

Understanding welfare: Social issues, policy and practice



UNDERSTANDING SOCIAL CITIZENSHIP

SECOND EDITION

Themes and perspectives for policy and practice

Peter Dwyer

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Understanding welfare: Social issues, policy and practice

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Disabled citizens?

In the past, many theorists from a wide range of mainstream political positions (for example, liberal, communitarian and Marxist) have been content to follow 'commonsense' ideas about disabled people lacking the capacities required to function as 'normal' citizens (Handley, 2003). T.H. Marshall's famous account of citizenship, for example, fails to consider issues of impairment and disability. However, his emphasis on the rights and responsibilities of able-bodied males, and the fact that many disabled people fail to enjoy basic citizenship rights in any substantive sense (Oliver and Barnes, 1991; Barton, 1993; Barnes et al, 1999; Barnes and Mercer, 2003), suggest that it would be premature to consider many disabled people as equal members of the community of citizens that Marshall envisaged. Issues of impairment and disability continue to raise a number of important questions about the potential for and limitations of citizenship. The following three areas are discussed:

- individual/medical models of disability;
- disabled people as active citizens;
- disability and welfare policy: progress under New Labour?

A social understanding of disability

Disabled people and their organisations have long articulated demands for a recognition of their rights as equal citizens (Oliver, 1996). Angered by a dominant, professionally constructed and administered 'medical model' of disability (intrinsicly linked to ideas of dependency), they have challenged by developing, alongside like-minded intellectuals, a *social model* of disability which focuses on the disabling attitudes, environments, practices and policies that are prevalent in contemporary society (Oliver, 1990, 1996; Barton, 1993; Barnes and Mercer, 1997, 2003). In **Box 7.1** Barnes et al

(1999) discuss how the *medical model* reinforces ideas of abnormality based on presumptions of individual biological and/or physiological inferiority.

Box 7.1: Individual/medical and social models of disability

The individual model

The focus is on bodily 'abnormality', disorder or deficiency, and the way in which this in turn 'causes' some degree of 'disability' or function limitation. For example, people who have quadriplegia cannot use their arms and are therefore unable to wash or dress themselves. However, this functional 'incapacity' is used as the basis for a wider classification of the individual as (an) 'invalid'. Once they have been categorised in this way, the 'disability' becomes their defining characteristic and their incapacity is generalised. This forms the basis for a 'personal tragedy' approach, where the individual is regarded as a victim and someone who is in need of 'care and attention', and dependent on others – a perspective which has been at the heart of contemporary social welfare policies designed to help disabled people cope with 'their disability' (Oliver, 1983, 1990; Finkelstein, 1993).

The recommended solution lies in curative and rehabilitative medical intervention, with an increasing involvement of allied health practitioners, psychologists and educationalists. To acquire an impairment is to become the object of professional attention.... The basic concern is to diagnose the bodily or intellectual 'abnormality' and advise on appropriate treatment.

The social model

In developing what became known as a social approach to disability, disabled people in Britain argued that it is society which disables people with impairments, and therefore any meaningful solution must be directed at societal change rather than individual adjustment and rehabilitation. The social model riposte to the individual medical approach is that 'disability is not the measles' (Rioux and Bach, 1994).

The Union of the Physically Impaired Against Segregation (UPIAS) was in the vanguard of those calling for an alternative model of disability. In its manifesto document *Fundamental principles of disability* (1976), UPIAS placed the responsibility for disability squarely on society's failures: 'In our view it is society which disables physically impaired people, disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society' (UPIAS, 1976, p. 14) ... the meaning of disability was turned on its head:

- *Impairment*: lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.
- *Disability*: the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. (UPIAS, 1976, pp 3-4)

Subsequent discussions among disabled people and their organisations have amended reference to physical impairments so that any impairment (including sensory and intellectual examples) falls within the potential scope of disability.

Whereas impairment is regarded as an individual attribute, disability is not. Instead, it is described as 'the outcome of an oppressive relation between people with ... impairments and the rest of society' (Finkelstein, 1980, p. 47).

