

Rethinking disability policy

Viewpoint
Informing debate

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There are concerns that reductions in benefits and public services will significantly and disproportionately affect disabled people. What progress has been made in disability policy in the last 20 years? Is it time to revisit underlying concepts and engage in wider social and economic debates?

Key points

- There have been some key improvements in both the socio-economic experiences of disabled people in the last 20 years, and in related government policies. Nevertheless, few disabled people are optimistic about what the future holds.
- Some aspects of the arguments made by disability organisations have been capitalised on by the politics and ideology driving recent and current policies in ways which disadvantage disabled people. In particular this has happened with the social model of disability and concepts of 'independent living', 'user involvement' and 'co-production'.
- In engaging with dominant policy agendas, we may risk losing touch with more fundamental issues concerning the welfare state. This may unintentionally contribute to the undermining of collective responsibility and redistribution.
- In campaigning for policies to tackle disabling barriers and enable equal access, we need to explicitly and vigorously promote the welfare state and the concept of social security in its broadest sense. People of all ages 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.
- In order to experience equal access to full citizenship, disabled people require some kind of collective and redistributive mechanism. Such redistribution needs to be in the context of a value system which values diversity and in which disabled people are treated as belonging and contributing to the communities in which they live.
- There is little room for making progress within the ideological framework driving current disability policies. We need to develop more radical challenges to the current disability policy agenda and engage in wider debates, particularly those which question the continuing pursuit of economic growth regardless of the damage done to the environment, to values and to humanity.

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Background

The main audience for this *Viewpoint* is individuals and organisations working to address the inequalities and social injustice experienced by disabled people. For 20 years, I researched these experiences and then worked within government (first in the Prime Minister's Strategy Unit, then with the Office for Disability Issues) as a consultant on disability policy. Now that I have stopped working, I wanted to take the opportunity to reflect on what progress had been made and, in particular, on why such progress was limited. My initial proposal was to write mainly about the past 20 years, but the pace and impact of government policies since the 2010 general election has inevitably led me to focus more on the current context than I originally intended.

I use the words 'we' and 'us' at various points in this paper. By doing this, I am identifying myself as a disabled person and as part of the disabled people's movement. This latter term is difficult to define and I use it to refer to a network of organisations run by disabled people, primarily staffed by disabled people. It used to be possible to distinguish between organisations 'of' and organisations 'for' disabled people, the latter term referring to charities (often impairment specific) that provide services to, and campaign on behalf of, disabled people. However, most of these now call themselves organisations 'of', in that they have disabled people on their management committees and most have now aligned themselves with the campaigns initially pioneered by the more grassroots organisations of disabled people. When I refer in this paper to 'disabled people's organisations' I mean these grassroots organisations, but will use the term 'disability organisations' to mean both those that were previously called organisations of, as well as those that always were organisations for, disabled people.

Introduction

There have been some key improvements in both the socio-economic experiences of disabled people in the last 20 years and in related government policies. We should not lose sight of this progress. Nevertheless, very few of us are optimistic about what the future holds. Obviously, there are concerns about reductions in welfare benefits and public services. Demos, for example, has calculated that disabled people of working age will be disproportionately affected by the public expenditure reductions set out in the 2010 budget (Wood and Grant, 2010); while the Norfolk Coalition of Disabled People has highlighted the cumulative impact of changes in benefits and taxes and cuts in local authority services and how these will significantly and disproportionately affect disabled people (Edwards, 2011).

It is also the contention of this paper that there are aspects of the arguments made by disability organisations which have been capitalised on by the politics and ideology driving recent and current policies in ways that are significantly to the disadvantage of disabled people. These concern, in particular, the social model of disability and the concepts of 'independent living', and 'user involvement' or 'co-production'. I want to look at the way governments have colonised and corrupted these ideas, and to start to identify some possible responses which may help with future progress on disability policies.

The significant shifts in policies affecting disabled people's lives which have taken place over the last 20 years have been influenced by organisations and individuals working both inside and outside the key decision-making bodies. Both approaches involve, to a greater or lesser extent, negotiating one's way across the policy agenda and require degrees of manoeuvring to make progress. This can include adjusting one's language to suit the prevailing discourse: many organisations now seeking funding find they need to use language which fits within the 'Big Society' agenda, whereas a few years ago it was politic to use terms such as 'active citizenship'. Some policy agendas are more amenable to advancing disability equality than others: the human rights agenda, for example, has provided particularly fertile ground over the last ten years, leading to the UN Convention on the Rights of Disabled People, which is now being used by disabled people in Britain and elsewhere to pursue the goal of independent living.

These are examples of the various ways in which people seize opportunities to work within dominant political agendas, in that disabled people (and progressive professionals and civil servants) seek out the words and phrases which will resonate with the dominant discourse. As Mike Oliver and Colin Barnes identify, the dilemma for disabled people's organisations is that 'To get too close to the Government is to risk incorporation and end up carrying out their proposals rather than ours. To move too far away is to risk marginalisation and eventual demise' (Oliver and Barnes, 2006).

One key example of past successes in finding opportunities within prevailing political agendas concerns the campaign for direct payments. The resulting legislation, passed by a Conservative government in 1996, fitted in with an agenda which sought the privatisation of services and an undermining of public sector trade unions. While disabled people's organisations did not support such policies, we did – when making the case for direct payments – use language which fitted well with the individualist political framework which was becoming more and more dominant. Thus we emphasised disabled people's rights to autonomy and self-determination, which resonated with the Conservative Government's agenda; and drew attention to the way a lack of choice and control could undermine human rights, which then fitted well with New Labour's agenda.

My concern is that – in engaging with the dominant policy agendas – we have lost touch with more fundamental issues concerning the welfare state, and that we have, unintentionally, contributed towards a steady undermining of collective responsibility and redistribution. From my perspective, this matters because I do not believe that the alternative – a small state and a market of private providers – will deliver the opportunities and quality of life which disabled people should expect in the twenty-first century.

I should make it clear that it is not my intention to undermine or criticise the valuable work that disabled people's organisations have done over the last 20 years, influencing governments to develop and implement policies intended to improve disabled people's life chances. My research since 1990, and my subsequent work with the Prime Minister's Strategy Unit and the Office for Disability Issues, relied on the pioneering ideas and campaigns of disabled people and their organisations. Like them, I looked for, and took advantage of, whatever opportunities there were within the prevailing political climate – in the way I have described above.

However, the current onslaught on services and benefits has led me to conclude that there is very little scope for making progress within the current political agenda. This discussion paper is an attempt to take stock and propose more fundamental changes which I believe are necessary if disabled people are ever to achieve full human and civil rights.

