Bert Massie Merseytravel Conference 3 February 2005

Speech by Bert Massie, Chairman of the Commission, to the Merseytravel Conference at the Maritime Museum, Albert Dock, Liverpool on 3 February 2005.

Maritime Museum, Albert Dock, Liverpool

May I start by thanking Merseytravel for inviting me to address you today? As a native Scouser I am always happy to be in Liverpool. On this occasion especially so because Merseytravel have taken their duty to promote the mobility of disabled people very seriously. You will have seen something of their services when you did your visits yesterday.

I can recall the days when independent mobility for disabled people was a wild dream some of us had. Today things are looking more and more promising for disabled people who want to use public transport services. The impact of regulations under Part V of the DDA setting access standards for buses and trains is increasingly being seen in the new vehicles coming into service. The work done of this even before the DDA was passed in 1995 has paid off.

Around a third of all buses are now of a low floor design and accessible to disabled people. Three thousand trains, which are compliant with the rail vehicle accessibility regulations, are now in service and more will follow in the next year or so. Since 1st January all new coaches purchased to be used on scheduled services will need to include features making them accessible to disabled people including a wheelchair lift.

The government has announced proposals to fill the last link in the transport chain by producing access regulations for taxis. However, we have been waiting for them now for 10 years since the DDA was passed and the DRC will be keeping up pressure to make sure that the timetable doesn’t slip any further. Taxis provide a crucial link in the transport chain.

1. Transport Infrastructure

Improvements to transport infrastructure have been a little slower. In particular, outside the main rail terminals many stations remain inaccessible to people with mobility impairments. However investment in customer information systems is making life easier for people with visual and hearing impairments. I understand that the Strategic Rail Authority is due to launch its accessibility strategy to channel investment in improvements to stations in the near future. I am encouraged by some of the work the SRA is doing on these issues and we must ensure it continues when the SRA is abolished.

Many local authorities have been modifying pavements to provide easy access to bus stops. And forthcoming duties under the Disability Discrimination Bill (of which more later) should bring pressure on those councils who have yet to act in this area. Hopefully it will also require the police to prioritise keeping bus stops clear so buses can get to the raised kerb.

As most of you will be aware, the DRC has already used its powers to support cases under the DDA to apply pressure on transport operators to end discrimination against disabled people. We will not hesitate to do so again, in particular to ensure that operators take their duties under the October 1st 2004 duty seriously.

Perhaps I should explain the approach the DRC takes to enforcing the DDA. Our help line is there to assist disabled people and companies and organisations that provide services to the public. If it looks like a disabled person is facing discrimination we have a team of caseworkers to try and find a solution. We can offer independent conciliation. However, if that fails we can use our legal powers. Like many laws the DDA contains a number of ambiguities that can only be resolved in the courtroom and they are the cases the DRC is most eager to support. We believe that such cases clarify the law and that such clarity helps every one. The Roads case and the case we supported against Ryanair did provide such clarity and reinforced the fact that the law is there and it must be followed.

2. The Roads Case

Last year the DRC supported the first ever case under Part 3 of the DDA to reach the Court of Appeal. We were delighted to win and overturn the earlier judgement of Norwich County Court.

Although the Court of Appeal made much of the unique circumstances of this case, it laid down some important principles as to how the DDA should be applied. These principles were subsequently supported by the second Court of Appeal case Ross and Ryanair and the BAA, which was also funded by the DRC.

Essentially the court said that when making a reasonable adjustment, service providers should seek to give disabled people a service, which was as close as possible to that experienced by non-disabled people.

Mr Roads' case involved Thetford Railway Station. As a wheelchair user there was level access available to him at both platforms. However, the route from Platform 2 to the front of the station involved a half-mile journey along a pot-holed road with no pavement. Mr Roads felt that having given at least 24 hours notice of his journey plans it was reasonable for Central Trains to provide a taxi to collect him from Platform 2. Central Trains offered to allow him to travel free of charge to Ely station where lifts made if possible for him to change platforms and return to

Thetford arriving at Platform 1. This additional journey would add over an hour to the 45-minute journey from Norwich.

The Court of Appeal supported Mr Roads contention that the provision of a taxi more closely approximated the travel experience of other passengers who could use the footbridge to cross the tracks to Platform 1.

All transport providers need to reflect on this judgement. They should ensure that where it is necessary to provide a service by way of a reasonable adjustment to overcome a barrier to disabled passengers, they do so in a way that meets the reasonable aspirations of disabled passenger and not simply by minimising inconvenience to themselves.

I suggest that 3 other points stem from this judgement.

First, that we need more fighters like Keith Roads. Disabled people who are determined to pursue their case so that they set a precedent that benefits all disabled people.

Secondly, this case stemmed from a decision some years ago to remove a barrow-crossing on safety grounds. At many small stations on relatively quiet railway lines the only realistic hope of being able to provide access to both platforms for passengers who cannot use footbridges is via a barrow crossing. The DRC believes that the policy on barrow crossings needs to be reviewed and safety concerns set in a proper assessment of the risks involved. Sorting out this problem should be a great deal easier than finding the funds to make stations up and down the country accessible.

