Citizenship and disabled people – Jenny Morris

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Introduction

The Disability Rights Commission (DRC) has a vision of a society in which all disabled people can participate fully as equal citizens:

The purpose of this paper is twofold:

- to propose a working definition of citizenship from a disability perspective, and
- to examine the public policy, and wider social and economic implications of the goal of enabling disabled people to be equal citizens.

The paper first sets the background to the current political debate on citizenship, before looking at what citizenship means for disabled people. The second section of the paper proposes a definition of citizenship made up of three aspects; sets them within the context of the current debates on citizenship; and discusses the barriers to each aspect. In so doing, the implications of the goal of enabling disabled people to be equal citizens are identified.

An earlier, and shorter, version of this paper was presented at a seminar convened by the DRC in March 2005. I am grateful to Stuart White who responded to the paper and to all those who contributed to the discussion.

Background

The DRC's work has been formulated against a backdrop of increasing political interest in the contested concept of citizenship.

During the last twenty years or so, the British government has, at various points, promoted different definitions of the term 'citizen'[1]. These definitions are part of government's identification of what are perceived to be the social, economic and/or political problems of the day and the term has been used in the promotion of policies as solutions to these problems. Sometimes these policies have involved the rights of individuals but more often, and more recently, it is individuals' behaviour that has been the focus in terms of both problems and solutions.

So, for example, John Major's Conservative government promoted the Citizen's Charter as part of encouraging a market approach to public services. Here the citizen was defined as consumer and it was the promotion of the consumer's right to choice which, together with privatisation, was considered to be the solution to the identified problem of inefficient public services. The Citizen's Charter was therefore situated within the liberal political tradition, originating in the seventeenth century, in which a limited state guarantees the freedom and formal equality of the individual.

Tony Blair's Labour government, while also emphasising consumer choice in the context of public services, has in addition launched a whole raft of policies aimed at encouraging people to be 'active citizens'. Here the emphasis, rather than being on the rights of individuals, is on the obligations that must be fulfilled in order to assure the health and stability of local communities and the wider society.

These more recent policies are in response to concerns that, in certain areas and situations, families and communities have become dysfunctional and are producing behaviour that is damaging to the wider social interest (as well as to the individuals and communities involved). There is also concern that levels of 'contentment', apathy and/or distrust are resulting in low levels of political engagement (in the form of voting or standing for office)

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[1] It was 20 years ago that Hugo Young wrote that "the buzz word emerging is something called citizenship" (Young, 1985).

and that this is potentially very damaging to our democracy. Thus citizenship education in schools is aimed at producing 'active citizens' who will vote, be involved in their local communities through voluntary activities, and feel responsible for the public spaces they inhabit.

David Blunkett, while Home Secretary, placed his approach to citizenship within the civic republican tradition of Aristotle's *polis*, where political participation was the means by which the citizen role was fully expressed (Blunkett, 2003a). However, it is also the more recent tradition of communitarianism that has clearly influenced government policy on citizenship. Communitarianism emphasises that cultural solidarity amongst individuals creates communities and social stability and that it is this community identity that is the basis of citizenship (Etzioni, 1995). Like the New Right, communitarians are concerned to reduce dependency on welfare and to encourage individuals to take responsibility for themselves and their families. Both traditions have debated the relationship between rights and responsibilities and whether rights are separate from, or contingent upon, responsibilities. The revised Clause 4 of the Labour Party constitution represents the unresolved conflict that persists today within the centre left, in its somewhat vague (and ungrammatical) statement: "Where the rights we enjoy reflect the duties we owe*"*.

Perspectives on citizenship (both political and academic) can also be divided into those that take an individualist approach and those taking a structuralist approach. For the former, it is the individual's capacity to make choices that determines the nature of citizenship; for the latter individual action is much more influenced by social and economic factors. As Pattie et al explain, "Choice based theories are exemplified in their purest form by economics…. In this world, individuals seek to maximise their utility by obtaining the highest return at the minimum cost from any course of action which they undertake" (Pattie et al, 2004, pp.138-139). Citizenship therefore emerges "from the choices which agents make, and these reflect the costs and benefits of the choice situation" (Ibid., p. 138). New Right theories of citizenship are heavily influenced by this perspective, but so too is New Labour – although to what extent is a matter of contention.

On the other hand, structuralist approaches to citizenship place more emphasis on social norms and values, and on individual

behaviour being shaped by social and economic forces. Citizenship is therefore rooted within communities and society. Communitarian and civic republican perspectives of citizenship place more emphasis on these structural influences than do either classical or modern liberal theories of citizenship.

Another way of looking at citizenship is to take TH Marshall's post-second world war writings on citizenship as a starting point. Marshall maintained, "Citizenship is a status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is endowed" (Marshall, 1950, p.28). There were three types of rights, he said - civil, political and social - and the development of citizenship in democracies involved three phases marked by the establishment of these three rights. Thus:

- Civil rights are those necessary for individual freedom – "liberty of the person, freedom of speech, thought and faith, the right to own property and to conclude valid contracts, and the right to justice" (Ibid. p.10).

- Political rights are "the right to participate in the exercise of political power" either as a member of a political authority or an elector.

- Social rights are "the whole range from the right to a modicum of economic welfare and security to the right to share to the full in the social heritage and to live the life of a civilised being according to the standards prevailing in the society" (Ibid. p.11).

A common criticism of Marshall's model of citizenship is that he did not place sufficient emphasis on the duties and responsibilities of citizenship.

Given the current political dominance of the civic republican and communitarian tradition of citizenship, it is probably not surprising that the DRC's aspirations for disabled people have been framed within a vision of citizenship as participation and contribution. While earlier debates about citizenship have tended to focus on rights (whether for individuals or for particular groups such as minority ethnic groups), current debates have been much more concerned with obligations and responsibilities. These concerns arise, not only from the identification of problematic behaviour

within some communities, but also from the current political dominance of issues which juxtapose state and individual responsibilities – including the current debates on pensions, health care, and incapacity benefit. Yet these policy debates are also informed by the liberal concept of the autonomous citizen, whose main requirement of the state is the protection of negative freedoms, thus allowing the exercise of individual choice and responsibility.

Perhaps most importantly, it is Marshall's concept of social rights that is currently seen as more contentious than civil or political rights. Analysis of the recent Citizen Audit argues that, "…a theory of citizenship has to address issues of responsibilities and obligations as well as rights. The latter cannot be taken for granted in a democracy when one person's rights are another person's obligations"(Pattie et al, 2004, p.17). Civil rights are relatively easy to enact since "there are few costs and great gains to be made by the average citizen" from the introduction of rights such as freedom of speech and impartial justice[2]. Political rights may be resisted by vested interests but once universal suffrage is achieved they are taken for granted. It is social rights that are the hardest to enact, "since redistribution means that one person's benefits are another person's taxes" (ibid. p.17). For the same reason, they can be harder to defend.

It is clear that the DRC needs to intervene in the current important debates about social rights, and the obligations and responsibilities of citizenship. Faced with a situation where most theoretical and empirical discussions about citizenship fail to consider disabled people, and where human and civil rights have yet to be fully extended to this group, it is also clear that we need to look more fundamentally at the whole question of citizenship and what it might mean for disabled people.

What does citizenship mean for disabled people?

Disabled people's perspective has been singularly absent from contemporary debates on citizenship, not just in Britain but also in other Western democracies (Meekosha and Dowse, 1997). The very language of the debate often excludes people who have

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[2] Some would undoubtedly question such optimism in the light of anti-terrorism legislation and its impact on particular social groups.

physical and/or sensory impairment, mental health problems or learning disabilities. Even feminist challenges to the dominant concepts of citizenship have, in inserting the private world of the family and women's caring role, still treated disabled people as absent.[3] It is very important, therefore, to take as the starting point the language and concepts which disabled people themselves have articulated as crucial to their status as equal citizens.

I want, therefore, to engage with current debates on citizenship by using three concepts that have been promoted by disabled people, and which are also relevant to the different ways of viewing citizenship. They are:

- Self-determination. This has been an important concept for both the independent living and self-advocacy movements. Within the wider citizenship debates, there is an assumption that individuals have capacity for free choice and, particularly within the liberal tradition, full citizenship involves the exercise of autonomy.
- Participation. This concept is often used by disabled people when engaging with the debate on social exclusion. In terms of wider citizenship debates, the concept includes the civic republican concept of political participation but also encompasses the broader concept of community participation.
- Contribution. Disabled people have emphasised the value of our contribution to economic and social life when we make the case for both anti-discrimination legislation and the resources required for a reasonable quality of life. Such arguments dovetail with the communitarian emphasis on responsibilities and reciprocity, and with debates on the limits to social rights.

