

Disability and the Academy: a British perspective

Background notes for an oral presentation

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Introduction

Since the 1970s there has been a generally productive, if sometimes difficult, symbiotic relationship between the emergent disabled people's movement and academic institutions such as universities and colleges in both Britain and the USA. This has stimulated the development of a new interdisciplinary approach to exploring and explaining disability now generally referred to as 'disability studies'.

In this presentation I will focus on the development of disability studies in the United Kingdom (UK). It is divided into three sections. The first part will describe the emergence of disability politics in Britain and its relationship to scholarship. This will be followed by a discussion of the development of disability studies at the University of Leeds. The third part will centre on wider developments in the UK and raise concerns about the discipline's future.

Disability politics and disability studies in the UK

Before the 1990s academic interest in disability was characterized by conventional individualistic medical explanations, and dominated by medicine and related professional interests. Social scientists concerned with this increasingly important area of enquiry tended to follow similar paths. While some writers recognized the significance of economic, social and cultural factors in the production of disability, the causes of the various deprivations and disadvantages experienced by disabled people were still largely located at the individual level.

Beyond medicine and psychology, readings of disability were dominated by sociologies of health and illness which centered in the impairment related experiences of people with 'chronic illness'.

The challenge to this orthodoxy came not from within the academy but from disabled people themselves. Although the origins of political activism amongst people with accredited impairments can be traced back to the nineteenth century it escalated significantly during the 1960s and 1970s.

Inspired by the political and social upheavals of the period, disabled people began to organize collectively in increasingly large numbers to protest against their incarceration in residential institutions, their poverty and the discrimination they encountered. Notable early examples include the American Independent Living Movement and the Swedish Self Advocacy Movement as well as the formation of The Disablement Income Group (DIG) in 1965 and the Union of the Physically Impaired Against Segregation (UPIAS) in Britain.

The British experience is especially important as it generated a radical and controversial new socio/political approach to theory and practice generally referred to as the social model of disability.

The UPIAS was an especially influential group in the history of social model thinking. Established in 1974 It functioned mainly through confidential correspondence and circulars circulated amongst its members. This literature had to be confidential because many UPIAS members were living in residential institutions. The views expressed in UPIAS documents resulted in the production of the UPIAS

Policy Statement and constitution first adopted in 1974 and later amended in 1976. A comprehensive discussion of the UPIAS analysis of disability is found in the 'Fundamental Principles of Disability' published in 1976 (UPIAS, 1976). This document contains a socio political re-interpretation of disability that draws the crucial distinction between the biological and the social. Thus:

- 'Impairment' denotes 'Lacking part or all of a limb, or having a defective limb or mechanism of the body'

And,

- 'Disability' the disadvantage of restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (UPIAS 1976: 3 – 4).

In contrast to previous definitions UPIAS re-defined 'disability' as something imposed on top of people with 'impairment's' lives, by a society that is intolerant of any form of biological flaw whether real or accredited - the responsibility for the disadvantage experienced by disabled people is shifted from the disabled individual to the organisations and institutions of contemporary society.

In order to put this idea into practice, Mike Oliver coined the phrase the 'social model of disability' in 1981. It was used initially for the training of social workers and professionals working in the disability field (Oliver, 1981

It is important to remember here what the social model actually is. It is a model, which is what social scientists call a 'heuristic device' or an aid to understanding. However, in

view of recent misplaced statements about what the social model actually represents (Shakespeare and Watson 2002) it is necessary to restate the following:

- One, a social model perspective does not deny the importance or value of appropriate individually based interventions in the lives of disabled people, whether they be medically, re/habilitative, educational or employment based, but draws attention to their limitations in terms of furthering their empowerment and inclusion in a society constructed by 'non-disabled people' for 'non-disabled' people.
- Two, in contrast to the conventional individual medical model of disability, it is a deliberate attempt to switch the focus away from the functional limitations of impaired individuals onto the problems caused by disabling environments, barriers and cultures.
- Three, it is an holistic approach that explains specific problems experienced by disabled people in terms of the totality of disabling environments and cultures. This includes inaccessible education, information and communication systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media – films, television and newspapers.