Thirdly, this case highlights yet again the importance of accessible design regulations for taxis being available as soon as possible. Frequently a reasonable adjustment involves the use of a taxi for at least part of a journey, and this is only viable if a taxi is available. The original Judge in the Roads Case was clearly influenced in deciding against Mr Roads by the fact that there is no operator running a wheelchair accessible taxi in Thetford, and therefore Central Trains would have to book one from Norwich.

The Ross v Ryanair and Stansted Airport involved the cost of using a wheelchair at an airport. The cost must not be passed on to the disabled passenger. One of the principles of the DDA is that disabled people should not face additional charges to use the same services as anyone else.

3. Disability Discrimination Bill

It's all very well investing in infrastructure improvements and new accessible vehicles, but if discriminatory attitudes prevent disabled people using them, we still won't achieve our aim of making public transport available to disabled people.

Sadly, all too often, the DRC Helpline receives calls from disabled people who have been left at the bus stop because the driver simply refuses to lower the ramp, or insist that the wheelchair space is cleared for use. Recently we heard from a woman who broke her finger operating a manual ramp when the driver refused to assist her.

I was recently at Heathrow Airport wishing to transfer between terminals 1 and 4. I waited for the bus connection and the bus duly arrived. It was equipped with a ramp and had a space inside designed for a wheelchair user. Terrific thought I, until the man driving the bus said I could not use it and that I had to phone for the "ambu-bus" because I was a wheelchair user. That would have meant waiting about 30-45 minutes. I think I might be the wrong person to whom to say this to and needless to say I got on the bus even though the driver was a very unhappy man. Disabled people really should not have to put up with nonsense of this sort.

Calls about the failures about the Disabled Passenger's Reporting Scheme are less frequent. However, DPTAC estimate that 30% of journeys supported by the scheme end in some degree of failure. I fear that the lack of calls to our Helpline probably reflects simply resignation on the part of disabled people rather than contentment with the service they receive.

However, changes being introduced in the Disability Discrimination Bill that is currently before Parliament will, we hope, go a long way to bring an end to these problems. The current exemption for transport providers from duties under Part III of the DDA in so far as the service consists of "the use of the mode of transport" is to be removed.

The DRC is writing a Code of Practice to provide guidance on what the new duties will mean for transport providers and disabled people. We believe that in the vast majority of cases this change to the DDA will make the sort of experiences I have just described unlawful.

Where travellers on the railways have booked assistance and it does not arrive, they may be able to bring cases under the DDA for the humiliation and inconvenience which they face as a result, together with any consequential financial loss. The same will almost certainly apply when bus drivers refuse to deploy the ramp, provided of course they are able to get to the kerb. And taxis drivers who bypass wheelchair users and almost immediately pick up someone who is not visibly disabled are also likely to be breaching the DDA. If current practices do not change I am in danger of becoming well off via my compensation claims for poor service.

These are important changes to the law which will enable disabled people to use an increasingly accessible public transport network with the confidence that they will not face the petty day to day discrimination which has discouraged many people from travelling to date. It will still need those who experience this discrimination to challenge it through the courts but so long as the DRC continues we stand ready to assist them.

There remains a worrying loophole in the way the Disability Discrimination Bill is to be introduced. Although it will include the power to extend the DDA to cover air and maritime services, the Government has said that for the time being it proposes to continue with the voluntary approach. The DRC does not believe that this approach is succeeding and calls on the government to put the current voluntary guidance on a statutory footing as soon as possible. Why should the Mersey Ferries be exempt? I'm not concerned about the Yellow Submarine!

Disabled people campaigned for the DDA for 20 years. Frequently they were told that voluntary improvements by service providers would end the discrimination they faced. Eventually the evidence built up to the point where the Government of the day realised that voluntary solutions would never stop discrimination. Our experience of talking to disabled people and regular calls to our Helpline give us ample evidence that there is no reason to believe that ferry operators and airlines will be any different from the rest of the service providing companies.

The new Disability Bill will also impose a duty of public services to promote the equality of disabled people. This will mean that all policies will need to be reviewed to achieve this objective. The DRC has just produced a draft code of practice on the new Public Sector Duty and I would urge you to let us have your comments on it as your views are important.

4. Concluding Remarks

I've been working on transport issues for disabled people for approaching 40 years now. We have come a long way. But there is still plenty more to do.

I can see that the pace of change is increasing. It may be 2020 before all trains and taxis are accessible to disabled people, but 40 years ago no one would have even contemplated that there would ever be accessible trains and buses.

But beyond accessibility there is another threshold to cross. I find, and so do many other disabled people I talk to, that at present it often falls on us to explain to transport staff how their access equipment works. I'm well used to taking control of the situation and making sure that the staff do what they should do. But not everyone possesses my confidence. We will have true accessibility when transport staff see a disabled person, realise that assistance is required, and take the initiative to find out what's the best way to assist them and make it seem like just seem like part of their day to day duties. When that happens, even the most nervous passenger will have a successful journey and as their confidence grows they will have greater freedom and many opportunities to fulfil their potential as an equal member of society.