Source: Barnes et al (1999, pp 21, 27-8)

In contrast to the individual/medical model, the social model locates disability firmly in the social sphere. Central to this approach is the assertion that people with impairments are no different from everyone else in that, as individuals, they differ in the range of things that they can and cannot do. Impairment affects the ways in which an individual's body and mind functions, but the quality of life enjoyed by disabled citizens is determined by a society's reaction to impairment (Williams, 1995). According to the social model, disability comes from:

The failure of a structured social environment to adjust to the needs and aspirations of citizens with disabilities rather than from the inability of disabled individuals to adapt to the demands of society. (Hahn, 1986, p. 132)

This failure to consider fully the needs of individuals with impairments denies disabled people their citizenship rights. Barnes (1991, 1992; Barnes et al, 1999) outlines how disabled people have long faced institutionalised discrimination in most areas of their lives. Pointing to a combination of enforced segregation within the education system, the labour market and various welfare services, and a hostile physical environment, Barnes argues that disabled people are effectively denied the civil, political and social rights that are central to the notion of citizenship. As Oliver (1996) notes, the state has played a central role in this marginalisation. Disabled people have identified structures, policies and professional practices within state welfare provisions that have exacerbated their social exclusion and promoted dependency. Arguably the citizenship rights for disabled people remain firmly anchored in rhetoric rather than reality (Barnes and Oliver, 1995).

The medical and social models of disability have been the subject of much subsequent debate. Morris (1991) and other feminist critics have, for example, questioned the extent to which the social model may obscure the different personal experiences of disabled people. A good short basic overview of these debates and critiques is offered in Handley (2003); Priestley (1998) also provides a useful discussion.

Active citizens

The struggles of disabled people for equality and recognition, and for their right as people with impairments to exercise full and effective membership of society, are ongoing (Priestley, 2003). In Chapter Four it was noted how a particular type of active citizenship has been constructed by the New Right that, to a certain extent, has been subsequently adopted by 'third way' thinkers and governments. Central to this notion of the *active citizen* is the idea that individuals should, whenever possible, assume responsibility for their own and their family's welfare via paid employment. Such responsible, active citizens also accept that charitable works, that is, the giving of private time and/or money to deserving, less fortunate members of the community, is also necessary. The collective struggle of disabled people's organisations and their allies provides an alternative model for active citizenship, one that is arguably more positive.

A number of authors (Oliver, 1996; Oliver and Barnes, 1998; Barnes and Mercer, 2003) outline and discuss the important role played by coordinating organisations run by disabled people themselves (for example, UPIAS [Union of the Physically Impaired Against Segregation], Disabled Peoples International, British Council of Organisations of Disabled People [BCODP]) in the long struggle for rights. As **Box 7.1** indicates, organisations such as UPIAS were at the forefront of the development of the social model of disability that refocused debates around impairment on issues central to citizenship. Indeed, organisations run and managed by disabled people (often referred to by the shorthand term the Disabled People's Movement [DPM]) have become an integral part of the wider challenge, by various new social movements, to the exclusive and paternalistic citizenship of the PWWS (see Chapter Four, this volume).

Marginalised by mainstream politics, the DPM has combined lobbying and direct action to force the claims of disabled people onto the welfare agenda (Barnes and Mercer, 2003). It has denounced the ways in which disabled people's welfare services have often been couched in the language of 'special needs' and instead has sought to articulate a challenge that combines the language of equal citizenship with an active struggle for rights. They have contested the traditionally dominant image of disabled

people as passive recipients of welfare, who lack both the competence to make decisions about their own needs and the ability to act as citizens in their own right (Oliver and Barnes, 1998). Increasingly, disabled people and their organisations have called for the right to define their own needs and for the autonomous definition and control of any welfare services that they may require to facilitate independent living (Oliver, 1996). The status of disability activists as 'active citizens' is thus confirmed through their ongoing acts of dissent and participation in a collective struggle for the rights that full citizenship should entail. In turn, the extension of such rights will offer many new possibilities for meaningful participation and increase both the individual and collective autonomy of disabled people within society. It is important to remember, however, that the struggles of disabled people are not solely about rights. Disabled people are also seeking to assume relevant responsibilities on a par with non-disabled citizens. They are looking to assume control of their own lives. Campaigns around independent living and the right to meaningful paid work are about empowering people with impairments and enabling them, whenever possible, to assume increased responsibility for their own welfare. The extent to which changes in welfare policy since the 1990s have helped to facilitate this process are considered next.

Disability and welfare policy in the UK: progress under New Labour?

