

Delivering Effective Policies and Structures on Equalities and Human Rights

Bert Massie

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Presentation by Bert Massie, Chairman, Disability Rights Commission.

Today you will have heard a number of views about the proposed Commission for Equality and Human Rights. My role is to present the perspective of the Disability Rights Commission and of many disabled people and disability organisations. In short, our view is that if the CEHR is established in an appropriate manner with safeguards for disabled people we think it would be better for disabled people and for the wider equality agenda if disability were part of the new organisation rather than separate from it. However, disabled people need to be convinced that it will be able to meet our needs at least as well as the DRC does now. If it can't, questions will be asked about whether the CEHR has anything to offer disabled people and, if the answer is no, it would be unwise to risk the future of disabled people.

This whole project has a sorry history. There was insufficient consultation before the Government originally announced its proposals. It was clear that the then responsible minister, Barbara Roche, had given insufficient thought to how disabled people's needs were different to those of other strands. There was insufficient appreciation of the history of the disabled persons movement and how disabled people had fought for over 40 years to win the right to make our own decisions and

direct our own lives. Disabled people were sick of well meaning but ill-informed do-gooders telling us what was good for us and what we needed. Disabled people adopted the slogan “Nothing about us without us”. It was disabled people who fought for the Disability Discrimination Act and for the creation of the Disability Rights Commission. The legislation requires at least half of the DRC’s commissioners to be disabled.

When the Government published its consultation document Equality and Diversity: Making it happen, it repeated the same mistakes. The preferred model in that document would have ensured that disabled people lost control over the agenda that shapes our lives. “Bring back the do-gooders”, it cried! It is hardly surprising that disabled people were less than enthusiastic.

This debate started with the Hepple Report. He said that equality legislation should be amended so it was consistent. All the strands covered by the European Directive should have similar rights. The strands of religion and belief, age and sexual orientation should have the same access to goods and services as the established strands. There should be a Single Equality Act. I entirely agree and would add that this should include a duty on public bodies to promote equality for all the strands, including gender. When we have done that, according to Hepple, we should consider a single body to promote and enforce the Act. Again, I agree. It should cover human rights. I fully agree and there is a dormant power in current legislation for the DRC to tackle human rights issues for disabled people.

But what is proposed is a promotion and enforcement body that oversees different rights for different groups. It is putting the cart before the horse. As for human rights, it appears the CEHR will only have a power to promote but not enforce them. That steps back from the current

dormant power and seems to imply that all the CEHR will be able to do is talk about human rights. Well, thanks but we can do that now. The CEHR needs power to act and not just talk.

These days we speak of multiple identities. I understand that, but I find myself increasingly attracted to the thought that we all have one identify with many facets to it and we will fulfil many different roles but remain one person. With the proposals before us, let us imagine an elderly disabled Muslim who wants to visit a nightclub but is refused admission. To assert his rights he must forget he is an elderly Muslim but remember he is disabled because that is where he has rights. Of over 8,000 cases of alleged discrimination the DRC has investigated fewer than 20 concerned more aspects of a person's identity than their disability. Of course everyone is a complex person but our evidence is that multiple discrimination is not as great an issue as discrimination based on one aspect of our identity.

One reason for the new body is the belief that an equality commission should protect the new strands. There are many ways of doing this without merging the current commissions and scant regard seems to have been given to them. Five years passed between the Disability Discrimination Act and the creation of the DRC. Disabled people know the futility of rights that cannot be enforced. The need to offer support for the new strands is one of the strongest arguments for the CEHR. However, we must strive to achieve an organisation that does that without undermining the position of disabled people.

Disability is different to other strands.

There is still a huge programme of disability legislation to be implemented. Other equality commissions have been around for over 25 years – the DRC for less than four. It

is no wonder we have much to do. In October the final parts of Part 3 of the DDA come into effect, nine years after the Act was passed. New employment rights come into force on the same date. Education rights inserted into the Act in 2000 will be fully enacted in 2005. Buses will not all be accessible until 2017. A consultation on the date by which all trains should be accessible is currently taking place. It is unlikely that the date will be before 2020 and that is a long time to wait to be able to visit a toilet on a train if you are a wheelchair user.

Parliament is currently considering a new and welcome draft Disability Bill. When passed, as I am sure it will be, it will give disabled people important new rights and fulfils the Government's election manifesto pledge. It will improve the definition of disabled people. It will end the bizarre situation that now exists whereby those operating accessible buses and taxis can refuse disabled people permission to travel. Disabled people are left at the bus stop because drivers will not let them on accessible buses: and it's legal. This Bill is expected to receive Royal Assent before the next general election. We then need to oversee its implementation. It will take us into the time scale of the CEHR and it is imperative they get it right. That means disabled people leading the agenda on disability. Like others, disabled people face ill informed prejudice. Social systems often work against us. But we don't just need to change attitudes we must change the physical structure of the society and the world in which we live. A hotel or pub can discriminate by announcing we will not serve disabled people, or they can put steps at the entrance thus ensuring wheelchair users can't get in. That is also discrimination. Also, disabled people, after many years of battle, have exciting times ahead as new rights come into force both this and next year.

The DRC already has plans for work stretching over 10 years. We need to be sure that this work will continue. We

are, for example, dealing with issues such as the issuing of Do Not Resuscitate Notices being placed at the end of hospital beds containing disabled people. Presumably some doctors think it is better to be dead than disabled. We are considering work on why people with learning disabilities are dying prematurely when treatment could have extended their lives. Discrimination against disabled people is not just a matter of ramps and access: it often concerns life itself.

Sometimes people are well disposed towards disabled people but seek to help us in such a way that they inadvertently harm us. When people put disabled people into residential homes for our own good they deny us the freedom to live in the community.

If the CEHR is to be acceptable to disabled people it must ensure that:

- a) disabled people have a major influence on the issues that affect us;
- b) there is no interruption to the work of the DRC and others to implement effectively the Government's hugely important, once in a lifetime, programme of legislative reform that stretches many years ahead, and
- c) it can deliver the services the DRC offers to disabled people.

The DRC has produced research showing that in other parts of the world a strand based or federal model is efficient and effective. However, some oppose this, preferring a more centralised structure. I do not insist that all strands have their own structure inside the CEHR but the DRC strongly believes that the support of the disability community in this country is dependent on a disability strand. The legislation must require at least one commissioner to be a disabled person. Some argue this

is unnecessary. They are wrong. In Northern Ireland the Equality Commission is organised on the lines of the so-called functional model. It started with one disabled commissioner and now it has none, despite the protests of the Chair. In Great Britain disabled people will not accept a body making decision about us without our participation. Protection must be enshrined in primary legislation.

There must be a disability committee or other structure on which at least half the members are disabled people. The disabled commissioner should chair it. This will deal with aspects of the CEHR's work that are of direct concern to disabled people. Of course it will operate within the broad structure of the CEHR and report to the Commission. It will work closely with other strands, such as race when issuing codes on the public duty to promote equality. And, of course, there are areas where work with other strands would be closer than at other times but is that not what diversity is all about? An equality commission that cannot recognise diversity is surely in for a difficult time. The DRC model is consistent with good corporate governance.

When the DRC was established we consulted many people about the services we should offer. Of course it is necessary to consider strategic issues but it is also necessary to support people here and now while building the Promised Land for tomorrow. Our help-line will this year deal with 120,000 enquiries, about 40% of these will be from employers or those providing services to the public. Our website now receives 80,000 hits a month. Most disabled people are not born disabled they become disabled. Often they need huge amounts of information on their rights and on other issues. Our help-line and website provides an important service. Our caseworkers will investigate up to 2000 cases of alleged discrimination. We resolve many without recourse to legal action. We also fund an independent conciliation service for non-employment cases. Of course, we will also use our legal

powers. Our first formal investigation was into the accessibility of web sites, an issue vital to disabled people.

We must also be expert in disability issues. When changing the environment so disabled people can function within it, it is no use talking in generalities. Precision is critical and that comes from people who live with the issues every day of the week, 24 hours a day.

In recent months the Department of Trade and Industry at all levels has shown growing signs of understanding the concerns of disabled people and of finding way to meet them. That is hugely encouraging and I very much welcome and applaud the effort they are making. Inevitably, they will face opposition from those who fail to understand the importance disabled people place on the issues I have mentioned. However, if the CEHR is to be effective it must meet the needs of disabled people. If it does not, why should disabled people be part of it? There would be some loss if disability was not part of the CEHR but it is unrealistic to expect disabled people to reject the progress of decades to be part of it. There is nothing that I have suggested that would in any way damage or harm other strands. We want to work with them. We want the CEHR to be a success but if it is to be so it must truly welcome diversity and that includes meeting the needs of disabled people.

Bert Massie

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Bert Massie Reflections on the Role of the Judiciary in Enhancing or Restricting the Civil Rights of Disabled People February 2004

I would like to start by thanking you for the honour of being invited to address you this evening. Dr Crossley Evans

was kind enough to send me a list of your previous speakers and I was somewhat daunted to note that I am only the second person to address this Convocation who is neither a peer nor a knight of the realm, or who does not hold a doctorate or a professorial chair. It was a somewhat intimidating list of people but I take some comfort from the fact that that, given some of the stresses in higher education at the moment, the wheelchair in which I am sitting is rather more comfortable than many professorial chairs.

Dr Crossley Evans also, rather rashly I thought, said I could talk about a subject of my own choosing. I shall resist the temptation to talk about my favourite football team. Instead I want to consider the extent to which law can create equality for disabled people. How good is Parliament in passing effective laws and what is the impact of the judiciary in their implementation? The reason why I think this subject has some merit and might be of interest is that I observe with some concern how courts and employment tribunals can undermine or misinterpret what I and others understand to be the will of Parliament. Of course, the judiciary do not see it that way because they use considerable brain power to understand what the politicians meant and what an Act of Parliament actually states.

In the case of much of the civil rights disability legislation I was involved to varying degrees in influencing the drafting and know of the compromises that were reached and why. I am reminded of Bismarck's comment that "If you like laws and sausages you should never watch either one being made". He was, I presume, talking about German sausages and not the great British Banger that was described by Lynn and Jay in the Yes, Prime Minister television series as an "Emulsified High Fat Offal Tube". I have avoided watching sausages being made but not laws.

The main issue I want to discuss this evening is how we can work with the judiciary so they can play an even stronger role in eliminating discrimination against disabled people and minimise the undermining of legislation that took so long to achieve. In doing so, I want to acknowledge the helpful role of the judiciary and of many members of the legal profession who are our close allies. As you might expect a good number do pro bono work, which is rarely acknowledged very widely. Others take their fees and thoroughly deserve them. However, things can and do go wrong. In the United States of America the Americans with Disabilities Act has been weakened by Supreme Court decisions that tightened the definition of disability so that some people who are protected by UK law would not now be protected in the USA.

Before I come to my main theme this evening I think it would be helpful if I painted some of the background scenery. When Angie Debo wrote her books on the native Indians of America she started by looking at the topic from the viewpoint of the native Indians and that gives a very different perspective from that which appears in Hollywood's westerns.

You will all have your own views about disabled people. For some it will be based on personal experience and for others it will be from the image you receive from the media or other sources. However, disabled people have our own perception of our place in the world and it is often a different perception to that held by non-disabled people. There are at least 8.6 million disabled people in this country and it would be foolish to pretend we all see the world through the same spectacles, but there are common strands.

I do not want to explore the history of disabled people because that would take too long. Disability is an intrinsic part of the human condition and only an early death will

prevent most people having a significant impairment at some point in their life. I do not, of course, just refer to those who use wheelchairs, who are a small minority. Think of those who experience one or more episodes of mental illness, or have Alzheimer's disease, epilepsy, learning disabilities or arthritis. Despite significant advances in medicine most disabled people will not be "cured" as many people still put it. Few blind people regain their vision and few deaf people regain their hearing. The common strand that most disabled people share is that we face discrimination because we are disabled. For many disabled people the response of society to our impairment is infinitely more significant than the impairment itself.

Historians and anthropologists might point out that such discrimination is not a universal phenomenon. However, in return I would argue that that merely reinforces the point that it is our social systems that define disabled people, much more so than our impairments. In Britain and in many other countries the approach to disabled people since the Second World War has been two pronged. On the one hand, society provides support through health and social services. On the other hand, society expects disabled people to try to adjust to society.

In the 1970's sociologists such as Vic Finkelstein began to argue that the difficulties disabled people faced were not due so much to their impairments as to the failure of society to make provision to meet their needs. This thinking led to what has become known as the social model of disability. There has been much written on it but the essence is that we should remove the architectural, cultural and social barriers that prevent disabled people from playing a full role in the community. This represents a major shift in the approach society should have towards disabled people. Rather than expecting disabled people to conform to a hostile society, disabled people argue that

society should change to meet our needs. This is familiar territory for sociologists.

The Committee on Restrictions Against Disabled People (CORAD), chaired by Sir Peter Large, that reported in 1981 was the first significant Government report that defined discrimination against disabled people as being more than non-disabled people being beastly to disabled people. It was as much about inaccessible buses, trains and buildings. There is in principle no difference to disabled people between being told that they can not enter a building because the building owner does not like disabled people, as has happened to people with learning disabilities, and being excluded because of fire regulations or a flight of steps. Discrimination against disabled people is not simply a case of people being beastly but of social institutions or physical structures that exclude disabled people on account of their impairment. A number of disabled academics, including Oliver and Barnes, have highlighted the many ways in which society discriminates against disabled people.

However, many people with discriminatory policies or behaviour did not appreciate the fact. They thought that were applying common sense. It is claimed that it is clearly unreasonable to expect a deaf person to have a job playing music, unless of course they are Beethoven or Evelyn Glennie. The argument continues that wheelchair users can't be expected to do jobs that require mobility, although many do have such jobs.

If a person or organisation does not appreciate that they are discriminating, it is unlikely they will think about their behaviour let alone change it.

Broadly speaking, the discriminators fell into two broad categories. One group knew they were discriminating and thought it was in their interest to do so. The other group

were discriminating but did not know it. What then should be the response in terms of social policy?

The viewpoint of the Government in the early 1980's was that the problems were a result of misunderstandings and that persuasion would be able to resolve issues because reasonable people would behave reasonably. Moreover, it was pointed out, laws could not make people love one another so they would have little effect in changing attitudes.

Disabled people took a different view. Although laws cannot make people change their opinions, they can make people change their behaviour and that in turn can affect attitudes. An obvious example of this is the failure of advertising to make motorists wear seat belts and the increased usage when the law changed. A more recent example is the law banning the use of hand held mobile phones while driving. However, if laws are to have effect they need to be enforceable and enforced. The Blue Badge parking scheme is a current example of a good law fallen to ruin through lack of enforcement.

Throughout the 1980's disabled people argued that we did not care what people thought about us provided they behaved in a way that was non-discriminatory. The only way to achieve that was to do what had been done in some other countries and pass laws banning discrimination against disabled people.

The Government continued to resist anti-discrimination legislation on behalf of disabled people, although throughout the 1980's a small number of helpful and important changes were made in the law to improve provision for disabled people. The major breakthrough came in the mid-1990's when, as a result of Opposition pressure and increasing pressure within the Government itself, the Disability Discrimination Act 1995 was passed by

Parliament. The battle to get the law through is worthy of a speech on its own, but not this evening.

At the time I was the Director of The Royal Association for Disability and Rehabilitation, and my staff and I were involved in trying to strengthen the Bill as it passed through Parliament. Part V, that gave the Government powers to introduce regulations to require taxis, buses and trains to be accessible to disabled people, was introduced into the Bill rather late as the Government had originally planned to exclude transport from the Bill. Many other agreements were reached as the Bill passed through Parliament.

Inevitably, the issue of health and safety was raised. Should the DDA take precedence over health and safety legislation or vice versa? Those of us who are disabled are long accustomed to having our lives restricted in the cause of health and safety. I can vividly recall the many times I have been turned away from cinemas and theatres on the grounds that I was a fire risk. Instead of tackling the issues, many places of entertainment avoided it by banning disabled people. Indeed, it was this type of discrimination that led to disabled people demanding legal protection.

To argue against health and safety laws is rather like arguing for the return of Saddam Hussein to rule Iraq. However, disabled people could see very clearly that there was a strong risk that health and safety legislation would be used to undermine the DDA. For example, who would judge the risk? In the past such judgements had always gone against disabled people.

Ministers and civil servants wanted the Act to work. It was agreed that the Act be drafted in such a way that it would only be possible to discriminate against disabled people on grounds of health and safety if the discrimination could

be justified. If there was a genuine case of danger to the disabled person or others, that might constitute reasonable justification. Health and safety legislation would have precedence over the DDA were the two ever in conflict. Disabled people were content with this providing it was not abused. There was a degree of trust that the judiciary would provide the protection. But was that trust justified?

When the DDA was passed in 1995, with its first provisions coming into force in 1996, there was no legal backup other than the trade union movement and some lawyers who would work pro bono to enable disabled people to enforce their new rights. This was put right in 2000 when the Disability Rights Commission was established.

The DRC's vision is a world in which all disabled people can participate as full citizens. We aim to achieve this vision by offering information and advice to disabled people, employers, those who provide services to the public and indeed anyone else who seeks our assistance. Our Helpline will receive about 120,000 calls this year with about a third being from industry. Through the Helpline we can give most people all the assistance they need. However, since 2000 our caseworkers have investigated over 7,000 cases of alleged discrimination against disabled people. In other cases, about 50 or 60 times a year, our efforts to conciliate fail and we have no option but to support a disabled person to bring legal action.

Happily we have enjoyed some notable successes. Last month we proved that Ryanair discriminated against disabled people by charging them for the use of wheelchair. We have clarified the law on involving disabled children in school activities and have played an active role in some of the other cases I shall outline shortly. There has also been an encouraging change in

public attitudes. I rather doubt that ten years ago the Sun newspaper would have retracted so quickly its headline "Bonkers Frank Bruno". It was clearly offensive, if not in the editorial offices of the Sun, to the rest of the country and the Sun responded to that. Having said that, there remains huge prejudice against mental health service users. Support for disabled people comes from many parts of the community. The Shariat Council at the request of the DRC clarified that Muslims should admit guide dogs into restaurants when they are working to assist a blind person. And to bring us up to date there is currently before Parliament a Draft Disability Bill that the DRC has been calling for. I gave evidence to the Select Committee a couple of weeks ago and am convinced that this major Government initiative should be warmly applauded. So more laws on the way!

We seek to use our legal powers strategically so we can clarify the law where it is vague or uncertain. We also sometimes take on simple cases on the basis that if we do not a disabled person will be denied justice. Clearly we need to ration the number of such cases we can support.

However, it is in the courtrooms and at employment tribunals that the law is tested and where the chasm opens when the judiciary interprets the Act. For the most part, for them the assurances given by Ministers and civil servants when the Act was a Bill, never took place. They read the words of the Act and seek to interpret them. Clearly some members of the judiciary are more sensitive than others and we have won some excellent judgements. However, some judgements are difficult to comprehend and in my view have undermined and weakened the legislation designed to protect disabled people. At the heart of the problem are our old friends health and safety.

In the field of employment a number of disabled people have been refused employment on grounds of health and safety. In some cases this was clearly a sensible decision but in other cases it is less easy to follow the logic.

Part of the problem lies in the way the Act is written. It does not sparkle with precision. Disabled people have always known that there are certain things we are unable to do or which would be dangerous for us to attempt. In such cases it is reasonable for an employer to discriminate on account of disability but be able to justify that discrimination. Clearly, it was never intended that employers should be able to use spurious reasons to justify an act of discrimination. We therefore look to Tribunals and the courts to set the level of justification. What has surprised us is the low level of justification that has been set.

I am conscious of the danger of cherry picking. There have been cases where courts and tribunals have clarified the law in helpful ways. A few examples:

Clarke v Novacold (1998 IRLR 420) clarified that if an employee is dismissed for a disability related absence the correct comparator is a person to whom the reason does not apply, namely a person who is able to attend work rather than a non-disabled person who has also been absent.

In Heinz v Kendrick (2000 IRLR 144) it was ruled that an employee may be discriminated against on the basis of a reason deriving from how their disability manifests itself even if the employer has no knowledge of the disability.

Jones v 3M Healthcare Limited and others reached the House of Lords (2003) where it was stated that the DDA covers post-contractual acts, such as the giving of references. This was an important clarification because companies who had been found to have discriminated

against disabled employees continued to discriminate in the reference they gave to the person's potential new employer.

However there is a negative side.

Jones v The Post Office (2001 IRLR 384) ruled that a reasonable reliance by an employer on an independent risk assessment, whether thought by the tribunal to be right, would exonerate an employer from a finding of unjustified discrimination. This is particularly damaging because many people employed to do risk assessments have no knowledge of disability. It is not surprising that some of the decisions raise eyebrows.

In an unreported case (Fowler v Snowden Books) it was found that a guide dog in a book shop was a health and safety risk. Heaven only knows what the dog was reading! In Rose v Bouchet it was ruled that a landlord could refuse to rent to a blind person for subjectively held views on safety.

