A Working Social Model?

Disability and Work in the 21st Century

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Introduction

There is little doubt that during the latter half of the twentieth century our understanding of disability and the complex process of disablement have been transformed. Since the emergence of the international disabled people's movement in the late 1960s, traditional individualistic medical explanations for the various economic and social deprivations encountered by disabled people and their families have gradually given way to a more socio/political account widely referred to as the 'social model of disability'. In contrast to the earlier more orthodox views the social model centres on environmental and cultural factors as the primary cause of disabled people's marginalisation. Of particular concern for disabled people and their organizations has been the systematic exclusion of people with accredited impairments from the world of work (UPIAS, 1976; Finkelstein, 1980; Oliver, 1990; Barnes, 1991; Abberley, 1996, 1997).

This paper will explore and evaluate the relationship between the social model of disability, work and politics. It will be argued that within a social model framework the concepts disability and work are inextricably linked, that recent policy developments in the employment field can have only a limited impact on the employment problems of disabled people, that meaningful change is possible only through a radical reformulation of the meaning of work, and that the foundations for this reformulation have already been laid.

Work and the Social Model of Disability

In contrast to recent suggestions to the contrary (Barnes, H *et al*., 1998), the relationship between disabled people and employment has been a central concern of the disabled people's movement and advocates of the social model of disability since its inception way back in the 1970s. For example, when formulating the 'Fundamental Principles of Disability' (1976), the Union of the Physically Impaired Against Segregation (UPIAS) stated that:

> 'In the final analysis the particular form of poverty principally associated with physical impairment is caused by our ***exclusion from the ability to earn a living on a par with our able bodied peers due to the way employment is organized***. This exclusion is linked with our exclusion from participation in the social activities and provisions that make general employment possible' (UPIAS, 1976; 14 (emphasis added)).

This insight has provided the stimulus for the development of the social model of disability and a variety of studies which centre on the way society is organized to the detriment of people with perceived impairments and their families. It is notable here that although the UPIAS were concerned primarily with people with physical conditions, subsequent analyses were extended to include all forms of perceived impairment regardless of cause. This was:

'in recognition of the fact that all physical conditions have psychological implications and that all intellectual impairments have physiological consequences. Also, those labels are generally imposed rather than chosen and that they are politically and socially divisive (Barnes, 1999; 577).

It is important to remember too what is actually meant by the social model of disability. Mike Oliver first coined the phrase in 1983 to reflect the growing demand by disabled people and their allies for:

'nothing more fundamental than a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environments impose limitations on certain groups or categories of people' (Oliver, 1983; 23).

Since then both activists and writers from within and without the disabled people's movement have written much about the social model. The result has been that the social model has been a, if not the, major catalyst for the increasing politicization of large numbers of disabled people and their allies throughout the world (Hasler, 1993; Campbell and Oliver, 1996; Charlton, 1998). It has also provided a firm foundation for the development of a fully formed 'materialist' account of the social creation of disability in the modern world (Oliver, 1990) as well as a workable analytical framework with which to understand and explain the particular

type of institutional discrimination encountered by people labeled 'disabled' because of perceived impairment (Barnes, 1991).

Inevitably, these developments have had an increasingly important influence on social policy at both the national and international levels. For example, many countries including Britain now have some form of anti-discrimination legislation to protect people with accredited impairments from unequal treatment (Doyle, 1995; Oliver and Barnes, 1998). Moreover, the World Health Organization's (WHO) revised definition of disablement, commonly known as ICIDH2, has attempted to incorporate several key elements of the social model analysis of disability (Finkelstein, 1998; WHO, 1999)

However, despite this success, or perhaps because of it, the social model is not without its detractors. Misinterpretation by some disability activists has led to claims that the social model precludes discussions of impairment, the importance of 'medical' treatments, and ignores questions of gender, minority ethnic status, sexuality, class and so on. Furthermore, recent developments within the 'academy' have given rise to a rejection of 'grand theorizing' reminiscent of that, which permeated the social sciences during the 1960s. Hence, the tendency for 'post' theorizing, whether it be termed 'postmodernist', 'post-structuralist' or 'post-fordist' and calls the renewed emphasis on personal narratives and experience (see for example, Hughes and Paterson, 1997; Wendell, 1997; Corker

and French, 1999; Shakespeare, 1997), and the analysis of the role of impairment in the process of disablement (Shakespeare, 1999).