The introduction of a number of UK policy reforms of significance for disabled people has been a feature since the 1990s. This section focuses on policy changes in three important areas, namely: social security benefits, 'community care' and anti-discrimination legislation. In part changes in policy and/or the organisation and delivery of welfare in these sectors can be seen as evidence of the success of the disabled people's organisations in getting their concerns onto the political agenda (Handley, 2003). Certainly, many of the assumptions made in relation to the respective rights and responsibilities of the state in meeting the needs of disabled people are being increasingly questioned. This is particularly evident when reforms of the social security benefit system are considered.

Work, welfare and disability

Disability is typically characterised by high levels of unemployment, poverty and social exclusion (Howard et al, 2001, ch 3). Research suggests that more than half of the disabled people who do not work would like to engage in paid employment, with many also believing that they are discriminated

against in the PLM (Heenan, 2002). As Hewitt (1999) notes, the New Labour government is keen to emphasise the right of disabled people to play a full role in society (DSS, 1998a). This crucially includes the right to work, which, as previously noted, the government now regards as *the* central duty of citizenship. Since its return to power in 1997, a central part of New Labour's approach has been to challenge certain assumptions about paid work, welfare and disabled people that have long been taken for granted. In 1997 the Social Security Advisory Committee (SSAC) reviewed policy options in relation to disabled people and the government's desire to promote work as the best form of welfare. It came up with four issues for further consideration (SSAC, 1997, pp 2-3, quoted in Hewitt, 1999, p 158):

1. The extent to which the benefit system should make provision for long-term sickness or disability (other than the additional costs directly attributable to disability) at a different rate from that of long-term unemployment benefit.
2. Whether ... the benefit system should reward those who have previously worked to a greater extent than those who have not, or have been unable to work.
3. Whether it is practical to develop a structure that provides greater incentive for those currently treated as incapable of work ... to move from benefit dependency into work, to at least some extent, without unfairly penalising or stigmatising those who are incapable of work.
4. Whether ... a structure can be developed that encourages those who can work, either for a part of a week or episodically, or can work full-time but with a limited capacity, but does not penalise those who, having attempted to do so, cannot, for good reason, sustain the attempt.

The backdrop for these deliberations was the increasing amount of social security expenditure going on benefits for sick and disabled people. Figures indicate that costs rose from £5 billion in 1979 to around £24 billion in 1996/97, although arguably they had peaked by this date (Hyde, 2000).

In the past both governments and citizens have generally tended to support the claims of long-term sick and disabled people for social security for two reasons. First, because disabled people meet commonly held views about legitimate need for the provision of financial support and care through the public welfare system. Second, because the cause of their inactivity in the PLM is seen by many as being beyond their control. In short, questions about whether disabled people are choosing to be idle are generally perceived as having little relevance because their inability

to work is 'obviously' linked to an individual impairment (see Dwyer, 2000a). These views may reflect wider ideas about disabled people being a 'deserving' case for largely unconditional collective support. It is important to note that such views have been identified as disabling by disabled people's organisations. Barnes (1992), for example, discusses how disabled people have challenged such discriminatory views and demanded the eradication of disabling attitudes and environments, so that they can realise the right to paid employment. Indeed, New Labour could possibly claim that their social security benefit reforms are motivated by a desire to encourage disabled people into work and support the wider right to work agenda of the DPM. Alternatively, perhaps they are indicative of a broader attempt to diminish the welfare role of the state, reduce costs and redefine social citizenship, so that entitlement to benefit becomes, whenever possible, conditional on accepting the obligation of paid work (Dwyer, 1998, 2000a; Hewitt, 1999; Hyde, 2000).

Certainly disabled people's access to benefits has been subject to a number of significant changes as part of a more general restructuring of social security provision in Britain (see Chapter Five). The previously noted approach of the SSAC appears to be focused on encouraging as many people as possible, who are currently in receipt of disability benefits, back into paid work, without simultaneously penalising 'genuine' claimants who cannot work because of impairment. As Hyde (2000) notes, in the past the system of disability benefits has been criticised for being expensive and failing to lift those disabled people dependent on benefits out of poverty. Also, prior to recent reforms (see **Box 7.2**), it could be argued that arrangements for the payment of special benefits to those who were long-term unemployed because of impairment created an administrative category of disability which effectively exempted those labelled in this way from having to take up the responsibility of paid work. The more rigorous approach to the administration of long-term out-of-work benefits by New Labour has attempted to tackle what it saw as the perverse incentives of the disability benefit system that it inherited.