In another unreported case (Marshall v Surrey Police Constabulary) a forensic scientist was refused employment because of her history of bi-polar affective disorder, as assessed by a doctor with limited experience of depression, and not withstanding effective control with medication. The employment tribunal ruled had not conducted a proper risk assessment based on the opinion of suitably qualified doctors. This was overturned on appeal when it was ruled that the tribunal should have given weight to the opinion of a consultant who had never met Ms Marshall, and whose report was commissioned after the police had rejected her, for the purpose of defending litigation. This illustrates how difficult it has become to challenge the decision of an occupational health doctor even when made solely on the basis of

paperwork without seeing the individual or seeking evidence from a specialist consultant.

The latest case to make my blood boil is Archibald v Fife Council (Court of Sessions 2003) that ruled that the reasonable adjustment concept in employment does not require redeployment except to a similar post. It does not, for example, entitle a road sweeper who becomes disabled to be redeployed to a clerical job for which she is competent but is unsuccessful in competitive interview. This is never what was intended when the law was being drafted and does not conform with the advice of the Code of Practice issued under the Act. The DRC has already agreed to fund an appeal to the House of Lords.

In these cases I would argue that the judiciary has undermined the Act quite severely. No doubt those involved believe they have made the right decision as they seek to interpret what Parliament intended. However, as someone who worked on the Act, I know that is not what was intended. If Parliament passes, as it did, The Disability Discrimination Act, it is reasonable to assume that the intention was to prohibit discrimination against disabled people. Surely the role of the judiciary is to uphold that intention and not weaken it in favour of the discriminator.

It can, of course, be argued that the judicial system contains safeguards against a decision that one of the parties involved believes is inconsistent with the original legislation. Decisions can be appealed. But such appeals are expensive and lengthy. For many people they are not a practical option. To some extent the law helps most those who can afford to use it. But at each appeal, reference will be made to the principal legislation and any subsequent case law. It seems to me that we lack a method to truly determine what ministers of the day intended to happen. In the final analysis the judiciary can

always say that if they have misinterpreted the will of Parliament, it is for Parliament to clarify the law. This is a rather neat escape route but in most cases is not the most practical.

I have been involved in promoting disability legislation for about 30 years. I estimate that the time lapse between a bright idea for legislation and the Sovereign signing the appropriate Act of Parliament is about ten years. The final parts of the original DDA will come into effect in October this year. That is 23 years after disabled people began campaigning for this legislation. As the economist John Maynard Keynes pointed out, in the long run we are all dead. I think we need a system that is rather faster and which produces results this side of the grave.

There is a principle that the judiciary must be independent of the Executive and, although I doubt the divide as a clear cut as it is sometimes presented, I do not wish to challenge it. Within the Europe Commission there is a procedure by which the judiciary can seek advice on what a piece of legislation was intended to achieve. If there was such a system in the UK I doubt it would serve us well because ministers and the civil servants would have moved on and the new faces that replace them might know less than those asking the questions. But it does suggest an approach that might be helpful.

The judiciary has an almost impossible task in attempting to read the minds of politicians, civil servants and lobbyists many years after an Act has been passed. Are there ways in which collectively we can assist them? I think there are.

The obvious starting point is for legislation to be written more clearly so the intention of Parliament is more obvious. It might take longer for Bills to pass through Parliament but it would be time well spent.

I believe tribunals and courts should be encouraged to have greater regard to Hansard and other official documents related to the legislation. For example, they could consult the explanatory memoranda that accompany Bills. We could go further. Why not give the judiciary access to Cabinet Committee papers and other relevant Government documents such as the Government's instructions to Parliamentary Council?

The DRC is charged with writing the Codes of Practice that support the DDA. These Codes are approved by the Secretary of State and by Parliament. Yet some courts seem to pay them scant regard. As these are approved by Parliament, I think there is a strong case for them to be accepted as the definitive interpretation of the law in cases of dispute.

Last year the DRC published a review of the DDA in the light of how it was working. One of our conclusions was that Employment Tribunals appeared to have a deeper understanding of the principles of discrimination than did the courts. This is probably because more such cases come before them. We recommended that the terms of reference for Employment Tribunals be extended so that cases relating to access to goods and services could be heard at Tribunals rather than in county courts. I believe there is great merit in this proposal.

There is a major role for the DRC in helping people to understand the law and the principles behind it and to explain how it can be followed in reasonable ways.

Even if all these suggestions bore fruit there would still be occasions when some members of the judiciary make judgements that clearly undermine the will of Parliament. There needs to be means to monitor those decisions and who makes them. If a particular member of the judiciary is consistently responsible, there should be means of

moving them to somewhere where they can do less damage. It seems to me that it would be better for the judiciary to address this issue themselves rather than having procedures imposed upon them. But I repeat my earlier point; we cannot rely on appeals procedures to right wrongs. Most people have no access to funds to support such action. They have to live with the injustice.

Finally, I think we should examine our law making machinery so changes in legislation can be made more speedily than at present. If an organisation charged with enforcing the law, as the DRC is in relation to the DDA, then the view of that organisation that the law is not working or is being undermined should be taken very seriously. The principle has already been agreed by Parliament, so it should be possible to fast-track amendments to the Principal legislation without it being at the cost of the legislative programme of the Government of the day.

I started by asking the question of whether the law can create rights for disabled people. My firm view is that rights for some imply obligations for others. That can only be achieved and given legitimacy by law. Most people in this country do not wish to discriminate against disabled people, yet the way in which we organise our society results in most disabled people facing discrimination every day. While it is in people's interest to discriminate they will continue to do so unless the law intervenes. Once we have laws they must be enforced. The DRC is part, but only part, of the answer. We need to find ways to make civil law enforcement more affordable. Also, as I said earlier, there is a case for expanding the role of Employment Tribunals.

Critically, I think we must find ways of ensuring the law is not undermined or weakened, however inadvertently, by those paid to uphold it. Perhaps we need to concentrate

more on the principles that underpin a law rather than the fine print so loved by the legal profession. Whatever the future, disabled people will always be part of our society. Our assertion that we are a civilised society must be measured by the extent to which we include all our citizens in the life of the nation and ensure we not only talk about equality of opportunity, but build a society that delivers it. That cannot be achieved by the DRC alone. We need the support and assistance of the wider population including those in this room. I hope I have persuaded you that it is a battle worth fighting.

Thank you for listening.

Bert Massie

February 2004

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Speech by Jane Campbell at the DRC independent living debate 2nd March 2004

DRC INDEPENDENT LIVING PUBLIC DEBATE 2
MARCH 2004

Jane Campbell
Chair SCIE
DRC Commissioner

Independence is something we all strive for, for it gives us confidence to tackle life's challenges. To me, Independent Living is inextricably linked to FREEDOM.

To withdraw or prevent an individual's independence must therefore be considered a punishment; after all, that's often how parents discipline children (you're grounded) or society deals with criminals. To this end, I would contend that independent living is a fundamental human right of disabled people, and to deny it is tantamount to punishment. And what is the crime? To be too expensive to support in the community? Or to be over six stone - too heavy to lift? Sometimes it feels like we are being punished for shortcomings of a social care system that finds it almost impossible to respond flexibly to meet Our Independent Living need.

On 2nd October 2000, when the UK government introduced the framework to take cases under the Human Rights Act, the then Home Office Minister Jack Straw said the intention was to do more than require government and public authorities to comply with the European Convention.

"Over time", he said, the Human Rights Act will bring about the creation of a human rights culture in Britain". Disabled people have much to gain from the philosophy of personal freedom and equal dignity that underpins the European Convention on HR, as it fits well with the fundamental principles of Independent Living.

So what are these fundamental principles of Independent Living as developed by the disabled people's Independent Living Movement?

Most people think it means 'doing things for yourself', for example, cooking your own breakfast, driving your own car or washing your own hair. Whilst, for some, this may be an important feature of their personal independence, for many others it is not. For many disabled people, the effort of achieving such physical independence traps them in a life style of unceasing hard work that simply curtails independence.

"Independent Living" means that disabled people have access to the same life opportunities and the same choices in every day life that their non-disabled brothers and sisters, neighbours and friends take for granted. That includes growing up in their families, being educated in the local neighbourhood school, using the same public transport, getting employment that is in line with their education and skills, having equal access to the same public goods and services. Most importantly, just like everyone else, disabled people need to be in charge of their own lives, need to think and speak for themselves without interference from others.

Here are some examples of disabled people's definitions of Independent Living:

- Independent living is a dynamic process. It is about creating choices and identifying solutions. It is a way of life that grows as you grow and develops as you develop

(John Evans, quoted in Making Our Own Choices)

- I'm a husband, a father and a breadwinner. And ten years ago I was in an institution where you couldn't even decide when to go to the toilet...you know, you can't really understand [independent living] if you haven't done it...your whole life changes.

("Jack" quoted in Independent Lives by Jenny Morris)

- Independent Living is the concept of the empowerment of disabled people and their ability to control their own lives.

(The National Centre for Independent Living)

- Independent Living is speaking for myself. Deciding where I go and what I do.

(People First, London)

My own definition is that independent living is a state of mind rather than a mental or physical capability.

In order to reach the same control and the same choices in every day life that non-disabled persons take for granted a number of prerequisites are necessary. For many physically disabled people like myself, the most important independent living requirements are personal assistance and accessibility to the built environment - accessible housing, for example. For other disabled people, perhaps those with learning difficulties or impairments that make communication difficult, advocacy and communication support are more critical. Without such services and environmental change, hundreds of disabled people can only choose between being a burden on their families or living in an institution, both of which run counter to the concept of Independent Living.

Services that support the development of independent living like Community Care Direct Payments, and the Independent Living Funds, are the result of a long

historical campaign for alternatives to institutionalisation – whether in care or at home.

It is too easy to forget that there are people who are effectively 'institutionalised' in their own homes because they haven't the means to go further than the front door, or worse still, their beds.

Under the existing framework, disabled people can in fact direct their personal assistance support in a way that suits their chosen lifestyles. In practice, however, professionals in the health and social services find it difficult, if not impossible to apply the philosophy of Independent Living when it comes to community care assessment. This is because existing community care policies and services place undue emphasis on assessments by 'social care experts', of a person's 'vulnerability' and the potential risks, which they pose, either to themselves or to others.

The idea that disabled people are 'vulnerable people' who need to be protected and 'cared for' only serves to reinforce perceptions of disabled people as passive 'recipients of care', rather than active citizens facing practical barriers to Independent Living. Assessing need through a filter of vulnerability produces the wrong solutions.

The 'care' approach to assessment is also based on a functional view of independence. As Ann Macfarlane puts it,

“IL means more than being able to make yourself a cup of tea and feed the cat.”

The dominant model does not view people who use support services as fully rounded human beings, with the same needs and aspirations as everyone else. As Gerry

Zarb said in his paper to the European Network on Independent Living (ENIL) conference last year:

“It's more like that they are implicitly viewed as mere 'vessels of care' that - putting it crudely - you feed at one end and clean up at the other!! (Sorry, but it makes me angry)”.

[PAUSE]

The Independent Living Movement has been pushing for new ways to assess a person's support requirements. These are to be based on a social model approach that identifies the barriers to participation rather than an individual's physical or mental incapacity. A social model approach is strengthened by the Human Rights Act because rights such as, the Right to Liberty, the right to respect for private and family life, and the right to freedom of movement are inextricably linked to attitudinal and environmental barriers.

However, even with an assessment based on minimising the barriers to participation, there will always be disabled people whom in order to exercise choice and control over their lives, require advocacy and other supported decision making resources, to better enable access to services. Such resources are essential to enable people access to their human and civil rights.

Without advocacy and other Independent Living support services many people - especially older disabled people - will 'choose' the residential care option because they do not see any viable alternatives, and/or because they are called upon to make such decisions in a time of crisis. By default, most adult disabled people of any age will accept a traditional assessment of their need. There is also a pressing need for access to advocacy for people who are

already living in institutions. Although National Care Standards are supposed to require examination of options for leaving residential care as part of the review process, the evidence demonstrates that this is not adhered to routinely.

Advocacy services are often found in Centres for Independent Living (also known as CILs). CILs are community-based organisations that are controlled by disabled people and provide a range of services that improve our access to Independent Living. CILs help us exercise our right to participate equally; to remain in the community. The right to a family life and parenthood has been central to CIL activity. The larger CILs encompass access to all aspects of society, including mainstream education, training, employment, welfare and support services, housing, transport, public buildings, leisure and information. There are 15 CILs in the UK and a number of similar organisations who provide roughly the same kind of services although they do not call their organisation a CIL. These centres for Independent Living have been a critical network for supporting Independent Living over 20 years.

AND YET, despite most peoples' intellectual acceptance that Independent Living is a fundamental human right, disabled people still find themselves living in institutional settings against their will. As so often happens in all walks of human endeavour, the gap between words and action must be narrowed.

The Housing support charity, John Grooms reported last year that 8,000 young adults are living in care homes primarily designed for older people. Between 1997 and 2002 the number of people with physical and sensory impairments in local authority supported residential and nursing care showed a modest decrease from just over

10,000 to just under 9,000.* For people with learning difficulties, on the other hand, there was an increase of nearly 20% from 25-½ thousand to more than 30,000.** The figure for users/survivors of the mental health system or the psychiatric system is even more dramatic, rising by more than 40% from about 8,000 to above 11,000***.

The Valuing People Support Team also estimates that there are still around 1,200 disabled people in long-stay hospitals.

*10,356 to 9,755

**25,446 to 30,345

***7,965 to 11,275

(Personal Social Services statistics).

While acknowledging that some disabled people, after considering all personal support options, choose to receive their support in a residential setting, I think it is deeply troubling to note that there are nearly 300,000 people supported by local authorities in institutional care, and less than 8,000 people currently receive direct payments to enable them to live independently.

Why is this? Well mainly because the funding structure of the community care system creates a financial incentive for the use of institutional care. If this is not the entire answer to the question “Why”, it is certainly the main one. There are significant numbers of disabled people who have attempted to leave residential care, only to be told their support costs more than their ‘placement!’ - that they exceed the Local Authority ‘usual cost policy’. Strangely enough, the more familiar local authorities become with Direct Payments and notions of independence, the more they seem to lay down policies whereby these so called ‘expensive’ users have little option other than to return to, or stay in, residential care.

I will give you an example of a woman who lives in an authority where they have taken analogous care cost very literally. She had been living in one room in a home for 5 years. The local Centre for Independent Living had worked with her to put together a personal independent living scheme. She had found a flat, assessed her needs in partnership with her social service care manager, prepared herself diligently for employing Personal Assistants, doing everything from preparing job descriptions, to learning PAYE. At the eleventh hour the Local Authority pulled out because the Direct Payment was going to cost the authority £130 more per month.

[PAUSE]

She is still living in that room.

Residential care is often only cheaper because it provides a lower level of support. The example above highlights how much more, and better quality support, she and the local authority would have got for an extra £30 a week. I would say that is good value in comparison with warehousing her in a home.

As research has demonstrated Independent Living cannot simply be accounted for in terms of Unit Cost Comparisons. Is no one figuring the long term cost benefits of such individuals living and contributing to their communities? How many people are we really talking about? Who is costing the social and psychological benefits of Independent Living? Prof Lord McColl, in a house of Lords debate, (during the passage of the Direct Payment Private Members Bill) drew our attention to the fact that disabled people who live in the community are a lesser drain on health care services. They present fewer high cost health issues - kidney infections, chest infections, stress related illnesses, were but a few of the examples he cited.

In the recent 'Olmstead' case, the Supreme Court in the United States ruled that unjustified isolation or segregation of disabled people through institutionalisation is a form of unlawful disability-based discrimination. The Supreme Court also ruled that Federal Government has an obligation to provide funding to keep people out of institutions.

The Disability Rights Commission believes that there are important lessons to be learned from this landmark ruling in the US and that the principles it has established are equally relevant here.

The government is very busy right now, developing the Single Equality and Human Rights Commission (expected to come into force in 2006). This could be the perfect forum to establish a body empowered to take up HR cases. Perfect, except for one major consideration: the challenge is to shift their emphasis from promotion of human rights to enforcement!

CONCLUSION

The arguments for a right to independent living are complex but vital. As I have said earlier there are several tasks to be initiated or developed and funded.

Firstly; there is an urgent need to commission the cost benefit analysis work, which I believe will provide evidence in the long term that independent living will bring down the cost that dependency brings to health care and welfare benefits.

Second: A right to independent living need to be enshrined in a new fully comprehensive Civil and Human Rights legislation.

Third; the government needs to commit to a minimum level of expected provision. This needs to be set a level where no one is forced to enter residential care against their will, no one is forced to become an “informal” carer for lack of any alternative, and no one has to turn down a job because they can not afford to pay for the assistance which will get them to work. Significantly, this also means that the government has to abandon the idea that there is “a point at which the cost of independent living becomes prohibitive”.

Finally, there needs to be a sea change in the way providers/commissioners work with users. This means respecting the view and voice of the user, and taking for granted that the objective is to meet user defined needs. This change has begun but there need to be more rewards to practitioners who demonstrate achievement in the following areas:

- Adherence to a social model approach to assessment of need.
- Ability to operate comfortably with disabled people's dignified risk-taking
- Ability to adapt the jobs that need doing (e.g. lifting people on to the toilet) rather than forcing users to adapt to restrictive working practices
- Have a greater knowledge base of Independent living.
- Ability to communicate in different ways – e.g. British Sign language, Makaton, pictures, Braille etc.)

By acknowledging and addressing these tasks and capabilities, I promise you we can enrich society in myriad

ways as well as improve the moral and physical health of the nation.

There is a growing expectation for this approach from disabled people, not just in this country, but across Europe and beyond.

Last year hundreds of disabled people from across Europe made the journey to the European Parliament in Strasbourg. It was called the 'Freedom Drive'.

This Freedom Drive originated from the European Network on Independent Living (ENIL) and is supported by Independent Living organisations across Europe.

The purpose of the Drive was to foster, and support, the active citizenship of disabled people in the European Union. Among the demands made by the delegation when they met with MEPs in Strasbourg were:

- Action to address the growing number of disabled people being institutionalised
- Promotion of the appropriate implementation of the philosophy of independent living
- Action to highlight and address the significant human rights abuses that many disabled people experience

The time is right, the expertise is available, the case has been made, for Independent Living. Its now up to us all, across professions and interest groups to work together for it to become reality for all disabled people regardless of impairment.

THANKYOU

Keywords: Disability rights; Disabled people; Independent Living

Bert Massie DRC tools to impact on disabled peoples chances in employment March 2004

Speech by Bert Massie, Chairman of the Commission to "Unum " New Beginnings - A Symposium on Disability and Work" on 11 March 2004.

I intend to focus my remarks today on the legal and policy tools that impact on disabled people's chances in employment. The tools that might make work - to use the phrase we have adopted for our work on the goods and services parts of the Disability Discrimination Act - truly Open 4 All.

As you probably know, the Disability Rights Commission is an independent public body set up to promote equality of opportunity for disabled people and to enforce the Disability Discrimination Act of 1995.

The DRC believes that we have three main means of working towards equality of opportunity for disabled people.

The first is promoting change in attitudes and behaviour, based on the principles that lie behind disability legislation. We hope to do this by tackling myths about capacity and cost, promoting sources of employment support – many of them provided by people in this room – and by increasing the confidence and capacity of those with rights and those with duties to respond positively to disability. We also believe that there is merit in effectively making the business and ethical case for change.

The biggest payoffs are likely to be where we can intervene strategically. For example, the DRC will work to ensure that small employers are aware of their new duties

from October 2004 and the business benefits of employing disabled people. After all, 85 per cent of small employers are in this category.

However, a micro business will recruit perhaps once every couple of years. The situation is very different in the public sector, where the government wants to find an extra 10,000 teachers, 9,000 police officers and 35,000 nurses. For this reason, and because of the opportunities presented by the coming public sector duty, we are also working with the public sector - to look at opportunities for improving practice in recruitment, development and retention.

The second tool for furthering equality is using the law very directly to redress wrongs - enforcing disabled people's rights through the courts and tribunals or using other tools such as formal investigations and voluntary binding agreements. Our focus is particularly on cases that clarify the law or interventions that achieve change in whole sectors. Where possible, we publicise cases to demonstrate the law's bite or examples of good practice.

The third tool at our disposal is learning from what works and what doesn't to change law and policy. That might be changes to the DDA. We produced our first Legislative Review last year and will continue to keep the law under review. It might also be attempting to influence government policy in education, employment, health and social care or transport policy.

So, three means for the DRC to contribute towards change – promoting the law and best practice; enforcing rights and duties; influencing legal and policy change.

Strategic promotion of the law and best practice

As you know, the Disability Discrimination Act has been coming into force in stages over the last eight years – the

next changes, in October, are substantial. They include the ending of the exemption from the Act's obligations for employers with fewer than 15 employees, the removal of the justification for discrimination defence and new duties for qualifications bodies brought about through the European Directive. Plus the need for providers of services to the public to consider making physical adjustments to their premises to allow disabled people to use them.

The fact of successive waves of rights and duties coming into force since 1995 – I won't rehearse them all here as you will be familiar with them – has often sharpened the minds of those with new duties.

Indeed, the mere fact of knowledge of the legislation often creates change. The DRC has assisted thousands of disabled people to use the law as a tool to achieve redress without recourse to the courts or tribunal.