Starting points

From its earliest years, the disabled people's movement has argued for a welfare state which would include user controlled, pro-active services, delivered within a framework of rights and entitlements and where there are meaningful rights of redress (see, for example, European Network on Independent Living, 1989). As Mike Oliver says:

[the welfare state remains] an essential ingredient for the development of a truly inclusionary society. That is to say, a society in which both disabled and non-disabled people can participate and realise their full potential and where the notion of disability and all its associated deprivations are little more than a dim and distant memory.
(Oliver and Barnes, 2009)

This statement is predicated on the social model of disability, on the distinction made between 'impairment' and 'disability' and the contention that it is the disabling barriers of discriminatory attitudes, inaccessible environments, and lack of enabling supports which should be the focus of social policy. 'Disability' is the oppression and inequality that people with impairments experience as a result of these barriers, and it is possible to envisage a society in which these barriers are overcome. Linked to this is the argument that investing in the provision of support for disabled people will benefit society as a whole.

Two of the key ways in which this vision was articulated during the late 1980s and 1990s are to be found in the various debates and campaigns around anti-disability discrimination legislation, and for independent living. The campaign for the Disability Discrimination Act, passed in 1995, brought about a shift away from a refusal by Parliament to even recognise that discrimination by employers and service providers existed, to an acceptance of the need for legislation to both outlaw discrimination and require the provision of adjustments to overcome barriers to equal access. This Act, and its successor passed in 2005, has the disadvantage of requiring a person to first establish that the nature and severity of their impairment comes within the definition of 'disabled person' laid down in the legislation and, in this respect, it is based on the medical model of disability. However, the requirement to make adjustments to the workplace or service provision in order to overcome the barriers experienced by people with impairments reflects a social model approach, although the requirement is limited by a definition of 'reasonable' which can include a judgement that an adjustment is too costly.

A social model approach is also implicit in one part of the benefits system, the Disability Living Allowance (DLA) – a cash payment in recognition of the additional costs that are incurred as a result of impairment. The key feature of DLA (like the Attendance Allowance and Mobility Allowance which it replaced in 1992 for people of working age) is that it is not means-tested and as such is the only aspect of the benefit system which is implicitly based on creating a 'level playing field' for disabled people – in the same way that child benefit is intended to compensate for the additional costs of bringing up children. Like the Disability Discrimination Act, the DLA – and its proposed replacement, the Personal Independence Payment (PIP) – therefore encompasses a social model approach, although the assessment process is also about identifying levels of impairment rather than experiences of disabling barriers, and the proposals for PIP seem to incorporate a corrupted version of the social model, as discussed below.

DLA enables people to make decisions for themselves as to how best to meet their additional needs. This aim was also articulated in the campaign for direct payments (in lieu of community care services arranged by local authorities), with disabled people arguing that, if they had the cash, then they would have choice and control over how and when assistance was provided and would be more likely to participate fully in their families, communities and wider society. It took until 1995 before the then Secretary of State, Peter Lilley, announced 'new legislation that will allow some disabled people more choice and control over their lives – the Community Care (Direct Payments) Bill' (House of Commons Debate, 17 November 1995).

Peter Lilley's use of the phrase 'choice and control' is significant: it was and is the phrase used by the disabled people's movement to define independent living and has been increasingly used, both by those arguing about what government should do, and by government itself. The Labour Government's *Improving the Life Chances of Disabled People* (Cabinet Office, 2005) adopted disabled people's own definition of 'independent living', as did the subsequent five-year *Independent Living* strategy published in 2008 with cross-party support (Office for Disability Issues, 2008).

The concept of independent living is discussed further below, in the context of policies on adult social care, but it is important to emphasise that the disabled people's movement has attempted to redefine the meaning of 'independent' and 'independence'. Instead of meaning 'doing things for yourself' or being 'self-sufficient', disabled people have insisted that 'independence', in the sense of autonomy and self-determination, is achieved by having choice and control over any assistance needed to go about daily life.

The idea that disabled people should have choice and control over the support they need to go about their daily lives was and is at odds with the ways in which 'care services' have traditionally been provided. We have made some progress away from assumptions that dependency automatically accompanies impairment. Direct payments – although still only received by a minority of disabled people who are eligible for social care support – played an important role in this cultural shift, which has occurred in the last 20 years. The campaign for an Independent Living Bill, presented a number of times in Parliament as a Private Member's Bill, although unsuccessful, also played a key part in gaining support for using resources in more empowering ways. This change of perspective – and particularly the recognition that disabled people should have choice and control over the support they need – is evident in much of the language used about adult social care by both the current and the last government.

While we are a long way from the vision of the welfare state articulated by the European Network on Independent Living in 1989, there has undoubtedly been significant progress in the policy framework, legislation and in attitudes. However, over the same period there has also been a steady undermining of the welfare state. The post-war consensus on the value of social rights has been steadily eroded, with the emphasis increasingly being on a more minimal role for government, confined to providing a framework for civil and political rights. The current political agenda is dominated by a widely-held belief that there are two key problems facing the welfare state: increasing and unsustainable expenditure; and the creation and maintenance of 'dependency' amongst those who rely on its cash benefits and/or services.

This undermining of the welfare state has a particular impact on disabled people in the context of both welfare reform and changes to the adult social care system. It is the contention of this paper that aspects of disabled people's campaigns against discrimination and for independent living have been, and are being, used to legitimise changes in welfare benefits and in adult social care in ways which will only lead to greater inequality and discrimination. In order to understand how best to respond, we need to first examine how such progressive ideas have been corrupted. The next section of this paper looks at the way such a corruption and misuse of the social model of disability is influencing welfare reform, before looking at recent and current developments in adult social care.

Welfare reform

Disability Living Allowance

Perhaps the most blatant corruption of the social model of disability (and also of the notion of ‘independence’) is to be found in the government’s proposals concerning a new assessment framework for the PIP, which is intended to replace Disability Living Allowance (DLA). The starting point for this reform is ‘that the complexity and subjectivity of the benefit [DLA] has led to a wider application than originally intended’ and the numbers qualifying need to be reduced in order for the benefit to be ‘sustainable and affordable’ and focused on the people who ‘need the greatest help to live independently’ (Department for Work and Pensions, 2010a).

