

English language version of:

Sapey, B. (2010) Politique du handicap: un modèle basé sur l'autonomie des personnes, *Informations Sociales*, 159, pp. 128-137.

Disability Policy: a model based on individual autonomy

Bob Sapey

Abstract

This paper examines the importance of a social model of disability for the UK disabled people's movement and how this has informed thinking about disability policy. The paper looks at changes in UK disability policy since 1948 and the move from institutional modes of welfare provided since the 19th century to the emerging policy of personalisation in which disabled people are expected to control their own care. The conflicting aims of disability policy and the aspirations of disabled people are discussed. The paper describes the changing role of social workers and considers some implementation issues that have arisen.

Introduction

Disability policy in Britain is undergoing some significant change. Over the last 15 years there has been a shift away from treating disabled people as passive recipients of welfare to viewing them as people with rights and the capacity to control their own care. There has also been recognition of the existence of disability discrimination and several attempts to make it illegal.

The rights and responsibilities agenda is connected to neo-liberal/ third way policies and is responsible for the introduction of social policy packages such as direct payments which enable people to pay directly for their own care. While a policy such as this appears to place the individual in a position of control, in its delivery it is not entirely what it seems, as for example a package such as direct payments is subject to fiscal restraints which are managed by social service departments. The disabled people's movement, in campaigning for an inclusive society, is highly critical of the form that recent government policy on anti-discrimination and social inclusion has taken, on the grounds that the rights that have been gained are situated within government neo-liberal policy rather than within the aims of independent living as set out by the disability movement. Despite anti-discriminatory legislation, government policy continues to focus on the individual as the problem rather than on the social context of disability.

The social model of disability

Since the 1960s, disabled people in Britain have conducted an organised campaign for independent living. A key point in the history of this movement was the publication of *Stigma*, a collection of essays about the experience of disability (Hunt 1966). Hunt's aim in this book was to avoid the

sentimentality or tragedy usually associated with writing by disabled people and to focus on the political experience of disablement. Paul Hunt went on to initiate the formation of the Union of Physically Impaired Against Segregation (UPIAS), which politicised the oppression of disabled people who were segregated by the system of care in the UK. This system offered disabled people few opportunities for economic and social inclusion and often resulted in forcing them to live in hospitals or nursing homes as it still does. The aim of UPIAS was to change disability policy so that disabled people would be in control of their own support services and could choose where and how to live. They argued for an incomes policy that would compensate disabled people for the additional costs they incurred as a result of their disability, hence giving individuals control over how they met their own needs. But the big idea of UPIAS that encompassed such strategies was to change the way the problems associated with disability were defined as individual, rather than social issues (UPIAS and Disability Alliance, 1976).

At that time the dominant definitions used by policy makers and practitioners in Britain (Harris 1971) and elsewhere in the world (Wood, 1981) held that disease led to the impairment of bodily functions which in turn restricted what people could do (disability) and as a consequence limited their participation in society (handicap). Policy and practice were therefore based upon the assumption that any restrictions or disadvantages that disabled people faced in their lives was the result of disease, an unfortunate chance event for the individual. What the founding members of UPIAS argued was that the social, economic and political disadvantages disabled people faced were due to their exclusion by others. These ideas were developed by Oliver (1983) into the social model of disability which quickly became the focus of disability politics in the UK. The social model informed the policy and practice changes sought by the disability movement in many spheres of life – for example health, education, employment and care. Moreover the model also had a positive impact on individual self esteem; many disabled people have described how they learned not to blame themselves for their disadvantage when they learned to understand disability as a social relationship.

The social model is not without critics and much theoretical work has been done to try and broaden the idea, particularly to be more inclusive of the experience of impairment and of the psychological and emotional experiences of being oppressed (Thomas 1999). However, others argue that the social model has become too dominant and that it constrains the way the UK disability studies academy thinks about disability issues (Shakespeare 2006). Shakespeare argues for an approach similar to the ICF (International Classification of Functioning, Disability and Health) (World Health Organisation 2002) which aims to combine the functioning of the individual with the social context of disablement. His criticism tends to gain support from professionals involved with disabled people and from academics in many parts of the world, especially Scandinavia, however within UK disability studies, the social model of disability continues to be seen as fundamental to the struggle for political change.