Keywords: Disability Discrimination Act 1995; Disabled people; Transport

Bert Massie CBI Diversity Conference 2005

Speech by Bert Massie to the CBI Diversity Conference 2005, QEII Conference Centre, London Wednesday 16th March 2005

Panel Debate Session: Learning and Gaining from Diversity

When the DDA was introduced in 1995, it was as a result of a disabled people demonstrating that relying on good will and exercising gentle persuasion were not enough to tackle the discrimination they experienced in their everyday lives.

Whilst some progressive employers, through having recognised the benefits of a more diverse workforce, or through having a greater sense of social responsibility had already begun ensuring that they were open to disabled people, many had not and discrimination was widespread. The final parts of that Act came into effect in October last year, extending the DDA to cover almost all employers bar the security services and armed forces.

Disabled people aspire to contribute to society like other people. Indeed, as we will all become disabled if we live long enough, we can argue that this is not about disabled people and employers but about all of us. Work and employment is at the heart of our society. People gain status as well as income from work. Most people prefer to work than to be unemployed and that includes disabled people. Sadly those unable to work and claiming state benefits often find they are excluded from much of national life. And while we must act to ensure that disabled people can take their rightful place in the work force, we must also respect the dignity of those unable to work. We must ensure that their lives are valued and that we use our collective resources to ensure they have the resources to live and enjoy life and not merely exist.

Those who work are generally in better health, have wider social contacts, a stronger sense of self-worth and status and receive the validation of society at large. Those in work are able to provide for their families, acquire assets such as a home of their own, and build up a sufficient pension for retirement.

For too long disabled people have been written off – the focus so often on what people cannot do, rather than what they can or could do. Some of these attitudes can be traced back to the start of the industrial revolution.

This exclusion can be seen written across life. With work at its heart, society has evolved without us, and this is reflected in a transport system which had not assumed that we would use it, a built environment which never expected us to be in it, a housing stock that did not expect us to live in it, an education system which has seen little point in investing in us, a health system which has placed less value on our lives, and a social care system which has sought only to keep us ticking over, not support our equal participation in everyday life.

All remain barriers to our being able to find, accept and keep jobs.

All are also reasons why many disabled people possess creative skills and innovative approaches to problem solving so far untapped by many employers. We could not survive without these skills.

As this audience will know the industrial landscape is constantly changing. A knowledge based society requires different skills to one based on manufacture. This will assist some disabled people more than others.

The evidence shows that different groups of disabled people face different types of prejudice.

Employers sometimes refuse to recruit people with mental health conditions on grounds that it will affect their judgement. It is perhaps fortunate that Winston Churchill was not denied the job as war time prime minister because of what he called his black dog days that we now recognise as a form of mental illness.

The armed forces are excluded from the employment provisions of the Disability Discrimination Act on grounds that disabled people are unfit to serve. Who would tell the inspirational military leader Lord Nelson that he was not ‘fit’ to serve in the armed forces? Looking overseas, the Commander in Chief of the USA armed services in world war II ran the war from his wheelchair. Despite their exclusion from the DDA the forces do employ a number of disabled people.

We could discuss people with hearing impairments being excluded from music courses on grounds that they cannot meet the academic standards required. Who would tell Beethoven that he couldn’t appreciate music?

And a man with no mobility or speech, reliant on a wheelchair to get around, a computer to articulate his words, and in receipt of round the clock care being told he can’t become an astro-physicist and undertake world-changing research into a unified theory of life, the universe and everything.....

But these are not just anecdotes because the good news is that 50% of disabled people of working age are working. They are Ministers and MPs, lawyers, nurses and teachers, parents and school Governors to name but a few – the active citizens who hold our society together.

The population is ageing – the workforce is shrinking.   We are already at the point where there are more people aged over 60 than under 14 – we are now officially a ‘mature society’, and this trend is projected to continue. Employers who fail to embrace diversity by removing barriers and embracing hitherto excluded groups will in time find they are losing out as employers compete for employees with diverse characteristics and requirements. Discriminatory policies are not just morally and legally wrong – they are unsustainable.

Yet disabled people still face unacceptable discrimination in their chosen careers and 50% remain outside employment. For people with mental health conditions the figure is nearer 80%. Disabled people actively want to participate and make a contribution where they can. But too often they are prevented from doing so. There are many disabled people who want to work, yet face unacceptable discrimination and unnecessary barriers to gaining employment. The DRC wants to see the number of disabled people of working age who are employed increase from 50% now to 60% by 2014 – about 686,000 more than today.   When we consider that 81% of non-disabled people of working age are currently in work, and that the Government has set a target of 85% overall, then this seems a fair and realistic ambition.

