

# **A future without disability?**

**Seminar at the Centre for Disability Studies, University of Leeds**

**Wednesday 1<sup>st</sup> February 2006**

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## **Opening remarks**

I'm really pleased to get the chance to talk with you all today.

At a personal level, it's a real privilege to get to do something with Colin.

Few others can lay claim to having played such an important part in shifting the way society thinks about and responds to an issue.

It is always worth remembering how recent it is that social model thinking entered the discourse, and how far it has taken us in such a short time.

This has not just benefited millions of people in Britain, but as we can see in the developing UN convention on the rights of disabled people, it is changing the lives of people around the world.

The direction provided by pioneers like Colin, Mike Oliver, Vic Finkelstein, Jane Campbell, Jenny Morris and others is carried through the Disability Rights Commission and will hopefully be carried into and beyond the body which will succeed us next year, the Commission for Equality and Human Rights.

Earlier this week the Disability Rights Commission (DRC), with the aid of the new leader of the Conservative Party, David Cameron, launched a set of key priorities for a new long term disability agenda and a major advertising campaign aimed at highlighting the inequality and injustice which continues to blight so many lives in Britain.<sup>1</sup>

At the launch event, our Chairman Bert Massie, gave a major keynote speech – ‘Achieving equality and social justice – a future without disability’<sup>2</sup> – and what I would like to do today is to expand on some of the key themes of that speech, the thinking underlying these themes and why we have recommended these 10 priorities.

There will be some ideas I put to you today that are not DRC policy, but which are nevertheless important issues to discuss in moving forward – and I couldn’t look for a better group to discuss them with!

## **The Disability Rights Commission.**

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<sup>1</sup> Changing Britain for good – putting disability at the heart of public policy. (2006) Disability Rights Commission [www.disabilitydebate.org](http://www.disabilitydebate.org)

<sup>2</sup> Achieving equality and social justice – a future without disability? (January 2006) [www.disabilitydebate.org](http://www.disabilitydebate.org)

Before I do, I want to say a little bit about the Disability Rights Commission.

The DRC was set up by an Act of Parliament in 1999 (the DRC Act) and opened for business in April 2000.

As many of you will know, a major criticism of the original Disability Discrimination Act when passed in 1995 (as well as quite reasonable criticism of the provisions themselves) was the absence of an enforcement and promotional body, mirroring provisions under race and gender statute (the Commission for Racial Equality and Equal Opportunities Commission).

On coming into office in 1997, the Labour Government had included a manifesto commitment to deliver full civil rights to disabled people.

Their first measure was the set up a 'Disability Rights Task Force' and its first major recommendation was that there should be a Disability Rights Commission.

The Commission has a range of powers at its disposal, including supporting individual cases of discrimination through the Courts or Tribunals or through conciliation, using our strategic legal powers, including powers of formal investigation (such as the investigation into health inequalities), 'group action', section 5 agreements in lieu of legal action, and with the advent of the Disability Equality Duty from the end of 2006, non-compliance notices to failing public authorities.

The DRC has also been unique among the equality commissions in supporting judicial review cases in which the Human Rights Act has been invoked – for example the ‘East Sussex’ case where two disabled sisters were found to have had their human rights under article 8 of the HRA (the right to personal development and participation in the life of the community) breached due to the misapplication of regulations by care staff managers concerning manual lifting and handling.

More recently, the Human Rights Act was employed in judicial review supported by the DRC concerning the case of Leslie Burke, a disabled man seeking to ensure that Doctors would not withdraw food and hydration in the event that he became unable to communicate his wishes to them.

We have limited resources for this work and so target them on legal interventions which we believe have powerful strategic value.

That is, a successful outcome which will have a transformative effect both for wide numbers of people and in tackling deep and persistent forms of discrimination.

We have a Helpline which between April 2000 and August 2005 received over half a million calls – far in excess of anything ever foreseen by Government and which has forced us to have to take tough decisions about whether to keep expanding it, taking resources from elsewhere in the organisation, or invest in other ways to get information and advice to those with rights and duties

under the DDA, including over the internet or through transferring our expertise to wider advice and information networks.

In October 2007 the DRC will close, and our functions and powers will be taken over by a new body, the Commission for Equality and Human Rights, which will also promote equality in relation to gender, sexuality, religion, age and from 2009 race.

The DRC has, overall, sought wherever it can to use the force or argument before relying on the argument of force.

That approach does not mean that in anyway our sense of injustice is diminished.

Rather, it is a question of strategy in how best to challenge it, and the law isn't always the best approach or the only driver for change.

For example, whereas agreeing the mutual benefits of change with employers and service providers can yield positive results including future partnership towards progress, the law can sometimes create adversarial responses, lead to little gain as a consequence, and damage any chance of pushing things forward.

We have all sorts of tools in our box and have to select the best ones to use for each job.

For example, we invest heavily in communications, including the advertising campaign launched this week, presence at major

events and conferences, speeches, media activity including promoting the outcomes of key legal interventions and so on.

These communications activities also augment our activities in relation to influencing public policy, and it is this part of our work that I am going to be focusing on today.