Here the social world is somehow reconstructed or rectified to accommodate a potentially endless variety of competing and ever-changing discourses, which tend to ignore or play down the very materiality of disabled people's lives. The end result is the clouding of the meaning of 'disability' as defined by the disabled people's movement and, most importantly, its impact on disabled people's lives; whether it be economic, political or social (Oliver and Barnes, 1998; Finkelstein, 1999).

Such approaches also tend to sidestep the contention those bodily differences, whether physical, sensory or intellectual, are materially shaped by the complex interaction between biological and social forces and processes. They overlook the contention that perceptions of impairment are culturally created in the same way as perceptions of gender, race, sexuality and so on, and that these perceptions vary with reference to time and place; a point made forcefully by a disabled writer, Paul Abberley, more than a decade ago (Abberley, 1987) and later developed by, amongst others, the Australian geographer Brendan Gleeson (1999). Equally importantly, they also fail to address the substantive body of work on the experience of 'chronic illness' produced be medical sociologists (Barnes and Mercer, 1996).

From a social model or materialist perspective then, perceptions of impairment and disability are inextricably linked to the 'mode of production' or the social organization of work. Consequently, there are several important points to be made about a social model analysis of work. One, it does not automatically mean that individually based interventions, whether they be medically, re/habilitative, educational or employment based, are of no value or always counter-productive. Two, it signifies a concerted attempt to shift attention away from the real or imagined functional limitations of individuals with perceived impairments and onto the difficulties caused by disabling environments both physical and social. Three, it rejects the notion that unemployment and underemployment among disabled workers can be understood in isolation from other factors such as education, transport, the built environment, access, ideology and culture. Finally, it recognizes that within the present context, policy developments in the employment field can have only a limited impact on the employment problems of disabled people and that, as a consequence, meaningful change is only likely through a radical reformulation of the meaning of and the organization of work.

Work, disability and policy?

There is universal agreement that disabled people are disproportionately disadvantaged in the current labour market. Various estimates from both official and unofficial sources suggest that people with accredited impairments are substantially more

likely to be unemployed and/or underemployed than contemporaries without perceived impairments, and that these disadvantages are not simply due to the functional limitations of individuals (Lonsdale 1986; Barnes, 1991; Hyde, 1995; 2000; Barnes, H. *et al*., 1998). Within the UK and, indeed, much of western society since at least the eighteenth century, the meaning of work has been organized around a particular set of values and principles; namely, the pursuit and maximization of profit, waged labour, and competition between individual workers. All of which effectively disadvantage or *disable* people with any form of perceived functional limitation/impairment, whether physical, sensory or intellectual, and the more overt the limitation/impairment the more severe the disadvantage or *disability*.

However, there is growing evidence that it has not always been like this (Albrecht, 1992; Davis, 1996; Gleeson, 1999), and that when work is organized around a different set of principles such as social necessity, obligation and interdependence, for example, people with accredited impairments can be included in rather than excluded from the workplace. It is notable to recall here that during the 1939/45 conflict nearly half a million hitherto 'disabled' workers were drafted into the labour force at various levels in aid of the war effort (Lonsdale, 1986; Humphries and Gordon 1992), and that immediately following the cessation of hostilities considerable Government effort was put into maintaining this situation due to the 'social obligation' (Thornton and Lunt, 1995)

felt towards these workers and to those who were injured as a consequence of war. Subsequently, of course, Government priorities changed and so did their labour market policies. Clearly then, as with perceptions of disability, the meaning and organization of work is a social creation, and like all social creations it is subject to change.