Many disabled people lack the skills required to compete equitably in the jobs market because they have been denied the opportunity to acquire them. Whilst contested by some, Digby Jones has said that by 2010 anyone without a level 2 qualification will be unable to find a job. All across the economy we are seeing a professionalisation of work, requiring applicants to hold qualifications assuring their suitability, where previously such qualifications were not required. The Government have also said a level 2 qualification is the minimum skills requirement of a modern economy. Currently 56% of disabled people do not even have a Level 1 qualification. Clearly dedicated action is required, by Government, public bodies, schools, providers of further and higher education, through apprenticeships, through lifelong learning and via initiatives such as pathways to work to provide opportunities for disabled people to improve their human capital so that they can compete on more even terms with non-disabled people. This is a vital plank of supporting disabled people's citizenship and in reaching our employment targets.

So how can employers help us get there?

Work is about much more than 'getting in the door'. Employers are well aware that developing and supporting their workforce is vital to the success of the business. Many employers are doing an excellent job in supporting disabled people in their workforce, because getting the best out of people is such a vital part of their role. HR departments have a primary task of investing in people, through ensuring training and development opportunities that contribute to retention and motivation, and promote 'careers' more than just jobs. Sensible employers know only too well that the costs of recruiting and developing new staff far outweigh the costs of retaining good staff. As well as getting disabled people in we need to ensure that they get on. That comes through training and support which promotes equal opportunities and policies that do not discriminate.

Responding to diversity will increasingly be a necessity for employers who wish to survive. Those employers who can rise to the challenges of the next 20 years – demographic change and its impact on the make-up of the workforce, changes in the psychological contract between employer and employee, changes in expectations around work-life balance and flexibilities, legislative change concerning the rights of previously excluded groups and the expectations of customers – will be the ones who thrive.

It seems we have a mutual interest. Let's work together for success.

Bert Massie
March 2005

Keywords: Disabled people; Diversity; Employers

Bert Massie Federation of Small Businesses March 2005

Bert Massie Speech to the 31st Annual Conference and Annual General Meeting of the Federation of Small Businesses, Birmingham, Friday 18th March 2005

Ladies and Gentlemen,

It is always a pleasure both to be and to speak amongst friends.

A description that I offer without hesitation to the Federation of Small Businesses.

And a description earned, in great part, both in the support and advice given to me personally and to the cogent advocacy of the cause of disability rights given more generally by Stephen Alambritis.

A great deal has been written in the media lately about small business leaders raging against recent changes to the Disability Discrimination Act. Changes which, for the first time in many of our lifetimes, gave rights to disabled people to receive fair treatment from shops and providers of a service that non-disabled people take for granted.

The response of the FSB and Stephen was measured and calm.

It was a response that pinpointed concerns but also recognised the compelling need for change.

In Stephen I think we have the perfect blend of a man passionate about defending the contribution that small businesses make to our country and its economy. But also a man who is willing to concede on a point well made – as the need to ensure that there should be no holds on where and how 10 million disabled people spend their money undoubtedly was.

The FSB’s response during the introduction of this new law ensured a grown up debate and allowed us to concentrate on the substance and not the froth.

And I thank him and you for that.

Maybe the antics of the media in this regard really do confirm the proverb that ‘my enemy’s enemy is my friend!’ Indeed, with enemies like Stephen, who needs friends!

But I am not here to speak to you about access, important though that is, but about a new frontier that the DRC is eager to make inroads into.

My subject is employment.

And what’s more, my aim is to convince you, that in the same way that we are successfully tackling and bringing down barriers in the way of disabled people getting served,

That there is another great challenge.

Perhaps the most decisive one.

Because it goes to the very base of negative attitudes that exclude and deny disabled people their chance to contribute.

And that is the challenge of making the place of work a place of welcome to increasingly more disabled people.

This week the Disability Rights Commission launched a major employment initiative aimed at ensuring that the more than half a million disabled workers, who are already contributing to the success of Britain’s small businesses, continue to do so.

It is an initiative aimed at sending out the message that people who develop long term health conditions while in work, can be supported to remain in work,
Can continue to make their contribution.

It is an initiative aimed at you.

On October 1st last year the DDA extended its employment protection for disabled people to all businesses with the lifting of the small business exemption. This means that, no matter what the size of the company or concern, businesses need to be sure that in all matters of employment potential or existing disabled workers are treated fairly.

Many have not been slow in making their view known on this extension of the law to cover small businesses. It has been received by some as yet another albatross around the neck of already struggling businesses who are just ‘in it to win it’. In it to generate the sales, to cover the costs, to pay the staff with hopefully something left to enjoy the fruits of their independence and enterprise.

Some have said this.

Other commentators have railed against yet another directive for small businesses to follow from people who know nothing about small business and everything about sticking their noses in where it is most unwelcome.

Another viewpoint.

Others again have seen the extension as an irrelevant distraction from the true litmus test that should determine everything that small business owners prioritise and do: whether it contributes to the bottom line of their business.

These are all opinions that have been strongly made from time to time – you may well have heard them. But are they the opinions and views of small businessmen and women?

Well it’s not Steve Madison’s view, the boss of Mascot Carpentry and Joinery in Northumberland. Ian Lamb – a joiner with the company for the last eight years, and a highly skilled one at that – is deaf. Steve’s adjustment? He and his wife are learning British Sign Language, an action that has not dented their £58,000 annual turnover but in fact has improved communications with all their staff.