### **The DRC – help or hindrance?**

But before I do I remember Colin once telling me that the disability movement had a problem with the DRC in that it effectively institutionalised the ineffective legislative arrangements and acted as a barrier to progress, and I just want to respond to that.

I can see the line of argument here, but there is a danger of missing a major opportunity if this perspective informs action.

The DRC *is* limited in its impact by the legislation, and arguably our existence does provide greater legitimacy to flawed legal provision.

But we are also empowered to advise government on how the legislation can be amended and improved, just as we did to considerable success in relation to the DDA 2005.

Equally we are empowered to advise government on how the broader task of securing equality of opportunity can be achieved.

And whereas in 1998 disabled people were forced to chain themselves to the gates of Downing Street to make their voices heard over the issue of welfare reform, in 2005 Ministers, including the Prime Minister, chain themselves to DRC's endorsement of their proposals.

I'm sure a reluctance to see more paint spilt on the gate of Downing Street is a major driver, but in the DRC disabled people have an institution with real influence.

If anything, disability rights is becoming positively institutionalised – in central and local government, in the HR departments of large employers, in the customer service plans of major retail and leisure service providers and so on - and the more that is the case, the greater power disabled people will hopefully have to determine the next stages of development.

It would be a more sensible strategy, in my view, for the disability movement to harness and exploit the developments of the last 10 years and to use them to take control over determining the next 20, than to reject them and in doing so act on the margins.

'Inside the tent pissing in', as someone once said.

Of course that won't be music to the ears of anti-establishmentarians and it would of course though be absurd of me to suggest that we are anywhere near our goals.

Which is why, given the DRC has only around 19 months left before it is replaced with the Commission for Equality and Human Rights, that it is so important to begin setting its agenda now.

### **Achieving equality and social justice – a future without disability?**

Some of you may have found the title of today's seminar a little curious.

Let me explain why I have used it here and for Bert Massie's speech on Monday.

As I will go on to explain, whole swathes of mainstream social and economic policy goals, from full employment, to tackling child poverty, skills to safer communities, preparing for an ageing population, will not succeed unless they address the existing and potential future circumstances of disabled people.

In this sense, public policy has no future without disability as a core consideration.

It is also to say that we cannot claim to have achieved equality and social justice whilst disability still exists.

And let me be absolutely clear what I mean by this:

The DRC is wedded to the social model of disability.

Our interest lies in promoting equality and social justice through transforming the relationship between people with impairments and long term health conditions and the political, economic, social, cultural, technological, legal and environmental factors which shape our lives.

We share the view of those social model pioneers I mentioned earlier that disability is the product of a negative interaction between people with impairments and long term health conditions and a world which has not yet extended equality and social justice to them.

A world of equality and social justice would therefore be a world without disability.

Which incidentally makes the whole notion of 'disablism' – a word which has caught on in some circles - rather problematic, but that's for another day.

### **Low expectations – the enemy of progress**

So if we agree on the social model of disability, and that disability is of itself symbolic of inequality and injustice, we then need to look at what stands between us and our goals, and how public policy can be an agent for achieving the sort of 'good society' we desire.

Let me begin by saying what I believe to be the most intractable problem we face.

Disabled people are not universally considered to have the capacity to be equal.

As the human rights academic Luke Clements has suggested, disabled people are not yet considered 'ripe for freedom in the same way that women, serfs and southern blacks once weren't.'<sup>3</sup>

For example, David Cameron speaking at our event on Monday said that whilst the equality agenda was absolutely right, it's important for politicians to think about the 'special needs of the profoundly disabled where the equality agenda is important but there is an element for some people who need very special treatment for their very special conditions'

Our attempts to deliver true emancipation are thwarted by the inability of society to conceive of disabled people as independent agents able to determine their own lives, or people who have the capacity to make an active contribution to society.

If the circumstances of disabled people continue to be perceived to be borne not out of inequality and injustice, but rather fate, society can continue to let itself off the hook.

And it is this lazy fatalism about the lot of disabled people which we have to get around.

It is deep-rooted, often woven into the fabric of our society and all the more pernicious in its effect as a consequence.

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<sup>3</sup> Clements L and Read, J. Disabled People and European Human Rights (2003) Policy Press

Our major enemy is low expectations.

Sometimes we choose to expect less out of a sense of compassion and fairness – for example to protect some people from having their benefits made conditional on searching for work.

Other times it is an overt lack of confidence in people's abilities, or because society is seeking to protect itself or others – for example in not accepting that someone could perform a particular job, or discomfort about sex education for young people with a learning disability.

In protecting people, whatever the motivation, we can deny their humanity.

I would argue that all forms of low or prejudicial expectations contribute to unequal opportunities.

I know Colin believes strongly that it is the competitive society which generates inequality.

He is right that it creates inequality in the sense that some will always have more than others, but that still leaves us with the issue of the degree to which people enjoy equality of opportunity to join in the competition in the first place

In arguing that the solution is to be found in a non-competitive society, are we not in effect suggesting that disabled people can't compete, even after barriers have been removed?