These three different concepts all engage with Marshall's three concepts of civil, political and social rights. For disabled people (perhaps more than for any other group) there are close relationships between civil, political and social rights, as we shall

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[3] Selma Sevenhuijsen's exploration of 'care' is typical in her exclusion of disabled people (Sevenhuijsen, 1998). Ruth Lister is unusual in that she identifies current debates and definitions as excluding disabled people but her alternative framework still fails to include people for whom impairment or illness has a fundamental impact on how they experience family, community, economic, social and political life (Lister, 1997).

see in our discussion of self-determination, participation and contribution.

1. Self-determination

Disabled people and their organisations have asserted disabled people's rights to self-determination while at the same time identifying the barriers and the action required to achieve it. Self-determination is about making decisions for yourself. For example, in making the case for people with learning disabilities' rights to citizenship, Simon Duffy states, "Put simply, if you have self-determination then this means you are in charge of your own life. If you do not have self-determination then other people are in charge of you" (Duffy, 2003, p.5).

In asserting disabled people's rights to self-determination, it has been necessary to argue, not only for the removal of barriers to self-determination but also for the provision of assistance which makes self-determination possible. So, for example, keeping someone with learning disabilities in a long-stay hospital creates a barrier to self-determination but closing down the hospital is not sufficient to enable them to exercise choice and control over their lives. They may also require support to make choices, manage their own money, seek employment, and so on. In many cases, they will also require changes in attitudes amongst non-disabled people in that, for example, local communities will need to be welcoming of people who in previous times have not been part of their lives and may, in some cases, be feared.

Self-determination and the current debates on citizenship
Disabled people's concern with self-determination echoes the concept of autonomy within the literature on citizenship. Autonomy refers to "the ability to determine the conditions of one's life and to pursue one's life projects" (Lister, 1997, p.16). The concept of autonomy or freedom is to the fore in the neo-liberal perspective on citizenship and also underpins some of the current debates about the future of public services. These debates put forward a vision of the citizen as an individual who is empowered by the availability and exercising of choice. The Conservative government of the 1980s and 1990s had promoted the idea of the citizen as consumer and Labour has continued with this in a number of its policies relating to the public sector and role of government. For example, the White Paper, *Modernising*

Government, published in 1999, stated that government is for "people as consumers, people as citizens" (Cabinet Office, 1999, p.2). The Office of Public Services Reform was set up in 2001 to help improve public services by promoting four principles, one of which is 'choice'.

Some analyses of current government policy see the focus on choice and the citizen as consumer as belonging within the neo-liberal tradition and, for example, trace Labour's promotion of choice within the health service back to Milton Friedman's promotion of vouchers for public services (Pollard, 2003; see also Needham, 2003). Yet Labour's espousal of choice for consumers sits alongside a support for civic republican and communitarian concepts of citizenship (as discussed below). David Blunkett, for example, when Home Secretary, wrote "citizens and communities are not just passive consumers of public services" (Blunkett, 2003a, p.6). Moreover, public services are seen as essential to tackling inequality and, in this respect, there is a recognition "that people do not start off with equal chances in life, so it is essential that specific support is provided for those who are particularly disadvantaged" (Office of Public Services Reform, 2004).

The government's promotion of choice and consumerism is, to a large extent, about models of service delivery and the key question is whether the market is the most effective delivery mechanism and whether the private and voluntary sectors should play a bigger role in providing publicly funded services. However, the issue for disabled people is not only about service delivery mechanisms but about whether levels of resources are sufficient to deliver self-determination. For example, vouchers for wheelchairs were introduced some years ago but have not delivered the choice that they were intended to because of their limited value. In contrast, an assessment which combines professional expertise with the disabled individual's knowledge and experience can, if the resources are available, result in the provision of equipment which would empower the person to exercise more control over their life. Centres for Independent Living make the same case about direct payments: too often direct payments and ILF grants are not provided at a level sufficient to deliver full choice and control, and the assistance people need to use cash to purchase the support required is not always available. Giving people 'choice' is therefore not sufficient to enable disabled people to exercise self-determination.

While the current government's promotion of the 'citizen consumer' is set in the context of (and to some degree in conflict with) the civic republican and communitarian agenda, a consumerist approach to public services is more unequivocally part of the liberal tradition of citizenship. It has been argued that the disability movement's campaign for direct payments is part of this tradition and that enabling disabled people to become consumers (by giving them choice and control through their purchasing power) promotes the notion of citizens as 'atomised individuals'. In fact, the campaign for direct payments does the reverse. Direct payments came about because of collective action by disabled people and their implementation depends on the support of disabled people's organisations to those individuals using direct payments. Moreover, the cash payments themselves are part of collective provision and redistribution of resources in order to address inequality and promote social justice. They are the result of positive action by the state.

In fact, the liberal political tradition of citizenship, particularly its current version adopted by the New Right, poses considerable problems for disabled people. The New Right defines freedom (self-determination) as the absence of coercion of or interference with individual action, and the state's role is the limited one of protecting such freedom.[4] However, the issue for disabled people is that such negative rights are not sufficient to deliver even simple autonomy. Impairment and disabling barriers impose limits on freedom of action and positive action is therefore required to deliver opportunities for self-determination.

A minimal role for the state – as envisaged within the liberal tradition of citizenship - means that any additional assistance and resources that disabled people require could only be provided voluntarily. Traditionally that has been the role of charitable organisations. Yet the ideologies and values that underpin charitable activity in Britain (and most Western democracies) treat impairment as personal tragedy and disabled people as 'dependent people' who need looking after. Within the Christian concept of charity (unlike the Muslim and Jewish traditions), charitable activity is a one-way relationship: disabled people are to be the subjects of good deeds and have no contribution to make themselves. None of this is compatible with the concept of self-

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[4] See the paper published by the Institute for Economic Affairs on *The Magic of Choice* for an example of the public service implications of this position (Institute of Economic Affairs, n.d.)

determination for disabled people. A minimal role for the state also means that it would be left up to individuals as to whether they changed their attitudes towards impairment and mental illness.

For disabled people therefore, self-determination cannot be achieved without social rights. However, neither can it be achieved if we are merely passive recipients of social rights. For disabled people, the extension of social rights in the post-second world war period was very limited and resources were used in ways which restricted their autonomy, namely by incarcerating people in various forms of institutional provision. Unless disabled people and their organisations are key participants in the evolution of social rights it is unlikely that they will achieve self-determination. In this respect, Anthony Giddens' distinction between hierarchical power (the ability of one group to exert their will over another) and generative power (participation in struggles against inequality) is useful (Giddens, 1991). This helps us identify how disabled people's autonomy has been constrained by our experience of inequality yet struggles against such inequality have been generated by, and have further promoted, self-determination.

The key example of this is to be found in the origins of the independent living movement in Britain. Residents at Le Court residential home were engaged throughout the late 1950s and 1960s in a struggle to have more autonomy in their lives and campaigned to be represented on the Management Committee in order to counter restrictive rules (Mason, 1990). These struggles then became the foundation stones for the redefining of 'independence' that generated the subsequent campaign by some individuals to move out of the Home in the 1970s and 1980s. While self-determination was only realisable once the various authorities concerned were persuaded to redirect their resources to enable people to live independently, the originating force came from disabled people themselves. Self-determination was both a motivating force for, and a product of, the struggle to influence how resources were used.

If we are to claim autonomy for disabled people – in order to assert our rights to citizenship – we need to re-examine the meaning of the word. Doyal and Gough's definition of autonomy is "to have the ability to make informed choices about what should be done and how to go about doing it" (Doyal and Gough, 1991, p.53). Traditionally, disabled people's autonomy has been seen to be

restricted by physical and/or cognitive impairment. In this sense, disabled people living at Le Court did not even have the 'ability' to choose what time to go to bed in the evenings. Their lack of control over their lives and their exclusion from society led researchers of their experiences to label them as 'socially dead' (Miller and Gwynne, 1972). Yet out of that experience of powerlessness came an assertion of self-determination that later led to a change in government policy – an example of what Doyal and Gough call 'critical autonomy'.

