Independent Living: The role of evidence and ideology in the development of government policy.

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Introduction

Until recent years, social policy has treated disabled people as being dependent and in need of 'care', rather than recognising them as aspiring to fulfil the same kinds of roles that non-disabled people do. This has meant that:

- Responses to needs have often created dependency, rather than enabling social inclusion and citizenship;
- Disabled people are expected to fit into services, rather than services being personalised to respond to individual need.

The government has recently committed itself to achieving independent living for disabled people and has set out new proposals for delivering this aim. This paper looks at

the role of both research evidence and the disability movement in influencing the proposals contained in the government report *Improving the Life Chances of Disabled People* (Prime Minister's Strategy Unit, 2005) and the Adult Social Care Green Paper (Department of Health, 2005). It also addresses the question of whether these new proposals further an individualist and consumerist approach to meeting needs, thus undermining the collectivism and public service ethos which have been such an important part of the welfare state.

The government's proposals

In January this year, the government published proposals to bring about an improvement in disabled people's life chances over the next 20 years. At the heart of these proposals was a commitment to promote independent living for disabled people and introduce "a new approach" which:

- Addresses all aspects of needs for support and/or equipment or adaptations
- Is personalised according to individual need and circumstances
- Is underpinned by the principle of listening to disabled people and acknowledging their expertise in how to meet their needs

- Maximises the choice and control that people have over how their additional requirements are met

- Provides people with security and certainty about what level of support is available

- Wherever possible, minimises the disincentive to seek paid employment or to move from one locality to another; and

- Uses existing resources to maximise social inclusion."[1]

(Prime Minister's Strategy Unit, 2005)

The new system proposed aims to give individuals choice and control over how their support needs are met, and replace the existing fragmentation of needs across different central and local government agencies and departments, by introducing individual budgets. Individuals would be allocated a budget, based on eligible assessed need, and they would choose how to use this budget, with advocacy support where needed. It could be taken as a cash payment (as direct payments operate now) or in the form of services, or a combination of the two.

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[1] This paper draws on work which the author did as part of the Strategy Unit team working on the report.

Individual budgets would enable a range of support needs to be met: personal care; family roles and responsibilities; access to the community, employment, voluntary work, training and education, and leisure activities. The budgets could be used to purchase equipment, personal assistance, transport, adaptations and/or advocacy. The funding sources to be included are: community care resources and social services expenditure on equipment and minor adaptations; the current Independent Living Funds; Disabled Facilities Grant; and Access to Work expenditure.

It is also intended to:

- Separate out the assessment of need from the determination of eligibility
- Bring about a cultural shift so that social care professionals are working to promote self-directed support
- Ensure that each locality has a user-controlled organisation, modelled on the existing Centres for Independent Living
- Promote closer working relationships between health and social care organisations and organisations of disabled people.

While the Strategy Unit report only covered disabled children and disabled adults of working age, its proposals on individual budgets were intended to be extended to older people and this is indeed what the new Green Paper does. The Adult Social Care Green Paper, published in March, proposes that individual budgets should be introduced for all those who use social care services, including the largest group - older people. It proposes that the new system should be piloted to test out different models for administering budgets, delivering support to use them and bringing the various sources of funding together. While the social work/care management role would remain for assessment and co-ordination of services for people and families who have 'complex needs', it is envisaged that type of help and information that many people would need to use individual budgets calls for more of a service brokerage or care navigator role than the traditional social work role.

What are the factors which have brought these policy changes about?

The *Improving Life Chances* report, and the accompanying analysis in the Strategy Unit's initial report (Prime Minister's Strategy Unit, 2004), are manifestations

of a fundamental change in attitudes towards disabled people in the last two decades. Twenty years ago, it was not commonly accepted that people with physical and/or sensory impairments, learning disabilities, and/or mental health problems are unfairly discriminated against; now we have a legal framework which recognises that such discrimination exists and declares it to be unlawful. Twenty years ago, it was generally assumed that poor life chances were an inevitable consequence of impairment or illness: now we have a policy framework which recognises that people are disabled by negative attitudes and unequal access to resources, rather than by impairment or illness in itself. This acceptance of the social model of disability (albeit often accompanied by an incomplete understanding of the approach) has been long campaigned for by the disability movement.