Moreover, many commentators are increasingly suggesting that the meaning and organization of work is currently undergoing major changes; changes which are as fundamental as those which occurred with the coming of the industrial revolution. The intensifying globalization of the world economy along with unprecedented technological development during the post 1945 period has meant that many western societies, including Britain, have shifted from what Wolf Wolfensberger (1989) termed 'a primary production' to a 'post primary production' economy. In other words, agricultural and manufacturing industries have given way to human services as the principal source of economic activity and employment. Indeed, for Manuel Castells (1996) this shift is as significant as industrialization. He terms this 'revolution' informationalisation, to reflect the new forms of production and power that have emerged in the last decades of the twentieth century.

Furthermore, it is often argued that this new 'mode of production' offers new employment possibilities for those who, hitherto, may have been excluded and labeled disabled (Cornes, 1991; Friedman,

1993; Barnes, H. *et al*., 1998). But it is important to remember here that, historically, access to technology has never been spread evenly throughout the population - disabled or otherwise, and that although information may have taken on a value rivaling that of the material products of industrialization, questions of ownership and control remain as relevant today as they ever were (Castells, 1996; Sapey, 2000). Alan Roulstone (1998) has distinguished between the different sectors of employment through his separation of 'computer workers' and 'technology users' in order to differentiate new from old forms of work and their implications for disabled people; in short, information technology is both enabling and disabling.

All of which serves to underline the fact that whilst new technology, deregulation and more flexible production techniques may prove enabling to some, to others they will almost certainly mean worsening social isolation, and new and enhanced forms of exclusion. Indeed, whereas in the nineteenth, and most of the twentieth, century an 'able body' was an essential prerequisite for inclusion in the workforce and a 'non-disabled status', so in the brave new world of the twenty first century an 'able mind may be far more important' (Barnes, *et al*., 1999; 225). In such circumstances the consequences for people viewed and labeled either 'with learning difficulties' or 'mentally ill', groups who are already disproportionately disadvantaged within the disabled community, are decidedly bleak.

It is essential, therefore, to remember that if people with accredited impairments are to access some of the 'benefits' of these post-industrial developments, then it is crucial that governments take a more committed and interventionist stance on the operation of the labour market.

Certainly, it is the case that over recent years politicians and policy makers have adopted the language of inclusion, and posited what at first glance may seem like social model solutions to the problems associated with disability in the workplace. The rhetoric surrounding the introduction of the 1995 Disability Discrimination Act (DDA), the setting up of the 'Disability Task Force', the development of the 'New Deal' programme, and the recent proposed benefit changes provide a wealth of examples (see for example MacAskill, 1999).

But for politicians and policy maker's rhetoric rarely accords with reality (Barnes and Oliver, 1996). Hence policies relating to the employment and underemployment of disabled people remain focused almost exclusively on the supply rather than the demand side of labour. As a consequence, strategies which target and highlight the functional limitations of individuals with perceived impairments are prioritized and supported at the expense of those which draw attention to and, therefore, implicitly if not explicitly, seek to resolve the stark inequalities of the social organization of work. In many ways the rhetoric has changed but, on the whole, the policies have not.

The recently introduced 'New Deal for Disabled People', for example, is targeted at people in receipt of disability benefits such as 'Incapacity Benefit' and 'Severe Disablement Allowance'. The programme includes a 'Personal Adviser Service' to help disabled people and 'those with a long term illness to overcome barriers to work'; various 'Innovative Schemes' to explore how to help disabled workers move into or stay in work; an 'Information Campaign' to improve knowledge of current employment services and to change attitudes of 'benefit recipients, employers and the public and a programme of research and evaluation' (New Deal, 1999; 1). There is a wealth of evidence to show that similar policies have existed in a variety of guises throughout the post 1945 period and that they represent nothing less than 'fifty years of failure' (Hyde, 1995).