Currently, two-thirds of DLA recipients qualify for an ‘indefinite’ award meaning that their impairment/ medical condition is not expected to improve. Under the new proposals, regular reassessments will be part of the system (except for those with a terminal diagnosis). The government’s consultation document states that the new benefit should ‘take account of the social model of disability’ (Department for Work and Pensions, 2010a) and a definition of the social model is given in an Appendix to the consultation. However, the government has interpreted a social model approach as meaning that the assessment should take into account the impact of ‘medical treatments and aids and adaptations’ on ‘people’s ability to participate in everyday life’, with the impression being that the new eligibility criteria may exclude, for example, someone who cannot walk but uses a manual wheelchair to get around.

Whereas disabled people have seen DLA as contributing towards a level playing field, by enabling them to meet additional costs associated with impairment and/or disabling barriers, the assessment for PIP will mean that where an individual ‘successfully’ uses ‘aids and adaptations’, this may well disqualify them for the new benefit. Two arguments are used to make this case. The first, more explicit (though rather questionable), one is that some aids and adaptations are available through other forms of state support (local authorities and the NHS) and that in such circumstances it would be wrong for people to effectively be ‘double-funded’. The second, more implicit, assumption is that using aids and adaptations ‘successfully’ makes people ‘independent’ and therefore not eligible for support from the state, the provision of such support being reserved for those who are ‘dependent’ (see Department for Work and Pensions, 2011a). This mindset is integrally linked to the promulgation of the idea that an increase in the number of people receiving ‘disability’ benefits is a sign of increasing ‘welfare dependency’ rather than a sign of an increasing number of people with impairments and of a society which makes resources available to attempt to create a level playing field.

It remains to be seen whether the attempt to reduce the amount of money spent on DLA/PIP will be able, in practice, to successfully (mis-)use the social model to narrow eligibility. In the context of reforms to out-of-work benefits, there is a more complex story to be unravelled, which centres on the meanings of ‘disabled’ and ‘disability’ and the way ‘illness’ has been treated in the politics of disability.

Reform of Incapacity Benefit

The proportion of adults of working age who are recorded as having a ‘limiting long-standing illness’ rose from 14 per cent in 1975 to 18 per cent in 1996, before falling back to 16 per cent in 2004 (Berthoud, 2011). As Richard Berthoud points out, there is a popular assumption that the rise in claims for incapacity related benefits, which also occurred between 1975 and 1995, is a result of people with trivial health conditions either exaggerating their impairments, or exaggerating the effect of impairment or illness on their ability to work. In fact:

... most of the growth in the prevalence of limiting long-standing illness ... has affected people at the more severe, rather than the less severe, end of the spectrum ... This suggests that the underlying trend is a true one, not simply associated with people’s reports of, or responses to, trivial conditions.

(Berthoud, 2011)

Berthoud’s analysis also shows that disabled people’s employment opportunities worsened from the 1980s up until the end of the century, in that the extent to which a disabled person was less likely to have a job than a non-disabled person (the disability employment penalty) increased from 17 per cent in 1987 to 28 per cent in 2000, and has remained at this level (Berthoud, 2011).

Disability organisations from the 1970s onwards have stressed the role of discriminatory attitudes in the high levels of unemployment amongst disabled people. The success of the campaign for anti-disability discrimination legislation was part and parcel of a challenge to the assumption that disabled people cannot work. This challenge meant persuading government and the public that it is not impairment (functional limitations) which prevents disabled people from working, but disabling social, environmental and attitudinal barriers. However, this progressive assertion has co-existed with an assumption dating back to the days of the Poor Law, but which is still prominent within current policy and public debates, that ‘the poor’ and ‘the disabled’ can be divided into those who ‘deserve’ assistance from the state and those who are mere ‘malingerers’. It is primarily this narrative which is driving the replacement of Incapacity Benefit with Employment and Support Allowance, just the latest in a series of attempts to reduce the numbers of people receiving benefits because they are considered too ill or disabled to take up paid employment.

The last Labour Government talked about ‘work for those who can, security for those who cannot’ and the Conservative Manifesto at the last election echoed this with the phrase ‘respect for those who cannot work’ and ‘employment for those who can’. Both phrases are predicated on the development of assessments, rules and sanctions which have the aim of separating out the ‘deserving’ from the ‘undeserving’ – while at the same time seemingly supporting the more progressive stance that most disabled people both want to and can work. Both also conflate a reliance on state benefits with ‘dependency’ and an accompanying assumption that, to be ‘independent’ requires being economically productive.

The role of ill health

Very few impairments, whatever their level of severity (except for significant cognitive impairment), prevent a person from doing paid employment *per se*. The much more important influences are, on the one hand the personal experience of ill health (see Thomas and Griffiths, 2010), and on the other hand, disabling attitudes and environments (which includes economic factors influencing the demand for labour). The problem is that there has been a tendency, in the context of disability policy generally, to underplay the impact of physical and mental ill health, and in the context of out-of-work benefits, governments have focused on individual motivations and behaviour rather than acknowledging the demand-side factors (employer behaviour and the general demand for labour) which influence disabled people’s employment opportunities.

Alongside the progressive assertion that disabled people are not necessarily ‘sick’, a dominant attitude within the policy debates on Invalidity/Incapacity Benefit (now Employment and Support Allowance) over the last 20 years or so has been that many of those receiving it are not ‘really’ sick. Thus Tony Blair said in 1999 that Incapacity Benefit (IB) is ‘not a benefit which compensates those who have had to give up work because of long-term illness or sickness – it’s an alternative to long-term unemployment or early retirement. That’s why it must be reformed’ (Blair, 1999, quoted in Griffiths, 2010). The Labour Government’s reforms were dominated by this assumption that most people on IB were in fact capable of working, and this view, like the reforms themselves, is driving the new assessment regime for Employment and Support Allowance. As Chris Grayling, Employment Minister, said in April 2011: ‘We now know very clearly that the vast majority of new claimants for sickness benefits are in fact able to return to work’ (Department for Work and Pensions, 2011b).

This latter statement is in fact misleading. Four out of ten ESA claimants are found ‘fit for work’ (though more than a third then appeal and 39 per cent are successful), while another third withdraw their applications (Department for Work and Pensions, 2011c). However, the more pertinent point is that this does not mean those found ‘fit for work’ actually return to work. In fact, recent DWP research found that only 37 per cent of those found ‘fit for work’ had returned to work one year later. Amongst those in the Work-Related Activity Group, only 5 per cent were helped into employment over the course of the year (Department for Work and Pensions, 2011d).

