THE DISABLED PEOPLE'S MOVEMENT - PUTTING THE POWER IN EMPOWERMENT

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(Paper for a seminar at Sheffield University Sociology Department 1996, updated '98)

In this paper I consider the development of 'community care' and 'civil rights', which have raised a number of important issues concerning the control and direction of disability policy and practice. I suggest that they are the product of two very different ways of looking at disability, each with its own history and power base. In recent years, as the two developments have come into contact, so has the clash revealed the disproportionate distribution of power and influence between their proponents. This has in turn heightened the need to resolve existing tensions arising from the way disability is defined and what this implies for disabled people and society generally.

The caring and controlling tradition

The roots of community care can be traced back well before the famous 43rd Elizabeth of 1601 consolidated the compulsory, secular, nation-wide system of poor relief known as the Old Poor Law. This-is important in any discussion about power and influence in the direction of disability policy, because the Old Poor Law also consolidated what disabled people have characterised as the "administrative model" (Finkelstein, 1993, p.37) in their dealings with people with physical and other impairments, inasmuch as it viewed them, then as now, as a problem requiring paid officials to define, classify, register, administer and control. The Poor Law laid a foundation for future disability legislation which interprets disability as being caused, not by the state of society, but by the state of a person's body and/or mind. This interpretation is referred to as the individual or 'medical model' of disability which, in the absence of a cure, requires intervention under the banner of 'care'.

In a discussion about the 'discovery' of disabled people in society and the building of the welfare state, Hunt 0 992) notes that the development of disability as an administrative category under the Poor Law is seen by Stone, not only in terms of controlling eligibility for the provision of welfare, but also exemption from certain obligations of citizenship. Stone says, "In the regulations of Poor Law administration and thus in the eyes of Poor Law administrators, five categories were important in defining the internal universe of paupers: children, the sick, the insane, "defectives" and the "aged and infirm." Of these, all but the first are part of today's concept of disability." Everyone else was defined able-bodied by default." (Stone, 1984, p. 40). Indeed, after the Poor Law was amended in 1834, the majority of workhouse inmates were in fact ".. physically and mentally disabled, the aged, the orphan and a wide variety of sick." (Wood, 1991, pp. 98 - 99). As a result, disabled people were socially stigmatised by a system that was designed first and foremost as a deterrence to the able-bodied.

The Poor Law officials were the forerunners of today's Social Services professionals, and it was of course in their interest to perpetuate their own administrative role. The extent of their success can be judged by the fact that, with amendments, the system endured for three and a half centuries until it evolved into the Welfare State, just after World War 11. The passage of the welfare state's safety net, the 1948 National Assistance Act, moved Aneurin Bevin to declare the that Poor Law was at last buried, showing how wide the gap between rhetoric and reality can often be. Certainly, Parliament had repealed the Poor Law on paper but it retained in practice some of its most time-hallowed elements, not least among which in Part III was its predilection for incarcerating disabled people in institutions and then obliging them and their families to pay towards the cost of

being segregated from the community. And of course, it was also careful to retain the administrative approach to disability for the new post-war generation of welfare officials.

Within this administrative tradition, the departmental officials who dreamed up 1community care' policy in the 1960s, would have done so as naturally as their seventeenth century predecessors did when they coined the phrase 'outdoor relief' to describe their policy of providing Poor Law help outside the workhouse. No account was taken of the discontent with the lack of community based alternatives to institutional provision which was growing among disabled people at that time. The struggles of disabled people to escape from, or reform the running of segregated residential institutions during the 1960s, and who knew the shortcomings of the system at first hand, were not significant in the official mind. Given their Poor Law legacy, their views and aspirations were of no consequence.

Turning the controlling tide

Against this background, there was little choice for disabled people other than to try and bring change in a more determined and organised way. The main medium through which this struggle for social change has found expression has been organisations set up and run by disabled people, initially as a reaction against the conditions of life that have been thrust upon them and then proactively, redefining disability as a socially constructed phenomenon, analysing and identifying the social barriers that prevented participation in the mainstream and taking action on solutions. Finally, their organisations have taken to the streets in pursuit of civil rights and other, related legislation, that would do something to gain a measure of control over their lives.

The reactive process of challenging those who were controlling disabled people's lives started towards the end of the last century with organisations like the British Deaf Association (BDA) and the National League of the Blind (NFB). In the same way that trade unions were forming to improve and protect the economic and social position of working people, so were these organisations concerned to improve the lot of people who were deaf and blind. The NFB registered as a Trade Union in 1899, no doubt informed and inspired by the workers movement in much the same way that civil rights struggles elsewhere fuelled the later stages of disabled people's self -organisation here in Britain.

These early organisations run by disabled people tended to seek improvements very much in the prevailing welfarist mode. The new deterrent Poor Law system had begun to crack under the strain of the economic, social and medical needs thrown up by industrialisation, and a number of self help and charitable organisations had emerged in response. Some ran workshops, paying only a pittance to disabled workers, and the NFB was set up by blind workers in such places. Given the various welfare enactments which came at the end of the nineteenth century in the areas of education, pensions and national insurance, it would have seemed natural to the newly emerging disabled people's organisations to pursue improvements in that mould.