I would actually argue that even within the idiom 'to each according to his needs, from each according to his abilities' a culture of low expectations could deny disabled people the opportunity to have their needs met in a fashion which facilitated their fullest contribution and so opportunity for self-fulfilment.

Saying that disabled people will not achieve equality in a competitive society does sound dangerously close to saying that disabled people will always be bottom of the pile in the social relations such economic arrangements generate, thus feeding low expectations.

How distant is that from advocating charity in place of citizenship?

Short of revolution, I have little choice in my role but to seek to promote greater equality of opportunity within the global realities of capitalism and the inequalities it generates.

Part of that process is in our view seeking to challenge and replace the culture of low expectations with a culture of high expectations focused on promoting disabled people's active participation in democratic, civic, family, economic, community and social life.

**Equal rights... equal responsibilities?**

The DRC's vision is of 'a society in which all disabled people can participate fully as equal citizens'

It would be fair to say that in the first 5 years of our existence we didn't give a lot of thought to what achieving this vision actually would entail, as we busied ourselves with delivering the agenda set by the Disability Rights Task Force.

During 2004 we did though begin to think a lot about citizenship, and in particular how disabled people fared within the 'social contract' which shaped citizenship in Britain at the beginning of the 21<sup>st</sup> Century, and the path which had led us here.

In 1982 a paper from the United Nations World Programme of Action on disability stated that '*As disabled people have equal rights, so they should have equal obligations. It is their duty to take part in the building of society.*'

It went on to spell out the importance of reciprocity:

*Societies must raise the level of expectation as far as disabled persons are concerned, and in so doing mobilize their full resources for social change. This means, among other things, that young disabled persons should be provided with career and vocational opportunities - not early retirement pensions or public assistance.*<sup>4</sup>

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<sup>4</sup> United Nations World Programme of Action Concerning Disabled Persons Objectives, Background and Concepts, 1982

In essence what this said and what we are saying now is that we will not commandeer the sort of public and political commitment to providing the resources and support disabled people require unless it is seen as an investment not just in disabled people, but in society as a whole.

But now, 22 years on are we yet in a position to say that equal rights should mean equal responsibilities?

During the time elapsed, the disability community rarely talked explicitly about disabled people assuming greater *responsibilities* when it discussed disability equality – instead focusing on achieving rights.

When it did talk explicitly about responsibilities, it was only ever *on condition* of establishing rights, even though it was recognised that disabled people could not establish equal citizenship without both equal rights and responsibilities.

This seems on the face of it to be a perfectly rationale response – society can't demand that people who do not enjoy equal rights and opportunities should nevertheless hold equal responsibilities.

And of course this has been a perfectly reasonable principle from which to defend disabled people from welfare conditionality for example.

But when we say this, is it heard in this way, or is it thought that we are saying that disabled people can't ever be expected do the same things as everyone else?

And is it what we really mean?

In relation to independent living, we talk of disabled people enjoying rights to self-determination, control and participation.

In effect we are talking about disabled people assuming greater levels of individual responsibility, both over their own lives and through doing so being able to organise life in order to play a more active part in the collective responsibilities of the wider community.

This is because individual responsibility (or control) is instrumental to achieving freedom, and freedom is the essential goal of independent living.

In this sense, rights are also instrumental – they are the means to the end, but not the end in itself.

Our real goal has always been to provide the practical means and to remove the barriers which prevent disabled people from assuming greater levels of control and responsibility – as parents, workers, advocates, volunteers, leaders and so on - so that they can 'participate fully as equal citizens'.

If promoting individual responsibility is a goal, then it demands that public policy pay specific attention to those personal, social and

environmental circumstances which confirm or deny such opportunities.

This is crucially important, because it points to what we should see as the real success criteria of public policy – not theoretical rights on the statute book, but the conversion of such rights into the genuine lived experience of freedom, participation and well-being.

### **Breaking the cycle of low expectations**

I would suggest that the reason many disabled people are not considered to be 'ripe for freedom' is society's persistent belief that they would not exercise this freedom responsibly – that they lack the capacity to hold responsibilities.

And without such freedom there is little chance of disabled people achieving equality.

So we have to find the way to break this cycle.

And the only way we can do so is through disabled people establishing recognition not simply for the theoretical rights and entitlements that they hold, but for the positive contributions such things have enabled them to make and the individual responsibility they have allowed people to assume.

We need to build a common sense of injustice concerning the circumstances of disabled people which is focused not on the failure of society to 'look after' disabled people but on the failure to

provide disabled people with the means to actively participate and flourish as human beings.

We need a major shift away from the minimum levels of social protection many disabled people are currently offered.

Instead, as Amnesty International's new campaign suggests we need to 'protect the human' by ensuring all enjoy freedom, respect, equality and dignity.

And getting to this point will demand a more explicit link is made between rights and responsibilities.

This is part of the process of embedding rights and extending opportunities.

And this begs some difficult questions – to what extent can one generation's suffering be justified on the basis of the opportunities it opens up for the next?

