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Abstract
[Excerpt] This chapter suggests that to overcome the problem of disabled people’s ongoing disadvantage in mainstream employment and, therefore, society, a radical alternative strategy is required that poses a direct challenge to orthodox thinking on work, and associate policies that centre almost exclusively on disabled workers. Building on long standing analyses from within the disability studies literature, it is argued that an holistic approach is needed that includes: a/ the reconfiguration of the meaning of work for disabled people; b/ the de-stigmatisation of associate welfare provision; and c/ that the theoretical and practical foundations for such an approach have already been laid (Abberley 2002: Barnes 2000: 2003: Oliver and Barnes 1998). It begins with an overview of theoretical considerations with reference to the concept of ‘independent living’ for disabled people and the social model of disability. Attention will then centre on the organisation of labour, the reconfiguring of work for disabled people, and its implications for work and welfare in the 21st century.

Keywords
disability, employment, labor, disabled workers, welfare

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‘Work’ is a four letter word?
Disability, Work and Welfare

Colin Barnes

(Invited Presentation’, Working Futures: Policy, Practice and Disabled People’s Employment’ University of Sunderland, Marriot Hotel Seaburn, 3rd December 2003),

Introduction

This chapter suggests that to overcome the problem of disabled people’s ongoing disadvantage in mainstream employment and, therefore, society, a radical alternative strategy is required that poses a direct challenge to orthodox thinking on work, and associate policies that centre almost exclusively on disabled workers. Building on long standing analyses from within the disability studies literature, it is argued that an holistic approach is needed that includes: a/ the reconfiguration of the meaning of work for disabled people; b/ the de-stigmatisation of associate welfare provision; and c/ that the theoretical and practical foundations for such an approach have already been laid (Abberley 2002: Barnes 2000: 2003: Oliver and Barnes 1998). It begins with an overview of theoretical considerations with reference to the concept of ‘independent living’ for disabled people and the social model of disability. Attention will then centre on the organisation of labour, the reconfiguring of work for disabled people, and its implications for work and welfare in the 21st century. .

Theoretical considerations

As the contributions to this book indicate disabled people are disproportionately disadvantaged in the labour market. This is because in western society since at least the eighteenth century, work has been organised around a particular set of values and principles; namely, the pursuit

and maximisation of profit and competition between individual workers. Both 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 impairment the more severe the disadvantage or 'disability' (Barnes 1991: Finkelstein 1980: Gleeson 1999: Hyde 1995: Oliver 1990: Stiker 1998). Hence, in his recent review of work, disability and European social theory Abberley (2002) has, argued that to address the problem of disabled people's exclusion from mainstream society:

> 'We need to develop theoretical perspectives that express the standpoint of disabled people, whose interests are not necessarily served by the standpoint of other social groups, dominant or themselves oppressed, of which disabled people are also members (136).

The thrust of Abberley's argument is based on three main points. First, that the eradication of environmental and cultural barriers associated with capitalism, will not generate a society in which all people with impairments are able to 'work'. Second, that previous social theories; functionalist, Marxist and feminist, cannot provide an appropriate framework for the development of policies that give disabled people equity in terms of either employment or living standards. Third, that paid 'work' need no longer be a key organisational feature of western 'developed' nations in the future.

The theoretical perspectives that reflect the standpoint of disabled people are expressed in the concepts of 'independent living' and the 'social model of disability'.

i. Independent living

The phrase ‘independent living’ first entered the English language in the 1970s following its adoption by disability activists in the USA. What became known as the American ‘Independent Living Movement’ (ILM) emerged partly from within the campus culture of American universities and partly from repeated efforts by disability activists to influence disability legislation. Due to the lack of community based support services for disabled people across the USA, several American universities developed various self-help programmes to enable students with ‘severe’ physical impairments attend mainstream courses. These later evolved into what became known as ‘‘Centres for Independent Living’ (CILs).

These new CILs were self-help organisations exclusively run and controlled by disabled people themselves. In contrast to other professionally dominated provision that focused almost exclusively on medical treatments and therapies within institutional settings, CILs provided a new and innovative range of services designed to enable people with impairments to adopt a lifestyle of their own choosing within, rather than apart from, the local community. Subsequently, these ideas had a considerable impact on disabled people’s organisations and disability policy throughout the world. There are now CILs or similar user controlled organisations providing services and support for disabled people and their families in many countries across the globe (Alonso 2003).

Part of the reason for this unprecedented success is the almost universal appeal of the concept of independent living within western culture. It is apolitical in that it appeals directly to advocates of the politics of the right and of the left, and is political in that the environmental and cultural changes needed to facilitate meaningful independent living for disabled people will benefit everyone regardless of impairment or status.