And surveys conducted by Manchester Metropolitan University found that the law is stimulating change: almost all 'good practice' employment measures were significantly more in evidence in 2002 than in 1995. For example, the proportion of employers adopting targeted recruitment measures rose from 12 per cent to 74 per cent in seven years.

And there's more. Evidence from the US suggests that when disabled people know about their legal rights, they are more likely to 'come out' about hidden impairments and to negotiate for adjustments at work – part of what is necessary to prevent a gradual slide out of work. Legislation, it appears, can change behaviour on both the demand and supply side of the employment transaction.

So, while we let people know that there is an iron fist within the velvet glove, the DRC has ensured that it does

all that it can to let people know about their rights and duties – and to show the benefits to the legislation.

The focus, for example, of the DRC's first campaign, Educating for Equality, was on letting education providers and disabled learners and their parents, where relevant, know about the law and why improving the situation of disabled people is so important. Disabled people's disadvantage in education is unacceptable on its own account. It also clearly has an impact on future work chances. Our survey of 18-25 year olds revealed that, sadly, young disabled people still fear that they will have fewer opportunities and earn less than their non-disabled peers. One of our aims is to raise those expectations.

The DRC's current campaign, Open 4 All, focuses on the new duties of those who provide services to the public coming in this October. Again, we took the approach of indicating that the law has bite but that there is a benefit to making changes – including to the bottom line. We used evidence of demographic change to indicate just what a mainstream issue disability is and worked with trade associations, business advisers and others to increase knowledge of how to respond positively to the law.

So far, so rosy. But what is changing in terms of rates of employment or disabled people's opportunities to progress and stay in work? Well, there has been a consistent uplift in employment rates for the last five years. This may be partly as a side effect of labour market expansion. Whatever the background, progress is clearly still too slow and the waste of talent through so few people being out of work is serious. In addition, those out of work are unable sufficiently to plan for their actual retirement.

Employment rates in the civil service remain static – and low - despite improvements on ethnic minorities and women. Promoting the law isn't always enough. Scope's

'Ready, Willing and Disabled' research of 2003 found that disabled people made an average of two and a half times as many job applications when they were looking for work yet got fewer job offers.

A 2001 evaluation of the Government's ONE programme found that despite acute labour shortages, only 37 per cent of employers said they would in future take on people with mental illness. Clearly that is a determining factor in the rate of people with long-term mental health problems who are working – just 21 per cent compared to 49 per cent of disabled people overall. The figures for people with learning disabilities are similarly low.

So, what about:

Using our legal powers more directly as a tool for chance?

Well, lest you think we are a soft touch, the DRC will help employers and service providers to get it right but we will also take firm action when they discriminate. We will promote good practice but we will and do also tackle discrimination through courts and tribunals.

Since 2000, when the DRC was set up, we have supported many thousands of disabled people to use the law to improve their situation – in employment, education, access to other services and even in transport, where individual rights are weak. You may have seen some of our recent cases in the media, such as the one against Ryanair and against a school that was unfairly excluding a young boy from all its Christmas activities.

In some instances, legal cases can help clarify the law. Our first case, on employment, involved someone with depression. The case was contested on the basis that the claimant wasn't disabled enough to attract the protection of the DDA. It went to the Court of Appeal who found that the claimant was disabled.

Another case involved a man with depression who applied for two jobs with the Probation Service. He was offered a job as a handyman but turned down for a job as community service supervisor on the assumption that someone with depression couldn't do a 'stressful' job - without considering the individual circumstances or looking at possible adjustments. He won at Employment Appeal Tribunal.

Cases can also set important legal precedents, such as the DRC case involving a company giving a poor reference to someone who had successfully taken them to a tribunal. That case usefully established that an employer could be found to have discriminated unfairly after the employment relationship has ended.

Alongside benefits to individuals and clarifying the law, legal cases can establish changes in policies across whole companies or sectors. They can send clear signals to employers about expectations of fair practice in recruitment, retention, reasonable adjustments or dismissal.

For example, a deaf man who applied for a job with an NHS trust in the medical records department was turned down on the basis that the job description said he had to answer the phone from time to time. As a result of a successful case supported by the DRC, the trust reviewed all its policies and procedures to ensure that unnecessary specifications of this kind didn't exclude good candidates from roles.

But is the DDA as it stands – whether promoted or enforced – enough to create systemic change? What broader policy considerations have an impact on disabled people's chances of employment?

Changing law and policy

Well, we are delighted that Government has introduced a draft Disability Bill. The changes in it will make a huge difference. It will improve the definition of disability, move from a reactive, punitive post hoc approach of legal cases to redress wrongs to, in the public sector at least, a proactive duty to root out systemic barriers to disabled people's participation, including in employment.

There are a few additional changes that we would like to see in the Bill, such as preventing recruitment questions on disability, except in highly specified circumstances – because we know that discrimination often creeps in when employers are able to do an occupational health check before job offer: too often, they see the word 'epilepsy' or 'depression' and think 'risk' – rather than thinking whether this particular individual can do this particular job, with adjustments as needed. . The power of tribunals to reinstate people would also be hugely welcome. For some disabled people, the opportunity to return to the previous place of work, familiar in terms of environment and role, will be their best employment opportunity. We would also like to see Tribunals have the power to instruct employers to change their practices.

In terms of broader policies affecting disabled people's lives, each major area – and we have identified these internally as education, employment, access to goods and services, including transport, and health and social care – has an impact on chances for work and in work.

Improvements in education and training at all stages of life are crucial to ensure that disabled people have a range of choices and also that young people grow up accustomed to disability, overcoming the all too frequent fear and embarrassment that affects many disabled adults.

Improvements to premises, not just in terms of physical access but also in signage and lighting should boost

employer's confidence in taking on disabled staff. We all know, indeed recent research from Leonard Cheshire and John Grooms has reminded us, just what an impact transport and housing can have on disabled people's quality of life and work choices.

Health and social care has some way to go before it provides a truly supportive base to enable many disabled people to manage disability effectively. If you have to wait for months for essential treatment or equipment or you cannot rely on the social care support that could make you independent, your confidence at work is likely to be severely undermined.

What about broader employment policy? A quick word on Access to Work. Research collated by the DRC demonstrates how disabled people value the Access to Work scheme; how it brings confidence about applying for or staying in work. However, the fact that so few employees and employers know about it is clearly a cause for concern. There are still delays, which can again affect that confidence in thinking about a new job – and mean that people are more likely to slide out of work at the onset of impairment. Also, given the changing nature of the conditions affecting those on incapacity benefit, support for those with mental health conditions might be considered an increased priority, particularly for staying in work, whereas the current emphasis of Access to Work is on getting people into work.

So, strong laws, advice and support to employers and employees, adapting policy to take account of learning and of new workforce challenges; larger employers, particularly the public sector, leading by example. And growing the confidence and capacity of employees and employers to respond positively to disability – for employers to see disabled people as potentially the best person for a particular job and for disabled people,

whether disabled from birth or acquiring a condition later on, believing that the correct framework of rights and support will enable them to stay in work or move to another opportunity. And for everyone, seeing recruitment, promotion and retention of disabled people as a central part of ensuring a healthy economy today and a just and civilised society for tomorrow.

Keywords: Disabled People; Employment; Law; Policy

Bert Massie Developments in Access and the Law April 2004

Speech by Bert Massie, Chairman of the Commission to joint DRC / Drivas Jonas Seminar on "The DDA 1995 Understanding the Respective Obligations of Landlords and Tenants" on 20 April 2004.

First I would like to thank Drivas Jonas for organising this splendid seminar.

One of the distinctive features of the DRC is that we try to listen our stakeholders – all of our stakeholders not only disabled people. We know that the DDA places significant obligations on large businesses and we take their concerns seriously. One subject that has been raised with great frequency is the respective obligations of landlords and tenants in relation to the DDA. We already knew that this was a complex area of law from our work on the statutory Code of Practice – we had some particularly intense discussions at the working group.

We asked Drivas Jonas to work with us in organising a seminar on the subject because of their track record in this area. Amongst much other work they are authors of the first good practice guide on planning and access for disabled people, published last year by the Office of the Deputy Prime Minister. An excellent publication and we applaud their work in this area and thank them for bringing together this excellent group to consider the hugely important subject of landlords and tenants obligations under the DDA

I am here to set the scene for the other speakers here today and will be talking about important new developments in the law in regard to providing more inclusive environments and services for everyone – including disabled people. I will naturally talk about the DDA but I will also discuss how disability features in

changes to the planning system, and the evolving role of the Building Regulations

The DRC

The Disability Rights Commission (DRC) is an independent body, established by Act of Parliament to eliminate discrimination against disabled people and promote equality of opportunity.

To achieve this, we have set ourselves the goal of "a society where all disabled people can participate fully as equal citizens".

The DRC:

- provides advice and information services for disabled people and service providers;
- supports disabled people in securing their rights under the Disability Discrimination Act (DDA); and
- campaigns to change policy and strengthen the law so that it works better and protects more disabled people.

So we have a broad remit in terms of promoting equality of opportunity for disabled people, and a particular responsibility for securing full implementation of the DDA.

Principles

Let me start by talking about our broader obligation to promote equality – and why an inclusive environment is the key to delivering equality of opportunity. Many of Britain's 10 million disabled people cannot access education, employment, social or political participation because they are physically barred from participation – No need for a no entry sign just leave in the steps or the heavy doors that will do the trick!

In the 21st century we all agree that it isn't acceptable to exclude people because they happen to be disabled. Yet it continues to happen all over the place. On the most basic level – on a Saturday you probably go out with your kids - watch them play football, go swimming with them or just go out for something to eat. You quite rightly take this for granted. But is it acceptable that many disabled parents don't have the right to go out with their kids in this way? The uneven path at the football grounds, the steps at the swimming pool or the terrible lighting and glass doors at the restaurant can stop them doing this. This has to change.

Inclusive design

An inclusive approach to the design of environments is the key to removing these artificial environmental barriers.

"Inclusive design" is not a fixed set of technical criteria, but a constantly evolving philosophy that guides the way we design our environment. Its goal is that of creating environments that can be used equally by everyone. Therefore, the design process must be constantly expanding to accommodate a diverse range of users, as we develop greater understanding of their requirements and expectations.

In relation to the built environment, inclusive design extends from conception, through the planning process, detailed design and construction, to occupation, management and operation. Each of these stages should be fully inclusive, involving disabled people and other potential consumers in their development and evaluation.

It is likely when making alterations to premises that you will need to comply with a variety of legislation - not just the DDA but planning duties, building and licensing regulations for example. By adopting inclusive design you

will be more likely to satisfy any obligations you may have under these duties.

What is an Inclusive Environment?

An inclusive environment is defined as one that can be used by everyone, regardless of age, gender, ethnicity or disability. It is made up of many elements such as society's and individuals' attitudes, the design of products and communications and the design of the built environment itself. It recognises and accommodates differences in the way people use the built environment and provides solutions that enable all of us to participate in mainstream activities equally, independently, with choice and with dignity.

An inclusive environment will be easily usable by as many people as possible without undue effort, special treatment or separation. It will also offer people the freedom to choose how they access and use the environment and allow them to participate in all activities it may host.

Inclusive design celebrates diversity and is a statement of equality. By applying high design standards to meet the access requirements of all users, the end design embraces everyone on equal terms.

An inclusive environment does not attempt to meet every single need but, by considering people's diversity, inclusive environments can break down barriers and tackle exclusion. It will often achieve solutions that benefit everyone, obviously including disabled people, but also other groups in society such as older people or parents with young children, and the community as a whole. Thus, access for disabled people will be part of the mainstream rather than something separate added on afterwards. But still some separation is needed in specific areas – for example, toilets and car parking.

Well that is the ideal – now lets look at some of the legal mechanisms – the sticks - to encourage people in that direction.

Legal developments

The DDA is the focus of our attention today, and has played a hugely important role in raising the profile of this issue but it is just one part of the jigsaw of laws which are promoting inclusive access for everyone, including disabled people. Increasingly we are seeing access for disabled people becoming more central to the legal framework within which built environments are planned and designed. And this is of course the best way all round- getting at right at the beginning involves no or minimal cost.

There have been very significant legislative progress over the last year.

The building regulations

As you will all know for many years Part M of the building regulations has set some basic accessibility standards. There is a link to the DDA in that if a building has met Part M of the building regulations then those aspects of the building which comply with the exact detail of Approved Document M will be exempt from having to make changes under the DDA for 10 years from when they were installed.

Just a word of caution at this point. Whilst Part M and the Approved Document will be useful, please don't rely on this entirely as it's application can be limited.

For example, the Approved Document specifies the clear opening width of a door and if your building has met the regulations and meets this detailed requirement, i.e. it has that clear opening width, then you won't have to change the width of the door. However, the Approved Document

doesn't address issues like the weight of the door, the door furniture or colour contrast. So you may well still have to change, or at least consider changing, these.

The law in this area is evolving quite rapidly at the moment – and in a very positive direction. Part M has been extended in content and scope from 1st May this year. The regulations now provide for facilities like automatic doors, audio enhancement and clearer signage to make access easier for all.

Even more significantly the Regulations now apply to existing buildings whenever they are altered or undergo certain changes.

The new Part M is not currently linked to DDA in the way that the old one was, but I expect that change will come shortly.

Furthermore, the Government has just announced a review of the building regulations which apply to housing - with a view to incorporating the lifetime home standards, with further work promised on meeting demand for homes designed for wheelchair access.

So lots of positive development regarding building regulations, turning to planning the news is also good.

Planning

The Planning and Compulsory Purchase Bill 2003, meandering through Parliament as I speak, contains for the first time a statutory duty on developers to submit access statements with their planning applications. This would apply to all developments with public access including services, employment premises and new housing but not domestic alterations.

Access Statements

An Access Statement is a really practical measure which supports inclusive design. It is a record maintained for the life of the premises that is updated whenever building works are undertaken. It should demonstrate how all potential users can utilise the premises, and that their access needs have been considered in its planning design and management.

The exact form of the Access Statement will depend on the size, nature and complexity of the building or space. However, each statement should define the following points:

- the policy and approach to access being adopted, including reference to the inclusion of disabled people
- any specific issues effecting access to the particular building or space, and solutions to overcome them
- the sources of advice and technical guidance followed, including any user consultation planned and undertaken
- the access strategy being implemented, and any action plan detailing the implementation of the access strategy.

The DRC is currently working with building professionals to develop model access statements and further information about how they work. We are also hopeful that they will be recommended in guidance associated with the building regulations.

These are living documents which we hope will be of tremendous use to those designing the buildings, providing services from those buildings and using the buildings.

Last but not least

DDA

The Disability Discrimination Act has since 1996 imposed a series of duties on those providing services to the public – Initially simply not to refuse service or offer worse service because of someone’s disability, but from 1999 service providers have had duties to make reasonable changes to the way services are delivered (or to provide extra services or aids where a disabled person finds it unreasonably difficult to use the service).

Changes to Buildings

From October 2004 all service providers will have to make reasonable improvements to the physical features of premises to make sure that disabled people don’t find it unreasonably difficult to use their services.

These are major changes and need planning well in advance, which is why the Government actually gave several years’ notice of these new duties in order to give some preparation time. Service providers have the choice between removing the physical feature, altering it, avoiding it or providing the service by a reasonable alternative means.

The DRC strongly believes the best solution for everyone is either removing or altering the physical feature. But this is just one of many grey areas in this Part of the DDA.

The DRC has produced a statutory Code giving guidance on Part 3 DDA relating to the duties of service providers. We attempted as best we could to shed light on some of these grey areas – For example, the question that all service providers quite understandably ask is “ what is considered ‘reasonable’?” In the Code we have a stab at answering this. We say that this will depend on all circumstances of the individual case including factors like the size and resources of the service provider and how many other improvements the service has made.

So the DRC sheds as much light as it can – through the Code, through other excellent publications, our helpline and advice.

Open 4 All

Specifically in relation to the new DDA duties coming in in OCTOBER we are running a major campaign called “Open 4 All”. This not only promotes the new duties but also provides information and emphasises that it’s important and achievable to include disabled people when you are providing services.

The campaign was launched last October and will run until the end of this year. We have an excellent website, Open4All.org, and I would strongly suggest you look through this site which contains a wealth of information about access to both buildings and services for disabled people.

But some of these "grey areas" will only achieve full clarity when they have been tested in the courts. The DRC will fund test cases to achieve clarity in the law – which is in everyone’s interest. Our present legal strategy identifies 83 grey areas which we would like to clarify. There is a particularly tricky grey area about the coverage of "common parts" – which I will leave our Drivas Jonas friend to explore.

Without wishing to end on a negative note I am sure that no one here will want to be party to those test cases. My advice to you for avoiding that - is simple: focus on the principles of inclusive environment with which I started my talk rather than the precise letter of the law – Which in some areas is not as precise as we all might want!

Everyone here – whether landlord or tenant – or indeed some "other" category - has a crucial role to play in ensuring our built environment is something that we can

all easily use. You may see this as a challenge but I would encourage you to see this as an opportunity and support those you work with to take the same view.

We will make this country accessible for disabled people. The only question is whether we do it slowly or quickly. If helped by friends such as yourselves it is a battle we will win quickly.

Keywords: Access; Built Environment; Disability Discrimination Act 1995; Landlords; Law; Service providers; Tenants

Bert Massie Does diagnosis matter to service users Disability and the Health Service April 2004

Speech by Bert Massie, Chairman of the Commission to the British Society of Rehabilitation Medicine Conference. Derby on 21 April 2004.

Introductory remarks

I should like to start by thanking you for inviting me to address you this morning. I very much regret I am unable to stay following my presentation. That is no fault of the organisers but of my diary, as I have to be in central London by lunchtime.

Having been asked to speak from the point of view of a "typical patient" I thought I should begin by asking myself a critical question: am I in any sense a "typical patient"? Am I more compliant - or more bolshy – than the next patient? More likely to argue the toss – or to trust the doctor implicitly? More likely to want to know everything about my diagnosis – or more keen to know other things, not connected to diagnosis, like my employment rights, or my options for adapted cars?

I reflected on my own use of the health service. I have spent only one or two nights in hospital since 1965 but most health care does not take place in hospitals. I see my GP once or twice a year but that is for a minor issue that is well under control. After considerable reflection I came to the view that I am an absolutely typical patient. Typical, that is, in being an individual – with my own requirements, just like every other patient. The NHS Plan, of course, states that health services should meet the individual needs and preferences of service users; and the Secretary of State has introduced a major programme on Patient Choice. So I – like other disabled people - simply

want to be treated equally to everyone else - in a way that is sensitive to our individual requirements and choices.

Employment in the health services

But before we run away with the idea that disabled people are always "patients" in need of help – a modern version of "poor unfortunates" - it is worth remembering what disabled people can give to health services. Disabled people exist increasingly around the bed, as health professionals – not just in the bed. We also exist around the Boardroom table, making major decisions on local health economies.

But at the DRC we too often hear of barriers faced by disabled people when they seek to work in or lead health services. I will give you just 4 examples:

1) Nicki Heazell is short of one arm and spent some of her childhood in hospital. She decided when young that she wanted to be a nurse. Yet when, in later life, she applied for training she was rejected on account of her impairment. This begs a question .With a national shortage of over 35,000 nurses, was there no way of enabling her to qualify and to undertake useful nursing work?

2) Mr Keane applied to be a medical records clerk. He met the criteria for the post but was not invited to interview because he was deaf and the NHS Trust assumed that he would be unable to do the job, which required some telephone work. Would it not be possible, in an age of increasing use of e-mail, and technology like text phones, to accommodate a qualified deaf person into a clerical team?

3) Heidi Cox is a wheelchair user and was accepted by Oxford University to study medicine. But because there was no agreement from the GMC that she could qualify –

given a range of required learning outcomes, including resuscitation - Oxford could not assure her that she would be able to qualify as a doctor. At a time when we are short of at least 15,000 doctors – and are actively recruiting doctors from the new EU states and elsewhere, according to a survey by the Financial Times last week – should we be denying talented young disabled people the chance to become doctors? Heidi Cox's ambition was to become a pathologist. One might wonder how often resuscitation skills are needed in that particular role.

4) After nurse Beverley Allitt killed children in her care, the Clothier Inquiry recommended that a "two year rule" should be applied in nursing – which meant that anyone who had received psychiatric treatment (including counselling or a short course of anti-depressants) in the previous 2 years would be barred from nursing or from entering nurse training. Some organisations adopted this recommendation, with the result that some individuals were lost to nursing on the basis of a blanket exclusion – rather than a proper assessment of whether the particular individual was suitable for the particular job or professional training; others tried to conceal their use of psychiatric services, which is a recipe for stress and (paradoxically) for greater risk to health services.

We still have a long way to go to eradicate discrimination – and blanket exclusions – of disabled people from professional life in the health services. It is ironic that the largest employer in Europe – since the abolition of the Red Army – and the employer that might be expected to have most expertise on disability, still erects unnecessary barriers to disabled people's employment and progression.

Patient choice

But, to get back to the current major policy priority of patient choice, it means providing health services that meet individual needs and preferences. But what if the individual is a disabled person – someone with a mobility impairment, or a visual or hearing impairment, or a learning or psychiatric disability?

