Disability, Higher Education and the Inclusive Society

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Abstract

This review focuses on the growing interest in the socio/cultural dynamics of the disability experience in universities and colleges of higher education in the UK; referred to here as a disability studies perspective. It is argued that this approach and the increased numbers of disabled students in the academy are due to the politicization of disability by the disabled people's movement and the symbiotic but fragile relationship between disability activists and academics and researchers. It is argued that although considerable progress has been made since the early 1990s, the future of this mutually beneficial relationship is in serious jeopardy due to the increasing influence of market and reactionary forces both within and outside institutions of higher education.

Key words: Academics, Disabled people's movement, Disability Studies, Post-modernity, Universities

Introduction

Much has changed over recent years with regard to disability and higher education. Until the 1990s, most British universities were virtually inaccessible to disabled students and staff (Barnes, 1991;

Leicester and Lovell, 1994). Disability and related issues were perceived almost exclusively as an individualistic medical problem and the exclusive preserve of university based medical schools and those involved in the education and training of what Finkelstein (1999) referred to as 'professionals allied to medicine' (PAMs). However, as we move ever further into the 21st century there are more disabled students in higher education, more support services for students with particular access needs (Riddell, et al., 2006) and disability is increasingly regarded as a socio/political issue by many social scientists and researchers. Consequentially there is now a burgeoning literature on the complexities of the disablement process from a variety of academic disciplines. These include anthropology (Kohrman, 2005), geography er and Parr, 1999), history (Borsay, 2005), the humanities (Snyder et al., 2003), philosophy (Tremain, 2005) psychology (Goodley and Lawthom, 2005) and sociology (Barnes et al., 1999; Barton et al., 2002).

All of this is due to the politicization of disability by the international disabled people's movement and the subsequent development of an interdisciplinary mode of enquiry known as disability studies rooted in

the social model of disability and sociological insights (Barton, 1996; Barton and Oliver, 1997; Barnes et al., 2002). Despite claims to the contrary (Shakespeare and Watson, 2002; Shakespeare, 2006) the social model of disability is nothing more or less fundamental than a switch away from focusing on the physical or intellectual limitations of particular individuals 'to the way the physical and social environments impose limitations upon certain groups or categories of people' (Oliver, 1981: 28). At the core of these developments lies the protracted interface between disabled activists and the academy, This paper will critically examine this relationship and this particular form of knowledge production in order to further our understanding of disability and the struggle for a more inclusive and equitable society.

Political Engagement and Higher Education

To understand the complexity of the relationship between political engagement and higher education it is important to remember that historically universities have fulfilled two main functions. Besides providing a particular form of advanced education for a certain minority of the population, they have provided the necessary facilities

for a select group of individuals to study a whole range of issues unfettered by the mundane demands of everyday life. Although this frequently abused privilege was reserved almost exclusively for the upper and upper middle classes, some universities, in accordance with their charitable status (sic) provided some form of support through sponsorship and bursaries for those deemed worthy but without (Barnes, 1996). Therefore the academy may be characterized as a locus of quiet conservatism rather than a force for radical social and political change.

However, at specific points in history universities and colleges of higher education have played a pivotal role in the generation and development of revolutionary social forces that have sought to bring about radical political and cultural change. Examples include European universities and the revolutionary movements of the 1840s and 1960s, American campuses and the civil rights and anti-Vietnam war campaigns of the 1960s and 1970s. Finally, the academy played a key role in the Cultural Revolution in the Peoples Republic of China in the 1980s culminating in the massacre at Tianamin Square on the 4th June 1989.

These examples aside, there can be little doubt that for most of its history the academy has been a reactionary rather than a radical political force. However, it has recently been argued that as we move ever further into the twenty first century we are witnessing farreaching changes not just in the role and organization of the university but also in the very nature of knowledge production itself:

'What is occurring today in our post-industrial society is a crisis not only in the structure of authority and in the cognitive structures of society, as was the case a few decades ago, but in the very constitution of knowledge as a result of the extension of democracy into knowledge itself"

(Delanty, 2001: 2).