Early exponents of independent living allied themselves with the ‘radical consumerism’ of the 1960s and 70s. Therefore it has a particular appeal to proponents of the ideological cornerstones of capitalist development such as economic and political freedom, consumer sovereignty, and self-reliance. This realisation prompted some critics to suggest that the philosophy and policies of the ILM favoured only a relatively small section of the disabled population: notably, young intellectually able, middle class white males (Williams, 1983).

However, this is a misrepresentation of what the phrase ‘independent living’ represents. Although they are often characterised as providing services for people with physical impairments only, historically, CILs have struggled to provide services for all sections of the disabled community. Where they have not, this is usually due to limited resources, material and human, and/or entrenched opposition from vested interests within traditional disability service provider organisations (Morgan et al. 2001: Glasby and Littlechild 2002). . .

Furthermore, in view of the dangers of mis-interpretation some disability activists, particularly in the UK, have adopted the terms ‘integrated’ or ‘inclusive’ living rather than the original ‘independent’ living to characterise the philosophy on which their activities are based. Such terms have a far greater appeal to the left of centre elements within Britain’s disabled people’s movement who recognise that humans are by definition ‘social’ beings, and that ***all*** humans, regardless of the degree and nature of impairment, are interdependent and, therefore, that a truly ‘independent’ lifestyle is inconceivable.

From this perspective, the ideologies and practices that justify the systematic oppression of people with

impairments within capitalist society are similar to those that legitimise the oppression of other disadvantaged sections of the populations such as women, minority ethnic groups, lesbians and gay men, and older people. Taken together they represent an increasingly costly and complex barrier to the development of a truly meaningful inclusive representative democracy.

ii. The Social Model of Disability

The social model of disability emerged from within Britain's disabled people's movement. In contrast to previous individual medically based definitions the Union of the Physically Impaired Against Segregation (UPIAS).re-defined 'disability' as something imposed on top of people with impairments lives by a society intolerant of any form of biological flaw (UPIAS 1976). Originally associated with physical conditions this reinterpretation was later expanded to include all impairments: physical, sensory and intellectual, by the wider disabled people's movement: both nationally and internationally (Barnes 1991).

Integral to this re-assessment is the assertion that all physiological conditions have psychological implications and that 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, and that the values and attitudes that generate labels are historically, culturally and situationally variable. Moreover, as the social model is frequently misrepresented in academic circles (see for example Shakespeare and Watson 2002) it is important to remember what it constitutes. A model is what social

scientists call a ‘heuristic device’ or an aid to understanding. Thus:

> ‘A good model can enable us to see something which we do not understand because in the model it can be seen from different viewpoints… it is this multi-dimensioned replica of reality that can trigger insights that we might not otherwise develop’ (Finkelstein 2002: 13).

The social model has been the catalyst for the increasing politicisation of large numbers of disabled people and their allies in the UK (Hasler 1993: Campbell and Oliver, 1996), and 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: Gleeson 1999), as well as a workable analytical framework with which to understand and explain the particular type of institutional discrimination encountered by people labelled 'disabled' because of perceived impairment (Barnes 1991).

In contrast to conventional individualistic medical approaches, the social model 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. It is not a denial of the importance or value of appropriate individually based interventions, whether they be medically, re/habilitative, educational or employment based, but draws attention to their limitations in terms of furthering disabled people’s empowerment and inclusion in a society constructed by ‘non-disabled people’ for ‘non-disabled’ people. It is therefore an holistic approach that explains specific problems experienced by disabled people in terms of the totality of disabling environments and cultures. It is therefore 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 (Oliver, 2004).

Consequently a social model analysis of the labour market raises several important points. One, disabled people's individual and collective disadvantage in the realm of paid employment is linked directly to the social organisation of work. Two, a social model account rejects the notion that unemployment and underemployment amongst disabled workers can be explained in isolation from other factors such as education, transport, the built environment, access, ideology and culture. Three, it recognises that within the present context, policy developments in the employment field can have only a limited impact on the employment problems of disabled people. Finally, that as a consequence of the above, meaningful change is only likely through a radical reformulation of the meaning and the organisation of work (Barnes 2000). .

Disability, work and welfare

There is substantive historical and anthropological evidence that the combination of industrialisation, urbanisation, and associate ideologies: liberal utilitarianism and medicalisation, provided 'scientific' legitimacy for the gradual but intensifying commodification of every day life. Hence, work became almost exclusively associated with wage labour and an employment infrastructure geared to the needs of those capable of engaging in this type of activity, and exclusion for those who could not (Finkelstein 1980: Gleeson 1999: Oliver 1990).

