



Disability Rights Commission

Disability Rights Commission submission to the Equalities Review

December 2005

Executive summary

1. The DRC's vision is a society where all disabled people can participate fully as equal citizens.

Whilst significant progress has been made towards this goal, disabled people are still amongst the most excluded in our society, experiencing not only significant social and economic exclusion, but also serious breaches of human rights.

Disability is also a major dynamic factor in wider patterns of social and economic inequality:

- 40% of the total number of people out of work are disabled, with employment rates of only 21% and 26% respectively for people with mental health conditions and people with a learning disability.
- 68% of households with children where both parents are out of work include at least one disabled parent
- At £9.52 an hour, the average gross hourly pay of disabled employees is about 10% less than that of non-disabled employees (£10.43 an hour)
- Only 39% of mothers of disabled children are in work compared with 86% of mothers of non-disabled children; and 55% of families with disabled children are living in or at the margins of poverty
- Parents of disabled children face on average three times the costs of parents of non-disabled children
- Between 1997 and 2004, the numbers of homeless households considered priority due to 'physical disabilities' increased by 24% and due to mental health problems by 65%

- Disabled 16 year olds are twice as likely to be out of work, education or training as their non-disabled peers.
- 30% of young disabled people expect to be earning less than their non-disabled peers by the time they are 30
- 40% of disabled people have no qualifications at all
- Of those in receipt of Disability Living Allowance, 37% have never used a computer
- Of those in custody of school age, over a quarter have literacy and numeracy levels of an average 7 year old.
- Over half of young offenders have dyslexia, compared to 10% of the general population.
- There has been a steep rise in the level of admissions to institutional care since 1997 (20% and 40% respectively for people with a learning disability and people with a mental health condition)
- Disabled people die earlier, often from preventable illness and experience unequal access to health services including cancer screening, immunisation and primary health care generally

2. To achieve our goal we believe we require an approach to equality which:

- Assures the same *freedom, respect, equality and dignity* for every citizen, with human rights as the bedrock of establishing more equal life chances
- Assures *equal lifelong chances* whereby the inequality which can emerge related to life changes – like the onset of an impairment or long-term health condition – is mitigated. Disability should not lead to avoidable loss of opportunities
- Is based on the principle of *substantive equality* whereby achieving equality involves different treatment to achieve more equitable results - rather than just treating people 'the same'
- Transforms the welfare state and/or its agents in supporting disabled people to *achieve equality through active participation* in family, community, economic, social and cultural life.

3. The DRC has a number of detailed recommendations to the Review, but our three overarching priorities are:

Culture and behaviour: evidence based interventions to generate changes in culture, attitudes and behaviour

An effective blend of social rights, human rights and civil rights. Social rights are particularly important for disabled people. The review should identify the reform necessary to secure and re-orientate the welfare state towards supporting independent living and participation. Human rights are critical.

Tackling poverty and poverty of assets (skills, financial inclusion, health, housing) including in families with disabled children and/or disabled parents

4. Our recommendations set out an ambitious agenda for change.

In the next 3 years we would expect to see changes that act as markers for a complete transformation of disabled people's position in society – including:

- more disabled people participating in civic and public life;
- policy makers understanding the significance of disabled people's participation to UK plc;
- an ongoing transformation of Britain's physical environment to ensure greater accessibility.

In ten years we expect to see real evidence that the major gaps of inequality are closing, for instance:

- Closing the gaps in educational attainment
- In employment
- In pay
- In travel (i.e. numbers of journeys made, confidence to travel)
- In health (reduced inequalities in health – particularly through

increased life expectancy amongst disabled people, and a reduced gap between those with a learning disability or mental health problem and other citizens. Currently these groups live on average at least 10 years less long than others)

We would also expect to see:

- An employment rate for disabled people of at least 60%
- Government being well on the way to overcoming child poverty including in families with disabled parents and/or children
- All disabled people to have genuine opportunities to acquire basic skills including ICT
- A framework of rights to independent living introduced. A significantly increased uptake of 'control/choice oriented' social services including individualized budgets
- Reduced incidence of the most problematic attitudes and behaviours reported by disabled people/ those with health conditions, including hate crime, harassment, patronizing or demonizing attitudes, rejection

In 40 years we would expect to see completion of a total cultural shift, involving:

- a reversal of the notion of disabled people as passive recipients of care or charity – replacing it with support for active citizenship
- An end to the notion of disabled people as implicitly 'vulnerable' and 'at risk'
- Full confidence amongst people with hidden impairments that they can 'come out' without fear of stigmatisation
- Building a culture of expectation in which full equality and human rights are realised *in practice*.

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1. Introduction

- 1.1 The Disability Rights Commission (DRC) was created by the Disability Rights Commission Act (DRCA) 1999. Section II of the DRC Act imposes the following duties on the Commission:
 - To work towards the elimination of discrimination against disabled persons;
 - To promote the equalisation of opportunities for disabled persons;
 - To take such steps as is considered appropriate with a view to encouraging good practice in the treatment of disabled persons; and
 - To keep under review the workings of the Disability Discrimination Act (DDA) 1995.
- 1.2 The DRC's vision is 'a society where all disabled people can participate fully as equal citizens'. By 'all' disabled people we mean explicitly women and men of different ages, ethnicities and faiths, from different communities and countries of GB, who also differ by factors including social class, sexual orientation - and particular experience of disability or health condition (see para 2.1 below). We welcome the opportunity to feed into a cross-cutting equalities review.
- 1.3 The DRC will close to time with the advent of the Commission for Equality and Human Rights (CEHR) currently expected in October 2007.
- 1.4 The DRC is currently facilitating the 'Disability Debate' which aims through research, consultation and deliberation to articulate public policy solutions to the priority issues standing between disabled people and equal citizenship in Britain.

This submission is informed by the priority issues identified

during phase one of the Disability Debate and is based on contributions from disabled people and their organisations, stakeholders across the public sector, and research evidence prepared on DRC's behalf by the Institute for Public Policy Research (IPPR) and Scottish Council Foundation

2. Disabled people, human rights, equality and the welfare state

2.1 Disabled people in Britain

Estimates of the number of disabled people in Britain vary according to the definition used. According to 2005 Government figures, around 11 million British people are disabled, approximately one in five of the population (Cabinet Office 2005). These figures are based on the DDA definition: a disabled person has a physical or mental impairment that has a substantial and adverse effect on day to day activities and has lasted/is expected to last for at least a year. This includes not only people traditionally considered 'disabled people' – those with mobility and sensory impairments – but also people with mental health problems (like depression, bi-polar disorder, schizophrenia, personality disorder), long term health conditions (cancer, heart disease, diabetes) and learning difficulties (from Down's syndrome to dyslexia). In 2005 the Government further expanded the definition to cover people with HIV, cancer and multiple sclerosis from the point of diagnosis, given evidence of discrimination faced by people in this situation.

We recommend that the Equalities Review talks consistently in terms of disabled people/those with long-term health conditions, to make clear that all those covered by the DDA are relevant to considerations of 'disability' equality. Otherwise there is a significant risk that those living with long term mental or physical health conditions will be viewed in public policy only in terms of their health needs, not their broader requirements for equality and social inclusion.

2.2 Human rights

Some of the most tenacious and common inequalities in relation to disability concern basic human rights. Human rights provide the basis for establishing disabled people's ability to exercise autonomy, participation and control over their own

lives, in ways which are generally uncontested for many other groups.

The DRC also believes that 'human rights' provides a vitally important framework of principles through which to unite all the equality 'strands' – extending to all as a minimum condition rights to freedom, respect, equality and dignity

Central to disability and human rights are the principles of autonomy and dignity. Whilst dignity itself is not included explicitly in the European Convention, it is acknowledged that this underpins the whole approach to human rights. One such case, involving two severely disabled sisters who due to a blanket ban on manual handling by their local authority were unable to participate in community life (or have some control over their own) was found to contravene the convention because it did not allow the sisters to live with dignity.¹

Further, life and death issues such as the use of non-resuscitation notices and the recent House of Lords case concerning the right to artificial nutrition and hydration also demonstrate the absolute fundamental nature of human rights to disabled people.²

When the Human Rights Act (HRA) came into effect in 2000, it was the expressed intention of government that the Act would do much more than simply oblige public authorities to comply. The aim was rather to create a culture of human rights within Britain.

Individual cases under the HRA have begun to shed light on the failure to achieve such a culture, demonstrating the harsh reality faced by many disabled people in having their basic human rights adequately met. Translating individual legal victories into the policy and practice of the public sector is a continuing challenge.³

¹ A&B vs East Sussex

² For example see *Burke vs GMC*

³ Butler, F (2005) Human rights and public services. IPPR

One only has to look at the increasing numbers being left without any choice but to live in 'care homes' and institutions to see how vital it is to confront such inequality.⁴ Without viable alternatives which would support living in the community some disabled people are segregated from the wider community in order that they can be provided with 'care', leaving them potentially more at risk of further human rights abuses such as degrading treatment and with severely restricted life chances. As the CRE has concluded, if you are segregated against your will you will experience inequality. Human rights statute can usefully augment (and be augmented by) equality statute in helping challenge and reverse such practice.