It would not be true to say that the £1million a year turnover of Design Matters in Buckingham hasn’t been affected by the continued employment of Adam Thomas as a kitchen designer after a motorcycle accident. Adjustments had to be made to make the work place accessible for Adam’s wheelchair on his return to work. But as Adam’s boss Richard Smithies has told me, turnover has increased because of Adam’s employment, not in spite of it.

‘He is a talented designer. He understands the needs of disabled customers and has been a loyal employee for over 20 years – repaying many times over the investment that I have made.’

Pack it Promotions, is a successful mailing house in Cardiff that distributes magazines, newsletters and goods for online businesses. It has a turnover of £1.4 million, a staff of 18 people. Oh, and by the way, half the staff are disabled people.

Half the 10 staff at Wiring Solutions in Peterborough are also disabled. It’s a family run business with a turnover of £600,000. Hilary Pearce said to me that the business is committed to developing its workers to their maximum with no exception being given to their staff with mental health and mobility impairments.

They thrive, the company thrives.

And I can go on: to Conquest Plants Nursery in Cheshire, three staff including Gregory who is blind; to Chantry Builders in Yorkshire- 42 staff with eight disabled workers making their contribution. To Oyster Design and New Media in Coventry and Outrageous Fortune, a fashion company in Southwold.

All make the case that disabled people are already contributing to the success of many small businesses up and down the country; that smart business are those that are able to find and nurture talent wherever it is.

Let us today scotch the myth that extending the DDA duty places an incubus or a burden on small businesses, that it poses some alien threat hitherto unknown to man; that it is bad for small businesses, and bad for business. Over half a million-disabled people are already working in small businesses; already making their contribution to the success of those businesses. And there are smart businesses who are making their workplaces open to disabled workers and who will continue to benefit from it.

There are businesses that have the set up to do more.

I say this because we have had an even bigger conversation with small business – over a 1,000 of you in fact – in a survey that represents the most comprehensive assessment of small business attitudes to disability in the workforce. The findings are as significant as they are challenging.

Significant because they confirm the conversations I have been having with small business about the contribution that disabled are making to business.

Challenging - because despite this we will need a more sustained and substantial effort to make inroads into the huge gulf that separates the large share of disabled people from becoming economically active, from getting in and getting on in work. I do not exaggerate when I say that it a challenge equivalent in scale, and undoubtedly equal in importance, as securing a place for women in the workplace was at the turn of the last century.

It is a challenge for us at the DRC to meet: one that Government has recently come to recognise that it has to tackle; and it a challenge that will be met with your vital contribution as well.

Smart businesses are already recognising that, like it or not, disability and long term health conditions in the workforce will have a greater profile. By 2020 half the UK population will be over 50. They know that disability increases with age, and that over one third of people aged between 50 and retirement age are disabled. This fact is informing smart businesses' approach to locating and securing talent, to keeping it and to supporting it. It is clearly this attitude that is driving the businesses that we spoke to in our survey who acknowledge and are ready to face up to this new landscape. In this new environment business simply cannot afford to allow the existence of a disability or a long-term health condition to get in the way of finding and keeping talented and able staff. Eighty eight per cent of the small businesses we spoke to agreed. They said that they did not see the existence of a disability or a long-term health condition as a reason not to offer a job.

Flexibility and adaptability will become the watchwords for negotiating this new environment. And the small businesses we spoke to also agreed that this was a vital means by which talent would not be missed and where their companies would lose out. Sixty two per cent of small businesses said that they would be flexible in working arrangements and conditions for candidates that had the skill and the enthusiasm for the job, with businesses employing fewer than nine staff willing to show greater flexibility. Even among firms not currently employing disabled people, 85% said that they could be flexible.

The biggest priority for small businesses is finding suitably qualified staff and keeping good people already working for you from moving on. And smart businesses are concentrating on what this means in the new environment of an ageing workforce. They are not wasting their time worrying about anti discrimination laws that are well and truly at the bottom of the list of their concerns.

So, perhaps uncharacteristically, I come here today to praise smart businesses and not to bury them. Smart businesses are employing disabled workers, possess positive and forward-looking attitudes that do not allow traditional employment practices to get in the way of taking on board the right candidate; they posses a natural flexibility – an essential ingredient to small business success – that is providing considerable benefits.

The message is clear from our research:

Small businesses that are already successfully employing and supporting disabled people in work have nothing to fear from their new legal duties.

Smart businesses that are already set up for dealing with the new environment of work, equally, have nothing to fear but everything to gain.

But of course there are less smart concerns.

And we know who you are.

Every third person sitting in this room today runs a company like this. One in every two of the bosses running these companies does not know that the world is changing

– and that disability is an increasing measure of this. Three in four of these companies say that it would be difficult to employ someone with a disability or health condition; they think employing disabled people is a drain on their finances, on their workforce. They think that for disabled people, employment is not about contributing but about taking – lots of sick leave! They have never employed a disabled person, but do not allow that fact to get in the way of making judgements about their capabilities. These companies are the most likely to discriminate. They are even doubtful about employing women!