This is particularly evident in the development of disability studies, which, from the outset, was driven by the insistence by disabled activists and their organisations that their experience be properly incorporated (Germon, 1998). Therefore, this may be understood as

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an extension of democracy into the academic production of knowledge about disability. Accordingly:

'The university in the age of mass education has been a major site for the articulation of democratic and progressive values, for instance of racial equality, human rights, feminism and social democracy'

(Delanty, 2001: 9).

Indeed, the latter half of the last century saw the emergence of new social movements representing women, Black and minority ethnic groups, lesbians and gay men and, latterly, disabled people. Whilst the fortunes and political impact of these movements has varied over time and place, their intellectual heart has often beaten and continues to beat within universities and colleges.

Furthermore, many of those involved in the production of what at the time seemed new and radical ideas worked in universities and colleges. This has certainly been the case with disability studies where there has been a fusion between the everyday struggles of

disabled people and their organizations and the writings of disabled and non-disabled academics. See for example, Albrecht et al., (2001), Barnes, et al., (2002) Shakespeare (2002) Swain et al., (2004) Davis, 2006). The outcome of this symbiotic relationship has been twofold. First, disability studies developed as an academic discipline in its own right based upon the social model of disability and the direct experience of the process of disablement. Second, the links between disabled people, their organizations and disability studies have remained relatively intact.

However, the precise nature of these links is becoming increasingly problematic, as the movement becomes more influential in political circles and therefore more diffuse, and disability studies becomes more popular as a legitimate field of scholarly enquiry. Again, Delanty makes this point in respect of knowledge production generally:

'With....the coming of new politics, the university has become a major site of battles of cultural identity, confrontations which have had major repercussions for the very meaning of

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discipline-based knowledge as well as historically informed canon'

(Delanty, 2001: 4).

Such conflicts have seen disability studies challenge the disciplinary orthodoxies of medicine, sociology and psychology in terms of the legitimacy of the knowledge they have produced about the causes and experience of disablement. Not only that, but the relationship between the disabled people's movement as the producer and transformer of a cohesive understanding of the collective experience of disability, and the academy as the producer and arbiter of all forms of knowledge about impairment and disability has also come under scrutiny. This relationship is explored below.

Disability Studies and Higher Education

In order to understand the complex relationship between universities and the disabled people's movement, it is helpful to consider three different perspectives identified by Finkelstein (1996). The first, the

'inside out' approach, may be linked to feminism and the women's movement and is clustered around the assertion that the personal is political (Morris, 1991). It argues that direct experience of a phenomenon is essential not only to facilitate an understanding of such experiences; but also for developing an appropriate political response. In some of the more extreme versions it is suggested that only those with direct experience are entitled to speak about it: only women can speak about women's experiences, black people can speak about the black experience, disabled people the experience of disablement and so on.

As a consequence, the British disabled people's movement includes some groups comprised solely of people with accredited impairments, both as individual members and as salaried employees. Others take slightly different positions in respect of what are often referred to as non-disabled allies. Some will not admit non-disabled people as members but will employ them as staff and other groups will admit non-disabled people to all areas of the organization, as long as disabled people remain in control (Barnes and Mercer, 2006). In sum, there is no one universal position on how the relationship between

experience and the movement should be constructed. The same is true of the way in which disability studies is taught and researched within the university. The relationship between experience and scholarship is constructed differently between different universities and the individuals and groups concerned (Gordon and Rosenblum, 2001; Albrecht et al., 2001; Barnes et al., 2002; Shakespeare, 2002; Davis, 2006).

For my part, there are a number of problems with the inside out approach. To begin with, it can take a position of exclusivity that can result in the marginalization of the group concerned. Most groups recognize this and while they may have a separatist element or wing, they nonetheless attempt to build relationships with the rest of the world. Additionally, as noted above, the inside out approach ultimately reduces experience entirely to the individual level rendering the prospect of producing meaningful analyses based on collective insights almost impossible. Finally, positions based exclusively on direct experience can often come across as special pleading - leading to the kind of experience based work which has been characterized as the 'true confessions brigade'; namely,

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'Those intent on writing about themselves rather than engaging in serious political analysis of a society that is inherently

disabling'

(Barnes, 1998: 146).

