

DISABILITY ACTIVISM AND THE PRICE OF SUCCESS: A BRITISH EXPERIENCE (*)

Colin Barnes

University of Leeds

c.barnes@leeds.ac.uk

Abstract:

To get too close to the Government is to risk incorporation and end up carrying out their proposals rather than ours. To move too far away is to risk marginalisation and eventual demise. To collaborate too eagerly with the organizations for disabled people risks having our agendas taken over by them, and having them presented both to us and to politicians as theirs. To remain aloof risks appearing unrealistic and/or unreasonable, and denies possible access to much needed resources (Barnes and Oliver 1995: 115).

Keywords: Disability, Activism, Policies, Education, Social Movements.

Introduction

Much has changed since the 1960s with regards to social responses to disability and disabled people both in Britain and across the world. Although still common in most countries negative assumptions about the meaning and causes of im-

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pairment, disability and health have been forcefully challenged by various groups of disabled people collectively known as the international disabled people's movement. They have rightly argued that whatever the nature or cause of the impairment, or condition, the main problems faced by people viewed as disabled, or 'with disabilities', stems from disabling environmental, economic and cultural barriers. Disability is therefore an equal rights issue on a par with other forms of unjustifiable discrimination and prejudice such as racism, sexism, heterosexism, and homophobia.

Taken together these developments have had a growing and significant impact on international and national policies for disabled people. This is especially the case in the UK (United Kingdom). The UK has had a particularly vibrant disabled people's movement since the mid 60s, and over the years it has had an increasingly important influence on Government thinking and policy in the disability field. In this presentation I will, first, explain the reinterpretation of disability as a socio/political issue as espoused by disabled people's organisations in the UK, second, explore the subsequent legislative and policy developments and, third discuss their relative impact on disabled people and their organisations. I will suggest that although disability activism has had an important impact on disability policy in the UK, this very success threatens to undermine its continuity and future.

Re-interpreting disability

Although political activism in the UK can be traced back to the nineteenth century and trade unionism amongst particular groups of disabled people it really took hold in the 1960s with the writings of disabled activists and the setting up of the Disablement Incomes Group (DIG). A key contribution was Paul Hunt's edited collection of essays by non-disabled activists entitled *Stigma, The Experience of Disability* (1966). Its contents challenged conventional wisdom regarding the personal 'suffering' experienced by individuals with impairments. The thrust of this challenge is exemplified by Hunt's assertion that:

the problem of disability lies not only in the impairment of function and its effects on us individually, but also, more importantly, in the area of our relationship with 'normal' people (Hunt 1966b: 146).

Clearly a distinction is drawn between the social lives and interests of 'able-bodied' and disabled people. The latter are 'set apart from the ordinary' because

they pose a direct ‘challenge’ to commonly held social values as they are perceived; ‘as unfortunate, useless, different, oppressed and sick’ (p. 146).

The DIG was established in 1965 by two disabled women and differed from previous and other ‘disability’ organisations of the period in that its membership was not specific to one type of impairment or condition, it was controlled and run exclusively by its members, and focused on the economic and social disadvantages experienced by the disabled population as a whole.

Inevitably DIG’s activities attracted the attention of both like-minded disabled people and some politically minded academics and researchers. Consequently as the 60s drew to a close its activities became clustered around Parliamentary lobbying for disability benefits, and the formation of a larger umbrella organisation: the Disability Alliance that included organisations of and for disabled people. The former are led, controlled and managed exclusively by disabled people themselves. The latter are organisations controlled, run and managed by non-disabled people; usually professionals.

