

Disability Studies and the Academy - past, present and future

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Since the emergence of the disabled people's movement in the latter half of the twentieth century there has been a steady growth of interest in disability issues amongst social scientists in universities and colleges, referred to collectively as the 'academy' (Delanty, 2001) throughout the world. This has generated a radical critique of conventional thinking and research on disability related issues, a large and expanding literature from various 'social science' perspectives, and the emergence of a new interdisciplinary area of enquiry generally known as Disability Studies (recent examples include Davis, 2010; Goodley, et. al., 2012; Watson, et. al., 2012). Initially disability activists and scholars played a crucial role in shaping our understanding of disability which sometimes resulted in an uneasy relationship between the disabled people's movement: organisations controlled by disabled people, and the academy (Barnes and Mercer, 1996). Over recent years this relationship has diminished raising some concern about the future direction of the discipline (Oliver and Barnes, 2012). This paper will trace the origins of these developments with particular reference to the UK and, to a lesser degree, the USA.

Re-interpreting disability

Before the 1980s, academic interest in disability within the social sciences was confined almost exclusively to conventional individualistic explanations linked in one way or another to medicine and medical concerns. An important early example is found in the work of the American sociologist Talcott Parsons. Bowing to established wisdom, Parsons (1951) viewed short-and long-term 'sickness' as a deviation from the 'normal' state of being and, therefore, a threat to economic and social activity or functioning. For Parsons, illness, and by implication, impairment is more than a biological condition; it is a social status and those cast in what he termed the 'sick role' have certain rights and

responsibilities. Thus, 'sick people' are relieved of the usual roles and responsibilities associated with non-disabled lifestyles. In return they are required to view their current status as unacceptable. To this end they are expected to seek help from those charged with the responsibility for fulfilling this task: namely, medical and rehabilitation professionals. Although Parsons' work has attracted widespread criticism from practitioners and activists alike, mainly for its deterministic tendencies, it has, nonetheless, had an enormous impact on the social sciences and professional thinking in universities and colleges throughout the world.

Following Parsons, the analysis of social responses to impairment or disability was mainly the preserve of academics concerned primarily with the reaction to and management of ascribed social deviance. A notable example is Goffman's (1968) account of the interactions between 'normal' and 'abnormal' people. However, many writers paid particular attention to the social construction of 'mental illness'. A psychoanalyst, Thomas Szasz (1961), went so far as to question the very existence of mental illness, the validity of psychiatry as a legitimate medical discipline, and the rehabilitation potential of psychiatric hospitals. He argued that the concept 'mental illness' represents little more than a mythical substitute for the various problems associated with modern living. Such ideas were given further impetus by the writings of the French philosopher Foucault who argued that mental illness, and other forms of ascribed social deviance, are social constructs generated by an increasingly dominant and moralistic social order (Foucault, 1975). Foucault's work has been particularly influential in a variety of fields including disability studies (Corker and Shakespeare, 2002).

Within sociology, interest in the general area of disability increased steadily during the late 1960s and 1970s with publications by Scott (1969), Albrecht (1976), Blaxter (1976) and Townsend (1979). Although each of these studies to varying degrees drew attention to the various economic and social consequences of the ascription of a disabled identity, the causes of disabled people's individual and collective disadvantage remained un-theorised and unchallenged.

The challenge to established views came not from within universities and colleges, but from disabled people themselves. British activists were especially important as they produced a radical new interpretation of disability that generated a new approach to disability practice and theory, commonly referred to as the 'social model of disability' (Oliver and Barnes, 2012). Grass roots organisations controlled and run by disabled people, such as the Union of the Physically Impaired Against Segregation (UPIAS) and the Liberation Network of People with Disabilities, provided the fertile ground for

disabled activists to explore and reconfigure the concept 'disability'. These 'organic intellectuals' (Gramsci, 1971) produced an impressive body of work which formed the bedrock for both the politicisation of disability and the development of disability studies in the UK and beyond during the 1990s and early 2000s. Key texts include Hunt (1966), UPIAS (1976), Finkelstein (1980), Sutherland (1981), Oliver (1990) and Barnes, (1991)..

Drawing on both personal experience and sociological insights, these writings posed a direct challenge to conventional thinking and practice on disability. Nonetheless, although the emergence of the social model of disability provided the 'big idea' (Hasler, 1993) for the mobilisation of disabled people, it was slow to find acceptance in universities and colleges in the UK.

