Council of Disabled People and the Disabled Peoples' International. Thus Oliver (1990) contends:

All disabled people experience disability as social restriction, whether these restrictions occur as a consequence of inaccessible built environments, questionable notions of intelligence and social competence, the inability of the general public to use sign language, the lack of reading material in Braille or hostile public attitudes to people with non-visible disabilities (p. XIV. Introduction).

Disability is thus a significant means of social differentiation. The level of esteem, social standing of disabled people is derived from their position in relation to the wider social conditions and relations of a given society. This perspective challenges both professional and public perceptions of disability. It involves more than changes to access and resources issues. It is about the struggle for rights, citizenship and anti-discrimination legislation (Equality Studies Centre 1994).

We must not assume that the social model is a fixed and unchangeable set of ideas. Various points of argument and critique exist between disabled analysts, activists and other non-disabled scholars about the adequacy or validity of particular interpretations. For example, there are those who locate the source of discriminatory and oppressive conditions and relations in the fundamental workings of the capitalist system. Thus the emphasis is on a political economy of disablement. Also, there are those who, while still committed to a materialist perspective, are influenced by feminist ideas and are concerned to emphasise the psycho-emotional dimension of disability. Finally, there are those influenced by post-modernism who maintain that the social model cannot adequately deal with the complexities of the global experience of disabled people, or deal with the challenges which impairment presents to notions of embodiment or the inter-connection between disability and other aspects of inequality.

These acknowledgements should not be seen as a desire to remove such debates, but rather as illustrations of the dialogue that is taking place within the disability movement and disability studies. For example, articles in local disability coalition publications (Gibbs 2002; WECODP 2002; Rae 2003) testify to this exciting openness. Several significant papers reflecting these debates can also be found in the journal, *Disability and Society*. Barnes, in attempting to address some of these issues, argues that the social model does not deny the significance of impairment related concerns, appropriate medical interventions, psycho-emotional factors, nor the significance of culture. He contends that the model:

...is a concerted attempt to *politicise* disability in order to provide a clear and unambiguous focus on the real and multiple deprivations that are impressed on people whose biological conditions are deemed socially unacceptable in order to bring about radical structural and cultural change. (Barnes, 2003, p. 10)

The fundamental importance of the social model in the struggle for equity and a non-oppressive, non-discriminatory world, is that this goes beyond the issue of disablement and is about the establishment and maintenance of a social world in which *all* people experience the realities of inclusive values and relationships.

A second feature of disability studies which is rooted in the social model concerns the priority that is given to identifying and critiquing all those individualistic, pathologising, sentimentalising and exclusionary assumptions and beliefs which have, and continue to inform discriminatory policies and practices in relation to disabled people. Understanding disability as a form of «social oppression» is one of the key features of disability studies. Exploring the centrality of institutional, structural, ideological and material barriers within society is a fundamental approach within disability studies. The offensive, unadaptive and hostile material conditions and social relations cumulatively contribute to the marginalisation, disempowerment and exclusion of disabled people. This is a major focus of critical analysis within disability studies (Swain; French; Barnes & Thomas 2004).

In his seminal paper in examining the concept of oppression in relation to disability, Abberley (1987) argues, viewing disability as oppression provides a basis for disabled people to both understand and transform their own situation. He contends:

To claim that disabled people are oppressed involves, however, arguing a number of other points at an empirical level, it is to argue that on significant dimensions disabled people can be regarded as a group whose members are in an inferior position to other members of society because they are disabled. It is also to argue that these disadvantages are dialectically related to an ideology or group of ideologies which justify and perpetuate this situation. Beyond this is to make the

claim that such disadvantages and their supporting ideologies are neither natural nor inevitable. Finally, it involves the identification of some beneficiary of this state of affairs (p.7).

Advocating that disabled people are oppressed necessitates engaging with the issue of power. From this perspective power is not viewed as a form of property which some people possess, but rather, as a set of relations involving the exercise of decision-making. This encourages particular forms of critical enquiry including, how, why and with what consequences does the exercise of power take place within particular sets of social conditions and relations? How are such developments justified and maintained?