Disabled people are only beginning to realise their rights under the HRA and in particular many continue to battle on issues surrounding 'independent living' – that is, the right to have equal choices, to exert control and possess independence in how one leads one's life; and the entitlement to services (like social care) that support active participation, rather than providing only 'life and limb' support which generates dependency. Those attempting to challenge inhumane or degrading treatment or lack of autonomy are confronted by both practical and jurisprudential problems. Those who may most need redress such as residents of private care homes, are confronted by the narrow interpretation of public authority within the human rights legislation, which excludes many potential perpetrators from the outset. In addition disabled people experience immense practical hurdles in accessing redress for rights violations and as Luke Clements has pointed out 'disabled people are not considered 'ripe for freedom' in the same way that slaves, serfs, southern blacks and women were once not thought ripe for it'.⁵

A further fundamental problem for disabled people seeking to access equal human rights is the long and ongoing battle to convince public authorities that they have 'positive obligations', where appropriate, to provide the resources necessary to

⁴ A 20% and 40% rise for people with a learning disability and people with a mental health problem respectively since 1997

⁵ Clements, L & Read, J

ensure that rights are practical and effective not [simply] theoretical or illusory'⁶

For disabled people it is insufficient that the state merely ceases to act in particular ways which violate rights. Rather it is often necessary that the state meets disabled people's human rights in a positive manner, which may mean treating them differently. Human Rights jurisprudence has historically been poor at recognising both disabled people's rights and inherent requirements for positive obligations that often accompany them. Whilst some progress has been made in this field in recent years we are still far from realising the potential of human rights legislation, or indeed a human rights culture that includes disabled people. For this to happen we need:

- A clear broad definition of a 'public authority' – as recommended by the Joint Committee on Human Rights
- Effective enforcement
- Public authorities to embrace a concept of human rights that incorporates positive obligations

2.3 Life chances or lifelong chances?

The DRC broadly supports the 'life chances' approach proposed by the Review. Specifically, we believe that achieving equality demands that basic rights of social citizenship are agreed and extended to (and expected for and by) all members of society.

As Tawney (1931) put it:

'..opportunities to rise are not a substitute for a large measure of practical equality, nor do they make immaterial the existence of sharp disparities of income and social condition. On the contrary, it is only in the presence of a high degree of practical equality which can diffuse and generalize opportunities to rise. Their existence in fact, and not merely in form, depends, not only upon an open road, but upon an equal start'.

⁶ Klug, F

It is important, however, to explore in greater detail what an 'equal start' means in practice. A 'life chances' approach tends to identify the circumstances of an individual at birth as the primary shaper of their destiny, for example in relation to gender, race or class. Clearly, such factors do shape the life chances of disabled people (and disabled people's children), and disability is an aspect of individual identity that is present for a significant number throughout their lives, seriously impacting upon their life chances.

However, it is not certain that a 'life chances' approach can effectively account for the impact of significant *life changes*. For the vast majority of disabled people, impairments and long-term health conditions emerge during the life course especially in older age (and disproportionately amongst those who are already living in poverty, with variation also in relation to gender and ethnicity).

In this sense, an 'equal start' needs equally to mean *mitigating* the social and economic circumstances which generate inequality when people have developed an impairment or long-term health condition. The goal should be that life chances should not be unduly influenced by the onset of an impairment or long-term health condition (or other life change). The rights of social citizenship must still be guaranteed, discrimination actively challenged, and positive steps to promote (and maintain) equal *lifelong chances* put in place. Such an approach is vital, for example, in tackling the high numbers of disabled people on Incapacity Benefit who have too readily lost their jobs at the onset of an impairment or long term health condition and subsequently found themselves plunged into poverty, unable to get back into work due to a mixture of poor skills, the unavailability of effective back to work support, age and disability discrimination. People in this situation - who might have been supported to keep work and status in the first place - then find themselves without the means or opportunities to participate in society and subject to widespread stigmatisation.

2.4 'Group proportionality' and individual life chances

The DRC agrees with the Chair of the Equalities Review that 'group proportionality' can be problematic. It can run the risk of generating a 'hierarchy of oppression', whereby one 'group' lays claim to greater action and resources than another on the basis of evidence ascribed (sometimes misleadingly) to the group as a whole. Group proportionality can also act to hide major inequalities within groups. For example, whilst 51% of disabled people of working age are working, the figure for people with mental health problems is 21% and for people with a learning disability 26%. Even within those two groups there are wide disparities. It can also lead to a failure to recognize causal intersections and mutual experiences between groups in society, missing opportunities for solidarity and sharing creative solutions and resources.

However, the alternative of viewing life chances only in individual terms leaves one with no purchase on trends in inequality and equality.

We do need to know, over time, the proportion of women and men, people from different ethnic communities or people with different experiences of disability/health condition who are (say) in higher level occupations, or who are dying young. This information tells us whether we are making progress towards closing the gaps of inequality – or not. This understanding needs to be fine-grained. It will be most useful if it can be analysed for different purposes on different dimensions of difference: to give an example, we need to understand trends in school exclusions of black boys who are assessed as having 'special educational needs' (i.e. looking at disability, race and gender - together).

Group proportionality needs to be subtler than it has been historically – without data gathering being overly burdensome. This is about smart information, not more information. The key is to collect information that is genuinely useful. The more it can be cross-referenced, cross-strand, the better.

In disability/health conditions, evidence is needed broken down by broad impairment group (egg physical, sensory, mental health, learning disability, long term health condition). DRC will be producing guidance on monitoring during 2006 which will address issues of categorisation.

It is important to look at the experience of exclusion faced by the full range of disabled people/those with health conditions. Some of the above groups are particularly likely to face discrimination – for instance, less than 4 in 10 employers even state that they will employ someone with a mental health problem (DWP 2001) and working age people with mental health problems have a non-working rate of 79% – so the inclusion of people with long term health conditions in the DDA and other equality and human rights initiatives is critical.

There is currently a huge mismatch between popular - and indeed policy makers' – understanding of who 'disabled people' are and definitions in legislation designed to protect people from discrimination. DWP research found that 52% of those covered by the legislation (even before the latest expanded definition) did not consider that they were disabled and that this was especially true of younger people. Research for the DRC with 1000 such people – i.e. those legally defined as 'disabled' but not personally defining themselves as such - found that reactions to the news that they would be considered disabled by law included being confused, upset, angry, patronised, insulted, depressed and scared (DRC 2005). Only 23% felt comfortable with the 'disability' term. This may not be surprising since they believed that for a person to describe themselves as disabled they must be dependent on others outside the home (84%), a wheelchair user (63%), bedridden (65%) or terminally ill (52%). They did not see themselves in this category, either because their impairment was not severe enough, or because they were too independent, or simply because their condition did not involve using a wheelchair.

These findings are echoed in research with other audiences including business and opinion formers, even civil servants responsible for Government policy. Business may have no idea

that they are employing or serving disabled people (as defined in law). DRC research with small employers found that, like the DDA-covered people described above, they generally believed disabled people to be highly dependent, usually wheelchair users. When they realised that 'Jo Bloggs' (with diabetes or heart problems) whom they employed was 'disabled' the whole concept of employing disabled people became slightly less alarming (DRC 2005).

The DDA definition simply does not map easily against the public's understanding of the term disability. Given the international wheelchair symbol to denote disability, and the use of wheelchairs and white sticks as ready visual markers across our culture, it is no surprise that the public – and key audiences like 'disabled people' themselves - categorically do not understand 'disability' to include diabetes, depression or heart disease. They have a much more limited view of what 'disability' is (DWP 2003).

This means that for 'disabled people' themselves it is largely hit or miss whether they can secure redress in the face of discrimination – because they generally have no idea a 'disability' law would apply to them. DWP/DRC 2004 found that even amongst people taking cases under the DDA, many had no conception they were 'disabled' until advised of this by someone else. Even where they had heard of the DDA, it had never occurred to them it might be relevant to them. They thought it was for those 'other' people – the really disabled, of wheelchair and white stick fame. As the report notes, 'given that less than half of the applicants had considered themselves to be disabled prior to taking their case, the small number contacting a specialist disability organisation is not surprising'.

The mismatch between policy and public definitions of disability creates obstacles to effective communication not only with those with rights – but also those with duties: employers, service providers, educationalists. Campaigns explaining to business that 11 million disabled people have a spending power of £80 billion a year can test credibility - because obviously 1 in 5 of us is not using a wheelchair or white stick.

Message testing with business audiences shows that this message is not well received (DRC 2005). It only begins to make sense if one knows that wheelchair users make up about 7% of 'disabled people' – and that the term disability covers a wide range of fluctuating health conditions, as well as permanent impairments.

Similarly approaches to including the experiences of disabled people in policy programmes do not meet their full potential if they permit policy makers to assume a narrow view of disability. Recent evaluation of DRC leaflets to the health sector confirmed that health service managers and staff still viewed disability access almost exclusively in terms of physical access for wheelchair users – when the problems reported even more commonly by DDA-disabled people (including wheelchair users) are attitudinal and systemic problems. Where what people most need is better trained GP receptionists or materials in Easyread, the primary care managers think 'access' means seeing a GP within 24 hours – or, in a disability sense, only getting through the door and into the toilet.