Both 'carrots' and 'sticks' are part of New Labour's reforms. The carrots take the form of a range of incentives to encourage disabled people into work. These include benefit enhancements (see **Box 7.2**) to ease the transition from welfare to work and tax credits specifically for disabled people who enter the PLM. The accompanying reductions in eligibility for benefits (people who fail the capability assessment are deemed capable of work and excluded from entitlement to benefit), and the requirement that claimants attend a job-focused interview as a condition of eligibility, help to ensure compliance. The abolition of Incapacity Benefit and its replacement with Employment and Support Allowance (ESA) under the 2007 Welfare

Box 7.2: Carrots and sticks: disability benefit reforms under New Labour

New Deal for Disabled People (first piloted in 1998)

- Targeted at those in receipt of Incapacity Benefit or Severe Disablement Allowance who must attend a work-focused interview.
- A guarantee that people can return to their previous level of benefit at any time within 12 months of taking a job.
- Job finders grant of £200 for each client.
- £50 a week top-up of pay for those taking part-time jobs for a period of six months.
- £75 per week to employers for six weeks following recruitment.

1999 Welfare Reform and Pensions Act

- A strengthening of the link between work and entitlement. Only those who have recently been in work and paid NI contributions are now eligible for Incapacity Benefit.
- New claimants of Incapacity Benefit must see a personal advisor for an interview about routes back into work as a condition of eligibility.
- The 'all work test' (since renamed the capability assessment) is introduced. This refocuses the medical examination used to determine eligibility for incapacity benefits to emphasise a claimant's capacity for work rather than their impairments.
- Introduction of the means testing of Incapacity Benefits. People in receipt of occupational or private pensions will have the benefit reduced by 50p for every pound these pensions rise above £85.

2007 Welfare Reform Act

- New rules introduced to phase out Incapacity Benefit.
- From October 2008 Employment and Support Allowance (ESA) paid to new claimants who are unable to work because of illness or disability.
- The majority of ESA claimants placed on a lower (that is, JSA rate) benefit for 13 weeks while their claim is assessed.
- The majority of ESA recipients expected to attend WFIs or undertake work-related activity as a condition of continued receipt of ESA.
- A minority of ESA recipients with severe impairments not subject to conditionality.

Sources: for more detailed discussions, see Hewitt (1999); Hyde (2000); Heenan (2002)

Reform Act (see Chapter Five, this volume, for more discussion) further emphasises the government's view that the vast majority of disabled people in receipt of disability benefits should be actively looking for paid work. Hyde (2000) identifies three ways of understanding the shift in approach that has occurred in relation to disabled people's rights to social security benefits. First, changes can be seen as part of a wider ideological shift towards conditional welfare inspired by New Right thinkers and taken up as part of 'third way' welfare reform, as discussed in Chapters Four and Five, this volume. Second, as previously noted, they may be part of a cost-cutting exercise. Third, the process can be understood as part of a wider economic strategy in which labour market policy aims to regulate workers, in order to promote low-paid work and provide a reserve army of cheap labour that meets the needs of capital (cf Grover and Stewart, 2000, 2002; Prideaux, 2001).

Although she acknowledges the concerns of critics (Barnes, 2000; Drake, 2000; Hyde, 2000; Roulstone, 2002), and recognises that the New Deal for Disabled People (NDDP) has its shortcomings, Heenan (2002) offers a more positive appraisal of the scheme. She points out that the NDDP has four main elements: schemes to explore pathways into employment, a personal adviser for each client, an information and research campaign to educate both clients and employers and an evaluation of initiatives. Informed by a qualitative user-focused study, Heenan argues that the NDDP is underpinned by an enabling, rather than coercive, ethic, which provides opportunities for disabled people to enter paid work if they wish. Overall Heenan's respondents were positive about the scheme, particularly the work of client advisers and the involvement of the voluntary sector. The voluntary organisation that won the contract through competitive tender for running the scheme was seen by respondents as more trustworthy and approachable than the state. A number of clients reported problems with government benefit personnel in the past. The personal adviser's role was seen as a fundamental factor in the successful transition to work. Respondents noted that emotional as well as practical support was offered, and many highlighted the importance of a period of 'in-job' support following employment.