Because as we break from the past there will be winners and losers – for example in the reforms of incapacity benefit.

As we move forward we will need to watch out for the traps that we can easily fall into when we still have a foot in the past, because it can do so much harm in moving forward, and this will at times be difficult.

Anti social behaviour orders (ASBO's) are a good case in point.

There have been various reports suggesting that a disproportionate number of ASBO's are being issued to people with mental health conditions, neurological conditions and learning difficulties.

Many people's first reaction to this is a sense of injustice.

But we need to ask some questions before we make our conclusions.

Firstly we should differentiate between penalising impairment-related behaviour (e.g. a boy swearing uncontrollably because of his Tourettes or a women trying to commit suicide because of her mental health condition) and people behaving 'anti-socially' who have impairments or conditions.

With the former we should be indignant about their treatment – ASBO's are in effect providing a legitimized vehicle for intolerance and are an entirely inappropriate measure to use.

With the latter, it is not as clear-cut.

We should be focusing on how to provide those individuals with the opportunities and capabilities not to behave in that way – to have the means to take responsibility for their actions.

To say that in every case an ASBO against a disabled person is wrong is to deny individual responsibility and again to help confirm low expectations

It is to say that disabled people as a rule cannot be trusted to hold freedoms responsibly.

Now some of you may be simply think of ASBO's as illiberal and wrong.

However, given 9 out of 10 people with a learning disability complain of harassment in their daily lives of the sort for which there would be no remedy through the criminal justice system, perhaps ASBO's have the potential to empower some disabled people to challenge the discrimination they face from other members of the public – allowing them to challenge one of the barriers which prevent them from establishing individual responsibility and freedom?

The new disability equality duty places a duty on the public sector to act to eliminate harassment against disabled people. Perhaps we want to see more ASBO's used to challenge harassment against disabled people?

## **Reciprocity in practice – shaping public policy**

To achieve our goals we have to change the terms of the contact between disabled people, the State and wider society – the nature of citizenship itself

The idea of reciprocity is a powerful tool in negotiating public policy.

For example, the DRC has been working hard over the last year to influence the Government's approach to welfare reform.

We want a fair balance of reciprocal rights and responsibilities between people on incapacity benefit, Government, employers and providers of into-work support.

We believe that if disabled people can work, they should work.

To achieve this, we believe there needs to be further steps to bring employers into line with their duties not to discriminate, rights to flexible working, changes to the rules around statutory sick pay, and disability leave.

We believe the Government, in contracting with the private and voluntary sector should use its powers of procurement to require that those organizations have demonstrably good practice in relation to disability equality.

We believe that providers whether public, private or voluntary should act within the framework provided by the new disability equality duty

We believe that wider barriers to work must be addressed, including real progress on the implementation of the Government's commitment to independent living.

We believe reform is needed, both to ensure all disabled people enjoy an acceptable level of social well-being and the opportunity to actively participate in society – barriers in the benefits system which have prevented people from entering public life or volunteering should be removed, and the system needs to respond flexibly and supportively to people with fluctuating conditions.

Our response to the Green Paper has been based on these positions. Unless they are all in place, we cannot give our full support....

**Organisation's of disabled people or organisation's *with* disabled people?**

We also need to look at the role of the voluntary sector in relation to disabled people's relationship with the wider community.

Many disabled people have voluntarily come together out of shared interest to deliver support and to affect change with a powerful impact through lobbying. In doing so many do play an active part in society – far more so than the average citizen.

But 'bonding social capital' of this kind should not deny 'bridging social capital' – breaking down the barriers which can exist between communities – and we need to think about this in the sort of participation we pursue and the types of organisations we seek to build.

Do we always want organisations of disabled people, or do we want organisations *with* disabled people as well?

As we move forward, will it be more helpful to have Centres for Independent Living run by and for disabled people, or disabled people as part of the leadership of institutions and services for the wider community where disabled and non disabled people interact with one another – Sure Starts, extended schools, City Learning Centres.

Is there a danger that by coming together, disabled people can sometimes set themselves apart?

## **Achieving equality and social justice**

So we begin with the social model, and we believe that our goal is ultimately disabled people with the means to take responsibility for their own lives and to actively participate and make contribution to society.

How do we get there?

Firstly, we need the means to secure equality of opportunity.

RH Tawney wrote in 1931 that equality is not about treating everyone the same, it is about recognizing and responding to difference, and his thinking on equality is again influencing mainstream political debate.<sup>5</sup>

He also cautioned that equality of opportunity was not only about 'an open road' but also a more 'equal start'.

I think these two principles are very much the essence of our approach to equality.

We do not seek equal treatment because treating everyone the same has the perverse effect of creating inequality.

Our interest is in equal results.

To achieve that we have to treat people differently.

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<sup>5</sup> Tawney, RH. Equality (1931)

That is why anti-discrimination legislation relating to disability includes the notion of 'reasonable adjustments'.

To treat people equally we could not make adjustments because it would be considered an unfair advantage.

In the context of the DDA, the purpose of the adjustments is to remedy or avert substantial disadvantage – different treatment for more equal results.