Finkelstein's second approach is the 'outside in' standpoint. This

emerged from some groups of disabled people themselves, partly

because of the way in which personal experience is often over-

privileged and over sentimentalized. A staunch critic of this approach

Finkelstein has recently stated:

'The political and cultural vision inspired by the new focus on

dismantling the real disabling barriers 'out there' has been

progressively eroded and turned inward into contemplative and

abstract concerns about the subjective experiences of the

disabling world'

(Finkelstein, 1996: 34).

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Advocates of the outside in perspective do not deny the importance of direct experience but argue that by itself it falls far short of what is required. In this context Finkelstein argues that while the direct experience of disabling barriers (inside) is important, it has to be located within a coherent political analysis (outside) of why these barriers exist in order to find ways with which to facilitate their eradication. This is why the relationship between the disabled people's movement and higher education is important; whilst the movement can provide direct experience, academics working from a disability studies perspective can provide a logical and consistent political analysis. Therefore, what is at stake is not whether such a relationship should be constituted but how it should be constituted and maintained.

Nonetheless, this position is not without its critics. Thomas (1999: 2004), for example, has recently argued that this perspective fails to take account of the achievements of groups like the women's movement who have rooted the bulk of their activities in the personal as political standpoint. Further, she suggests that it is structured upon an erroneous and naive separation of the private and public spheres

that is no longer tenable in the post-modern world of the twenty-first century. Finally, she suggests that the solution to this problem is to write oneself into the picture; that is to be explicit about the relationship between subjective experience (inside) and objective action in the wider world (outside).

The third approach is that of 'outside out' and is the one favoured by most accredited experts of all kinds including academics. It has its origins in the nineteenth century and the development of positivism as a worldview. Central to this is the assertion that the social world can only be properly understood through the application of the principles of rational thought and the natural sciences (Giddens, 2006) and not by building upon personal experience as the two previous positions discussed would suggest. The outside out position has been instrumental in sustaining the ethos and high status of the academy throughout its existence. Inevitably therefore most universities and colleges have sought to construct themselves as organizations devoted almost exclusively to the production of value free knowledge. However, in recent years this approach has increasingly come under attack. In response, many academic

institutions and subject disciplines especially within the social sciences are now trying to incorporate direct experience into their work (Truman et al., 2000).

However, in many respects these attempts seek to justify and sustain the position of those associated with institutions of higher education as the ultimate arbiters of what counts for meaningful knowledge. An influential example is the recent work of Martin Hammersley (1995: 2000). Who, while providing a detailed analysis of research based upon the other two positions, suggests that ultimately, it is the role of the academic researcher to produce knowledge through the reliance and use of objective research procedures. A further example is that of Dyson who 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 the insider and outsider positions (Dyson, 1999).

Perhaps unsurprisingly the outside out standpoint also gives rise to a number of problems, not least that this is precisely the role that universities and colleges have assigned themselves for most of their

history. This, as already mentioned, is one of reaction and conservatism. Moreover, some recent attempts to take lay experience seriously by some academics and researchers have reproduced in a less radical form the work, ideas and experience of others and therefore are prone to accusations of colonization. For this reason it is argued that attempts to build meaningful working and fruitful relationships between the universities and disabled people and their organizations based on the outside out position should be treated with the utmost caution (Barnes et al., 2002).

Higher Education and Post-modernity

The above analysis suggests that the orthodoxy of the outside out position is no longer tenable. There are several reasons for this. First, in the post-modern world of the twenty first century the generation of knowledge is becoming much more diffused throughout society.

Consequently, the university is no longer the only or even the most important producer of what counts as useful or meaningful knowledge (Castells, 1996). Second, the traditional symbiosis between the state and higher education is more fragile than it once was. This is

especially evident with the increasing encroachment of market forces into university life. Finally, the rise of new social movements over recent years has precipitated a growing challenge to the right of academics to decide what counts as useful and meaningful knowledge. Hence, the primary function of the academy in the new millennium is to enhance its role in the public sphere in order to facilitate the effective democratisation of knowledge.

Furthermore:

'In organized modernity the university was important in shaping social citizenship; today it has the additional task of cultivating technological and cultural forms of citizenship'

(Delanty, 2001: 10).

In light of the above, it may be suggested that until recently,

The university has contributed relatively little in terms of nurturing our
understanding of social citizenship for disabled people and, therefore,
we cannot be confident that it will perform adequately the extra task
of nurturing our perceptions of technological and cultural citizenship
in the future.