Disillusioned by this explicitly narrow benefits focus championed mainly by non-disabled people, a breakaway group was formed by erstwhile DIG members including Paul Hunt and Vic Finkelstein: a disabled South African who had been imprisoned and subsequently deported from South Africa for his opposition to apartheid. This relatively small but hugely influential group of disabled activists, many of whom, including Paul Hunt, were living in institutions at the time, identified themselves as the Union of the Physically Impaired Against Segregation (UPIAS). Drawing upon their individual and collective experience their manifesto entitled *The Fundamental Principles of Disability* (1976) contains a socio political re-interpretation of disability that draws the distinction between the biological and the social. Thus,

‘Impairment’ denotes ‘Lacking part or all of a limb, or having a defective limb or mechanism of the body’

And,

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

In contrast to previous definitions UPIAS re-defined ‘disability’ as something imposed on top of people with ‘impairment’s’ lives, by a society that is intolerant of any form of biological flaw whether real or imagined (UPIAS, 1976).

In order to put this idea to practical use, Mike Oliver coined the phrase the ‘social model of disability’ in 1981. It was used initially for the training of social workers and professionals working in the disability field (Oliver, 2003) and, later, as the main mechanism for delivering Disability Equality Training (Gillespie Sells and Campbell, 1990; Rieser and Mason, 1990) as opposed to ‘Disability Awareness Training’ which was usually constructed around traditional individualistic impairment specific considerations and concerns.

It is important to remember here what the social model actually is. It is a model, which is what social scientists call a ‘heuristic device’ or an aid to understanding. 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-dimensional replica of reality that can trigger insights that we might not otherwise develop’ (Finkelstein, 2002: 13).

There are three main points that have been made repeatedly about the social model of disability.

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

In short, the social model of disability is a tool with which to gain an insight into the disabling tendencies of modern society in order to generate policies and prac-

tices to facilitate their eradication. It is not a theory although it has been the foundation for the development of a fully comprehensive materialist account as expressed in the work of Mike Oliver (1990) Brendan Gleeson (1999) and Carol Thomas (1999).

However, it is often argued that the conceptual division between impairment and disability upon which the social model rests is false (see for example, Tremain 2005).

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

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

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

Also integral to this re-assessment is the assertion that all physiological conditions have psychological implications and all psychological problems have physical consequences. It is therefore an inclusive concept that encompasses all sections of the disabled community including, for example, mental health systems users and survivors.

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

Clearly then:

The social model is not about showing that every dysfunction in our bodies can be compensated for by a gadget, or good design, so that everybody can work an 8-hour day and play badminton in the evenings. It's a way of demonstrating that everyone - even someone who has no movement, no sensory function and who is going to die tomorrow - has the right to a certain standard of living and to be treated with respect (Vasey 1992: 44).

Politics, practices and policies

Inspired by this re-definition of disability and the various civil rights struggles across the world, particularly in the USA, British organizations controlled and run by disabled people began to multiply in the late 1970s and early 80s. These included local groups such as the Derbyshire Coalition of Disabled People, established in 1981 (now known as the Derbyshire Coalition for Inclusive Living: DCIL), and national organizations such as the Spinal Injuries Association (SIA),

In 1981 seven of these organizations came together to form a national umbrella body: the British Council of Organizations of Disabled People (BCODP). By the turn of the century it had a membership of 130 organizations representing over 400,000 disabled people (BCODP, 2001). The main aim of these organizations was to campaign against the institutional discrimination and prejudice that characterized the experience of living with impairment in British society. This revolved around the demand for comprehensive anti-discrimination legislation and greater user involvement in the development and delivery of services for people with ascribed impairments.

i. The Campaign for Anti Discrimination Legislation

The first attempt to get an anti discrimination law on to the statute books was made in 1981. But the Thatcher Government of the 1980s was unsympathetic arguing that there was no evidence of discrimination against disabled people. Fourteen attempts and thirteen years later, the 1995 Disability Discrimination Act (DDA) was passed.

