The Disabled Peoples' Movement and its Future

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It is now well documented that our understanding of the complex process of disablement has changed considerably since the middle of the last century. Whichever way you look at it disability can no longer be explained solely in terms of an individual's functional limitations. It is now widely recognised by politicians and policy makers that the various economic and social deprivations encountered by disabled people are due to social forces. Whilst the politicisation of disablement is due to several factors a major catalyst for change was the groundswell of political activism amongst disabled people and their organisations: the disabled peoples' movement, during the 1960s and 70s. This paper charts: a/ the growth of disability activism b/ its influence on disability policy and c/ its relative decline as a radical force for change. Whilst this is the current situation in most nation states attention centres mainly on the British experience.

Grass-roots mobilisation

Politics is about the struggle for power and influence. But power and influence are distributed unevenly in all societies with some groups better placed than others to secure their interests. In western type capitalist societies such as the UK power is exercised through national and local institutions such as Parliament and local councils. Accountability is legitimised by periodic public elections. Politicians may also be influenced by pressure group activity, public campaigns and lobbying by individuals and groups. But since wealth, status and power are closely linked power is dominated by the upper and upper middle classes.

All of which makes the politicisation of disability by disabled people that more remarkable. Historically people with all kinds of impairments were viewed as socially inadequate and systematically excluded from all manner of economic and social activity. Also since the nineteenth century their interests were increasingly represented by cadres of disability professionals and professionally led impairment specific organisations that perpetuated an individual medical view of disablement.

This began to change in the 1950s. Internationally, this was a period of relative economic stability, rising affluence, and civil unrest and activism amongst the dispossessed: women, 'Black' people and disabled people. Disabled people's groups in countries as diverse as the USA, Netherlands, Sweden and Japan began to campaign against their exclusion from mainstream society (Barnes and Mercer, 2010: Oliver and Barnes, 2012).

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). DIG was established in 1965 by two disabled women and differed from previous and other disability organisations as its membership was not specific to one type of impairment. It was also controlled and run exclusively by its members, and focused on the economic and social disadvantages experienced by the disabled population as a whole (Campbell and Oliver, 1996). .

Inevitably DIG attracted the attention of politically active academics and researchers. Hence 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 run by disabled people. The latter are controlled and managed by non-

disabled people and professionals.

Disillusioned by this narrow benefits focus a breakaway group: the *Union of the Physically Impaired Against Segregation* (UPIAS),.was formed by erstwhile DIG members. This relatively small but hugely influential group of disabled activists were responsible for the conceptual distinction between the biological (impairment) and the social (disability), the re-interpretation of the latter as social oppression, and the social model of disability (UPIAS, 1976: Oliver, 1981).

The rise of the American *Independent Living Movement* (ILM) at the turn of the 1970s was particularly influential in drawing attention to the importance of self help, user led services: *Centres for Independent Living* (CILs) and political campaigning. Following the arguments of the American women's and civil rights movements the ILM maintained that disabled people were a minority group denied basic civil rights and equal opportunities that could only be resolved by legislative change. This contrasted with the UPIAS interpretation of disability as social oppression to be addressed by radical social change rather than piecemeal legislative reforms evident in capitalist societies (UPIAS, 1976).

Nonetheless the combination of the reinterpretation of disability as social oppression and the activities of the ILM were an important impetus to disability activism in Britain. British organisations controlled and run by disabled people began to multiply in the 1970s and early 80s. These included national organisations such as the *Spinal Injuries Association* (SIA) and local groups like the *Derbyshire Coalition of Disabled People* (DCODP) established in 1973 and 1981 respectively. In 1981 seven of these organisations came together to form a national representative body: the *British Council of Organizations of Disabled People* (BCODP) which adopted an amended UPIAS definition of impairment and disability that included all impairments regardless of cause. By the turn of the 1990s it had a membership of 80 organizations representing over 200,000 disabled individuals (Barnes, 1991).