Three key points need to be made, therefore, in terms of self-determination as an important component of disabled people's citizenship:

- A need for support to make choices does not mean that someone cannot experience self-determination
- In order for disabled people to have equal opportunities to be full citizens, it is necessary to take action to remove barriers to self-determination and, for some disabled people, it will be necessary to use resources to support self-determination
- The action to be taken must be determined by disabled people themselves.

One obvious question is whether everyone, whatever their impairment, should be assumed to have the potential to exert self-determination. Some may argue that people with the label 'profound and multiple learning disabilities', for example, cannot exert self-determination, whatever the level of support, because of their level of cognitive impairment.

I would argue against drawing this conclusion, certainly at this point in time. Firstly, because as already discussed, we need to re-define self-determination to include situations where people need support to exercise autonomy. Secondly, because although there are some examples of people with significant cognitive impairment receiving support to exert self-determination, we do not have enough experience of these situations, and their potential, to make judgements about any limitations caused by impairment.

If self-determination is a key aspect of what it means to be a 'free and equal citizen' then this should be our aspiration for all disabled people.

Barriers to self-determination

The context in which someone experiences physical and/or sensory impairment, or learning disabilities, or mental health problems can, and all too often does, limit self-determination. These limitations need to be addressed if disabled people are to experience equal opportunities for full citizenship. It is not the intention here to provide a comprehensive account of the barriers to self-determination but to highlight the most important issues that need addressing if disabled people are to achieve equal opportunities for this aspect of full citizenship.

The threat to life

The most significant way in which a disabled person's self-determination can be limited is when life-saving treatment is withdrawn or withheld without their consent. In July 2004, the High Court ruled that the General Medical Council's guidelines on withdrawal of artificial food and fluid constituted a breach of Articles 2, 3 and 8 of the Human Rights Act 1998 (Burke v. The General Medical Council). This is undoubtedly significant in protecting disabled people's right to self-determination but the legal action was only necessary because doctors, and others, commonly take decisions about the 'best interests' of disabled people based on their own, not the disabled person's, perception of the quality of our lives. As Jane Campbell points out, the Court's decision was significant in that it redresses the imbalance of power inherent within the GMC's guidelines between doctors and disabled people (Campbell, 2004).

However, disabled people continue to be vulnerable to other people's judgements that our lives are not worth living, or are of lesser value than non-disabled people's. Such judgements still implicitly and sometimes explicitly influence our chances of survival. One example is the refusal to consider heart transplants and, sometimes, other heart treatments for the largest group of children and adults who have heart disease in Britain – those have Down's Syndrome. When asked to defend this policy, the medical director at Harefield Hospital said 'It's not just Down's we are seemingly discriminated against. It is anybody with any disability. We take, when faced with a choice, the person who is the most *whole*, as it were'. (*The Guardian Weekend*, August 10 1996, p.18).

The DRC's review of evidence prior to carrying out its current formal investigation into access to health care for people with mental health difficulties and people with learning disabilities drew attention to the higher mortality rates amongst these groups. People with learning disabilities experience preventable mortality rates four times higher than the general population while mortality rates for people with schizophrenia or manic depression are higher than those of the general population even when deaths from suicide are discounted. Until disabled people have equal access to health care we will experience inequality in opportunities for self-determination.

Direct and indirect discrimination
A person cannot achieve self-determination if they experience direct or indirect discrimination. The two starkest manifestations of the discrimination faced by disabled people are unequal access to educational and training opportunities and higher rates of unemployment and economic inactivity.

Working age disabled adults are less likely to have Level 2 qualifications and above than non-disabled adults (Department for Work and Pensions, 2004) and are twice as likely as non disabled people to have no qualification at all (Disability Rights Commission, 2005). One in four disabled 19 year olds[5] are not in education, training or employment, compared to one in ten non-disabled 19 year olds and disabled young people are only half as likely to be in higher education as non-disabled young people, although this participation rate has been increasing (Youth Cohort Study, 2003).

The government has set targets for increasing the numbers of pupils achieving at least 5 GCSEs at Grade 3 or above, and also for increasing qualifications of working age adults. The percentage of disabled adults with at least Level 2 qualifications has been increasing at about the same rate as for non-disabled adults but is starting from a lower base (Department for Work and Pensions 2004); the pattern of inequality remains unchanged therefore (Disability Rights Commission, 2005). The educational attainment of pupils with special educational needs (SEN) does not appear to be increasing (and in some respects is diminishing) but this may be because of increases in the numbers of pupils with SEN who

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[5] This excludes young people who have been in special schools.

have cognitive impairments. The way in which the Department for Education and Skills gathers information does not enable us to measure direct or indirect discrimination in the education system. All aspects of education and training policies will have an important impact on disabled children and adults' opportunities for self-determination – and we need better data to be able to monitor the effect of policies and practice.

Only half of disabled adults of working age are in employment, compared with four out of five non-disabled people. Employment opportunities are particularly limited for people with learning disabilities and for people who use mental health services - only 20% of whom are in employment (Disability Rights Commission, 2005). The two main policies which aim to change this situation are reforms to the benefit and employment support systems and the implementation of the Disability Discrimination Act. Debates concerning incapacity benefit and employment support tend to assume that it is individuals' lack of motivation or self-confidence that are the key determinants of whether someone gains employment. From disabled people's point of view, in contrast, employment opportunities are curtailed by discrimination and the lack of support or adjustments necessary to take up and remain in employment. As the DRC has pointed out, "progress needs to be made on removing barriers and provision of additional support before individuals can be expected to take on more personal responsibility" (Howard, 2004, p.18).

Although the DDA recognises discrimination to be a major barrier to employment opportunities, there is a fundamental flaw at the heart of the legislation in that it affords protection from discrimination and rights to 'reasonable adjustments' to tackle disabling barriers, not on the basis of whether discrimination has occurred or adjustments are required but on the basis of type and level of impairment. As the Joint Committee on the Draft Disability Discrimination Bill stated, "If the DDA was based on the social model of disability, it would offer protection to anyone who could prove less favourable treatment (discrimination) on the grounds of impairment. This is the same type of protection from discrimination afforded by the Race Relations Act 1996 and the Sex Discrimination Act 1975" (Joint Committee on the Draft Disability Discrimination Bill, 2004, p.21).

A lack of entitlement to choice and control over necessary support

An important component of self-determination is having control over whatever support is required to go about daily life. This is a point made most forcefully by the independent living movement – and is confirmed by recent research on older people's experiences which found that "even when older people's ability to do things on their own was compromised, they were able to maintain their sense of independence if they felt a sense of autonomy over how and when help was received" (Parry et al, 2004, p.2).

However, this 'sense of autonomy' is undermined by a lack of entitlement to choice and control over the support many disabled people require. For example, many, particularly older disabled people, are forced to move into institutional provision. This often happens by default, because the current systems for providing health and social care contain financial incentives to provide residential care rather than to support independent living (Prime Minister's Strategy Unit, 2005, pp. 65-66). The numbers of disabled people below retirement age in residential care have been increasing in recent years (National Statistics/Department of Health, 2004). Disabled people's access to self-determination will remain limited while there is no entitlement to support to live in their own home.

Another key aspect to this barrier to self-determination is that disabled people have no entitlement to the support some need in order to communicate. This means they can be denied access to a basic human right which is also essential to self-determination (Morris, 2001, pp15-22). When a child is denied the support they need to communicate their preferences and to make choices, this can mean they move into adulthood with little or no opportunities for self-determination. Non-disabled children gradually learn to make decisions with the assistance and guidance of family, peers, teachers, etc. Disabled children often do not experience this gradual taking on of decision-making. This limitation is caused by both a failure to meet needs relating to impairment - three quarters of 'severely disabled' children have unmet needs for equipment for example (Beresford, 2003) – and by negative attitudes about disabled children's rights and abilities to make choices (Morris, 1998).