In short, the social model of disability is a tool with which to gain an insight into the disabling tendencies of modern society in order to generate policies and practices to facilitate their eradication. It is not a theory although it has been the foundation for the development of a fully

comprehensive materialist account as expressed in the work of Mike Oliver (1990) and the development of disability studies in the academy in the UK.

However, it is often argued that the conceptual division between impairment and disability upon which the social model rests is false. But the UPIAS redefinition of impairment and disability was a deliberate attempt to separate the biological and the social. To suggest that such a distinction is false is like suggesting that the distinction between the individual and society is false. Whilst such assertions may be of interest to philosophers and some social theorists, I believe that they have little, if any, practical value in terms of research, policy and practice.

This is not to say that the term 'impairment' is not problematic since it is generally understood to refer to damaged or weakened bodies. It may be relevant when used in relation to someone's reduced capabilities as a result of accident or illness, but is less so with reference to congenital conditions and those that do not affect people's capacity to do things. Those of us born with impairment only usually realise we are 'different' when we come into contact with other non-disabled people.

Moreover It is important to remember too that although originally limited to physical impairments, shortly after its development, the UPIAS definition was adapted and adopted by the disabled people's movement, both nationally and internationally, to include all 'impairments': physical, sensory, intellectual.

Also integral to this re-assessment is the assertion that all physiological conditions have psychological implications and all psychological problems have physical

consequences. It is therefore an inclusive concept that encompasses all sections of the disabled community including, for example, mental health systems users and survivors.

This is in recognition of the fact that labels are generally imposed rather than chosen, and, therefore, socially and politically divisive. It also encompasses, implicitly if not explicitly, the notion that like 'disability' the meaning of 'impairment' is a social construct too. Indeed, a key feature of social model literature is that 'attitudes' toward disabled people are historically, culturally and situationally determined.

Besides providing the 'big idea' for the mobilization of disabled people across the UK during the 1980s, the genesis of the social model opened the way for scholarly writings on the various structural forces, economic, political and cultural, that shaped disabled people's lives.

The first academic course devoted exclusively to the experience of disablement, entitled **The Handicapped person in the Community** in the UK, was initiated by an interdisciplinary team at the Open University in 1975. A major figure in the development of this course was Vic Finkelstein, a disabled South African activist and writer and founder member of UPIAS.

Yet apart from the OU course, academic interest in the UK rarely moved beyond traditional medical or psychological approaches until the establishment in 1986 of the international journal *Disability, Handicap and Society*, renamed *Disability and Society* in 1993, by Mike Oliver and Len Barton. Drawing inspiration from the writings of disabled people and their organizations the journal initially

focused exclusively on the socio//political/cultural dynamics of the complex process of disablement. In doing so it provided a key catalyst for the establishment of disability studies as a legitimate area of scholarly enquiry at both at the national and international levels.

The year 1990 witnessed the publication of Mike Oliver's ***The Politics of Disablement***, a book that provided the first comprehensive theorisation of the socio/political interpretation of disability. Drawing on a variety of influences, including personal experience, the writings of disabled people such as Vic Finkelstein (1980) and Paul Hunt (1966), and the sociological insights of Karl Marx, August Comte, and Antonio Gramsci, amongst others, it provides a thorough and rigorous theoretical exploration of the materialist and ideological foundations upon which contemporary responses to disability are based. It has had a considerable influence on disability thinking both within and without universities and colleges across the world.

The following year saw the publication of ***Disabled People in Britain and Discrimination: a case for anti-discrimination legislation*** (Barnes, 1991). This book provided an authoritative analysis grounded in history of the extent of institutional discrimination encountered by disabled people in key areas of contemporary society. These included education, employment, benefits, health and social support services, the built environment, leisure, the media and political institutions. The study was devised, sponsored and controlled by disabled people and their organizations; in particular, the British Council of Disabled People (BCODP) – Britain's national umbrella for organizations controlled and run by disabled people themselves; now known as the UK Disabled People's Council.