These developments coincided with an upsurge in disability activism around the world. This resulted in the formation of *Disabled People's International* (DPI) in 1981. Its first world congress was held in Singapore in 1982 and attracted 400 delegates from 40 countries including the BCODP. They agreed a common programme based on a definition of disability similar to that of the BCODP and the empowerment of disabled people through collective political action. For DPI the prerequisite for change lay in the promotion of grass roots organizations and the development of public awareness of disability issues. Its slogan, 'Nothing about is without us' (Charlton, 1998), has been embraced by disabled people's organisations around the world.

Consequently political activism intensified in rich and poor countries alike. This includes the development of services run and controlled by disabled people, political campaigns for anti-discrimination laws and a politicised disability culture and art. British organisations such as the SIA established user controlled 'care attendant' schemes in 1973. Members of DCODP founded Britain's first *Disability Information and Advice Line* (DIAL) in 1976. Five years later disabled residents in the *Le Court Cheshire Home* set up the UK's first 'direct payment' and housing programme: *Project 81*, to enable disabled individuals leave institutions and live in the community with personal assistants. Britain's first CILs appeared in Hampshire and Derbyshire in 1985. A year later a national conference on Disability Culture was held in Manchester (Barnes and Mercer, 2006). 1996).

As indicated above campaigns for laws to outlaw discrimination on the grounds of impairment originated in the USA. The first attempt to get anti-discrimination legislation (ADL) in Britain was made in 1981. But the Conservative Government of the 1980s supported by several large disability charities controlled by non-disabled people were unsympathetic arguing that there was no evidence of discrimination against disabled people (Oliver and Barnes, 2012).

Evidence to the contrary based on a social model analysis of official statistics was initiated by the BCODP in 1989 and published in 1991 (Barnes, 1991). This report helped fuel the campaign for ADL. Although public demonstrations by disabled activists originated in the UK in the 1930s they increased significantly in the early 90s with the formation of the *Direct Action Network* (DAN) in 1991. Subsequent campaigns called for the promotion of

independent living and user controlled services including direct payments or 'cash for care' type schemes. These and similar initiatives across Europe and the rest of the world had an important impact on policy and practice at the national and international levels.

The integration of disability issues into mainstream policy and practice

Due to the moral obligation felt toward the large numbers of disabled soldiers and civilians following the Second World War many countries introduced welfare policies dealing explicitly with disability issues. In wealthy states such as the UK these covered education, employment, health and rehabilitation services. This resulted in the development and expansion of a host of 'special' services provided by government and non-government organizations (NGOs) staffed by non-disabled professionals.

But rather than facilitate disabled people's empowerment and inclusion into the mainstream of community life, these services are often segregated and disempowering and so achieve the reverse. They serve only to compound assumptions that people with impairments are somehow different from everyone else and a burden to themselves, their families and the   community at large (Swain and French, 2009).

The problem of disablement became an increasingly important issue for politicians and policy makers in many countries during the 1960s. This was due to several factors in wealthy states like Britain including rising affluence and expectations, an increasing 'disabled' population', the rising cost of welfare, and disability activism. This prompted the introduction of policies intended to improve disabled people's lives and combat discrimination by governments across the world. Early examples include the UK's 1970 *Chronically Sick and Disabled Person's Act* and the American *Rehabilitation Act* of 1973.

Following a protracted campaign initiated by the BCODP the British Government introduced the *Disability Discrimination Act* (DDA) in 1995. Criticized from the outset for its overtly medical definition of disability and limited focus, subsequent amendments focused on education, employment, transport and goods and services. It was largely ineffectual and replaced in 2010 by the *Equalities Act* to cover all forms of unfair discrimination.