Communications campaigns, leaflets and training materials that rely on the term 'disabled people' are highly unlikely to generate change beyond those with physical or sensory impairments – because that is the group the reader/viewer assumes is meant. Worse, the whole message may be viewed as suspect – because it is misunderstood at a basic level of who we are talking about.

We propose that the Equalities Review does not look at health issues and disability issues separately – but looks at the experience of exclusion of people living with the full range of long term impairments and health conditions. There are common experiences across the range – the need for flexible adaptations in the external environment, for attitudinal change, for support for independent living, for personal adaptation to manage one's own condition or impairment - sometimes in suddenly changed circumstances, e.g. following a traumatic accident. There are also differences – between permanent and fluctuating conditions, impairments involving pain or fatigue and

those that are pain-free etc, as well as differences by level of deprivation, ethnicity, gender and other factors. What is needed across this range is an approach to equality that consistently values the human rights and contributions of people who are mentally or physically different from a supposed 'norm'; and that takes a fine-grained approach to understanding differences within and between these categories.

Sometimes, 'group proportionality' is created by external factors which lead to the prioritization of one group's disadvantage over another. For example, disabled people, people from ethnic minority groups and gay people are subjected to hate crime, harassment and overt prejudice. However, Government policies to foster 'good relations' are arguably driven by strategies to preserve public order, as much as by the motivation to tackle hate crime and prejudice per se. Groups who are subject to hate crime but who are not perceived as a threat to public order are not factored in and so resources are unevenly distributed. The distribution of resources to achieve equality is influenced by wider drivers including engagement of the media, public scandal, public health, the economy and 'fear of the mob'. Whilst achieving equality can benefit from harnessing these drivers, their impacts also need to be mitigated if equality is to be achieved. Knowledge of the position of 'groups' (including where they intersect with one another) is important because this can help us understand whether a hierarchy of prejudice is being pursued, so that corrective action can be taken.

Parity of esteem has to be accorded to resolving the inequality experienced by all individuals who do experience it. That can mean different levels of input, to achieve greater equality of outcome.

2.5 **Substantive equality**

The DRC advocates substantive equality. That is, an approach to equality which recognises that equal treatment (formal equality) is not the answer to tackling inequality, but that achieving equality demands change and positive action both at

the institutional and individual level. In this sense, equality is not about identity but about difference. This is already reflected in the Disability Discrimination Act which allows for reasonable adjustments to be made to policies, practices and procedures, the physical environment and in relation to the provision of 'auxiliary aids and services'.

Substantive equality is a model which we would anticipate shaping any approach to equalising both life chances (including realising human rights) and promoting equality of opportunity.

For example, in relation to Professor Millers advocacy of a 'social minimum', this would only deliver more equal life chances to disabled people if it took proper account of the additional living costs associated with having an impairment or long-term health condition. If a 'social minimum' income failed to take account of these additional outgoings it would fail to deliver more equal life chances.

In the context of employment, whilst some disabled people may not have the 'natural ability' to do a particular job without support and adjustments, if these are put in place the picture changes: their potential is released and they are able to fulfil the role.

This point is essentially what the disability movement has come to call the 'social model' of disability. That is, an abandonment of the notion that it is the individual's impairment or long-term health condition which predicts their life chances, in favour of the view that the social, cultural, organisational and physical environment 'disables' them. Equally changes to that environment can facilitate their participation. Many disabled people will continue to require specific adjustments and support in order to fully realize their individual potential and take advantage of equality of opportunity throughout their lives. It is not enough only to improve initial life chances.

The goal of the Disability Equality Duty, imposed on public authorities by the DDA 2005, is to achieve equality of opportunity for disabled people by ensuring that due regard is

paid to the promotion of disability equality. The statutory Code states: “The objective is that disabled people should have full opportunities and choices to improve the quality of their lives, and be respected and included as equal members of society. If such equality were achieved this would mean for example, at a very basic level, that disabled people who rely on additional assistance for their daily living, such as getting up and dressed, would have the same ability to determine the time at which they get up and go to bed as non-disabled people. Where public authorities can, by giving due regard to this goal, facilitate such an outcome they are required to do so.”

The DDA 2005 makes it clear that authorities must have due regard to the need to “take steps to take account of disabled persons’ disabilities, even where this involves treating disabled persons more favourably than other persons.”

The DRC believes that if fully implemented both the non discrimination provisions and the disability equality duty can make substantial progress for disabled people’s equality. The issue of full implementation is partly a matter of strengthened legal enforcement mechanisms (These issues are discussed in section 7.3). In respect of the disability equality duty it is clear that a strong Government lead from central Government is also needed for it to achieve its full potential.

If due regard is given to the duty to promote disability equality this would mean many of the issues of policy cited below would be redressed. For example, the duty explicitly requires due regard to be given to the need to ‘encourage participation by disabled persons in public life’. This would require not only public authorities to consider their own public appointments processes but also DWP to review the barriers to participation created by the benefits system.

In our view giving due weight to disability equality would require concerted action by the Government to tackle the problems laid out below. Whether Government and public authorities in fact respond in this way is as yet untested.

2.6 Making the welfare state fit for purpose

The formula on which much of the welfare state is based fails significantly in the goal of achieving equality (in terms of human rights, life chances or equality of opportunity) for disabled people, and in many ways acts in direct contradiction to it. More often than not it creates dependency rather than empowering individuals to take control over their own lives, secure their rights, accept responsibilities and achieve their potential.

For example, our social security system is still founded on a notion of disability explained in William Beveridge's 'Plan for Social Security' published in 1942, as 'the inability of a person of working age, through illness or accident, to pursue a gainful occupation'. This is in clear contradiction to the goal of eliminating discrimination and promoting equality of opportunity, which should enable many disabled people to work. Equally the provision made for those considered unable to work does not guarantee rights to social citizenship, instead frequently resulting in social and financial exclusion, health problems, stigmatization and dependency.

Similarly, the configuration and goals of social services are frequently at odds with the goal of promoting human rights and equality. Guided by a 'duty of care', resources are targeted at those deemed most 'vulnerable' and 'at risk', with eligibility guided by the extent of 'incapacity' (and so 'need'), often resulting only in 'life and limb' support. All too often social services prioritize reducing risk and providing 'care' for people – but do not assist them to *take* risks, to build their independence and to contribute to society as citizens.

Examples would be that people with learning disabilities can often be successful parents, with the right support – but are subjected to judgments about the 'risk' they might pose to their children that are never applied to other parents.

Social and health services need to be transformed to support disabled people's contributions – reversing the notion that

disabled people are only passive recipients of care, and instead supporting their active contributions as citizens.

Securing equality and human rights where disabled people are concerned will demand a serious rethink of the role played by the welfare state – in particular how it can be refocused onto securing equal life chances and promoting equality of opportunity.

There are clear economic and social imperatives for these reforms. For example, John Hawksworth (2005) estimates that a working age employment rate approaching 90% will be needed to offset the effects of an ageing population and stabilise public spending in 2050 at current levels of GDP (42%). He concludes that the most likely scenario is that ‘future Governments will be faced with difficult choices between continuing with the recent direction of policy in areas like health, education and measures to tackle child and pensioner poverty, which would imply significant tax increases in the long run, and adopting a much tougher stance on public spending growth, particularly but not only in lower priority areas’.

Legislation, policy and practice which generate dependency are therefore increasingly incompatible with our long-term requirements as a country. There is a clear mutuality of interest in re-configuring the welfare state such that it supports active participation and independence, and so human rights and equality, through both establishing more equal life chances and actively supporting individuals to contribute to family, economic, community, social and cultural life.

For disabled people in particular, social rights – the right to support for independent living – are fundamental to equality. Civil rights alone are not enough, since many disabled people require not only freedom from discrimination but also support structures to enable full participation.

3. **Progress made**

As noted in 2.1, disabled people and people with long-term

health conditions are a hugely diverse group, and progress towards equality has been uneven, with different milestones for different 'groups' and the significance of key milestones is contested. For an excellent chronological history and simple timeline of disability rights (including in the post-war period) 'Disability and Social Policy in Britain since 1750' (Borsay 2005) should be read. Campbell and Oliver 1996 document the history of the disabled people's movement, including the direct action of people living in nursing homes in the 1970s – who at one stage disobeyed the requirement to be in pyjamas after their early (very early) evening meal and wheeled themselves to the pub to continue debating disability politics.

4. **The ‘most persistent and stubborn inequalities’ and their causes**

The DRC has identified a series of priorities for action, falling under four broad and intersecting headings:

Opportunities for disabled people to make a *recognised contribution* and interact with the wider community on more equal terms

- Promoting active participation in public, civic and community life
- Securing an acceptable outcome of welfare reform
- Narrowing the employment gap

Securing the *individual support and assistance* disabled people require to exercise the rights and responsibilities of citizenship

- Ending involuntary institutionalization
- Securing rights and entitlements which facilitate independent living across the life-course

Building *inclusive communities* in which social, environmental, economic and institutional conditions facilitate equal citizenship

- Community safety – tackling hate crime, harassment and bullying
- Improving housing opportunities and conditions

Improving disabled people’s personal and material assets

- Tackling child poverty and wider barriers to children and young people’s life chances
- Improving vocational and personal skills
- Tackling health inequalities

Details are provided below.

4.1 Increasing participation in public, civic and community life

Why important?