It is also the essence of independent living – different people need different things to achieve the same results – the more 'equal start' Tawney talks about.

Related to this concept is the 'capability theory' developed by the development economist Amartya Sen.<sup>6</sup>

Sen argues that different people have different degrees of capability through which to convert a given resource into the same results.

Therefore, to look at resolving world poverty from the perspective solely of income is to ignore a multitude of other critical factors influencing how that income can be put to use by different people – their access to basic amenities such as water, their ability to live free of disease and so on.

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<sup>6</sup> E.g. See Sen, Amartya. *Developments in Freedom* (1999) Oxford University Press

If we apply this to the circumstances of disabled people, it draws our attention to the added costs of living with an impairment or long-term health condition.

Some of these added costs relate to factors which are borne out of having an impairment or condition. Others are products of the environment.

But it means that efforts to tackle the poverty experienced by so many disabled people cannot be achieved only through ensuring that disabled people are not living in income poverty, because this ignores the facts that disabled people do not enjoy the same 'capability' to convert that income into the same outcomes because of the additional costs of doing so.

A more equal start demands that disabled people are supported to overcome what Sen calls (perhaps unhelpfully within our work) capability deprivation.

### **Promoting equality**

So, a vision of equality in which justice, opportunities and resources are re-distributed in order to provide disabled people with a more 'equal start' and to remove the barriers which stand in the way of disabled people reaching their individual potential.

From December 2006, public authorities will have new positive duties under the Disability Discrimination Act 2005 (DDA) to

actively eliminate discrimination and promote equality of opportunity for disabled people.

Many public authorities will be required to develop disability equality schemes, mapping how they will meet the duties.

In developing these, they are required to involve disabled people.

I have already set out the role I believe greater levels of participation amongst disabled people can play in transforming expectations and embedding rights.

I also believe it is only way public authorities will deliver schemes which have any real impact on disabled people's life chances.

Participation should be seen both as a long term goal and a means to an end.

That is why the 10 priorities for action we set out this week begin with increasing disabled people's active participation in public, civic and community life.

It is also why in his speech, Bert Massie called for all political parties to include at least one disabled person on shortlists for vacant seats, for the Public Appointments Commissioner to set a target of 20% public appointments to be filled by disabled people, and for Government to require that any voluntary or private sector organization bidding to run public services to have a demonstrable

commitment to disability equality, including in the leadership of its organization.

As I said getting inside the tent....

### **Developing a new agenda**

Which brings me on to the Disability Debate.

The Commission decided in early 2004 that it was time to start thinking about a long-term agenda for action.

Many of the recommendations of the Disability Rights Task Force were on their way to having been delivered and clear change has occurred over the last 10 years.

Some good foundations had been laid but we know full well that disabled people continued to experience deep and persistent social exclusion in many areas of life.

We chose to focus specifically on achieving our vision of a society in which all disabled people can participate fully as equal citizens.

Jenny Morris was commissioned to produce a paper on 'citizenship and disabled people' in February last year which was discussed at a seminar last March.

You can read that paper on our disability debate website ([www.disabilitydebate.org](http://www.disabilitydebate.org))

That informed a paper called 'Shaping the future of equality' which we published last June.

We also launched a new interactive website and a series of further papers including one on risk and another on interaction – not for straight consultation but to stimulate discussion and debate about the priorities for a new forward looking agenda.

We also commissioned two pieces of research – one looking at disabled people's social and economic circumstances in 2005, the other forecasting important trends to 2020.

We hope to publish these, produced for us by the Institute of Public Policy Research, later in the year.

Around 2700 people registered on the website and we received somewhere in the region of 700 specific contributions through a range of media – opinions, ideas and responses – during the period

More importantly, and uniquely for a public body, people were able to talk to one another via the website message-board which was unmediated other than on one occasion where we felt compelled to advise a contributor of their risk of libel.

Through these discussions and the research, the DRC has generated a series of long-term aims, and 10 priorities for action in achieving them.

## **Our vision**

Our vision, as set out by Bert earlier this week is of:

A society in which we accept that it is not our differences that make us unequal but our failure to acknowledge and accept them.

A society in which we extend to one another the same high expectations and the means to realise our full potential.

A society which moves forward together, in which all play their full part and where no one is forgotten or left behind

### **10 priorities for action**

To achieve this we have set out 10 priorities for action which we believe are collectively critical to achieving both our aims and many of the core ambitions of this, and very likely future governments.

These are spelled out in more detail in the publication I have handed out today, so I am going to just provide an overview now.

### **Participation in public, civic and community life**

Our first priority is increasing disabled people's active participation in public, civic and community life.

As one participant in the debate noted: **‘The government seems good at talking about helping the disabled yet does not accept that we can be useful within the community’**

Participation is important in increasing the voice and influence people have in shaping the world around them.

It provides greater opportunities for people to make a recognised contribution, outside or over and above paid employment, and to interact with non-disabled people on more equal terms, so helping to transform attitudes and behaviour towards disabled people.