There has been much criticism of the new Work Capability Assessment (WCA), but the main problem is in the application of the behavioural model on which it is based. This is the bio-psycho-medical model, an approach recommended by large insurance companies such as UnumProvident (see Rutherford, 2007; UnumProvident, 2003). This model ‘recognises that psychological and social factors influence a patient’s perceptions and actions and therefore the experience of what it feels like to be ill’ and concludes that ‘Personal choice plays an important part in the genesis or maintenance of illness’ (Wade and Halligan, 2004). Although a holistic approach to illness is undoubtedly important, the combination of the bio-psycho-social model and a government target of reducing the numbers eligible for ESA/IB by one million by 2015 is creating a punitive and stigmatising narrative about large numbers of people claiming they are too sick to work when they are in fact capable of working.

The contention that most people on IB could work is accompanied by one of two assumptions. The first, more punitive, assumption is that there is a high level of ‘malingering’, even though all the evidence is that this is extremely rare (Department for Work and Pensions, 2010b). The second, more ‘benevolent’, assumption is in using the terms ‘disabled people’ to refer to IB/ESA claimants, which recognises that most disabled people want to and can work and that it is disabling barriers which have got in the way. This is an image of a ‘disabled person’ as someone who uses a wheelchair or who is blind or perhaps deaf, or someone with a mild-moderate learning difficulty, the implicit assumption being that they do not experience any ill health associated with their impairment.

However, this description does not fit many people who are in receipt of long-term benefits for which they qualified because of ill health and previous payment of national insurance contributions (sometimes after many years of employment). Analysis of the needs of people on incapacity benefit in the early 2000s indicated that the majority ‘do not fit the traditional stereotype of ‘disabled persons’ and are better described as ‘chronic sick’ or prematurely retired. Indeed, the main problem today is ‘long-term sickness’ in people over the age of 50 years’ (Waddell and Aylward, 2005). It is also important to recognise that – not only in Britain but across all developed countries – between a quarter and a third of those receiving ‘disability benefits’ do so because of mental health difficulties and that most of these would not describe themselves as either disabled or having a ‘disability’ (OECD, 2010). Moreover, it is significant that most of the current accounts of people’s difficulties with the WCA and ESA system – published through websites such as Broken of Britain (<http://thebrokenofbritain.blogspot.com/>) – seem to concern people who have chronic health conditions. These often criticise the assessment process for failing to take account of individual experiences of illness, pain and fatigue.

The Pathways to Work programme run by the previous Labour Government to some extent recognised the importance of ill health in creating barriers to work, by promoting partnership working between Job Centre Plus and local NHS bodies to provide Condition Management programmes for those with long-term health conditions who might be able to obtain paid employment. An evaluation of the seven pilot areas found that optimal results were obtained when there was a strong working relationship between Job Centre Plus and local NHS bodies, with involvement of the private and voluntary sector. Even then, only one in five participants had taken up employment during the course of the pilot programme (Ford and Plowright, n.d.). It is interesting that UnumProvident itself has said it is only able to assist 15 per cent of claimants on its sickness insurance back into work (UnumProvident, 2003). The treatment and management of long-term health conditions has certainly not figured much in the current government agenda on enabling people on IB/ESA to take up paid employment, with the emphasis being on questioning whether people really are in such poor health that they cannot work.

Such assumptions are part and parcel of the application of conditions and sanctions to be applied to those claiming benefits, thus continuing the extension of conditionality to out-of-work benefits which has been evident over the last fifteen years or so (Dwyer, 2004). There is now very little of the insurance element of the welfare state remaining and, in this context, the notion of ‘welfare dependency’ – and the perceived need to combat such dependency – has become more and more dominant. The emphasis is on the individual as ‘the problem’ and it is the individual – most often their attitudes and motivation – that is required to be ‘fixed’. The word ‘vulnerable’ (discussed further below) has come to be increasingly applied to those ‘deserving’ of support (not only in the field of adult social care but also in the context of welfare benefits) while a much larger group is identified as ‘welfare dependent’ and, at worst, fraudulently claiming to be ‘disabled’.

Defining disability

Alongside the failure to properly acknowledge the role of illness, there are confusions created by using the term ‘disability’ to refer to impairment rather than disabling barriers. This is particularly apparent in the inappropriate use of the term ‘disability benefits’, leading to the situation where, across the OECD countries, ‘many people on disability benefits do not claim to have a disability’ (OECD, 2003). If the word ‘disability’ in this context is taken to mean ‘impairment’ then many of the people whose level of physical or mental ill health has been sufficient to enable them to qualify for ‘disability’ benefits would not choose to apply this word to their situation. This feeds into the negative reactions against people who do not fit the stereotype of a ‘disabled person’.

This then supports political and popular narratives which both focus on individual behaviour and motivation as the key factor in determining whether someone is in receipt of long-term benefits. This focus requires an increasing use of conditions and sanctions so that ‘the over-arching objective is to influence the behaviour of as many working age benefit recipients as possible in order to move them into work, avoid long-term benefit receipt and protect the taxpayer’ (Gregg, 2008).

Barriers to employment

The insistence by disability organisations that disabled people want to work, and could work were it not for unequal opportunities created by disabling barriers, has frequently been used by politicians to support policies to reduce the numbers claiming IB/ESA (see, for example, Griffiths, 2010). However, such an argument obscures the experience of physical and mental ill health. There is also little attention paid – in the context of policy debates on welfare benefit – to the reasons for increasing levels of mental ill health amongst the populations of all developed countries, but in particular amongst more unequal societies such as Britain and the United States (Wilkinson and Pickett, 2010). Nor is much attention paid to the role of employer when someone loses their job because of illness and then has difficulty gaining new employment, unless they can convince an employer that they are ‘cured’.

It is important to recognise that, in the context in which work is currently organised, levels of sickness amongst workers is inevitably an issue for employers, particularly in an economy dominated by small and medium sized companies. A combination of anti-discrimination legislation and promotion of more positive attitudes amongst employers may well create more employment opportunities for people who experience reasonable health but have a static impairment, where adjustments can be made to overcome barriers. However, when an employer is faced with someone whose condition is associated with ill health and frequent times when they cannot work, such policies are less likely to be successful.

The focus on individual motivation and attitudes serves to underplay, on the one hand, the importance of illness in creating long-term unemployment and, on the other, the disabling barriers of unequal access to health care (regionally, across different minority ethnic groups, as well as by those who have conditions which are more difficult to diagnose and treat), and negative attitudes amongst employers and fellow employees.

As well as this failure to take a social model approach to those whose level of ill health impacts on their ability to work, there is a failure to recognise the disabling barriers experienced by those whose impairment is not associated with poor health. The Work Capability Assessment may – in measuring functional limitation (i.e. impairment) – conclude that someone has a ‘capacity’ to work and, indeed, many people whose physical, sensory or cognitive impairments are not associated with ill health, pain or fatigue, have insisted that they can and want to work. However, using a social model approach, they may still be disabled in the sense that they experience barriers to employment which are external to themselves and over which they have no control. The current system is unlikely to tackle these disabling barriers in that the focus, whether someone is placed on Job Seekers Allowance or in the Work-Related Activity Group, is on the individual rather than the socio-economic context in which they experience unemployment.