This is not to deny that the limitations to its coverage mean the Disability Discrimination Act (DDA) does not deliver full civil rights or that, in using a medical model approach to the definition of who is covered by the legislation, it limits protection from discrimination to those who meet certain definitions or levels of impairment. However, in its concept of 'reasonable adjustment', the legislation goes a long way towards promoting the social

model of disability. By including within the legal definition of discrimination, failures to address barriers that exclude disabled people, the DDA requires positive action to be taken to enable disabled people to have equal access to opportunities. Anti-discrimination measures for disabled people are not about being treated the same as non-disabled people but about taking the additional action required to address disabling social, environmental and attitudinal barriers.

The adoption of the goal of independent living by the *Improving Life Chances* report is also a reflection of the success of the disability movement in challenging the notion that, if you need assistance to go about your daily life, then you are a 'dependent person'. Disabled people have argued instead that independence is achieved by having choice and control over the assistance required and that this choice and control is essential to enabling people who need support to access their human and civil rights.

The influence of the disability movement in bringing about a fundamental shift in policy has been threefold: a change in attitudes towards disabled people; practical demonstrations that giving people choice and control

works; and research evidence that this is an efficient use of public resources. The history of independent living is the history of a grass roots movement struggling against political and professional institutions and of winning those institutions over to its perspective and aims. As Fiona Williams has pointed out, the recasting of the welfare agenda in the last 20 years has not only been played out within the politics of Old Labour, New Labour and the New Right, but has also been profoundly influenced by the grassroots movements amongst those groups who are particularly reliant on the welfare state for their life chances (Williams, 1999, p.668).

However, there remains a lack of understanding about what the disability movement means by 'independent living' and a belief that the emphasis on 'choice and control' is (a) not an appropriate approach to the needs of all service user groups, and (b) that the approach plays into the hands of those who argue that the state should have only the minimal role of protecting individual rights and that social rights should be limited. Before looking at some of these political criticisms of the emphasis on choice and control I want to briefly examine the role of research evidence in influencing government policy.

The role of research evidence in influencing government policy

In spite of the Labour government's commitment that policy should be determined by evidence of 'what works', arguably social policy has been most influenced by ideology. This was certainly the case with the previous Tory governments. My argument is that the disability movement has had some major successes in influencing the development of social care policies, but that certain developments in the funding and carrying out of research have also had a key role to play.

In the late 1980s and1990s there were important changes in the relationship between research subjects and those commissioning and carrying out the research – changes that had a profound effect on research in the field of community care. The main arena in which this happened was the funding activities of the Joseph Rowntree Foundation (JRF), but the changes in the way the Foundation funded community care research were also adopted, to a greater or lesser extent, by some other funding bodies: for example, the National Lottery Charities Board (now the Big Lottery Fund) – acting on the advice of the JRF's Programme Advisor – adopted the social model of disability in its guidance for researchers. There

has been criticism of the limitations of both the JRF's approach and that of other funding bodies (Oliver, 1997) but the point to be made in this context is that it was research, primarily funded by JRF, based on the social model of disability which influenced the Strategy Unit's report – rather than research which remained uninfluenced by the politics of the disability movement.

The relationship (both formal and informal) between the disability movement and the Joseph Rowntree Foundation was a natural one in the sense that the Foundation's funding activities had always been determined by the principle that research should "provide the tools and the impetus for change towards a more just society" (Ward, 1997, p.32). In 1988, the Foundation set up a Disability Committee, and this, and the later Community Care and Disability Committee adopted a number of important principles:

- Ensuring that the membership of the Committee included disabled people with relevant expertise
- Consultation with disabled people and their organisations
- Funding applications were expected to take a social model approach to disability and to demonstrate the involvement of disabled people in both setting the

research agenda and influencing the carrying out of research

- 'Staying with' research issues, so that programmes of research were developed with a view to influencing policy and practice.

The Foundation funded the influential work by the British Council of Organisations of Disabled People which made the case for anti-discrimination legislation (Barnes. 1991), and also a series of seminars on researching disability. Initiated by Mike Oliver and Len Barton, these seminars brought together disabled people and non-disabled researchers to explore and promote an understanding of the social model of disability. They resulted in guidelines adopted by the JRF on how funders should involve disabled people in their activities, a national Conference and a special issue of *Disability Handicap and Society*, (Vol 7, No 2, 1992).

