

## **Bert Massie speech UCL & Bindmans Annual Debate Human Rights Culture – A Social of Legal Phenomenon?**

**Tuesday 15th May 2007  
University College London**

I will address this topic from the perspective of disability rights and disabled people, not because our experience is unique (although in some ways it probably is) but because I want to explore the extent to which that perspective casts light on what is a matter of critical importance for everyone in this country and especially for anyone who is involved in the CEHR, as I am as the DRC's Transitional Commissioner.

When I was a young disability rights campaigner in the 1970s, it would have seemed an idle dream to suppose that disability would by the end of the 20th century be established not just here but in America, the Commonwealth and throughout Europe as a rights issue. In those days, the politics of disability were still embryonic. It would take some time before disabled people themselves developed a new 'social model' of disability to underpin a concerted challenge to the notion that the right policy approach to disability could possibly be anything other than based on a charitable or welfare model. It was not until 1995, nearly twenty years after the Sex Discrimination Act and the Race Relations Act, that the DDA put to bed for good the notion that the proper response to the disadvantage experienced by disabled people is one of pity rather than indignation.

It is tempting to conclude that the advent and relative success of the DDA suggests that disability rights needed to take legal shape before anyone could feel confident that they were here to stay. There is some truth in that: it is every campaigner's ambition to see his or her efforts

translated into government policy and then converted into enforceable law. The symbolism, the message that legislative step sends out, the credibility and authority that goes with legislation and all its paraphernalia are not to be sneezed at. There is certainly a sense in which disability rights came of age with the passage of the DDA.

But there is a price to pay for making it to the statute book, and in the disability field there is no need to look further than the USA to see how disabled people have had to struggle with a 'backlash' against the legalism of disability rights, especially in the labour market.

I've nothing against lawyers, of course, and I have to say that the DRC and disabled people more generally have been well served by the legal profession, by the courts and the senior judiciary in the past decade. I take a lot of pride too in Michael Rubenstein's published view that disability rights and the legal work of the DRC are among the great success stories of the last twenty years on the equality law front.

But there is no need to be a social theorist to wonder whether litigation, especially within a common law jurisdiction, is the best way to achieve controlled social change. The sheer uncertainty of the legal process, its cost, its individualism and its preoccupation with process rather than substance can leave all but the most thick-skinned damaged for life, regardless of the outcome.

More importantly, there is the little matter of interpretation: how can campaigners and legislators be sure that the judges, hardly the most radical occupational group, will hold the line, transfer legislative intention into judicial decision, and uphold the law in a shape and form that is recognisably that espoused by those who were its advocates from the outset?

The answer of course is that you can't be sure. That is why we at the DRC have been so careful about choosing the right cases to fund and why so much of our legally-related work has not been about litigation at all, but about alternative and more constructive forms of dispute resolution (such as conciliation), about preventative work through statutory codes of practice, non-statutory guidance and 'education' (in the broadest sense of the word), about the dissemination of good practice and other instruments of social and cultural change, such as policy advice to government and work with the media. The reality is that although the DDA establishes the framework for these activities and just as importantly creates the language of rights with which disabled people can now interpret their experience, the task of embedding the law, making its values a living reality in the daily lives of disabled people cannot be a matter just, or even especially, for lawyers.

So what about human rights? Does the same apply? I should say first of all that it strikes me as odd to conceive of disability rights as anything other than human rights, as though equality and human rights were separable and distinct. There is of course a conventional and perhaps helpful distinction to be drawn between human rights and civil rights but the territory occupied by disabled people in their struggle for better lives is increasingly that associated with social care and healthcare, independent living, inclusive education and cultural participation, the sort of territory closely identified by the human rights concepts of dignity, proportionality, participation and autonomy. In speaking of disability rights it seems to me that I have already been talking about human rights, albeit just one specific manifestation of what human rights might look like in practice.

But I need not stop there because the DRC and disabled people at large have increasingly begun to make self-

conscious use of human rights law as a vehicle for interpreting their experience, resolving disputes and achieving change. And we have done so in a way that is very similar to the approach we have taken to the DDA. We have been wary of entrusting matters of life and death, independent living, and personal autonomy to the courts but we have not been afraid to do so where the prospect was the elucidation of how human rights principles might be applied to a practical situation, achieve a balanced and proportionate response for the individuals concerned and provide a template for the resolution of other similar disputes. Such opportunities do not come along every day but they have come along from time to time, and the DRC, and others, have intervened in cases to do with just these issues. The East Sussex manual handling case has been mentioned in many discussions like this but I will mention it again because it is a good example of what can be achieved.

A and B are two disabled sisters, 26 and 22 years old respectively, both with profound physical and learning impairments. They have always lived at home, in a specially adapted house. Even so, getting out of bed or into the bath means they have to be lifted by their carers. Over the years, there had been increasing tension between the family and the local authority over whether the lifting should be done manually or with the use of special hoisting equipment, which the sisters hated. The DRC became involved because this case was the tip of a 'no-lifting' iceberg: stories abound of disabled teenagers going to school in nappies because no one is allowed to lift them on to the toilet and of older disabled adults unable to leave their houses because their carers are forced to rely on hoists for any necessary lifting. Things like going to the shops, which would in practice be perfectly manageable with relatively modest amounts of lifting, then become impossible. This was the situation facing A and B, and the DRC without hesitation associated itself with the

claim that the local authority's manual handling policy was unlawful and unjustified, and that it had got the balance between the safety of its employees and the needs of its disabled clients entirely wrong. In his compelling judgement in favour of A and B, Mr Justice Munby drew upon the jurisprudence of the Strasbourg court, with its emphasis on 'the physical and psychological integrity' of the person, to find at the heart of that integrity the central value of 'human dignity':

Turning to the positive dimension of what the achievement of that human dignity might require of a public authority, the judge remarked that:

'The other important concept embraced in the "physical and psychological integrity" protected by Article 8 is the right of the disabled to participate in the life of the community... This is matched by the positive obligation of the State to take appropriate measures designed to ensure to the greatest extent feasible that a disabled person is not "so circumscribed and so isolated as to be deprived of the possibility of developing his personality".'

This is inspirational stuff. But what was even more important was that the judge engaged in the task of addressing the specific social care policies being applied by the relevant authorities and of importing into that task human rights principles. Beyond that there was the tricky business of spreading the word so that others would follow suit. We like to think we had a reasonable measure of success but that is not the issue. This case offers a model of how human rights law can be used to put human rights principles into practice, engage with the underlying social policy considerations and offer the prospect of dissemination.

That I would argue is a model that the CEHR would do well to consider favourably. It is a model that suggests to

me that too stark a distinction between legal and social phenomena is simplistic but that of course what matters in the lives of disabled people is that legal phenomena (rules) are translated into social phenomena (practices) that can touch and transform their daily lives. Without that act of translation there is a very real danger that human rights principles will fall easy prey to what Conor Gearty calls the 'crisis of legalism', the very crisis that accompanied the success of human rights in making it to the domestic statute book. The problem with legalism is not just that it leads to narrowness and loss of perspective. More importantly, it sends the message that lawyers are the final and authoritative arbiters of what human rights means in practice. Instead of human rights being used to generate real public benefit in a non-legalistic and emancipative way they are then likely to be absorbed within an existing legal culture that is at best a last resort and at its worst quite stifling. In that case we can forget about human rights culture altogether and resign ourselves to the rule of lawyers in human rights matters, as in so much else.

If the 'crisis of legalism' is real, where can we look for the remedy? Hardly to a Bill of Rights, I would suggest, and anyway in the Human Rights Act we have something more democratic and potentially more transformational. When the Government introduced the HRA it was already mindful of the need to avoid the pitfalls of legalism: it spoke of its desire to create a 'human rights culture', and the HRA itself was cast in terms so 'open-textured' that it has been described as more a 'mission statement' than a piece of social reforming legislation of the more conventional kind. Others have emphasized the importance of putting human rights talk at the heart of 'public reasoning' and of developing human rights principles as 'an articulation of social ethics' independent of law.

Since September 2001 the task of rescuing human rights from their detractors and from exclusive association with 'security' has become more acute. A broader understanding has been promoted by increasing attention to the way in which human rights can complement the Government's push for public service reform: the Audit Commission reported in 2003 on the failure of public service to embrace human rights principles since the introduction of the HRA; the British Institute of Human Rights, Carers UK, the Institute of Public Policy and the DRC have all sponsored reports along similar lines; the Equality Act 2006 paves the way for a new Commission for Equality and Human Rights which will have an express legislative remit to 'promote' (but not enforce by way of individual human rights litigation) the protection of human rights; and even more recently the Department for Constitutional Affairs has published a review of the HRA which highlights the continuing challenge of embedding human rights in public consciousness and in public sector practice.

At a practical level, domestic and international example provides illustration. The domestic Equality Commissions and NGOs have begun to use public interest interventions in human rights cases as a device for embedding human rights principles in public service delivery (e.g., the DRC interventions in the East Sussex and General Medical Council cases); and the Equality Act 2006 expressly empowers the CEHR to make human rights interventions of this sort. The DRC has for some years run a conciliation service for disability discrimination cases on goods and services, and in America ADR has been used extensively by the Equal Employment Opportunities Commission in labour disputes concerning disability. This year the UN has produced its first human rights instrument of the 21st century: the Convention on the Rights of Persons with Disabilities. This is a human rights instrument that establishes a framework for making sense of the

experience of disabled people in human rights terms, in terms, that is to say, of the central human rights principles of autonomy, equality, participation, proportionality and solidarity.

So, in answer to the question, 'human rights culture – a social or legal phenomenon', I give the answer that it is of course 'legal' to the extent that the notion of 'rights' is essentially a legal one, that the language of the law provides the lexicon with which the basic quality of those rights are articulated, and that it is human rights legislation that codifies human rights principles in a way that creates a framework for non-legal initiatives.

