

Independent Futures: policies practices and the illusion of inclusion

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There has been much progress over recent years in relation to social attitudes and responses to disabled people in many countries across Europe and other western states. A socio/political or 'social model' type analysis of disability is now enshrined in national policy statements in many nations and greater user involvement in provision and service delivery is firmly established on the political agenda. Many countries have anti-discrimination laws to prevent unjustifiable discrimination against disabled people. All of which is due almost entirely to the activities of the international disabled people's movement.

Yet despite these apparent gains, there is still a long way to go, as the experience of the overwhelming majority of disabled Europeans remains one of economic and social exclusion. However, further progress may be inhibited by the acceptance of disability issues on to the mainstream political agenda as it threatens the very survival of that which put them there; namely, the disabled people's movement.

To explain this claim this presentation will focus on the current situation in the UK and is divided into three main sections. The first focuses on politics, politics and practices, the second describes the experience of

disability in post millennium Britain, and the third provides an insight into the key issues and concerns that have to be addressed in the on going struggle for a more equitable and just society.

Politics, policies and practices

Inspired by the re-definition of disability as a socio/political rather than an individualistic medical problem (UPIAS 1976: DPI 1982) 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). These included national non-impairment and impairment specific groups such as the British deaf Association (BDA), The National League of the Blind and Disabled (NLBD), People First (a national organization representing people with

the label 'with learning difficulties' and the UK Coalition of People with HIV and AIDS. 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 (Campbell and Oliver, 1996; Barton, 2001). .

i. The Campaign for Anti Discrimination Legislation

The first attempt to get an anti discrimination law on to Britain's statute books was in 1981. However, 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.

This was due to several factors:

- The 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 BCODP, 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 (Oliver 1990).

- This about face may 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.
- The success of disability activism in the USA had led to the introduction of the Americans with Disabilities Act (ADA) (Shapiro 1993; Charlton 1998).
- Conclusive evidence of the extent of institutional discrimination against disabled people was provided by BCODP sponsored research 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 (Campbell and Oliver, 1996).

The Conservative Government responded with the introduction of the DDA in 1995. It has been amended several times since 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.

Moreover, a recent report published by the Public Interest Research Unit chronicling the limited impact of the DDA over its first decade stated:

'Based on a largely discredited model of Disability, the (Disability Discrimination) Act is

probably beyond repair. We would like to see it replaced with a civil rights act which properly addresses discrimination' (PRIU 2006: 4)

Also, since its inception:

'the DRC's neglect of its enforcement powers, along with the difficulties individuals face in taking action themselves, has helped ensure that the majority of discriminators have got away with committing unlawful acts' (PRIU 2006 cited in Coalition 2006: 6).

ii. User Involvement and Independent Living

The growing demand by disabled activists 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 traditional 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 (Morris, 1993: 2005: Priestley, 1998: Charlton. 1998).

This is especially pertinent to orthodox approaches to educational provision for children and students with

accredited impairments. In response, various self-help groups and user led organisations began to emerge in the 1970s. However, 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 2001, research indicated that there were eighty-four user-controlled organisations providing services to disabled people (Barnes and Mercer 2006).

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 under-funding and lack of investment by national and local government agencies and non-user led organisations within the voluntary sector (Barnes and Mercer 2006).

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. In April 2003, it became mandatory for local authorities to offer direct payments to service users. Hitherto, the legislation had been permissive as many authorities were reluctant to provide 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 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 are placed centre stage in planning and delivering services. Most significantly, the PMSU maintains that 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 (DH) and the Office of the Deputy Prime Minister. A new Office of Disability Issues (ODI) has been 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 2006 and beyond

i. Community based support and the culture of 'care'

Although disabled people's organisations have championed direct payment schemes as a prerequisite for independent living for more than two decades in the UK the numbers of people 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.

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 on-going 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 DH and the ODPM. An indication of their understanding of their role is illustrated in the policy document: 'Independence, Well Being and Choice' (DH 2005).

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'.

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 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).

ii. 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', 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'.

ii. 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. Support will 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).

Notably, 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).

iii. Education

Although disabled people and their organisations have campaigned for inclusive education and the Special Educational Needs and Disability Act introduced in 2001 claims 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).

iv. 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.

v. 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).

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).

vi. 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. 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) 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', 'practical' 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).

vii. 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 further compounded 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.

In addition, 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 people 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.

Viii. Funding Inclusion

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: The Illusion of Inclusion

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 organisations 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 must 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. Therefore, 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.

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

The success of the disabled people's movement in bringing disability issues and independent living on to the mainstream political agenda in the UK and elsewhere is a major achievement. However, that achievement inevitably results in incorporation into the mainstream corridors of power. Whilst this is to some degree unavoidable, incorporation often leads to political neutralisation; this is the opposite of what is needed. As indicated above, institutional discrimination and prejudice remain a major problem for people with accredited impairments and labelled 'disabled' in Britain and throughout Europe. Their eradication is only possible 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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