The key issue that the Foundation 'stayed with' during the 1990s was that of independent living. Their involvement started with my own research project (Morris, 1993), which consulted with organisations of disabled people about the definition of independent living and looked at comparative experiences of residential care, community care services,

and cash payments.[2] This research was followed by a whole programme on independent living which included Gerry Zarb's work on the costs and benefits of direct payments, a project which paired a traditional research organisation, the Policy Studies Institute, with the British Council of Organisations of Disabled People (Zarb and Nadash, 1994). Most of the research projects funded involved organisations or individuals representing its research 'subjects' throughout the process. For example, a number of JRF-funded projects carried out by the Norah Fry Research Centre originated in the ideas of local people with learning disabilities who were also involved in various aspects of the research (see Ward, 1997); people with learning disabilities from People First were provided with training and support to carry out evaluations of the experiences of people with learning disabilities who moved from institutional care to living in the community (People First, 1994); and the Social Policy Research Unit here at the University of York pioneered involving older people as research advisors (Tozer and Thornton, 1995).

The Foundation tried hard to ensure that disability organisations had access to research in their campaigning

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[2] Direct payments were at that point illegal but the Independent Living Fund had been set up in 1988 and provided cash payments to increasing numbers of disabled people; and some local authorities had been persuaded by disabled individuals and organisations to make various forms of 'indirect payments'

activities and sought to directly influence government itself by, for example, setting up the Task Force (chaired by Janet Lewis, then its Director of Research) on the disincentives to paid employment amongst disabled people created by community care charging policies. The evidence assembled (Howard, 2001), and the involvement in the Task Force of civil servants, not just from the Department of Health, but also from the Treasury, together with some judicious political lobbying by key disabled individuals, persuaded the government in 2001 to disallow earned income in the means test for direct payments, ILF grants and community care services. At a time when government's general approach was characterised by increased 'targeting' of resources – i.e. means-testing – this was an important victory for the univeralist principle. Of course, it also created a clear injustice in treating pension income differently from earned income and this injustice strengthens the case against community care charging policies generally.

It wasn't just disabled individuals such as Mike Oliver who influenced the Foundation's funding practices, but also allies such as Sally Baldwin who, as member of the Community Care and Disability Committee (and who was also a member of the Advisory Group for my research)

played a key role in enabling research to be funded which sought to empower disabled people, rather than merely treating them as research subjects. Such 'research for change' is very different from the days when two researchers from the Tavistock Institute were invited by some disabled people in a Cheshire Home to research their experiences, in the hope that this would highlight the oppression they faced but which merely added to their stigma and isolation by labelling them as "socially dead" (Miller and Gwynne, 1972).

By the time the Prime Minister's Strategy Unit started its scoping work on the 'Improving Life Chances' project in 2003, there was a body of research and evaluations, informed by the social model of disability, which both put forward a definition of independent living and made the case for policies that would deliver this aim. Crucially, there was also increasing practical experience of the benefits of giving individuals choice over how their support needs were met and, in particular, a pilot project was being run (as part of the implementation of the national learning disability strategy) using individual budgets. These pilot projects were motivated by a belief that disabled people, including those with the most significant

cognitive impairments, should and could have control over their lives and be fully included in society.

However, although it is unlikely that a commitment to promote independent living would have been adopted by government without this research and practical evidence, it can also be argued that individual budgets fit nicely into a political ideology which is more concerned with the individual consumer than with collective solidarity and that the notion of 'choice' undermines public services. This is the second issue I want to address in this paper.

Is the government's emphasis on 'choice' undermining public services?

When I explained individual budgets to my daughter, her reaction was 'How does that differ from the Tories' proposal for education vouchers?' This astute comment echoes criticisms of the previous Tory and current Labour government's emphasis on 'choice' in public services. After all, there is a strong argument that the Conservative government's enactment of direct payments in the 1990s was more a result of their desire to privatise public services than an espousal of the ideals of the disability movement. To understand whether this is a valid concern

in the context of individual budgets we need to engage with the wider debates on public services, citizenship and social rights.

'Choice' and human rights

The concept of 'choice' is an integral part of political debates about citizenship and the role of the state.   Part of the opposition to the promotion of choice rests on the assertion that treating users of public services as consumers undermines the relationship between citizens and the state. It is argued that an ethos of 'customer care', borrowed from the private sector, encourages service users to act solely in their individual self-interest and that the individual goals of customers undermine the collective goals of public service (Needham, 2004). New Labour's focus on choice in public services is therefore seen as part of a consumerisation of the relationship between government and citizen (Needham, 2003, pp.21-26).