Even when the focus is not on individual attitudes to work, it is still more common for other supply-side factors (i.e. characteristics of the unemployed person) to be highlighted in policy debates on levels of unemployment rather than factors – such as employer discrimination and lack of employment in a particular area – over which individuals have no control. For example, low levels of qualifications are often cited as a reason for disabled people’s higher rates of unemployment. Yet, at every level of qualification, ‘a disabled person is much more likely than a non-disabled person to be lacking, but wanting, work – to such an extent that a disabled person with a degree is more likely than a non-disabled person with no qualifications to find her/himself lacking, but wanting, work’ (Palmer, 2010). The importance of low skill levels in explaining low levels of employment amongst disabled people has also been undermined by Richard Berthoud’s recent study of employment trends. He concludes ‘very little of the overall growth in the number of disabled people without work can be explained by the skills effect’ (Berthoud, 2011).

Conditionality allows little or no room for policy responses to demand-side factors, and although Berthoud’s analysis of long-term trends in sickness/incapacity benefits challenges assumptions that disabled people’s employment chances are affected by the economic cycle, it also suggests that:

... disabled people have always been more disadvantaged in regions with persistently high unemployment rates. Almost the whole of regional variations in the availability of jobs is born by disabled people, with non-disabled people enjoying consistent prospects wherever they live.

(Berthoud, 2011)

Welfare paternalism – a ‘state knows what’s best’ approach, against which the disabled people’s movement campaigned so effectively during the 1980s and 1990s – meant that disabled people were identified as objects of pity and charity. It has now been replaced by liberal paternalism – where the state aims to ‘help people to help themselves’ – which applies more malicious stereotypes to people who are not economically productive. I now want to look at the other area of the welfare state, adult social care, which plays an important role in determining some disabled people’s life chances.

Adult social care

While direct payments (and individual/personal budgets) have undoubtedly made a real difference to some disabled people’s lives and challenged the assumption that a passive dependency inevitably accompanies impairment, they have also played a role in the undermining of public services, and in the shift towards the marketisation of services. It is important to be clear that I am not arguing against direct payments or personal budgets; purchasing power and control over resources is clearly an important way of gaining control over how support needs are met. However, it is not sufficient in many cases and not the only way to achieve choice and control. With the current redesigning of the adult social care system to enable the national rolling out of personal budgets, the piloting of personal health budgets and the forthcoming white paper on the long-term funding of adult social care, it is important to take stock and assess what would be the most productive policies for promoting disability equality in the coming years.

Many disabled people and other commentators have been well aware of the contradictions, and dangers, inherent in pursuing a social policy aim of boosting individuals’ purchasing power. As Sapey and Pearson acknowledge, ‘Direct payments do make use of free market principles and there can be a contradiction between the individualism of this approach and the need for collectivity in the responsibility for welfare’ (Sapey and Pearson, 2004). They go on to say:

Direct payments need to be seen as an integral part of a collective approach to the provision of support. Implementing direct payment schemes provides a possibility of promoting independent living and access to mainstream economic and social life, but also could become a threat to collective responsibility for welfare and the notion of caring communities if it is interpreted within an individualist framework. The challenge is to do the first and not the second.

(Sapey and Pearson, 2004)

The problem is that we seem to have more or less lost the battle for ‘collective responsibility for welfare’ with the rise of an ‘individualist framework’, which – while it started in 1979 – gained an increasing hold under New Labour and is rapidly triumphing under the current government.

So now is the time to revisit some key concepts and principles, and at the same time challenge the seemingly inexorable undermining of the welfare state. In the context of adult social care, I want to contribute to this debate by looking at the meaning and use of the terms ‘independent living’ and ‘user involvement/ co-production’.

Independent living

For the last 30 years or so, disabled people have struggled to redefine the meaning of the words 'independent' and 'independence'. This struggle came out of the socio-economic experiences of people whose impairment meant that they relied on others for assistance with daily living tasks. It was articulated by people such as John Evans and Paul Hunt, who insisted that it was not physical impairment which had taken away choice and control over their lives but the way in which the state used the resources allocated to support them. The residential home in which they lived denied them basic autonomy, but, once they had control over those resources they were able to regain control over their lives.

Choice and control over the way assistance is provided is therefore at the heart of the disabled people's movement's definition of independent living. However, as Ken Davis pointed out in 1984, the use of the term can be misunderstood:

People not directly concerned with disability issues usually interpret [independent living] in an ordinary, commonsense way, i.e. that disabled people want to be self-reliant without help; or that we did not wish to be dependent or to rely on other people; or that we wanted to think and do things for ourselves.

(Davis, 1984)

In contrast, the disabled people's movement's concept of independent living implied a fundamental challenge to the way that society and its institutions should respond to disabled people's needs and experiences. Underpinning the concept is the social model of disability – a focus not on the individual and impairment as the problem but on the need to address social, economic and environmental barriers. This approach means recognising that it is these barriers, rather than functional impairments, which get in the way of individual autonomy and self-determination, creating disadvantage and social exclusion. It also means that disabled people should have choice and control over how any assistance they might need is provided – in order to enable autonomy and self-determination. Most importantly, since independent living is a necessary component of full citizenship for disabled people, it should be provided as a right, and not dependent on charity or professional discretion.

The disabled people's movement has focused – over the last 30 years – on the ways in which institutions of the welfare state have constructed disabled children and adults as dependent and excluded them from mainstream society. Special schools and colleges, day centres and residential homes have all done this, and – as Oliver and Barnes pointed out, 'all could be targeted instead by cash benefits' (Oliver and Barnes, 2009). The introduction of direct payments, and now personal budgets, mark significant progress towards the dismantling of dependency-creating institutions, as do recent developments of, for example, including special needs education funding in personal budgets.

However, the disabled people's movement's concept of independent living has been overshadowed by the use of the word 'independent' by those articulating a political vision which assumes that paid employment is the gate through which we all have to pass in order to achieve true 'independence' – a vision which has a minimal state as its ultimate goal. There is also evidence that, within adult social care services, the language of the disabled people's movement has been adopted but not the values or philosophy underpinning it (see for example Beresford *et al.*, 2011).