What is not in doubt is that every day these businesses are tottering on the brink of survival; that the lack of foresight and vision at the top of the business means that these are companies in the risk business; that as a result sooner or later these companies will be getting a visit from the DRC.

But I cannot blame the gaps in employment levels between disabled and non-disabled people on the third of small businesses that simply do not want to know. In Britain today only half the number of disabled people of working age are in work compared with 81% of non-disabled people. Over one million people with disabilities claiming incapacity benefit want to work. At the same time employers and business continue to raise concerns about skills gaps and labour shortages. If markets are thought to be the most efficient and effective means of allocating scarce resources, how do we explain such market failures to secure work for people that want it to the businesses that need it? What possible justification could there be to allow talent and ambition to be wasted in such magnitude?

For too long society has circumscribed disabled people’s involvement to nothing more than the passive recipients of care and support. With this view cemented in place whole areas of life have become anathema to disabled people and with it attitudes to justify these exclusions have become commonplace. Work is one of those areas. To make progress in this area attitudinal barriers – like the physical barriers obstructing access to services – must come tumbling down and clear a path for more disabled people to contribute in the workforce.

Government has a job to do in this area and at last they are getting the message that real, bespoke mechanisms of support need to be provided to enable disabled people to work. Evidence from their own pilots on helping people off incapacity benefits and into work shows how incredibly successful they have been in placing disabled people into real jobs, increasing their incomes, tackling poverty. With credible and robust levels of support people written off by the labour market are making their way back into work. I congratulate the Government on its proposal to spread this initiative across the country so that all disabled people on benefits but who want to work can get the support they need to do this, so that they can rejoin the workforce or join it for the very first time.

But business too has a role to play: to conquer that attitude that doubts the contribution that disabled people can make; to see the evidence of their own experience and to be emboldened to go the extra mile. A half of the total of small businesses that we spoke to want to be good employers, have strong and positive views about disabled people. You say that you would be flexible about working hours. These businesses understand disability and have no doubts that disabled people could contribute to your team. But you still think that it would difficult to employ disabled people.

I am telling you, you are the best set to employ a disabled person, and you are our potential partners in the challenge of making disabled people belong to the world of work. If each of these companies took the small step needed to employ a disabled person we could reduce these punishing unemployment levels. We would achieve it by the power of individuals like you simply behaving logically and in the interests of your business.

Fifteen per cent of small businesses are nearly there – you’re nearly there because you do employ disabled people already and have seen how easy it has been, how well your company has done since then. Your company is the kind that values and invests in its staff, it is a well-run organisation and does well because of that. Yours is a company that should have no fear in making its workplace a place for disabled workers.

You company can do more.

Your company should do more.

And I tell you, your company needs to do more to convince its non disabled workers that you value them.

Nearly a quarter of them of them think that you would show them the door if they developed a long term condition according to a poll we commissioned from MORI; that you would not support them to remain in work.

The figure is higher in small businesses.

What an irony in the context of what you have said to us. And what a pressing need to do more to tell your workforce that flexibility in conditions and work are a watchword for your business. That valued workers in your firm with hidden disabilities have nothing to fear.

Doing more will mean that talented staff will have no reason to leave your company if they develop a disability or a long term health condition in later life.

Doing more will open your business up to retain existing good staff and the estimated 1 million disabled people who can and want to work.

Doing more will cement disabled people’s place in the workplace contributing fully as equal citizens in our society.

With Government and business by our side, we can tackle the blight of wasted talent,
Deliver real opportunities to disabled people, And send into retreat false notions of disabled people’s capacity or willingness to contribute.

Let’s get to work!

Keywords: Disability Discrimination Act 1995; Disabled people; Employment; Small businesses

Bert Massie National Commission for Disabled People- Malta June 2005

Abridged version of speech given by Bert Massie, Chairman of the Disability Rights Commission, Great Britain to the National Commission for Disabled People, Malta, 25 June 2005.

Perhaps I can start by saying how pleased I am to be here today and to apologise for my inability to speak to you in your own language. We are fortunate in having the services of interpreters to translate my words into Maltese. We also have sign language interpreters so our deaf colleagues can be fully included in our discussions.

However, we do have a common language. This is the language of discrimination, which unites disabled people throughout the world. We all know what it is like to live in a society that takes insufficient account of our needs.

Perhaps I should describe what I mean by discrimination. It is the systematic denial of civil and human rights: a denial of the right to be full and equal citizens. In some cases we are denied the right to life itself.

I very much welcome the links the DRC has developed with the National Commission for Disabled People here in Malta. This is my second visit and since my first visit, colleagues from Malta have visited the DRC offices in London and Manchester. I have a great respect for the disability leaders here in Malta and I know that we have a common cause.

Perhaps I should say a few words about the DRC. It was established in 2000 and that was set up following an act of Parliament. It has a governing body of 14 Commissioners who are appointed by the Secretary of State. At least half should be disabled people. At the moment over two thirds are. We have an excellent chief executive and a team of about 200 people.