However, this perspective fails to understand the profound importance for disabled people of choice as a means to accessing human rights. If you rely on others for assistance with personal care, for communication, for living an 'ordinary' life, then having choice over how that

assistance is provided is – disabled people have argued – the only way of protecting fundamental human dignity and of achieving autonomy. I have argued elsewhere that this is not to place the provision of personal assistance (or indeed other social care services) on a par with consumer services (Morris, 2001). To depend on others for assistance in intimate tasks is not the same as depending on a mechanic to service your car. In each situation, we want the assistance to be reliable, competent and we want to be treated with respect, but there are qualitative differences in the experiences - differences that are rooted in the experience of impairment. Julia Twigg's qualitative research on older people's experiences of being bathed highlights this quite clearly: "One person, strong and able, stands above and over another who is frail and physically vulnerable, forced to rely on their strength and goodwill. Being naked in the face of someone who is not, contains a powerful dynamic of domination and vulnerability, and it is often used in situations of interrogation and torture as a means of subjugating the individual" (Twigg, 2000, p. 21). Choice and control over how and by whom such assistance is provided is crucial to addressing the vulnerability created by this unequal power relationship.

It has been the lack of choice which consigns people to segregated forms of service provision, which institutionalises disabled and older people within their own homes, leaves them vulnerable to abuse and restricts their ability to participate in family and community life. The *Improving Life Chances* report drew on experiences of tailoring support to meet individuals' needs which – in contrast - not only increase the quality of their lives and protect them from abuse but are also a more effective use of public resources. This is not an 'empty consumerism' but a fundamental questioning of whether we should be using resources to keep people in situations – whether in institutions or within their own homes – which undermine their human rights. To take just two examples, a lack of choice and control for some people with learning disabilities creates behaviour which is difficult for others to deal with and can lead to costly residential placements that separate people from their families and communities (Ryan, 1998; Sanderson, et al 1997); a failure to provide personalised support for older people can result in inappropriate and over-use of medication (Stokoe, 2001).

Disabled people's support for choice is not a support for the 'consumerisation' of public services, or an acceptance that we are all 'atomised individuals', or an argument for a

minimal state. It is a demand which came out of collective struggle against a welfare system designed and run without the input of those using it, which believed, and still believes, that it is acceptable to separate people from their families and communities because it is cheaper to do this than support them to live independently. 'Choice' over how a person's support needs are met is integrally linked to human rights and to the concept of independent living.

'Choice' and independent living

However, it is also the case that the word 'choice' as it is commonly used in current debates on public services does not really reflect the full sense of its meaning for those who use social care services. It is important not to lose sight of the fact that the independent living movement uses the phrase 'choice and control' rather than just the word 'choice', and that having control over the assistance needed is an integral part of the demand for independent living. While the phrase is associated with those disabled people of working age who are involved in the independent living movement, the same words are used by many older people to define 'independence'. As research on their views found, "…choice, control and self sufficiency were central to older people's perceptions of independence. Although good health, the ability to

maintain personal mobility and being able to live in your own home were commonly associated with being independent, independence was only felt to have been lost if you were unable to exercise control and choice over key aspects of daily living" (Parry et al, 2004, p.1)

The Disability Rights Commission, which has adopted an entitlement to independent living as one of its policy aims, sets out a general definition of independent living:

> The term independent living refers to all disabled people having the same choice, control and freedom as any other citizen - at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations.
> (Disability Rights Commission, 2002)

There are three elements to this definition, which are also to be found in most other discussions of what independent living means. Firstly, there is an assertion that disabled people should have the same opportunities for choice and control in their lives as non-disabled people; secondly there is a challenge to the usual interpretation of the

words 'independent' and 'independence'; and finally, the aspiration that any assistance required should be under the control of disabled individuals themselves. As Simon Brisenden, an early pioneer of independent living, wrote 'Independence is not linked to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it' (Brisenden, 1989, p.9).