Since the 1980s the notion of independent living and user controlled services has had an increasingly important influence on government policies in both rich and poor states. In 2002 there were some 86 CIL type organizations offering independent living services controlled and run by disabled people. In 1988 the Government set up the *Independent Living Fund,* a national body to provide funding for the growing numbers of disabled individuals wanting direct payments to organize their own support system. The 1996 *Community Care (Direct Payments) Act* legalized direct payments by local authorities and this became mandatory in 2003 (Barnes and Mercer, 2006). .

These developments were accompanied by a flurry of initiatives at the international level. In 1971 the United Nations (UN) introduced the *Declaration on the Rights of Mentally Retarded Persons.* The *Declaration on the Rights of Disabled People* followed in 1975. It nominated 1981 the *International Year of Disabled People. Moreover,* 1983–1992 was proclaimed the UN *Decade of Disabled Persons.* A raft of similar initiatives followed due to complaints by disabled activists that the first UN Decade prioritised disability in rich 'developed' nations to the detriment of the situation in poor 'underdeveloped' states.

The UN *Convention on the Rights of Persons with Disabilities* and its *Optional Protocol* was adopted in December 2006 and is widely regarded as a major step forward in the struggle for equality for people with impairments and labelled 'disabled'. This is the most comprehensive document yet produced on the rights of disabled people and intended as 'legally binding' on any country that ratifies it. The British Government signed and ratified the Convention on the 8th June 2009 (Oliver and Barnes, 2012).

Clearly then much has changed. There is no doubt that these policies have given thousands of disabled people unprecedented levels of control over their lives. But poverty remains a common experience for the overwhelming majority of people with impairment in all countries. Despite social model and rights rhetoric, individualistic medical perspectives continue to hold sway in policy circles both nationally and internationally: notably a

situation that is underpinned by recent trends in disability studies (Oliver and Barnes, 2012). Therefore the structures of oppression remain largely unchecked. This is attributable to the incorporation of disability politics into the mainstream political agenda and the relative decline of the disabled peoples' movement as a radical force for change. This is especially evident with reference to the British experience.

The assimilation of disability issues into mainstream politics

Although disability activism was at its height in Britain in the mid-1990s, the effective neutralisation of a radical disability political agenda was already evident by its integration into mainstream politics. In contrast to the initial emphasis on grass roots mobilisation and inclusion Britain's disabled peoples' movement as represented by the BCODP focused almost exclusively on campaigns for anti-discrimination legislation and independent living.

As both the rights and independent living approaches have considerable social capital within capitalist societies this is understandable as it raised the profile of disability issues nationally and generated political activism amongst previously un-politicised sections of the disabled population. Also these campaigns were joined by traditional disability organisations and charities. Indeed, although the BCODP had initiated the campaign for ADL in 1990, a year later it was taken over by RADAR (the then *Royal Association for Disability and Rehabilitation*). Despite its introduction and subsequent amendments ADL has had little impact within the UK and indeed elsewhere. Even where legal frameworks exist, challenging the denial of rights through the law courts is costly in terms of resources and time. As indicated earlier the overwhelming majority of disabled people and their organisations in both rich and poor nations rarely have either. Furthermore the idea of individual and social rights is the outcome of neo-liberal thinking and has little relevance to those living in non-western cultures.

Yet in 1997 BCODP joined a *Disability Rights Taskforce* of various 'stakeholders' including representatives of organizations for disabled people, parents groups and employers' organizations set up by the incoming *New Labour Government*. Besides recommending amendments to the DDA, it called for the establishment of a *Disability Rights Commission* (DRC). The DRC began operations in 2000. In common with previous British equal rights commissions for 'race' and gender its principal roles revolved around education and research. Although all had the power to enforce the law they proved largely ineffective (Harwood, 2005; 2006), were abolished in 2007, and replaced by the equally ineffectual *Equalities Commission* in 2010.