However, it is those non-legal initiatives that are the key to the identity and creation of a human rights culture. It is only when human rights become a set of positive values which, almost unconsciously, inform public debate and the analysis of social conflict, that the phenomenon of a human rights culture can be said truly to have emerged. That I would conclude is a social phenomenon, and importantly so. Were we to concede that it was anything else, we would be consigning human rights to the status of nothing more than a parlour game for well-intentioned but essentially other-worldly social reformers, and even worse to legal game of snakes and ladders in which the winners could never be anyone other than the lawyers who set the rules and threw the dice. That I suggest is a prospect that disabled people, and indeed the CEHR, will not want to countenance.

Keywords: Commission for Equality & Human Rights; Disability rights; Disabled People; Human Rights

## **Improving Services for People with Learning Difficulties and Mental Health Problems: Implications of the DRC Formal Investigation on Health Inequalities for Primary Care.**

Presentation to Primary Care 2007, PCT and SHA Programme, NEC, Birmingham, 11th May 2007

Gerry Zarb, Head of Health & Independent Living Strategy, Disability Rights Commission

### **Why we carried out the FI**

We undertook this investigation because significant international research evidence showed that people with learning disabilities and mental health problems are more likely than other citizens to die young and to live with physical health problems, many of which are potentially preventable. We wanted to understand this experience in England and Wales so that we could recommend changes to primary care policy and practice that would help 'close the gap' in physical health inequalities.

*Far too many people...are dying in their 40s, 50s or even younger – far more than in the wider population. Whenever I hear of someone else dying young I always wonder what could have been done to prevent it' (Cliff Prior, former Chief Executive Rethink.)*

We wondered the same thing across England and Wales. Are people with learning disabilities and/or mental health problems experiencing worse physical health and dying younger than others? If so how do we 'close the gap'?

### **How we carried out the FI**

This investigation is unique internationally in bringing together 3 powerful sets of data to inform robust recommendations:

- New research. The most comprehensive study of primary care records and mental health issues in the world (8 million primary care records), coupled with Area Studies in 4 areas, extensive consultation with service users and providers and evidence reviews. This enabled us to undertake detailed exploration of health inequalities, barriers to services and potential solutions.
- Collating existing evidence through extensive literature review.
- Written and oral evidence analysed by a high level Inquiry Panel - chaired by David Wolfe, a Barrister at Matrix Chambers specialising in disability, health and public law - who generated recommendations designed to work practically in the newly configured national health services.

### **Findings on higher rates of major diseases**

We found that in England and Wales, people with learning disabilities and people with mental health problems are much more likely than other citizens to have significant health risks and major health problems.

For people with **mental health problems**, these particularly include obesity, smoking, heart disease, high blood pressure, respiratory disease, diabetes and stroke.

For example:

- Women with schizophrenia are 42% more likely to get breast cancer than other women.

- People with schizophrenia are 90% more likely – ie nearly twice as likely – to get bowel cancer (the second most common cause of cancer death in Britain). This is a completely new finding internationally. It has significant implications for services and for targeting of the bowel cancer screening programme.
- 31% of people with schizophrenia and CHD are diagnosed under 55, compared with 18% of others with CHD.
- 21% of those with schizophrenia who have a stroke are under 55, compared with 11% of others who have a stroke.
- 23% of those with schizophrenia and respiratory disease are diagnosed under the age of 55, compared with 17% of others with respiratory disease.

For people with **learning disabilities**, the main conditions observed in the FI included obesity and respiratory disease.

- People with learning disabilities had 30 per cent higher rates of respiratory disease than the remaining population at 19.8% compared to 15.5%.
- People with learning disabilities were more likely to be obese. The rate of obesity in all those with recorded body mass index (BMI) was 28.3% in people with a learning disability, compared to 20.4% for the remaining population.

- People with learning disabilities also have much lower rates of cancer screening plus lower levels of checks once they have diabetes or stroke. So, there is a very high level of unmet need.

For other health conditions such as diabetes, stroke and ischaemic heart disease, rates were lower amongst people with learning disabilities than in the remaining population. However, the figures in the analysis may be under-estimates: it is known that diabetes, for instance, is often under-diagnosed, primary care records may not accurately reflect the extent of health problems, and the health needs of people with learning disabilities often remain unidentified.

### **Dying younger**

Both groups are not only more likely than other citizens to develop some significant health problems; they are also likely to develop them at a younger age. Once they have them, they are also likely to die younger than other people.

For example, our clinical data analysis concluded that: 'Five-year survival rates show lower survival rates for patients with mental health problems for almost all key conditions' (including stroke, diabetes, respiratory disease).

People with learning disabilities also die younger than other citizens, and have high rates of unmet health needs, which may contribute to early death.

### **Why the inequality?**

There are several reasons for inequalities, including social deprivation, poverty, lifestyle, access to health

assessments and treatments and side-effects of anti-psychotic and mood stabiliser medication.

However, the differences cannot be explained by social deprivation alone. For example, even after accounting for social deprivation, people with schizophrenia or bipolar disorder who have major physical health problems are more likely to die sooner than others with the same health problems

### **Minimum expectation: getting 'the same' treatment**

Despite these stark findings, the response from primary care services and from government has been very patchy.

In primary care, these high risk groups are actually less likely to receive some of the expected, evidence-based checks and treatments than other patients and efforts to target their needs specifically are ad hoc.

- For people with mental health problems, although annual health checks have been incentivised through the General Practitioner (GP) contract, some standard treatments and tests – for example cholesterol checks and statins for people with heart disease, and spirometry for respiratory illness – are received less often than for others with heart disease or respiratory illness.
- For people with learning disabilities, some checks are given less often. People with learning disabilities who have diabetes have fewer measurements of their body mass index than others with diabetes and those with stroke have fewer blood pressure checks than others with a stroke. They have very low cervical and breast cancer screening rates. We found that health

checks identify significant unmet health needs amongst people with learning disabilities; and that when a second health check is given one year later further significant unmet need is identified, some of it serious. Despite this, regular health checks have not been introduced in England (although they are being introduced through incentives in Wales).

- Both people with learning disabilities and people with mental health problems experience 'diagnostic overshadowing', that is reports of physical ill health being viewed as part of the mental health problem or learning disability – and so not investigated or treated. This could mean that levels of ill health are even higher than our figures suggest.
- There are some impressive examples of positive practice in primary care. There is also extensive evidence that primary care services are not generally making 'reasonable adjustments' – simple things like making appointments by email, providing treatment information in alternative formats or sending text or phone appointment reminders. These have been required by the Disability Discrimination Act since 1999.

In mental health policy too, there are some excellent developments. The Quality and Outcomes Framework (QOF) in the new GP contract includes measures to review the physical health of people with serious mental health problems. The need to address physical health inequalities is also included in the Mental Health National Service Framework, with a focus on reducing smoking rates and improving services for long-term physical health conditions. However, these have not been translated into wider health policies like the primary care access initiative

or relevant National Service Frameworks (NSF) like the NSF on diabetes.

At government level, these groups have not been systematically targeted by programmes to reduce health inequalities which have mainly focused on socially deprived areas. Whilst important, this alone does not meet the needs of people with learning disabilities and/or mental health problems, who will only attain more equal health outcomes through targeted attention in health improvement, promotion, access to services and equality of treatment.

To give one example, there are more obese people with learning disabilities and/or mental health problems than there are obese people in Birmingham and Coventry combined. To tackle the problem of obesity among people with learning disabilities and/or serious mental health problems would thus have a greater impact than to do so across these two cities. A national programme to tackle health inequalities in England would not ignore whole cities like Birmingham or Coventry and yet people with learning disabilities and/or mental health problems have, to date, been ignored in national health inequalities programmes.

### **Meeting the physical Health needs of people with mental health problems and learning disabilities**

The findings from the FI show very clearly that there is often a lack of access to basic and routine health care. Sometimes that's related to assumptions about patients capacity to be active partners in managing their own health and sometimes it's the result of a failure to make basic adjustments to enable people to access primary care, screening programmes and so on.

The FI Report makes many recommendations on how to tackle this problem. For example:

- AMSPAR, the Practice Manager Network, the RCGP, the RCN, the BMA, NICE and the NPSA should collaborate with user groups to draw up guidance to encourage and support the implementation of the FI recommendations. The guidance could include accessible versions of typical documents (such as patient information leaflets) which GP practices could then adapt to their local circumstances
- Community Mental Health Trusts and Community Learning Disability Teams have an important role to play in supporting people with learning disabilities and/or mental health problems to access facilities and opportunities that can improve their physical health. Sometimes that can be as simple as making sure that they give them proper information about how to access mainstream services and on resources like the Expert Patient Programme.
- The Department of Health should work with the BMA and AMSPAR to consider requiring that, over time, everyone working as a receptionist in a GP practice or other primary health care setting should demonstrate specified competencies or hold an appropriate qualification which includes a substantial disability equality and awareness training element, explicitly including learning disability and mental health.
- The Department of Health, RCGP and BMA should work with user groups to develop and then distribute to GPs a “good practice” guide on how to go about including in patient records information about whether individuals have learning disabilities, for the purposes of recording access needs and offering those people

health checks. (It appears that GPs are likely to already have good records of which of their patients have mental health problems.)

- The RCGP, RCN, NHS Employers and DRC should work with user groups to develop and deliver disability equality and awareness training programmes and materials for GP practice staff and others involved in decisions relating to, and the provision of services to, people with learning disabilities and/or mental health problems. The training should be evidence based and pay particular attention to the needs of people with learning disabilities or mental health problems including in particular giving guidance on dealing with “capacity” questions and on issues around confidentiality, particularly for a disabled person who is supported by a carer, an advocate, a key worker, or similar person.