Current debates on 'compulsory treatment orders' and the definition of 'capacity' illustrate the potential legal limits on people's rights to have choice and control over the responses to their

needs. Also of significance is the evidence that 'reinstitutionalisation' is occurring in terms of responses to mental health needs. Between 1990 and 2001, there was a 24% rise in the number of involuntary admissions to psychiatric services in England (Priebe et al, 2005, p.124). About two thirds of people in prisons have mental health problems (Davies, 2004; Singleton et al, 1997) and the prison population in England increased by 57% between 1992 and 2002 (Priebe et al, 2005, p.124). Coercive responses to impairment and/or mental illness are a major issue for disabled people of all ages. Amongst older people in residential and nursing homes, for example, there is evidence of inappropriate use of anti-psychotic medication – 30% are prescribed such medication whereas only about 10% have psychotic symptoms (Stokoe, 2001). And there is increasing concern that some young people with special educational needs and/or mental health problems are being 'criminalized'. About 60% of those referred to Youth Offending Teams have SEN (NACRO, 2003) and there is anecdotal evidence that a high proportion of the increasing numbers of young people subject to Anti Social Behavioural Orders (and the increasing number jailed for breaching them) have special educational needs.

2. Participation

A common theme for disabled people and their organisations has been the promotion of the right to be included in mainstream society and to participate in family, community and national life. Such inclusion requires that disabling barriers are removed and needs relating to impairment are met, thus making possible disabled people's full involvement.   This participation both requires and gives expression to self-determination, and like self-determination is an integral part of being a citizen.

Participation and the current debates on citizenship
Participation is key to the civic republican concept of citizenship – membership of a political community, joining with others to make decisions which are then respected by all, and by so doing achieving true freedom. Indeed, the tradition makes the case that citizens are only truly free when they participate in shaping the political decisions that affect their lives.

The modern concern with civic republicanism is articulated in the first sentence of Bernard Crick's introduction to a collection of papers about a 'citizenship culture': "How can we become a citizen culture, a country whose inhabitants think it normal, right and even pleasurable to be concerned with and actively involved in public affairs?" (Crick, 2001, p.1). Across the political spectrum there is concern about a perceived decline in public trust in politicians and political institutions and an associated decline in political participation. Since 1997, a series of Local Government Acts have brought in various measures to encourage voting, devolve political responsibilities and extend the role of local government (for example by giving local authorities a general power to promote the social, economic and environmental well-being of their communities). Various 'think tanks' have attempted to stimulate the debate on democracy and citizenship, and the Economic and Social Research Council launched a Democracy and Participation Programme to address a "number of key concerns about the current state of British democracy and participation".

However, concern about levels of participation has not just focussed on participation with the political process but also on a wider definition that encompasses people's involvement in, and responsibility for, their local communities. The government has promoted greater participation in local services and communities, and supported an increasing role for community and voluntary organisations in all aspects of public services. As Marian Barnes has stated, public agencies "are being enjoined…to develop partnerships with community organisations. …. Communities are no longer only a target for policy, but are also seen as a means of delivering it" (Barnes, 1999, p.87).

The Office of the Deputy Prime Minister (ODPM) and the Home Office have been the government departments most concerned with citizenship, supported by the Treasury. Both departments (or in the case ODPM its predecessors) have long been concerned with community development and the role of citizens and self-help in tackling urban deprivation and socially disruptive behaviour. In the 1960s and 1970s, this concern led to the ill-fated Community Development Projects[6]. Following the 1997 general election, ODPM set up the Social Exclusion Unit and launched the

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[6] See, for example, Community Development Project, 1976. *Gilding the Ghetto: The state and the poverty experiments*, Home Office Urban Deprivation Unit.

Neighbourhood Renewal Strategy, whose implementation has included a range of initiatives concerned with community development.

The Home Office set up the Active Communities Directorate, the Civil Renewal Unit, the Active Citizenship Centre and the Community Cohesion Unit. The role of civil renewal and active citizenship in tackling a wide range of social problems is the particular mission of the previous Home Secretary, David Blunkett who, when Secretary of State for Education, ensured that that Department also concerned itself with citizenship by launching citizenship education in schools.

Concepts of 'civil renewal' and 'active citizenship' have been used in the promotion of policies aimed at changing people's behaviour. It is argued that anti-social and criminal behaviour will only be reduced by increasing people's commitment to their local community, and that unless political apathy and disaffection is replaced by community and political engagement then our democracy is undermined. Both the philosophy and the aims of government are apparent in the explanation which appears on the website of Home Office Civil Renewal Unit:

> Civil renewal is at the heart of the Home Office's vision of life in our 21st century communities. As a political philosophy it has been around for centuries but it is, increasingly, being taken up by public bodies, people working in the voluntary and community sector, and active citizens in their own communities, as the effective way to bring about sustainable change and improve the quality of people's lives.
> Civil renewal can happen anywhere, from the most deprived communities to the most affluent. It takes place when people become actively engaged in the well being of their communities and are able to define the problems they face and tackle them together with help from the government and public bodies.[7]

Labour's second term of office has seen a greater emphasis on local accountability and participation than in the first four years. The government is now espousing less centralised regulation

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[7] Home Office Civil Renewal Unit, www.homeoffice.gov.uk/comrace/active/civil/index.html, accessed 10.01.05

(fewer but 'smarter' targets), more local autonomy (through Local Strategic Partnerships and Local Public Service Agreements), and increased capacity amongst the voluntary sector – although this has been a concern of Labour since taking office in 1997 (for example, *The Compact on Relations between Government and the Voluntary and Community Sector*, published in 1998).

The Local Government Association issued a manifesto in September 2004, making "the case for putting local government at the heart of civil renewal".[8] It sets out a vision of "independent self-governing communities" where citizens "have a common sense of ownership and pride in the place where they live or work [who]…feel connected to the community because of its distinctive history and heritage and because it is a place whose future they are helping to shape" (Local Government Association, 2004, p.6).

This vision uses another important concept - that of 'social capital'. The government has formally adopted the OECD definition of social capital as "networks together with shared norms, values and understandings that facilitate co-operation within or among groups" (Home Office Civil Renewal Unit, 2003, p.46). The Office for National Statistics is designing a set of questions, to be added to the General Household Survey, intended to measure social capital, while the Audit Commission has added a score on social cohesion to the assessment of local councils' performance.

So where are disabled people in all of this? While the government is concerned that certain groups in society are not fulfilling their role as active citizens and that this is undermining our democracy and the viability of some communities, disabled people may be more concerned that we are denied the opportunity to be active citizens and that this is undermining the rights of disabled people.

In a complex society such as ours civic participation takes many different forms and opportunities. One City Council has estimated, for example, that there are 3,300 positions within its district that "require active citizens to fill them, including positions for councillors, parish councillors, non-executive members of Primary Care Trusts, school governors, magistrates, and community representatives on housing association and regeneration boards"

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[8] On the LGA website, http://www.lga.gov.uk, accessed 7th January 2005.

(Local Government Association, 2004, p.16). Government policies such as the transfer of council housing to housing trusts have increased the number of positions requiring 'active citizens'.

However, initiatives to encourage 'active citizenship' tend not to treat disabled people as potential active citizens. Although the Department for Work and Pensions has the target of "working to improve the rights of disabled people and to remove barriers to their participation in society", this target does not seem to be reflected in any of the initiatives for promoting 'active citizenship' that ODPM and the Home Office are responsible for. Indeed, sometimes these initiatives have reaffirmed the assumption that disabled people are passive recipients of care rather than active citizens. This is how, for example, disabled people are represented in the Home Office report on community self-help when it is stated that "networks [linking local residents to each other] are central to: the care of children; support for old, sick, disabled and isolated people….." (Home Office Active Community Unit, 1999, p.1). This is the only reference to disabled people in this report.

In 2004, of 15,437 public appointments only 545 were of people who self-defined as disabled (Cabinet Office, 2004b, p.5).[9] Disabled people are a bit better represented amongst local authority Councillors: 10.8% of Councillors in England and Wales in 2001 and 8.7% of those in Scotland in 2003 reported that they had 'a long term illness, health problem which limited their daily activities or work' (Department for Work and Pensions, 2004). However, this compares with 22% of adults in Britain who say that they have a long-standing limiting illness or health problem.

While the government has set targets for increasing the number of women (to 50%) and members of minority ethnic groups (to 7 or 8%) to public appointments made by Ministers, no target has been set for disabled people. Instead, there is a rather vague aspiration of "increasing the number of appointments held by people with disabilities [sic]" (Cabinet Office, 2004a, p.8). The Home Office has a public service agreement target of increasing community participation by 5% between 2001 and 2006. The Citizenship Survey, carried out in 2001, 2003 and 2005, is measuring fulfilment of this target. The first two surveys did not measure

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[9] These figures only relate to appointments which are subject to the approval of Ministers. It does not include appointments made by the Lord Chancellor to tribunals, nor appointments made by the various public bodies themselves.

disabled people's participation rates - although they did measure that of women and minority ethnic groups. Indeed, the only reference to disability was as an 'object' of formal volunteering (together with 'health and social welfare'). However, the Department for Work and Pensions reports that disabled people's community participation will be measured in the next survey (Department for Work and Pensions, 2004).