We have a helpline based in Stratford-upon-Avon and this takes about 140,000 calls a year. Most of these are from disabled people and their relatives but we also received calls from employers and organisations that provide services to the public.

We can resolve most difficulties fairly quickly. However, sometimes it does appear as though an organisation is discriminating against disabled people. We have a casework team, which will investigate that case and seek to resolve the difficulties. Usually we are able to find a solution that is acceptable to all. If we cannot and the case does not concern an employment issue, we can use an independent conciliation service that is funded by the DRC. Equally, there are occasions when we need to use the full might of the law and we have an excellent legal team that initiates 40-50 cases every year. We prefer legal cases that have a major strategic importance and help to clarify the law and might extend the rights of disabled people. The Archibald case that I shall mention later did just that.

The DRC produces the Codes of Practice to help people understand the disability discrimination act. By writing these Codes we helped to influence the law because the courts have to take account of them, even though the codes not themselves constitute law.

We also have are duty to keep the law under review and to make recommendations to the government where we believe changes are needed. One recommendation we made was that the law should be a duty imposed on the public sector of the economy to promote the equality of disabled people. This has now been introduced into the law and will come into effect next year.

Within the United Kingdom legislation for disabled will has evolved slowly. There was very little between 1919-45 although some efforts were made to establish workshops for blind people. Generally speaking disabled people were marginalised by society. People with severe mental illnesses spent much of their lives in mental illness hospitals. Disabled people had no rights and usually had short lives.

The Disabled Persons (Employment) Act was passed in 1944 as Britain approach the end of World War II. This required employers with more than 19 employees to employ a percentage of disabled people. Unfortunately, the law was never really enforced. 1944 also saw the Education Act, which extended education opportunities throughout the country, including to disabled people but excluding those with learning disabilities. In 1948 the National Assistance Act introduced the National Health Service and basic social service provision. It is worth reflecting that these major social initiatives took place when Britain was virtually bankrupt as a result of World War II. However, it took until 1970 for further significant legislation aimed at improving the lives of disabled people.

The Chronically Sick and Disabled Persons Act 1970 improved access to social service provision. It introduced the blue badge scheme. It also required public buildings to be accessible to disabled people in so far as was a reasonable and practical. It soon became apparent that it was hardly ever reasonable or practical so disabled people continue to face a life of exclusion. You can see that at this there was the first introduction of policies that reflect part of what later became known as the social model of disability. By recognising that inaccessible buildings contributed towards discrimination we began to move away from an impairment based model.

Much has been written about the social model but in essence it is very simple. We know that most disabled people will never be cured so the only way to enable them to participate is to remove the barriers in society.

This can raise a number of interesting issues. For example, is dyslexia a disability? I would argue it is. We know it is an impairment, but that would not have mattered 300 years ago when few people could read or write. I had been privileged in the last few days to visit a number of your beautiful churches in Malta. They're all decorated with wonderful pictures depicting scenes from the Bible. The church knew that the parishioners could not read the Bible so introduced people to its stories through wonderful pictures. Today we need to use more modern technology to enable people with this impairment to learn from the printed word. Another example is sign language. There is a Bedouin tribe where many of the members have hereditary deafness. As a result all the tribe, including those with hearing, use sign language. Again, you can see that adjusting the environment enables disabled people to be included. Inevitably this is a long process but we will only ever end it if we get on with the task now.

It was not until 1974 that people with learning disabilities were seen in the UK as educable, so for this group of people civil rights is a relatively recent phenomenon. The social model of disability was emphasised by Peter Large in his 1977 report Can Disabled people Go Where You Go? The answer was usually no. That report was followed by the Committee on Restrictions Against Disabled People. It pointed out that inaccessible buildings or buses discriminates as much against people with impaired mobility as much as somebody's hostile attitude. It called for changes in the law. Of course, some said that laws cannot make people love each other. This is, of course, true. However, laws can regulate how people behave towards each other. In 1981 we had the

International Year of Disabled People and a new Education Act, which promoted the inclusion of disabled people into mainstream schools.

However, the government in the UK were reluctant to pass comprehensive legislation outlawing discrimination against several people. They did introduce a number of partial measures that were helpful but limited. For example, Part M of building regulations required new buildings to which the public were admitted to be accessible. We did not get more comprehensive legislation until 1995 when the Disability Discrimination Act was passed.

I shall now give a very brief outline of the Act but if you would like more information I would suggest you visit the DRC web site.

Part One defines disabled people. In general terms the Act covers those who have an impairment which affects their everyday activities. It also includes people with facial disfigurements or with a history of mental illness because they also face discrimination on account of their impairment. The new Disability Discrimination Act 2005 will extend this definition to include people with HIV or cancer.

Recent research has shown that about 48% of people covered by the DDA do not consider themselves to be disabled. There is a genuine dilemma. At what point does somebody with mild stress become somebody with mental health difficulties? At what point does a slightly arthritic joint become arthritis which affects their activities? Many deaf people do not regard deafness as an impairment but as a language issue. At what extent does the shortness of breath become a heart problem, which affects their life? Definition is therefore problematic.