Independent living is essentially a challenge to the place of disabled people in society. As Adolf Ratzka, another independent living pioneer, stated 'Independent Living is a philosophy and a movement of people…who work for self-determination, equal opportunities and self respect' (Ratzka, n.d.). 'Choice and control', it is argued, is essential in order to achieve self-determination, while self-determination in its turn is a crucial part of citizenship. This brings us back to addressing the criticism that promoting 'choice' in public services undermines the wider social role of citizenship by instead treating people as individual consumers and that this, in turn, undermines the role of the state in tackling inequalities.

'Choice' and citizenship

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

In another paper I have looked in some detail at what citizenship means for disabled people and how it relates to current debates on citizenship.[4] While engaging with those debates, my starting point was the language and concepts which disabled people themselves have articulated as crucial to their status as equal citizens. Here, I want to briefly explain the three main elements which – from the point of view of disability movement – are crucial to citizenship and then discuss how one of them in

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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).

[4] This paper *Disabled people and citizenship* was commissioned by the Disability Rights Commission and will appear on their website.

particular is important for the current debates on public services. The three elements are:

- Self-determination. As already mentioned this has been an important concept for the independent living movement; it has also been key to the self-advocacy movement of people with learning disabilities. Self-determination is about making decisions for yourself: "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).   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 order to argue for the right to be included in family, community and political life. 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, for example the recent discussions about 'conditionality' and benefits (Stanley and Lohde, 2004).

Arguably, self-determination is the most important element of what citizenship means for disabled people. Without self-determination, people are unable to participate or to make a contribution.

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, which sees self-determination as the absence of coercion of, or interference with, individual action. The state's role is therefore the limited one of protecting

individual freedom. Some analysts of current government policy see the focus on choice and the citizen as consumer as belonging within this 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).

It has been argued that the disability movement's campaign for direct payments colluded with the neo-liberal approach to the state. Indeed many Labour local authorities and public sector unions saw direct payments as the New Right's Trojan horse which would lead to a privatisation of social care services.[5] It would be easy, within this perspective, to see individual budgets in the same light.

In fact, the liberal political tradition of citizenship, particularly its current version adopted by the New Right, poses considerable problems for disabled people. While the New Right defines freedom (self-determination) as the absence of interference with individual action, and the state's role is the limited one of protecting such freedom, the issue for disabled people is that such negative rights are not sufficient to deliver even simple autonomy.

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[5] In fact, of course, the privatisation of social care services (or the shift from the provider to the commissioner role amongst local authorities) has proceeded apace uninfluenced by the take-up of direct payments.

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) assume that impairment is personal tragedy and disabled people are to be looked 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-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, old age 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. As far as disabled people were concerned, the

extension of social rights in the post-second world war period was done in ways that restricted their autonomy, particularly 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 the 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' which 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 (one of the original issues they campaigned on). As already mentioned, their lack of control over their lives and their exclusion from society led to 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 which later led to a change in government policy – an

example of what Doyal and Gough call 'critical autonomy'. It was the realisation that, just because they needed help with going to bed, this did not mean that they had to be put in their pyjamas at 6 o'clock in the evening. This is what the social model of disability is about: that it is not impairment in itself which restricts what someone can do, but the lack of choice and control over the required assistance. This is not about empty choices or consumerism or the application of market forces to undermine public services; instead it is about fundamental rights to self-determination which, if denied, prevent certain groups of people from being fully part of society.

In asserting disabled people's rights to self-determination, it is necessary to argue, not only for the removal of barriers to self-determination but also for the provision of assistance in ways 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 be provided in their daily lives in ways which enable them 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 for disabled people therefore relies on other people's and the wider society's responses to their individual needs.

Self-determination, which is key to disabled people's status as full and equal citizens, cannot be achieved without:

- The removal of barriers
- The provision of necessary support
- Choice and control over the support required.

A demand for choice and control is not, therefore, about the state having a minimal role. Neither is it a demand which undermines public services. Rather such collective provision is crucial to disabled people's equal citizenship. Moreover, direct payments – which are very much the forerunner to the current proposal of individual budgets - 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. Both direct payments and

individual budgets 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.

Are the current proposals sufficient to deliver self-determination for disabled people?

While there is limited understanding of the importance of self-determination for disabled people amongst critics of 'choice' in public services, the government's proposals themselves do not adequately address what is required for self-determination. I want to finish this paper by identifying some gaps in the current proposals which, if not addressed, will limit their effectiveness.