Amongst all the government initiatives about citizenship, the Russell Commission, set up in 2004 to develop a new national framework to increase youth volunteering and civic service by young people, is unusual in its consideration of disabled people's participation. Its Consultation document identified that young disabled people are one of a number of groups on whom particular attention needs to be focussed in order to increase their levels of participation: one of the consultation questions was "How can we ensure that more young people with disabilities gain access to volunteering opportunities?" (Russell Commission, 2004, p.24). Both the Russell Commission and the Joint Committee on the draft Disability Discrimination Bill highlighted that the Disability Discrimination Act does not cover volunteers. The Joint Committee also recommended that the Government review the case for making funding available to provide reasonable adjustments for volunteers, in the same way that the DWP, through the Access to Work programme, makes funding available for reasonable adjustments for employees (Joint Committee on the Draft Disability Discrimination Bill, 2004, p.95).

In spite of the general failure to consider disabled people in policies which encourage active citizenship (and in spite of the barriers to participation discussed below) disabled people and their organisations have, in fact, had quite an influence through their levels of participation in local communities and national democracy. The most obvious examples are the successful campaigns for the Disability Discrimination Act, for the Disability Rights Commission, and for the extensions to the DDA currently going through Parliament. The independent living movement brought about a change in government policy on direct payments and its influence, together with that of the self-advocacy and survivors' movements, are very apparent in the recent report of the Prime Minister's Strategy Unit (Prime Minister's Strategy Unit, 2004a).

Barriers to participation

Nevertheless, in spite of these manifestations of disabled people's participation, there remain significant barriers and there is a continued struggle for acceptance and for the resources that would enable us to participate on an equal basis. Methods of participation are often themselves excluding: for example, meetings relying on the spoken word and on printed material (and often involving jargon particular to a group or context) are the most common method of community participation. The basic form of political participation – voting in local and national elections – is still not accessible to all disabled people (Scott and Morris, 2001; Daone et al, 2004) and many people are excluded (by design or by default) from jury service.

In discussing some of the key barriers to disabled people's participation the intention, as with the discussion on self-determination, is not to provide a comprehensive analysis but a brief discussion of the public policy issues which need to be tackled to enable disabled people to participate as full citizens.

Poverty
A 'reasonable living standard' is commonly accepted as a necessary requirement for participation in 'the normal activities of society' (Burchardt et al, 1999, p.231) Official statistics on poverty illustrate that many disabled people experience a standard of living which is not sufficient to enable them to participate fully in society, even before the costs of impairment are taken into account and that disabled people have a greater risk of living in poverty (Prime Minister's Strategy Unit, 2004a). Indeed, charging policies for community care and residential services can create poverty: for example, the Personal Expenses Allowance for those whose residential care placements are funded by their local authority is £18.10 a week – arguably this is not enough to enable someone to participate in society.

Analysis of the standard of living of disabled people, taking into account both extra costs and disability related benefits, indicated high rates of poverty amongst disabled people which are not reflected in official statistics (Zaidi and Burchardt, 2003). In addition, this analysis found that 'a worryingly high proportion of those who face extra costs receive no extra costs benefits at all: 9 per cent of non-pensioners and almost one-third (30 per cent) of

pensioners. The particularly large gap for pensioners may be related to the fact that there is no help with mobility-related costs for those who become disabled over the age of 65.' (Ibid. p.48) Recent detailed analysis of the extra costs faced by people with physical or sensory impairments concluded that disability related benefit levels fall significantly short of the amount needed for "an acceptable and equitable quality of life" (Smith et al, 2004).

Moreover, reductions in the comparative values of benefits undermine disabled people's relative standard of living. While benefit levels have increased in real terms, all types of income support benefit (retirement pensions, incapacity benefit, income support and so on) have been declining as a percentage of average earnings over the last 20 years. For example, invalidity/incapacity benefit for a single person has declined from 23% of average earnings in 1982 to 15.3% in 2002 (Department for Work and Pensions, 2003). This is also the case with Disability Living Allowance: while the real value of the highest care component has increased, as a percentage of average earnings it has declined from 14.2% to 12.1% between 1992 and 2002, while the higher mobility component decreased from 9.9% to 8.5% (Department for Work and Pensions, personal communication, 2003).

The operation of the benefits system can be a barrier to participation
Disabled people's organisations have argued that benefit rules, and also a lack of information and negative attitudes amongst some Benefit Agency staff, inhibit disabled people from considering public appointments. Although there is only, as yet, anecdotal evidence of this, the Cabinet Office's Working Party on public appointments and diversity recommended that the Department for Work and Pensions "should consider whether the current rules on Incapacity and Income-related Disability Benefits discourage people with disabilities from applying for public appointments" (Cabinet Office, 2004a, p.18).

The rules and experiences of the benefits system can also discourage disabled people from becoming involved in less formal methods of participation. According to the *Shaping our Lives* project (a national service user network) "Health and social care service users have highlighted that there is an increasing tension between service user and government commitments to get

involved and contribute to local communities, and the day to day working of the benefits system" (Shaping our Lives, 2004).

Inadequate rights to participation
Just as social rights are necessary to enable disabled people have self-determination, so they are also necessary to enable us to participate. Yet the legislative framework through which such social rights are delivered creates barriers to participation. Not only are there inadequate resources made available, but the legislation through which such resources are delivered is based on assumptions of dependency. The community care framework uses the National Assistance Act definition of a disabled person as someone who is "blind, deaf or dumb, or who suffers from mental disorder of any description and other persons who are substantially and permanently handicapped by illness, injury or congenital deformity". As the Prime Minister's Strategy Unit points out, "This definition is out of date, offensive and does not provide a useful starting point for enabling disabled people to fulfil their roles as citizens" (Prime Minister's Strategy Unit, 2005. p.60).

The implementation of Part 3 of the Disability Discrimination Act does open up possibilities for the removal of disabling barriers. However, what rights there are to participation are often inadequate or difficult to access. People who take on important roles of, for example, school governors or local councillors often find it difficult to get their access needs met (Morris, 2004; Joint Committee on the Draft Disability Discrimination Bill, 2004); and, as already mentioned, there is no protection from discrimination or entitlement to reasonable adjustments for disabled people who wish to participate in their local communities by volunteering.

A lack of support for, and barriers to, 'community presence'
In order to participate in the community, disabled people need to be present in the community and there are still many barriers to this. Large numbers of disabled people – particularly older people and those with significant learning disabilities can only get their needs for support in their daily life met by moving into institutional or 'congregate' forms of provision which separate them from their local communities and networks (Morris, 2003). Disabled people in general are less likely than non-disabled people to be present in local communities by, for example, going to the cinema, attending arts events, or visiting a library, a museum or other public attraction (The Arts Council of England, 2001).

Support for activities which would involve people being present in their local communities is not generally covered in community care assessments; increasingly resources are only available for a very limited range of activities – basically to keep people from risk of physical harm and not even to keep their home or themselves clean, let alone to participate in social activities or community life (Social Policy Ageing Information Network, 2001). Recent research found that older people who were allocated direct payments did not receive funding for social activities and could only engage in activities outside their home by being 'creative' in their use of the funding provided (Clark, et al., 2004).

Unequal access to health care can create barriers to participation
Another significant barrier arises from disabled people's unequal access to health care. Many disabled people – and perhaps particularly those learning disabilities and/or mental health difficulties - experience unequal access to primary health, as the DRC's review of evidence on these two groups' access to health care illustrates. Inadequate health care can make worse or create impairment or illness, and this reduces people's ability to participate in their local communities - as one professional put it, many people with learning disabilities are "not well enough to lead ordinary lives" (Morris, 1999).

Attitudinal barriers to participation
There are two common attitudes towards disabled people which create barriers to participation. The first is that disabled people are commonly considered to be in need of 'care' and this undermines other people's ability to see us as autonomous people. There is an assumption that it is legitimate, even necessary, for other people to make decisions for us. Therefore, we are not recognised as actors in community participation but as recipients of other people's community participation.