Moreover, the coming of the 1995 Disability Discrimination Act (DDA) has done little to resolve the situation. The Act is based on the orthodox view of disability: impairment is the cause of disablement rather than the way society is organized. Hence, the idea that disabled peoples' legitimate requests for adjustments and change are considered somehow unrealistic and unnecessary is retained. The law provides only limited protection from direct discrimination in employment, the provision of goods and services, and in the selling or letting of land.

Protection is limited because, as in all employment discrimination legislation, the onus is put firmly on the individual to prove that discrimination has taken place. But unlike other disadvantaged groups such as women and people from minority ethnic groups, for example, before they can begin the process of litigation the disabled worker must first demonstrate to an Employment Tribunal that they are in fact 'disabled' under the terms of the Act. Failure to do so means that a case cannot be brought. To date, most of the cases are withdrawn or settled before a full tribunal hearing, seventy four per cent, while a further ten per cent are dismissed (Meagre, *et al*., 1999). The overwhelming majority of employers, over 90 per cent, are not even covered by the Act and those that are can easily claim exemption if they can demonstrate that compliance would damage their business (Gooding, 1996). It is noteworthy too that evidence from the USA suggests that since the introduction of anti-discrimination legislation: the 1990 Americans with Disabilities Act, unemployment among disabled Americans has actually increased rather than decreased (Charlton, 1998).

Furthermore, until recently there was no enforcement mechanism with which to monitor and police the Act. This was in stark contrast to the situation in America and other UK anti-discrimination legislation such as the 1975 Sex Discrimination Act (SDA) with its Equal Opportunities Commission (EOC) and the 1976 Race Relations Act (RRA) and the Commission for Racial Equality (CRE). But the effectiveness of these bodies has been very limited. Indeed, sexism, heterosexism and racism are as

evident today as they were in the 1970s. A key factor in explaining the relative failure of the SDA and the RRA is the semi-autonomous status of the EOC and the CRE. Although 'independent', funding and appointments are controlled by politicians and policy makers. Consequently successive unsympathetic governments have been able to coerce both organizations into concentrating the bulk of their activities on 'education and research' rather than enforcement (Gregory, 1987).

After intense lobbying from a variety of sources Tony Blair's Government established the Disability Rights Commission (DRC). It began operations in April 2000 and will 'work towards the elimination of discrimination against disabled people'. Chaired by Bert Massie, previously the Chairperson of the Government sponsored Royal Association of Disability and Rehabilitation (RADAR), the UK's largest disability organization controlled and run by non-disabled people the DRC has fifteen commissioners including representatives of employers organizations. The DRC has the power to take up cases on behalf of individuals and organizations. But early indications suggest that, like the EOC and the RRA, its main functions will include the production of new codes of practice, the updating of existing ones, the provision of information and advice for 'employers, businesses, service providers and disabled people', conciliation, and to 'conduct research' (Wilkinson, 1999; 12).

Given the nature and extent of the discrimination encountered by disabled people there is little here to suggest that the DRC will be any more successful than its contemporaries for gender and race.

To work or not to work?

There is little doubt; therefore, that without a further reformulation of the meaning and organization of work large sections of the population labeled 'disabled' will almost certainly remain disproportionately disadvantaged in the British labour market. Indeed, to some extent the foundations for these changes have already been established.

Moreover, the present Government's avowed commitment to getting more people with accredited impairments into employment through 'welfare to work' type schemes and the development of more flexible and less demeaning 'benefit' systems is, in broad terms, commensurate with the on going demands of the disabled people's movement. But in many ways these policies are not really new and their impact will be significantly tempered by the fact that, as yet, politicians have been reluctant to tackle the very real environmental and social barriers disabled people encounter within the world of work.

Unfortunately, inaccessible built environments, transport, and communication systems remain major obstacles for disabled people wishing to enter the world of work. Equally important, if

people with perceived impairments are to be encouraged into paid employment then work must be made more socially and financially rewarding. All too often the type of jobs offered to disabled people are low status, low waged occupations with poor working conditions and few opportunities for advancement. The new 'tax credit' scheme for disabled workers and the introduction of the minimum wage may be seen as a partial recognition of this problem. If developed further these and similar solutions would go some way in addressing the 'distribution dilemma' that has plagued western social policy throughout history (Stone, 1984).