Britain's campaign for anti-discrimination legislation gathered momentum in 1985 with the setting up of the Voluntary Organizations for Anti-Discrimination Legislation (VOADL) Committee, renamed Rights Now in 1992. This heralded an

uneasy alliance between organizations controlled by disabled people, such as the BCOOP, and the more traditional organizations for disabled people, like the Spastics Society, renamed SCOPE in 2001. Hitherto, the latter had been reluctant to support the campaign for a disability rights law.

This about face can be explained by several factors. The late 1980s witnessed a further radicalization of increasingly large sections of disabled people and political activity both in and outside the conventional corridors of power. Conclusive evidence of the extent of institutional discrimination against disabled people based on Government figures was provided by BCOOP initiated research: 'Disabled People in Britain and Discrimination; the case for anti discrimination legislation' published in 1991 (Barnes, 1991). The Disability Direct Action Network (DAN) was formed in 1993 and several high profile demonstrations followed. These initiatives increased public attention to the demand for civil rights legislation for disabled people.

The Conservative Government responded with the introduction of the DDA in 1995. It has been amended several times since its inception and now covers a range of issues including education, employment, transport and goods and services. However, the DDA has been criticized for its essentially medical definition of 'disability' and its limited scope and impact mainly because, as is so often the case with similar legislation, it is replete with various get out clauses and caveats that inevitably give only limited protection under the law.

In 1997 the incoming New Labour Government set up the Disability Rights Taskforce involving various 'stakeholders' including representatives of organizations both for, and of, disabled people, parents groups and employers' organizations. It produced a report in 1999: 'From Exclusion to Inclusion' that included a demand for further amendments to the DDA and the establishment of the Disability Rights Commission (DRC). The DRC was established in 2000. In common with previous British equal rights commissions its principal roles revolve around education and research. The DRC does have the power to enforce the law but the overwhelming majority of cases that it deals with result in reconciliation rather than prosecution.

ii. User Involvement and Independent Living

The growing demand by disabled people and their organisations for much greater involvement in social support or 'care' services is because, historically, welfare provision in Britain, as in most developed countries, has been founded upon tra-

ditional individualistic medical notions of disability. Hence an army of professional experts steeped in the medical or ‘personal tragedy’ model of disability dominates welfare provision in both the statutory and voluntary sectors. Provision is therefore overly paternalistic, dependency creating and essentially exclusionary.

In response various self-help groups and user led organisations began to emerge in the 1970s. But as the decade progressed events in the USA, notably the concept of ‘independent living’ and the emergence of Centres for Independent Living (CILs) had a particular appeal for disability activists. While its meaning is contested most accounts underline the significance of support for user-led services for everyday living in the community. Politically neutral in the sense that it appeals to both the politics of the right and the left, independent living is distinguished from other ways of meeting disabled people’s support needs in two key respects:

- Human beings, regardless of the nature, complexity and/or severity of impairment, are of equal worth, and have the right to participate in all areas of mainstream community life.
- Whatever the character and severity of an impairment, individuals should be empowered to make choices and exercise control in their everyday lives (Bracking 1993; Morris 1993; Charlton 1998).

In broad terms CILs are organisations run, managed and controlled by disabled people that provide a range of services designed to give disabled people and their families support to live independently in the community. In so doing they have played a pivotal role in disabled people’s struggle for equal rights and citizenship. The Hampshire Coalition of Disabled People (HCIL) and DCIL opened Britain’s first two CIL’s simultaneously in 1985. Hitherto, both organisations had made a significant contribution to the development of user led services in the UK.

In 1981 members of HCIL developed a ‘care attendant’ and housing programme’ known as ‘Project 81’ that provided the blueprint for the development of direct/indirect payment schemes in the UK. These are cash payment schemes paid directly to service users that enable them to buy support in the form of a ‘care’ attendant, or personal assistant (PA), rather than be dependent upon statutory or voluntary services that are generally controlled and run by someone else. During the late 70s the founders of DCIL working from within a residential home established Britain’s first telephone Disability Information and Advice Line (DIAL) in response to a general lack of appropriate disability information. A national network followed in 1981 known as DIAL UK. However, although there is now over

500 local DIALs across the UK, most of which are run by disabled people, non-disabled people no longer control the national body.