Critics such as Drake (2000) and Hyde (2000) remain unconvinced. Both believe that satisfactory opportunities for the meaningful employment of disabled people are few and far between. They argue that the current benefit system fails to provide genuine social citizenship rights for disabled people who do not work:

In sum, the government has restructured social security so that the system focuses more narrowly on people with

severe impairments, older disabled people (that is, those over pensionable age) and disabled children. (Drake, 2000, p 430)

The latest reforms of social security provision (that is, the Welfare Reform Acts of 2007 and 2009) appear likely to herald an era in which benefit recipients (including many disabled people) will increasingly be subjected to the personalised conditionality regimes championed by Gregg (2008). The promise of more intensive individualised support alongside this to enable individuals back into paid work may not be enough to ensure meaningful employment for many. As Barnes (2000) reminds us, personal advisers and schemes to change employers' attitudes have been tried before and failed. Throughout their period in office successive New Labour administrations have introduced a complex range of reforms for disability benefits. The main outcomes of these reforms will be an increase in the number of disabled people who will face cuts in their social security benefits and/or have little choice but to return to paid work in the future. Disabled people have long struggled for the right to work, but it should be remembered that citizenship also involves the right to adequate social security. Recent reforms diminish rather than enhance that right.

Disabled people and community care

The community care policies of today have been fashioned by a range of changes and concerns that have emerged since the 1980s. A political desire to enhance consumer choice and promote a *mixed economy of care* was an essential part of the Conservative government's welfare agenda in the 1980s. A general recognition that state-run long-stay care institutions were outdated and inappropriate, and economic concerns about their costs, combined to bring community care to the fore. The basic idea behind *community care* is that older and/or disabled people who require care should be supported in their own homes whenever possible. In many cases this translates into familial carers (often, but not exclusively, women) caring for other members of their family (for a fuller discussion, see Parker and Clarke, 2002; Blakemore, 2003, ch 10).

The 1990s saw some significant care legislation enacted (see **Box 7.3**). The 1990 NHS and Community Care Act sought to rationalise the management of care. Local authority social services departments were charged with assessing and providing a package of care tailored to the needs of individual clients. The idea behind the creation of an internal market was, theoretically, to promote greater choice. Rather than a local authority having a duty to provide services directly, they were charged with making an assessment of an individual's needs and then putting together a package

of services (provided by a range of public, private or voluntary agencies) to best meet those needs. In reality many needs remained unmet due to the budgetary constraints placed on local authority social services departments (Blakemore, 2003). However, the ability of a majority of disabled people to exercise any consumer choice was also virtually non-existent, as those reliant on welfare benefits had to take what they were given by local social services departments (Barnes et al, 1999). Furthermore, feminist scholars had begun to highlight the contribution of familial carers in providing care in the home. The 1995 Carers (Recognition and Services) Act placed carers' needs at the centre of community care policy, a development that is not without pitfalls as far as those in receipt of care are concerned (Parker and Clarke, 2002). A conflict between the rights and agendas of disabled people and those of familial carers is a distinct possibility. Furthermore, conflicts of interest may also occur between disabled people who purchase care and the individuals they employ as personal assistants to provide it (Spandler, 2004).

Box 7.3: Significant community care legislation

1990 NHS and Community Care Act

The aims of the Act were to promote/prioritise the option of people being cared for in their own homes and the enhancement of consumer choice.

Created an internal (or quasi-) market system of social services. Local authorities required to act mainly as purchasers of services provided by a range of other private or voluntary organisations.

Local authorities required to draw up care plans that were based on 'client/needs-led' assessments.

1995 Carers (Recognition and Services) Act

Carers who provide 'care on a regular basis' to a person who has been, or will be, assessed for community care services are entitled to an assessment of their own situation.

Local authorities have to take into account the results of the carer's assessment when making decisions about services to be provided to the user.

1996 Community Care (Direct Payments) Act

Allows direct payment to be made to a disabled person so that they may purchase a package of care from a range of providers.

Local authorities have a choice of providing this option, rather than a duty to provide it.

2001 Health and Social Care Act

Extends the approach of the 1996 Community Care (Direct Payments) Act. Disabled people aged 16-18 are eligible to apply for direct payments, as are persons with a parental responsibility for a disabled child.

Concerns about such issues have informed the fundamental critique of community care developed by disabled people's organisations and certain academics. First, these critics argue that the very notion of 'care' may enhance the negative view of the person being cared for as 'dependent'. Second, they note that there is a tendency for community care to favour the language and approach of an individualised medical model of disability in which disabled people are seen as 'deserving' but rather unfortunate recipients of support. Third, they point out that the rhetoric of empowerment and choice may hide a reality in which a right to a measure of collective support is giving way to a norm of individually purchased and/or familial care (Morris, 1993; Barnes et al, 1999; Ackers and Dwyer, 2002; Parker and Clarke, 2002).