Some of the Reports most important recommendations relate to the issue of access to regular **health checks**. This is particularly important in relation to conditions such as obesity, diabetes etc and for particular risk groups like people with schizophrenia or bi-polar disorder. Health checks should be triggered at particular points – including admission to psychiatric hospital. This is obviously particularly important for people who have under-used primary care and are likely to have unmet health needs, including for instance people with undiagnosed heart conditions for whom certain medications may pose significant risks. Groups such as African-Caribbean men and homeless people are also likely to be at particular risk.

Our discussions with Dept of Health indicate that they accept the need for regular health checks. Their recently published response to the FI states that:

“DH remains committed to introducing regular, comprehensive health checks for people with learning disabilities. We believe introducing health checks is a vital step as the evidence shows these are the best way to improve the health of people with learning disabilities. PCTs have a vital role in ensuring that health checks are undertaken. The Department of Health has commissioned the NHS Primary Care Contracting Team to develop a primary care service framework, which will help PCTs commission health checks for people with learning disabilities in general practice. This will be available in 2007/08. In addition, in future contractual negotiations with GPs, one of our priorities will be access to regular health checks for people with learning disability.”

### **Access needs and the DDA**

If we are going to make real progress on tackling the unequal access to health care that the FI has highlighted one of the key issues will be getting things right at the point of access. That means making sure that we are able to identify disabled patients and their access needs. So one of the key recommendations from the FI is that Department of Health, the Royal Colleges and BMA should work with user groups to develop and then distribute to GPs a “good practice” guide on how to go about including in patient records information about whether individuals have learning disabilities, for the purposes of offering those people health checks.

We’d also like to see Connecting for Health and the Care Records Standards Board actively encouraging the practice of offering disabled people the opportunity to record their access requirements.

Another key recommendation was that the RCGP and RCPsych should encourage their members to ensure that they pay particular attention to providing people with learning disabilities and/or mental health problems with full information in an accessible form about the benefits and side effects of medication (including in relation to physical health effects), particularly psychiatric medication where prescribed to people with mental health problems in order to enable patients to exercise a properly informed choice about their treatment options.

The Dept of Health's current review of the New registration template also provides an opportunity to make sure that access needs are included as part of the basic information set collected when patients register with a GP. It really shouldn't be any more difficult than recording someone's address or telephone number so we would be disappointed if this opportunity is missed.

Probably the biggest challenge in dealing with access barriers however is simply getting everyone to really understand what access means - and raising awareness to the level that such understanding is reflected in everyday interactions with patients.

This is especially important for people with learning disabilities, where communication, attitudes and behaviour have a much greater bearing on making healthcare accessible than any physical or material barriers.

As the FI Inquiry Panel noted in their report:

“It was remarkable from our evidence that many practitioners did not realise or acknowledge that such significant barriers to accessing their services existed. For instance: ‘Some practice staff expressed bewilderment as to why there should be any issues for

people with learning disabilities and/or mental health problems getting their needs understood. This view came from staff who are doing their best to be kind and considerate. However it could create problems for people trying to make an appointment or getting their needs met once they are attending for an appointment.'

In a similar fashion, practitioners responding to our consultation often noted that they treated everyone 'the same'. For instance:

'As a practice we do not discriminate, any patient is welcome to use the practice services in the normal way.'

This suggests that practitioners do not generally understand that achieving equal outcomes often means needing to treat people differently – by making adjustments.

The DDA has, since 1999, required all service providers – including primary care practitioners – to make reasonable adjustments. But, getting access right isn't just about compliance with the DDA. Much more importantly, it can make a real difference to the effectiveness of the healthcare provided to patients. Clearly, there are very limited or inefficient mechanisms in place for practitioners to record and share information about people's disability related needs (access needs, preferred mode of communication, advocacy needs, the relevant effects of people's impairments and so on). As long as that is the case, it is hardly surprising that practitioners are ill-equipped to provide people with the best possible health care. And, if practitioners are hampered by this information or knowledge gap we clearly need to focus attention on developing systems and procedures to help them overcome it.

## Getting Commissioning Right

In addition to what health professionals do at the front line it will obviously be important for key recommendations from the FI to be reflected in strategic commissioning and planning. The Dept of Health are currently drafting a new commissioning framework for PCTs and SHAs so, again, this provides a timely and positive opportunity to help get commissioning right so that everyone can access good quality health care.

Some of the key issues that commissioners of services (practice-based commissioners, primary care trusts, local health boards and local authorities) need to consider include:

- Monitoring trends in morbidity, survival rates, diagnosis, condition management and patient experience as part of local strategic assessments of needs so that planning and commissioning can be informed by reliable baseline intelligence.
- Building robust disability access and quality standards into all contracts with providers, in the public, private and voluntary sectors (including support to enable people to take an active part in managing their own health care).
- Ensuring that PCTs commission primary care services which include regular health checks for people in in-patient care, people in high risk groups requiring specific interventions (e.g. people with hypertension, diabetes), physical health checks for people with schizophrenia or bi-polar disorder, and groups such as African-Caribbean men and

homeless people who are known to be at particular risk.

Strategic commissioning also needs to identify groups needing outreach, in-reach or new service models to ensure they get primary care, to QOF standard, wherever they are and whoever treats them

For example, Department of Health, PCTs, the Royal Colleges and BMA should work together to ensure that residents in residential homes and other institutional settings receive equal access to GP services, which they are entitled under the GP contract (including ensuring that GPs work in partnership with residential care home managers around issues such as appointment times). PCTs should also ensure that such health checks are also available to people being admitted to or leaving prison and other long stay institutions.

## **Future agendas and challenges**

As you will have seen, the DH published their initial response to the FI in March this year.

We particularly welcome the establishment of a DH delivery group, chaired by the Director of Commissioning, to take forward planned activities and will do as much as we can to help make this work.

We also welcome the production of an action plan with associated timelines. We will however want to try to make sure that some of the planned actions are more closely aligned with specific recommendations from the FI as several are either quite vague or simply restate activities that are already in train.

We particularly welcome the emphasis on the potential role of local commissioning to ensure that targeted actions are developed at the coal face. The DH's new Commissioning Framework offers a real opportunity to tackle directly some of the barriers to healthcare identified in the FI - so we hope that the opportunity will be grasped with both hands.

The DRC is very disappointed however that DH do not accept the validity or benefit of breaking down PSA targets by disability groups - especially as much of the data could be made available from existing records. We still firmly believe that health inequalities will not be finally consigned to history unless and until this vital step is taken.

The Healthcare Commission has also recently highlighted the issue of monitoring. In their Count me in report published in March they note that: "High quality data is essential for monitoring and improving the access of patients to healthcare, the quality of care they receive and the outcomes of that care. This applies to all patients with mental health problems and learning disabilities .....

Currently, the recording of disability, including learning disability, is not a requirement in the data routinely collected by the Department of Health. We ask the Department of Health and the Health and Social Care Information Centre to consider the inclusion of information about disabilities in patients' records." DRC will be working with the Healthcare Commission and others to progress this issue.

Looking to the future, our work at DRC is now focused on encouraging implementation of the recommendations from the FI. As we will be closing down at the end of September 2007 we are also working on influencing priorities for the new CEHR.

The recent history of how people with learning disabilities fare in the health care system highlights that there are major problems here. Mencap have suggested that this amounts to nothing less than institutional discrimination.

I know many people who work in the health care system would find it difficult to accept that but there is clearly no doubt that awareness and understanding of the needs of people with LD falls well short of what's needed and what is acceptable. DRC and the new CEHR will continue to play a part in changing that but it really needs all stakeholders to take up the challenge.

More generally, the Disability Equality Duty that came into force in December 2006 also provides an important and necessary tool for monitoring progress on improving access to healthcare for all disabled people and – in particular – for ensuring that PCTs are held to account for implementing the objectives set out in the new commissioning framework. DRC will be working with the Healthcare Commission and others to make a start on this scrutiny process in the time we have remaining and will be reconvening the FI Inquiry Panel in July to review progress and make recommendations for further action by CEHR after we have gone.

The challenge of ensuring high quality health and social care for all is set to grow as Britain's population ages. Although there are likely to be improvements in the health and well-being of older people, the likelihood of impairment and poor health increases with age. More disabled children and young people are also living longer with complex conditions. This requires specific focus if we are to get to the bottom of the barriers that disabled people face and make sure that equitable outcomes are achieved.

Keywords: Formal investigations; Health inequalities;  
Learning disabilities; Mental health; Primary care

## Speech by Sir Bert Massie, Westminster Briefing

Organised by 'The House Magazine' May 2007

I want to talk about disability rights and the thinking behind the CEHR project, about the sort of thing a CEHR might be and the part that disability might play in it. In doing that I will say something of what I think disability rights amount to at present and of the way the equality and human rights wind is blowing more generally. My proposition will be that the distinctiveness of disability rights is something for the CEHR to celebrate and to nurture, a presently unique resource for tackling the question of how human rights and equality can coalesce.

But first, let me say something about the DRC's position. It is no secret that the DRC was sceptical about the CEHR project from the outset. When Barbara Roche, the then Minister for Women and Equality, introduced her review of current arrangements as long ago as May 2002, the DRC took what she had to say very seriously and took very seriously too her Green Paper's desire to consult on possible structures for a single equality body. The seductive rationale behind the idea was clear enough: strength in unity; administrative efficiency; one-stop shop for business; a new start and a new culture. And indeed the DRC formally acknowledged in its response to the Green Paper the potential gains on the cross-cutting front, although even here the apparent lack of commitment to a single equality act to codify the current hotchpotch of more than 35 statutory enactments on equality issues did seem to smack of putting the organisational cart before the legislative horse.