Some disabled people warned of the dangers of the term 'independent living'. Almost 30 years ago, Ken Davis pointed out that it is relevant that the disabled people's movement in this country borrowed the term from the United States, 'a country (founded on a Declaration of Independence) which still promotes rugged individualism and untrammelled personal freedom as the epitome of human development' (Davis, 1984). Moreover, in some contexts, some disability organisations' own rhetoric has seemed to owe more to the 'doing things for yourself' concept of independence and thereby helped create a confusion around what is meant by 'independent'. Thus, for example, during the government's attempts in the late 1990s to move DLA into the local authority budget for community care, the Disability Alliance argued that DLA 'promotes independence and self reliance' (Disability Alliance, 1998).

The disabled people's movement has struggled for years to move away from a definition of 'independent' as 'doing everything for yourself'. While progress was marked by government's formal adoption of the definition of independent living (Cabinet Office, 2005), this has been overtaken by the current emphasis on individuals being 'independent' by being part of 'alarm clock Britain', getting out and earning their living and looking after their families, and moving away from any idea that one can look to the state for anything other than a minimal role – with the exception of those who are so 'vulnerable' that they are in need of being 'looked after'.

The other defining characteristic of this definition of 'independent' is, of course, that the emphasis is on the individual as the 'problem', and that it is therefore the individual – most often their attitudes and motivation – which is required to be 'fixed'. We have to admit that we have made little progress in changing the popular conception of 'independent' and 'independence' as meaning 'doing things for yourself', not being reliant on others and that – in using these meanings in its attack on the welfare state – the current government is merely tapping into such common understanding.

It is also significant that the original vision of a new system of adult social care, set out in *Improving the Life Chances of Disabled People* (Cabinet Office, 2005), based on self-assessment and individual budgets over which disabled people would have control, has developed into the current programme of 'personalisation'. 'Independent living' as defined by the disabled people's movement requires self-directed support – in other words, assistance which is under the control of the person requiring support. In contrast, the current transformation of adult social care (called Putting People First under the last government and rebranded as Think Local Act Personal by the current government), as Peter Beresford has identified, seems to be more about 'personalised' services. Crucially the funding is lacking for the infrastructure of advice, support and advocacy required to enable people to truly exert control over resources (Beresford, 2009) and the emphasis is instead on personal budgets and direct payments as mechanisms for expanding the private market in social care, reducing the role of local authorities as providers (see www.thinkpersonalactlocal.org).

In any case, like direct payments, personal budgets can only be a means to an end. In reality, a lack of appropriate options and of the necessary information and support to exercise choice can act as significant barriers, as research on disabled people's experiences of having control over a budget found:

Participants felt that exercising choice was only meaningful if choices were 'real', i.e. they included options that met individual preferences and that people had access to information to make 'informed' choices ... Most participants thought their desired options were still either not available or limited. Many felt that they did not have access to information that could enable them to make informed choices.

(Rabiee and Glendinning, 2010; see also National Audit Office, 2011)

In Control, the organisation which originally promoted the idea of individuals having control over the resources allocated to them, argued that such a system would save money and demonstrated that supporting people with significant learning disabilities to lead ordinary lives costs less than the institutions in which they were commonly placed. The argument of reduced bureaucracy and a better use of resources was taken up by think tanks and commentators in the last five years or so, with Charles Leadbeater, for example, arguing that introducing personal/individual budgets could result in savings as high as 45 per cent (Leadbeater, 2008). With a projected funding gap of £6 billion if the budget for adult social care only rose by 2 per cent per year until 2025 (Kings Fund, 2010), such possibilities for making savings were attractive to both the last and the current government.

However, unlike those individuals with whom In Control initially worked, the majority of people receiving adult social care are not in expensive institutional settings but receive only a few hours of domestic support per week (most being people over the age of 80). The introduction of personal budgets is in itself unlikely to achieve much in the way of cost savings – certainly initially, though better outcomes may well be achieved (Carr, 2010). However, like direct payments, the idea of handing individuals control over resources, rather than providing services, fits well with a wider political agenda of reducing public services and the role of the state. Moreover, in the context of increasing demands on the adult social care budget, personal budgets are easier to cut than existing services and responsibility can be placed on individuals to achieve 'efficiency savings'. There is a real danger that personal budgets will achieve a further individualisation and marketisation of social care without the level of resources and infrastructure required to deliver choice and control.

The failure to incorporate the disabled people's movement's definition of 'independent' into adult social care policies has been accompanied by the persistent assumption that there are people who are incapable of exerting choice. This assumption is tied up with the concept of 'dependence' or, to use what is becoming a more popular term, 'vulnerability'. Indeed, as the terms 'dependent' and 'dependency' are increasingly applied (in a punitive way) to those who rely on welfare benefits, the word 'vulnerable' is being used to distinguish those who are 'deserving' of state support in contrast to those whose 'welfare dependency' is seen as a problem.

In this context, there is a danger that autonomy or self-determination is equated with individual responsibility and 'freedom' from 'dependency' on the state. While 'dependence' on state resources (albeit delivered through private service providers) is considered to be legitimate for those whose impairment is so significant that they supposedly cannot exert choice, where impairment is considered to be no barrier to making choices then the goal is for such individuals to take responsibility for meeting their needs themselves. These ideas are particularly prominent in the context of welfare reform but are also apparent in the use of the terms 'user involvement' and 'co-production'.

User involvement, co-production and the Big Society

'User involvement' is a term commonly applied in the context of people who use public services, such as social care, insisting that they be involved in decisions about how such services are run. The legitimacy of the demand was increasingly recognised by governments from the 1980s onwards. Indeed the 1990 community care reforms were followed by the setting up of a National User Involvement Project, and all the way through the various stages of adult social care reforms over the last 20 years, the involvement of service users has been given significant support by both central and local government (albeit inadequately resourced and sometimes ineffectively executed). The moral and political justification for 'user involvement' is encapsulated in the slogan, 'Nothing about us without us', originally adopted by Polish Blind Workers between 1946–51 and subsequently used by disabled people's organisations throughout the world.

Similar ideas were developing in different contexts in the United States where, from the 1970s onwards, there was increasing recognition by local politicians that good outcomes from public services could only be achieved with the full involvement of those using services. Policing, for example, can only be successful, they recognised, with the consent and involvement of the local population; and waste can only be recycled if you can persuade people to sort their rubbish into different categories. The term 'co-production' was applied to this involvement and partnership, and recently became a popular concept in public policy in Britain, seized upon by think tanks and those seeking to influence policy development. Often, but not always, the language used echoes the criticisms of welfare paternalism by disabled people and their organisations. So, for example, the Office for Public Management talked of how co-production is about working 'with rather than [doing] unto service users' (Cummins and Miller, 2007).