Government figures tell us that there are 8.6 million disabled people in the UK, about 1 in 7. Unsurprisingly, they make much greater use of health services than non-disabled people. This means that every week more than 1 in 7 of the 1.4 million people getting NHS services at home, of the 800,000 people making out patient visits, and the 3000 having heart operations are disabled people. We are talking about very large numbers indeed.

It is, therefore, impossible to deliver on patient choice or meet service standards without meeting the individual needs of disabled people. For instance, to ensure everyone is admitted, transferred or discharged in A&E within 4 hours of arrival means, for patients with hearing impairments, having an induction loop system in place, BSL interpreters on call and staff trained to communicate effectively with people who lip read. Or, to ensure everyone can get an appointment with a GP within 48 hours, involves making the service accessible to wheelchair users.

Getting access right for disabled people also tends to help everyone else. Members of the general public often pick up "Easyread" health education information – intended for people with learning disabilities – in preference to the regular version, because it is short and straightforward. Equally, parents with buggies benefit from improved physical access intended for wheelchair users. Disabled taxpayers themselves expect public services that meet their access and other needs.

Beyond choice of health services – to social participation

I do not need to tell an audience of rehabilitation specialists that for disabled people the important areas of choice do not centre just on which hospital to go to, or when to have a GP appointment.

It is also about how long-term services can be provided on the disabled person's own terms, in ways that enable us to lead the lives we wish to lead, participate in the things that matter to us. For instance, for many newly disabled people the critical issues are being supported to keep your job, or your college place; your home; your marriage or partnership; your role with your children. If some of these things can't be sustained – for instance, a scaffolder with a major spinal injury may need a career change - then people want support to find an alternative occupation.

Recent work by DWP with the Royal College of GPs and Faculty of Occupational Medicine shows that when someone is newly disabled or develops a long-term health condition, there is a critical period between 6 and 28 weeks, when efforts to regain employment or seek new employment are most likely to succeed. After 28 weeks the chance of the person ever working again plummets. Many doctors are, with the best of intentions, signing people off sick for longer than is necessary or desirable but not giving sufficient attention to the long-term effects. For some disabled people getting back to work quickly is the best treatment. This does not, of course, mean this is always the right option. Disabled people need health services to support them in their life choices – not just their health service choices. Life is about more than using health services – but those services can make the difference between a fulfilling life and one that feels empty, because the support is not there to enable participation.

Disabled people want health and social services on their own terms. That means going beyond individual choices – to input at a strategic level, on whole service systems, standards and inspection regimes. For instance, disabled people have a great deal to contribute to debate on what the new proposed Department of Health standard "dignity and respect" should mean in practice. It also means more direct control by disabled people over services. Direct payments, whereby disabled people are given the financial resources to, are an important way to achieve this: managing your own services, by employing personal assistants who can support you to do what you choose to do, whether it is dancing or hang-gliding or being a chartered accountant. As Julia Winter (who is disabled) put it in the Guardian recently, with direct payments "you can say "it's a lovely day: let's not worry about the housework, let's go out!" You can be spontaneous. You can live" (Guardian 14 April 04).

Direct payments are on the increase in Britain – but the availability is still patchy both geographically and in terms of impairment type. People with mental health difficulties or learning disabilities are much less likely than other disabled people to obtain direct payments – although where it has been tried it is working well.

Do health services treat disabled people fairly?

We know that some health services have developed excellent approaches to improving services for disabled individuals, for instance:

- Including access needs on the electronic patient record, so that someone with a learning disability who needs extra time to communicate with a health professional does not have to explain this again and again to different staff

Systematic logging of any access problems experienced, to feed into service-wide improvements

Simple access improvements like visual displays of appointment times so that deaf people know when their appointment comes up

Questions in the regular patient survey about disabled people's experiences, used to improve services

Disability equality training for everyone from Board members to receptionists

Good practice is, however, often left to small individual projects and is not mainstreamed. Surveys reveal some significant problems faced by disabled people in using health services. For instance, despite 1999 NHS Executive targets for all front-line NHS staff to receive disability awareness training, a 2003 survey of PCTs found that 90% of them had no compulsory disability equality training; 50% had no training at all or did not know whether they had any; and only 50% had consulted disabled people about the services they provided (1) Surveys of disabled people regularly identify problems in access, staff communications and attitudes. Knight et al found that 60% of deaf people reported that primary care was inaccessible to them (2)

Decisions in life and death situations reveal that some disabled people experience discriminatory assumptions from health professionals that their "quality of life" will be less than that of a non-disabled person, which can influence decisions about rationing of surgery, withholding or withdrawal of treatment and use of "do not attempt resuscitation" notices. This has been of particular concern to the DRC and has heavily influenced our views on issues such as Physician Assisted Suicide. We have too many, albeit anecdotal, examples of doctors pressurising disabled people to agree that no effort should be made to

preserve their lives if their health deteriorates. It would appear that some doctors think it is better to be dead than disabled. As most of them have no personal experience of either it is difficult to know how they reach their decision, if it is not merely prejudice. The DRC believes that before we can sensibly discuss the right to die we must first ensure we have the full support systems and services in place to enable disabled people to enjoy the right to live.

There is some particularly worrying evidence that some groups of disabled people die younger than non-disabled people, and live with greater morbidity, partly because of unequal access to health screening, assessment and treatment. One London study found that people with learning disabilities were 58 times more likely to die before the age of 50 than other citizens. (3) This is a startling result and it would be helpful for the research to be replicated. However, even if the disparity were only half as great as 58 times it would be shocking; and we would expect particularly high attention to this at-risk group in terms of health service access and quality. Instead access to basic health services – assessments, health promotion, regular health checks and screening, treatment – can be lower for these groups.

Similarly people with long term mental health problems die on average 9-10 years younger than other citizens. Sometimes physical complaints are seen as "all in the mind" and not investigated or treated. As one mental health service user put it:

"I had a cupboard full of valium for my palpitations – but no one identified my major heart disease".

Part of the role of the DRC is to ensure that disabled people do not receive a lower standard of service than people who are not disabled. This applies to the health service as much as it does to high street retailers or

employers. We have a number of ways of doing so. If a disabled person suspects that they are being discriminated against unlawfully they can approach the DRC for assistance in bringing a legal case. In most cases we can resolve issues without access to the courts but we do support about 60 cases a year in the courts and tribunals. We have also supported judicial reviews when health trusts or local authorities have failed to support disabled people because of ill-conceived blanket bans on lifting disabled people. Latest guidance on this issue is much more sensible and helpful.

In some cases the discrimination is not so obvious but is there nonetheless. This appears to be the case in the delivery of health services to people with learning disabilities or users of mental health services. The DRC is extremely worried about these inequalities in health experienced by disabled people. But we need to know more about the nature of the problem and seek solutions to it

Over the next few months the DRC will be giving increasing attention to addressing health care inequalities as they affect disabled people. One outcome of this is likely to be a more formal legal intervention later in the year. We must act on the basis of evidence. The timing is right as health inequalities are high on the Government agenda, especially in the light of the recently published Wanless Report; but to date these initiatives have not addressed the health inequalities experienced by disabled people. We plan to work collaboratively with health partners to put that right, by coming up with workable, tested approaches to improving health outcomes and access for disabled people. We believe that access to basic health care services is a fundamentally important issue for disabled people. We welcome input on this issue from health professionals, disabled people and others.

There are also still physical access barriers to many health services – think of all those dentist surgeries above shops – and we are working with health service organisations through our Open For All campaign, to provide guidance and information on how access can be improved. From October 2004, all service providers – from health services to supermarkets – will have to consider changes to physical features or premises to overcome barriers to access for disabled people.

Does diagnosis matter?

I was asked to address the core question of this conference – does diagnosis matter to disabled people?

In terms of clinical treatment of course it matters. It helps determine optimum courses of treatment, based on evidence.

But in terms of patient choice, social participation and fair treatment it matters much less.

The "individual needs and requirements" of patients are not prescribed by their diagnosis. To take a simple example, one blind person may want communication in braille, the next on tape, the next in electronic form to suit voice activated software. It is neither possible nor desirable to determine choices on the basis of a diagnosis, or impairment type: the individual should instead be asked for their needs and preferences, which should then be entered into their electronic record, so that the information follows the patient; and that they need explain only once what their access needs are.

Diagnosis also does not help much in enabling social participation. The scaffolder with a spinal injury needs support and encouragement to get a different type of job. This requires engagement with his interests and aptitudes. Knowing his diagnosis will not help determine whether a

customer service or data analysis role would suit him best. Encouragement means understanding the process of change he is going through and supporting him through it – a process which is not determined by his diagnosis.

Interestingly research in rehabilitation and mental health shows that diagnosis is not associated with later employment outcomes – the association is instead with people's motivation to work and the level of support and encouragement that they are given.

Diagnosis is also not greatly useful in ensuring fair treatment. The person refused a job or entry to nursing training on grounds of their particular impairment might wish that they could hide it. Diagnosis is no protector from discrimination – and it can be used as the grounds to discriminate.

Looking to the future

The major programme in health and social services to improve patient choice and control could over time significantly improve health care for disabled individuals; certainly the objective of patient choice cannot be met without addressing disability, given the very high numbers of disabled people using health services. It will increasingly mean that health professionals have the key responsibility of providing options and advice so that people can make their own informed decisions. This means treating individual service users, including disabled service users, not as impairment groups – but as individuals.

Choice needs to be balanced by equity. Here, disability rights are beginning to make a difference. Ten years ago it was unusual to find public services – from major tourist attractions to shops or theatres – that paid attention to disabled customers. Today it is commonplace to have signed and audio-described theatre productions, lifts with

the information displayed in braille, shops that offer assistance to disabled customers. We are in the middle of a cultural shift – and it is affecting health services.

Earlier I talked of 4 examples of barriers to employment and progression in the health services. The outcomes in those cases were as follows.

1) Nicki Heazell did not give up after being refused entry to nurse training. Her reaction to the many rejections was, in her own words “Sod it; I’m going to be a nurse”. She was eventually accepted for training and is now working as a staff nurse and is advising the Department of Health on ways of improving employment opportunities for disabled people. One of her specialities is advising people

2) Mr Keane challenged the refusal to employ him as a medical records clerk, by using the DDA (Disability Discrimination Act), with the support of the DRC. He won his case and received compensation – and the NHS Trust decided to review its policies and procedures to make sure other disabled people were not unfairly excluded in the future.

3) Heidi Cox challenged the GMC under the DDA. She was not successful, since at that time the GMC as a qualifying body was not covered by the DDA. However, from October 2004 qualifying bodies – those that set competency standards for professional entry – will have to ensure their standards do not discriminate on grounds of disability. The DRC is working with a range of qualifying bodies to help them develop fair and effective competency standards.

4) For people who have received psychiatric treatment in the last 2 years, there is now no bar to entering nursing training or remaining in nursing. New Department of Health guidance on Mental Health and Employment in the NHS states: ‘As the largest employer in the UK, the NHS

should set an example showing that discrimination is taken seriously and will be eradicated.... It is extremely unjust, a waste of human potential, a great cost to society and potentially unlawful to exclude anyone from employment simply because that person has experienced or experiences mental health problems....The “2-year rule”... is no longer to be used in the NHS’ (4)

The DDA - and the cultural shift it is stimulating in Britain - mean barriers to disabled people are beginning to be torn down. Major developments in the health sector – the increasing emphasis on long term services (as in the NSF for long term conditions) and on services for older people, the pressure for individualised services and choice, the need to fill major professional employment gaps – will all drive change that could benefit disabled people’s participation. The DRC will be working through our proposed investigation and through partnerships with the Department of Health, Scottish Executive and a range of health and social care organisations to improve services and employment opportunities for disabled people.

But this will not be achieved by focusing only on diagnosis. Diagnosis is important – but it is only the beginning of the story.

Bert Massie
21 April 2004

(1) Campion 2003 Fair Treatment. London: Leonard Cheshire.

(2) (Knight J, Heaven C and Christie I (2002) Inclusive Citizenship: The Leonard Cheshire Social Exclusion Report. London: Leonard Cheshire).

(3) Hollins (1998) ('Mortality in people with learning disability: risks, causes, and death certification findings in

London', *Developmental Medicine & Child Neurology*, 40:
50-56"

(4) (Department of Health 2002).

Keywords: Disabled people; Employment; Health service;
Patients; Treatment

Bert Massie What can the CEHR offer to disabled people and other groups who experience discrimination April 2004

Speech by Bert Massie, Chairman of the Commission to the Mainstreaming Equality Conference, Liverpool University, Liverpool on 28 April 2004.

I would like to start by saying what a pleasure it is to be speaking in Liverpool, my home city and the city in which I cut my teeth many years ago seeking ways to eliminate the discrimination that blighted the lives of so many disabled people. Since those days in the 1960s much has changed to improve the lives and life choices of disabled people. More needs to be done but let us acknowledge that there have been significant achievements, some of which have been beyond our wildest and most surreal dreams of 40 years ago.

I have been asked to consider the implications for disabled people of the proposed Commission for Equality and Human Rights. Overall, provided that the CEHR gives continuing high priority to getting things right on disability, the DRC believes the new single Commission could play an important role in tackling not only group-specific discrimination but also cross-cutting causes of discrimination and good practice. We believe disability can enrich the work of the CEHR and can be enriched by it. There are important issues still to be resolved but we believe they can be resolved successfully. It is essential that the CEHR gives continuing high priority to disabled people and their rights: disability discrimination differs from other forms of discrimination in some important respects; there must be no loss of momentum in making a reality of the present decade-long programme of disability rights reform; and disabled people will not give up what they

have secured in terms of direct representation and influence with respect to disability rights.

When the Department of Trade and Industry first announced its proposals the DRC was very critical about the lack of thought that appeared to have been given to such an important issue. The needs and views of disabled people had received no consideration. I do not intend to rehearse those criticisms today. I did so in a speech I gave in London on 4 February and if you are interested in reading it, it is available on the DRC website www.drc-gb.org, as this paper will be in a week or so. Instead, I want to look ahead and consider how we can make the CEHR work for disabled people and for the other groups that will be covered by it. I think this is particularly important because it will be much easier for the CEHR to fail than succeed. It is clear that from day one it will have a number of serious fault lines in its powers. These need not be fatal but they will be damaging and are the seeds for future disharmony. Before I consider this in more detail and suggest ways forward, I would like to outline the DRC's approach to the CEHR and to civil and human rights for disabled people.

My starting point is the nature of discrimination that disabled people experience. We all know about the discrimination that is based on prejudicial and negative views of other people based on nothing more profound than their skin tone, gender, sexuality, age, religion or a disability. It seems that some people believe that they have some characteristic that makes them superior to other people. Some hold such views because their roots draw nourishment from the rich soil of ignorance. Education and persuasion might well change the minds of such people. It is easy to overlook that racist views that were commonly held just twenty years ago are not only rejected by most people but are judged to be morally unacceptable. Increasingly, they are also legally

unacceptable. Others will not be persuaded to change their views but laws can regulate their behaviour.

Disabled people have faced prejudice for many years. Disability has often been used as a metaphor for evil. We all know of Shakespeare's portrayal of Richard III. Whatever, Richard's strengths or weaknesses, there is no historic evidence that he was disabled or deformed. But the connection of physical disability and an evil mind was too strong for the Bard to resist. Disabled people are long accustomed to the discrimination that emanates from the negative views of others about our place in the world. In addition to this type of prejudice disabled people face another type of discrimination and it is this. For most of history it was assumed that it was our task to conform to a society that took no account of our needs. Disabled people see it differently. We turn Darwin on his head and say it is manifestly impossible for us to change to fit into a hostile society. Instead, society must change to meet our needs. That means that the transport system and the built environment should be built so disabled people can gain access to them. It is a simple truth that in this way every one gains, even those who are not disabled. This is the principle that informs the Disability Discrimination Act 1995.

In 1981, the report by the Committee on Restrictions Against Disabled People, chaired by Peter Large pointed out that only legislation would make building owners make their buildings accessible, lead to accessible transport systems or stop insurance companies loading the premiums of disabled people even when there was no evidence of higher risk. Despite this, the Thatcher administration argued that people did not wish to discriminate and that education and persuasion would do the trick. In fairness to that administration, they did initiate a number of measures that were helpful to disabled people, especially in the area of mobility and the built

environment. What was missing was an overarching strategy to promote the civil rights of disabled people. And in the areas of employment and access to goods and services discrimination was rampant. Persuasion was not working and, realistically, without legislation was never going to.

The Major administration introduced the DDA in 1995 because further delay had become untenable. Later this year, nine years later, the final parts of the DDA will come into effect. The Act, as then passed, exempted most employers from its provisions. That will also be put right later this year. There were a number of other major weaknesses in the DDA. Education was virtually excluded. The current Government put that right when it passed the Education and Special Needs Act 2002. There was also no enforcement mechanism. Instead of a Commission like the DRC there was created an Advisory Committee. Under the chairmanship of David Grayson it did a good job but had very few powers and could not support disabled people to bring cases under the Act. The law tends to help most those who can afford to use it. I considered the role of the Judiciary in enforcing the DDA in a speech I gave at Bristol University on 23 February. It is also available on our website.

When the Government passed the Disability Rights Commission Act 1999 it fulfilled a manifesto commitment but also gave great thought to the type of organisation they were creating. One of the most basic tenets of the disability movement in Britain and worldwide is that disabled people should have the major input on disability policy. By law at least half of the DRC commissioners must be disabled. In fact, two thirds are. This is important because although non-disabled people have an important contribution to make, it must surely be right that those most affected by the policies should have the major say in determining them. There is also a long and sad history of

non-disabled people setting the policy for disabled people and getting it wrong: not out of malice but because they failed to understand how disabled people lived and wanted to live. A large proportion of the success of the DRC has been as a direct consequence of the large number of disabled people in influential positions within the Commission working with non-disabled people who have taken the trouble to view the world in the same way as disabled people and have used their skills to help us achieve our objectives.

We knew that the DDA needed amending. It is to the credit of the Government that they have grasped this issue. I have already mentioned the new laws on education. In addition, the Government has introduced a new Disability Bill that is currently being considered by Parliament. It is an exciting Bill and I congratulate Marie Eagle who, in her role as Minister for Disabled People, has worked so hard to produce it. The Bill, when enacted, will extend the definition of disabled people, bring public transport services more fully into the DDA, and end some other current exemptions from the Act. It will also place a duty on public authorities to promote the equality of disabled people. The importance of this new public duty should not be underestimated. At the moment we are seeking to prevent discrimination but in future public authorities, and that includes Liverpool University, will have a duty to promote equality. It is a major shift of emphasis.

The DRC has a heavy workload. In October of this year all organisations that provide goods or services to the public will be required to ensure that their services are accessible to disabled people. This does not mean that all the buildings must be accessible but that the service must be. Employers who employ 15 or fewer people will be covered by the employment provisions of the DDA. These

are important changes and will take time to implement effectively.

Moreover, we will have a new Disability Act. It is expected to be implemented in stages between 2005 and 2006. We need to write a Code of Practice on the new transport provisions, update current Codes, and lay the ground for the new public duty. The implementation of the first provisions on the DDA in 1996 and ending with the implementation of the new laws in 2006 will represent a decade that will have seen more legislative change to promote the rights of disabled people than has taken place at any time in the recorded history of this country. A remarkable achievement! But it will not end in 2006. The enacting of a law is but the first step on its journey to full acceptance and enforcement. There will be much to do after 2006.

The DRC is also concerned about other aspects of disabled people's lives that are not covered by equality legislation. One example of this is Independent Living. Another is the access of disabled people to health services. These topics are best considered under human rights legislation. The DRC Act does contain a power, currently dormant, to allow the DRC to assist disabled people to exercise their human rights but the Government has declined to enact this section of the Act on the basis that the whole issue was being considered in the debate on the proposed Commission for Equality and Human Rights. Let me now consider the CEHR.

When the European Employment Framework Directive was passed it was inevitable that some changes would be necessary. The Directive gave protection in employment against discrimination on account of age, sexual orientation or belief systems. Five years passed between the DDA being approved by Parliament and the DRC being established with powers to enable disabled people

to enforce the rights that Parliament had granted. Disabled people know of the futility of rights on the statute book that cannot be enforced in practice. The rights of the new strands will be in effect by 2006. There had to be a mechanism to enable them to enforce those rights. Other options apart from the CEHR could have met this objective but it is clear that the CEHR is the Government's preference.

The DRC has never opposed the CEHR in principle. Nor have most organisations of and for disabled people, although some like the Association of Disabled Professionals have opposed in principle. Our, and others, objective has been to ensure that the full agenda I described earlier is delivered. That will take about 8 to 10 years from now. We also need to ensure that the pressure is maintained for further changes. In April 2000 the DRC published its first legislative review of the DDA. I am pleased that the Government have accepted a number of our recommendations. Inevitably perhaps, they have not accepted them all. I am not too disappointed because I believe that in the fullness of time they will be accepted and implemented: but it does take time and we need to ensure that there is a Commission that will be careful not to drop the ball and will eventually score the goal. The biggest danger of the ball being dropped will arise if disabled people lose control of the agenda. One of the mantras of the disability movement is "Nothing about us without us". There is no possibility of this happening at the DRC but because the first proposals for the CEHR assumed a model in which all the stands were merged there could be no assurance that the disability agenda would not slip. In Northern Ireland the Equality Commission is operated on this basis but, despite the protestations of its chair, Dame Joan Harbison, it does not have a single disabled commissioner. That is outrageous and very worrying. The DRC has, therefore, in its many representations to Government over the last year, sought

to find a structure for the CEHR that will enable it to serve all the strands but also ensure that the work of the DRC will continue within the new commission and that disabled people will still be very influential.