But more importantly, it seemed obvious to the DRC that there was a serious risk that so much of the progress made in the previous decade on disability rights – progress achieved very largely by disabled people

themselves – was in danger of being discounted, the distinctiveness of that legacy lost amidst the rush to embrace a brave new world of mainstreaming, matrix management and cross-cutting initiatives. Besides, the DDA had not even been fully implemented (and still hasn't), the DRC was still in its infancy, and the legislative and policy agenda on disability was daunting. The timing could hardly have been worse. Expressly asked in the Green Paper what it thought about the proposed structures for the new set-up, the DRC in effect said 'not much', and outlined a federal model that aimed to get the best of both worlds: a cross-cutting and mainstreaming umbrella, beneath which there would flourish dedicated and expert business units of strand-specific executive committees and operational teams to ensure effective strand-specific delivery on the ground. The CRE appeared to propose something quite similar with its plan for what it originally called 'variable geometry'.

But was the DRC really justified in getting so worked up about it all? Surely in the 21st century the place of disability rights is secure? Surely disabled people can now be confident of a fair crack of the whip on resources and representation? It would be nice to think so, and in a climate of opinion where pessimism is tantamount to treason, and to be utterly clueless is to be 'on a steep learning curve', I am probably at risk of being sent to the Tower for even harbouring the thought that such confidence might be misplaced. But that is precisely the thought that I do indeed harbour and which I will share with you.

I have visited generic equality commissions in several parts of the world. In Northern Ireland the Disability Unit was abolished and disabled people regret that. However, the DRC works closely with the Northern Ireland Equality Commission and we are pleased they have been able to draw on our expertise for Codes of Practice etc In

Australia I was told we were mad to abolish the DRC. In New Zealand, despite an integrated Commission, they have created a separate Mental Health Commission. Malta has retained a Disability Commission.

But to get a real take on what is materially distinctive about disability and why any of this matters, let's cut to the DDA: how does it shape up when compared to the other pieces of legislation in the field?

It is of course tempting to see disability rights as much the same as the earlier generation of race and gender rights contained in the Sex Discrimination Act and in the Race Relations Act of thirty years ago. On that account, disability rights, like rights on gender and race, are essentially a matter of 'simple' equality, of equal treatment, a matter of satisfyingly neat symmetry: if you just treat disabled people the same as everyone else, you are out of the discriminatory woods.

DDA case law (admittedly not always the most obvious place to turn for illumination) helps dispel any such simplistic assumption. The first big Court of Appeal case on the DDA (Clark v Novacold) scotched the notion that simple equivalence or equal treatment is the key to disability rights. Under the DDA at least, equality is, paradoxically, about being treated differently, not the same.

The seminal concept here is the celebrated notion of 'reasonable adjustment'. As we all know, it is the duty of employers (and others with obligations under the DDA) to make reasonable adjustments to their practices, policies and procedures that translate the ideal of equal outcome into effective action. The centrality of the 'reasonable adjustment' provision has recently been spelt out in no uncertain terms in the House of Lords case of Archibald v Fife Council (a case, incidentally, which the DRC funded)

and I'll quote Baroness Hale because she puts it so bluntly, and so authoritatively:

'[In the cases of the SDA and RRA] men and women or black and white, as the case may be, are opposite sides of the same coin. Each is to be treated in the same way. Treating men more favourably than women discriminates against women. Treating women more favourably than men discriminates against men. Pregnancy apart, the differences between the genders are generally regarded as irrelevant. The 1995 Act, however, does not regard the differences between disabled people and others as irrelevant. It does not expect each to be treated in the same way. It expects reasonable adjustments to be made to cater for the special needs of disabled people. It necessarily entails an element of more favourable treatment'.

In other words, in answering the question 'what are disability rights all about', the notion of reasonable adjustment is central. The DDA is not just about equal treatment or even equality of opportunity. It is about doing something positive to achieve equal outcomes.

The importance of that positive accent in which the DDA is enunciated is highlighted by two critical developments that have occurred even since Barbara Roche unveiled her plans in May 2002. First of all, there is the proliferation of public sector equality duties which effectively turn discrimination law on its head, shifting the emphasis from supposed 'victims' and individualised forms of remedial redress to potential perpetrators and collective prevention. We have had the Race Relations Amendment Act for several years, with its public sector duty on race as a response to the Stephen Lawrence report. Something similar on disability came into force last December and on gender just a few weeks ago. It can only be a matter of time before the scope is extended even further in

response to the Government's much-delayed Discrimination Law Review, no doubt as an integral part of any Single Equality Act initiative.

Secondly, there is the rather late, some would say reluctant, inclusion of human rights within the proposed CEHR domain, the promotion and protection of a new 'human rights culture' emerging as an important 'pillar' of the new institution. The precise theoretical linkage between equality and human rights is contentious, but one example of what it means in practice can be gleaned from those human rights cases which touch upon disability rights, cases heard in Strasbourg and since the Human Rights Act came into force in October 2000 in this country too, cases about the participation of disabled people in social and cultural life, about the provision of health and care services, about equality and human rights as they touch upon matters quite literally of life and death for disabled people. What is striking about these cases is the way they articulate what commentators have called the 'third wave' of human rights thinking: not so much the 'negative liberty' enshrined in the individualistic eighteenth-century first wave or even the more communitarian second wave associated with the 1948 Universal Declaration of Human Rights, but instead the ECHR's emphasis on the participatory and positive duties imposed by Article 8 (the right to private and family life) and Article 3 (the right to life itself), duties which ensure that disabled citizens are not prevented from developing their own personalities, from developing social relations and from engaging in society more generally as equal citizens. The point was well put by the judge (Mr Justice Munby) in the recent East Sussex case on manual handling regulations in which the DRC intervened. In addition to emphasising the centrality of the concept of 'human dignity' to the ECHR, he remarked that

'the other important concept embraced in the 'physical and psychological integrity' protected by Article 8 is the right of the disabled to participate in the life of the community...This is matched by the positive obligation of the State to take appropriate measures designed to ensure to the greatest extent feasible that a disabled person is not 'so circumscribed and so isolated as to be deprived of the possibility of developing his personality'.

What we have here then is a sort of seamless coherence in the positive approach to equality and human rights realised in the reasonable adjustment provisions of the DDA, in the emerging popularity of the positive public sector duty as a legislative device, and in the broad conception of human rights increasingly adopted by the courts when considering the situation of disabled people.

Why does any of this matter? Is it just a question of special pleading on the part of the DRC, an expression of precisely the sort of identity politics the CEHR vision is intended to counter? In fact there is much more to it than that. What is at stake is more than just the bringing to fruition of the disability rights agenda as an end in itself (important though that is) but instead the nurturing of the disability rights adventure as a new way forward on equality and human rights strategies and so as a model for rights talk and practice more generally.

What might that mean for the CEHR? I am suggesting that it puts at a premium the nurturing of the disability rights agenda, to ensure that those new rights are properly embedded, the connections made, the lessons disseminated. The primary vehicle for achieving that end must be a properly resourced and respected Disability Committee, of the sort enshrined in the Equality Act itself. As was clear at the time from the strong lead of Patricia Hewitt, when Secretary of State for Trade and Industry, and from the narrative contained in the Government's own

White Paper and its response to the consultation on it, the Committee was put in statute precisely to ensure, beyond any doubt and without being potential prey to the ambitions of 'here today gone tomorrow' adventurers, that the CEHR is in a position to respond effectively to the distinctiveness of disability, albeit without that strand-specific perspective detracting from the ability of the CEHR to deliver on its cross-strand equality and human rights remit. That ambition is reflected in the legislation: it gives wide delegated powers to the Committee, and even when the CEHR opts for cross-strand delivery it must consult the Committee formally on the cross-strand proposals to ensure that disability is properly covered before the proposals are put into effect.

In short, the position is as I described it when I launched the DRC's new Disability Agenda earlier this year: the DRC fought hard for a dedicated Disability Committee with executive powers, not to keep disability outside the CEHR's main business but rather to make sure that disability can never be left out.

In general, it should of course be anticipated that an effective Committee will in fact contribute significantly to the cross-strand aspirations of the CEHR. To that extent, the work of the Committee, far from being at odds with the overall ambitions of the CEHR, will be integral to them, wherever possible reinforcing and even shaping the agreed 'direction of travel' for the CEHR as a whole. Social policy is a case in point. The DRC's Disability Agenda, in a way which is strikingly compatible with the Equalities Review, attempts to make the connections between disability policy and social policy more generally, especially as it affects other equality strands or disadvantaged groups within the community. Its 'central proposition' is that 'a sustainable future for Britain demands levels of prosperity and productivity that can only be achieved if everyone is empowered to play an

active part'. It is an agenda for 'all those who live in poverty, who have little control or choice in their lives, who are victims of abuse or live in fear, who needlessly suffer poor health and die prematurely, whose life chances are constrained by poor educational opportunities, who live in poor housing, and who never get the chance to show what they can do'. Above all, it expresses the belief that 'when disabled people contribute to families, communities and wider society, everyone benefits'; and it does so in the expectation that it can help the CEHR establish an influential role at the centre of British life and thereby create a society 'where all disabled people can participate fully as equal citizens'.

The overall vision must be one of a society in which everyone (disabled and non-disabled alike) can flourish and participate fully as equal citizens. That vision is set against a context of emerging social transformation: globalization, demographic change, the creation of a knowledge-based economy, advances in information and communication technology, public sector reform and new challenges to long-held beliefs about identity and social cohesion. That intensity of social change invites the development of new strategies to achieve equality and a meaningful human rights culture.

Such a vision does not, of course, exclude realistic recognition of the ways in which disability equality entails distinctive priorities, for example, accessible environments, 'life and death' decisions, SEN, mental ill-health (and the distinctive perceptions of the world and the self that can be associated with it). That distinctiveness is after all consistent with the analysis contained in the Equalities Review, with its emphasis on the differential experience of specific groups, including disabled people, who at several stages of the life journey are among the most disadvantaged.

In the case of disability rights, the participatory model of equality is trumps. It is a human rights model, indeed a very 'human' model: it assumes shared values embodied in the keywords 'dignity', 'respect', relative 'autonomy' and 'proportionality'; it is not comparative; and it presupposes an irreducible base of individual worth as an instrument of personal and collective well-being; above all it takes a positive view of 'common humanity', and gives primacy to shared and stable characteristics, to the unavoidable human propensity to interdependence.