Indeed, bringing pressure for more or better welfare characterised disabled people's organisations until the situation changed with the formation in the early seventies of the Union of the Physically Impaired against Segregation. This group paved the way for a civil rights struggle when it redefined disability as: "the disadvantage or restriction of ability caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities." (UPIAS, 1976, p.14).

By this 'social model' approach, UPIAS pointed the way out of the cul-de-sac in which disabled people's bodies were blamed as being the source of their problems. For the first time, socially created disability was charged with being a particular form of social oppression which could be overcome only by disabled people themselves taking the lead in a struggle for social change. It

was a stage in development that grew rapidly from the early 1980s, with the emergence of many new organisations controlled by disabled people. Notable among these was the Disabled People's International (DPI) which was formed by disabled people, as Driedger (11989) describes, in response to the rejection by the disability professionals who ran Rehabilitation International (RI) of a motion which called for them to share power in RI equally with its disabled members.

In 1981, the British Council of Disabled People (BCODP) was formed and became Britain's representative body on DPI through its regional framework, and this in turn gave rise to a flood of member organisations controlled by disabled people round the country. This whole world-wide network is underpinned by the social model of disability, united in Britain around the need for anti-d iscrim i nation legislation in the form of a comprehensive and enforceable Civil Rights Bill, and its member organisations work in a variety of ways to remove the social barriers which prevent the full participation of its members as equal citizens in mainstream social life.

The clash of opposing ideas

Shakespeare sees this growth of activity among disabled people in the broader context of late twentieth century "new social movements" engaged in the struggle for genuine participatory democracy, social equality and justice, which have arisen out of the crisis in industrial culture. (Shakespeare, 1993, pp. 249 -264). Armed with it's social model of disability and demand for equal citizenship, this movement was on course for a confrontation with the established controllers of disability policy from the very beginning.

During the 1980s, whilst the previous Conservative government was grappling along with many industrial societies, with the problem of restructuring state welfare, the disabled people's movement was painstakingly building up through its democratic organisations a very different campaign for civil rights. Predictably enough, this quickly ran into opposition, given the clash of opposing ideas. An early taste of the blunt use of power came when the government rejected the recommendation of the Committee on Restrictions against Disabled People (CORAD) that "there should be legislation to make discrimination on the grounds of disability illegal" (Large, 1982. p.53). Some 14 further rejections followed until an attempt to kill a Labour member's Civil Rights Bill in 1994 went so badly wrong that the Tories were embarrassed into bringing in the 1995 Disability Discrimination Act (DDA). Their hostility to the idea that disabled people should enjoy the same rights and share the same opportunities equally with everyone else is reflected in the Act's medical definitions, limited scope, allowances for 'justified discrimination', and poor provisions for implementation and enforcement. Accordingly, it encountered wholesale rejection by the disabled people's movement and its supporters.

On community care, it was not until it encountered a critical Audit Commission (1986) report that the Tory government got down to thinking about legislation. The latter was followed by the Griffiths Report (DHSS, 1988) and, in due course, by a White Paper, Caring for People (DHSS, 1989). During this process there was some consultation with the newly emerging disabled people's organisations. The Audit Commission (1986) report drew a critical response from BCODP (1987) and Sir Roy Griffiths met some disabled people's organisations as he prepared his Report. By comparison with the influence wielded by vested interests outside the disabled people's movement however, these consultations made very little impression on the essential features of the legislation when it eventually followed in the shape of the NHS and Community Care Act (1990).

In the administration of the new Act, the Tories had been persuaded that local authorities should continue as successors to the power first given to them over four hundred years before in 14 Eliz 1572, an Act "for the punishment of vagabonds and the relief of the poor and impotent." (Fisher and Jurica, 1977, pp 590-598). It was interesting to see this Elizabethan conjunction of punishment and care reflected in Tory measures designed to punish so-called welfare fraudsters

and layabouts within their own overall plans for the restructuring of state welfare. However, in Tudor England, times were different inasmuch as they waited until you were a pauper before the authorities intervened - today Social Services Departments have the power to intervene, then turn disabled people into paupers through assessments, means tests and charges for residential or community care.

Thus the controlling ethos of Social Services remained intact, as did their medical model basis of community care. To be sure, community care may deploy some of the rhetoric of the disabled people's movement: independence, choice and control together with buzzwords like user empowerment are common enough in Guidance and other documents. And indeed, a nod toward the existence of the movement can be discerned in the requirement on local authorities to involve 'users' in planning. But the practice is still dominated by administrative concerns, and the overall effect has led Finkelstein (1997) to consider that the version of community care currently on offer is "..a pernicious influence in maintaining the boundary between disability and normality, just at a time when disabled people are challenging the artificiality of this and other boundaries that constrain our, and non-disabled people's lifestyles." (Finkelstein, 1997, p.13).