I was pleased when the DTI agreed to establish a taskforce to advise on the White Paper to be published in Spring. The Taskforce did not meet for long enough to enable consensus to be reached on the more tricky issues but it did enable the various players to get to know each other and to learn more of their hopes and anxieties. It is welcome that a summary of their discussions is being placed on website of DTI's Women and Equality Unit, and this makes interesting reading.

We are told that the White Paper will be published in the Spring. I noted while driving through Sefton Park here in Liverpool that the blooms were bobbing in a balmy breeze, so I assume the White Paper is imminent. I also hope the DRC will be able to give it a warm welcome. But that depends on its content. We will be looking for comfort in a number of areas to achieve the objectives I have already outlined. However, there are already indications that the White Paper will say some helpful things on disability and I would like to thank Maria Eagle and her fellow ministers for their input.

In the CEHR it will be impossible for the majority of the commissioners to be disabled. It will have broader functions than the DRC and that will need to be reflected. There should however be a commitment that at least one commissioner will be a disabled person. In view of the experience in Northern Ireland we would expect this to be included in the primary legislation that establishes the CEHR. Although the CEHR will not be a representative organisation in the conventional sense, the only rational reason for establishing it is to serve those who face discrimination. It must work with discriminators but it is not

being established for their benefit. Disabled people must have some ownership of it if it is to serve us. I think the same argument could be made for all the other strands and that is why the DRC argued for a strand based model in which all the strands would be represented. I respect the view of those who oppose a strand-based model and hope they will respect the DRC's view that there must be a disabled commissioner. The DRC would have no objection if the BME community wanted their own commissioner, or indeed any other strand. They will be able to work collectively because if the CEHR fails any strand it risks failing as an organisation and therefore serving nobody. It is in our individual interests to recognise other people's.

However able the disabled commissioner might be he or she cannot act alone. I think that there must be a disability committee within the CEHR and that at least half of its members must be disabled. It should have executive powers on disability specific matters and have an appropriate budget to carry out its functions. Again there will be some objections to this. Could the disability work of commission distort the structure and work of the CEHR? I don't think it will. It has a huge amount of work to do. It is also difficult to see how the disability agenda can be implemented without such a structure. Disabled people and our supporters would not remain silent if the work initiated by the DRC ground to a halt. We do not want the CEHR to be embattled with one of its major stakeholders.

Again, this committee and its role should be enshrined in legislation. If disabled people are to have faith that it represents a solid commitment to disabled people, it should not be possible for the committee to be dissolved prematurely. Ideally, it should exist for at least ten years from the start of the CEHR. However, Parliament operates in five year terms, so we could live with a review

of the disability committee after, not before, it has been in existence for at least five years. But it must be a genuine review and disabled people and their organisations must be consulted. It should not be assumed that there will be change even though by 2012 much of the current disability agenda should have been delivered. There will, of course, be a new agenda but those involved at the time should address the best way of dealing with that. However, the committee should be backed by a sizable Disability Unit, which is fully resourced for the tasks it must take on, particularly successful implementation of the legislative changes.

This does not mean that disability within the CEHR will operate separately from the main organisation. It makes sense to work with the other strands. We can learn from and support each other. We are already working with the Commission for Racial Equality on how we can best introduce the public duty I outlined earlier. The EOC has been pressing for a public duty on gender. This to me, makes perfect sense and I hope the Government will find ways to address this issue. Indeed, why not extend the public duty to all six strands?

When a single equality commission was first proposed in January 2000 in the Hepple Report, it called first for a Single Equality Act to equalise the rights of all the strands to the highest standard. While the nature of disability would still require some special provision for disabled people, the failure of the Government to introduce a Single Equality Act is disappointing. It means that many of the gains of the CEHR will not be realised because of the asymmetric structure of the rights of the people it seeks to protect. It also means that a large part of its future campaigning work is pre-ordained. We will have to fight to ensure that the new strands obtain the same rights to goods and services as the three traditional strands enjoy.

It is not too late for the Government to address this and give the CEHR a better start.

A major concern for disabled people is the whole question of human rights. It seems likely that the CEHR will have powers or perhaps even a duty to promote human rights but it will not have powers to help people enforce their rights. The Government has explained its position with clarity. In the March 2004 edition of Policy Review Magazine, Lord Falconer wrote that the Government wanted a human rights culture rather than a litigation culture. On that basis there was no need for the CEHR to have powers to enable people to enforce their human rights. This makes it more difficult for disabled people to enforce our rights for our dignity to be respected in health and social services. While we can all agree with Lord Falconer that we want a human rights culture, I think we will fail to achieve that without the power to enforce the law. This has been the experience in disability rights legislation. Moreover, there is no reason not to give the CEHR human rights powers. The three existing commissions currently bring fewer than 250 legal cases a year collectively. Most disputes are resolved without access to the courts but only because discriminators know the law can be enforced. The current commissions can hardly be regarded as litigious and when we do use our powers it is strategically. For example, of the eight significant DDA cases reported by the expert lawyer, Michael Rubenstein, in his recent Industrial Law Society lecture, seven were supported by the DRC. Giving the CEHR effective human rights powers would give added value to the roles of the current commissions. I hope the Government will not lack the courage to grasp this nettle.

A major role of the CEHR is to promote social cohesion. I don't intend to attempt a definition of this elusive concept today, but it seems to me self evident that the CEHR cannot promote it without if it fails to exist within. The

greatest way to promote disharmony within the CEHR is to create a situation in which each strand has to battle for resources to end discrimination against that strand. Of course there will be many ways of working together in our mutual interests. We all have many facets to our personal identities. Most physically disabled people are aged over 60. There is no reason to believe that the percentage of disabled people who are gay, lesbian or bisexual is any lower than in the population at large. Disabled people are part of every ethnic and cultural group, so we have much in common. But all the strands have aspects that are unique and although resources will always be finite there must be sufficient resource to enable each of the strands to do what is necessary. Add to this that the new Commission will be responsible for three very major new strands as well as having some form of human rights remit and a regional and local presence to support, you can see the resource that will be needed.

If the CEHR is to be more than the sum of the current commissions with new duties added it must have adequate resources. It is not acceptable to merely add together the incomes of the current commissions and suggest that there can be economies of scale and that these saving will meet the costs of the three new strands. It will produce a weak CEHR. It must have a decent budget and that will need to be in the region of £100 million pounds a year. We must also ensure that this modest amount is not reduced over the years by inflation. The CEHR must not be a produce of the bargain basement counter.

If we get these essentials rights the CEHR really could be a major advance. The various strands are already working together. We all have much to offer and collectively we could change our society for the better. Instead of talking about celebrating diversity we should be able to create a society in which we value people

regardless of age, religion or belief. We should ensure that race, gender and disability, as well as age, sexual orientation, and religion and belief are qualities that make life interesting for us all and gives us a country in which equality is the practical experience of all our lives and not merely a hope for a distant future.

Bert Massie

Keywords: Commission for Equality & Human Rights; Disability Discrimination; Disability Legislation; Human rights

Bert Massie Implementing the Disability Discrimination Act in Higher Education and the draft Disability Discrimination Bill May 2004

Speech by Bert Massie, Chairman of the Commission to the Equality and Diversity in Higher Education conference at Liverpool John Moores University on 6 May 2004

It's good to be able to come to talk to you all today.

I thought I'd begin by reminding you where we've come from with a short story concerning a young disabled woman who wanted to become a nurse.

Nikki had a difficult birth which resulted in her having to have her left arm amputated when she was two weeks old, in addition to other complications experienced during her early childhood. As a consequence, her early life involved frequent visits to hospital.

It was this experience that led Nikki to develop a lifetime ambition to become a nurse. Barely past being a toddler, Nikki had decided what she wanted to do in life and how she wanted to make a contribution.

She worked hard throughout school and in further education to get the qualifications she would need to get onto a nursing degree course, her vocation becoming ever more important to her. She was fortunate to have teachers and others around her, encouraging her along the way.

And then she began applying for nursing degree courses. And then the refusals began to come back.

The Universities would not accept Nikki onto their courses because in their view she would not have the required manual dexterity to undertake the tasks required of a

nurse and so in their view would not be able to complete the course or be registered to practice.

All of this happened before Part 4 of the DDA came into force in September 2002.

Nikki had no right of redress to challenge these refusals. A lifetime ambition dashed. Commitment and talent wasted. One less nurse when we have a desperate shortage.

And that's why the DDA is so important.

Not just because Nikki would have been able to challenge these decisions, or because it requires Institutions to scrutinise their admissions policies, the way they organise curriculum and assessment, their accessibility, the support they provide and perhaps most fundamentally their attitudes and assumptions concerning what disabled people have to offer and can achieve.

The DDA is fundamentally important because it aims to remove barriers and in doing so unlock potential.

But of course we still have a way to go. In January 2002, the National Audit Office reported that disabled people aged 18 are less than half as likely to go into higher education than their non-disabled peers.

Discrimination and disadvantage does not disappear overnight – it is deeply rooted - not just in attitudes and assumptions but within the built environment, organisations and systems, within tried and tested ways of doing things, within professional norms, within the way we learn and the way the world is presented to us.

And it is not simply a thing of the past. Unforeseen discrimination and disadvantage can easily emerge in the future if we do not bring issues of equality and diversity centre stage.

But there are good signs.

More and more Institutions are recognising the talent and potential of disabled people and finding innovative ways to remove barriers and support their learning.

Disability officers are tireless in their quest to find workable solutions to ensure disabled students can participate.

Organisations such as the National Disability Team and Skill continue to fly the flag of disability rights whilst working as constructive partners with Institutions to develop and disseminate good practice.

The key funding and professional bodies have all worked alongside DRC and Skill to get advice on the DDA duties to Institutions and their members.

Institutions have benefited from additional capital funding of £40 million pounds per year between 2004-5 to 2005-6 to improve physical accessibility and programme funding to develop good practice courtesy of the Higher Education Funding Council for England and the Department for Education and Skills.

The second set of DDA duties, to provide auxiliary aids and services, came into force in September 2003. It is a little early to detect how well these are bedding in.

As you will be aware, further duties, concerning physical access come into force in September 2005. Universities will need to have audited their estates and put in place plans to make reasonable adjustments, such that existing and future disabled students are not placed at a substantial disadvantage.

Since September 2002, the DRC's Helpline has dealt with almost 6000 specific queries concerning education and the DDA. Key themes include:

Institution's viewing Disabled Students Allowance as the sole vehicle for providing auxiliary aids and services, and students being left without vital equipment and support as a consequence

The duties not being owned Institution-wide – particularly not by teaching staff where there appears to be reluctance to adopt more inclusive teaching practice – for example: instances where students have been told they can't tape record lectures, or are not provided with notes in advance, even where this is part of the learning agreement between the student and the institution.

No clear lines of responsibility in Institutions, meaning students are passed from pillar to post to ensure their most basic requirements are met

Numerous cases of students failing to obtain adjustments to examinations – quite often with Institution's citing the rules of external professional or awarding bodies as justification

Disabled students being excluded from the social life of University because Student Union buildings are not accessible and Unions have few resources to make adjustments.

On this latter issue of course, we may not know the full extent of physical access barriers until the last part of the duties come into effect in September 2005. We hope we won't be flooded with cases in this area because Institutions will have had plenty of time to prepare and avoid such litigation!

In terms of the impact on students of discrimination: many are distracted from their work, are unable to take-up and enjoy the social aspects of University life while they are busy sorting out adjustments, talk of giving up their courses, suffer stress and depression and, particularly for those for whom University is the first step towards

independent adult life, have their confidence in the wider world severely undermined by their experiences.

The cases have also highlighted some loopholes in the legislation as well as some major systemic barriers to disabled people's participation.

A major barrier, as highlighted by Nikki's case, concerns academic standards. A combination of misperceptions concerning disabled people's abilities, the nature of reasonable adjustments and what in fact constitutes an 'academic standard' have led to a number of instances of discrimination.

Additionally, the DRC is concerned that an unfortunate product of education being increasingly geared towards the needs of employers, is that academic standards and competency frameworks of vocational qualifications might embody the underlying causes of discrimination and disadvantage experienced by disabled people in employment. That is to say, disabled people experience discrimination in our education system, because it is meeting the demands of employers.

In the case of Heidi Cox vs the General Medical Council, Heidi needed certain adjustments, as a wheel chair user, to be made to her course so that she could complete it. Although such adjustments could readily be made by Oxford University, the GMC argued that they so diminished the quality of the course that it could not be validated for qualification purposes. The GMC suggested though that if Heidi had already started her course of studies and then become disabled, the adjustments to the course would have been acceptable. The case was lost because the GMC argued they were not a Trade Association and so not covered by the DDA at that time.

The amendment of Part 2 of the Disability Discrimination Act to cover qualifications bodies from October 2004 should have some bearing on this situation.

There is still debate as to which bodies are or are not covered by these duties. This leaves uncertainty concerning bodies which are not, in the view of the Government, bodies which confer qualifications for the purposes of facilitating a person's entry into particular trades or professions, including bodies which set the standards in which qualifications are set, but who do not themselves confer the qualification. DRC will look at opportunities to clarify this issue in the coming months.

Lessons can be learnt from the new duties, even where they may not directly apply.

The duties will make it unlawful for qualifications bodies to discriminate against a disabled person in the conferring of a trade or professional qualification by that body.

Whilst the duties will not require qualifications bodies to make adjustments to genuine 'competencies', they will be required to scrutinise what is and is not a genuine 'competency'.

Generally, there is a difference between a competence standard and the process by which attainment of the standard is determined.

For example, a requirement that a candidate must complete 12 qualifying sessions for qualification as a barrister, which usually consists of attending 12 dinners is unlikely to be considered a competency.

This is important because the answer to whether something is a competence standard will significantly affect both the rights of the disabled person and the duties of the qualifications body.

That is to say, the reason a disabled person may not be able to demonstrate a competency may be because the qualifications body has failed to make an adjustment to the way attainment of that competency is determined, not because they do not actually possess the requisite competencies.

Whilst Institutions currently have duties to make adjustments to testing and examination arrangements, it is DRC's experience that some have failed to do so, asserting the rules of external qualifications bodies as justification. From October 2004, we can use the DDA to scrutinise these rules to ensure they concern genuine competencies. Institutions may be found to be aiding and abetting qualifications bodies if discrimination occurs, so there is an additional impetus for Institutions to scrutinise competencies and make their views known to qualifications bodies if they believe them to be discriminatory.

We are also aware of practice whereby students who have had adjustments to exams and tests and pass these tests successfully, then find that the adjustment is noted on their exam certificate or alongside it. We are concerned that in some instances this may constitute unlawful discrimination.

Disabled people are also precluded from a wide range of trades and professions because they are not able to, or are not perceived to be able to, demonstrate the full range of competencies required to obtain entry qualifications. Yet within these trades and professions, a range of roles exist which do not all require post-holders to put into practice the entire range of competencies they would need to demonstrate to pass the course.

This is the case in nursing.

DRC supported a young woman who applied to go on a nursing degree course. An educational psychologist

assessed that with the appropriate support she would do well in both academic and practical elements of the course, and yet the University refused to admit her because they feared that by conferring the degree, this in turn would register her to work in all areas of clinical practice, including in areas they considered might present a danger to patients or in which she would not be able to demonstrate the required level of competence.

Additionally, in employment, a person who becomes disabled may be entitled to a reasonable adjustment which means that what is held to be a competency within a professional qualification can be altered or delivered by another as support for that individual.

This is not an attack on academic standards – they are clearly important and the DRC has no desire to diminish standards where they are objective and fair. We do however wish to see a level playing field, and this might require scrutiny concerning the relevance of standards, their consistency with modern employment practices and the rights of employees, and the ways they influence admissions, teaching and learning, and assessment.

Of course, before all of this, young disabled people need the educational opportunities to achieve in school and further education.

By achievement, the DRC is not only interested in educational attainment, though we believe this is crucial. We also want disabled people to hold the same life skills, hopes and aspirations as non-disabled people.

In November 2002 we surveyed the aspirations and experiences of young disabled people. We found many with low expectations concerning educational and employment opportunities.

A significant number felt that they were actively discouraged by their teachers in school to consider higher education. A third said they did not expect to be earning the same as their non-disabled peers by the time they were 30.

The DRC wants to transform both society's and disabled people's expectations.

We have recently submitted our next 3 year strategy for approval by the Secretary of State for Work and Pensions. In education we want to close the qualifications gap between disabled and non-disabled people aged 16-24 and also ensure disabled peoples full participation across school and college life.

We want disabled people to enjoy:

- A framework of rights which secure equality of opportunity

- A fair and barrier-free system of qualifications and curriculum

- Inclusion across the whole life of our schools and colleges

- Disability equality as a guiding principle of policies, practices and programmes

- More opportunities to work in the education sector as teachers and lecturers

- DRC will work hard over the next 3 years, with our key partners, to seek to achieve these aspirations.

A key lever will hopefully be provided by changes to the DDA itself.

The draft Disability Discrimination Bill currently before Parliament takes forward a number of the legislative recommendations of the Disability Rights Task Force which reported to the Government on achieving civil rights for disabled people in 1999.

Of most significance to the Higher Education sector is the draft duty on public authorities to prevent discrimination and promote equal opportunities for disabled people.

Many of you will be familiar with the provisions of the Race Relations Amendment Act, which came in the wake of the inquiry into the Metropolitan Police's handling of the investigation of the murder of Stephen Lawrence. The inquiry had highlighted 'systemic' discrimination within the Met – that is, factors within its structure, organisation, systems, policies and approach – that had a disproportionately negative impact upon minority ethnic communities. The legislation that followed requires public authorities to take proactive action which is both 'relevant' and 'proportionate' to root out systemic discrimination and also to actively promote equal opportunities.

The provisions in the draft Disability Discrimination Bill broadly mirror those of the Race Relations Amendment Act. Subject to its successful passage through Parliament, the Act will require public authorities, in everything that they do, to take action to eliminate unlawful disability discrimination and promote equality of opportunity.

The draft Bill also proposes regulation-making powers, enabling the Secretary of State to introduce what are called 'specific duties' on the public sector. We hope that the Government will use these powers to introduce duties equivalent to those in the Race Relations Amendment Act, requiring higher education institutions to develop schemes setting out how they will meet the duties.

The draft Bill is currently subject to pre-legislative scrutiny, the Scrutiny Committee will respond on 24 May 2004, and we are hopeful that a Bill will be announced.

We are eager to learn from the experiences of public authorities in implementing the Race duties, and also to

ensure that those with duties have high quality, practical and timely advice on their legal duties.

During the next year we plan to work with the Learning and Skills Council to develop a pilot disability equality scheme, ahead of the legislation coming into force, in order to identify how the law will work in practice, iron out difficulties, learn and to use this learning in the development of advice and guidance for the education sector. Later this month we are meeting with colleagues from Higher Education Funding Council for England, the National Disability Team, the Equality Challenge Unit and DfES to begin scoping out what the duty may mean for higher education and how we can work together to support institutions in implementation

During 2005-6 we will be developing non-statutory guidance for the further and higher education sectors and we will do this in the consultative manner that is characteristic of DRC's approach.

For progressive Institutions, implementing these new duties is likely to be a process of consolidating existing strategy and programmes, be it your DDA implementation programme, widening participation or Aim Higher strategies, or broad equalities policies and programmes, for example.

For those who have had their heads in the sand, or who have calculated that they can afford to pay-off individuals who bring cases against them, we are looking at a whole new ball game.

It is likely that, as with the CRE, the DRC and its successor the Commission for Equality and Human Rights, will be empowered to issue non-compliance notices to those Institutions who fail to get their house in order. We do not require an individual complainant to do this.

It's time for those Institutions who have failed to embrace the spirit of the existing legislation, instead opting for fending off legal action brought by individual disabled students, to think again.

There are some other legislative changes on the horizon. The Government have yet to implement elements of the EC Directive concerning vocational training. We hope these will be implemented across the Post 16 education sector, in order to prevent Institutions having different duties pertaining to different courses. It would follow that Part 4 of the DDA will be amended to implement the Directive. On the ground, these changes are likely to mean little to those of you already making reasonable adjustments. In the Courts, it will mean that Institutions will not be able to justify direct discrimination or failure to take reasonable steps. DRC will need to revise the Post 16 Code of Practice in due course to take account of these changes.

Finally, the Commission for Equality and Human Rights.

The Government's has set out its vision on the formation of a single Commission that will tackle discrimination and disadvantage in Britain for all its citizens. The Disability Rights Commission is working constructively with the Government and others to make this vision a reality. The CEHR task force, of which DRC was a member, has recently completed its work and made a series of recommendations to the Government, who will shortly publish a White Paper concerning the Commission.