There was a proliferation of user led organisations throughout the UK during the following decades. In 2000 research indicated that there were only eighty four user controlled organisations providing services to disabled people (Barnes Mercer and Morgan 2000). Employing a narrower definition recent official estimates suggest that there are currently only twenty two fully constituted CILs or 'disability organisations either providing a similar role or working towards becoming a CIL (PMSU 2005:70). These organisations provide a range of services clustered around a social model analysis of disability and the 'seven needs for independent living' identified by DCODP in 1985. These include: information, peer counselling, housing, personal assistance, technical aids and equipment, transport; and an accessible environment, education and employment support, Disability Equality Training, and individual and collective advocacy. It is important to note that although many of these organisations aspire to provide a full range of disability related services this is not possible in the majority of cases due to chronic underfunding and lack of investment by national and local government agencies and non-user led organisations within the voluntary sector.

However, these initiatives coupled with an escalating welfare budget and an ongoing swing to the right in British politics led to moves towards the involvement of disabled service users in the planning and delivery of services. An early example was the 1986 Disabled Persons (Services, Consultation and Representation) Act, although it was scarcely enforced (Bewley and Glendinning 1994). A year later the Government introduced the Independent Living Fund (ILF). Half the trustees were nominees of the Department of Health and Social Security (DHSS), with the remainder from a user led organisation DIG. The ILF was established for a maximum of five years with a budget of £5 Million, and had the power to make 'direct payments' to a small number of disabled people to help organise their own support system by employing personal assistants (PAs).

Moreover, the idea of disabled service users as consumers was further evident in the 1996 Community Care (Direct Payments) Act. This legislation empowered local authorities to make direct payments to certain groups of disabled individuals; notably, adults 'with physical disabilities' who are below retirement age; namely 65 years of age. Subsequent amendments such as the 2000 Carers and Disabled Children Act, 2002 Community Care and Health (Scotland) Act, extended this provision to other service user groups such as parents of disabled children, disabled young people under eighteen, and those over retirement age. However, from April 2003 it became mandatory for local authorities to offer direct payments to

service users. Hitherto, the legislation had been permissive and many authorities had been reluctant to offer this option favouring instead the delivery of traditional professional led services.

Following widespread consultation with various stakeholders including disabled people and their organisations the Prime Minister's Strategy Unit published the *Improving the Life Chances of Disabled People* report in January 2005. This document is especially important as it accepts unequivocally a social model definition of disability and the importance of introducing policies to enable disabled people to achieve independent living. It states that:

By 2025 disabled people in Britain should have full opportunities and choices to improve their quality of life and vital members of society (PMSU 2005; 4).

To realise this goal practical measures are advanced to enable disabled people achieve 'independent living'; improve support systems for families with disabled children, facilitate a smooth transition into adulthood for disabled young people and improve support and incentives for disabled workers for getting and staying in employment (PMSU 2005: 4). At the core of this strategy lies the promotion of independent living which following the Disability Rights Commission (DRC 2002) is defined as:

all disabled people having the same choice, control and freedom as any other citizen – at home, at work and as members of the community (PMSU 2005: 58).

Under such proposals, individual choice and control would move to centre stage in planning and delivering services, and materialise as 'individual budgets'; or what disabled people's organisations referred to as direct payments. Most significantly, the PMSU maintains that Centres for Independent Living (CILs) should be at the heart of these policy developments.

By 2010 each locality (defined as that area covered by a Council with social services responsibilities) should have a user led organisation modelled on existing Centres for Independent Living (PMSU 2005: 76).