<u>'Choice' is not sufficient to deliver self-determination</u>

To a large extent, the promotion of choice in public services is about models of service delivery and the belief that 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. 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.

<u>Expenditure on self-directed support needs to be seen as a form of investment</u>

Political and economic factors meant that neither the Strategy Unit's report, nor the Green Paper, promise an increase in resources. As a consequence, neither initiative has sufficiently recognised the economic case for expenditure on independent living. *Improving Life Chances* referred to evidence that increased demands on health and social care budgets can result from a failure to provide housing adaptations or equipment and that more personalised support can increase people's ability to take up paid employment and fulfil family responsibilites. Yet the implications of this have not been followed through. In particular the opportunity has been missed to take a more holistic and transparent approach to public expenditure: if the cost implications for other budgets of not increasing

expenditure to promote independent living were taken into account the economic case for such increased expenditure would be obvious. The Green Paper is particularly disappointing in this respect. Not only is there no recognition of the additional resources which could be released by tackling disabling barriers and delivering self-directed support but the opportunity has been missed to promote the role of social care in enabling disabled and older people to fulfil family roles and responsibilities and to participate and contribute as citizens.

<u>Self-directed support is necessary to self-determination and this requires a fundamental cultural shift in the provision of social care</u>

There is a danger that the implementation of individual budgets will lose touch with the origins of the idea: they are being piloted by the In Control project as a way of changing the organisation of social care "so that people who need support can take more control over their own lives and fulfil their role as citizens" (see www.selfdirectedsupport.org). The *Improving Life Chances* report envisaged both a change in the role of professionals and an increased role for user-led organisations:

The new system would require a cultural shift so that social care professionals are working to promote self-directed support. Such a shift would be encouraged by closer working relationships between health and social care organisations and organisations of disabled people

(Prime Minister's Strategy Unit, 2005, p.78)

A key part of bringing about this cultural shift was the proposal that "By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a user-led organisation modelled on existing Centres for Independent Living" (Ibid., p.76). However, the Green Paper on adult social care makes no such commitment. Past social policy, developed and delivered without the full involvement of disabled people and their organisations, led to public resources being used in ways which disempower people and deny human rights. These mistakes will be repeated if the involvement of people who need support to go about their daily lives is not placed at the heart of the proposed new system.

<u>None of the proposals will deliver an entitlement to independent living</u>

When the Prime Minister's Strategy Unit consulted disabled people and their organisations about what an entitlement to independent living would look like, the most common response was that it would involve a right to not be forced to move into residential care. Such a right is necessary because, while strictly speaking people cannot be forced into residential care, in reality this happens by default because local authorities – being required to make the most cost effective use of their resources – cap expenditure on support at home to the costs of residential care. This results in particular discrimination against older people as they are forced into residential care at lower care costs than people below retirement age (Morris, 2004). The increasing numbers of young people with high levels of needs are also at risk of moving into residential care as they move into adulthood, because support services and housing are often not available to met their needs.

However, the government's current commitment to 'choice' did not extend to giving people the choice not to have to move into residential care. Instead, the Strategy Unit proposed and the Green Paper implemented, a consultation on

the merits of a 'right to request' not to live in a residential or nursing care setting, taking full account of the particular issues faced by the individual, and considering the financial, organisational and legal implications of both the staus quo and alternative options. This 'right to request' would require service providers to make explicit the reasons behind their decision to recommend residential care, including cost considerations.

(Department of Health, 2005, p.32)

This is a long way short of the legal protection that disabled and older people require if they are to avoid being forced into residential care.

Conclusion

Over the last twenty years, local and national disability organisations have had some significant successes in promoting independent living. Research, conducted using the social model of disability and involving disabled people and their organisations, has played a key role in influencing policy development.   The influence of both this research and the disability movement is apparent in current government proposals contained in the *Improving*

Life Chances report and the Green Paper on adult social care.

Nevertheless, there is still limited understanding, across the political spectrum and within the research community, of what independent living means and what is necessary to achieve it. The independent living movement is vulnerable to - from the left - attacks on choice in public services, and - from the right – attacks on levels of public expenditure. It is important that these debates are informed by an understanding of the importance of choice and control for disabled people, and by research into whether and how expenditure on independent living – for people of all ages – should be seen as a form of social and economic investment.

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