In 1994 the BCODP set up an Independent Living Committee to promote independent living and CIL development. This resulted in the setting up in 1996 of an associate but separate organisation: the *National Centre for Independent Living* (NCIL) to focus exclusively on these issues. Although initially intended to promote direct payments and support CILs, Later NCIL began to provide consultation and services to traditional service providers including professionally led initiatives such as 'In Control'. NCIL became a completely separate organization in 2000.

Interest in independent living has had a profound impact upon governments across Europe due to their growing concerns over increasing welfare budgets and criticisms by disabled activists over the dependency creating policies of professionally run state services. Consequently giving people money, whether individually or through organizations has a particular appeal to politicians and policy makers intent on cutting costs. In the UK the *Community Care (Direct Payments) Act* (1996) and subsequent amendments (2000 and 2003) are examples of this cash solution.

This marketisation of welfare has undoubtedly transformed the lives of some but not all. In the UK for example the numbers of people receiving 'cash for care' remains small' relative to the total service user population, Access varies considerably between local authorities and is especially low for 'parents of disabled children, mental health systems users, and people with learning difficulties. The promotion of independent living and the increasing commodification of welfare have also led to intense competition amongst service providers.

This has led to a significant reduction in the numbers of CIL type organisations and user controlled services unable to compete with professionally led agencies and charities for lucrative government and local authority contracts.

Further the penetration of the market into state sponsored welfare may not end there. Policy makers have eagerly seized upon the idea of giving people cash instead of services and rolling out a programme of personalised health budgets. Coupled with their plans for privatising health care provision, these developments could effectively mean the demise of 'health care for all, free at the point of delivery' in Britain (Oliver and Barnes, 2012).

All of which has had serious implications for the disabled peoples' movement. The coming of the DRC and NCIL effectively pulled the rug from under the BCODP as the former became the official champion of disability rights and the latter independent living services. Hence there was a corresponding decline in funding, membership and support during the last decade. This has not been abetted by it changing its name to the United Kingdom's Disabled People's Council (UKDPC) in 2006.

The escalating global economic crisis and the ensuing austerity measures introduced by Britain's Conservative led Coalition Government which came to power in 2010 has added a further twist to this story. Cut-backs in funding policies meant that NGOs are required to work together to access funds. This has resulted in organisations of and for disabled people pooling resources to access government finance. NCIL for example has now merged with RADAR and the *Disability Alliance* as *Disability Rights UK* (RADAR, undated). UKDPC and 7 other disabled people's organisations have come together as *Disability LIB* (Listen, Include Build) to support disabled people's organisations (Disability LIB, undated). And estimates suggest there are between 650 and 1000 'user led organisations' (ULOs) in the UK Blackmoor and Hodgkins, 2012, p. 72).

Although little is known about these groups regarding aims, function or political aspirations, there is little evidence of a groundswell of coherent political activism beyond opposition to government cuts in public services which have a disproportionate impact on disabled people and their families' (see for example *Disabled People Against Cuts* (DPAC) undated). Whilst such initiatives are perfectly understandable they have yet to present a meaningful alternative to what's gone before.

Discussion

This paper has covered the growth of disability activism since the middle of the last century. It has shown how the politicisation of disability by disabled activists at the international and national levels posed a significant challenge to societal responses to people with impairments. Their demands for policy initiatives to secure disability rights and independent living have had a notable impact on policy and practice both nationally and internationally. This has resulted in the inevitable incorporation of disability politics into a mainstream political agenda and the effective neutralisation of the disabled peoples' movement.

Whilst the introduction of policies to secure disabled people's rights and independent living have undoubtedly benefited large numbers of disabled people especially in wealthy states such as the UK these benefits have been only marginal and are extremely fragile. The overwhelming majority of disabled people in all societies remain the poorest of the poor. And the policy gains that have been made are now under serious threat due to the on-going global economic crisis. Whilst these development have generated a new found militancy amongst disabled activists in Britain as exemplified by DPAC, it is as yet unclear whether they can generate a meaningful challenge to the structures of oppression that characterise capitalist Britain.

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