The responsibility for implementing this new vision rests with all government departments, including the Department of Health (DoH) and the Office of the Deputy Prime Minister. A new Office of Disability Issues (ODI) is to be established staffed by civil servants from other Government departments accountable to the Minister for Disabled People. To ensure disabled people's involvement a National Forum of Organisations of Disabled People and an Independent Living Task Force both of which are to be chaired by the Minister for Disabled People.

Clearly then much progress appears to have been made particularly over the last fifteen years but the important point here is how have these policies impacted on the lives of disabled people and their families, and, equally important, what is the likely impact of the most recent policy developments outlined in the Improving the Life Chances report.

Disability in Britain in 2005 and beyond

Community based support and the culture of 'care'

Although disabled people's organisation have championed direct payment schemes as a pre-requisite for independent living for more than two decades in the UK it is important to note that the numbers of people using receiving 'cash for care' is relatively small. Recent Government estimates suggest that although approximately 1.46 million people received community based support during the year 2003/4 in England alone, 4 percent more than in the previous year, only 17,300 adults aged 18 and over were in receipt of direct payments, although this represents an 80 percent increase on 2003-4 when the figure stood at 9,600 (DoH 2005b: unpagged). Furthermore, there are proportionately fewer service users accessing direct payments in Northern Ireland, Wales and Scotland (Riddell et al., 2004; Pearson 2005).

Availability is influenced by several factors These include local politicians ongoing commitment to traditional professional led services, limited budgets, trades union concerns, lack of support by 'care' managers and some professionals and inconsistencies in assessment procedures (Barnes 2004:2).

Responsibility for implementing community support for disabled people and all service users in the UK rests with the Department of Health (DoH) and the Office of the Deputy Prime Minister. An indication of the DoH understanding of its role is illustrated in the policy document: 'Independence, Well Being and Choice' published 2005 (DoH, 2005) two months after the PMSU document mentioned above. However, beyond the endorsement of the use of direct payments and individual budgets as a means of delivering support, there are relatively few new or innovative policy suggestions. There is no mention whatsoever of a social model analysis of disability nor, indeed, a definition of independent living, and the document is replete with the language of 'care' rather than 'rights'.

Moreover, the DoH document is couched in the language of 'care'. Disabled activists and their organisations regard the concept of 'care' as the opposite of what

they want from government policy or service providers and that it also misrepresents what people need to live independently and as equal citizens in the community:

I'd say we don't want to be cared for at all. I would say that we want to be facilitated, supported and empowered.... care to me has connotations of custody and lack of control and looking after somebody who is getting sick and getting worse.... Caring and care in the community is about control – maintaining us in a certain position – and it's about seeing disabled people as people with individual problems. It's not empowering at all (Campbell, cited in Williams 1997: 94).

Indeed, the PMSU Report states clearly that:

One of the most significant barriers to enabling disabled people to be full citizens is the culture of care and dependency within health and social care structures. Associated with this “culture of care” is a failure to see expenditure on independent living as a form of economic and social investment. Instead of meeting disabled people's additional requirements to enable them to improve their life chances, resources are used in a way that maintain and create dependency (PMSU 2005: 60).

Equal worth

A crucial issue for advocates of a social model of disability and independent living is the importance of policies of equal worth for disabled and non disabled people. Selective abortion for unborn children with impairments was made legal during the 1960s. It remains so today and although the PMSU document adopts a social model account of ‘disability’ which is defined as:

the disadvantage experienced by an individual... resulting from barriers to independent living or educational, employment or other opportunities, that impact on people with impairments or ill health’ (PMSU 2005: 5).

Yet there is no attempt to address the concerns of disabled people and their organisations regarding selective abortion for unborn children with accredited impairments and euthanasia practices for people with ‘terminal illness’.

Support for families

Mainstreaming in the 'Improving Life Chances' report is linked to support for families with disabled children, the transition to adulthood for young disabled people, and help and incentives for disabled people to secure and stay in employment. In recognition that disabled children are more likely to live in poverty than non-disabled children the Government contend that families with a disabled child should have access to individualised budgets in order to access 'ordinary lives' through effective support in mainstream settings. This support is to be provided by a 'key worker' whose functions include, information, communication and 'care' coordination. Educational information and support is to be provided by Special Educational Needs Coordinator (SENCO).