When seen in that light, the situation of disabled people is quite simply the paradigm of all human experience and of the more general obstacles to fulfilment and well-being. The strategies for overcoming those obstacles (legal, political, cultural) will therefore unavoidably resonate in the experience of anyone who endures human frailty, disappointment, cruelty and exclusion. A vision for disability rights is quite simply a vision for equality and human rights that transcends 'strand' or other parochial forms of identity.

From that broad vision, there emerge four key policy priorities:

First, independent living: in particular, building reform, culture change and investment in social care; accessible, decent housing and adaptations; support for families with disabled children; and a more accessible environment

Secondly, personal security and belonging: in particular, recognising violence in care relationships as domestic violence; taking proactive measures to prevent hate crime and hostility, and ensuring an effective criminal justice response; taking action to promote good relations, especially through better interaction; and tackling 'malevolent benevolence', the lingering traces of an outmoded medical and

social welfare response to the disadvantage faced by disabled people

Thirdly, economic participation and well-being: in particular, seeking engagement with welfare reform and development of employment programmes; widening training and skills development opportunities; ensuring affordable accessible childcare for disabled children; achieving a universal right to flexible working

Fourthly, equal access and opportunity: in particular, achieving an effective single equality act; promoting involvement and democratic participation; ensuring effective data collection by government and other public bodies; implementing Secretary of State DED duties in 2008; implementing all DRC Health, Fitness Standards and Website FI recommendations; and influencing developments in relation to education, health, housing and local government.

These priorities represent a first response to the challenge of bridging the equality gap, of making real the aspirations of Trevor Phillip's recently published Equalities Review, and of achieving resonance over time for the CEHR as a whole. But they will not bear fruit unless the CEHR's primary stakeholders, those who experience systemic disadvantage, are engaged by the CEHR and its emerging agenda. The ethos of the disability movement is captured by the slogan 'nothing about us without us'. The DRC has worked hard to ensure that disabled people, as its primary stakeholders, are directly involved in shaping its work. The DRC has also been mindful of its other stakeholders, whether business, government, voluntary sector or media. To keep that momentum going, it will be vital for the CEHR to keep on consulting and involving disabled people in the development of medium and long-term strategies; to keep on encouraging advisory groups comprising some of those most marginalised (e.g. those with learning disabilities, those with mental health difficulties); to keep on reaching

out to those who might be suspicious of disability (and indeed other) rights, especially employers and service providers who are inclined to see equality and human rights as the imposition of an expensive layer of red tape; and to keep on ensuring that all communication (and indeed all services) are accessible to everyone, including disabled people, and that materials are produced in a variety of languages and formats (large print, Braille, EasyRead, on tape etc) as a matter of course.

The DDA has been hard won. Many of its provisions, especially those incorporated in the DDA 2005, have not yet been tested, let alone embedded (e.g. goods and services, public functions, housing, education and transport). The distinctiveness of the DDA entails that guardianship of the legislation should be a priority for the Committee, and indeed for the CEHR. The challenge is to use its 'positive accent' to reinforce and embed the policy priorities by providing ammunition in the way of news stories and empirical case studies, and by ensuring that the law remains fresh and emancipative not stale and confining. In practice, this means devising a legal strategy that will enable the effective, sparing and purposeful use of legal powers to reinforce the overall objectives of the Committee (and of the CEHR); giving priority to the funding of cases that are not just about employment; producing and keeping under review statutory and non-statutory guidance to business and public sector providers in these areas; securing 'agreements in lieu of enforcement' that fall within these sectors; monitoring the development of the DDA and the jurisprudence associated with it (i.e. being the repository of expertise on how the DDA is going at grass roots level and periodically recommending law reform); ensuring that conciliation services are used effectively by the CEHR to bring about organisational and sectoral change within the context of Parts 3, 4 and 5 DDA (Part 2 conciliation residing with ACAS and being susceptible to influence but not direct

control); and ensuring that the DED is enforced effectively and strategically (i.e. making sure that its success is measured by impact and outcomes not bureaucratic compliance)

And yet I find many questions about the CEHR keep entering my mind. Will the Disability Committee be supported? The Act says it should be allocated adequate resources. Will it be? Will the CEHR be bold enough to serve and involve disabled people, as the DRC has done? Will the CEHR be wise enough to have a big vision and do big things while also appreciating the need to support particular groups with particular needs, such as disabled people? I don't yet feel confident in answering affirmatively. I hope one day I shall be able to do so.

These approaches will be necessary on disability, but they will further the interests of others too. There is much talk these days of 'the light touch' approach to regulation and no doubt such an approach will quite properly underpin the CEHR's work. If that light touch is not all too rapidly to make the CEHR a soft touch, we must finish the job on disability rights, and finish it in such a way that not just disabled people, but indeed all people, disabled or not, can reap the considerable rewards that lie uniquely in that direction. Anything else would be to squander a once in a lifetime opportunity for the CEHR and for the hugely diverse population it must seek to serve.

THE END

Keywords: Commission for Equality & Human Rights;  
Disability Rights; Disabled people

## Reflections on the DH-DRC Partnership Framework and future challenges and opportunities

**Keynote address at DH-DRC Partnership Forum, London, 28th March 2007**

Gerry Zarb, DRC

### Achievements so far

The Framework identified key priority areas for partnership working between DH and DRC and set out joint action to improve the rights, independence, choice and inclusion of disabled people through ongoing development of the health and social care system.

Quite a lot has been achieved, especially on practice issues. Some of the key outputs have been:

- Joint guidance for DH policy makers (Promoting disability equality in policy making to support national priorities for health and social care), incorporating a protocol for early consultation with DRC on policy proposals of particular significance to disabled people, issued in April 2005.

- Publication of a series of joint DH/DRC guides for Acute Trusts and Primary Care Trusts on the DDA and how to make a difference to the experience of disabled people using health services.

- Development of plans for a disability equality training strategy for the NHS workforce.

- Joint working to build on the recommendations from DRC's Formal Investigation into primary health care for people with learning disabilities and mental health problems.

- Liaison between DH and DRC on production of the Department's Disability and Single Equality Schemes and guidance for public authorities on how to effectively involve disabled people in order

to comply with the forthcoming statutory duty to promote equality for disabled people.

Production of a protocol with the Healthcare Commission for ongoing communication and liaison.

Commissioned an independent evaluation of the impact of the “You can make a difference” guidance issued to NHS organisations to test the effectiveness of the communications strategy and the recommended practice models.

Joint work between DRC, DH and NHS Employers to develop and promote good practice guidance for NHS organisations on disability monitoring in their role as employers.

The Framework has perhaps been less successful at the strategic level in terms of high level influencing of health and social care policy. Some of the things we haven't done or haven't completed include:

DRC auditing of DH's communications policy against disability equality requirements – mainly because there hasn't been a communications policy to audit.

DH supporting DRC in developing links with the Expert Patient Programme and Information for Choice to ensure that disability equality and access issues are mainstreamed into these initiatives.

DH, the Healthcare Commission and CSCI working with the DRC to develop tools and guidance to support the inspection of performance on disability equality and compliance with the statutory duty to promote equality for disabled people – although work on this has got going more recently.

DH and DRC working together to embed disability equality considerations in initiatives to promote

health, e.g. those flowing from the public health white paper, Choosing Health. DH and DRC working in partnership to develop and steer a sustained programme of action to communicate disability equality messages to DH policy makers. This remains an important challenge for the future however.

## **Future challenges and opportunities**

### **Tackling health inequalities**

Governments cannot meet targets to reduce premature death or reduce health inequalities without focusing on groups with the poorest health. For socially excluded groups, poor health makes it even harder to work or participate in communities; and for Britain as a whole there are potentially avoidable health and welfare costs.

Amongst those missing out on good health are disabled people - not just in relation to their primary impairment or long-term health condition but because social deprivation, unequal access to health services and other factors put them at greater risk of illnesses that in many cases could be prevented.

The DRC formal investigation, for example, found that people with learning disabilities and/or mental health problems were more likely than other citizens to experience most killer diseases and risk factors, including heart disease, stroke, respiratory illness, diabetes, some cancers, smoking and obesity. They became ill younger and died faster. Potentially avoidable ill health creates additional barriers to achieving independence and to participation.

The DRC welcomes DH's recent response to the FI – we are still looking at this and will give DH a considered assessment shortly.

We particularly welcome the establishment of a working group to take forward planned activities and will do as much as we can to help make this work.

We also welcome the production of an action plan with associated timelines. We will however want to try to make sure that some of the planned actions are more closely aligned with specific recommendations from the FI.

We particularly welcome the emphasis on the potential role of local commissioning to ensure that targeted actions are developed at the coal face. The DH's new Commissioning Framework offers a real opportunity to tackle directly some of the barriers to healthcare identified in the FI – so we hope that the opportunity will be grasped with both hands.

The DRC is very disappointed however that DH do not accept the validity or benefit of breaking down PSA targets by disability groups - especially as much of the data could be made available from existing records. We still firmly believe that health inequalities will not be finally consigned to history unless and until this vital step is taken.

The Healthcare Commission have also recently highlighted the issue. In their Count me in report published earlier this month they note that:

“The quality of data available is an important issue. High quality data is essential for monitoring and improving the access of patients to healthcare, the quality of care they receive and the outcomes of that care. This applies to all patients with mental health problems and learning disabilities, including those from black and minority ethnic groups. .... Currently, the recording of disability, including learning disability, is not a requirement in the data routinely collected by the Department of Health. We ask the Department of Health and the Health and Social

Care Information Centre to consider the inclusion of information about disabilities in patients' records.”

So now the Department is going to have two Commissions nagging them over this issue instead of just the one!!