Participation in public, civic and community life is both an outcome, and a means to an end. Participation is important in increasing the voice of disabled people, in providing greater opportunities for disabled people to make a recognised contribution, in fostering interaction between disabled and non-disabled people on more equal terms, in transforming attitudes and expectations, and in providing disabled people with opportunities to acquire skills and experience.

Key facts

- Many disabled people do play an active part in community life – often far more so than non-disabled people – and contribute a great deal to building social capital. But this is frequently unrecognised, disabled people’s organisations lack capacity and security, and links between disability organisations and other groups are patchy meaning that ‘bridging social capital’ is not as developed as ‘bonding social capital’.
- Disabled people have a particularly low representation in public appointments – currently 3% (and where disabled people are in public life it is disproportionately public appointments which relate to disability)⁷
- One in four (26%) of disabled respondents to one survey said they had experienced difficulties participating in leisure activities, such as going shopping, going to the cinema, concerts or eating at restaurants.
- DRC research suggests that 73% of those with mobility and sensory impairments have difficulty in accessing goods and services
- 40% of disabled people are fearful of travelling by public transport compared to only 22% of the overall population
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⁷ Cabinet Office. 2004. Delivering diversity in public appointments

- The DDA does not cover volunteering and schemes such as Access to Work are not available for civic or community activity
- Real or perceived disincentives in the benefits system prevent significant numbers from contributing in ways other than paid employment⁸
- A range of other barriers – e.g. transport and the built environment – make participation difficult
- A social care system developed on the basis of dependency and ‘need’ rather than enhancing and supporting independent living and active citizenship.

4.2 Closing the employment gap, including via effective welfare reform

Why important?

In addition to the value of work itself as a route out of social exclusion, and a key means to transform expectations and attitudes, projected squeezes on public expenditure over the next decade mean that optimising the numbers of disabled people in work is central to sustaining the level of investment in public services necessary to deliver an equality agenda overall. That also includes ensuring that those who are unable to work experience social well-being. The welfare state remains premised on notions of disability which are in contradiction to promoting equality of opportunity.

Key facts

- 40% of the total number of people out of work are disabled - many live in poverty⁹
- Only 51% of disabled people are in work, falling to 21% of people with a mental health condition and 26% of people with a learning disability¹⁰

⁸ Howard, M. 2005. Equal citizenship and incapacity benefit reform

⁹ Labour Force Survey Spring 2005

¹⁰ Labour Force Survey Spring 2005

- DWP estimates that an 80% employment rate overall is required to offset effects of an ageing population in terms of public spending as a % of GDP
- Unless achieved, 'future Governments will be faced with difficult choices between continuing with recent direction of policy in areas like health, education, child and pensioner poverty, implying significant tax increases, and adopting a much tougher stance on public spending, particularly in lower priority areas'¹¹
- Increasing the employment rate of disabled people is therefore key to securing wider social rights including in relation to education, social care, health and pensions
- Social security system still premised on William Beveridge's plan for Social Security published in 1942 in which disability is defined as 'the inability of a person of working age, through illness or accident, to pursue a gainful occupation'. Clearly such a notion is in stark contrast to anti-discrimination or pro-equality of opportunity measures¹²
- Securing a fair outcome in relation to people whose circumstances mean they genuinely cannot work relies on optimising the number of people of working age who can work moving into work (including potentially extending the official retirement age – which will also increase the numbers of disabled people in the labour market)

4.3. Ensuring all people are not obliged to live in an institution or in a particular living arrangement

Why important?

Where disabled people find themselves removed from the wider community against their (or their parents') will, either proactively or because of the absence of alternative options, the results are profound. It is not just the individual who is affected; it also constrains our wider aims of generating a society in which all disabled people can participate fully as equal citizens.

¹¹ Hawksworth, J. 2005. How far can a higher employment rate offset the upward pressures on public spending as the population ages?

¹² HMSO 1942, Social Insurance and Allied Services

Key facts

- Since 1997, a 20% and 40% increase in admissions to residential or nursing care respectively for people with a learning disability and people with a mental health condition.¹³ Whilst one factor may be hospital closures, there is also evidence of building new institutions, seemingly for reasons of cost containment
- At the end of March 2004, there were 61,100 residents of institutions who were supported by councils: 59% were people with learning difficulties, 21% had mental health problems and 18% were adults with physical or sensory impairments¹⁴
- Moves towards inclusion in mainstream schools have (contrary to media reports) progressed very slowly over the last decade
- There is no statutory right to choose not to live in an institution (as proposed in the draft UN convention on the rights of persons with disabilities)
- This may in some case represent a breach of Article 8 of European Convention on Human Rights, and Disability Equality Duty – i.e. rights to personal development and participation in the life of the community
- Higher risks of exploitation and abuse in institutions (for example the Healthcare Commission is to investigate the care of people with a learning disability across England having identified serious failings and cases of potential abuse in Cornwall; evidence of people with a learning disability in residential care having election polling cards thrown away by staff emerged during DRC's 'Right to Vote' campaign
- Few people living in institutions have any tenancy rights or the right to choose with whom they live
- Isolation denies the transformative impact of participation and interaction with wider community in building inclusion

¹³ ONS/DH 2003 Local Authority Supported Residents in Staffed Residential and Nursing Care in England 1997-2002

¹⁴ DH 2004 Percentage of adults receiving a social service following a community care assessment by primary client type and age group in England 2003/4

4.4 Securing rights and entitlements which support independent living throughout life

Why important?

Many disabled people require dedicated support, assistance and resources to achieve human rights, establish more equal life chances and realise their potential at every stage of life. An equality agenda is without value to many disabled people unless independent living is at its heart. Yet existing statutory rights and entitlements are not delivering the means for independent living – in some cases they act in complete contradiction – and are subject to tight financial restrictions. The assumptions which underpin their design and delivery focus on managing vulnerability, risk and dependency rather than promoting choice, control and participation.

Key facts

- Services and support are currently not provided as a right, but based on professionally assessed ‘needs’, frequently not orientated towards supporting individual choice, control and participation and in a context of severely restricted resources¹⁵
- Perverse financial incentives including cost-capping are currently leading local authorities to promote institutional care above community living for those with ‘high support needs’
- Services such as social care are not perceived as a social and economic investment, but as managing ‘dependency’, and often infected with risk averse policy and practice

¹⁵ DRC 2005. Independent living – the right to equal citizenship

premised on the notion that disabled people are implicitly vulnerable and 'at risk'¹⁶

- There still exists a lack of support in relation to the use of Direct Payments with markedly low take up amongst some groups, sometimes a result of local authorities' unwillingness to sanction payments to people with learning difficulties or mental health conditions¹⁷
- Education reforms could put effectiveness of SEN framework at risk through delegating funding directly to schools without an effective mechanism to ensure it is used for the intended purpose and to best effect
- Government is contemplating focusing Access to Work scheme only onto small employers which could reduce support for disabled people especially those working in Government/public sector

4.5 Eliminating hate crime and harassment

Why important?

Disabled people have a higher than average fear of crime, and significant numbers report regular experience of physical and verbal abuse and intimidation, affecting their well-being and participation. Identifying the root causes of the prejudice which drives this situation will also help in identifying the factors which need to be addressed in promoting belonging more widely.

Key facts

- In a study commissioned by the Disability Rights Commission and Capability Scotland, nearly half of the 160 respondents said they had experienced verbal abuse, intimidation or physical attacks because of their disability.¹⁸
- More than a third of incidents were physical attacks and almost a third said they experienced attacks at least once a month.

¹⁶ DRC 2005. Whose risk is it anyway?

¹⁷ Pillai, R et I. 2005. Disability 2005. IPPR/DRC (unpublished)

¹⁸ Hate Crimes against disabled people in Scotland (2003) DRC Scotland

- Experts found there was a general perception among disabled people that the police could not help. Only 40% of victims had reported incidents to the police.¹⁹
- According to the Scottish Crime Survey 2000, 10 % of those with ‘limiting health problems’ felt that fear of crime had a great effect on their quality of life, compared with only 2.3 % of those with no health problems and 2.2 % of those with non-limiting health problems.²⁰
- Despite hate crimes against disabled people having been formally recognized in the Criminal Justice Act 2003 (though not yet in Scotland), there is little evidence of co-ordinated nationwide action in terms of strategies to prevent hate crime and harassment against disabled people, address access to justice, or to factor disabled people into social cohesion and community safety strategies.²¹

4.6. Improving housing conditions and opportunities

Why important?

Without equal chances to establish a secure and appropriate home, disabled people will not be in a position to realise the other objectives set out in this agenda. This includes issues relating to availability, affordability, accessibility, conditions and tenure.

Key facts

- Between 1997 and 2004, the numbers of homeless households considered priority due to ‘physical disabilities’ increased by 24% and due to mental health problems by 65%.²²
- In England, disabled people and people with long-term health conditions are more likely to be living in housing which does not meet the ‘decent homes standard’ (highest in

¹⁹ Hate Crimes against disabled people in Scotland (2003) DRC Scotland

²⁰ Scottish Crime Survey 2000

²¹ Hidden Lives (2005) Turning Point

²² ODPM 2005

private rented housing, followed by local authority housing, owner occupiers and housing associations)²³

- Only about half of disabled children live in suitable housing and 23% of disabled adults are living in unsuitable housing
- The Lifetime Homes standard has not been integrated into the decent homes standard and pressures concerning housing density are leading to smaller dwellings unsuited to people using wheelchairs²⁴
- Disabled people are less likely to own their own homes, and are twice as likely to be social housing tenants, meaning a significantly higher number of disabled people are experiencing inequality in relation to assets²⁵

4.7. Tackling child poverty and promoting disabled children and young people's life chances

Why is this important?