Secondly, disabled people are often treated as not 'belonging' to the communities in which they live. The Social Exclusion Unit's inquiry into the experiences of people with mental health problems found rejection, or fear of rejection, by the community to be the most important cause of this group's social exclusion (Social Exclusion Unit, 2004). One in four disabled people, and almost one in two people with mental health problems, have experienced hate crime or harassment. Verbal abuse is a common experience

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of people with learning disabilities and a significant minority are physically abused when going out and about in the community.

3. Contribution

Disabled people make a contribution to the social good as volunteers, parents, and family and community members but are often assumed to be unable to take on such responsibilities. In contrast there has been much emphasis on The cost of not enabling disabled people to make a contribution through paid employment runs into several billion pounds (Prime Minister's Strategy Unit, 2004a, p.130). The removal of disabling barriers and provision of support to make disabled people's contribution possible should therefore, it has been argued, be seen as a form of social investment.

Contribution and the current debates on citizenship
Current debates on citizenship focus on the need for individuals to fulfil certain responsibilities and there is a strong assumption that it is the fulfilment of these responsibilities that qualifies them for full citizenship. This assumption is articulated not only in the debate about what and whether conditions/obligations should be attached to the receipt of benefits, but also in the encouragement of active citizenship. Thus participation, an important element of citizenship in its own right, is also a form of contribution, of fulfilling the responsibilities of citizenship. Indeed, current debates perhaps focus more on the *responsibility* to contribute than on the value in itself of people's contribution to the social good – or indeed on the right of people to contribute.

Concepts of equality and reciprocity are also important here. Thus, in promoting greater equality and the extension of assets, David Blunkett has written "a citizen cannot truly be an equal member of the community if he or she is reduced to a state of permanent dependency on the support of others. If a person is simply reliant on income transfers, he is not genuinely free and enabled to participate" (Blunkett, 2003b, p.16). And analysis of the Citizen Audit argued that "…powerful norms exist in British society which support the idea that individuals should not free-ride on the efforts of others. These norms are ultimately responsible for making civil society and the state effective" (Pattie et al, 2004, p.267).

Politicians and commentators have also been much taken with the finding of the Home Office Citizenship Survey that 96% of people agree "you can't demand rights as someone living the UK without also accepting the responsibilities" (Blunkett, 2003a, p.8). Pattie et al develop this position further by arguing that low levels of participation amongst the poorest in society are at least partly responsible for the increasing levels of inequality: "…the demand for state intervention to provide redistributive rights is very much influenced by individual resources. It is the uneducated, the low-status and the low-income citizens who are most likely to make these demands. But their relative lack of interest in participation constitutes a real barrier to the implementation of policies which will promote state intervention to reduce inequality and redistribute income….It is perhaps not surprising that inequality in Britain has grown over the last twenty-five years" (Pattie et al, 2004, p.267-8).

There are three problems for disabled people posed by these recent debates on the responsibilities of citizenship.
- Firstly, the question needs to be raised as to whether there are some disabled people who, whatever action is taken to address disabling barriers, are still likely to be 'reliant on income transfers'. And if this is the case, does this mean that these disabled people cannot access full citizenship?
- The second problem is that to follow the arguments put forward by Blunkett and Pattie et al would be to accept that disabled people will not achieve social rights without fulfilling the responsibilities of citizenship. Yet for disabled people, social rights are necessary in order to fulfil these responsibilities.
- Finally, current debates on the responsibilities of citizenship tend to assume that the only responsibility at issue for disabled people is that of taking up opportunities to move from receiving benefits to earning a living. When the wider concept of active citizenship is discussed, the only place for disabled people seems to be as recipients of other people's citizenship responsibilities.

Current debates on incapacity benefit illustrate some of these issues. Politicians' and commentators' pronouncements about people on Incapacity Benefit, the majority of whom come under the DDA definition of disabled person, contain unhelpful assumptions about disabled people's motivations to seek paid employment (see, for example, Prime Minister's Strategy Unit, 2004b). Yet nine out of ten people who move onto incapacity benefit hope to move

back into employment and disabled people who are economically inactive are just as likely to want to work as non-disabled people and, amongst disabled men, the proportion is higher (Prime Minister's Strategy Unit, 2004a, pp. 128-129). The fact that 40% of those who start claiming IB will still be unemployed a year later and only one in five of these will then find work within five years is influenced not just by impairment in itself but also by inadequate responses to health problems, limited local job opportunities, transport difficulties and discrimination.

As Stuart White points out, "reciprocity is an idea that cuts two ways. If it justifies placing responsibilities on citizens to make a productive contribution to society, then it also demands that those who carry these responsibilities have sufficiently good opportunities and rewards for meeting these responsibilities" (White, 2004).

When current debates on the responsibilities of citizenship move beyond the issue of benefits, it is rare for disabled people to figure other than as recipients of other people's responsibilities. As we have identified, there is an assumption that once someone needs support to go about their daily lives, they are passive recipients of care. The only contribution that those who receive such support are expected to make is a monetary one through the charges that are made for community care services. This is a double-edged sword: charging policies reduce people to the income level which is considered to be just sufficient to live on and which certainly makes participation in the community difficult; and at the same time people are not expected, or helped, to make any other contribution to their family, community or society. While the 'informal care' provided by non-disabled people has started to be recognised as an important source of social capital, this is not the case for the contribution that disabled people make, either within their families or to wider networks and communities. Such lack of recognition undermines disabled people's *rights* to make a contribution.

However, a few developments do encourage disabled people's contribution by recognising that as potential or current users of services they have valuable expertise and experiences. For example, the emphasis placed on 'user involvement' following the implementation of the NHS and Community Care Act 1990 was an explicit recognition of the contribution that service users could

make to "creating good quality and cost effective services….and enabling commissioners to be accountable" (Department of Health 1996, p.1). Over the years, the involvement of service users has become accepted as an important way of increasing both accountability and effectiveness of public expenditure.   To take just one example, the Commission for Social Care Inspection (like its predecessor the Social Services Inspectorate) recruits disabled and older people to be involved as lay assessors in inspections of services, as do some local authorities. Worcestershire Social Services, for example, have recruited and trained older people to inspect residential homes, stating that, by such involvement, older people are making "valuable contributions to their community" (Age Concern Press Release *Elderly to inspect care homes*).

This type of contribution rarely figures, however, in the debates on citizenship. Neither is there much recognition of the many years of struggle by disabled people to set up organisations providing advice and information, peer support and other forms of self-help. For example, one of the main providers of advice and information to disabled people, Disability Advice and Information Line (DAIL), was founded by Ken Davis, a disabled man who, having moved out of residential care into a home of his own, set up the service. DAIL "not only contributed to the breakdown in the knowledge monopoly held by professional disability experts but also gave disabled people a deeper sense of the increased choices possible for those wanting to live independently in their own homes in the community" (Finkelstein, 1991). There is now a national network of over 160 local disability information and advice services run by and for disabled people.

Nor do debates on citizenship recognise that disabled people and their organisations have, through their contributions to the political process over the last twenty years, brought about significant changes in both attitudes towards disabled people and society's responses to their needs. The widespread acceptance of the social model of disability is an important testament to disabled people's contribution to changes in the way society treats a fifth of the population. Although these changes have not gone far enough, the progress that has been made is a major contribution to not just the well-being of disabled people but to social capital. Combating social exclusion, building diverse yet cohesive communities is a key part of the government's agenda and this aim cannot be realised without disabled people playing their full part. The

inclusion of people with mental health difficulties, for example, has been found to have benefits for the rest of the community in that there is an increase in social capital – "qualities of trust and tolerance, levels of civic engagement and association" (Wilkinson, 1996, quoted by Dunn, 1999, p.64).

Nevertheless, there is a long way to go and matters are not helped by a lack of understanding amongst those leading the debates on active citizenship of the action required to enable disabled people to fulfil the responsibilities of citizenship. This lack of understanding is reflected, for example, in the resources for citizenship education in schools. Although the model lesson on 'disability' provided by the Department for Education and Skills contains information about the Disability Discrimination Act, the main message is, "see the ability not the disability". [10] This is essentially a medical model, individualist perspective in that the focus is on the individual (albeit on their 'abilities' instead of their impairment) rather than on the environment and actions of individuals and society that may discriminate against and exclude them. Such a perspective suggests that those responsible for these materials have not familiarised themselves with the perspective of those disabled people and organisations who have made a significant contribution over the last twenty years to bringing about changes in the place of disabled people in society.[11] Until a clear understanding of the social model of disability is incorporated into the debates on citizenship, disabled people will continue to experience unequal access to full citizenship.