It should be remembered at this point that government intervention in the way the labour market operates is not new; nor is it confined to policies for disabled people. Since at least the industrial revolution successive governments have played a major role in structuring and restructuring the labour market through grants and tax concessions for industrialists and employers in order to generate and sustain economic growth and maintain political stability. With regard to the employment of so called disabled people, as noted earlier, various 'demand side' initiatives were implemented during and immediately following the 1939/45 war to include this section of the workforce in the world of work. Examples include the Employment Quota Scheme, reserved occupations and sheltered workshops. There is general agreement too that such policies are effective when supported by committed and responsible Governments (Thornton *et al.,* 1997; Roulstone, 1998; Hyde, 2000).

If the present Government is serious about getting disabled people into work then similar policies might be reintroduced and strengthened. Additionally, they could set targets for all Government departments and state organizations to achieve in respect of employing disadvantaged workers, including organizations such as the health service, local authorities, universities and so on. Further, in its dealings with the private sector it could use similar targets to enforce contract compliance. Finally, it could switch the grants it gives to the voluntary sector to organizations controlled and run by disabled people whose record in employing people with perceived impairments puts the traditional voluntary sector to shame (Oliver and Barnes, 1998). Indeed, the British Council of Disabled People's National Centre for Independent Living and the overwhelming majority of the growing network of Centres for Independent/Integrated Living employ only disabled workers (Barnes *et al.,* 2000).

With careful implementation such a strategy would not detract from the effectiveness of the organizations involved or, indeed, the overall performance of the economy. There is substantial evidence that given a supportive environment many workers with perceived impairments are just as economically productive as 'able bodied/minded' peers (Kettle, 1979; Prescott-Clarke, 1990; Roulstone, 1998; Simons, 1998). Additionally, removing large numbers of people from the state benefit system would reduce public spending; something which both policy makers and the overwhelming majority of the disabled workforce appear to want.

It is important to point out here that this is not to suggest that *everyone* with an accredited impairment can or should be expected to work at the same pace as 'non disabled' contemporaries or that all disabled people can or should work in the conventional sense. To expect people with 'severe' or multiple and complex impairments to be as 'productive' as non-disabled peers is one of the most oppressive aspects of modern society.

Indeed, as noted above, work is a social creation; what is considered work at one point in time may not be perceived as such in another. Moreover, to radically reconceptualise the meaning of work beyond the rigid confines of waged labour is not unprecedented in the modern context. For instance, in their attempt to assert the role of women in a predominantly patriarchal society, the women's movement has successfully redefined the meaning of work to include housework and childcare. Furthermore, growing evidence suggests that because of the difficulties encountered when trying to balance the requirements of parenthood with those of the workplace, a situation which is especially problematic for those at the foot of the class system, many women are now beginning to seriously question the organization of the modern labour market. As long ago as 1983 Angela Philips pointed out:

> 'It was having a baby which.... brought home to me with real force the hopelessly unbalanced nature of a society which is

organized solely for the people without a responsibility for children' (cited in Philips, 2000; 2).

She calls for far more flexibility in the workplace and the introduction of policies designed to address the very real financial and practical needs of both women and men who, at present, are often seriously economically and socially disadvantaged if they choose to become parents (Philips, 2000).

Similar arguments are commensurate with a social model analysis of the oppression of disabled people within late capitalist society. After all such an approach constitutes more than simply a reaction to existing inequalities, it warrants a systematic and considered attempt to challenge and overturn the ideologies and cultural values upon which those inequalities are based.