However, as indicated earlier, the emergence of disability studies and the growing interest in the socio/cultural dynamics of the process of disablement by social scientists generally gives cause for cautious optimism. Indeed, our knowledge and understanding of the complexity of the experience of disability has been greatly enhanced by the symbiotic relationship between disabled people and universities whether that relationship has been constructed from an outside in or an inside out position (Barnes et al., 2002)..

Given the increased interest in disability in universities, it is likely that as the body of knowledge concerning disablement grows it will in turn help facilitate the further inclusion of disabled people into the mainstream of society. All of which, of course, is dependent upon the links between the disabled people's movement and the academy remaining in tact, and being allowed to flourish. This is especially important because although a disability studies perspective is increasingly prevalent within the social sciences, little is known of its influence on other disciplines essential to the facilitation of a more

inclusive society. Examples include architectural studies, civil engineering and transport studies.

However, whether this is possible is less certain due to the rapidly changing conditions of post-modern society and growing concerns over the future of the disabled people's movement. These concerns are the result of several factors. Notably, these include the insidious colonization and professionalisation of disability politics by non-representative organizations controlled and run by non-disabled people, especially since the late 1990s, and the ongoing lack of investment by local and national governments in grass roots and national representative organizations controlled and run by disabled people themselves (Oliver and Barnes, 2006).

Higher Education and a Disability Studies Perspective

There is little doubt therefore that if the links between universities and the disabled community are to continue to be mutually beneficial then academics and researchers must be actively involved with disabled people and their organizations on a continuous basis. Yet the

intensifying marketization and bureaucratisation of academic life means that establishing and maintaining protracted involvement with grass roots organizations is increasingly arduous. The growing influence of policies clustered around the rhetoric of economic rationality within institutions of higher education is of major concern. Since the mid 1990s there has been a heightened emphasis on economic viability, fiscal relevance, and competition within and between universities that have their roots in business interests and thinking. This has contributed to the growing significance of assessment-led learning and the vocationalizing of scholarship. Managerial strategies have emerged that have little sympathy for the development of meaningful critical theory and political analyses that challenge established thinking and values. In a recent discussion of the impact of globalization and market priorities on academic activities, Simon (2001) maintains that such forces have brought into serious question the very nature of what constitutes critical thought in university life. The extent to which we can still talk of the transformative capacity of intellectual endeavour is one that needs urgent and serious consideration.

All of which has particular relevance to disability studies in terms of the dangers of being incorporated into these burgeoning institutional processes and demands. From the 1980s onwards there has been a systematic de-radicalization of much that now passes for mainstream sociology, and even the transformative potential of specific disciplines, such as gender studies and race and ethnicity studies, for example, is now being called into question (Hooks, 1984; Sheldon, 1999). Similarly, exponents of a disability studies perspective need to be wary of a similar fate, as they have already attracted their fair share of criticism from disability activists in America (Linton, 1998) and in the UK (GMCDP, 2000).

Furthermore, the combination of heightened teaching, research and administrative responsibilities in most universities and colleges means that, all too often, academics and researchers have little time to be actively involved in 'non-academic' activities such as attending local group meetings on a regular basis, for example. Additionally, academics generally have been perceived as part of the problem rather than the solution by many activists within the disabled people's movement. Consequently, many organizations have neither the

inclination nor the resources to support meaningful academic involvement. The situation is exacerbated still further by the growing sense of 'research fatigue' amongst disabled people and their organizations as a direct result of the increased attention paid to them by academics and researchers over recent years (Barnes and Mercer, 2006).

Nonetheless universities and colleges are likely to remain the seedbeds for tomorrow's politicians and policy makers. Therefore, it is important that disabled people's perspectives are properly represented within the academy. However, recent research suggests that whilst there has been an increase in the numbers of disabled students in higher education, those who have benefited the most are already the most socially advantaged. Disabled students are more likely to come from upper/middle class backgrounds and are less likely to be members of minority ethnic groupings. The majority are male and tend to be slightly older than non-disabled peers. Particular types of impairment predominate including dyslexia and 'hidden' impairments such as epilepsy and diabetes. Equally important most disabled students are reluctant to adopt a disabled identity and only a small minority are aware of disability politics and the disabled people's movement. Moreover, although all universities and colleges of higher education now have a dedicated disability services unit, the rhetoric of support is rarely matched by the reality of provision. In old universities particularly, learning support is something of a novelty and many lecturers are reluctant to accept the fact that it is both justifiable and necessary to provide additional help and devise alternative modes of assessment for students with particular access or communication needs (Riddell et al., 2006).