### **Promoting Independence, well-being and participation**

As I have said, the recently published Commissioning Framework for Health and Well-being has the potential to make a real difference to disabled people. As Patricia Hewitt states in the introduction to the framework:

“Our health service is still too focused on commissioning for volume and price, rather than for quality and outcomes. Too much long-term care is provided in institutional settings. Health inequalities still exist. There is too much of a focus on treating illness rather than preventing it. There are too few providers, and we need to do more to incentivise innovation and join up services. Excluding elective care, individual choice for many patients remains limited and we need to strengthen local voice.”

This is a very accurate analysis of where we are and the challenge we face. It also highlights the importance of developing a new and more coherent approach to the relationship between health and social care.

It's impossible to underestimate that particular challenge and it will take more than a new commissioning framework - although that is definitely a welcome step in the right direction. For example, while we have had provision for pooled budgets since 1999 these have never been widely embraced and more recently pressures on NHS budgets have seen PCTs withdrawing from some of the joint arrangements that had been developed.

## **Promoting equality and human rights**

Looking beyond the current partnership framework, we need to focus now on influencing priorities for the CEHR.

The recent history of how people with learning disabilities fare in the health care system highlights that there are major problems here. Mencap have suggested that this amounts to nothing less than institutional discrimination.

I doubt the Department would accept that but there is clearly no doubt that awareness and understanding of the needs of people with LD falls well short of what's needed and what is acceptable. DEAL will help but needs all stakeholders to take up the challenge and there needs to be a real concerted effort to roll out a national education and learning strategy.

More generally, the DED also provides an important and necessary tool for monitoring progress on improving access to healthcare for all disabled people and – in particular – for ensuring that PCTs are held to account for implementing the objectives set out in the new commissioning framework. DRC will be working with the Healthcare Commission and others to make a start on this scrutiny process in the time we have remaining and will be reconvening the FI Inquiry Panel later this year to review progress and make recommendations for further action by CEHR after we have gone.

Finally, the issue of national monitoring and targeted action within national programmes like Spearhead that I talked about earlier will also need to be revisited and that will definitely be near the top of the list of our recommendations for CEHR's forward agenda.

The challenge of ensuring high quality health and social care for all is set to grow as Britain's population ages.

Although there are likely to be improvements in the health and well-being of older people, the likelihood of impairment and poor health increases with age. More disabled children and young people are also living longer with complex conditions. This requires specific focus if we are to get to the bottom of the barriers that disabled people face and make sure that equitable outcomes are achieved.

Keywords: Disabled people; Health care: Health inequalities: Social care

## **Speech by Sir Bert Massie 27 February 2007 Disabled people, personal security and the criminal justice system**

Speech delivered by Sir Bert Massie, Chairman Disability Rights Commission to mark launch of the Crown Prosecution Service policy on disability hate crime 27th February 2007

### **Introduction**

Firstly let me say I'm delighted to be here.

Delighted because of what is being marked today.

Delighted because this marks another critical step on the journey towards equality for our disabled citizens.

And delighted because it is rare that I get to officiate a film premier....

The film you are about to see, which the DRC commissioned, will be shown in cinema's across the country next month to highlight the daily harassment many disabled people - and in particular people with a learning disability - experience in their everyday lives.

It's called 'Nice Day' and here it is: (the film will be available on the DRC website soon)

I wanted to begin with our film today to remind us all why we are here and why the policy the Crown Prosecution Service is launching today is so critical:

Because it is our collective duty to ensure that nobody should lead their life in a constant state of insecurity, stress and fear.

Because we believe that everyone has an equal right to expect to be protected and offered fair redress by our criminal justice system.

And because we recognise that to date the Criminal Justice System has not uniformly achieved these goals with respect to many disabled people.

In the short time I have today I want to briefly expand on these points and to position today's development within a wider framework of action I believe is required to improve the personal security of disabled people.

Acknowledging progress

But first, it would be remiss of me not to acknowledge all the progress we are making.

Disabled people's rights to protection from harm have begun to be secured - for example the special measures provision of Youth Justice and Criminal Evidence Act 1999 and the Protection of Vulnerable Adults (POVA) scheme.

From last December, the Disability Equality Duty has required public bodies to take positive action to address inequality, promote positive attitudes and eliminate harassment and the Commission for Equality and Human Rights has duties to act to eliminate hate crime against disabled people.

Innovative approaches are making a real difference to people's lives in certain parts of the country.

People in Partnership - a joint venture between organisations like People First and the Police in Hertfordshire - has produced a fantastic resource for people with learning difficulties to know what to do when they come up against verbal abuse and harassment.

In Preston, disabled people are to get a dedicated Police Community Support Officer to help reduce crime and improve confidence.

The DRC and the Crown Prosecution Service are working together to help promote the CPS's 'Witness Profiling' initiative, the aim of which is to give those with a learning disability equal access to justice. This is achieved by support being offered to witnesses to enable them to give evidence in criminal proceedings, resulting in justice being done in individual cases where, previously, prosecutions may not have been brought.

Important today, of course, is Section 146 of the Criminal Justice Act 2003, enacted in April 2005, which means that in England and Wales there is legal recognition of hate crime against disabled people.

Unfortunately, despite the issue of hate crimes against disabled people being first raised in Scotland, disabled people north of the border still have no equivalent protection in law, or recognition of the harm that it causes as those in England and Wales.

We are now in the bizarre situation that if were to be harassed because I am disabled in Devon I would have redress, but if the same thing happened when I was on holiday in Dumfries I would not. Hopefully that anomaly will be dealt with soon.

Here though we now have some powerful tools to work with and some good ideas to roll out across the country.

And it is critical that we use them.

Trivial and inevitable?

Disabled people's experience of hostility stretches across a wide continuum – from opportunism, exploitation of

perceived vulnerability, to neglect, bullying, abuse, violence and murder.

A disabled person may get mugged as the perpetrator exploits a perceived advantage;

A disabled child may get bullied because they are seen as different.

A person may be ridiculed because their impairment-related behaviour makes them stand out and is seen as 'funny'.

The language which stigmatises disabled people and people with mental health conditions – 'mong', 'spaz', 'nutter', 'wacko' - is common and accepted parlance throughout our society today.

Two men taunt a man with learning difficulties and then push him into a lake at a shopping centre in Essex. He drowns. During sentencing the Judge remarks on how others at the scene had managed to 'restrain themselves' by only taking part in the taunting and not the drowning.

Often this hostile behaviour has been ignored or dismissed as trivial by those institutions that we look to provide us with protection.

Tragically it is often accepted as inevitable by disabled people.

These life experiences are not trivial.

Nor in my view are they inevitable.

They symbolise disabled people's unequal status in our society and stand in the way of progress towards equality.

That is why proposals for tackling these issues are at the heart of the Disability Agenda which the DRC launched earlier this month.

Because to be and feel unsafe for reasons related to our personal character is disempowering.

It utterly disrupts our lives.

It means we cannot do with confidence the things we need or want to do like hold down a job or go for a night out

It attacks our sense of belonging in society

It affects our physical and mental well-being.

Personal security is a human right.

Our relative experience of it an issue of equality.

'Vulnerable' and 'hard to reach'

I want to call today for us to scrap two terms which I believe act against progress.

Firstly I want to ask you all to stop referring to people as 'vulnerable', and secondly, I want you all to refrain from ever using the term 'hard to reach'.

People are made vulnerable by two things: being labelled vulnerable, and be left in vulnerable situations.

I am by no means an expert on crime, but I fail to see how we protect older and disabled people by labelling them vulnerable.

It is tantamount to labelling them 'easy prey'.

It actually makes people more likely to be targeted, and it shifts the focus away from the problem.

It suggests that their comparative lack of safety is somehow an intrinsic quality, rather than a fault-line in our society or institutions.

We will not move forward until we accept that people are not themselves vulnerable, but that they find themselves in vulnerable situations when we fail to address their relative lack of safety.

And our failure to have done so does not make them 'hard to reach'.

It means we have failed to reach them.

It means we are not delivering human rights and we have yet to extend equality to all.

And by accepting this account we can begin to identify far more clearly what the problems are and what we need to do to address them.

Personal security at the heart of promoting equality and human rights

From our conversations with people working in the Criminal Justice System, there is indeed an open admission and seeming consensus that equal access to justice for disabled people has been accorded low priority and investment.

A new poll by Ipsos/MORI commissioned by the DRC and published today finds that across England and Wales, a third of all disabled people say they 'don't feel safe from harm when out and about in their local area' rising to 37% for women and 46% for those with mental health problems

And a quarter say its difficult, or very difficult, to use the police services in their area.

It is clear then that we need investment, reform and culture change across the system and at every level to offer redress, protection and to prevent such crimes happening in the first place.

Disabled people need equal access to justice - from the Police through to the Courts.

And the wider community needs to know both this and the intolerance of the criminal justice system to crimes perpetrated against them.

And this includes people living in situations where the criminal justice system rarely treads.

Two recent cases of people being attacked and abused in NHS institutions have received considerable amounts of news coverage.

I strongly suspect this is just the tip of the iceberg.

Yet crimes such as rape, theft and assault, including those carried out by staff, are being dealt with as workplace management issues and without the involvement of the police.

The perpetrators are being sent for retraining rather than to jail. At worst they have lost their job.

And what had they to fear? A bad inspection report?

They were able to commit such criminal acts with impunity because the people living in those institutions were left in such a vulnerable, powerless situation.

We believed they were being 'cared for', and so could come to no harm.

Are the citizens who live in these institutions, or who rely on services and support to live their lives in the community not part of the responsibility of our criminal justice system?

Why weren't the Police involved immediately there was suspicion of such behaviour?

Does community policing extend to people in such institutions?

If it doesn't then it is failing to protect our citizens.

These appalling attacks on disabled people's human rights, which are often minimised by being termed 'abuse', are crimes, possibly hate crimes, and should be dealt with as such by the Criminal Justice System.