Far too many young disabled children continue to leave school with few prospects, under-qualified and under-prepared for successful independent adult life, often resulting in poverty and exclusion during adulthood. Childhoods are blighted by poverty, with immediate impact on well-being. Families are damaged, and the full potential of other family members, including mothers of disabled children, is not fully realised with clear impacts on gender equality and for the economy. A high proportion of families living in poverty include one or more disabled parents.

Key facts

- Children who grew up in poverty in the 1970s did consistently worse at school, were six times less likely to enter higher education, one and half times more likely to be unemployed and earned 10% less during their lifetime²⁶

²³ English House Conditions Survey 2001

²⁴ ODPM 2005

²⁵ PMSU Life Chances of Disabled People. 2005. Cabinet Office; WCHS 1998; SCHS 2002

²⁶ Paxton and Dixon. 2005. The State of the Nation. IPPR

- 55% of families with disabled children are living in or at the margins of poverty with 86% of mothers of disabled children not working compared with 39% of mothers of non-disabled children²⁷
- 68% of households with children where both parents are out of work include at least one disabled parent
- 32% of lone parents out of work are disabled
- A DRC survey in 2002 showed considerably lower expectations amongst young disabled people concerning their life chances – for example 30% expected by age 30 to be earning less than other people their age
- A 2002 study estimated that 1 in 4 young people with learning difficulties had left compulsory education with no transition plan in place
- Disabled 16 year olds are twice as likely to be out of work, education or training as their non-disabled peers.
- Of those in custody of school age, over a quarter have literacy and numeracy levels of an average 7 year old.
- Over half of young offenders have dyslexia, compared to 10% of the general population.

4.8. Increasing vocational and personal skills

Why important?

Economic restructuring over the last decade has vastly increased the demands of employers for highly skilled and qualified workers, and this trend is expected to continue – building towards the ‘knowledge economy’. At the very least all employers will demand basic ICT skills, and ‘soft skills’ in relation to communication, negotiation and interpersonal behaviour. The ‘personal capacity’ of individuals is known to influence the outcomes they achieve from public services. Disabled people overall fair extremely poorly in relation to vocational and personal skills.

²⁷ Russell, P. 2002. Child Poverty and disability. End Child Poverty Campaign

Key facts

- In 1986 20% of workers were required to have a Level 4 (higher) qualification. By 2020 it is projected that demand will be 40%²⁸
- If current trends continue by 2020 almost half of all employment would be in higher occupations²⁹
- In 2003 40% of disabled people had no qualifications at all
- Employers have warned that without at least a basic grasp of IT skills people will find it increasingly difficult to find work
- Of those in receipt of DLA, 37% have never used a computer, while only 37% have used the internet³⁰
- ICT use is lower among disabled people and people with a long term health condition even after accounting for the older age profile
- Increasingly business and public services are employing ICT at the front line of their services to drive down costs, meaning potentially poorer access and outcomes for those unable to use ICT
- In 2003 27% of disabled people aged 16-24 had no qualifications whatever, compared to 12% of non-disabled people of the same age.

4.9 Tackling health inequalities

Why important?

Without more equal health outcomes, disabled people will not establish equal life chances. Health strongly influences opportunities to work, participate, exert control, to live independently and to get on in life.

Key facts

²⁸ Pillai, R. 2005. Disability 2020 IPPR/DRC (unpublished)

²⁹ Pillai, R. 2005. Disability 2020. IPPR/DRC (unpublished)

³⁰ Social Exclusion Unit. 2004. Breaking the Cycle

- Disabled people die earlier, often from preventable illness, experience unequal access to health services including cancer screening and immunisation and primary health care generally³¹
- The DRC formal investigation has found that people with a learning disability or mental health condition are far more likely to have diabetes, respiratory illness, coronary heart disease which makes participation harder for these already excluded groups
- National programmes on health inequalities largely ignore disability related inequalities
- Some groups – those in institutions, homeless people and some ethnic minority communities are especially not likely to get high quality health care

³¹ Nocon, A. 2004. DRC (unpublished)

5. What works in tackling these inequalities?

We focus particularly on how to reduce discrimination and promote equality, as this fits the role and expertise of the DRC.

Link and Phelan argue that stigma (discrimination³²), has four components:

- 1) distinguishing between and labelling human differences;
- 2) linking the labelled persons to undesirable characteristics;
- 3) separating 'them' (the labelled persons) from 'us',
culminating in
- 4) status loss and discrimination that lead to unequal outcomes or life chances.

They also argue that 'stigma is entirely dependent on social, economic and political power'.

This model is a useful framework for thinking through which approaches and types of programme are most likely to create change.

5.1 Tackling prejudice and stigma

To take first the 4 components of discrimination/stigma, in turn. There is no evidence in the field of disability that downplaying differences reduces discriminatory attitudes or behaviour.

Attempts to use this approach in public campaigns have tended to meet with scepticism (as when young people responded to a campaign that we all experience mental health difficulties by not believing it – 'they're just trying to frighten you, it's like with AIDS'). Evidence suggests it is rather more promising to tackle the second component, to subvert the linkage of the labelled person to undesirable characteristics – to say, in effect, yes we are different and that is positive, or beautiful (as in the statue of Alison Lapper currently in Trafalgar Square) or at least neutral.

³² We use the term discrimination to describe the overall process termed 'stigma' by Link and Phelan. For discussion of the respective merits of these concepts see Link and Phelan 2001, Sayce 2003

A recent New Zealand campaign emphasising the positive contributions of people with mental health problems, involving a national rugby hero who declared his mental health difficulties alongside ordinary people, has measurably improved public attitudes across New Zealand (Ministry of Health 2003). It appears to have helped replace the stereotype of helplessness and/or dangerousness with images of people with something to offer.

Key to success here is testing messages to ensure they actually are seen as favourable by the disabled people (it is all too easy to replace one stereotype with another) and do work with the audience. The DRC has market tested and evaluated messages and specific products and has won a number of awards for disability-specific campaigns and products and would be happy to share this experience if helpful. This includes winning several short film awards for the DRC Talk video, Public services annual report of the year, 2 European platinum marketing awards for Employment campaign and 2004 annual report, European marketing gold award for Employment radio advertising on hidden disability, Institute of Public Relations finalist for Educating for Equality and Open 4 All campaigns.

To replace 'undesirable' with 'desirable' characteristics requires attending to very specific stereotypes and identities, since research shows tackling specific stereotypes head-on can work (Penn and Martin 1998). Promoting the very general message that discrimination against any human being is wrong will not dislodge highly specific stereotypes and prejudices.

For example, in Britain in the late 1990s, when public attitudes towards 'disabled people' were becoming more accepting through campaigns and increased participation, social distance towards those with mental health problems actually increased (Department of Health 2003).

A PR company working on a 2003 European Union public information campaign 'Down with discrimination' in employment

found it challenging to devise images and messages that 'worked' across race, gender, disability, age, sexual orientation and religion/belief.

They settled for an image of robots in the office – to caricature the horrors of a European workplace without diversity. Whilst this was a clever resolution of a tricky brief, it would be very surprising if it reduced prejudice towards all the sub-groups whom the new laws are designed to protect (migrant workers, travellers, older people, gays and lesbians...). Specificity is required.

Moving on to the third component of discrimination, to stop the separation of 'them' and 'us', this is the area with the best evidence of effectiveness.

The most consistent research finding on reducing discrimination or stigma is that attitudes improve as a result of contact or familiarisation with a person/people with experience of disability or mental health problems (see Angermeyer et al 1987, Angermeyer and Matschinger 1997, Hayward and Bright 1997, Link and Cullen 1986, Penn et al 1994, Penn et al 1999, Penn and Martin 1998, Read and Law 1999, Roessler 1995, Desforges et al 1991, Meise et al 2000, Alexander and Link 2003).

Opposition to mental health facilities disappears once the facilities open and neighbours 'see service users as people' (Repper et al 1997). Contact appears to reduce fear of the 'other' and to increase empathy. Contact affects attitudes whether or not the contact is voluntary (Link and Cullen 1986, Corrigan et al 2001, Desforges et al 1991). Contact can be retrospective or prospective – in other words, engineering contact as an anti-discrimination intervention promises to be effective (Couture and Penn 2003). Evaluation of training on disability awareness consistently finds that it is hearing from someone with personal experience of disability that stays in the mind and influences attitudes over time (whereas other information from training is largely forgotten).

Research into what types of contact have most impact on which attitudes and behaviours is not yet conclusive (Alexander and Link 2003). Wider research into the impact of contact in relation to groups facing discrimination (eg ethnic and religious minorities) shows that key factors are that people should come together under conditions of equal status, in situations where stereotypes are likely to be mildly disconfirmed (but not too much – not so that the person can be viewed as an exception), where there is inter-group co-operation, where participants can get to know each other and where wider social norms support equality (Hewstone 2003). There is some evidence in the disability field that supports these conclusions, particularly on equal status (Corrigan and Penn 1999) and co-operative activity (Desforges et al 1991).