Since the emergence of the disabled people's movement, the idea of 'independent' living, and disability arts and culture, the concept of a 'disabled identity' has taken on a whole new meaning, which in many ways serves to undermine traditional assumptions about disability and work. The idea of 'independent' living is not about independence in the conventional sense; it is really about 'interdependence'. Of course, historically, independence has been linked to perceptions of 'normality', and 'dependence' with 'abnormality', accredited impairment and 'disability'. As a consequence, modern society is increasingly geared to the presumed needs of a mythical 'able bodied/minded' majority and

those unable to conform are penalized accordingly, both economically and socially. All of which ignores the fact that ***all*** human beings are, if only by necessity, ***interdependent***. There is no qualitative difference between disabled and non-disabled people with respect to basic human needs. People with accredited impairments have the same needs as everyone else in terms of health care, education, housing and so on. Moreover, in the UK, as in much of the contemporary world, wealthy people depend on others to perform many of the basic tasks of everyday living and, it is generally the case, that the more wealthy they become the greater their dependence on others. Yet they are perceived as 'independent' only because they have the resources with which to exercise control. The struggle for 'independent' living, therefore, is about equal access to health care, educational, housing etc., and also about the struggle for resources and control.

One element of this struggle was the recent and successful campaign for the introduction of 'direct' and 'indirect' payment schemes to enable disabled individuals to employ 'personal assistants' to do the every day tasks they are unable to do themselves. The coming of such schemes, with the setting up in 1987 of the Independent Living Fund (ILF) and, more recently, the passing of the 1996 Community Care (Direct Payments) Act, has meant that many people with perceived 'severe' impairments, although 'unemployed' themselves, are now engaged in the employment of others. Many personal assistance users employ as many as five or six people over the course of a week. Besides

generating employment for others, running such schemes involves effort, skill and responsibility. Surely in any other context such activity would be regarded as work?

Moreover, the recent unprecedented expansion of user led involvement in the development and delivery of these and other services has also meant that more and more disabled people now spend their 'free' time actively involved in service provision of one form or another. Furthermore, the coming of the disability arts movement has precipitated the generation of a whole range of cultural activities involving both disabled and non-disabled individuals which, taken together, constitute meaningful alternatives to the various 'non disabled' cultures which continue to permeate late capitalist society. A positive disabled identity and lifestyle need not and must not be determined by an individual's ability to participate in a labour market constructed around conventional 'able bodied/minded' ideals.

Discussion and implications

All of this may be located within the growing awareness amongst academics and policy makers that the continued development and, therefore, future stability, of a 'western style' economy such as that of Britain is inextricably linked to the complex and ever changing relations between production and consumption (Giddens, 1997; Castells, 1996; Baumann, 1988). This should be coupled with the recognition that, regardless of their role within the 'conventional'

labour market, people with accredited impairments and labeled 'disabled' are both producers and consumers of a vast array of services upon which many so called 'able bodied' people depend; they are, therefore, an essential component within the context of this equation.

Equally important is the realization that many of the issues raised here are not peculiar to the 'disabled' population. Since at least the 1970s both unemployment and underemployment have been common experiences for many other sectors of society. Lone parents, people from minority ethnic communities and workers under twenty-five and over fifty are especially vulnerable. There is ample evidence that, in common with many western type economies, the British labour market is failing to distribute income and wealth to significant minorities other than those labeled 'disabled' (Meadows, 1996).

It is also the case that without radical social change, the intensifying pace of technological development will almost certainly exacerbate the situation further. The problem of how to accept life without paid employment and prepare for 'significant living without work' can no longer be confined to what the Warnock Committee termed 'handicapped people' (Warnock Report, 1978; 33). Furthermore, as the boundaries between what is and what is not considered a socially acceptable condition become evermore blurred, as they most surely will if only because of the changing demography of the UK and recent developments in

genetic medicine, changes which are evident throughout much of the 'western' world, the significance of this realization will become evermore important.

Taken together then these developments make the on going struggle for the widespread rejection of the current inequitable organization and distribution of paid employment, and the call for the meaningful re-evaluation of what is and what is not to be considered work all the more urgent.

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