However, there is no clear statement that inclusive provision should be the norm either in nursery, pre-school or school placements. Concern has been expressed that 'specialist' alternatives may be considered if everyone involved with the child agree that inclusive provision is inappropriate (Breakthrough UK 2005: 13).

Education

Although disabled people and their organisations have campaigned for inclusive education and the Special Educational Needs and Disability Act introduced in 2001 claim to address discrimination in education, segregated 'special' provision continues to flourish. Recent figures suggest that since the turn of the century progress toward inclusive education has stalled. Indeed, over the period 2002 – 2004 one third of the Local Education Authorities (LEAs) in England increased the segregation of disabled pupils into segregated settings (Rustemier and Vaughan 2005).

The transition to adulthood

As the majority of disabled children have non-disabled parents with little knowledge of disability issues it is important to address their fears and concerns. It is equally important to recognise that several factors contribute to disabled young people's prolonged dependence on their families. These include the absorption of disability and child related benefits into the familial budget, parental over protection, unemployment and underemployment, lack of peer contact, and the

cumulative emotional and psychological implications of social exclusion known variously as ‘felt stigma’ or ‘internal oppression’ (Barnes and Mercer 2003).

Acknowledging that the transition to adulthood is a particularly difficult period for disabled young people, the Government maintain that,

many disabled teenagers, especially those with learning difficulties, could benefit from children’s services well beyond the current age cut offs for these services. To address this children’s services...., should move to include all disabled people up to the age of 25, and should support disabled young people living at home or moving in to independent living (PMSU 2005: 12).

Such a policy effectively perpetuates the infantilization of young disabled people and tends to sidestep the widespread view that for young people generally the key to adult status is securing paid employment.

Employment

In most industrialised countries paid work is a key signifier of class, status and power. This means that people on the margins of the labour market encounter a variety of economic, political and social deprivations. This form of distributive injustice is widely experienced by disabled people throughout the ‘developed’ world (Marin, Prinz and Queisser 2004).

The latest figures for the UK suggest that 50 per cent of disabled people are ‘economically inactive – neither working nor actively seeking work - compared with 15 per cent of non-disabled people. Although unemployment amongst people labelled with ‘learning difficulties’ and or designated ‘mental illnesses’ is especially high ‘for all impairment types labour market disadvantage is substantial’ (NEP 2005: 15-16).

Moreover, there are disproportionate numbers of disabled people in less skilled, lower paid jobs with fewer promotion prospects, and an over-representation in specific occupations or congregated in sheltered workshops. Disabled people are particularly under-represented in the professions and management jobs, where there are higher earnings, job security and opportunities for promotion. Disabled men working full time earned on average 25 percent less than their non-disabled counterparts while the wages of disabled women were only two thirds that of disabled men (Burchardt 2000).

As with previous policy initiatives since the 1950s most of the employment section of the 'Life Chances' report is given over to “improving” the disabled person. Whilst this approach may have some value, it has not been able to significantly reduce unemployment amongst disabled people, and ultimately confirms the established orthodoxy that disabled people are unable to work due to personal deficits (Roulstone 2002).

Hitherto official and sociological analyses of work and disability have failed to address in sufficient depth or breadth the various social and environmental barriers that confront disabled people in the labour market. As a consequence many writers from within a disability studies perspective drawing upon the insights of the philosophy of independent living and the social model of disability have argued for a reconfiguration of the meaning of work in order to remove the stigma associated with unpaid labour (Barnes and Mercer 2005).