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Nonetheless, when work is organised around a different set of principles, such as social necessity and interdependence, for example, employment becomes less exclusionary. For instance, in Britain during the 1939//45 conflict many hitherto excluded groups such as women

and disabled people were drafted into the labour force at various levels to aid the war effort. 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. Subsequently, government priorities changed and so did their labour market policies. Similar patterns are evident in other western countries such as the USA, for example (Russell 2002). Clearly, as with perceptions of disability, the meaning and organisation of work is a social creation and subject to change (see also Coleridge in this volume).

Moreover, many commentators are now suggesting that the meaning and organisation of work has undergone changes that are as fundamental as those that accompanied Industrialisation. The intensifying globalisation of the world economy along with unprecedented technological development in the post 1945 period has meant that many western societies have shifted from what Wolfensberger (1989) termed 'a primary' to a 'post primary production' economy. In short, agricultural and manufacturing industries have given way to human services as the main source of employment.

More recently, Beck (2000) argues that the traditional work environment and lifelong working, has given way to a much less stable situation in which skills are devalued, jobs lost, and welfare reduced or eliminated. He maintains that to offset the social and political instability that will inevitably ensue, new ideas and models must be developed. The way forward requires democratically organised local, national and trans-national networks of active citizens. Everyone, he maintains, must have the right to be included in a new definition and distribution of work in order to address the threat of large scale social exclusion. This will include movement in and out of paid

employment and forms of self organised artistic, cultural and political ‘civil labour’ involving equal access to comprehensive social protection.

But whilst much is made of the role of active citizens in this and similar analyses, little is said about the role of government, disabled people and/or their organisations. This is important since the experience of work instability and social exclusion has characterised disabled people’s work experiences for much of the last century, and that if this situation is to be resolved government intervention is fundamental. It is important to remember too that government involvement in the way the labour market operates is not new nor is it confined to policies for disabled people. Throughout modern history governments throughout the world have played a major role in structuring and restructuring the labour market through grants and tax concessions for industrialists and employers in order to sustain economic growth and maintain political stability. With regard to the employment of disabled people, as noted earlier, in the UK various 'demand side' initiatives were implemented during and immediately following the 1939/45 war to facilitate their inclusion into the workforce.

Hence, if governments are serious about getting disabled people into paid work then similar policies might be reintroduced. In Britain for example, ministers could set targets for all government departments and state organisations, including the National Health Service, local authorities, universities and so on, to achieve in respect of employing disadvantaged workers, In its dealings with the private sector they could use similar targets to enforce contract compliance. They could also divert the grants they give to the voluntary sector to organisations controlled by disabled people whose record in employing people with perceived impairments puts the traditional

voluntary sector to shame (Calvi 2003: Oliver and Barnes 1998).

Certainly politicians and policy makers have recently 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, 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. But rhetoric rarely accords with reality and policy remains centred largely on the supply rather than the demand side of labour. As a consequence, policies which target and highlight the functional limitations of individuals with perceived impairments are prioritised and supported at the expense of those which draw attention to and seek to resolve the stark inequalities of the social organisation of work (Roulstone 2002: OECD 2003). The rhetoric has changed but, on the whole, the policies have not.

Indeed, the Blair Government's avowed commitment to getting more disabled people 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 remain reluctant to tackle the very real environmental and social barriers disabled people encounter daily. Equally important, if people with perceived impairments are to be encouraged into paid work then employment must be made far 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 'tax credit' scheme for disabled workers and the introduction of the minimum wage may be seen as a partial recognition of this problem. But the impact of such policies in the current work environment is limited. Institutional discrimination against disabled people in British society remains largely unchecked.

Consequently, where legislation exists enforcement must be properly funded and made highly visible; naming and shaming those who act in discriminatory ways. Where legislation is currently being considered, again governments must make the appropriate arrangements to ensure enforcement commissions are properly in place and that individual responsibility is not left to disabled people themselves. It is important to point out here, however, 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 (Oliver and Barnes 1998).