Drake (1999) argued that approaches to disability policy can be described in terms of their intention towards disabled people and these include: eradication; ignore and deny; isolation in institutions; integration for some; adjust environment and; acknowledge citizenship. From the 18th to the end of the 20th century it is possible to identify strands of the first five of these within UK disability policy. It is not however, until the arrival of anti-discrimination legislation and direct payments that there is any sign of acknowledgment that citizenship and civil rights may be part of the policy makers'

intentions. Subsequent government policy papers have identified the values which underpin citizenship and which it is claimed should apply to all vulnerable groups in society¹. Sadly, there is little sense in trying to apply such principles within the institutional settings in which many disabled people remain incarcerated. Piggott and Grover's (2009) analysis of developments in unemployment and incapacity benefits would also suggest that it should not necessarily be assumed that policy equals practice, and that there never has been an intention to apply these principles in any meaningful way. Furthermore, they argue that recent changes have made the criteria and conditions for receipt of benefits much tougher and that failure to conform to the way the government believes disabled people should behave could result in considerable loss of income.

Doubts about the extent to which disabled people can call the changes a success are also raised by the toll taken on the disabled people's movement. Since the mid 1990's the leading organisations have become weaker and the debate as to how and why this collapse has happened continues. However, one of the key issues concerns whether an individual rights-based approach within a market of care has compromised the principles of the social model of disability, leading to the loss of a unifying idea (see Oliver, Barnes and Finkelstein in Oliver 2009:133-153).

The institutional care

In 1948 the post-war Labour government passed the National Assistance Act as part of their attempt to bring in a system of universal health, welfare and social security, but personal social services remained subject to administrative assessment by local government officers and this perpetuated the dehumanising way in which services had been provided under the Poor Law (Sapey 1993). Twenty years later the UK parliament voted for a range of community services to be made available, making, amongst other things, public buildings accessible (Chronically Sick and Disabled Persons Act 1970). However these provisions were not financially supported by central government, hence services were developed piecemeal by local authorities. A further twenty years on and the NHS and Community Care Act 1990 was passed, its main aims being to create a mixed economy of care so as to reduce the role of local authorities.

Disabled people continued to campaign for civil rights and independent living and many were quite sceptical about the ideology of these free market reforms. Morris (1993) was very critical of the implications of the words used to describe the policy, *Caring for People*. In her view this perpetuated the control of disabled people by their carers and she argued that people wished instead to be 'cared about'. In 1994, Roger Berry MP tabled a private members bill in the House of Commons, the Civil Rights (Disabled Persons) Bill. Like the ten parliamentary bills on this subject that had gone before, this one was drafted in conjunction with the disabled people's movement. It received support across political parties and in both houses of parliament, but failed at the final stage when it was forced to run out of time by the Minister for the Disabled. The backlash this time was severe and the minister, Sir Nicholas Scott, had to resign after a campaign in which his daughter was a leading protestor. The government responded by introducing their own bill which became law the following year – the Disability Discrimination Act 1995. This act was widely criticised at the time as lacking teeth and being based on an individual model of disability. Opponents from within the disabled people's movement would have preferred legislation that obliged society to be accessible rather than giving disabled people the right to take individual action when they experienced

¹ I am grateful to my colleague Linda Piggott for her analysis of government policy documents.

discrimination. However, the act has since been amended to increase its scope and has become one of the foundations of the current approach to disability policy in Britain. For the first time it became possible to view access and inclusion as legally enforceable issues and over time this law has gained in strength, an outcome that Whitfield (2008) has argued was intended by those who drafted the original bill.