At the heart of this perspective is the extent to which disabled people are able to exercise control over their lives including their bodies. They are involved in a struggle to capture the power of naming difference itself. An emancipatory meaning of difference is one of the key interests of disability studies. This involves breaking out of a subordinate role; refusing to acquiesce to a stigmatised social identity and developing a sense of pride in ones self. The challenge this involves can be seen in the personal reflections of a disabled activist called Brisenden (1986) who argued that «impairment» is a metaphor for a socially unacceptable person and that disabled people «are seen as abnormal» because we are different; we are problem people, lacking the equipment for social integration' (p. 3). He maintains that such a perspective compares disabled people against an assumed notion of «normality» which «leads to neurosis and is the cause of much guilt and suffering». This is the context against which the struggle for change needs to be understood.

In the next section of the paper, I want to briefly illustrate how some of the ideas and interests derived from Disability Studies have informed inclusive education postgraduate courses that I have taught with colleagues in two universities over the past fifteen years.

Inclusive Education

How inclusive education is defined is of central importance and a major challenge facing the development and maintenance of such courses. Given the brevity of the paper, it is not possible to provide an insight into the process of learning, debate and dialogue, we continued to have over this crucial issue, the essential features of our position underpinning the courses included, clarifying both what it is not, and what we believe are its essential features.

Inclusive education is not about the assimilation or accommodation of individuals into an essentially unchanged system of educational provision and practice. This is how in many ways integration was conceived. It is not fundamentally concerned with the well-being and thus inclusion of specifically categorised pupils such as disabled pupils. It is about the inclusion of such pupils but it is not the sum total of what inclusion means and involves. It is not about placement or the removal of a child from one context into another. Inclusion is not about dumping children into an unplanned, under-resourced context although this often happens under the guise of inclusive decision-making. It is not a state. Inclusive education is not an end in itself, but a means to an end, that of the realisation of an inclusive society. Inclusion is concerned with the process of increasing and sustaining the participation of *all* people in a society, school or community and simultaneously endeavouring to decrease and remove all forms of exclusionary processes (Booth, 1996). It will as Ainscow (1999) maintains, involve the removal of all forms of discrimination and deciding what needs to be changed and how. Questions of social justice, equity, human rights and non-discrimination are central to the issue of inclusion.

Social Creation of Categories

Disability studies is centrally concerned with the identification, understanding and critiquing of the varied forms of discrimination and exclusion that constitute the disabling barriers in society.

The Inclusive Education courses were based on an informed conviction that something is wrong and offensive with current policies and practices in education and that these are deeply rooted in fundamental inequalities within society generally. These inequalities are not a natural, inevitable or unchangeable fact of life. Also, different aspects of exclusion interact and compound the complexities of the issues involved. Nor can any single factor effectively remove these barriers. A central commitment to inclusive thinking and practice is characterised by an unwillingness to tolerate all forms of discrimination. Inclusive education is seriously interested in the multi-faceted ways disadvantage and exclusion are conceived, understood, experienced and changed. Thus, for example, inclusive thinking involves a critical stance towards a system of educational provision and practice that is fundamentally based on selection, competition, credentialism and individualism. The key concepts and ideas that legitimate the existing assumptions and values of the current system are thus the subject of critical interrogation including, what constitutes «ability», «learning», «achievement», «disability», «special needs» as well as the issue of «inclusive education» itself. (Corbett, 1996).

The Issue of Change

Disability studies is concerned with understanding for a purpose, that of real and effective change. In relation to disabled people, this means giving priority to their voices in terms of the *contexts* in which they are being expressed, the *content* of these voices including their possible contradictions and the *outcomes* of such perspectives. Their concerns, interests and ideas are viewed as central to any attempt to introduce alternative conceptions, relations and practices. In other words, «nothing about us without us».

The question of change is a central feature of the Inclusive Education courses. This is not viewed as being concerned with minor modifications, reform or merely attitudinal change. Priority is given to raising questions, developing understandings about the necessity of systemic, transformative change. Nor is the focus of attention primarily on the issue of 'special needs' or special education, but on the educational system generally. The struggle for change inevitably seeks to address questions of power and control and thus inclusive education is part of a transformative, political project. Within these courses it is recognised that education cannot do this alone and thus there is a need for collaborative relations with other groups and organisations in the struggle for change.