It may be argued of course that this is recognised by government ministers by the use of the phrase ‘work for those who can and security for those who cannot’ (DWP 1998: iii). But in a cultural environment that generally only values and recognises paid employment as the norm, such a phrase fails to address the stigma associated with unemployment and the social and psychological consequences for those excluded from the work-place. Rather it compounds them since it implies that those excluded from employment cannot and do not work. But this is not the case. Therefore to overcome this problem a radical re-appraisal of the meaning of work for disabled people that goes beyond the rigid confines of paid employment is long overdue. With reference to domestic labour, feminists have adopted a similar strategy in their

attempts to assert women's citizenship in a predominantly patriarchal society (Lister 1997). For disabled people, however, this re-conceptualisation must go much further because although many unemployed disabled people, both female and male, do housework, and have childcare, and/or 'caring' responsibilities many do not.

Thus, the re-configuring of work must include the every day tasks that non-disabled people take for granted such as getting out of bed, washing, dressing and so on. This idea is not unprecedented within the social sciences. For example, Corbin and Strauss (1988) identified three types of work associated with 'illness' management: a/ 'illness work' including activities like organising and administering medication, doing physiotherapy etc.; b/ 'everyday work' such as household tasks and interactions with family and professionals; and c/ 'biographical work'. The latter involves strategies that disabled people adopt in order to incorporate impairment into their everyday lives. This might involve developing ways of making sense of their condition and explaining it to others.

Further, disabled people and their organisations have long since recognised that living with impairment in a disabling society involves a great deal of effort and work. This is clearly evident in the various guides and handbooks now available for the recruitment of personal assistants (PAs) to enable people with 'severe' impairments achieve an independent lifestyle. For example, Carl Ford and Richard Shaw (1993), divide the work that PAs might have to do into three distinct but related categories: personal, domestic and social. Personal work might include getting the disabled person out of bed, dressing them, feeding and so on. Domestic work includes things like housework, shopping, cooking. Social tasks could include accompanying the disabled person on social occasions like going out for a meal, to the cinema or the pub. The

point is that all these activities have been defined in one way or another as work.

Notwithstanding that since the emergence of the disabled people's movement, independent living, disability arts and culture, the concept of a 'disabled identity' has taken on a whole new meaning that in many ways challenges traditional assumptions about disability and work. In particular, the disability arts movement has generated of a range of cultural activities involving both disabled and non-disabled individuals which, taken together, constitute a meaningful alternative to the various non disabled cultures which permeate late capitalist society (Finkelstein 1996: Peters 2000).

The development of direct and indirect payment schemes has meant that many disabled people, although technically 'unemployed' themselves, are now employers. Many PA users employ as many as five or six people over the course of a week. Furthermore, the recent expansion of user led involvement in the development and delivery of services has also meant that more and more disabled people spend their 'free' time actively involved in service provision of one form or another. Interestingly, although successive governments since the 1980s have actively sought to encourage service user involvement, none have recognised this type of activity as a meaningful form of work that warrants a suitable financial reward.

A further corollary of these developments is the need for a re-evaluation of disability related benefits and welfare systems within the workings of the economy. Escalating welfare costs are due to a variety of factors: demographic, economic, political and cultural; not least of which is the on going government failure to address the structural barriers to disabled people’s meaningful involvement in the conventional workplace. As a result disability related

premiums and welfare systems are fundamental to societies geared almost exclusively to non-disabled lifestyles. But rather than being viewed as a drain on the national economy they should be considered an indicator of collective social responsibility and social justice. It should also be remembered that disability and related benefits are not passive in the sense that they go straight into the recipient's pockets, they are circulated throughout the economy in terms of generating employment, goods and services. As noted above in the UK and elsewhere increasingly large sections of the workforce are employed in the human service sector. They are therefore dependent on disabled people and other disadvantaged groups for their very livelihood. Rather than stigmatise and penalise those in receipt of disability or related benefits and services, politicians and policy makers should be striving to develop a more equitable and less stigmatising distribution system.

This re-configuration of the concept work should not be construed as an alternative to the on-going struggle for disabled people's participation in the workplace rather it should be seen as complimentary to it. It draws on and is commensurate with disabled people's standpoint, as represented by the philosophy of independent living, and a social model analysis of the oppression of disabled people in late capitalist society. This is because it constitutes more than simply a reaction to existing inequalities, but represents a concerted attempt to challenge and overturn one of the key cultural values upon which those inequalities rest.

Discussion

This discussion may be located within the growing realization amongst academics and policy makers that the continued development and, therefore, future stability, of a

western style economy such as the UK is inextricably linked to the complex and ever changing relations between production and consumption (Bauman 1998). This should be coupled with the recognition that, regardless of their role within the orthodox work environment, disabled people are both producers and consumers of a vast array of services upon which many non-disabled people depend; they are, therefore, a fundamental component within this equation. Moreover, 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 that are evident throughout much of the 'western' world, the significance of this realization will become evermore important.

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