It provides opportunities to acquire new experience and confidence which may help people find employment.

Participation is fundamentally important to people’s sense of status and belonging.

For Government and the wider community, it ensures the potential of all individuals is harnessed to improve our community life, with positive pay-offs in relation to issues such as cutting crime, improving public services, ongoing participation in education, re-engagement in democratic processes and improving mental health and well-being.

The new Disability Equality Duty, introduced by the Disability Discrimination Act 2005 requires public authorities to take action to promote disabled people’s participation in public life, to promote

positive attitudes towards disabled people and to actively involve disabled people in the development of policy and plans.

Yet disabled people are more likely to be targeted as objects of voluntary and community activity than supported to be active citizens themselves.

Disabled people represent 20% of the population but have a particularly low representation in public appointments currently an average of around 3% across England, Scotland and Wales <sup>7</sup>

Only 6% of all volunteers are disabled people<sup>8</sup>

The Disability Discrimination Act does not cover volunteering and schemes such as Access to Work are not available for public or civic appointments

Real or perceived disincentives in the benefits system prevent significant numbers from contributing to society in ways other than paid employment <sup>9</sup>

So we will be exploring how we can increase opportunities for disabled people to actively participate in public, civic and community life.

## **Narrowing the employment gap**

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<sup>7</sup> Cabinet Office, 2004 *Delivering Diversity in Public Appointments*

<sup>8</sup> CSV:RSVP, 2000 *Disability need be no handicap* London:CSV

<sup>9</sup> Turner & Beresford, 2005 *Contributing on Equal Terms: Service User Involvement and the Benefits System* London: SCIE

<http://www.shapingourlives.org.uk/Downloads/benefitsreportoct05.pdf>

Our second priority concerns more disabled people getting into paid employment

Employment continues for most to provide the best overall escape route from poverty and exclusion, providing not only greater financial security but also independence, status and social interaction. As we live longer, our individual and collective ability to make financial provision for retirement through our working lives is ever more important.

Of the total number of people of working age out of work in Britain, 40% are disabled<sup>10</sup>

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 disability<sup>11</sup>

Almost a third of working-age disabled adults live in income poverty. This is higher than a decade ago, double the rate for working age non-disabled adults and higher than the rates for either pensioners or children.<sup>12</sup>

68% of households with children where both parents are out of work include at least one disabled parent and 32% of lone parents

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<sup>10</sup> Labour Force Survey, 2005

<sup>11</sup> Labour Force Survey, 2005

<sup>12</sup> Palmer et al, 2005 *Monitoring Poverty and Social Exclusion 2005* York: Joseph Rowntree Foundation <http://www.jrf.org.uk/bookshop/eBooks/1859353983.pdf>

out of work are disabled, meaning disabled people's unemployment plays a major part in child poverty.<sup>13</sup>

The Joseph Rowntree Foundation recently reported that a disabled person with a degree is less likely to find work than a non-disabled person without any qualifications at all.<sup>14</sup>

At any given level of qualification a disabled person is more likely than a non-disabled person to be low-paid. The disability pay gap is 10%<sup>15</sup>

It will be impossible for the Government to meet its target of an 80% employment rate without redressing the inequality disabled people experience in the jobs market – and that target is key to sustaining public services

We need to get more people into work and ensure more people get on at work and stay in work.

### **Ensuring that no-one is obliged to live in an institution or particular living arrangement against their will**

The right to choose where and with whom to live is a basic human right which continues to be denied to many disabled people.

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<sup>13</sup> DWP, 2003

<sup>14</sup> Palmer et al, 2005 *Monitoring Poverty and Social Exclusion 2005* York: Joseph Rowntree Foundation <http://www.jrf.org.uk/bookshop/eBooks/1859353983.pdf>

<sup>15</sup> Palmer et al, 2005 *Monitoring Poverty and Social Exclusion 2005* York: Joseph Rowntree Foundation <http://www.jrf.org.uk/bookshop/eBooks/1859353983.pdf>

As one participant told us 'I live in a care home and want to live independently. I can't afford this so I remain in a care home.'

Without this basic level of self-determination and control, it is impossible to achieve equality.

Many who live in residential institutions have no residency rights such as a tenancy agreement, the ability to choose who to share their living space with, or freedom of movement.

Those living in institutions have no rights of appeal to leave them, are often unable to access the support they need to live in the community, and cannot get enough 'points' to be re-housed.

Our wider goals cannot be achieved unless we follow the lead set by the draft UN Convention on the Rights of Disabled Persons that no one should be obliged to live in an institution or particular living arrangement.