The Nature and Purpose of Research

Disability studies has raised the question of the ways in which a great deal of research is part of the disabling barriers in society. The impact of the social model of disability on the nature of decision-making, the forms of relationships in the research process and the notion of expertise, are part of the creation of a new agenda requiring a fundamental shift in thinking and research practice. This is about the establishment of «emancipatory research» as a central feature of disability studies.

We have drawn on such ideas to inform the ways in which the issue of research is dealt with on the Inclusive Education courses. This includes not only a critical examination of the presuppositions, values and intentions of the researcher, but also the ways in which these become institutionalised in the conditions and relations of research production in higher

education. Students are encouraged to develop a self-critical approach covering the purpose, process and outcomes of research. This involves exploring such questions as:

- What is research for?
- Who decides on the agendas, topics and ways of understanding research?
- What is the relationship between the researcher and the participants in a project?
- Who benefits from this relationship?
- Who decides how the findings are to be communicated and disseminated?
- To what extent is research a political act?

Students are encouraged to recognise the difference between laudable research intentions and actual practices.

A crucial intention informing these courses has been encouraging students to recognise the complexity and contentious nature of these ideas and of the importance of their work in the struggle to establish the meaning and value of inclusive research approaches.

Conclusion

By raising three particular examples from the field of disability studies and identifying some of the ways we have applied them in an Inclusive Education course, a range of serious questions can be highlighted. For example:

- In what ways does an understanding of disability issues help students to think critically about other forms of discrimination and exclusion including those in education?
- What constitutes «criticality» in this process?
- To what extent does student informed awareness lead to empowerment in their personal and professional lives?
- How does the learning process deal with the importance of contradictions, conflict, doubt and uncertainty?
- How far does this approach encourage open, honest debate?

This analysis has been a personal perspective based on experiences and understandings accumulated from research and teaching. In terms of the relationship between Disability Studies and the development and teaching of Inclusive Education courses, their future quality and effectiveness will be contingent on drawing on and critically engaging with the writings, poetry, songs of disabled scholars, and activists from within the disability movement. This material offers a wealth of significant ideas, insights, understandings and questions that lecturers and students need to seriously engage with. This will include, conceptual, theoretical, explanatory, practical dimensions of such work.

It is not only the content of the curriculum that needs to reflect the perspectives of disabled people, but also, the construction of such courses, and where possible, aspects of teaching, should involve disabled individuals. In advocating this, we are aware of the dangers of tokenism on the one hand, and the academicisation of teaching programmes on the other, which need to be carefully monitored and critiqued.

One of the most seriously under-examined areas of work within Disability Studies, relates to the development of an informed understanding of the real connections between, for example, class, race, gender, sexuality, age and disability. Thus, Disability Studies must continue to explore issues of equity, social justice, exclusion, citizenship and inclusion, factors which are beyond the question of disablement. This requires creative relationships with colleagues working on other dimensions of inequality and discrimination in a process in which listening, learning and developing respect will be essential for all the parties concerned.

Finally, and no less importantly, the advancement of Disability Studies requires not only a much greater integration, awareness and understanding of cross-cultural issues, but also, of the whole question of globalisation and its impacts on the lives of disabled people (Barton & Armstrong 2008). This will be a powerful counter-force to the view that dominant values, practices and taken for granted power-relations of particular societies, are universal and unquestionably applicable. It can help to expose the specific, contingent and culturally constructed nature of social phenomena, which have traditionally been regarded as fixed. Learning about other societies, engagement with inequalities, discriminations and exclusions, have been prioritised within these courses with the intention of stimulating an informed basis for using such insights to critically reflect on our own assumptions, practices and understandings. (Barton & Armstrong, 2000).

The intention of this paper, has been to provide a brief and personal account of the dynamic and creative relationship between insights and interpretations derived from Disability Studies, and the content and intent of specific Inclusive Education courses including the question of inclusivity itself. These are complex and contentious conceptions, and thus need to be continually monitored and evaluated. This is part of a constant process of engagement in which the barriers to inclusion need to be identified, challenged and changed. In relation to both research and teaching, their planning, implementation and outcomes, this is a necessary, serious, disturbing and exciting activity.

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