Where disabled people have ongoing significant roles as employees, bosses or teachers - or are trainers, with status – this is likely to impact positively on the attitudes of those around them. There are provisos – the impact will not occur if the person hides their impairment, or if non-disabled people see them as so different from their stereotypes that they do not generalise from this individual, and instead see him or her as an ‘exception’ (Hewstone 2003).

Compared to contact, specific information has less research backing as an effective changer of attitude. Wolff et al (1996) found in one study that attitudes changed as a result of a community intervention – in which neighbours were given information and met service users - even though knowledge did not increase at all.

Link et al 1999 note that at a time in the US when public awareness about mental illness had grown, the desire for social distance remained just as strong. Knowledge does not seem to be either a necessary nor a sufficient condition for attitude change.

Inclusion itself is a powerful way of changing non-disabled people’s beliefs. Recent British research finds that the group with highest DDA awareness and the most inclusive attitudes

about disability are people who 'know someone who is disabled at work' (DRC 2002). Inclusive schools also influence non-disabled children to hold more accepting attitudes towards disabled children (Gray 2002).

A key challenge is thus to make it safer for disabled people to assert the right to participate. It is encouraging that a recent American survey of professionals and managers with mental health problems (from across industries and sectors) found that the vast majority (87%) had disclosed at work; and most (61%) had no regrets. One of the factors significantly associated with disclosure was awareness of the Americans with Disabilities Act. Anti-discrimination law can thus encourage confidence – and at best deliver greater safety to disclose (Ellison et al 2003). Increasing the proportion of disabled people who know their rights is crucial. Eurobarometer found that only just over a third of Europeans would know their rights if they experienced discrimination.

Practical approaches to enabling disabled people to be included in schools, workplaces and community activities – on equal terms - can potentially create a virtuous circle, in which attitudes improve and make it easier for more disabled people to participate. Research shows that the factor making employers most likely to employ a disabled person is having employed a disabled person in the past: success breeds success.

There is a considerable evidence base on how to enable inclusion, particularly in the employment field, as this has been the highest priority in public policy. Key findings are that just changing the person – treating their impairment or health condition – has little effect on employment. There is no consistent relationship between diagnosis, severity of impairment, social skills and vocational outcome: some people with very significant impairments work successfully, others with much milder conditions do not. In mental health, motivation and the type of support offered are much more significant. The characteristics of help and support that have been demonstrated to be important include a focus on competitive

employment (real work); eligibility based on consumer preference; rapid job search and minimal pre-vocational training (it's better to get into a real workplace than have lots of pre-work preparation); vocational issues integrated into the work of mental health teams; attention to consumer preferences (i.e. it makes a difference whether someone wants the job) and time-unlimited support tailored to the individual's needs. The support has to be flexible – to come in and out as the person's condition fluctuates. 'Place and train' i.e. supporting someone to get a job and offering support and training on the job works better than 'train and place' i.e. doing the training first.

There are big gaps in the research evidence – for instance, there is very little on what enables disabled people to achieve promotion and leadership. The emphasis has been much more on attaining basic entry level jobs – whereas disabled people want careers and opportunities like all other citizens and often face insuperable barriers to achieving their potential.

5.2 Equalising life chances and power

Link and Phelan also argue that discrimination is based on power (see above). They state that it is not enough to label and disparage another group for them to become 'stigmatised': psychiatric service users, for instance, may label some doctors 'pill pushers' and treat them differently from other clinicians. This does not make these doctors a stigmatised group, because patients 'simply do not possess the social, cultural, economic and political power to make their cognitions about staff have serious discriminatory consequences'. This means that anti-discrimination work must either change the deeply held attitudes and beliefs of powerful groups that lead to labelling, stereotyping, setting apart, devaluing and discriminating; or it must limit the power of such groups (Link and Phelan 2001) – or both (Sayce 2003).

In order to address power and to address the fourth component of discrimination – unequal life chances and outcomes – power balances need to shift. One way is through use of legislation.

The DDA 1995 does appear to be making some difference to disabled people's opportunities and lives. For all the DDA's weaknesses and contradictions (DRC 2003, DWP/DRC 2004) it does seem to have been instrumental in, for instance, the increase in employer action to improve practice on recruiting and retaining disabled people. In 1995, 12% of employers had targeted recruitment measures, whereas by 2002 the figure was 74%. In 1995 27% had delivered disability awareness training to managers, whereas by 2002 the figure was 52%. In 1995 25% reported adapted interview procedures, whereas by 2002 the figure was 60%. In 1995 48% monitored employment participation by disability; by 2002 the figure was 70% (Manchester Metropolitan University 2003).

This coincides with a period in history in which the proportion of disabled people in employment rose slightly – from 43% in the mid-1990s to 51% by 2005. Whilst causes were multiple – including a tight labour market and increased cultural awareness of disability – it is at least possible that the new law, and the raised expectations and practical advice that it stimulated, contributed to the improved employment position of disabled people. Some employers became market leaders and instigated excellent practices in employing disabled people/those with health conditions, which had not occurred before the DDA 1995.

Able2 is an employee network for BT people with disabilities. This provides impartial and confidential advice and runs a series of roadshows where people can discuss their needs with senior BT managers. The shows promote ability, not disability, challenge stereotypes and focus on possibilities and ways to break down barriers faced at work by people with disabilities.

eNable is a project designed to improve the working life of all BT people with disabilities. Its objective is to provide guidance and provide the necessary adjustments to help realise the full potential of all people. eNable provides a package of services, consultancy and dedicated specialist support, including:

- A helpline to provide expert advice and assistance to people who are, or become, disabled, or whose capabilities are restricted
- Guidance on job re-design, suitable alternative duties and provision of equipment and services
- Improved advice to managers on their responsibilities under the UK Disability Discrimination Act
- Support to new recruits with disabilities to ensure they feel valued and supported.

BT's Able to Work project increases the number of disabled people employed in our call centres. Recruits come from Remploy, an agency helping people with disabilities find work. Call centres, which have a high turnover of staff, provide new employment opportunities for disabled people who can demonstrate the right skills and commitment.

BT has joined the Fast-Track scheme of Scope, the disability charity. The programme places disabled graduates in employment for a year and provides personal development training and career development through regular reviews, appraisals and individual career plans. This increases graduates' employability

and had undertaken a wide range of activities to improve the way they catered for disabled students. These included disability awareness training for staff and improved access to the curriculum and teaching methods. It will be interesting to assess whether these activities impact over time on levels of qualification and opportunity amongst disabled students.

Batheaston Primary School prides itself on an ethos that welcomes diversity, identifying children as individuals who are all highly valued. Central to this ethos is the school's policy for Inclusion, where local children with disabilities are helped to participate equally beside their peers. Academically, the school is praised for helping children of all achievement levels to make very good progress and achieve high standards. In 2003, Ofsted said "The school's emphasis on inclusion is central to everything it does: it seeks to produce children who think of themselves as responsible citizens of the world, as well as of members of their own and their local community". An important part of this approach is the action taken by the senior management team meeting all statutory requirements and, in keeping with the school's inclusive outlook, ensuring that all pupils have equal access to the curriculum and associated resources.

Leeds University, like most city campuses, has a maze of buildings put up over the course of a century or so, for most of which period disabled students were conspicuous by their absence. But Leeds has transformed itself into one of the most disability friendly universities in the country. In 2002, the University completed an eight-month audit of its buildings and allocated £1.2 million to improve access to the campus. At Leeds they focus on the experience of disabled people in accessing the campus, providing useful information such as an access map of the main campus that can be downloaded from the website. The University also ensures that disabled students can live-in close to the campus, and disabled students can

usually stay in University accommodation for the whole of their course.

Some particular cases taken under the DDA have served to highlight discrimination through publicity and achieved emblematic status at least within disability circles, for instance:

- Bob Ross challenged the low cost airline Ryanair over the charge of £18 for use of a wheelchair at Stanstead airport. He argued that it was discriminatory that disabled people were charged more for their travel than non-disabled people. He was successful both in Court and at appeal in 2004, with the result that Ryanair and British Airport Authorities had to review their charging policies for disabled people overall.
- Lee Buniak, a child with learning disabilities, attended a mainstream school but was in effect excluded from most school activities. He was the only child not to be in the school photo and he was not included in the school nativity play. Despite resources being agreed for his support, he was left alone in a room at school – or at home – for large parts of the week. His family won a case of disability discrimination and the story, accompanied by heart-warming pictures of his inclusion in a new school, were splashed across the tabloid press.

Finally, power can be addressed by means other than purely legal. One simple way is to place power directly in a disabled person's hands – for instance the power to employ one's own support, through direct payments. Research finds that direct payments increase user satisfaction and potential for participation in social and other activities. As Julia Winter (who is disabled) put it in the Guardian recently, with direct payments 'you can say "it's a lovely day: let's not worry about the housework, let's go out!" You can be spontaneous. You can live' (Guardian 14 April 04).

5.3 Strategic intervention to achieve social change

Link and Phelan's review of evidence finds that for anti-discrimination programmes to be effective they have to be multi-level and multi-faceted.