In 1990s, a number of Centres for Independent Living were pursuing new approaches to organising social welfare. This involved disabled people directly employing their own care staff, rather than officials of the local authorities doing it for them. Research from within the disability movement (Oliver and Zarb 1992; Zarb and Nadash 1994) found that the quality of life of disabled people was significantly improved when they were able to purchase their own personal assistance and that they were able to do so more efficiently than could large local authorities. In the political climate of that time such an approach to independent living had much appeal to the government as it fitted with their privatisation and marketization policies. The government response was to pass the Community Care (Direct Payments) Act in 1996. Initially social service authorities were permitted to offer cash payments in lieu of care services to disabled adults below retirement age, but by 2004 this had not only been extended to all community care service uses, but it also became a right. Since then the policy of personalisation of care has attempted to give similar control over resources used to provide access in other sectors such as housing and employment. The government describe these changes as moving,

... from the model of care, where an individual receives the care determined by a professional, to one that has person centred planning at its heart, with the individual firmly at the centre in identifying what is personally important to deliver his or her outcomes.

(Department of Health 2008:4)

Although the language of this policy – self directed support, individual budgets – continues to reflect the market principles unpinning politics in the UK during the past 30 years, it does represent at least a partial success in the campaign for civil rights.

Social workers as care managers

One of the UPIAS strategies was to campaign for independent living as a right. However, by the mid 1980s the main concern of the British government was the spiralling costs of social welfare brought about by prime minister Margaret Thatcher's attempts to encourage the privatisation of social care. Her government had been funding private care providers to the point where the funding mechanism was out of control and furthermore, virtually all the increase in expenditure was for segregated care (Audit Commission 1986). Their aim through the NHS and Community Care Act 1990 was to control expenditure through the mechanisms of the marketplace which they tried to achieve by giving yet more authority to local councils and their social care administrators. Social workers became care managers and disabled people became service users as the language of welfare adapted to the ways of the market.

The role of care managers was to assess individual need, to purchase the care services that were required by disabled people to meet those needs and then to regularly review that need in order to know if the services were still required. The title care manager was chosen instead of case manager so as to focus the role of social workers on managing budgets, rather than to continue the individual

casework model that had dominated social work since the 19th century. At the same time computerised assessment and review systems were brought in which led to greater standardization and to some extent changed the social work role to one of data inputting (Sapey, 1995). Whilst some social workers were resistant to this change, others embraced the idea that they were managers and that they were working with a new technology. Many local authorities also split their staff into two groups, the purchasers (care managers) and the providers, those who retained a more traditional social casework role; the latter being commissioned by the former. While all the changes that had occurred to the organization of social care since 1948 had assumed a continuing role for social work, the consultation over personalisation asked a different question.

Do you think that there should be professional social work involvement in some or all assessments?

(Department of Health, 2005:37)

While the outcome of that consultation is that social workers will be expected to act in more of an advisory role, the question itself signified the wish to focus on the relationship between disabled people and welfare services rather than leaving that to professionals.

Oliver (2004) suggests a useful model for analysing the implementation of welfare policy with three identifiable approaches – humanitarian, compliance and citizenship. With the humanitarian approach, services are provided out of goodwill to individuals perceived as less fortunate, but the providers remain in control. This was reflected in the 1948 decision to leave the decisions about what was needed with welfare administrators (local government officers) and although service users were expected to be grateful, instead they have been very critical. In the compliance approach providers adopt a minimalist approach to meeting the legislation and this has become more common as disability policy has focused on rights. This approach will often focus on basic physical needs rather than social inclusion and will cause immense dissatisfaction. The citizenship approach which disabled people hope will emerge from the personalisation policy is one in which disabled people are treated as full citizens with rights and responsibilities. They are valued as workers, as service users and as voters.

However, research into the provision of direct payments tends to suggest that a citizenship approach is rare. Implementation varies according to the political control of welfare, with authorities controlled by Conservative more likely to adopt the market approach (Barnes *et al.* 2004). Practitioner enthusiasm may vary so that while some social workers sympathetic to the schemes were working within less enthusiastic organizations (Stainton 2002), others have felt their professional status is threatened by the changes and have argued that disabled people are too vulnerable to be allowed to control their own lives (Glasby and Littlechild 2002). The result is that the spread of direct payments has varied both geographically and by service user groups, with some groups such as people with mental health problems, receiving virtually no service at all.