The DRC welcomes the Government's commitment to ensuring that the new Commission will cater for the distinct needs of disabled people and that the important reforms on the law on disability discrimination will continue. We are pleased that the Government has acknowledged the importance of human rights in

achieving equality, but disappointed that the new commission will not have power to bring human rights cases.

However, we are still concerned that the Government does not explicitly plan to harmonise the law on equality. The Government's stated commitment that the new Commission should aim to achieve equality for all must imply dealing with the current patchwork of equality legislation, which provides comprehensive cover for some but scant protection to many. The argument for Single Equality Act to accompany the new commission is now compelling.

So we've come a long way in a short time, but there is still a way to go and a number of challenges ahead of us.

And this is probably a good point to come back to Nikki. I omitted to tell you there was a happy ending. In Nikki's own words, each time a refusal came back she thought 'sod you – I'm going to be a nurse'. And her persistence thankfully paid off. One enlightened University in the Midlands recognised her commitment and potential and admitted her to the course. They made adjustments and provided the support she required. Nikki passed the course with flying colours and is now a practising nurse.

She has chosen to specialise in working with patients who have had a stroke, and is uniquely able to advise them how to live with the use of only one arm.

This is what disability rights is really about:

- Transforming expectations
- Accepting that our individual differences are more often than not our individual strengths
- Embracing potential, not pinpointing deficiency
- Enabling everyone to make a contribution
- Removing unnecessary and avoidable barriers

And in doing so ensuring fairness and equality for all.

Thank you.

Keywords: Disability Discrimination; Higher Education;
Qualification bodies

Bert Massie Rights and Duties the Legal Requirements May 2004

Speech by Bert Massie, Chairman of the Commission, to the Neil Stewart Associates Conference on Disability and Access to Services, in London on 18 May 2004.

Introduction

Thank you all for coming today, and I hope you enjoy what looks like an interesting and informative day. My role this morning is to tell you about the Disability Rights Commission and to give you an idea of what the Disability Discrimination Act requires. In addition, I'll briefly explain what the DRC has been doing to help organisations prepare for the new law through our campaign, Open 4 All.

The DRC

The Disability Rights Commission is an independent body, established by an Act of Parliament to eliminate discrimination against disabled people and promote equality of opportunity.

To achieve this, we have set ourselves the goal of "a society where all disabled people can participate fully as equal citizens".

The DRC

- provides advice and information services for disabled people and service providers;
- supports disabled people in securing their rights under the Disability Discrimination Act (DDA); and
- campaigns to change policy and strengthen the law so that it works better and protects more disabled people.

The DRC has a broad obligation to promote equality of opportunity for disabled people in Great Britain; an essential element of this is an inclusive environment. Many of Britain's 10 million disabled people cannot access education, employment, social or political involvement because they are physically barred from participation.

Access for Disabled People

Accessing a service is part of every day life, visiting the library, or the doctor's, or going out for dinner, or taking your children swimming or even taking all those wine bottles to the recycling centre. You quite rightly take this for granted. But is it acceptable that many disabled parents are unable to take their kids out because of thoughtless design? Is it acceptable that many young disabled people can't attend the youth centre with their friends? The uneven path in the swimming pool car park, the steps at the community centre or the terrible lighting and glass doors at the restaurant can stop them doing this. This has to change.

There are almost 10 million disabled adults in Great Britain who try to access services every day, not only do they have £50 billion to spend annually at your leisure centre or in the local town centre but they are potentially all voters and they are all taxpayers.

In October last year the DRC launched an NOP survey to examine disabled people's experiences of service provision. The survey found that 70% of disabled people with mobility problems have experienced difficulties using services, particularly when trying to use leisure facilities.

All of this adds up to an awful lot of disabled people who are being excluded from local services and therefore excluded from their local communities.

Here's an example:

When a public meeting was called to discuss planning and conservation issues affecting her street, Sue, like many other residents, wanted to attend. But the public meeting was held in an upstairs room at the offices of the Council, a converted house in the town. There was no lift, and Sue's disability made it impossible for her to climb the stairs. When a second meeting of interest to her was publicised, Mrs Levy got in touch to ask what arrangements could be made so that she could attend. "They initially suggested that councillors could carry me upstairs, and then said that if I was able to tell them in advance which meeting I wanted to attend they could move the meeting to a ground floor accessible venue in the church hall next door."

So far so good – but when Mrs Levy saw the notice of the next meeting and rang the council she was told that the meeting venue couldn't now be changed because it had already been announced. She was then told by the Council that moving the meeting would cause too much disruption, and that the extra cost of hiring the adjoining hall could not be justified. "They said that if I told them which part of the meeting I was interested in they would move downstairs for that item – so I was expected to sit in a room downstairs and wait while 140 people attended a meeting upstairs!

And another example:

When Ann received her first invitation to attend a breast screening unit in her local town, she immediately responded to the request to call "if you cannot walk up eight steep steps unaided." Ann, whose chronic conditions include different types of arthritis, diabetes and heart disease, and who is wheelchair-dependent outside, was concerned about the word "unaided."

She called the centre and explained it would be

impossible for her to climb the stairs of the mobile unit without help. When she called she was told that she could not bring a carer with her because there wasn't enough room and the staff were not allowed to help her because of health and safety regulations. When they supplied Ann with a floor plan of the mobile unit, it became apparent it would be almost impossible for her to access the service anyway because there was little room for her wheelchair.

Ann was offered an alternative – screening at the main clinic in a centre 80 miles away in Swansea but she would have to make the journeys at her own expense. Luckily, Ann contacted her GP who arranged for her to be screened at her local hospital, just half a mile from the mobile unit's base. "Apparently they made an exception for me, but how else could I be screened?" she says.

The Disability Discrimination Act

Since 1995 the Disability Discrimination Act has already introduced major new rights of access for disabled people to almost every form of service provided to the public; everything from the hospital, to the bank, to the local park.

As a service provider you should already be ensuring that your policies and practices open up rather than close off services to disabled people and consider what other help or other equipment you could provide to improve access for disabled people.

We get a large number of calls to our helpline about these duties that are already in place. One example is a caller who had asked his local council to send all letters in Braille. The caller was told this could not happen and that he must call in each time he received a letter and request that it now be sent out in Braille. The caller pointed out that he could not read the letter so how was he meant to know who it was from.

The questions I would ask you are has your organisation looked at all its policies and procedures to ensure they aren't preventing disabled people using services? Do you have a method of ensuring that you provide that particular help or equipment that will improve access for disabled people? Also very importantly how do you monitor this and ensure all the staff in your organisation are involved?

The final part of the service providers' duty to make reasonable adjustments to physical features comes into force on 1st October this year.

You will have to look at what reasonable improvements you can make to the physical features of premises to make sure that disabled people don't find it unreasonably difficult to use your services.

These could be major changes and need planning, which is why the Government gave nine years notice of these duties in order to give you time to prepare.

Some service providers have already taken these duties to heart and are making substantial and strategic changes, and I can see some of you in this audience.

However with less than six months to go, research indicates that others are confused or unaware of these duties and some have their head firmly in the sand!

What happens in October 2004?

Service providers are required to do what is reasonable – and this will depend on a number of factors, most obviously the cost of the adjustment weighed against the resources of the business.

The DRC has produced a statutory Code giving guidance on Part 3 of the DDA relating to the duties of service providers. We attempted to shed light on some of these

areas – for example, the question that all service providers quite understandably ask is “what is considered ‘reasonable’?” This will depend on all the circumstances of the individual case including factors like the size and resources of the service provider and how many other improvements the service has made. It's really about horses for courses.

For example, it's unlikely that a small community hall, run by voluntary committee and with a very small income would be required to provide new completely accessible toilets. However, the situation may be very different for the council assembly halls or a large music venue.

It is also important to remember that you are trying to make your service accessible, not necessarily the premises in which you operate, its time to think laterally! For example could you move services to a more accessible part of the building?

Within the Act, service providers are given the choice between removing the physical feature, altering it, avoiding it or providing the service by a reasonable alternative means.

It is important to say that the DRC strongly believes the best solution for everyone is either removing or altering the physical feature.

The reasonableness approach does, however, mean that large and well-resourced service providers, such as yourselves, will be expected to do much more. We have examples of banks, supermarket chains and local authorities spending millions of pounds on physical improvements to their premises in order to improve access to services.

Large service providers in all sectors will be expected to have a positive approach to access improvements. Ideally

this will be a plan of improvements drawn up in consultation with disabled people, and crucially with expert advice, which are clearly achievable within a reasonable time.

The DRC obviously hopes that in the vast majority of cases that situations of discrimination can be avoided and that providers of services and disabled people can work together to get things right. Having said that we are fully committed to ensuring that disabled people have the right to use services in the same way as anybody else and we see this October as a real turning point.

These new duties apply to anybody providing a service, whether you charge for it or not. I've noticed that many of you here today are from the public sector or local authorities.

These changes will have a significant impact on local services whether these are provided by the local council, voluntary organisations or other bodies on your behalf.

Disabled people aren't some special group who are only interested in social services, they are regular all round users of local services-customers just like anyone else.

We aren't just talking about putting a ramp up the front of the town hall, although that might be useful. We are talking about improvements to the premises where a whole range of services might be delivered from including:

- Libraries

- sports centres and swimming pools

- youth centres

- housing offices

- the street environment

- information and advice centres

- recycling centres

- finance and social services offices

estate or community halls
parks and open spaces
and every other service the council provides to the
public.

The DRC and the Local Government Association have produced an excellent Strategy which sets out in the clearest terms how local authorities can succeed in improving their services for disabled people. But other organisations, be you public sector bodies or businesses can learn from this strategy.

There are some very clear lessons from the strategy that you will need to take on board to succeed:

Leadership - these kind of service improvements can't happen without leadership from the senior levels within an organisation, this needs to be strategic leadership and commitment from the council leader or the Chairman and managerial leadership from the chief executive and senior management team

Diversity - access to services for disabled people must be recognised as part of the important diversity and equality work that organisations are engaged in. Increasing access for disabled people is an important factor in tackling social exclusion and in increasing the numbers of people who use your services, not just disabled people

Mainstream - disabled people are your customers, staff, voters and every day people in the street, so improvements to ensure they can use services must be the responsibility of everyone within an organisation, from the chief executive to the reception staff

Get on with it... there really isn't any time to spare and the days are ticking away to this October.

A note about websites

One particular area which may require specific attention is that of websites. The DRC recently conducted a formal investigation into company websites and found that over 8 in 10 websites were difficult for disabled people to use. This meant that they found it impossible to pay their council tax, open a bank account or buy theatre tickets online. Despite the fact that many changes are very simple to make, the fact remains that many businesses and services aren't doing it.

The website you provide is a part of your service, and should also be accessible to disabled people.

Open 4 All

Specifically in relation to these new DDA duties the DRC is running a major campaign called "Open 4 All". Launched by the DRC in October 2003, we have been working with business and professional organisations, local government associations and the health service, to spread the word that these new duties are coming, and to offer practical advice about improving services.

The DRC has an excellent website which provides up to date information, advice and links for service providers. For details of how the new law affects you, please log on to www.open4all.org.

This is a great opportunity for all organisations providing services not only to meet their obligations but to open up your services to the large numbers of disabled people, and their friends and family, in your community.

We will make this country accessible for disabled people. The only question is whether we do it slowly or quickly. If helped by friends such as yourselves it is a battle we will win quickly.

Enjoy what looks like a very interesting day and please help us make Britain Open 4 All!

Keywords: Access to services; Disability Discrimination Act 1995; Disabled People

Accentuating the Positive Disability Rights and the idea of a Commission for Equality and Human Rights

A talk to the Industrial Law Society by Nick O'Brien, Legal Director at the Disability Rights Commission given at St. Catherine's College, Oxford on 10 September 2004

Oxford is probably as good a place as any to speak of social exclusion, and this college dedicated to St Catherine especially so. In the nineteenth century when Hardy's Jude Fawley, and whole generations of women, working class and non-Anglican men, were locked outside the gates of this university, the college that was to become St Catherine's began life as a society for matriculating students too poor to gain entry to the university. It is incidental to the merit of this socially inclusive initiative that the name of St Catherine was taken by mistake. For their meeting place the early students apparently used dining rooms on Catte Street, just by the Bodleian library, and 'Catte' was mistakenly thought to be an abbreviation of Catherine, from which the modern college took its name. There can't, I suppose, be many Oxford colleges named after a café (as Terry Eagleton once observed), but the fact that this one is lends it a particularly pleasing ambience for this part of the proceedings.

I say that because my subject today is, in a sense, social exclusion, being kept outside the gates, and what can be done about it, and in approaching it I want to talk about two things: first, about disability rights, about whether there are such things, what they amount to and what they might become; and secondly, about what disability rights tell us about the idea of having a combined Commission for Equality and Human Rights, in other words about what contribution disability rights might make to our thinking and practice on equality and human rights more generally. My argument will be that there is a distinctive dimension to

disability rights, a quality that distinguishes disability rights from other equality rights as currently framed, such as those to do with race and gender, yet which also offers a compelling model of what equality and human rights, and so social inclusion, might be about across the board. On this account, far from disability being the poor relation on the equality scene it turns out to be pivotal to a proper understanding of what equality and rights talk are for: in other words, disability is in fact the point at which the various strands of a Commission for Equality and Human Rights might fruitfully converge. But I want to do more than this. I want as well to say something about the sort of institution an equality commission is (and in so doing I will briefly touch upon the sort of institution the Disability Rights Commission has so far been) and about the place of law within its practice.

But first of all: is there such a thing as disability rights and if so what do such rights amount to? It may seem perverse to ask this preliminary question. Yet the answer has not always been uncontested. At the philosophical level there are those who, although not unsympathetic to the cause of disabled people, would argue that the idea that those who are disabled have absolute claims upon the community at large as a matter of right, as opposed to as a matter of benevolence, is misconceived, that the proper response to the disadvantage experienced by a disabled person is not indignation but sorrow or pity. Politically, this philosophical position has in the past been translated into social policy that identifies disability as the object of social welfare initiatives and benefits, supplemented wherever possible by the work of the major disability charities. It was not until the enactment of the Disability Discrimination Act 1995 (DDA), a rather late arrival on the anti-discrimination scene, that disabled people in this country enjoyed for the first time a reasonably comprehensive (although far from exhaustive) set of positive rights to supplement welfare provisions. The path that had led from the campaigns of

Vietnam veterans in America to the inclusion there of disability on the civil rights agenda and in due course to the Americans with Disabilities Act of 1990, had at long last found its way to the statute book here too. So whether disability rights quite fit the 'natural rights' bill, as 'positive rights' they have made a fairly grand entrance and are very definitely here to stay.

What then of those positive rights: what sort of thing are those disability rights enshrined in the DDA? 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 nearly 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 (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 TDG Ltd t/a Novacold*, 1999 IRLR 318) scotched the notion that simple equivalence or equal treatment is the key to disability rights. As Mummery LJ put it,

'Less favourable treatment of a disabled person is only discriminatory under s. 5 (1) if it is unjustified. Treatment is less favourable if the reason for it does not or would not apply to others. In deciding whether that reason does not or would not apply to others, it is not appropriate to make a comparison of the cases in the same way as in the [SDA] and the [RRA]. It is simply a case of identifying others to whom the reason for the treatment does not or would not apply. The test of less favourable treatment is based on the reason for the treatment of the disabled

person and not on the fact of his disability. It does not turn on a like-for-like comparison of the treatment of the disabled person and of others in similar circumstances’.

In short, in the opinion of Mummery LJ, the interpretation of the DDA ‘is not’, as he put it, ‘facilitated by familiarity with’ the SDA and RRA.

From *Clark v Novacold* it emerged in effect that it is not enough for an employer to acquiesce in the knowledge that he or she has treated a disabled employee just the same as they would treat a non-disabled person (equal treatment) nor is it enough to have created the ever-elusive ‘level playing field’ (equal opportunity). What matters is that the result for the disabled person is the same as it would have been for an otherwise similarly placed non-disabled person: they get the job, keep the promotion, escape dismissal (equal outcome). By implication, if it takes a bit more effort or imagination, or even cash, to achieve that end, then so be it. Equality is, paradoxically, about being treated differently, not the same.

The seminal concept in advancing equal outcomes of this sort is that of ‘reasonable adjustment’, the domestic version of the ADA’s ‘reasonable accommodation’. 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 emphasised in the House of Lords case of *Archibald v Fife Council* (a case, incidentally, which the DRC funded). As Baroness Hale remarked,

‘[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. The question for us is when that obligation arises and how far it goes'.

In other words, in answering the question 'what are disability rights all about', the notion of reasonable adjustment is central. In *Archibald*, Lord Hope chose to characterise this positive dimension as 'positive discrimination', insofar as it entails 'an element of more favourable treatment'. However, when viewed in the context of the DDA as a whole, it is arguable that the obligation to make reasonable adjustments just is the effective achievement of equality for disabled people. Reasonable adjustments are then not so much a vehicle of positive discrimination in favour of disabled people, an add-on to what is strictly necessary, but rather a means (in fact the means) of avoiding discrimination in the first place.

It is this positive dimension of disability rights that provides the best clue to what those rights might become. For many years, academic commentators, and others, have suggested that shifting attention from the potential victims of discrimination to the potential perpetrators by the creation of positive duties to promote equality is the best way forward if equality is taken to mean more than the mere avoidance of individual instances of discrimination. The success in Northern Ireland in changing the religious composition of the workforce is cited as a compelling

example. Here we have the Race Relations Amendment Act, of course, and the Government now promises something similar both on disability (in the forthcoming Disability Bill) and on gender (as described in the recent CEHR White Paper, Fairness for All). These initiatives represent a sea-change in the legislative approach to equality in this country, and at the same time recognise the substantive values underpinning equality legislation: sea-change, in that this is a move away from an emphasis on individual victims, retrospective remedial litigation and individual redress, to the collective benefits for disadvantaged groups of systemic and active changes in policy. The latent political charge of anti-discrimination legislation is laid bare in all its potentially subversive colours.

So what does this have to do with the idea of a CEHR, with the aspiration to bring together the various EC strands of equality with human rights to create a more potent force for social change? First of all, it suggests that whether or not the 'lived experience' of disability discrimination is fundamentally different from any other form of discrimination, the legislative arrangements, at least, for achieving equality for disabled people are fundamentally different from those on race and gender, sexual orientation, religion and age. This is not just a difference of degree but a difference of kind. But secondly, and more importantly, what is different about disability legislation points to one version of the sort of legislative strategies that are needed to combat inequality and social exclusion in all its cross-strand manifestations. Once again it is the 'positive' dimension of the reasonable adjustment provisions that turn out to be crucial, the refusal to acquiesce in equal treatment and the willingness to transcend that limited strategy by insisting on 'going the extra mile' (as it were) to make the positive interventions that will actually deliver substantial equality of outcome rather than merely formal symmetry. The importance of

this positive dimension falls into relief when set in the context of three other considerations: first, the underlying philosophical models of equality; secondly, the thinking behind the gradual introduction of positive public sector duties on race, disability, gender (and possibly religion); and thirdly, the emergence of a broad conception of human rights that puts a premium on the positive duties of the state, on mutuality and community at the expense of Enlightenment notions of individual civil liberty.

Christopher McCrudden, the Professor of Human Rights in this university, helpfully identifies four basic models of equality. First and most familiarly to lawyers is the individual justice model, with its emphasis on redress for individual victims of irrational prejudice and disadvantage. Here the keyword is 'discrimination' and of course this is the model that lies behind the gender and race legislation of the 1970s, to a large extent the EC general framework directive and to a much lesser extent the DDA. Second is the group justice model, with its recognition that there is a social dimension to inequality, that individual instances of 'discrimination' are embedded in social practices and institutions and so inform the experience of entire groups of people who share a common fate of social disadvantage, and here the keyword is 'redistribution', redistribution that is of social goods and benefits. Third is the identity model, which recognises the cultural dimension of disadvantage and seeks to remedy the experience of cultural exclusion by celebrating diversity and embracing difference, and here the keyword is precisely 'diversity' as the cornerstone of multiculturalism. And finally there is the participatory model, with its emphasis upon social and civic inclusion and the recognition that the achievement of flourishing individual persons and groups entails their ability to participate in the dance of a fully integrated social life, and here the keyword is 'participation', the rather Olympian notion that it's the taking part that really counts.

Clearly there are tensions between these four models and it would be rash to argue that any one model captures all the richness that the concept of equality denotes. Indeed elements of all four models are ever-present in actual debates about public policy and to a greater or lesser extent they all lurk beneath the surface of the EC general framework directive. But if I had to pick out the two that come closest to the government's plans for a CEHR, I would choose redistribution and participation. It is the linkage between these two models that grounds the government vision of a new human rights culture that can in turn disclose a truly participatory experience of citizenship. It is also this linkage that transcends the more limited notions of discrimination and identity. At the heart of the CEHR vision lies the recognition that the entire equality project is an exercise in social change, that such change can only be achieved by the positive acts of powerful agents to foster active participation in key institutions, whether political, social or economic, and that positive steps towards inclusion of this sort can best be achieved in the round rather than as piecemeal initiatives to the advantage of particular minority groups who are in need of special protection.