The built environment

Disabled people when compared to non-disabled contemporaries do not have equal access to housing, this is especially so for people who use wheelchairs, whether in the public or private sector. This is not taken fully into account in the report. There is evidence that the adoption of accessible or 'Lifetime Homes' standards for newly built housing is both popular with householders and financially cost effective (Rowe 1990; Cobbold 1997). Also as part of the 'The London Plan: Spatial Development Strategy for Greater London' (GLA 2004), all new homes are to be built to Lifetime Home standards, whether constructed by local authorities, registered social landlords or private developers. The Government has yet to make such a policy mandatory across the UK.

Moreover, the combination of inadequate community based support and the scarcity of accessible housing mean that many disabled people have no choice but to live in residential homes. Most disabled people, especially those with high support needs, are fearful of being forced into 'residential care' (Breakthrough UK. 2005: NCIL 2005), which is viewed as the antithesis of independent living.

Moreover, there is little meaningful discussion of the problems disabled people encounter with regard to the built environment generally in recent Government literature, particularly the PMSU Report. This is important as although there has been some significant improvement over the last decade or so, disabled people still encounter considerable difficulty gaining equal access to public buildings and amenities. This is due to the extensive use of the terms 'reasonable', 'practi-

cal' and 'impractical' throughout UK legislation and policy statements that serve to effectively undermine any concerted moves to eradicate this form of structural inequality. Indeed,

Enforcement and compliance is, therefore, left to building inspectors and consultants, which in turn leaves questions of rigour and consistency open to debate (Prideaux 2005: 35).

Implementation and Disability Activism

Despite these concerns the Government's appetite for the development of independent living for disabled people is evidenced further by an ambitious and impressive list of proposals for a phased programme of target setting and policy reviews and the devolution of responsibility for implementation to all government departments. Lead responsibility in Government for implementation will rest with the Minister for Disabled People who will be responsible for the newly formed ODI, the National Forum for Organisations of Disabled People, and the Independent Living Task Force, mentioned earlier.

Whilst there is a great deal of emphasis in the PMSU Report on the importance of disabled people's involvement in these policy developments it is not really clear how this involvement is to be enacted. Certainly the ODI is to be staffed by people who have been seconded from other Government departments but there is no mention in the PMSU report of the need for them to have experience of impairment or knowledge of disability issues. Concern is compounded further by the fact that government departments have a poor record in the employment of disabled people standing at only 4 per cent in 2005 (Kotecha 2005). A more effective approach would be to ensure that people with an awareness of disability and independent living issues are integrated fully into all government departments at all levels, nationally, regionally and locally.

Also the National Forum is to be chaired by the Minister for Disabled People but apart from the reference to organisations 'of' disabled people there is no clear indication of who will be included in the Forum's membership. The issue is clouded further by the statement that:

There must be a sustained effort to build up the capacity of organisations representing disabled people and their ability to work together and with other partners. Government contracts have the potential to assist this process (PMSU 2005: 186).

Since the emergence and relative success of the disabled people's movement, nationally and internationally, the boundaries between organisations 'of' and 'for' disabled people have become increasingly blurred over recent years. Although several of the latter have now apparently joined campaigns for disabled people's rights and laid claim to the notion of independent living, their commitment to user accountability and meaningful involvement is open to question. This is reflected by the fact that, in concert with government departments, their record on employing disabled workers is consistently poor especially in positions of authority (Oliver and Barnes 1998; Calvi 2003).

Furthermore, the rationale behind the Government's intention to set up a national forum for organisations of disabled is seriously open to question given that there are two well established national autonomous bodies that already fulfil this role; namely, the British Council of Disabled People, established in 1981, and the National Centre for Independent Living (NCIL) set up in 1997 specifically for the purposes of supporting user led organisations and CILs in the promotion of direct payments and independent living.