Disability studies at the University of Leeds

The UK's first fully formed Disability Studies programme was established in the School of Sociology and Social Policy at the University of Leeds in 1992 with the setting up of the Disability Research Unit (DRU) by Colin Barnes. The DRU was the home of the BCODP Research Unit until 2000, and was renamed the **Centre for Disability Studies** (CDS) in 1999. Although firmly rooted in applied sociology, the change of name was deemed necessary to reflect the growing interdisciplinary nature of disability studies. CDS now has a core staff of five full time academics, three of who are disabled, based in the School and fourteen associate members in other schools across the University.

From the outset the DRU has retained firm links with organizations controlled and run by disabled people such as the BCODP and sought to reflect and develop their insights and interests within a scholarly framework in order to further the struggle for a more equitable and just society. This has resulted in a range of activities including research, teaching and related knowledge generation and transfer.

i/ Research

Drawing upon work on discrimination for the BCODP, CDS has developed and promoted user led 'emancipatory' disability research in the UK (Barnes and Mercer, 1997) on a range of disability issues including disabling imagery and the media, independent living, user led services, 'care' and disabled people, and access to the built environment for

several local, national and international agencies (<http://www.leeds.ac.uk/disability-studies/research.htm>).

ii/ Teaching

The CDS teaching programme began in 1992 with *An Introduction to Disability Studies*; an undergraduate second and third level optional module. A post graduate Diploma/MA in *Disability Studies* followed in 1993. These courses are still offered by the School. And most importantly due to popular demand the post graduate programme was expanded to include a distance learning option in 1998 and five other taught courses in 2005 on disability and related fields such as: gender, health and illness, race and ethnicity, Special Education and social policy.

The primary focus of each of these schemes is the inter-relationship between theory policy and practice. Unlike previous courses dealing with disability related concerns in Britain and elsewhere, the focus was and remains clustered around:

- the re-definition of disability by disabled people and their organizations,
- the 'social model of disability' and,
- work inspired by the theoretical insights and analyses provided by disabled scholars in Britain and the rest of the world.

Since its inception the post graduate programme has recruited 340 students; half of whom are international students. Several have gone on to further study and many

now hold key posts in local, national and international disability organisations in both the statutory and voluntary sectors. Currently there are 100 undergraduates, 40 postgraduates and 12 research students studying disability with CDS in the Department of Sociology and Social Policy (<http://www.leeds.ac.uk/disability-studies/teaching.htm>).

iii/ Knowledge generation and transfer

From the outset dissemination has been central to CDS policy. This has included ground breaking international conferences and seminars bringing together disability scholars and lay audiences on various topics. These have included *Illness and Disability* (1995) *Doing Disability Research* (1997), *Disability and Development* (1999), *Teaching Disability Studies* (2000), *User Led Services* (2001), and *Direct Payments* (2007). Seminars with visiting speakers are a regular feature of CDS activity and average around four each semester. Throughout its history CDS has attracted visiting research fellows from other countries including Germany, Finland Korea, Japan, Portugal and Sweden (See <http://www.leeds.ac.uk/disability-studies/events.htm>.)

CDS staff, along with colleagues from the Universities of York and Lancaster, established Britain's *Disability Studies Association* (DSA) with a conference in 2003. The DSA conference is now a bi-annual event. In 2006 and attracts over 250 participants from all over the world.

In 1996 I founded *The Disability Press*. An independent publisher devoted exclusively to disability issues that has produced books and reports in accessible formats such as

Braille and large print for people with particular access needs.

To-date the *Disability Press* has produced nine edited collections and five research reports and sold over 4000 items. In terms of content, these publications have provided an unprecedented and innovative forum for the writings of pioneers and newcomers to the field. They include the early work of now established scholars such as Dan Goodley, Mark Priestley, Alan Roulstone, Marcia Rioux, Tom Shakespeare and Emma Stone (<http://www.leeds.ac.uk/disability-studies/publish.htm>).

Other knowledge transfer activities include the establishment of the world's first internet disability discussion list in (1995) and *The Disability Archive UK* (1999). The former is an international forum for scholars and researchers engaged in disability studies. It provides a vehicle for discussion on all aspects of research within the field of disability studies – theoretical, political and practical. Its principal aim is to provide an opportunity for researchers, students and disability activists to share their ideas, information and news, particularly amongst researchers and activists working from a social model or social interpretation/ understanding of disability and related issues. The list attracts over 200 contributions per week from contributors from all over the world, Archives of past discussions and debates are available from September 1998 (<http://www.leeds.ac.uk/disability-studies/discuss.htm>).