Barriers to making a contribution
Barriers to contribution are similar to those that get in the way of self-determination and participation and action to address those barriers would increase disabled people's contribution as citizens. We have already mentioned some of the ways in which disabled people's contribution is not sufficiently recognised. Briefly, the following are some further key issues that need to be addressed within public policy.

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[10] *Disability Issues*. www.teachernet.gov.uk Accessed 24.01.2005.
[11] It is also ironic that the website fails to conform to accessibility guidelines on websites and therefore probably breaches Part 3 of the DDA.

<u>Some groups of disabled people are assumed to have nothing to contribute</u>

Systems for delivering support are based on assumptions of, and are about, dependency and deficiency. This applies to both the social security system and to the community care system. The concepts of reciprocity and contribution are only applied to people of working age who are judged capable of working and there is an assumption, within the range of social policies, that those who cannot achieve paid employment have nothing to contribute. For example, NVQ Level 2 is said to be the 'minimum attainment for fulfilling participation in a flexible, modern economy'. This excludes people whose cognitive impairment means they cannot achieve Level 2 and it is this group who are most at risk of having no 'meaningful activity' as they enter adulthood. If certain groups of people are considered to have no contribution to make it is much harder to argue for resources to enable their participation in society.

The origins of the National Assistance Act 1948 (which lays down the definition of disabled person in terms of entitlements to support), and of the NHS and Community Care Act 1990 (which provides the framework for the delivery of support), are to be found in the Poor Law which not only laid down the criteria by which people would be deemed eligible for support but also exempted recipients from certain obligations of citizenship (Stone, 1984, quoted by Davis, n.d, p.1). There is an underlying assumption that, if someone meets the eligibility criteria for support under community care legislation, then they are not expected to fulfil the responsibilities of citizenship. Such an assumption goes hand in hand with an approach to disabled people which "interprets disability as being caused, not by the state of society, but by the state of a person's body and/or mind" (Davis, n.d., p.1).

Receipt of support from the state, or from major voluntary organisations, therefore takes place within contexts and relationships where there is little recognition or room for reciprocity. Assumptions that disabled people have nothing to contribute set up a self-fulfilling prophecy whereby this attitude then leads to a failure to deliver the support needed to enable disabled people make a contribution. This is particularly the case for older people: "Because older people are seen by many as

dependent and frail, rather than as citizens with a contribution to make, the response of public services is often limited. Services for older people have been seen to be predominantly focused on a narrow range of intensive services that support the most vulnerable in times of crisis; older people are seen as NHS and social care 'problems'." (Audit Commission, 2004).

A lack of support to make a contribution

An inevitable result of these assumptions that if you need support then you have nothing to contribute is the failure to provide the assistance that disabled people require in order to fulfil their responsibilities as citizens. One key such example concerns the responsibilities of parenthood.

When a disabled person becomes a parent, or a parent acquires an impairment or mental health problem, their ability to fulfil the responsibilities of parenthood is commonly undermined by both negative attitudes and a lack of appropriate support. Disabled parents are assumed to be exempt from the responsibilities of parenthood (in that they are not considered to be fit to be parents) and, at the same time, there is not sufficient support available to enable them to carry out the tasks of parenthood (Goodinge, 2000; Morris, 2003). This is particularly the experience of people with learning disabilities and those with mental health difficulties, who commonly experience great difficulties in gaining access to the support they need to be good parents and thus risk losing their children into care.

One good example of a number of ways in which disabled people experience barriers to carrying out their responsibilities as parents concerns the responsibility to ensure children attend school. The Department for Education and Skills informs parents that 'If your child is registered as a pupil at a particular school, you must ensure that they attend regularly.' (Department for Education and Skills, 2000). The emphasis is on parents' responsibilities to make sure that children attend school each day and, indeed, this is a key contribution to the social good. Yet getting children to school is a major problem for some disabled parents. Parents who have sought assistance with this aspect of their parenting role from social services or from the local education authority have found that the responsibility tends to be passed between different agencies and departments. Local education authorities commonly

deny any responsibility for assisting disabled parents yet at the same time insist that parents fulfil their responsibility (Morris, 2004).

The Department for Education and Skills also encourages parents to be involved in their children's education and, to this end, produces a series of *Learning Journey Guides* to provide parents with information about what their children are doing at school at different stages in their education. However, although this information is available in braille, audiocassette and large print, and in some minority community languages, it is not available in BSL video format or in a format suitable for people with learning disabilities. When asked whether information was available in BSL video format, the DfES responded, "While the Department tries to ensure that its information is produced in such formats that allow the majority of parents (or other interested people) to access them we cannot produce items in every possible language or format" (Morris, 2004).

<u>Lack of recognition and under-resourcing of disabled people's organisations</u>
Government support for community involvement and the myriad of initiatives to expand the capacity and role of voluntary organisations tend to treat disabled people's organisations as invisible. While both the Treasury's cross-cutting review of the voluntary and community sector (HM Treasury, 2002) and the Compact framework recognise Black and minority ethnic organisations as key players in the VCS and as having particular interests and difficulties, there was no similar recognition concerning disabled people's organisations. This invisibility of our perspective is particularly problematic given the historical role of charities in the social exclusion of disabled people. There is little understanding within these initiatives of the importance of the distinction between organisations <u>of</u> and organisations <u>for</u> disabled people. The latter – particularly the major disability charities – have played an important role in the past in providing services which deny self-determination and prevent people from participating in their local communities. Moreover, through the images and messages of their fund-raising activities these charities promoted the view that disabled people have nothing to contribute. Some of the major charities have been influenced by the ideas of the disabled people's movement, but many of them

still operate in ways that disempower and exclude those on whose behalf they operate.

While government seeks to increase the capacity of the voluntary and community sector, organisations <u>of</u> disabled people arguably are facing a low point in their history. Local organisations find it increasingly difficult to get adequate funding from their traditional source – social services authorities – and are in unequal competition with 'organisations for' in bids to run Personal Assistance Support Schemes. It is not unusual for local disability organisations to be in competition with larger organisations who have designated contract and fundraising officers – resources which are not available to most disabled people's organisations.

All these barriers to making a contribution are made harder to overcome by the emphasis – within current citizenship debates – on people's *responsibilities* to make a contribution rather than on their *right* to make a contribution. A focus on responsibility places the onus on the individual to fulfil certain roles, with the underlying assumption that it is individual failings – such as lack of motivation – that are the cause of a failure to make a contribution. From disabled people's point of view, if their right to make a contribution was recognised this would be the starting point for addressing the attitudinal, social, economic and environmental barriers which prevent them from being full and equal citizens.

Citizenship and social justice

Self-determination, participation and contribution all need to be achieved if disabled people are to have 'equal opportunities' to be 'equal citizens'. In exploring these concepts we have also asserted that it is not impairment which determines whether disabled people can be full and equal citizens, but socially constructed barriers. The disadvantages experienced by disabled people are examples of social injustice and it is therefore impossible to address disabled people's potential for full citizenship without discussing values.

Indeed, a widely recognised definition of civil society is "an arena of uncoerced collective action around shared interests, purposes and *values*" (Centre for Civil Society, 2004, my emphasis). The government recognises this in various ways: for example, the Home Office review of support for community capacity building

started from the position that community development is "a value based activity" and adopted six core values: social justice; participation; equality; learning; co-operation; environmental justice (Home Office Civil Renewal Unit, 2003, p.3).

The Disability Discrimination Act itself is based on both a recognition that discrimination exists and a determination that our society should not tolerate it. With its concept of 'reasonable adjustment', the DDA also recognises that, if disabled people are to experience equal access, we require positive action to be taken and (sometimes) additional resources to be made available. Like the DDA, citizenship for disabled people means some limitations on non-disabled people's autonomy. This limitation takes two main forms: challenging and changing previously held attitudes and behaviour; and redistribution of resources for the action required so that disabled people can exercise self-determination, participate in society and make a contribution.