These issues have been central to the critique of community care developed by disabled people involved with the Independent Living Movement (see Morris, 1993). In many respects the 1996 Community Care (Direct Payments) Act can be seen as an outcome of sustained campaigns by disabled people for empowerment and increased control over their own lives. As **Box 7.3** illustrates, the Act gives local authority social services departments the power to make direct cash payments to individuals in lieu of community care services. The emphasis is on enabling users of services (that is, disabled and/or older people) to achieve maximum choice and control over their support services. Once a disabled person receives the payment directly they can purchase their care from any suitably qualified provider. However, local authorities are not duty bound to provide direct payments, but rather have the option of providing direct payments to users if requested. The legislation is also problematic in a number of other ways. The provision of direct payments still remains reliant on professional judgements about a person's needs and abilities. The requirement that a person 'possesses the mental capacity' to manage direct payments can rule out certain people. For example, Roulstone and Morgan (2009) note

that many people with learning difficulties are deemed to be ineligible to receive direct payments. Nonetheless, direct payments do help to facilitate independent living and empower significant numbers of disabled people, some of whom have been able to employ personal assistants for the first time. The government has been keen to endorse and expand this approach. In 1997 they extended the scheme to cover people aged 65 plus and the 2001 Health and Social Care Act further expanded its scope (see **Box 7.3**). In spite of the government's enthusiasm, it needs to be borne in mind that in the decade following the 1996 Community Care (Direct Payments) Act under 5% of those eligible for a direct payment were receiving one (Davey et al, 2007).

The various advantages and disadvantages of direct payments are noted in **Table 7.1**. Pearson (2000) discusses further the tension that exists between the two discourses commonly used to interpret direct payments, that is, empowerment and social justice and market-based consumerism. He notes the positive potential of direct payments, but questions whether they may yet be another example of the state attempting to distance itself from its welfare responsibilities and reduce its overall costs. A great deal also depends on how direct payment policy is implemented in different localities. The quasi-market system now in place encourages diversity between localities and this has important implications for the idea of social citizenship. Differing opportunities and rights to care, dependent on locality, ensue; some users will be able to access and make use of a range of options/providers and others will not. This may well be problematic for the idea of common citizenship and the notion of equality of status.

Individual budgets and 'self-directed' support: the next steps?

New policies are currently being implemented in England to further extend the choice and control available to disabled people and older people, in respect of the care and support they receive. As Glendinning (2008) notes, the language involved in several influential government policy statements has shifted with the term 'direct payments' being replaced by discussion of 'individual budgets', for example, *Improving the life chances of disabled people* (Cabinet Office, 2005), *Independence, well-being and choice: Our vision for the future of social care for adults in England* (DH, 2005) and *Opportunity age* (HMG, 2005). 'Individual budgets' moves things a step further on from 'direct payments'. The idea is that an individual budget would allow the various resources and funds to which an individual is entitled to be pulled together to enable people to secure a flexible range of care goods and services from a wider range of providers than those that are available under direct payment schemes. "For example an individual budget may

be used to pay informal carers (including close relatives living in the same household), or to purchase goods and services from local authorities" (Glendinning, 2008, p 454), both of which are not normally allowed under direct payment rules. A series of pilot schemes was established between 2006 and 2008 to explore how individual budgets may work in practice and these are currently being evaluated.

Table 7.1: Advantages and disadvantages of direct payments

Disadvantages	Advantages
The disabled person has to take on the responsibilities of an employer	Personal support is controlled by the disabled person
It can be time-consuming and complex; need to open and manage a dedicated bank account as required	A cost-effective way to provide care
Problems in interactions with local authority, for example late payment to dedicated account so no money to pay wages	Choice is enhanced Control over who enters your home Flexibility
In times of high employment it can be difficult to recruit people with the correct range of skills and attitude	Evidence to suggest improvements in quality of care Promotes autonomy/reduces dependency of disabled people