So I lay down a challenge today to the Police, the relevant statutory bodies including the Crown Prosecution Service:

Let us bring this shameful situation to an end by rooting out and prosecuting the perpetrators of such crime using the powers we now have if appropriate.

And by doing so let's send a signal that as a country we will not accept or turn a blind eye to such behaviour and that anyone engaging in it will pay a heavy price.

And let us look at new ways to offer protection and redress to those who require the assistance of others to live their daily lives inside or outside institutions.

In doing so I believe we will help begin a transformation in society's attitudes towards disabled people, and help tackle the sort of experiences shown in the film, which, whilst not necessarily within the scope of what we might call 'hate crime' are clearly on the same continuum and which stand in the way of the society we are seeking to create.

As today's policy statement notes, achieving these goals requires a joined up and concerted effort across the Criminal Justice System and beyond.

But do not under-estimate how important a milestone this report is.

This policy statement sets out a challenge – a challenge to services and agencies that have failed disabled people in the past to ensure that there is now equal access to justice and that crimes committed against people because they are disabled no longer go unchecked.

I welcome it whole heartedly.

Thank you

Keywords: Criminal justice system; Disabled people; Hate crime

## Creating an alternative future

### **Speech by Bert Massie at launch of DRC's Disability Agenda 14th February 2007**

Good morning and I should like to begin by thanking all of you in Cardiff, Edinburgh and London for coming along today.

Just over a year ago I gave a speech across the road here in London at Westminster Central Hall where I set out the Disability Rights Commission's priorities for action for the Agenda we are launching today.

The central proposition of my speech that day was that there remained a complacent attitude – what I called a lazy fatalism – in society, in the media, amongst our politicians – about the deep and persistent social and economic disadvantage faced by our disabled citizens.

It was quite a bold proposition given all the progress we have made.

Britain has got significantly better for many disabled people over the last decade.

It is easy to forget just how recently there was no such concept 'disability rights'.

As recently as 1994 - the year Tony Blair became leader of the Labour Party, Nelson Mandela was elected as President of South Africa, and Hugh Grant attended 4 weddings and funeral - it remained perfectly legal to discriminate against disabled people.

By the end of 2006 it was against the law to discriminate against disabled people in virtually every area of life.

And not only that - new duties now require the public sector to take positive steps to actively promote our equality.

And of course at the mid-point of this decade of change came the DRC.

I am honoured to have had the opportunity to lead the DRC over the last seven years.

Perhaps one should be humble on such occasions, but I'm going to buck the trend.

I believe were it not for the DRC, in partnership I hasten to add with many of you here today we would not have witnessed this transformation and I am proud of what we have achieved.

It wasn't that long ago that I was severely restricted if I wanted to go out to dinner, the theatre, or even shopping.

I, and many like me, were quite literally shut out.

Imagine what that does to your sense of belonging....

Now I and millions of others today and in the future can plan life with so much more confidence, enjoy so much more of what life has to offer and live so much more of our lives alongside everybody else as our built environment, transport system, public spaces and services finally begin to dismantle the barriers.

In our information age, to have no access to information can frequently mean to have little access to life itself.

Yet it is only in the last few years that people have been able to demand the information they need to live their lives in a format they can access and understand.

So has begun the process of empowering millions of our citizens to exert greater control over their own lives, achieve independence and participate fully.

Many young people coming to the end of their school years will worry whether their exam results will help them to progress to college and university.

Before 2002 disabled school leavers faced the additional worry that whatever their achievements it remained perfectly legal for colleges and universities to discriminate against them and refuse them entry.

And many did.

Since 2002 our entire education system has been covered by the Disability Discrimination Act.

Massive strides have been made to open up education opportunities to disabled pupils and students, which in turn opens up many more of life's opportunities to them.

From October 2004 disabled people could anticipate physical access to train stations, but unfortunately had no rights to get on the trains.

Good for disabled trainspotters; not so good for anyone wanting to make a journey.

In December our transport system finally came under the full coverage of the DDA.

It will be a while before the whole transport system is physically accessible, but progress is considerable.

Here in London every single bus is wheelchair accessible.

At last disabled Londoners are on the move, and hopefully the rest of Britain will take London's lead and make travel

accessible well ahead of the distant deadlines of 2017 for buses and 2020 for trains.

In December last year the Scottish Parliament launched the findings of its Disability Inquiry, and I am proud of the central role DRC Scotland played in that process as we developed the Disability Agenda.

The Inquiry reached cross party consensus on the steps that need to be taken to secure disabled people's participation and opportunities to flourish in employment, education and public life.

In the second part of this morning's proceedings, those of you at Dynamic Earth will have the chance to judge just how dynamic the different parties who will be competing for power in this May's elections are on these issues.

In Wales, the DRC working in partnership with the Wales Assembly Government and others, delivered the world's first congress of young disabled people.

This resulted in the Assembly's Equality of Opportunity Committee conducting a two year investigation into services.

Panels of young disabled people joined politicians in questioning witnesses - a truly innovative and inclusive way of bringing young people into politics.

These are just some of our achievements.

All you need do is look around you and it is clear life has moved on.

But not for everyone.

In some cases things have got worse.

And it is clear that without action now, the challenges of the coming years will create new patterns of inequality and disadvantage which Britain is ill-able to afford.

Today is an opportunity to celebrate all that we have achieved, but more importantly it is a day to come together and acknowledge all that is left for us to achieve.

Let there be no room for complacency....

....when a disabled mother tells us how overjoyed she is of her daughter's impending 8th birthday.

Why?

Because from the age of 8 social services will recognise her daughter as a carer with rights and might occasionally relieve her of her responsibilities.

Is this really acceptable for a 21st Century Welfare State?  
A Welfare State propped up by infants?

..... or when a working mother of a disabled child is described by her employer as 'lazy' for wanting to take time off to care for her child, and accused of using her child to manipulate her working conditions.

Let there be no room for complacency....

.....when many families with disabilities say they are at breaking point.

With public services tearing them apart, not holding them together, how long will it be before a British Ashley X?

Let there be no room for complacency...

... when adults with a learning disability living in NHS institutions are attacked and abused and the staff responsible are sent for training rather than to jail

Let there be no room for complacency....

....when almost one in three young disabled people are outside any form of employment, education or training and a quarter feel they can do nothing to change their lives

....when 80% of people with mental health problems are out of work

and let there be no room for complacency....

..when the first words to a grieving mother from a GP attending to the sudden death of her daughter who happens to have Down's syndrome are....

.....'well, I suppose it's for the best isn't it?'

If such things are allowed to go on, then I stand by my words - that this represents a lazy fatalism - unparalleled in my view - about the essential value, worth, well-being and life chances of millions of our citizens.

The positive developments of the last decade have undoubtedly helped to create a more open road for disabled people to be and do the things they want to in life.

But at the same time the public services, resources and support many require to take up these new opportunities have either not materialised, remain at odds with these goals or have gone into decline because of rationing.

Many disabled people have been invited to look up to the stars...only to find the ground opening up beneath them.

And this is why, just as the DRC has offered leadership during the last decade, so with the launch of today's Disability Agenda we are seeking to offer leadership for the next.

The Disability Agenda is about completing the job we started - achieving a society in which all disabled people can participate fully as equal citizens.

It offers direction for tackling the issues I have highlighted and many more through reform, investment and culture change across our public services....

....Public services founded upon the principles of promoting dignity and respect and delivering the means for people to participate, achieve their potential and secure a healthy and prosperous life.

And importantly, it is also about refreshing our approach to disability equality, so that it is fit for a new era of leadership from the Commission for Equality and Human Rights

It is great to be joined on this platform today by my friends Trevor Phillips, the Chair of the new body and Dame Jane Campbell both a DRC and CEHR Commissioner who will lead its disability committee.

The Disability Agenda is not just about disabled people.

It is about all those who experience disadvantage because we fail to put in place the means by which disabled people can achieve equality.

Let me give you some real life examples:

There are one in three children living in poverty who have a disabled parent – amongst Bangladeshi families with disabled parents the children face an 83% risk of growing up in poverty  
The 6 million unpaid carers – mostly women - often out of work, impoverished, in poor health and likely to experience poverty in retirement

The families of disabled children, many at breaking point

The baby boomers expecting to enjoy their retirement in their own home, blissfully ignorant of the fact that social services will not be there when they need them, that most of our housing stock remains inaccessible and that the Government refuses to act.

And just as tackling disability equality issues will help deliver equality for others, so also the approach to tackling discrimination and promoting equality is one I believe others can benefit.

We begin from the belief that equal treatment does not deliver equality, because to treat everyone the same way fails to acknowledge our diversity.

To achieve equality, we have to respond to and treat people differently.

For example, in disability rights we have embodied such an approach in legislation in the form of duties to make reasonable adjustments, and I believe we can build on this approach within a single equalities Act.

That is why this is an agenda which will help CEHR achieve its goals overall. If it does not deliver this Agenda, it will fail as an organisation.

Which brings me to my final point today.

Yes, I sometimes worry that there is a complacency which allows these things to go on.

I worry that some may believe that disability rights is a done deal.

But when I consider who is attending this event today in Cardiff, Edinburgh and London, and the sheer numbers of

people who got in touch to say how much they would have liked to be here, and I see not only disability activists but...

...the leaders of organisations including the Equal Opportunities Commission, Carers UK and the Learning and Skills Council

Age organisations, BME groups, and those who have promoted lesbian and gay rights,

People from child poverty groups, think-tanks, the police, human rights campaigners,

Political leaders and many many more who have come together to say:

'this Agenda is a shared agenda...our agenda....'

It is clear to me that such complacency is not one shared by those of you here today and that we share a common mission to sort these things out

And in these changing times – with national elections in Scotland and Wales, local elections across England, a Prime Minister elect and a resurgent opposition, we need together to ensure that all political parties who are serious about victory recognise that this is their agenda too.

With so many marginal seats, the votes of disabled people and their families could be the deciding ones.