This is a grand and ambitious vision, and it is of course too soon to say whether the CEHR model proposed in the recent government White Paper has any chance of doing the trick. There are nevertheless two specific concrete developments that point in the same direction: the proliferation of public sector duties; and the development of a broad interpretation of human rights in ECHR case law (and it is in the context of these two developments that I will a little later reflect on the sort of thing an equality commission like the DRC is and the place of law within it).

Another professor in this university, Sandra Fredman, Professor of Discrimination Law, has long argued that taking individual anti-discrimination cases goes only so

far, and that the lessons on gender and race in this country and elsewhere are that it simply does not go far enough to make a real difference, to bring about life-transforming and sustainable change for what she calls 'out-groups'. That same conclusion largely informed the thinking behind the Hepple Report on equality law in 2000 (and I know that Sir Bob Hepple will speak to this conference tomorrow about how he sees the current state of play). The limitations of the legal process – its incorrigible individualism, its inadequate remedies, its indefeasible casuistry – make it a poor vehicle for real social change. This is not to say that there are no important local victories along the way. Of course, there are. You in this audience assembled here have probably won most of them. But the signs are that the big battles that redraw the social equality map are fought outside the courtroom, outside the legal process and outside the anti-discrimination framework. It is the desire to move away from that anti-discrimination model that offers a place to a different type of legal device altogether, the sort of positive public sector duty that removes attention from the potential victims to the potential perpetrators, and requires public sector bodies to take positive steps to promote equality for particular groups. At present such duties exist on race only. But the government will promise something similar in the forthcoming Disability Bill currently before Parliament; the CEHR White Paper has proposed legislation on a gender public sector duty; and in the present post 9/11 climate it can only be a matter of time before such duties are extended to religion and beyond, perhaps even to the private sector or at least so far as to encourage the sort of public procurement regime that has long been credited in the USA with real impact. But whether or not such extension develops quickly or slowly, the desire to 'accentuate the positive' sits immovably at the centre of current legislative strategy on equality law. The old anti-discriminatory model, although still part of the

equality picture, no longer rules the roost in the way it did a generation ago.

So what of the human rights side of the 'equality and human rights' equation? Francesca Klug, Professor of Human Rights Law at The London School of Economics, has drawn attention to three waves of human rights thinking. The first is that associated with the Enlightenment and with the 'rights of man' agenda that informed the French Revolution and the American Declaration of Independence, and here the emphasis was upon the 'negative' liberty from oppression by the state and the Church afforded to the newly emancipated individual. The second wave occurs after the Second World War and is associated with the 1948 Universal Declaration of Human Rights. It was this new wave of human rights thinking that pushed the boundaries beyond the negative liberty of the Enlightenment to a broader conception that embraced centrally the notions of the dignity of the human person, and of the importance of community in a flourishing human life. If the Enlightenment celebrated the atomised individual, safe within his or her solipsistic universe, 1948 offered a vision tempered by the horrors of the Holocaust in which the notion that the emancipated individual could be relied upon to deliver the social goods was finally trounced. Restraining individual power over others by the reinforcement of the boundaries of community had become the new ideal, and the obligations of the state to promote restraining community of this sort were as much to the fore as the 'keep out' notices that characterised the eighteenth-century edicts to Church and state.

More recently still, the Strasbourg court's interpretation of the ECHR has given new life to the theme of mutuality and reciprocity that animates also the 1948 Declaration. Since this is an audience largely of lawyers I will risk mentioning very briefly a few cases by way of illustration, since a law

lecture somehow feels inauthentic without them (and I am incidentally grateful to the DRC's Special Adviser and my colleague Caroline Gooding for much of the analysis that follows). Let's start with the landmark decision in the 1998 case of *Botta v Italy* (1998 26 EHRR 241). Although the claim itself was unsuccessful, the Court's decision demonstrated a striking degree of realism about disabled people's experience of social exclusion. Most important, the judgement established that Article 8 of the ECHR (right to private and family life) imposes positive obligations on the state to facilitate access for disabled people to essential economic and social activities, and to a range of recreational and cultural activities as well. The particular claim was brought by a physically disabled man resident in Milan who could not use a private beach in Italy not so far from Rimini because of the lack of ramps and toilets. It does not take much familiarity with the Italian way of life to realise that exclusion from the beach might be construed as a breach of human rights, hard though that might otherwise be to comprehend on a Friday afternoon in Oxford. Relying on Article 8, Mr Botta argued that he was unable to enjoy a normal social life which would enable him to participate in the life of the community not because of what the State had done but because of what it had failed to do, namely, discharge its positive obligations and monitor compliance with domestic provisions relating to private beaches. In the process of dismissing the complaint on the facts, the court held that the State did indeed have obligations of this sort where there is a direct and immediate link between the measures sought by the applicant and his or her private or family life. The opinion of one of the judges, Mr Bratza is especially pertinent:

'Although the object of Article 8 is essentially that of protecting the individual against arbitrary interference by the public authorities...this provision may nonetheless, in certain cases, impose on those States positive obligations

inherent in an effective respect for private life even in the sphere of the relations of individuals between themselves...Such positive obligations may exceptionally arise in the case of the handicapped in order to ensure that they are not deprived of the possibility of developing social relations with others and thereby developing their own personalities. In this regard, the Commission observes that there is no water-tight division separating the sphere of social and economic rights from the field covered by the Convention. This is an area in which a wide discretion must inevitably be accorded to the national authorities. Nevertheless, the crucial factor is the extent to which a particular individual is so circumscribed and so isolated as to be deprived of the possibility of developing his personality’.

In respect of Article 3 (right to life), the landmark decision is *Price v UK* (2001 34 EHRR 1285), a case concerning a disabled prisoner. Ms Price is a survivor of thalidomide. She was committed to prison for three days for contempt of court in the course of civil proceedings. In prison she had to put up with conditions that prevented her from going to the toilet or keeping clean properly, where it was dangerously cold and she ran the risk of developing bed sores. The judgement of Judge Greve is especially telling:

‘In a civilised country like the United Kingdom, society considers it not only appropriate but a basic humane concern to try to ameliorate and compensate for the disabilities faced by a person in the applicant’s situation. In my opinion, these compensatory measures come to form part of the disabled person’s bodily integrity. It follows that, for example, to prevent the applicant, who lacks both ordinary legs and arms, from bringing with her the battery charger to her wheelchair when she is sent to prison for one week, or to leave her in unsuitable sleeping condition so that she has to endure pain and cold – the latter to the extent that eventually a doctor had to be

called – is in my opinion a violation of the applicant's right to bodily integrity. The applicant's disabilities are not hidden or easily overlooked. It requires no special qualification, only a minimum of ordinary human empathy, to appreciate her situation and to understand that to avoid unnecessary hardship – that is, hardship not implicit in the imprisonment of an able-bodied person – she has to be treated differently from other people because her situation is significantly different'.

This is good powerful European stuff, demonstrating the positive dimension of human rights, the third wave, with particular application to the situation faced by disabled people. But what about 'bringing rights home' (as the government is so fond of saying – or at least used to be) and an example of a domestic decision involving disabled people that draws upon the same stream of positive participatory thinking and language? The case of *The Queen (On the Application of (1) A (2) B) v East Sussex County Council (CO/4843/2001)* will do nicely (with the additional advantage for what I want to say about the place of law in the work of the DRC that it is a judicial review case in which the DRC intervened as a third party).

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 reasoning in *Botta*, 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':

'True it is', he said, 'that the phrase [human dignity] is not used in the Convention but it is surely immanent in Article 8, indeed in almost every one of the Convention's provisions. The recognition and protection of human dignity is one of the core values – in truth, the core value – of our society and, indeed of all societies which are part of the European family of nations and which have embraced the principles of the Convention'.

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".'

What these cases tell us then is that there is a sort of seamless coherence in the positive approach to equality 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 Strasbourg and domestic courts when considering the situation of disabled people, and all this within a framework that prioritises the philosophical models of equality as redistribution and especially participation for social groups, not just discrete individuals.

I want now to turn to slightly more parochial territory, to the role of an equality and human rights commission in taking forward this legislative and political agenda. I would suggest there are three main models of what an equality commission generally is supposed to be. First of all there is the 'advocacy' model, encouraged by the idea that a commission is there to represent the interests of an especially vulnerable minority, to fight its corner in the world at large. Secondly, there is the idea that a commission is first and foremost a regulator, the wielder of the big stick, keeping the forces of discrimination at bay. And thirdly, there is the notion that the overriding ambition of a commission should be to act as an instrument of social change, perhaps doing a bit of advocacy and regulating along the way, but always as a means to an end and never as an end in itself.

It has been tempting in the past (especially perhaps for lawyers) to see the CRE, EOC and DRC as a mixture of advocate and regulator, as law enforcement agencies, whose primary purpose is to take discrimination cases on behalf of needy individuals and thereby to wield the big stick and at the same time fight the corner of the most vulnerable in society. On this account, a commission becomes a curious amalgam of law centre and legal aid provider, whose success can be gauged by the number of

successful cases pursued. The key accountability questions then become how much of the budget is put aside for law enforcement, how many cases do they take and how many do they win. The questions of why such and such a case is taken, or of whether those cases, or indeed cases in general, actually make much lasting difference to the equality agenda then become subordinate. This approach still surfaces quite frequently in the current debate about a CEHR, with much anxiety being generated about whether 'promotion' is going to oust 'enforcement', the latter being conceived primarily as litigation.

I want to suggest that, if the preceding analysis of the way the equality wind is blowing is correct, this perception of the role of a commission is misconceived. I will do so by reference, briefly, to the experience of the DRC, which as you will be aware has been around now for just over four years. When the DRC opened in April 2000 the DDA was still in the process of being phased in gradually. Indeed it still is. The main provisions on employment and services had come into force in 1996, with important extension of the reasonable adjustment provisions on services having been implemented as recently as 1999. Part 4 of the Act on education was not due for implementation until 2002, and the final extension of the duty on service providers to make physical changes to premises does not occur until October this year, with a similar extension to universities and colleges next September. In the meantime, the employment provisions have been extended to include from October all employers, not just those with fifteen or more employees; and the new Disability Bill will, as already mentioned, change the landscape again with the introduction of a public sector duty as well as a wide range of refinements to the DDA proper. In other words, the legislative environment that gave birth to the DRC has been, and continues to be, highly volatile.

At the same time, the DDA itself was not exempt from criticism at the outset. As you may remember, it was introduced by William Hague when Minister for Disabled People in the beleaguered Major government and bore the marks of considerable parliamentary buffeting. Its critics pointed especially to the 'medical model' definition of disability, the low justification defence threshold and the patchy coverage as hugely damaging. The early research on the use of the DDA suggested that there had been wide use of the employment provisions, with several thousand cases having been brought and a number of important interpretative decisions having emanated from the higher courts on appeal. By contrast Part 3 had scarcely troubled the scorers, with as few as 53 cases having been commenced in the civil courts in the first three years.

Faced with this situation, the DRC decided that it needed a very targeted or 'strategic' approach if it was to make the best of a less than perfect legislative job. First of all, it was vital to keep an eye on the way the legislation was being used and to let Government know about it, and to that end the DRC quickly produced a major legislative review that has set the agenda for the subsequent phase of law reform. It set up a conciliation service to cover services cases and so provide a possibly more attractive forum than the civil courts for the resolution of disputes, and that service has enjoyed relative success with high settlement rates (in the region of 70%) and about 150 cases being dealt with that way each year. It took an 'enabling' approach to the provision of advice and information, establishing a helpline which has taken about 100,000 calls each year, a quarter of which have been from business and public service providers, and deploying a casework team, not so much to 'go on the record' as acting for litigants but rather to help each year a couple of thousand disabled claimants to help themselves. And at the same time it devoted a lot of time to updating the

existing statutory codes of practice on services and employment, so that there was a reliable interpretative resource available, whether or not the case law kept pace; it completed a formal investigation into the provision of website services as a counter-balance to the preponderance of individual employment cases; and in the background it kept chipping away at false perceptions of disability and low awareness of the legislation with all the tools in the modern communications and 'best practice' armoury (I should say, incidentally, that the EOC and CRE had for some time pioneered a number of these strategies too).

It is probably for others to judge the success of these efforts, but if I had to characterise this package of strategies I would say that they represent primarily neither law enforcement nor straight promotion but rather the 'mobilisation' of the law through a variety of devices: conventional litigation, ADR, awareness raising, 'empowerment', a mixture of prevention and cure, all as a way of taking forward an agenda of social change. For it is that in my view that the DRC has seen itself as, much more than as 'advocate' or 'regulator'.

To demonstrate the distinctive approach to the law that this model entails I want to conclude by describing two particular clusters of cases which have engaged the legal efforts of the DRC: the first is to do with moderating the disastrous impact of *Jones v the Post Office*, and the second is to do with using intervention in judicial review cases as a device for reaching corners of the social landscape that by and large elude the grasp of the DDA.

In *Jones v The Post Office* (2001 IRLR 384), the Court of Appeal considered the justification defence against claims of less favourable treatment. Its conclusion that the justification threshold is low reinforced previous case law in the lower tribunals and confirmed the worst suspicions

of disability activists that the DDA is potentially a discriminators' charter. In the months following Jones, the DRC received a number of requests to fund cases that applied the judgement and so seek to modify it by that route. A quick reactive approach was tempting, not least in the interests of demonstrating that the DRC is no pushover. Thanks especially to the wise counsel and skill of Pauline Hughes (the DRC's Head of Legal) and, I should say, of Robin Allen QC who advises the DRC's Legal Committee, a more measured approach was adopted. This entailed an oblique but ultimately successful strategy. In *Collins v The Royal National Theatre Board Ltd* (2004 IRLR 395), a case involving a carpenter who lost part of a finger, the Court of Appeal took a step in the right direction by agreeing with the DRC that the justification of a failure to make reasonable adjustments (a rather large stone left unturned in Jones) must relate to circumstances other than those taken into account for the purposes of deciding whether the adjustment is reasonable or not; otherwise, the result would be hopelessly circular. As Sedley LJ put it,

'...the extant statutory provision about discrimination by failure to make adjustments has something close to the shape which it will explicitly acquire when the amendments come into force in October 2004. As it happens, that is also the shape adumbrated in the original White Paper, which proposed a justification defence for less favourable treatment but not for failure to make reasonable adjustments. What is now s. 5 (4) was not in the initial Bill but, we are told, entered it just prior to the report stage of its passage in the House of Lords. For the present, the justification which it affords of a failure to make reasonable adjustments is not ruled out but is, on a proper reading of the DDA, heavily restricted.'

So far, so good. But the full impact of Jones on justifying detrimental treatment still remained largely untouched.

However, in *Archibald v Fife Council*, the House of Lords made it clear that 'the arrangements' which might attract the reasonable adjustment duty are very broad indeed, as is the 'duty' itself. 'Arrangements' turns out to cover just about anything that might put a disabled person at a disadvantage, including the job description itself and the extent of a person's liability to dismissal if they become incapable of doing the job so described. As Michael Rubenstein has helpfully put it in his IRLR editorial for 8 August 2004,

'The breadth given to the components of the reasonable adjustment duty mean that more DDA cases will start – and end up – as adjustment cases. The control mechanism is reasonableness. The employer has to do no more than is reasonable. Reasonableness in an adjustment case, however, is not the band of employer discretion established by the Court of Appeal in *Jones v The Post Office*. It is an objective test of what a reasonable employer ought to do, made more rigorous by the removal as of 1 October of the possibility of justifying failure to make a reasonable adjustment'.

And, he might have added, 'in the interim by the Court of Appeal judgement in *Collins v The National Theatre*'.

Finally in this cluster of employment cases there is the Court of Appeal judgment in *Nottinghamshire County Council v Meikle* (2004 IRLR 703). In *Meikle*, which concerned a school-teacher who developed a visual impairment and was eventually dismissed on grounds of incapacity following an extended period of sick-leave, the Court of Appeal considered the effect of s. 5 (5) of the DDA, which provides that the question of whether less favourable treatment can be justified is subject to consideration of the effect of a failure to make a reasonable adjustment in the first place. The local authority argued for a very narrow construction,

suggesting that the only issue was whether there should have been any adjustment to the sick-leave policy before it was invoked to justify reduction of Ms Meikle's sick-pay. Keane LJ, expressly adopting the decision in Collins, remarked,

'A tribunal does have to consider what the position would have been if the employer had complied with his section 6 [reasonable adjustment] duty. That is what the final part of the subsection [s. 5 (5)] indicates by the words, 'even if he had complied with the section 6 duty'. In the present case, it is clear from the findings of the tribunal that Nottingham County Council had failed in a number of respects to comply with that duty, in particular (though not solely) in regard to enlargement of written materials and the provision of more non-contact time for Mrs Meikle. The proper approach was to ask whether NCC had shown that, if all reasonable adjustments required by section 6 to her working conditions had been made, Mrs Meikle would have been absent for over 100 days and thereby liable to the reduction in sickness payment.'

To which the answer, in the judgment of Keane LJ, was a resounding 'no'.

So what does this cluster of cases suggest about the character of an equality commission and its use of litigation? To my mind, it suggests that an equality commission should regard itself almost as a guardian of its substantive legislation, with a firm commitment to supporting cases in a way which only it can. In this instance, what was distinctive about the DRC approach was its ability to pursue a consistent thread of argument in the higher courts in a number of quite separate but related cases, and so moderate a potentially damaging decision for the integrity of the DDA (Jones) not by head-on collision but by a more subtle and oblique approach. In the end, the net result is that the depressingly low threshold

established in Jones can be moderated by the operation of s. 5 (5). And this will still matter after 1 October because although it will not be possible to justify 'direct discrimination', it will be possible to justify other 'disability-related discrimination' – but thanks to these cases, not very easily.

The second cluster of cases has already been alluded to. In the case of A and B mentioned earlier, the DRC intervened as a third party in a judicial review case, and in so doing was able to put before the court policy considerations which might not otherwise have attracted much, if any, attention. Just as importantly, the case involved health and social issues that are not easily addressed in the course of conventional anti-discrimination claim brought in the civil courts under Part 3 of the DDA. By intervening in cases of this sort the DRC not only has the opportunity to play a distinctive role in the judicial process, a role very different from that of a conventional adversary, but also gets to concerns of disabled people which, although of critical importance, are scarcely touched by the DDA. In three other cases, two decided recently (*Burke v The General Medical Council*, a case concerned with the circumstances in which artificial nutrition and hydration might be withheld, and *Manchester City Council v Romano and Samari*, a case concerned with the eviction of disabled Council tenants on the grounds of their allegedly anti-social behaviour) and one to be heard in November (*N v St Bartholomew's Hospital*) concerning a disabled child who was denied ventilation for asthma on 'quality of life' grounds), the DRC has made similar interventions, adducing the Human Rights Act in support of positive obligations on the part of public authorities to engage the participation of disabled people in quite literally 'life and death' decisions. In *Burke*, Munby J put the DRC's approach very well:

'The DRC was joined in the proceedings as an interested party. I had to consider the position of the DRC in R (A, B, X and Y) v East Sussex County Council and the DRC...I need not repeat what I said save to emphasise that in this case, as in that, I have been greatly assisted by the DRC and by the submissions of its counsel, Mr David Wolfe. In this case, as in that, the DRC was able to deploy, to the greatest assistance of the court, a particular and highly relevant informed expertise which none of the other parties could bring to the task in hand. Both cases illustrate the important role that, in appropriate cases, bodies such as the DRC have to play in litigation, affording our courts the kind of valuable and valued assistance that courts in the United States of America have for so long been accustomed to receiving from those filing amicus curiae briefs'.

Let me conclude. As the recent White Paper demonstrates, a CEHR can be expected to play lots of roles, some would say too many. I hope that I have persuaded you that the roles of legal aid provider and law centre should not be among them. The distinctive quality of disability rights, with the privileged place afforded to 'reasonable adjustments', accentuates the positive, and the advent of a panoply of positive public sector duties together with the emphasis in a broad interpretation of human rights upon the positive duties of public authorities to make real the participation of disabled people in social and civic life, reinforce that positive accent with which the DDA is enunciated. If there is to be a CEHR, the DRC expects to see disability rights at the heart of it, not because disability rights are in themselves more important than any other sort of rights, or because the DDA is so recent a piece of legislation, or because the future legislative agenda on disability is so heavy (although some of these things may be true), but because disability rights offer a new way forward, a way forward that is consistent with broader policy and legislative

developments both here and throughout Europe, and which, most importantly of all, make sense of the notions of equality as redistribution and participation. So, the future on equality and human rights is still rather bright (notwithstanding the Conservative Party's planned review) and, if not exactly orange, at least decked out in that rather pleasingly azure tint of the EC disability blue badge scheme. And that's progress of a sort on the path to swinging open the socially exclusive gates. I hope the nineteenth-century forebears of this college would approve.

SEPTEMBER 2004

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

Bert Massies presentation to the Neurological Alliance November 2004

Presentation on 4 November to the Neurological Alliance
"The Patient's right - but whose responsibility?" London,
by Bert Massie, Chairman, Disability Rights Commission

I would like to start by saying how pleased I am to be here today as the Neurological Alliance brings together a number of disability organisations and others to work in a common cause. I think it might be helpful if I explained something of the work of the Disability Rights Commission (DRC) and in particular our recent activities relating to the latest duties that have come into effect under the Disability Discrimination Act. I would then like address some of the issues we are considering in the fields of health and social care provision.