And this brings us to a key point about disabled people's opportunities for citizenship. While this paper has argued that self-determination, participation and contribution make up the key elements of what it is to be a citizen, it is also necessary to identify what kind of value system – what kind of society – enables disabled people to experience these elements of citizenship. Clearly, people who experience impairment and/or illness are at a disadvantage in a society and an economy where the market is the sole arbiter of opportunities and life chances. Disabled people require some kind of collective mechanism whereby group resources are redistributed to provide the additional requirements that individuals need to experience self-determination, to participate and to contribute. Moreover, such redistribution needs to be in the context of a value system which values diversity and where, therefore, disabled people are treated as belonging and contributing to the communities in which they lived.

An economic case is often made for anti-discrimination legislation, and could also be made for disabled people's equal access to citizenship – the DWP recently announced that disabled people's annual spending power is £80billion (DWP Press Release 3rd December 2004) and the 'business case' for employing disabled people is a common argument (see for example, National Employment Panel's Employers' Working Group on Disability, 2005). However, there is another – arguably stronger – case to be

made for the action required. Firstly there is the issue of what kind of society we want. The experiences of people who need positive action if they are to achieve full citizenship hold up a mirror to the kind of society we are.[12] In a society where life chances are entirely dependent on individual wealth and ability, inequality and intolerance will be played out in the disadvantages experienced by people with physical or sensory impairments, or learning disabilities or mental health problems. In a society where life chances are determined by redistribution of resources and a high level of social capital, the self-determination, participation and contribution of disabled people will be a reflection of an egalitarian society characterised by trust, inclusion and mutual support.

Secondly, such experiences also predict to currently non-disabled people what the future holds for them should they themselves (or those they love) acquire an impairment or experience mental illness. Arguably, we don't need to have recourse to John Rawls' 'veil of ignorance' in making the case of redistribution (Rawls, 1971) – one in four of the population in Britain are defined as disabled within the meaning of the Disability Discrimination Act and this figures rises to almost one in two over the age of 65 according to the Family Resources Survey 2002/3. It is in all our interests that we work towards a society that promotes self-determination, participation and contribution for everyone, regardless of their experience of impairment or illness.

What action is required?

Within the current public policy framework there are both opportunities and barriers to disabled people's access to full and equal citizenship. If the DRC's aim, set out at the beginning of this paper, is to be achieved the opportunities will need to be seized and the barriers addressed. They include:

1. The forthcoming Disability Equality Duty provides an opportunity to ensure that the myriad of initiatives currently underway to encourage active citizenship and promote community development fully address the barriers experienced by disabled

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[12] This is a phrase used by Clare Palmer, whose 19 year old daughter has significant cognitive impairment, who told me: "The lives of people like Elinor hold up a mirror to the values of our society. You've just got to look at the life of someone who has a label of 'profound and multiple learning disability' to see that society's reaction to her has been driven by an unwillingness to make sufficient resources available to enable her to have as good a quality of life as possible."

people. The role of local disability organisations is crucial here. Some local groups have, for example, fought to ensure that local Community Strategies both 'mainstream' disability issues and contain a particular focus on disabled people. However, these local groups are under-funded and – in order to fulfil their important role - require capacity building amongst both disabled individuals and organisations.

2. The agenda set out by the recent report from the Prime Minister's Strategy Unit (*Improving the Life Chances of Disabled People*) would, if fully implemented, go a long way towards achieving the DRC's goal (although their timescale is longer). In particular:
- the promotion of independent living would enable disabled people to achieve self-determination, participate fully in, and contribute fully to, family, community, social and economic life
- addressing the personalised support people need to get into and remain in paid employment, together with tackling discriminatory and ill-informed attitudes amongst employers, would similarly promote equal access to the three elements of full citizenship
- the goal that each local authority area should have a disabled people's organisation, modelled on the existing Centres for Independent Living, will help to promote active citizenship amongst disabled people in their local communities.

However, the report has its limitations that need to be addressed:
- there is no firm commitment to giving people an entitlement not to have to move into residential care in order to get the support they need
- there is no firm commitment to redistribute and use resources in ways which enable disabled people to be fully included in society
- there are no proposals to address the high risk of poverty experienced by disabled people or, in particular, the failure of disability benefit levels to meet the additional costs of impairment or illness
- its proposals are made in the context of continuing stigmatisation of people receiving incapacity benefit while at the same time there are significant cutbacks in the DWP

making it difficult to deliver the personalised support the report identifies is needed to help people into work

- the report does not cover people over retirement age. There is an urgent need to address the negative attitudes towards older people, the inadequate resources and disempowering services provided within the community care framework, and their consequent social exclusion.

3. The new Disability Discrimination Act provides some much-needed improvements to the original legislation but does not go far enough. In particular, we need:

- legislation based on the social model of disability rather than the medical model
- an entitlement to independent living
- better protection from discrimination and entitlements to reasonable adjustments within housing and transport provision
- extension of protection from discrimination and entitlements to reasonable adjustments in all 'active citizenship' roles, for example amongst volunteers and all public positions.

4. While progress has been made in recent years in terms of promoting the social inclusion of people with mental health problems, we need to ensure that there is not, at the same time, increasing numbers of people being compulsorily treated. We also need to gather evidence about the increasing population of young people (including those under the age of 16) who are detained in secure units or prisons, and examine whether their incarceration is a result of a failure to meet needs relating to impairment and/or disabling barriers.

5. We need to continue to challenge attitudes about what it means to be a person with a physical and/or sensory impairment, or learning disabilities, or mental health problems, but – more than this - we need to replace the institutional manifestations of these attitudes. Underpinning all the material barriers to self-determination, participation and contribution are assumptions about disabled people: our needs and how best to meet them; our feelings and aspirations; our worth and humanity. "To be disabled means to be unable to function socially as an independent citizen having the same rights and expectations as 'normal' people and that the management of disability demands life-long care and

professional expertise" (Finkelstein, 1991, p.19). As Colin Barnes points out, the construction of people with impairments as in need of 'care' has "resulted in the generation of a thriving and costly 'disability' industry comprised of state institutions, private businesses, charities and voluntary organisations staffed by vast armies of professional helpers including doctors, nurses, therapists and social workers" (Barnes, 2004). And as Frances Hasler, Mike Oliver, Gerry Zarb and others have identified there is a fundamental conflict between the community care system and the principles of independent living (e.g. Zarb et al, 2000).

The whole 'care industry' – and the legislative framework on which it is based – needs to be replaced. Instead we need legislation and structures that promote the principles of the independent living movement. In 1992, the British Council of Organisations of Disabled People (now the British Council of Disabled People) identified these principles as:
- that all human life is of value
- that anyone, whatever their impairment, is capable of exerting choices
- that people who are disabled by society's reaction to physical, intellectual and sensory impairments and to emotional distress have the right to assert control over their lives
- that disabled people have the right to participate fully in society (Morris, 1993).[13]

6. At the same time as campaigning for legislation and structures that would deliver these principles, we need also to challenge what it means to be a 'good citizen'. Excluding disabled people from mainstream society was for a long time considered to be 'natural' and justified, and is still for some groups of disabled people. Indeed, as Vic Finkelstein points out, those individuals who have been involved in excluding disabled people from mainstream society have been given civic awards for their work. From disabled people's point of view: "There is a singular lack of awareness that there may be something profoundly undemocratic about able-bodied people supporting the systematic removal of disabled people from their communities, that it is only able-bodied

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[13] These principles were written by a group of people involved in the British independent living movement brought together to inform a research project on independent living. Since then the principles have been used (sometimes with adaptations) by a number of different people and organisations, both nationally and internationally.

people who write glowingly about each other for having done this to disabled people and that it is able-bodied people who give themselves awards for this contribution to the isolation of disabled people from the mainstream of life" (Finkelstein, 1991, p.19).

We need to redefine 'good citizens' as people who promote the values of an inclusive society and who contribute towards the realisation of the principles of independent living. It is these people who deserve our respect, and to be given the 'honours' of citizenship, rather than those who contribute towards our exclusion.

Conclusion

If, in 15 years time, disabled people really do have "equal opportunities to participate and contribute as equal citizens", this will mean that we have a society where difference does not mean you cannot 'belong', but where instead our common humanity is recognised and valued. We all benefit if everyone can achieve their potential through self-determination, and maximise their participation within and contribution to families, communities and society. Disabled people and our organisations need to make the case therefore that these values benefit everyone and that ours is not a minority cause but should be a universal aspiration.

Jenny Morris
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