The arrival of disability studies

Until the 1990s, studies of 'disability' in British universities were typically located within a narrow range of academic disciplines including medicine, psychology, special educational needs and social work. Sociologists, despite their traditional focus on social inequality, were content to situate the analysis of disability within medical sociology and sociologies of health and illness perspectives. These are characterised by a largely a-theoretical tradition of socio-medical research driven by practical medical, health service concerns and interactionist, phenomenological perspectives. The outcome is an extensive literature that documents the extent and nature of chronic illness, its consequences for daily living and its impact on social relationships, the sense of self and identity (Barnes and Mercer, 2010).

Consequently, Britain's first disability studies course was not developed within a conventional university setting. It was conceived and developed by an interdisciplinary team at the Open University (OU) in 1975. A key figure in the production of this programme was a disability activist, Vic Finkelstein. The OU was an appropriate location for this new course as its emergence signalled a new and innovative approach to university education. In its first year the course recruited over 1,200 students, including professionals, voluntary workers and disabled people. As disabled people were increasingly involved in the production of teaching and learning materials, the course was updated twice before its abolition in 1994. The final version of the scheme was re-titled 'The Disabling Society' to reflect its wider content (Swain et al., 1993).

Similarly, the social dynamics of the disability experience were introduced on to the mainstream academic agenda in the USA and Canada in the 1970s. Again the link

between disability activism and higher education was the key to this development. Disability rights advocates and scholars concerned with disability came together at several conferences and realised that they shared similar interests and goals. A major catalyst for bringing these two groups together was the 1977 'White House Conference on Handicapped Individuals' which attracted over 3,000 delegates. As in the UK, these early activities generated a small but significant body of work primarily within the field of medical sociology. Important early examples include Bowe (1978) and Zola (1982). These and other studies drew attention to the disabling tendencies of American rehabilitation programmes and American society generally.

Even so, in contrast to the British approach, this literature failed to recognise the theoretical and analytical importance of the distinction between the biological (impairment) and the social (disability) integral to a social model analysis. Arguments for inclusion are couched within US traditions of minority group politics and individual consumer rights. These approaches have only a limited utility in capitalist societies characterised by vast inequalities of wealth and power such as the USA (Russell, 1998; Frances and Silvers, 2001; Oliver and Barnes, 2012). However, over recent years a more radical perspective has appeared, spearheaded by a small but vocal band of mainly disabled writers working in the humanities and cultural studies fields in universities in North America, Australia and New Zealand. This has resulted in the demand for a more critical interdisciplinary approach to the study of disability more in keeping with advocates of social model perspectives (Clear, 2000; Hahn, 2002).

All of this has stimulated important debates about the role and development of the social model of disability within university settings and also relations between disability activists and professional academics. This is because, historically, universities have been a predominantly reactionary rather than a truly radical political force for social change (Delanty, 2001). Furthermore, the coming of the social model and, subsequently, disability studies poses a complete contrast to the kind of orthodox thinking hitherto generated in large part by scholars working in the established disciplines of medicine, sociology and psychology (Barnes et al., 2002).

Disability studies in the academy

When thinking about the links between universities and the disabled people's movement it is useful to consider three distinct strategies. These are the 'outside out', 'inside out' and 'outside in' approaches. The 'outside out' position is the one favoured by most professional 'experts' and academics. It is rooted in the positivist traditions of

the nineteenth century and is clustered around the idea that the social world can only be properly understood through the application of the principles of rational thought, the natural sciences, and the pursuit of 'objective' knowledge (Giddens, 2006). Since this perspective is widely regarded as value free and politically neutral, it is the one that has sustained universities and colleges and those who work in them for most of their existence (Barnes et. al., 2002).

However, over recent years this perspective has increasingly been called into question. This is almost certainly due to the surfeit of information generated from various sources outside universities (Delanty, 2001) and the growing use and misuse of social statistics by politicians and the media (Oliver and Barnes, 2012). One outcome of this situation is that some universities and subject disciplines are now striving to include lay experiences in their research.

Yet in many ways this amended or 'realist' approach still situates the professional scholar as arbiter of everything that counts for acceptable and meaningful knowledge. For instance, Dyson (1999) refers to himself as a 'professional intellectual' rather than a positivist. He has recently argued that the academy has a role to play as 'instigator and sustainer of rational debate' between academic and lay communities.

Clearly then the 'outside out' perspective, largely because of its claims to value freedom and political neutrality, does not sit easily with the radical politics of oppressed groups. Moreover, by attempting to incorporate and re-interpret lay knowledge and experiences, academics and researchers are in danger of doing what they have always done; that is, colonising and reproducing in a less radical form the work, ideas and experience of others. Unsurprisingly, therefore there is a general concern about the role of academics amongst Britain's disabled peoples' movement (Barnes and Mercer, 1996; Finkelstein, 1996; Germon, 1998; Thomas, 2007). Consequently, attempts to build meaningful working and fruitful relationships between the academy and disabled people and their organisations based on the 'outside out' position should be treated with the utmost caution.