The Office for Disability Issues and the Department of Health have each adopted co-production as a key part of the development and implementation of policies and it has figured in both the Putting People First programme and its successor, Think Local, Act Personal. The concept – particularly in the context of the reform of adult social care – is closely tied to that of social capital, its origins being in the recognition that public services rely on their users bringing their own expertise and experience to achieve good outcomes. It fits well, therefore, with the disabled people's movement's insistence that people should not be treated as passive recipients of 'care' but as active participants in decisions about their lives and how support should be provided. Direct payments, individual/personal budgets and the 'personalisation' agenda in general have often been cited as examples of co-production in that disabled people are said to become co-designers and co-producers of services (e.g. Leadbetter, 2004).

Informal networks are an important part of this scenario in that social capital also resides in the support that people receive from friends, family and local communities – and, ideally, disabled people's contribution is enabled and recognised so that these are reciprocal relationships. However, while it is important that, for example, a person with learning difficulties' social interaction is not confined to those who are paid to support him/her, this focus on informal sources of support opens up opportunities for removing state (i.e. collective and redistributed) resources and services. Thus, policy discussions which had previously taken place primarily in the context of the reform of adult social care are now also situated within the so-called Big Society agenda. This means that what was previously meant by co-production (and social capital) is now entangled with the government's aim of reducing the size of the state.

An example of this entanglement of the progressive goal of building inclusive communities with the policy of reducing public services and resources can be seen in the following extract from a recent document issued to local authorities implementing the personalisation agenda in adult social care:

Social care transformation is not limited to personal budgets or even to public services targeted at people eligible for state support. It is also about how people help themselves and each other as individuals, in groups and communities and how they make best use of the resources available for all citizens in their area. State resources are under strong pressure and are only a small part of what is available in communities. Sustainable local social care strategies will recognise this, supporting community capacity so that people are not limited to the passive role of 'service user'.

(Department of Health, 2010)

Proponents of the Big Society, such as Conservative MP Jesse Norman (2009), blame what he calls the 'huge growth of the state' for the country's economic problems and for the slow progress in tackling social and economic disadvantage. The Big Society, he says, 'stands as a thorough repudiation of and corrective to that ideology' (Norman, 2009). The language of social capital is easily subverted to be about the duty of families and communities to 'care for their own', and fits neatly into the Big Society agenda. It also echoes some of the language and assumptions dominant during earlier stages of the development of community care policies, in particular the assertion that 'Care in the community must increasingly mean care by the community' (Department for Health and Social Security, 1981).

While co-production was never a term adopted by the disabled people's movement, the way in which some local disabled people's organisations developed their services could be argued to be a more meaningful partnership between service providers and service users. One example is the following description of how Derbyshire Centre for Independent Living developed its services:

- oppressed people confront and define their internalised oppression;
- they found peer support structures to share and value their experience;
- a framework for strategic planning is derived from this experience and an understanding of its social context;
- development work defines the further technical support needs of the supported group, and pilots practical solutions;
- job descriptions and competences are defined around the needs and goals identified;
- practical application feeds back further information about development needs.

(Gibbs, 1999)

This is a description of how a service can be driven by the needs and perspectives of its users and how it can be accountable to them in meaningful, rather than tokenistic, ways. As Disability Lib have pointed out, within the current agenda on civil society 'There is an emphasis on people and communities taking charge and creating solutions for themselves, which disabled people and our organisations have a solid history of doing' (Disability Lib, 2010). However, since the accompanying policy involves a reduction in state expenditure, the necessary infrastructure – and specifically user-led organisations – far from being properly resourced, is currently experiencing unprecedented levels of funding reductions.

Undermining the welfare state

The changes that have taken place in the fields of welfare reform and in adult social care share a common narrative in that there is a desire to target resources on the 'most vulnerable' while encouraging individual responsibility and 'independence' amongst the rest. This rests on the aim, in the welfare reform context, of distinguishing between people who are 'really' disabled/sick and those who are not; and in the adult social care context, on a narrowing of eligibility criteria and on a means-test to distinguish those who should pay for their own care.

These two policy fields also share an opening up of functions, previously carried out by the public sector, to private sector companies. In the field of welfare reform, the insurance industry has both influenced the development of ideas and policies, and benefited from the new contracted out assessments and employment support services (see Rutherford, 2007). In adult social care, both residential and home care provision are now almost entirely provided by the private sector, a development fuelled by the desire to drive down unit costs and legitimised by ideas of choice and consumer empowerment. Employment support contracts based on 'payment by results' are intended to increase dramatically disabled people's employment rates, while competition within a market of social care providers is intended to enable service users to access good quality services.

Within the ideas dominating the current welfare reform and adult social care policy frameworks there has been a refusal to recognise that, if disabled people's life chances are primarily dependent on their earning power (the 'work is the route out of poverty' policy), they will inevitably experience high levels of disadvantage and deprivation within current economic conditions. As Colin Barnes identifies, 'the pursuit and maximisation of profit and competition between individual workers' disables 'people with any form of perceived functional limitation/impairment, whether physical, sensory or intellectual, and the more overt the impairment the more severe the disadvantage or "disability"' (Barnes, 2003). In other words, the nature of paid work in industrial urban societies means that many people with impairments and/or poor health are excluded from the labour force. Currently, many more are excluded than need to be because of discriminatory attitudes and a lack of adaptations, equipment and support. But it is important to recognise that many people will always be excluded from paid work as long as work is organised in the way it currently is.

The disadvantages that come with the experience of impairment and/or ill health in the context of the British labour market have in fact worsened during the last 30–40 years or so. This is not because of an increase in the number of 'malingerers' but because the UK economy is integrally linked to the global economy. The availability of low-waged labour within the emerging economies, together with the dramatic increase in the global supply of highly educated workers, affects the employment opportunities, pay levels and working conditions of most people in this country (see Hanley, 2011). However, globalisation particularly affects those who employers would not choose to employ unless there is a shortage of labour supply. Moreover, unemployed and 'economically inactive' disabled people are disproportionately concentrated in parts of the country which have experienced deindustrialisation and have yet to recover (see Crisp, 2008) and, as already mentioned, it is this regional aspect of labour demand which has particular implications for disabled people (Berthoud, 2011). Throughout the world, there are many different factors influencing the demand for labour. Yet these wider, very important, determinants of disabled people's employment opportunities are rarely mentioned in the policy debates on how to tackle high levels of unemployment and economic inactivity.