So...we have travelled a long way.

But the task is far from over.

In the 6 months remaining of the DRC's life, during my tenure as a Commissioner at CEHR and beyond I look forward to working with you all to turn this agenda into reality.

Together we can create an alternative future.

Thank you

Keywords: Disability policy; Disabled people; Public policy

## **“Extending Horizons: Accessibility to Next Generation Networks”**

Speech by Bert Massie, Conference organised by COST  
219ter, Tuesday, 16 January 2007  
BT Centre, London

Thank you for inviting me here to speak to you today.

There is no doubt that the communication revolution has opened up the world and will continue to do so at a swift rate. By opening up access to information and communications, technology enables us to do things we otherwise could not. When we are discussing e-accessibility, we are not only talking about access to the product or service, we are essentially asking the question “How can we make the world easier to interact with for disabled people?”

At the Disability Rights Commission we recognise how vital communication technology is to delivering the change we want to see for disabled people living in Great Britain today. The Disability Rights Commission wants a society where all disabled people can participate fully as equal citizens. Communications technology has an incredible potential to help us deliver this goal.

For those of you unfamiliar to our history, the Disability Rights Commission was established by Parliament in 2000 as an independent body to promote the equality of disabled people and also to ensure the Disability Discrimination Act is enforced in Great Britain. The Government has provided us with appropriate funding of just over £20 million this year and we have about 200 staff plus outsourced Helpline and Conciliation services.

We also have a range of legal powers we can use to prevent discrimination against disabled people or to seek redress following a case of discrimination. The Disability

Discrimination Act 1995 built on a number of measures designed over the years to remove the obstacles disabled people face in our every day lives. The Act defines disabled people and creates employment and education rights, amongst other measures.

Of relevance to our discussion today is the duty on those in both the private and public sector who provide goods or services, regardless of whether they are paid for or provided free, to ensure that those goods or services are accessible to disabled people. It is unlawful to refuse a service, to charge more, or to offer disabled people a lower standard of service on grounds of their impairment. In addition, reasonable adjustments must be made to ensure disabled people can use the service. The word reasonable is important. The DDA is not about putting people out of business.

Whilst we don't have time today to talk in detail about the work of the DRC, rather appropriately, you can read about us on our web site at [www.drc-gb.org](http://www.drc-gb.org) or just put Disability Rights Commission into a search engine and you will find us.

For many disabled people, new developments in technology have been the ideal tools to deliver greater freedoms and enable them to live independent lives.

Goods and services are increasingly delivered online. The internet has become both the local and global market place. In sales, most high street shops, supermarkets and even specialist outlets have gone online. Similarly, customers can find out about goods and services and buy from each other and from business in all parts of the world. One estimate has suggested that by 2009, 25 per cent of all shopping will be done on the internet. With accessible technology, more disabled people have the opportunity to get what they want delivered to their door,

opening up more and more opportunities for living independently.

Accessible technology and services can also provide greater opportunities for disabled people to play a part in choosing who runs their country and their services, through methods such as online voting. Considering the shameful inaccessibility of far too many polling stations, this can only be a good thing.

Public services are increasingly online too. The targets sets in 2000, to ensure all public services were online by the end of 2005 were very nearly met. The Government has committed to spending 6.8 billion over ten years on upgrading IT in the NHS. The new systems include an online booking system, a centralised medical records system for patients, e-prescriptions and fast computer network links between NHS organisations. The potential for the greater independence that this offers for people with long term health conditions is undeniable.

However, too many disabled people are not benefiting from the opportunities these technologies could give them. A report by the Social Exclusion Unit noted that: “of those in receipt of Disability Living Allowance, 37 per cent have never used a computer”. In our policy paper ‘Changing Britain for Good’, the DRC noted that ICT use is lower among disabled people than other citizens even after accounting for the older age profile.

In a short period of time the World Wide Web, with its global reach and versatility, has had a huge impact on the way we live, work and study. It’s potential for contributing to the delivery of a genuinely inclusive society must be realised to the full. However, to deliver the benefits, this technology needs to be accessible.

Let’s just focus on one issue – website accessibility. The DRC recognised the problems encountered by many

disabled people concerning websites and in March 2003 we decided to conduct a formal investigation into the accessibility of websites undertaken under the leadership of my then fellow Commissioner Michael Burton.

We commissioned City University to conduct the research for us. They examined the home pages of 1000 websites in the private and public sector which were assessed against the WAI guidelines. Fewer than one in five websites conformed to even the lowest priority checkpoints for accessibility. Although many organisations that commission websites claim that they are alert to the needs of disabled people there is scant evidence of this concern being transformed into action.

The people who devised the WAI guidelines readily acknowledged that the checkpoints alone were not a guarantee of usability and that websites should be user tested by disabled people. We therefore established a panel of disabled people in the following impairment groups: blind, partially sighted, dyslexic, physically impaired and hearing impaired.

The panel evaluated 100 websites selected from the original sample of 1000. The results were that 76% of the attempted tasks were completed successfully but, by definition, 24% of the tasks were failed. But this success rate was unequal depending on the panel member's particular impairment. For example, people with physical or hearing impairments succeeded in 85% of the tasks and the rate among people with dyslexia was only 2% lower. Partially sighted people succeeded with 76% of the tasks but this dropped to 53% for blind people.

Our investigation enabled us to identify the problems different groups of people experienced when using websites. Blind people were frustrated by the incompatibility between screen reading software and Web

pages. This meant that assistive technology was unable to detect some links or it proved impossible to highlight text using text-to-speech software. Cluttered and complex page structures created difficulties as did the failure to provide ALT text for images.

Partially sighted users complained of inappropriate use of colours and poor contrast between content and background. They also identified incompatibility between Web pages and accessibility software used, for example, for magnification. Poor layout of pages and confusing and disorientating navigation mechanisms were also difficulties. Predictably graphics and text sizes that were too small were also problems.

Physically impaired users, hearing impaired users and the users with dyslexia, were also disadvantaged by poor navigation mechanisms. The users with dyslexia complained of poor layout and complicated language or terminology on web pages. Adoption of best design practices could resolve many of these problems and make the websites easier for everybody to use.

The DRC concluded that there was a need for best practice guidance. So we worked with the British Standards Institution to produce PAS 78, a publicly available specification on the commissioning of websites.

The BSI specification has drawn together advice from the DRC and other key stakeholders to outline good practice in managing the design of websites that are accessible and usable by disabled people. This specification gives recommendations for the management of the process of, and guidance on, upholding existing W3C guidelines and specifications; and involving disabled people in the development process and using the current software based testing tools that can assist with this. The guidance equips those who are responsible for commissioning and

managing the development of websites the tools and knowledge to ensure their agents deliver genuinely accessible websites rather than merely pay lip service to the ideal. I hope it will be widely used in the public and private sectors alike.

Our investigation demonstrated that most websites are inaccessible to many disabled people and fail to satisfy even the most basic standards for accessibility recommended by the World Wide Web Consortium. It is also clear that compliance with the technical guidelines and the use of automated tests are only the first steps towards accessibility: there can be no substitute for involving disabled people themselves in design and testing, and for ensuring that disabled users have the best advice and information available about how to use assistive technology, as well as the access features provided by Web browsers and computer operating systems.

Organisations that offer goods and services on the Web already have a legal duty to make their sites accessible. It is clear from the investigation that these duties are not being fulfilled.

The situation revealed is unacceptable, but not inevitable. There are already enough examples of good practice to suggest that improvements can readily be made. The Disability Rights Commission, in its quest for a society where all disabled people can participate fully as equal citizens is determined to ensure that this new and powerful technology does not leave disabled people behind.

The World Wide Web, this indispensable tool of modern life, is only an adolescent in age. Whilst in the last ten years it has become universally used, we are already repeating the mistakes we made in relation to the built

environment for many years. Just as so much of the physical world remains inaccessible we are permitting the owners of websites to make the cyber world inaccessible. Yet, as with the physical world, better access for disabled people means better access for all. We cannot rely on Web designers to do the right thing any more than we could rely on architects to design accessible buildings unless the law forces them to do so.

The essence of all this is that while we believe that winning hearts and minds is important we do not rely on it. Discrimination will only be eliminated if there are strong laws and those laws are enforced.

The DRC's work on website accessibility has set the standard. We have identified the issues, investigated them and sought to rectify them through advice and guidance. Now we expect to see results. And where we do not see results we will use the powers we have to prosecute.

The message for national and European wide government is clear; persuasion on its own will fail unless it is supported by law. However, law on its own will not resolve the problem. We need to train web designers on the needs of disabled people, as we have had to train architects. We need to get the message across - accessible design is good design – it benefits everyone.

The 'Design for All' principle, of getting things right from the beginning so that products and services can be used by as many people as possible, is fundamental in this pursuit and I commend the work of the COST 219 Action in pursuing this goal. Across Europe, 'Design for All' is leading the way in creating an awareness of the paramount importance of inclusion of all of the population and thus limiting the necessity of special adaptations.

Accessible technology is a way to break down barriers. It has the potential to open doors for disabled people that

we never thought possible. But all the opportunities will come to nothing if you can't get in the door.

Last year, the need for improved accessibility of the Internet and other information technologies, was the focus of the UN International Day of Disabled People. Introducing the day, Kofi Annan said: "Access to information and communication technologies creates opportunities for all people, perhaps none more so than disabled people, as the development of the Internet and these technologies takes their needs more fully into account, the barriers of prejudice, infrastructure and inaccessible formats need no longer stand in the way of participation".

I want every one of the 10 million disabled people living in Great Britain to be able to participate in these new developments, by accessing not just the technology itself, but all the opportunities that are being delivered through these interfaces. We need to work together to build new systems and technologies that are accessible and inclusive. Therefore I warmly welcome the work of Cost 219 and the aims of this conference in seeking to deliver this goal.

Keywords: Disabled people; website accessibility