In a similar vein to earlier discussion around direct payments (see **Box 7.1**), underpinning the enthusiasm of those who advocate individual budgets is a belief that they enhance the control and choice available to older people and disabled people in need of care. As she makes clear in her discussion, Glendinning is, in principle, in favour of user choice and control, but she also recognises that their promotion within a quasi-market system may not be entirely straightforward for several reasons. First, choices in any real sense may be unavailable in particular areas. This point is endorsed by Roulstone and Morgan (2009), who argue that a 'lottery of provision' alongside localised 'professional ambivalence' may combine to deny individuals choice and control in any meaningful sense. Second, any access to choice, where it exists, may depend on the availability of relatives or friends who are willing and able to act as advocates to negotiate a suitable package care and support on behalf of a disabled or older person. Third,

many of the current providers of home social care who hold large block contracts with local authorities may be reluctant to become involved with a plethora of individuals, each holding a personalised direct payments account, particularly if they feel it reduces their capacity to service bigger and potentially more profitable contracts. Fourth, and linked to the previous point, it is possible that individuals who are seen as either troublesome or having complex or problematic care needs will effectively be excluded by providers who decline the opportunity to service particular older and/or disabled purchasers' needs.

Arguably the consumerist foundations on which the personalised direct payments approach is based undermine more traditional notions of collectivised citizenship. As previous discussions in this chapter have illustrated, it needs to be remembered, however, that such traditional notions of citizenship often excluded and stigmatised disabled people in the past. Where they are available and work well, the advent of direct payments and, more latterly individual budgets, not only enables disabled people to manage personalised care packages that meet their needs, but also offers a further significant advantage in respect of wider citizenship debates. Such policies offer disabled people real opportunities to exercise the duties associated with active citizenship which run counter to negative discourses that routinely associate disabled people with welfare dependency (Rummery, 2006). Nonetheless, as welfare policy looks to promote self-directed support by looking to promote the choice and control of disabled people and older people, care must be taken to ensure that the baby is not thrown out with the bathwater.

Policy has to account for a diversity of disabled people who may be at very different vantage points in terms of their readiness for self determination. Ironically, in moving away from the enforced collectivities of day services and the absence of a Centre for Independent Living or user-led organisation in every locality there is a risk of individual support solutions fostering enforced individualism and isolation. (Roulstone and Morgan, 2009, p 343)

Towards equal citizenship rights for disabled people?

The 1995 Disability Discrimination Act gives individuals the legal right to take employers to court if they feel they have been discriminated against because of their disability. However, a number of critics (Barnes, 2000; Gooding, 2000; Woodhams and Corby, 2003) have reservations about the ability of the Act to challenge wider disabling institutional practices and cultures. They note four main drawbacks. First, the Act is underpinned

by, and reinforces, the dominant medical model of disability. Impairment is seen as the cause of disability rather than wider social structures and organisation. Second, disabled people have to prove that they are disabled, as defined by the Act. A person is only considered disabled if they have:

A physical or mental impairment which has a substantial and long-term adverse effect on his [sic] ability to carry out normal day-to-day activities. (Section 1[1], cited by Woodhams and Corby, 2003, p 63)

If they fail to convince a tribunal on any one of the 'substantial', 'long-term' or 'normal' requirements, a claim against an employer is likely to be dismissed. Third, as the individual has to prove categorically that discrimination exists, only limited protection is provided. Fourth, the majority of employers are not covered by the Act. Although critics recognise that there needs to be a system for individual complaint, they also hold that a positive duty on employers to promote equality should be prioritised in anti-discrimination legislation.

Initially there was no official body to enforce, monitor and police the Act, but this changed with the establishment of the Disability Rights Commission (DRC) in April 2000. The Commission had the power to take up cases on behalf of disabled individuals or groups; however, it appeared to be more concerned to educate employers rather than challenge those with discriminatory employment practices. Barnes believes that:

Given the nature and extent of discrimination encountered by disabled people there is little here to suggest that the DRC will be any more successful than its contemporaries for gender and race. (2000, p 449)