The DRC has run several campaigns – Educating for Equality, Open 4 All, and a recent employment initiative – that have combined tested messages targeted to form a pincer movement (for instance, at both service providers, on their duties, and disabled people, on their rights), helpful products and the stick or threat of the law. Evaluations suggest these do appear to have influenced behaviour in key sectors, although causation in such complex programmes and environments is always hard to pinpoint. These campaigns and products associated with them have won a number of awards, see above.

However, if the DDA has achieved some changes, through a smart combination of promotion, strategic litigation and practical help/tools, there are more gains to be had from a much more proactive and systemic legal framework.

The DRC believes that the combination of the positive action already required in the 'reasonable adjustments' provisions of the DDA, the shift of attention from the victim to the perpetrator inherent in public sector duties, and the broad conception of human rights increasingly adopted in Strasbourg and the domestic courts, could act as the basis for a CEHR committed to being an agent of social change, rather than a mere advocate or regulator³³

Positive action for disabled people is embedded in the existing DDA, especially through the concept of reasonable adjustment:

'From Clark v Novocold it emerged in effect that it is not enough for an employer to acquiesce in the knowledge that he or she

³³ Accentuating the positive – speech by Nick O'Brien www.drc-gb.org

has treated a disabled employee just the same as they would treat a non-disabled person (equal treatment).

What matters is that the result for the disabled person is the same as it would have been for a similarly placed non-disabled person: they get the job, the promotion, escape dismissal (equal outcome). By implication, if it takes a bit more effort or imagination, or even cash, to achieve that end, then so be it. Equality is, paradoxically, about being treated differently, not the same' (O'Brien 2004).

Public sector duties promise to extend positive, proactive action:

'The success in Northern Ireland in changing the religious composition of the workforce is cited as a compelling example....These initiatives represent a sea-change in the legislative approach to equality....in that this is a move away from an emphasis on individual victims, retrospective remedial litigation and individual redress, to the collective benefits for disadvantaged groups of systemic and active changes in policy' (O'Brien 2004).

Changing power balances in the longer term will involve a systemic and integrated legal strategy, coupled with promotion to those with duties and rights, practical help, mainstreaming into policy the requirements of 11 million (differing) British citizens and greatly increased opportunities for disabled people to hold leadership and senior positions throughout British society.

One example of strategic use of legal interventions in the disability field concerns the issue of manual lifting and handling. Two women with physical and learning disabilities challenged East Sussex County Council's policy that staff should not get involved in manual lifting and handling. Disabled people's requirements to be helped in and out of bed, or the bath, presented a risk to staff's backs; so policies preventing staff from manual lifting and handling were put in place.

Following the case, other examples emerged, including one in which Ms Wolstenholme from Milton Keynes had slept in her wheelchair for months, apparently because staff were not permitted to lift her. Ms Wolstenholme weighed 7 stone. She stated that when 5 health officials visited her to decide if they could use slings or hoists to lift her, she fell. 'I asked them for help. They did not. They watched me crawling on the floor'. The Sunday Telegraph commented 'This is the horrible terminus of an obsession with health and safety: 'carers' who are able to stand aside and watch as a desperately ill woman struggled on the floor – because they have been indoctrinated into believing that it would violate health and safety regulations'. (Sunday Telegraph 14 September 2003)

In other instances, elderly relatives noted that they lifted the disabled person in and out of bed whilst care staff stood by. K. Maddison of Dewsbury managed to secure home care for his wife, but writes:

'We soon found out that we were paying more than £5 an hour for a service that was completely useless because of the tasks the carers were not allowed to do. Banned tasks included lifting the patient; giving the patient a shower (even though we have a special wheelchair and shower); administering prescribed medication (over the counter stuff was OK); moving patient's position in chair or bed; opening or closing a window above head height; assisting patient with toileting'. (Daily Mail September 16 2003)

In the East Sussex case the judge ruled that the dignity and independence of disabled people is so important that some manual lifting is an inherent and inescapable feature of the task for which care workers are employed. An approach is required that attends to both staff health and safety – which can be addressed through training and agreed protocols – and the independence and dignity disabled people.

The judgement prompted reviews of policies beyond East Sussex. As *Therapy Weekly* reported the judgment:

'When Charles Dickens's Mr Bumble said that "the law is an ass" he obviously hadn't encountered East Sussex County Council. Or witnessed the good sense of the Honourable Justice Munby. What on earth would Mr Bumble have made of the council's asinine decision to rule out manual handling by care workers in all circumstances?...Whatever the reason, it's hard to understand and harder still to condone the blatant disregard for the human rights of two severely disabled women who brought the case – and all the other disabled and elderly people who must have suffered silently and unnoticed in the "care" of this local authority or any other council to have introduced wholesale prohibitions on manual handling. It's good to know that – thanks to the good justice Munby – it is now "likely to be unlawful" to leave disabled or older people lying on the floor in their own excrement while a hoist is imported to their home'. (Therapy Weekly 27 February 2003)

Following the judgment the DRC worked with the Health and Safety Executive to produce and disseminate revised guidance (practical tools). The media and political attention given to the case – for instance, Tony Blair cited it in a speech about needing a more balanced approach to risk in 2005 – helped to generate improved debate about the balance between independence and health and safety (promotion). It appears that an approach combining strategic legal intervention, promotion and practical tools can begin to shift practice in ways that make a difference to disabled people on the ground, by chopping away at entrenched examples of discriminatory treatment.

6.0 What does the DRC want over the next 40 years?

6.1 In one year

- Good progress on implementation of the recommendations contained in the Prime Ministers Strategy Unit Life Chances of Disabled People report including an Independent Living Task Force
- An evidence-led, influential final report of the Equalities Review
- Robust cross Government and public sector support for the

- Disability Equality Duty,
- An evidence based, effective and fair welfare to work reform programme
 - To be secure in the knowledge that CEHR will be able to progress DRC (and the other equalities commissions) legacy, and be an effective and respected organization for disabled peoples rights

6.2 In three years

The DRC's own 'Disability Agenda' (forthcoming) to have helped shape the overall forward agenda on equality and human rights

- CEHR to have had a high impact one year in, with a clear, evidence-led strategy, sufficiently resourced, capitalising on common goals, not mired in in-fighting and employing multi-faceted strategic interventions to bring about social change
- The Pathways to Work programme (or equivalent) to cover Britain
- People to have a right to refuse to live in an institution
- Independent living and disability equality to be the success measure of key public services
- Public authorities to have clear and ambitious disability equality schemes and to be proactively considering how they assure human rights
- A specific dedicated and ambitious strategy to equip disabled people with skills for work and life
- Targeted action to tackle child and family poverty and implementation of PMSU recommendations concerning life chances of disabled children and young people
- Tackling hate crime, harassment and bullying against disabled people to be fully addressed by the 'Respect' agenda and action to promote community cohesion
- Effective implementation by Govt Departments and agencies of DRC Formal Investigation recommendations in the areas of web access, health inequalities and access to careers.
- Strategy and action to actively increase the numbers of disabled people participating in public, civic and community life
- Action to increase housing opportunities and improve

conditions

- Policy makers increasingly understand the breadth of who disabled people/people with health conditions are and their central significance to the social and economic success of UK plc.

6.3 In 10 years

- An employment rate for disabled people of at least 60%

Clear evidence of 'closing the gaps' in key life domains:

- Closing the gaps in educational attainment
- In employment
- In pay
- In travel (i.e. numbers of journeys made, confidence to travel)
- In health (reduced inequalities in health – particularly through increased life expectancy amongst disabled people, and reduced gap between those with a learning disability or mental health problem and other citizens (currently these groups live on average at least 10 years less long than others))
- Government to be well on the way to overcoming child poverty including in families with disabled parents and/or children;
- All disabled people to have genuine opportunities to acquire basic skills including ICT
- A framework of rights to independent living introduced and uptake of 'control/choice oriented' social services including individualized budgets significantly increased
- Marked increased in levels of participation in public, civic and community life

- Use, satisfaction with and outcomes from public services, including public transport, significantly increased
- Major reduction in number of disabled people reporting homeless, corresponding with a major increase in the numbers of disabled people living in decent, affordable and suitable housing
- Reduced incidence of the most problematic attitudes and behaviours reported by disabled people/ those with health conditions, including hate crime, harassment, patronizing or demonizing attitudes, rejection

6.4 In 40 years

- **All disabled people experience human rights in practice.** Human rights should be the baseline of any future agenda, both as a matter of principle and because of the continued restrictions on many disabled people's dignity, autonomy and even life itself.
- **Equal chances over the life course.** Disabled people should be able to anticipate acceptable standards in terms of social and material conditions and well-being, both as a mark of social citizenship but also because as Tawney (1931) puts it '(equal opportunity) depends, not only upon an open road, but on an equal start'.³⁴ The 'start' should refer both to childhood opportunities and to equal chances from the moment of developing an impairment or long term health condition, when disadvantage so frequently kicks in.
- **A cultural shift,** both in terms of support for equality and human rights as core facets of British life, and the specific transformations needed in views of disabled people/ those living with health conditions. In particular:

³⁴ Tawney, RH. 1931. Equality

- a reversal of the notion of disabled people as passive recipients of care or charity – replacing it with support for active citizenship
- An end to the notion of disabled people as implicitly ‘vulnerable’ and ‘at risk’
- Full confidence amongst people with hidden impairments that they can ‘come out’ without fear of stigmatisation
- Building a culture of expectation in which full equality and human rights are realised *in practice* will demand that disabled people’s rights are linked to facilitating their contribution. As stated in the UN’s World Programme of Action Concerning Disabled Persons: ‘*as disabled people have equal rights, so they should have equal obligations. It is their duty to take part in the building of society*’³⁵
- **Greatly increased individual and collective power of disabled people to exert control over their own lives and influence local and national decision-making.**

7.0 Three priorities for the Equalities Review

Culture and behaviour: evidence based interventions to generate changes in culture, attitudes and behaviour

An effective blend of social rights, human rights and civil rights. Social rights are particularly important for disabled people. The review should identify the reform necessary to secure and re-orientate the welfare state towards supporting independent living and participation. Human rights are critical.