The DRC

The Disability Rights Commission is an independent body, established by an Act of Parliament to eliminate discrimination against disabled people and promote equality of opportunity. It has 15 commissioners, 10 of whom are disabled.

We have set ourselves the goal of "a society where all disabled people can participate fully as equal citizens".

The DRC

- provides advice and information services for disabled people and service providers;
- supports disabled people in securing their rights under the Disability Discrimination Act (DDA); and

campaigns to change policy and strengthen the law so that it works better and protects more disabled people in a better way.

We have a legal duty to promote the equality of disabled people. There are a number of ways to address this but the main one we adopt is to seek to remove the barriers that prevent disabled people achieving equality. It remains a sad truth that many of Britain's 10 million disabled people cannot access education, employment, social or political involvement because they are physically barred from participation.

Access for Disabled People

Accessing a service is part of every day life, visiting the library, or the doctor's, or going out for dinner, or taking your children swimming or even taking all those wine bottles to the recycling centre. Most people rightly take this for granted. But is it acceptable that many disabled parents are unable to take their kids out because of thoughtless design of the physical environment?

In October last year the DRC launched an NOP survey to examine disabled people's experiences of using the services everyone else can use. The survey found that 70% of disabled people with mobility problems have experienced difficulties using services, particularly when trying to use leisure facilities.

All of this adds up to an awful lot of disabled people who are being excluded from local services and by implication excluded at least in part from their local communities.

The Disability Discrimination Act

Since 1995 the Disability Discrimination Act has already introduced major new rights of access for disabled people to almost every form of service provided to the public; everything from the hospital, to the bank, to the local park.

On 1 October the final sections of Part 3 of the DDA came into effect. It is a complex piece of legislation but in essence it is simple. The law now says that people or organisations that provide services to the public must ensure that disabled people can also use and benefit from those services. If a physical or other barrier prevents disabled people using the service the barrier should be removed or altered or the service provided in another way. However, the law introduces the concept of reasonableness.

Service providers are required to do what is reasonable – and this will depend on a number of factors, most obviously the cost of the adjustment weighed against the resources of the business.

The DRC has produced a statutory Code giving guidance on Part 3 of the DDA relating to the duties of service providers. We attempted to shed light on some of these areas – for example, the question that all service providers quite understandably ask is “what is considered ‘reasonable’?” This will depend on all the circumstances of the individual case including factors like the size and resources of the service provider and how many other improvements the service has made. It's really about horses for courses.

For example, it's unlikely that a small community hall, run by voluntary committee and with a very small income would be required to provide new completely accessible toilets. However, the situation may be very different for the council assembly halls or a large music venue.

It is also important to remember that that it is the service that is required to be accessible, not necessarily the premises from which it is normally provided, its time to think laterally! For example could the services be moved to a more accessible part of the building?

It is important to say that the DRC strongly believes the best solution for everyone is either removing or altering the physical feature where that is possible.

The reasonableness approach does, however, mean that large and well-resourced service providers will be expected to do much more. We have examples of banks, supermarket chains and local authorities spending millions of pounds on physical improvements to their premises in order to improve access to services.

Large service providers in all sectors will be expected to have a positive approach to access improvements. Ideally this will be a plan of improvements drawn up in consultation with disabled people, and crucially with expert advice, which are clearly achievable within a reasonable time.

The DRC obviously hopes that in the vast majority of cases that situations of discrimination can be avoided and that providers of services and disabled people can work together to get things right. Having said that we are fully

committed to ensuring that disabled people have the right to use services in the same way as anybody else and we see October 2004 as a significant date in the rights of disabled people.

The new duties apply to anyone providing services to the public. It could be a local authority services such as libraries, youth centres or housing offices. It could be the local shop, pub or café. It could be your local hospital, GP surgery or your favourite football club.

Open 4 All

For the last year the DRC has been running its open for all campaign to inform disabled people and business about the new duties. Our campaign will continue for a little time yet but we also need to highlight the new employment duties because with the exception of the armed forces virtually all employers are prohibited from discriminating against disabled people. You can get more information about the new duties from our website: www.open4all.org.

A note about websites

One particular area, which may require specific attention, is that of websites. The DRC recently conducted a formal investigation into company websites and found that over 8 in 10 websites were difficult for disabled people to use. This meant that they found it impossible to pay their council tax, open a bank account or buy theatre tickets online. Despite the fact that many changes are very simple to make, the fact remains that many businesses and services aren't doing it.

The website is a part of a business service, and should also be accessible to disabled people.

Creating Change

Of course, we cannot rely on assuming people will do the right thing. Sometimes they need to be forced to act and the DRC has a range of legal powers that we will not hesitate to use. The DRC assisted Mr Ross to bring his case against Ryanair who discriminated against him and other disabled people by charging them for the use of a wheelchair. We won that case but Ryanair are appealing and the appeal will be heard next week. We are continuing to support Mr Ross. We have also won major legal cases in the Court of Appeal and in the House of Lords that have helped define the definition of disabled people and that have emphasised that employers have a duty to consider another job for an employee unable to continue in their current job because of the onset of impairment. Our Impact Report for 2003-4 gives many other examples that show the DRC is getting results. You can read it on our website.

Do health services treat disabled people fairly?

We know that some health services have developed excellent approaches to improving services for disabled individuals, for instance:

Including access needs on the electronic patient record, so that someone with a learning disability who needs extra time to communicate with a health

- professional does not have to explain this again and again to different staff
- Systematic logging of any access problems experienced, to feed into service-wide improvements
- Simple access improvements like visual displays of appointment times so that deaf people know when their appointment comes up
- Questions in the regular patient survey about disabled people's experiences, used to improve services
- Disability equality training for everyone from Board members to receptionists

Good practice is, however, often left to small individual projects and is not mainstreamed. Surveys reveal some significant problems faced by disabled people in using health services. For instance, despite 1999 NHS Executive targets for all front-line NHS staff to receive disability awareness training, a 2003 survey of PCTs found that 90% of them had no compulsory disability equality training; 50% had no training at all or did not know whether they had any; and only 50% had consulted disabled people about the services they provided.

Surveys of disabled people regularly identify problems in access, staff communications and attitudes. Knight et al found that 60% of deaf people reported that primary care was inaccessible to them.

Decisions in life and death situations reveal that some disabled people experience discriminatory assumptions from health professionals that their "quality of life" will be less than that of a non-disabled person, which can influence decisions about rationing of surgery, withholding or withdrawal of treatment and use of "do not attempt

resuscitation" notices. This has been of particular concern to the DRC and has heavily influenced our views on issues such as Physician Assisted Suicide. We have too many, albeit anecdotal, examples of doctors pressurising disabled people to agree that no effort should be made to preserve their lives if their health deteriorates. It would appear that some doctors think it is better to be dead than disabled. As most of them have no personal experience of either it is difficult to know how they reach their decision, if it is not merely prejudice.

The DRC believes that before we can sensibly discuss the right to die we must first ensure we have the full support systems and services in place to enable disabled people to enjoy the right to live. However, we appreciate that this is a subject on which people have strong views on both sides of the argument. Some organisations, including some here today, have argued that the DRC should support disabled people would want the right to instruct doctors to end their lives. We would be more comfortable with that position if we could first ensure that disabled people had the right to life and the right to social care support so that disabled people did not feel they were a burden on their family and friends. It remains a sad truth that although health care in Britain is free at the point of delivery social care is rationed and attracts heavy charges. The greater your need, the more you pay. It is difficult to believe that this iniquitous situation does not influence the views of some about the quality of their life. I was pleased that the DRC was able to support Mr Burke in his case against the General Medical Council. He wanted to ensure that treatment would not be withdrawn against his wishes. He won his case but the GMC are appealing, as is their right. But the case does show that while some disabled people want the right to assistance to end their lives, others are fighting to keep the right to live.

I mentioned earlier that we are concerned about the quality health provision for mental health service users and people with learning disabilities. There is some particularly worrying evidence that some groups of disabled people die younger than non-disabled people, and live with greater morbidity, partly because of unequal access to health screening, assessment and treatment. One London study found that people with learning disabilities were 58 times more likely to die before the age of 50 than other citizens. This is a startling result and it would be helpful for the research to be replicated. However, even if the disparity were only half as great as 58 times it would be shocking; and we would expect particularly high attention to this at-risk group in terms of health service access and quality. Instead access to basic health services – assessments, health promotion, regular health checks and screening, treatment – can be lower for these groups.

Similarly people with long term mental health problems die on average 9-10 years younger than other citizens. Sometimes physical complaints are seen as "all in the mind" and not investigated or treated. As one mental health service user put it:

"I had a cupboard full of valium for my palpitations – but no one identified my major heart disease".

Part of the role of the DRC is to ensure that disabled people do not receive a lower standard of service than people who are not disabled. This applies to the health service as much as it does to high street retailers or employers. We have a number of ways of doing so. If a disabled person suspects that they are being discriminated against unlawfully they can approach the

DRC for assistance in bringing a legal case. In most cases we can resolve issues without access to the courts but we do support about 60 cases a year in the courts and tribunals. We have also supported judicial reviews when health trusts or local authorities have failed to support disabled people because of ill-conceived blanket bans on lifting disabled people. In one case we supported, three nurses refused to lift someone of only eight stone so she had to sleep in her wheelchair. This is an outrageous way to treat people. Latest guidance on this issue is much more sensible and helpful but was it really necessary to resolve it in the courtroom?

In some cases the discrimination is not so obvious but is there nonetheless. This appears to be the case in the delivery of health services to people with learning disabilities or users of mental health services. The DRC is extremely worried about these inequalities in health experienced by disabled people. But we need to know more about the nature of the problem and seek solutions to it. I will shortly be announcing the measures we propose to take to address this issue.

In the field of physical impairments we still have much to do to support disabled people in a health and social environment. It never ceases to amaze me the difficulty disabled people experience in obtaining equipment as basic as a suitable wheelchair. Many disabled people have to resort to buying equipment because the State will not provide it. We know that disabled people are disproportionately represented in the lower income groups yet they have to buy equipment that is so expensive that one can only wonder by what alchemy the price is determined. If we are serious about disabled people achieving maximum possible independence, we need to ensure that as a country we provide them with the

equipment that will assist them and of course then maintain the equipment.

We still have a long way to go before the DRC can achieve its goal but a start has been made.

Looking to the future

The major programme in health and social services to improve patient choice and control could over time significantly improve health care for disabled individuals; certainly the objective of patient choice cannot be met without addressing disability, given the very high numbers of disabled people using health services. It will increasingly mean that health professionals have the key responsibility of providing options and advice so that people can make their own informed decisions. This means treating individual service users, including disabled service users, not as impairment groups – but as individuals.

Choice needs to be balanced by equity. Here, disability rights are beginning to make a difference. Ten years ago it was unusual to find public services – from major tourist attractions to shops or theatres – that paid attention to disabled customers. Today it is commonplace to have signed and audio-described theatre productions, lifts with the information displayed in Braille, shops that offer assistance to disabled customers. We are in the middle of a cultural shift – and it is affecting health services.

The DDA - and the cultural shift it is stimulating in Britain - mean barriers to disabled people are beginning to be torn down. I have today mentioned health and social care but we need to look across all aspects of disabled people's lives. There remains much to do in the field of education.

Disabled people are more likely to have no academic qualifications and that has an impact on employment rates. Financial hardship remains a feature of the lives of far too many disabled people. There is a huge agenda ahead. But let us not overlook the positive and encouraging successes of recent years. The civil rights agenda for disabled people is being delivered and the evidence is all about us. In future years we must consolidate and build on that success. We must also look beyond civil rights to human rights and ensure disabled people in Britain can live with dignity and self-determination with the full support that a wealthy country can and should provide to its disabled citizens.

Bert Massie

Keywords: Disabled People; Disability Rights Commission; Disability Discrimination Act 1995; Health; Social care

Jane Campbell's speech from the Withholding Treatment Conference Royal Society of Medicine 10th December 2004

Royal Society of Medicine Symposia: Withholding Treatment

SESSION TWO: WHOSE 'BEST INTERESTS'?

It's my life –it's my decision?

Jane Campbell

10 November 2004

As many of you will know, on July 30th 2004, Judge Munby delivered his verdict in the High Court, in the case of Regina versus the General Medical Council. Regina in this case acted for Mr. Oliver Leslie Burke, a 43-year-old man with cerebella ataxia. Mr Burke challenged the GMC's guidelines set out in its pamphlet, "Withholding and

Withdrawing Life Prolonging Treatments: Good Practice and Decision Making” 2002.

In the main the Court found for Mr. Burke, although the GMC was given leave to appeal. The Disability Rights Commission intervened in the case and I gave evidence as an expert witness. We support the decision of the Court and will seek for it to be upheld on appeal.

I want to take the time this morning to explain our reasons and to give you examples, demonstrating the importance of the case to me personally as well as other severely disabled people.

We see the Court’s verdict as marking a significant event in the history of disability rights within UK healthcare provision. It aims to balance the power relationship between Doctor and patient. Both have a breadth of knowledge and experience not available to the other. The Court considered the knowledge base of both patient and doctor to be of equal merit and that neither should take precedence over the other as a matter of course. And that in the final analysis the patient's wishes to life prolonging treatment should be provided for unless if by doing so, it prolonged an intolerable situation.

When I heard the verdict I felt a surge of euphoria for two reasons. Firstly, for my own future safety, secondly, because the Court understood, perhaps for the first time, that Doctors should not be asked or expected to pass sole judgement on what is “in the best interest” of the severely ill or disabled patient. I know that many physicians across the UK were equally relieved. When life and death decisions have to be taken it is time to share the burden. Who better than with the patient or their chosen close relatives, friends and advocates that they trust?

Society is changing. There is a growing acceptance of diversity, which includes the most profoundly disabled people. Yet we must not forget the social backdrop to severely impaired lives.

When I was born, doctors told my mother to take me home and enjoy me, as I would die within a year. As so often with severe impairment and medical diagnosis, there was no certainty, it is not an exact science. Fortunately, they were wrong. I have good reason to thank the many doctors and other hospital staff who got me through a childhood of chest infections and other life threatening illnesses.

Yet 40 years later, doctors treating an eighteen-month-old child, with the same impairment (Spinal Muscular Atrophy) decided they would not provide ventilation to help her through a chest infection. Her parents did not accept this decision and challenged it in Court. There she was known as 'Baby C'. Her doctors argued that her "disability was too terrible to live a quality life". In addition she would need "total bodily care for the rest of her life" and this would be a "burden on state resources and family support". The Court ruled for the hospital having received advice from a range of doctors, who all categorically stated that no one with this diagnosis could live beyond the age of 2 and that if they did, life would be a living hell.

Adults with SMA, including me, could have told a very different story but we only found out about the case after the child's death.

The doctors' evidence to the Court made value judgments about dependency, which really bothered me. If they consider 'Baby C's of this world would be better off dead then surely I would be too?

In fact, during the winter before last, I was rushed into A&E with severe pneumonia in both lungs and nearly

faced the same fate as baby C. The consultant who was treating me said: 'You're very ill. If you go into respiratory failure I presume that you won't want to be resuscitated and ventilated.' I was taken aback by this and asked, 'Well, why?' He answered that the chances of weaning me off would be very remote – 'And you wouldn't want to live on a ventilator.' I replied that meant I would die. So, of course, I wanted to be ventilated. He looked a little puzzled but let it drop.

I thought that was the end of the matter. The next day I was in intensive care when another consultant in a very senior position said the same thing. 'If you go into respiratory failure - and it's looking likely - then I'm sure you won't want to be anywhere near a ventilator.' Again I protested but by now I was very scared that lifesaving treatment would be withheld. My husband rushed home, got a picture of me in my graduation gown receiving my doctorate, came back to the hospital and screamed that 'This is my wife, not what you think she is and has. You do everything for her just as you would for anybody in this situation. She has everything to live for.'

Then they changed their minds. Excellent treatment kicked in. But surely such extreme measures should not be needed for me to access life-saving treatment? This should be my right – a right to life. Nevertheless I forced myself to stay awake for the next 48 hours, fearful that if I went to sleep I'd never wake up.

The doctors' view of both my life then and how it might be affected if I should become ventilator dependant led them to make assumptions about my "best interests" that were wholly misguided. Doctors, especially in emergency treatment settings, see disabled people at their most vulnerable. This is why it is so important that doctors understand the lives of disabled people no matter how seriously they may present. You cannot go on diagnosis

alone – the lived experience is often drastically different from the textbook example.

These two examples go some way to demonstrate why it is imperative to change the way quality of life judgments are made. Medicine is not immune to society's deeply held prejudices about severe impairment. Doctors operate in a world that still sees disabled people as tragic victims of our condition or diagnosis, being without dignity or purpose

It is not unusual for me to overhear “I would rather be dead than live like that”. Terms such as “wheelchair bound”, and “handicapped” appear daily in the press without their pejorative meaning being questioned. This backdrop influences the medical profession as it does everyone else. Doctors are subject to the same influences and negative stereotyping of disability as everyone else. For example, “research on the attitudes of accident and emergency doctors found that only a fifth imagined they would be glad to be alive if they were quadriplegic, whereas over 90% of people with quadriplegia reported they were glad to be alive” .

The drip-drip of negative opinion is not limited to the ordinary man or woman on the street. Just two weeks ago the Nobel Laureate Sir John Sulston, stated “parents should not bring a clearly disabled child into the world”. He went onto say, “If we can select children who will not be severely disadvantaged then we should do so”.

Only last month Minette Marrin, the Sunday Times columnist, wrote of a visit to a hospital ward for people with severe learning difficulties. “The air was full of the noise of pain”. The patients “all appeared to be in great distress”. She noted that they were “tenderly cared for by wonderful nurses” but concluded, “they were absolutely

wretched". In her view, "there are times when medicine, which is supposed to relieve suffering, can be even more cruel. There are fates worse than death". She couldn't be clearer than that – better dead than disabled. Her message to the medical profession was equally clear – do less, not more.

This for me is why the Court's judgement in the Leslie Burke case is so important. It recognises that pivotal importance must be attached to the patient's view of quality of life. I believe Mr Justice Munby sought to strike a balance between the patient's wishes and the doctor's professional judgement. He highlighted parts of the GMC's guidance that failed to give equal weight to patients' expertise in their own situations and their right to make decisions about the withdrawal of their end of life treatments.

1. For example, the doctor's only obligation under part of the guidance is to "take account of" (though without being under any obligation to give effect to) what are referred to as the competent patient's "wishes", "preferences" and "views". It is the responsibility of the doctor in charge of the patient's care to "make the decision".

2. The Guidance placed too much reliance on the doctor's assessment of the patient's "quality of life" in determining "best interests". The Court decided that the higher test of "intolerability" was needed.

This judgement in my view, redresses the balance of power over who decides and on what grounds, life-prolonging treatment is withheld or withdrawn. I now feel we have a more healthy relationship between doctor and patient. Safer too. Where decisions are made in an environment of knowledge about the life, or expected life, of the patient, beyond their diagnosis.

At SCIE (the Social Care Institute for Excellence), where I have a great fortune to be the first chair, I have come to value the importance of using knowledge from three distinct sources when making critical and important professional judgements:

- service user experience,
- research evidence
- and practice knowledge.

At SCIE we call this an inclusive knowledge base.

When making his judgement Judge Munby said how useful the Disability Rights Commission's intervention had been in understanding the complexity of making decisions concerning disabled people.

"I have been greatly assisted by the DRC and by the submissions of its counsel, Mr David Wolfe. In this case, ..., the DRC was able to deploy, to the great assistance of the court, a particular and highly relevant informed expertise which none of the other parties could bring to the task in hand"

The DRC and organisations of disabled people have come to understand that processes of life and death decision-making desperately needed a radical overhaul to meet a desired cultural shift towards inclusivity and human rights. Now a shared decision-making relationship leaves doctors less vulnerable to bad judgements about quality of life and "best interests" can emerge. However, like any change it contains intellectual challenges and a need to grapple with deep prejudice.

Until now debate on issues of medical ethics have involved doctors, clerics, ethicists, the great and the good. But patients, disabled people, users remained outside the door. This is now changing.

The courage of Leslie Burke – as so often, one person - will be remembered in years to come. There are many doctors who are willing to take up the baton and run with this new relationship. Our chief medical officer is currently grappling with how to support a new healthcare service that can see and challenge health inequalities. You can imagine my sincere pleasure, when Liam Donaldson said in a recent lecture, “Jane Campbell’s story...crystallized the centrality of the balance of power between doctors and patients to the debate about what represents good medical care.” (Liam Donaldson, p. 8)

The planning committee for this symposium asked both Tim Helme and me to speak from the point of view that “It is my decision”. But there should be no absolutes in the decision-making process because every circumstance is different and no individual can have absolute autonomy within an interdependent society. That may infuriate some who view this in black and white terms. But we need to focus on how decisions are made now and on how we want them to be made in the future. I feel the journey to good decision-making on withholding or withdrawing treatment, is going in the direction of shared ownership between patient and doctor, let us not turn back now.

Thank you

Keywords: Disabled people; Health; Medicine; Withholding treatment