Additionally, as disability studies perspectives become more mainstream, the more attention they are likely to attract from scholars of the 'outside out' persuasion; many of whom, for a variety of reasons, see their primary role as problematizing that which need not necessarily be problematic (see for example, Corker and Shakespeare, 2002). Hence, those working within a disability studies framework are inevitably drawn into seemingly evermore complex and tedious debates that become in many ways almost unrecognizable to those without some form of formal academic training. This is a major problem for many disabled people as they

have only a limited access to education and higher education in particular (Hurst, 1998; PMSU, 2005; Riddell et al., 2006).

Whilst this intensification of scholarly debate may be viewed in a positive light, as it heightens the level of knowledge production both inside and outside the university, it poses particular problems for those of us struggling to communicate effectively with both the disabled and academic communities. For instance, Mercer (2002) reports that researchers have raised several important issues when trying to balance the demands of a user led 'emancipatory' disability research agenda with those of the academy.

Besides re-enforcing the cultural divide between academics and the general public, these considerations can effectively neutralize the political implications of a disability studies perspective, in much the same way that feminism has been effectively neutralised within British and American universities over the last couple of decades.

It is worth noting too that the status and income generally associated with university life has the added risk of seducing academics into thinking that their views are more important than they really are.

Here, it is useful to remember that one definition of the word 'academic' is 'of theoretical interest only, with no practical application'. If this is what a disability studies perspective is to represent then we have failed those who provided the intellectual foundations for its development: disabled people and their organisations.

Discussion and Conclusion

Given the above analysis the extent to which academics can continue to be effective in building collaborative relationships between disabled people and higher education is open to question. From an academic standpoint, the work produced is often uneven in both quality and impact. Also, the fulfilment of 'emancipatory principles' are not easily demonstrable in much of the research already produced (Stone and Priestley, 1996). However, as has been suggested elsewhere, these are ideals towards which we should be aspiring, and which are, and should be, subject to change during the ongoing process of engagement (Barnes, et al., 2002). Yet the initiation and maintenance of an ongoing and positive dialogue with disabled people, both at the individual and collective levels, is fraught with difficulty. Building

mutually beneficial relations with disabled scholars is one thing, achieving them with grass roots disability activists or disabled people with little or no interest in disability issues and concerns is a far more difficult proposition.

Indeed, one of the greatest difficulties concerns the growing dilemma emanating from the demands and tensions of writing for both an academic and a lay audience as It involves issues of accessibility, values, purpose of writing, and the regulatory influence of scholarship and the academic role. The peer review process in particular, the results of which involve status and money at an individual, departmental and university level, means that we are in constant danger of justifying that which we seek to critique. Within the academic community this is a divisive process (see, for example, Barnes, 1996: Bury, 1996: Shakespeare, 1996). Such considerations can only serve to exacerbate the fragile relationship between representatives of the academic and non-academic communities. Hitherto, the links between universities and disabled activists and representative grassroots and national organisations has been due to the activities of a small group of committed individuals from within

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and without the academy. Hence channels of communication and accountability remain problematic and precarious. Therefore:

There is a need to develop a meaningful structure for debate and analysis which brings together academics and activists, which reflects a wide range of perspectives and which is open and accountable to the wider movement. Inevitably this will involve us in discussions about *how* we facilitate debate which is encouraging and supportive whilst also providing opportunity to develop, to learn, to challenge and to disagree. This will mean creating different fora and using different media and engaging in sustained development work'

(Germon, 1998: 254).

In order to achieve this formidable but desirable goal a disability studies perspective must continue to support and develop the outside in approach to disability scholarship and research. Failure to do so will almost certainly result in the severance of established links between the disabled community and higher education.

There can be little doubt that this would be the opposite of what is needed in the struggle for a more equitable and just society.

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