Tackling poverty and poverty of assets (skills, financial inclusion, health) including in families with disabled children and/or disabled parents

³⁵ UN World Programme of Action Concerning Disabled Persons ‘Concepts, Principles and Objectives’

8.0 Priorities for CEHR

- Conceptualising the pursuit of human rights, equality and good relations firmly on the basis of ‘positive obligations’ with a clear articulation of the role of social rights
- Specific action to secure disabled people’s human rights and evidence based approaches to promoting a human rights and equalities culture, including changes in attitudes and behaviour
- Exploiting commonality across strands, not focusing on conflicts. For instance, disabled people, women (including black and minority ethnic women) have a strong interest in improved independent living services. These would enable disabled people and family members (particularly women) who support them to have maximum economic and social participation. This is a potential win-win for disabled people, older people, carers and employers.
- Agreed thematic programmes, in key areas of policy and implementation, so that a blend of tools – promotion, practical resources, strategic litigation – can be used together to achieve measurable change. **Thematic areas might include public services reform, education/skills, employment, health, criminal justice**
- CEHR internal standards: being exemplary on disability equality, in relation to all types of disability/health condition experience, in CEHR’s governance, employment, service provision and access functions.

7.2 Priorities for wider Government

- Implementation in full of the Prime Minister’s Strategy Unit report on the Life Chances of Disabled People, including an Independent Living Task Force
- A cross departmental commitment to disabled people’s human rights and equality, led by the new Office for Disability Issues
- Tackling both the economic and social exclusion of

disabled people in ways which are 'self re-enforcing' e.g. orienting public services towards the goal of participation, thereby transforming employment and economic opportunity through an equal transformation of social, health, housing and other public services. This would be cost effective by disestablishing dependency-creating systems

- Roll out of Pathways to Work nationally
- Investment in a specific skills strategy aimed at disabled people e.g. through partnerships to improve ICT and other key skills
- Ending poverty amongst disabled children and their families
- Adopting a single unified conceptual approach to disability/ health conditions across public policy based on independent living as a right
- Implementation of forthcoming DRC formal investigation recommendations concerning health inequalities
- Disability equality impact assessment of all policy and legislation
- Action to increase levels of participation by disabled people in public, civic and community life, including volunteering

7.3 Using the law and statutory instruments to achieve change

The evidence of disabled people's social exclusion and disadvantage outlined above makes clear the need for sustained Government action, both legislative and otherwise. In the past services and the infrastructure have been designed in a way which fails to take into account the particular needs of disabled people, as part of the general public. This leaves a substantial legacy of barriers to participation. In too many areas these old, exclusionary, ways of operating persist.

The duty on the public sector to promote disability equality, introduced by the DDA 2005 (coming into force in December 2006) marks a significant step forward in tackling these issues of systemic discrimination.

To date the DDA has focused on providing individual redress for individual acts of injustice, acting in a retrospective fashion after the damage is done. The DDA is also limited in scope excluding areas of key importance such as transport. Although some progress has been made by way of the DDA 2005, there is still some way to go. Discrimination on ships and airplanes is still not prohibited by any law. This is but one example. It is unrealistic to expect that the enormous backlog of exclusionary practices and environment can be adequately tackled on this individualized basis.

The Disability Equality Duty marks a fundamental shift in legal approach, putting the onus for change on the public sector, rather than on disabled individuals, and addressing the issue of systemic discrimination.

However, the new duty is untested. Early indications from the implementation of the race duty are that some strengthening may be needed. The private sector is not addressed.

A clearer legal framework, and strong political support, is needed to ensure that where services are contracted from the private sector this process promotes equality. Research evidence from USA,ⁱ and the extensive interviews with employers conducted by the Cambridge Review (known as the 'Hepple Report') of anti-discrimination legislation,ⁱⁱ all emphasised the effectiveness of this approach. Consideration should also be given to imposing at least some elements of this proactive duty approach to the private sector.

The duty to promote equality works principally by seeking to embed equality considerations into the routine operation of the public sector. The mechanisms for securing enforcement (primarily through compliance notices by the Commission, and secondarily through judicial review) are limited. Those at grass roots who are most aware of the deficiencies of an authority will generally have to rely on the Commission to challenge an authority.

Relying solely on a CEHR to oversee a sustained momentum of change is inadequate. Government inspection regimes and regulatory mechanisms need to have a firm legal foundation, and adequate resources and expertise, to ensure that those authorities who fail to promote equality receive a clear message that this is unacceptable,

In addition, the law needs to be changed so that legal cases brought by parties other than the CEHR become a more effective mechanism for systemic change. For example, tribunals should have the power to recommend to employers changes to their practices, where a case brought by an individual reveals clear shortcomings. Tribunals are not at present allowed to make policy recommendations to an employer where there is no direct link to the complainant. For example, if an applicant establishes that they were discriminated against by being harassed because of their disability and they resign as a consequence, under the law as it stands a tribunal cannot make a recommendation that the employer adopt an anti-harassment policy because that would have no effect on the former employee.

Another means of amplifying the effect of individual cases is to increase the level of damages in appropriate cases, so that the deterrent impact is increased.

More fundamentally the legal framework needs to more adequately capture the 'group dimension' of discrimination, reflecting the fact that practices which disadvantage one person because of their disability (or indeed race, gender etc) may often affect a group.

Indirect discrimination is the mechanism which is generally held to best capture this dimension of discrimination. This concept does not apply to disability, being replaced with the duty to make reasonable adjustments. In many ways this is a very useful approach. However, it is only focused on individual complaints and remedies, diluting its potential power.

Applying the indirect discrimination concept to disability equality may be a desirable change. However, at present the potential of indirect discrimination to tackle 'group discrimination' and dismantle systemic discrimination is blunted by the individual focus of the litigation process and remedies.

The CEHR, and other interested parties such as trade unions, should have the power to institute proceedings in their own name, or jointly with individuals where there is common problem affecting a number of person. (The Cambridge Review of anti-discrimination legislation made a number of helpful recommendations on this point). Mechanisms for bringing group claims or 'class actions' need to be simplified and extended. Once again evidence from USA reveals the potential impact of class actions and remedies, where they are applied.

To illustrate what is needed: if an employer adopts a redundancy process which clearly disproportionately impacts upon disabled people what is needed is a mechanism for this group (or a trade union on their behalf) to challenge the process in advance, and for a tribunal to be able to order a change to the process before the group had lost their jobs!

Likewise, the CEHR will have some inherent human rights powers, including the ability to hold general inquiries and to *promote* compliance with the Human Rights Act. However, the powers themselves are fairly limited and human rights enforcement remains in the hands of publicly funded legal services (legal aid). As public funding for cases of this nature are extremely restricted by way of stringent criteria, the CEHR should have the option to fund stand alone human rights cases in certain circumstances. This includes in cases where these are combined human rights and equality issues present (and the equality issue falls 'away' prior to the case concluding) and in cases where the matter relies on or proposes to rely on a matter relating to his/her disability.ⁱⁱⁱ

At the very least the CEHR should have the ability as recommended by the Joint Committee on Human Rights to seek judicial review of the policies, actions or omissions of a

public authority where it believes these to be in violation of the Convention rights.^{iv}

The law can play an enormously influential role in tackling social disadvantage and dismantling systemic discrimination. However, the legal framework needs to move further to capturing the group dimension of discrimination, whether through strengthening and extending the public sector duty, strengthening and embedding the current panacea of human rights enforcement tools, using contract compliance, introducing class and representative actions or introducing more systemic and persuasive sanctions against those who discriminate.

ⁱ Marshall, R; Knapp C.B, Liggett, M.H and Glover, R.W (1978)
Employment Discrimination: The Impact of the Legal and Administrative Remedies

ⁱⁱ Hepple, Bob et.al (2000) *Equality a New Framework Report of the Independent Review of the Enforcement of UK Anti-Discrimination Legislation* Cambridge Centre for Public Law Oxford, Hard Publishing

ⁱⁱⁱ At present this power has been transferred from the DRC Act as a latent (in-active) power requiring an order by the Secretary of State to activate it – we believe this should be done so as part of the enabling legislation of the CEHR.

^{iv} JCHR *Commission for Equality and Human Rights: Structure, Functions and Powers 11th Report of Session 2003-04* p.36