The foundations for the 'inside out' approach are based in the interactionist, phenomenological traditions favoured by medical sociologists mentioned above and, later, the women's movement. Proponents argue that the direct experience of a particular phenomenon is necessary not only to facilitate a thorough and meaningful analysis and understanding, but also to engender an appropriate political response. However, this can easily lead to the claim that only those with direct experience of a phenomenon are entitled to analyse and discuss it. Hence, only women can articulate about women's experiences, black people the black experience, disabled people the

disability experience and so on.

Whilst there is no consensus on this particular issue amongst academics, the same can also be said of the UK's disabled peoples' movement. Some disabled people's organisations, including members and staff, are exclusive to disabled people. Some groups employ non-disabled people as support workers. Others adopt a more inclusive approach and have 'non-disabled allies' in their membership and in their workforce (Barnes and Mercer, 2006).

It is evident, therefore, that the 'inside out' approach is potentially exclusionary and reductionist. Because of the heterogeneity of the disabled population and the fact that not only people with ascribed impairments encounter oppression, exclusivity can easily lead to the marginalisation of both groups and individuals. Such a position is frequently politically and academically counter-productive. Furthermore, as noted earlier, the 'inside out' position ultimately reduces experience to the individual level and, therefore, negates the production of meaningful analyses and policy recommendations based on collective insights. Finally, studies based entirely on personal experience often read as little more than special pleading and are characteristic of what the disabled activist Hunt (1966, ix) termed 'sentimental biography'.

The alternative, the 'outside in' position, emerged from within disabled people's organisations partly in response to the ways in which experiential accounts have historically been individualised and/or medicalised by social scientists. Advocates do not deny the significance of direct experience but maintain that by itself it is not enough. Disabled people's experiences of disabling barriers (inside) must be located within a political analysis (outside) of why these barriers exist and how to eradicate them (UPIAS, 1976; Finkelstein, 1996). To facilitate such accounts they must have firm working links between the disabled people's movement and the academy, since the former can provide the experience and the latter a coherent and scholarly political analysis. What is at stake, therefore, is not whether such a relationship should be constituted, but how it should be constructed and maintained (Barnes et al., 2002; Oliver and Barnes, 2012).

Critics have suggested, however, that this is an essentially masculine account that undermines the views of the women's movement and advocates of the 'personal is political' standpoint. Thomas (2007) suggests that the most appropriate solution to this problem is for academics to write themselves into the analysis and be explicit about the relationship between subjective experience (inside) and objective action in the wider world (outside). Others have gone further and argued that this approach is based on

what they consider an outmoded ideology: the social model of disability, that is no longer tenable in the postmodern world of the twenty-first century and, therefore, in need of revision (Shakespeare and Watson, 2002).

Such arguments have led to the emergence of a 'second generation' of academics from a variety of disciplines (Watson, et al., 2012; Goodley, et. al., 2012) who advocate a more holistic 'critical disability studies' agenda that prioritises complex theoretical debates about the body, impairment, identity and discourse over and above those dealing with the economy, politics and social policy. It is an agenda that is more in keeping with the work of medical sociologists and the inside out approach rather than that advocated by disability activists and their organisations.

Given the recent incorporation of disability issues into government circles and the growing threats to disabled lifestyles posed by recent cuts in disability services due to the on-going global economic crisis in Britain and elsewhere, it is difficult to see how this agenda will benefit disabled people and their families. All of which raises important questions about the future of disability studies and its relations with disability activists and their organisations.

Conclusion

This paper has demonstrated how the re-interpretation of disability by disabled activists during the 1970s has had an important impact on the perceptions and analysis of disability within universities and colleges in the UK and the USA. Although slow to become established, this approach has attracted considerable attention in universities over recent years. Whilst this is to be welcomed as it signifies a growing recognition of the importance of the issues, it should also be treated with some caution (Sheldon, 2006). The recent and growing individualisation of disability studies within the academy by some disability scholars signifies nothing less than a reaffirmation of traditional academic values and the effective de-politicisation of the discipline.

Indeed, the rebranding of traditional individualistic social science perspectives of disablement as 'critical disability studies' (Goodley, 2011, Goodley et al., 2012) has little relevance beyond the sterile confines of the university seminar room and those intent on re-asserting impairment as the primary cause of disabled people's economic and social disadvantage. In view of the enormity of the challenges facing disabled people and their organisations in the coming decades both nationally and internationally this is the very opposite of what is needed.

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