Set up in 2000, the *Disability Archive UK* is the world's first electronic resource devoted exclusively to disability studies. It contains over four hundred items including books, monographs, research reports, journal articles, polemics

and other material covering all aspects of the socio dynamic of the disability experience. Freely available online, the Archive provides disabled people, students, researchers and scholars with an interest in disability issues with access to the work of others whose writings may no longer be easily available in the public domain in order to inform current and future debates on disability and related subjects. It includes the complete works of pioneers such as Paul Hunt, Vic Finkelstein, Jo Campling and Mike Oliver, as well as recent studies by the World Health Organisation and the recently abolished Disability Rights Commission. The Archive is periodically expanded and updated to include other material as and when it becomes available (<http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>).

Discussion: Disability studies in the UK and its future.

There has been a major shift in disability politics since the early 1990s both nationally and internationally. Britain now has anti-discrimination legislation to prohibit discrimination against disabled people. The Government set up a *Disability Rights Commission* (DRC) in 2000 which was incorporated into the newly formed *Equality and Human Rights Commission* (EHRC) in 2007. They also established an *Office for Disability Issues* (ODI) in 2007 and the rhetoric of the social model of disability and independent living abounds in Government literature and policy statements.

Furthermore, many of the traditional disability charities controlled and run by non disabled professionals who were once not particularly enthusiastic about disability politics now openly campaign 'on behalf of' disabled people rights.

As a result many disabled activists and one time leaders of grass roots organizations are now employed by Government or traditional charities. They are therefore no longer representative of disabled people generally and in many cases have little contact with local organizations. .

Additionally, as government investment in the setting up and funding of government agencies such as the DRC and ODI has increased, funding for representative organizations controlled and run by disabled people has diminished. This has been exacerbated further by increased competition for the limited government funding available, by 'safe' disability charities and organizations who have now adopted the language of disability politics. Hence, Britain's once powerful disabled people's movement is now in some disarray and as a consequence its influence over the academic agenda has similarly declined.

In tandem with these developments there has been a growth in academic interest in the socio/political dynamics of the disability experience. Indeed, *Disability Studies* is now firmly established as a legitimate area of scholarly enquiry in British universities and colleges of higher education. In addition to the CDS at Leeds there are now research centres specializing in disability and related issues at the universities in Birmingham, Dundee, Glasgow, Lancaster and Manchester. Disability studies perspectives are also firmly embedded in a variety of courses across the UK. Britain's *Disability Studies Association* (DSA) was formed in 2003 by CDS and colleagues from the universities of Lancaster and York in 2003 and held its first international conference in September that year which attracted over 200 delegates from all over the world (<http://www.disabilitystudies.net/dsaconf2003/dsa2003.htm>). It is

now a biannual event and its fourth conference will be held at Lancaster this year (2nd - 4th September).

Consequently the discipline's short term future would seem to be assured. But whether this is sustainable in the long terms is another issue. As indicated above disability studies emerged from within the disabled people's movement. Its agenda and credibility has been closely linked to its on going relationship with disabled people and their organizations. But this relationship has waned over recent years. As a consequence research agendas are increasingly being set by government and government sponsored agencies. Similarly academic concerns and debates are increasingly prioritized over political and practical issues and concerns.

All of which is likely to result in a further severing of the links between disability scholars and disabled people and their organizations. For me this would be a tragedy and will, I believe, inevitably result in the discipline's demise.

References

Barnes, C. 1991 (second impression 1994) *Disabled People in Britain and Discrimination: A Case for Anti-Discrimination Legislation*, London: Hurst and Co Ltd.

Finkelstein, V. 1980: *Attitudes and Disabled People*, New York: World Rehabilitation Fund.

Hunt, P. (ed.) 1966a: *Stigma: The Experience of Disability*, London: Geoffrey Chapman.

Oliver, M. 1990: *The Politics of Disablement*, Basingstoke: Macmillan.

UPIAS, 1976: *Fundamental Principles of Disability*, London: Union of the Physically Impaired Against Segregation.

All references cited in this paper are available at the Disability Archive UK <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>