Throughout the years of disabled people's self-organisation and collective struggle, what has been most fundamentally amiss boils down to two main issues: first, a limpet like attachment by the disability establishment to a 'medical model' view of disability; second, the disproportionate distribution of power and influence between those who control disability policy and disabled people themselves. The weight of policy and practice still largely rests on the backward but convenient tradition of assuming that disabled people are different, have special needs and that their dependence requires the intervention of properly trained people who care and provide for them. This contrasts with the weight of policy and pressure in the disabled people's movement which is based on the conviction that all people are vulnerable and interdependent, and that we all have needs which are best catered for in a society which celebrates difference, which guarantees everyone's rights and freedoms, and which supports and provides equal opportunities for everyone to participate in everyday human affairs.

Resolving tensions

The desire of the previous government to impose 'care' was much stronger than any wish to confer on disabled people the kind of ordinary civil and social rights which, were they denied to the non-disabled population, would give rise to widespread social unrest. In 1997, new Labour came to power at the May elections and with the change came an unfamiliar wave of hope and optimism for the future. However, it soon seemed as though Labour's support for civil rights in opposition had weakened now they were in power. There was no trace of it in the Queens Speech, nor even a mention of Britain's six million or so disabled people, many of whom had voted Labour into office. Labour's new Ministerial team contained no one with Cabinet status having sole responsibility for disability affairs. Instead, it was tagged on to a Junior Minister's employment brief, apparently as a bit of an afterthought.

This brought back and heightened the distrust stemming from seemingly endless years of Tory hostility towards civil rights, and it was not until the close of 1997 that some confidence, albeit cautious, began to be restored. Labour's Minister for Employment and Disability Rights, Andrew Smith MP, then started to act on promises made in his Conference speech earlier in the year of a Task force to consider how best to secure comprehensive, enforceable civil rights for disabled people within the context of wider society, and to make recommendations on the role and functions of a Disability Rights Commission. However the extent to which legislation might occur within the lifetime of the present Parliament may well depend on the movement's capacity to build support and maintain pressure on the government. Much less doubtful is that the DDA, warts and

all, is here to stay for some time, perhaps until Labour has worked out its wider rights programme which includes the incorporation of the European Convention on Human Rights into UK law.

At the start of 1998 new tensions have arisen not just because of the slow progress on comprehensive civil rights legislation, but also over the intentions of new Labour on welfare reform. The focus in the opening weeks of the new year is on Labour's review of disability benefits, an element of state welfare which, in disabled people's experience, is clearly in need of reform. Under Labour, the hope was that this task would be undertaken positively but the opening gambits have suggested that a crude cost cutting exercise is afoot and that, in order to fulfil its election pledges, the government is simply finding money where it feels it is likely to meet the least resistance. On community care, one of the last gasps of the outgoing Tory government, under pressure from the disabled people's movement, was to introduce legislation allowing local authorities to make direct payments which would enable disabled people to pay for and control their own personal assistance needs. Such direct payments are discretionary, the eligibility criteria are tight and social services departments still assess, decide how much and control the conditions under which the cash is doled out. There is thus much room for improvement since the disabled people's movement regards the right to independence and the resources needed to enable them to live full and productive lives as a fundamental human rights issue. However, the detail of Labour's overall policy on disability benefits and community care in relation to its welfare to work proposals and within its wider rights agenda, has yet to become clear.

The need to resolve the tensions arising from such uncertainties is becoming as important to government popularity as it is for disabled people. The social model of disability demands an holistic approach to disability policy and a social welfare system which is geared to support it. Finkelstein and Stuart have speculated about the kind of services that might emerge if social model principles informed the facilities needed by disabled people. In their view, such a future system would need to ditch the medical model 'cure or care' approach in favour of provisions which recognise disabled people's rights, empower and enable them to control their own lives. Such a system would "...be conceived in terms of 'support' and would acquire an enabling role in the same way that public utilities (eg. postal services, railways, water and electricity supplies, etc.) are created by able-bodied people for able-bodied people to enable more satisfying lifestyles. As such, they (would) form part of the necessary public support network which enabled both full participation in society and citizenship rights." (Finkelstein and Stuart, 1995).

Where the new Labour government stands on such matters remains to be seen and, at this stage, disabled people are not anticipating very many radical changes in basic assumptions about the nature of the problems they face. They are aware that the disability industry has gathered a lot of power in the four centuries or so of its development since the Old Poor Laws. They are aware that powerful vested interests, both political and professional, calculate that they have more to gain from keeping disabled people dependent than from liberating and supporting their independence. The political climate may be changing, but the battle for disabled people's citizenship rights remains to be won.

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NOTE

Ken Davis is a disabled activist who became interested in disability issues a few years after an accident left him with a spinal injury whilst serving in the RAF in 1961. He is a founder member of a number of disability organisations including the Union of the Physically Impaired, DIAL UK, Derbyshire Coalition of Disabled People and the Derbyshire Centre for Integrated Living. A former miner and Labour councillor, he now lives in Clay Cross.