Conclusion

The government discourse is about change and citizenship, but their critics from within the disabled people's movement suggest that the policy of personalisation may in fact be a compliance approach, designed to appease disabled people but in reality following an individualised understanding of disablement. The government guidance on implementing this policy (Department of Health 2008)

calls for social workers to become advocates and brokers instead of assessors and gatekeepers. This could mean a significant and long overdue shift in their relationship with disabled people, but social service authorities will still retain control via the financing of care. One of the major deficiencies of the 1948 welfare reforms was the failure to remove the local authority welfare administrators from their role as the arbiters of need and consequently as the people who design and distribute services. That role has been reinforced, supported and capitalised on by politicians of all persuasions since the 19th century. Much more will have to be done to ensure that the current policy can be implemented in ways that meaningfully change the experience of disabled people.

References

- Audit Commission (1986) *Making a reality of Community Care*, London, HMSO.
- Barnes, C., Jolly, D., Mercer, G. Pearson, C., Priestley, M. and Riddell, S. (2004) Devolving direct payments: A Review of policy development in the UK, paper to the *Disability Studies: Putting Theory into Practice* conference, Lancaster University, July 26-28, 2004
- Department of Health (2005) *Independence, Well-being and Choice: Our vision for the future of social care for adults in England*, Cm 6499, London, Department of Health
- Department of Health (2008) *Local Authority Circular: Transforming Social Care*, LAC (DH) (2008)1
- Glasby, J. and Littlechild, R. (2002) *Social Work and Direct Payments*, Bristol, The Policy Press.
- Harris, A. (1971) *Handicapped and Impaired in Great Britain*, London, HMSO
- Hunt, P. (1966) *Stigma: The Experience of Disability*, London, Geoffrey Chapman
- Morris, J. (1993) *Community Care or Independent Living*, York, Joseph Rowntree Foundation
- Oliver, M. (1983) *Social Work with Disabled People*, Basingstoke, Macmillan
- Oliver, M. (2004) 'The Social Model in Action: if I had a hammer' in C. Barnes and G. Mercer (eds) *Implementing the Social Model of Disability: Theory and Research*, Leeds, The Disability Press.
- Oliver, M. (2009) *Understanding Disability: From Theory to Practice*, Basingstoke, Palgrave Macmillan
- Oliver, M. and Zarb, G. (1992) *Greenwich Personal Assistance Schemes: An Evaluation*, London, Greenwich Association of Disabled People
- Piggott, L. And Grover, C. (2009) Retrenching Incapacity Benefit: Employment Support Allowance and Paid Work, *Social Policy & Society*, 8(2) 159-170
- Sapey, B. (1993) Community Care: Reinforcing the Dependency of Disabled People, *Applied Community Studies*, 1(3) 21-29
- Sapey, B. (1995) Social Services and Communication Technology: a User Perspective of the Implementation of a Care Management System in a Social Services Department, *New Technology in the Human Services*, 8(1), pp. 2-9.
- Shakespeare, T. (2006) *Disability Rights and Wrongs*, London, Routledge
- Stainton, T. (2002) Taking Rights Structurally: Disability, Rights and Social Worker Responses to Direct Payments, *British Journal of Social Work*, 32, 751-763.
- UPIAS and Disability Alliance (1976) *Fundamental Principles of Disability*, London, Union of Physically Impaired Against Segregation and The Disability Alliance
- Whitfield, G. (2008) *Bringing the social model of disability to bear in the making of government policy: Some observations on eureka moments and years of utter frustration*, unpublished paper for CeDR Seminar, Lancaster University, 9th December 2008

Wood, P. (1981) *International Classification of Impairments, Disabilities and Handicaps*, Geneva, World Health Organisation

World Health Organisation (2002) *Towards a Common Language for Functioning, Disability and Health: ICF*, Geneva, World Health Organization

Zarb, G. and Nadash, P. (1994) *Cashing in on Independence*, London, Policy Studies Institute for the BCODP