Funding

Equally worrying is the assertion that no additional funding is to be made available for the implementation of these proposals. The financial implications of eradicating exclusion and implementing independent living policies and practices cannot be overlooked. There is almost universal agreement that the economic consequences of social exclusion are no longer acceptable and that a thorough cost benefit analysis of independent living is likely to show that in the long term these can be considerably reduced if not eliminated altogether. However, it is naive to assume that the introduction of policies to facilitate meaningful independent living for disabled people can proceed without substantial investment by central government.

Discussion

To facilitate greater user involvement in the development and delivery of services, people have to feel empowered. But empowerment cannot be imposed from above, it must be organic in that people must want to empower themselves. With limited resources, chronic under investment and varying degrees of opposition from traditional service providers, the disabled people's movement and its member organ-

isations have, by example, had a major impact on the way social services and supports are delivered. In so doing they have empowered thousands of disabled people across the UK. If this process is to continue it is essential that appropriate funding be made available to local organisations led, managed and controlled by disabled people, particularly in the process of delivery and infrastructure of direct payments, and freed of local authority regulation and control. This is fundamental to independent living and should be managed and delivered by an overarching representative body of disabled people (Barnes 2004; Breakthrough UK 2005).

Given the recent history and devolution of government in the UK, separate agencies should be established in England, Scotland, Northern Ireland and Wales. Sufficient resources should be made available to ensure that these structures are able to develop and support national networks of user led initiatives that are sensitive and responsive to impairment, ethnic and cultural diversity within the disabled population at the local level. Furthermore, much of the rhetoric surrounding independent living revolves around enhancing individual ‘choice’ in provision.

However, the main self determination issue for disabled people is not simply about service delivery mechanisms, but about whether levels of resources are sufficient to deliver the required services. All too often funding at the local level is insufficient to enable people to access the services needed to live independently. This must be rectified if meaningful independent living is to become a reality. Additionally, any significant shift in service delivery should include a radical reappraisal of the role of professionals and social support workers. As part of this change in approach, user led organisations should be actively involved in professional development and training (NCIL 2005).

Moreover, the concept of independent living encompasses the full range of human experience and rights. As a consequence it poses a direct challenge to contemporary capitalist societies such as the UK, and more globally. This is because people with designated impairments will always experience varying degrees of economic, political and social disadvantage in societies organised around the core capitalist values of economic rationality, the profit motive, and individualism. Indeed, to achieve a lifestyle comparable to their peers, disabled people need far more than simply user-controlled services. To attain independent living disabled people need equal access to mainstream schools, jobs, transport, houses, public buildings, leisure etc. or ‘all the things that non-disabled people take for granted’ (Bracking 1993: 14).

Given the limited ambition of recent Government initiatives in this regard, little significant progress will be made without further changes. Furthermore, these

will have significant resource implications, as effective barrier removal will not be achieved 'on the cheap'. These short-term costs must be offset against the long term gains of a barrier free environment in which socially created dependence is considerably reduced if not eliminated altogether. Whilst such a policy may fly in the face of recent economic and political trends, it is important to remember that the notion of a fully inclusive and equitable capitalism is unrealistic. Yet it is apparent that the level and forms of social exclusion have in some (but not all) areas diminished slightly over recent years, although a clear social division remains. There is much that needs to be done if these divisions are to be eliminated. The limited progress of disabled people in a relatively 'rich' country such as Britain must however be set against a far less certain improvement in social inclusion for disabled people in relatively 'poorer' countries.

Final word

It is my firm belief that the only way such policies are likely to be introduced is through the further development of disability activism in the UK. The success of the disabled people's movement in bringing disability issues and independent living on to the mainstream political agenda is a major achievement. But that achievement inevitably results in incorporation. Whilst this is to some degree unavoidable it is also the case that incorporation more often than not results in neutralisation. This is the opposite of what is needed. As indicated above institutional discrimination and prejudice remain and take a variety of forms in the UK. Their eradication is only likely through the further activities of a vibrant and autonomous disabled people's movement. The recent policies of the current British Government threaten to undermine such activities and, indeed, the very existence of the movement itself.

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