Since 1997, there has been a 20% and 40% increase in local authority placements to residential or nursing care respectively for people with a learning disability and people with a mental health condition.<sup>16</sup>

A commitment in the Prime Minister's Strategy Unit report 'Improving the Life Chances of Disabled People' (2005)<sup>17</sup> to

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<sup>16</sup> National Statistics/DH figures to 2003  
[http://www.performance.doh.gov.uk/HPSSS/TBL\\_C7.HTM](http://www.performance.doh.gov.uk/HPSSS/TBL_C7.HTM)

<sup>17</sup> Prime Minister's Strategy Unit, 2005 *Improving the Life Chances of Disabled People*, London: HM Stationery Office [http://www.strategy.gov.uk/work\\_areas/disability/index.asp](http://www.strategy.gov.uk/work_areas/disability/index.asp)

consult on the ‘merits of a right to request not to live in residential care’ was not included as a specific consultation question in the subsequent Adult Social Care Green Paper, and not mentioned at all in the version of the paper made accessible to people with a learning disability<sup>18</sup>.

### **Securing rights and entitlements that facilitate independent living across the life course**

Strongly linked to the previous priority is securing rights to independent living

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.

For many disabled people, our entire agenda rests on achieving this objective.

Yet existing statutory rights and entitlements in relation to social services 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 supporting choice, control and participation.

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<sup>18</sup> DH 2005 *Independent, Well Being and Choice*, London: HMSO  
<http://www.dh.gov.uk/assetRoot/04/11/53/42/04115342.pdf>

Perverse financial incentives including cost-capping are leading local authorities to promote institutional care above community living for those with 'high support needs' as evidenced by significant rises in admissions to residential and nursing care since 1997

Of adults with a learning disability living in the community, 52% live with their parents and 12% with other relatives (Emerson, 2005)<sup>19</sup>

Research by Turning Point found that 20,000 people with a learning disability don't have anything to do during the day, leaving them isolated from the community and compounding low expectations of themselves and from others<sup>20</sup>

The DRC is working with Lord Ashley of Stoke to help him introduce an Independent Living Bill to the Lords this Spring.

### **Making disabled people safe in their communities – tackling hate crime, harassment bullying and negative stereotyping**

To achieve equal citizenship, the disproportionate rates of violence, harassment, bullying, rejection and the fear experienced by disabled people of all ages must be systematically addressed.

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<sup>19</sup> Emerson et al, 2005 *Adults with Learning Difficulties in England 2003/4*

<http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsStatistics/fs/en>

<sup>20</sup> Turning Point, 2005 *Hidden Lives – Improving the life chances of people with a learning disability*

Feeling or actually being unsafe or unwelcome - from shunning or rejection to violence, harassment and negative stereotyping – has a significant negative impact on all people’s health and sense of wellbeing. It also has significant impacts on people’s ability to participate both socially and economically in their communities. Safety and security, and the right to live free from fear and harassment, are at the core of disabled people’s priorities.

Research by Mencap found that 9 out of 10 people with a learning disability reported having experienced harassment<sup>21</sup>

One in four disabled people fear being alone after dark, compared with one in ten non-disabled people<sup>22</sup>

8% of disabled people in London suffered a violent attack during 2001/2 compared with 4% of non-disabled people<sup>23</sup>

Research by Greater London Action on Disability (GLAD) found that ‘The attacks have a major impact on disabled people. Around a third have had to avoid specific places and change their usual routine. One in four has moved home as a result of the attack. Many disabled people are not confident that the police can help to stop the incidents.’<sup>24</sup>

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<sup>21</sup> Mencap 2000 *Living in Fear* <http://www.mencap.org.uk/download/fear.pdf>

<sup>22</sup> Prime Minister’s Strategy Unit 2005 *Improving the Life Chances of Disabled People*, Stationery Office [www.strategy.gov.uk](http://www.strategy.gov.uk)

<sup>23</sup> Mayor of London, 2003 *Another Planet? Disabled and Deaf Londoners and Discrimination* [http://www.london.gov.uk/mayor/eydp-2003/disability\\_capital\\_report.jsp](http://www.london.gov.uk/mayor/eydp-2003/disability_capital_report.jsp)

<sup>24</sup> *Greater London Action on Disability (GLAD) Disabled people and the police – a new relationship?* London: GLAD/MPA.

In looking at this area, we hope to come up with a strong profile for disability within the 'good relations' strand of CEHR's work

### **Improving disabled people's housing conditions**

A secure home is the foundation stone without which much of our agenda is unachievable. Disabled people experience higher than average housing problems – from homelessness, to standards, suitability, choice and access to home ownership. A poor housing situation has major impacts upon wider experiences and opportunities.

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%<sup>25</sup>

In England, people with impairments and long-term health conditions are more likely than others to be living in housing that does not meet the 'decent homes standard'<sup>26</sup>

23% of disabled adults are living in unsuitable housing<sup>27</sup>

Many disabled adults living in institutional settings, supported housing or with relatives are unable to establish sufficient 'points' for social housing, preventing their move to independent life.

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<sup>25</sup> IPPR, *Disability 2005* unpublished

<sup>26</sup> Prime Minister's Strategy Unit 2005 *Improving the Life Chances of Disabled People*, Stationery Office [www.strategy.gov.uk](http://www.strategy.gov.uk)

<sup>27</sup> Survey of English Housing, 2003/2004

The Lifetime Homes standard has not been integrated into Part M of the Building Regulations and pressures concerning housing density are leading to smaller dwellings unsuited to people using wheelchairs

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 assets

### **Ending child poverty and disadvantage – removing the barriers to disabled children and young people’s life chances**

Achieving the Government’s historic commitment to end all child poverty by 2019 demands targeted action to overcome the poverty experienced by families with disabled children – 55% of whom live in or on the margins of poverty.