He also argues that certain fundamental issues need to be tackled if the world of paid work is to become the norm for many disabled people. First, there is a need to tackle the issue of disabling environments. Workplaces, buildings and transport systems need to be made accessible to people with a variety of impairments. Second, there is a need to provide work that is 'socially and financially rewarding', rather than low-paid, low-status work that characterises the employment of many disabled people at present (cf Drake, 2000). Barnes (2000) believes that there is a need to enforce employment quotas on companies and that government could take the lead by setting targets for all state departments and agencies to employ disabled people. It could also ensure that only those private sector companies that employ a set quota of disabled workers are awarded government

contracts. The government could further help to facilitate an increase in disabled people's paid employment by shifting its funding priorities from mainstream voluntary sector organisations to those that are controlled and run by disabled people themselves. Many of these already actively recruit and employ a high number of disabled staff; the majority of charitable bodies that serve disabled people do not. Drake (2000) similarly argues that a league table of employment statistics could be set up by the DRC as part of a social inclusion audit, so naming and shaming employers who are not employing disabled people. Whatever the tactic, the government could, and should, be more proactive in setting the agenda for increasing disabled people's employment by tackling institutional prejudice and inertia. In October 2007 the government established the Equality and Human Rights Commission, which took on the work of its three predecessors which previously dealt separately with equality issues in relation to: gender (the Equal Opportunities Commission, or EOC), 'race' and ethnicity, (the Commission for Racial Equality, or CRE) and disability (the DRC). It remains to be seen if this umbrella body will be any better at advancing the rights and opportunities of disabled people in the future.

Tackling their systematic exclusion from full enjoyment of their rights as citizens has long been a key concern of the DPM. The legislation of the last decade, particularly in relation to direct payments and, perhaps, anti-discrimination, indicates that disabled people's organisations and their allies have enjoyed some success in influencing welfare policy. Nonetheless, disabling attitudes, practices and policies continue to exist in many public and private settings. While these remain, it is too soon to consider disabled people as full and equal citizens.

Summary

- A dominant medical model of disability that focuses on individual impairment and personal tragedy serves to individualise the causes and solutions of disability.
- The social model challenges this approach and shows how social and economic structures and institutionalised practices work to disable people with impairments and deny them their rights as citizens.
- Faced with exclusion and prejudice, disabled people and their organisations and allies have used the concept of citizenship to argue for equal rights.
- The DPM presents an alternative model of *active citizenship*. Their active participation in a collective struggle for recognition and equality contrasts with the dominant contemporary notion of active citizenship that emphasises individual responsibility and charitable works.

- The provisions and practices of the welfare state have served to deny or infringe the social citizenship of generations of disabled people (Oliver, 1996).
- Legislative changes (for example, the introduction of direct payments) since the 1990s indicate that disabled people and their allies have made some progress in challenging the oppressive practices and policy of the past.
- Disabling attitudes, environments and policies continue to impinge on the ability of many disabled people to exercise their rights and responsibilities. They are thus denied the equality of status that citizenship implies.

Further reading

Disability by Barnes and Mercer (2003) provides the best up-to-date, short introduction on disability and the issues discussed in this chapter. The chapter by Morris (2003) in Ellison and Pierson's book *Developments in British social policy 2* is especially useful for those interested in developments in community care under New Labour.

Website resources

The journal *Disability & Society* is published six times a year. Available at www.tandf.co.uk/journals/carfax/09687599.html it is a good place to keep up to date with recent debates and developments.

The Centre for Disability Studies at the University of Leeds has an excellent website that has links to a large range of other sites and an extensive literature archive: www.leeds.ac.uk/disability-studies/



Race, ethnicity, citizenship and welfare

This chapter raises a number of important questions about the links between formal (legal) citizenship and social citizenship (that is, access to welfare rights). The following areas are discussed:

- the formal and substantive dimensions of citizenship;
- beyond a simple black–white divide;
- nationality and immigration legislation in the UK: exclusive citizenship;
- refugees, asylum seekers and welfare policy in the UK;
- New Labour and ‘race’.

Formal and substantive citizenship

The definition of citizenship outlined by Faulks (1998) in Chapter One implies that citizenship works on many levels. This section illustrates how formal legal aspects of citizenship relate to issues of membership, and how ‘race’ and ethnicity may in turn be significant in terms of inclusion and exclusion. Citizenship is a formal legal status but also has a substantive dimension to it. Brubaker (1992) distinguished between these *formal* and *substantive* elements of citizenship status and concluded that many minority ethnic groups were disadvantaged in relation to both. *Formal citizenship* designates in a legal sense ‘membership of a nation state’ and also, therefore, access to rights and duties that accrue to citizens. Questions about *substantive citizenship* deal with the extent to which those who enjoy the formal legal status of citizen may, or may not, enjoy the rights (including rights to welfare) that ensure effective membership of a national community. Brubaker concluded that many minority ethnic citizens faced exclusion in terms of both formal membership and substantive rights. This may be due to deliberately racist policy or because individuals from minority