The economic conditions affecting the UK economy over the last 30–40 years have therefore, on the one hand, created ever-greater demands on the welfare state while the global economic pressures on governments to create low taxation and low regulation environments are, at the same time, driving reductions in public expenditure. We are told that demographic pressures (increasing numbers of older people) mean that the adult social care system is no longer financially viable; and that the working population cannot bear the tax burden required to support the high numbers of working age people who are classified as economically inactive.

It is these types of pressure which have been inexorably driving the desire to reduce public expenditure and, at the same time, to shift provision of public services into the private sector where large, often multi-national, companies have identified opportunities to make a profit.

However, the financial crisis facing the 'care industry' calls into question whether there is a profit to be made out of people who need support in their daily lives (except from a small group of wealthy people). It remains to be seen whether the employment support market will be a profitable one, but this seems unlikely given the low success rate of the Pathways to Work scheme (see National Audit Office, 2010) and of private insurance companies' limited success in supporting people back into work rather than pay out on their insurance policies (for example, as mentioned above, UnumProvident only manages to get 15 per cent of its claimants back to work).

It is not only the current social policy agenda which fails to offer most disabled people any future other than that of poverty and social exclusion. It is also the current economic framework within which we all live.

What changes should disabled people be campaigning for?

In order to have any chance of success in our campaigns for policies to tackle disabling barriers and enable equal access, we must start from an explicit and vigorous promotion of the welfare state and of the concept of social security in its broadest sense. We need to do this because people of all ages 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. In order to experience equal access to full citizenship, disabled people therefore require some kind of collective and redistributive mechanism to provide the additional requirements needed. Moreover, such redistribution needs to be in the context of a value system which values diversity and where disabled people are treated as belonging and contributing to the communities in which they live.

There are three specific arguments which I believe we should be making in order to have any long-term prospect of making progress on disability equality. However, as outlined in my fourth point, such progress requires a very different economic system than the current one, an issue which I have only touched on and which requires engaging in the much wider debates about the global economy and the forces which determine all our life chances.

Extend the concept of 'reasonable adjustments' to the welfare state

Disabled people need the kind of welfare state which is not a mere 'safety net' but which invests in tackling disabling barriers and in providing resources to meet the additional costs related to impairment. DLA is an example of a reasonable adjustment which takes a monetary form – although of course it is not sufficient to cover full costs. A similar approach should be taken to out-of-work benefits and employment support in that both should be seen as reasonable adjustments, on the one hand compensating for loss of income while at the same time tackling disabling barriers to employment.

In making this case, we need to counter the idea that welfare payments are nothing more than a drain on the economy. They should instead be seen both as 'an indicator of collective social responsibility and social justice' (Barnes, 2003) and as increasing the spending power within the economy: low income households spend most of their money within local economies and disabled people are particularly reliant on labour-intensive services, thereby generating employment.

Welfare payments (and adult social care services) are therefore not only crucial to delivering 'reasonable adjustments' for disabled people, thereby increasing their well-being and life chances, but are also key to the wider health of the economy. Both need to be freed from the stigmatisation and social exclusion which is associated with being in receipt of either, and their contribution to a socially just society fully recognised.

Defend and extend the principle of universalism

A key part of placing social justice at the heart of the welfare state is the need to defend and extend the principle of universalism. It is only an accident of history (the ideological origins of social care) that has prevented social care being treated the same as child benefit and DLA. Both parents and disabled people have additional support needs and society decides whether, and on what basis, to fund those needs. We should be making the moral case for delivering these additional support needs in a way which creates a level playing field, and this means abolishing means-testing of payments for services which are intended to address the additional needs that disabled people (of any age) have as a result of illness/impairment and/or disabling barriers.

Develop ways of delivering services and meeting needs which are co-produced with the people who use such services

The current theorisation and practice of so-called 'co-production' is not radical enough, in that it is not empowering, accountable or democratic enough to bring about the fundamental changes that are required. Those who have a direct interest in the nature and quality of support must have the power to decide how services are delivered. This is the only way to not only deliver choice and control, but also to avoid the levels of abuse which are still far too common in many different contexts.

Part of this must also be a revival and renewal of the concept of a public service ethos. The private sector, with its emphasis on profit and primary responsibility to shareholders, can never operate in the same empowering way that – in theory – a public service could. In our justifiable attacks on the traditional welfare paternalism which dominated the social care profession, we have lost sight of what a public service ethos should be. Support services which determine whether disabled people have autonomy, and are able to participate and contribute to society, should be based on a clear set of moral principles. This does not necessarily mean that services can only be delivered by central or local government but it does mean that organisations cannot be driven by the pursuit of profit, because their priorities will always, in the last if not the first resort, be those set by shareholders rather than by service users.

Move away from a sole focus on disadvantages experienced by disabled people to address the underlying causes of inequality more generally

Current working practices and developments in the labour market (insecure employment, long hours, low wages, etc.) are bad for people's health and are incompatible with enabling anyone with poor and/or fluctuating health to maximise their ability and opportunities to work. At the same time, global downward pressure on wages makes it harder and harder for governments to apply the 'less eligibility' principle (i.e. that someone should always be better off in work than out of work) to welfare benefits, and the global mobility of capital creates more and more pressure to cut public expenditure and reduce employee protection measures (to lessen the 'tax burden' and to create a more 'flexible' labour market). If we are to have any hope of winning the argument for investing in the welfare state, we have to also address the question of what kind of welfare system is viable and sustainable in modern economies which can no longer rely on the level of tax revenues associated with mass employment. This means addressing the dysfunctional ways in which our economy is currently configured; challenging what it is to be economically productive; exploring how to raise the resources required to fund a level of welfare payments and services which would secure disabled people's human and civil rights; and promoting democratically accountable ways of both developing and delivering services.

It is beyond the scope of this paper to fully develop this fourth point, but it is my contention that – if the disabled people's movement is to have any hope of making progress – it is these wider debates with which we have to engage, in particular those which question the continuing pursuit of economic growth regardless of the damage done to the environment, to values and to humanity.

Conclusion

This paper has aimed to start a discussion, within the disabled people's movement, of what should be our focus over the next few years. It is based on the premise that there is little room for making progress in the context of the ideological framework which is driving the current government's disability policies. We need, instead, to be developing much more radical challenges to the current disability policy agenda, some of which I have touched on above. Successful policies depend on sustainable and adequate resources, and we therefore also need to move out of the disability policy agenda and engage with broader political and economic debates and developments for it is these which will determine whether such resources are ever to be available.

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About this paper

This *Viewpoint* was written by Jenny Morris, initially as a critique of progress in disability policy over the past 20 years. The pace and impact of government policies since the 2010 general election led the author, herself a disabled person and long-term consultant on disability issues, to focus on the present-day situation and suggest ways forward for making progress on disability equality.

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