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.

For example, disabled 16 year olds are twice as likely not to be in any form of education, employment or training, and 60% of referrals to Youth Justice Boards are young people labelled as having SEN.

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.

86% of mothers of disabled children don't work compared to 39% of mothers of non disabled children.

Access to appropriate and affordable childcare is a major barrier for parents of disabled children - the Government's Childcare Bill offers a new opportunity to ensure that local authorities do provide sufficient and appropriate childcare for all children.

### **Enhancing vocational and personal skills**

35% of people in Britain with no formal qualifications are disabled.

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. At the very least it is anticipated that all employers will demand basic ICT skills, and 'soft skills' in relation to communication, negotiation and interpersonal behaviour.

If we see equal citizenship not just as access to basic material conditions, but also as enjoying the same levels of control and personal freedom most people feel, then we must also address the

personal capacity of individuals to exert choice and control. The extent of an individual's personal capacity is also known to influence strongly the outcomes they achieve from public services – for example, people's grasp of ICT, or their ability to comprehend their rights and responsibilities and negotiate positive outcomes from public services.

We need to ensure that all disabled people optimise vocational and personal skills they need to live independently and get on in life.

In 2003 40% of disabled people had no qualifications at all <sup>28</sup>

In 1986 20% of workers were required to have a Level 4 (higher) qualification. By 2020 it is projected that demand will be 40%<sup>29</sup>

Of those in receipt of DLA, 37% have never used a computer, while only 37% have used the internet<sup>30</sup>

### **Tackling health inequality**

Disabled people, who make up around a third of NHS users in Britain die earlier, often from preventable illness, experience unequal access to health services including cancer screening and immunisation and primary health care generally.

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<sup>28</sup> Labour Force Survey, 2005

<sup>29</sup> Ippr, 2005 *Disability 2020* unpublished

<sup>30</sup> Social Exclusion Unit, 2004 *Breaking the Cycle of Social Exclusion* ODPM  
<http://www.socialexclusion.gov.uk>

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

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 and other heart conditions which makes participation harder for these already excluded groups

There is a much higher rate of obesity amongst people with learning disabilities. The figure for women with learning disabilities is particularly high at 40%.<sup>31</sup>

Over 60% of people with serious mental health problems smoke. Providing the right support for them to quit could play a significant part in helping Government achieve its target of reducing the proportion of the British public who smoke from 28% to 24% by 2010<sup>32</sup>

People with learning disabilities, especially more severe learning disabilities, have much lower rates of cervical screening, mammography and other routine tests than other citizens

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<sup>31</sup> DRC, 2005 *Equal Treatment: Closing the Gap: Interim Report of a Formal Investigation into Health Inequalities*

<http://www.drc-gb.org/newsroom/healthinvestigation.asp>

<sup>32</sup> *ibid*

Some groups – those in institutions, homeless people and some ethnic minority communities are especially not likely to get high quality health care

**Ensuring that future legal and institutional arrangements for promoting equality and human rights are sufficiently well designed with regard to securing disabled people's rights**

Our final priority concerns future legislative and institutional arrangements for promoting equality and human rights.

For the Commission for Equality and Human Rights (CEHR) to succeed, it will need an approach to promoting human rights, equality and good relations which addresses fully the experiences of disabled people. This includes its ability to address the specific factors shaping the life chances and opportunities of disabled people, the design and interpretation of equality legislation and the quality of CEHR as an organisation able to represent disabled people's interests.

For many disabled people, it will be particularly important that CEHR is empowered to effectively protect and promote human rights.

The CEHR will take over the DRC's work from October 2007 and will play a central role in delivering this agenda and progressing wider work once DRC closes.

Disability rights demand a particular focus on 'reasonable adjustments', positive obligations and social rights which are not mainstreamed into wider equality and human rights thinking – we need to secure this approach within the CEHR

The Government has committed to introducing a single equality act to replace existing anti-discrimination laws. A review is underway – we need to make sure it improves upon the DDA

We need to think how our agenda fits with the three CEHR strands of promoting human rights, equality and 'good relations'.

The DRC is unique among the equality commissions in having made use of human rights statute to secure disabled people's rights. We need to share our learning and build on this experience.

## **Conclusion**

Our agenda is about removing barriers, giving disabled people the means to realize more equal life chances and to transform expectations by promoting and supporting disabled people's active participation in society.

Equally, it is about achieving core public policy goals and preparing Britain for the future.

A future, as Bert said, without disability.

Because disability signals our failure to have dismantled the barriers which stand in the way of a more equal and just society.

And that failure can no longer be said to be an issue for a minority – it is something the majority will pay for directly.

Everyone will pay indirectly.

We have it within our power to take a new direction

Our requests are perfectly reasonable.

I hope you will all play a part as we develop and seek to secure this agenda

Thank you