This might well lead you to ask whether definition matters at all. I would argue that it does because we need to plan services and for that we need to have some idea of numbers so budgets can be planned. We therefore need to move to a position were no impaired person is ashamed of admitting they are disabled. As a society we need to appreciate the value of diversity. Of course, we already do this in the animal world and a great deal of effort is being expended to reduce the number of species facing extinction. We rejoice at the range of flowers and plants in our gardens. Why then does the human race have some difficulty valuing in diversity within our own species?

There is, however, another issue that we are beginning to consider at the DRC. It is this: should we define disabled people or define the discrimination? Many people seeking to defend discriminatory activities in Britain start by arguing that the person who has experienced the discrimination is not disabled. We will be issuing a consultation paper on this topic later in the year.

Part Two of the Act makes it unlawful for employers to discriminate against disabled people in recruitment or other employment policies. An important part of this provision is the requirement to make reasonable adjustments to enable people to do the job. Most adjustments amount to no more than changes in managerial procedures. Occasionally, equipment may need to be provided but this is really no different in principle to the employer who supplies computers to his staff rather than ballpoint pens because the computer increases their output. An appropriate designed workstation does much the same. Despite the law some employers still discriminate and in the last few months the DRC has won a major legal case against a local authority in Scotland which dismissed a woman who had been a street cleaner and became disabled. They should have tried to find to another job that she could do. Instead she was required to compete for every job in a clerical capacity on a competitive basis. The local authority argued that allowing her to apply was a reasonable adjustment. It was quite clear that she was perfectly capable of doing many of the jobs for which she applied but the local authority appointed somebody who they believed was a stronger candidate. The House of Lords ruled that they should have given her one of the other jobs and this judgement will have major effects throughout the UK. She went on to become a major staff member for another employer and his showed how the local authority had lost a very useful employee through poor employment policies.

Of course, we sometimes lose cases. One case that still irritates me concerns a worker in a job in which he was required to wear protective boots but because of his impairment he was unable to do so. An interpretation of our health and safety rules meant he lost his job although he posed a danger is nobody and only a tiny one to himself. Health and safety legislation over rules the DDA and I think we do need to examine whether it is always appropriate that it should do. In short, we need a more sensible interpretation of what is meant by health and safety and whether we need to establish a better balance.

Government figures suggest that about 51% are disabled people of working age are in work. This compares with 80% of the non-disabled population. It is unlikely the figures will ever be identical but we do need to increase the number of disabled people of working wage are in work. It should be possible to get this figure to 60% and this is one of the DRC targets.

Part Three of the Act relates to access to goods and services. This does not invariably mean access to buildings. It is the service that needs to be accessible although in some cases the best way to provide the service is to make the building accessible. Although Malta is quite warm, it is not very realistic to eat a meal on the street outside a restaurant in London in the middle of January. So, where possible, it makes sense to make the building accessible. I am so astonished by how many restaurants deny access to blind people accompanied by guide dog. This is almost invariably unlawful.

It is also necessary to ensure that financial services do not discriminate against disabled people. I recall some years ago that when I was seeking to buy travel insurance the broker informed me that there would be a premium on the price. When I asked him to investigate why, he informed me that the insurance company thought that as a wheelchair user it would take me longer to cross the road and I was therefore at greater risk. I told him to tell insurance company how they thought I had reached the age I then was if I have not learnt how to cross the road. The price was reduced. Although insurance companies are permitted to charge extra if there is an increased risk, they have to be able to prove that the extra risk does exist and, of course, they usually then find that is no evidence of extra risk.

Part Four covers education and new legislation since the 1995 Act means that the provisions of the DDA now cover universities and colleges of further education that must not discriminate. This also covers examinations and I am pleased that the work the DRC did with the teaching unions in the United Kingdom subsequently proved helpful here in Malta during your own negotiations. This cooperation between equality commissions can only be positive.

Part Five covers transport. When the DDA was first passed only the design of certain transport vehicles was covered. The Act has recently been amended and from next year the full Part Three rights will also apply to those using transport services. The DRC has published a draft code of practice which, again, is available on our website.

Aviation and maritime travel are still excluded but the government does now have powers to bring them under the DDA. I suspect it will be necessary to do this. As you may know, the DRC supported a case against Ryanair and BAA because disabled people who needed a wheelchair to travel through the airport but did not have their wheelchair were being charge the use of the airport wheelchair, when as a reasonable adjustment it should be free of charge.

Looking ahead new agendas are appearing. As well as eliminating discrimination cases against disabled people, we also need to promote the concept of independent living. We need to support disabled people in empowering themselves to live life on their own terms. Here in Malta, as in other countries, there is a strong and important parents movement as those parents seek facilities and services for their children. This is entirely understandable but the real challenge is to enable the parents to let go and enable their children to fight their own battles. I have been told that people with learning disabilities cannot do this. Certainly, some can't but in my experience a growing number of people with learning disabilities are seizing their own agenda and controlling their own lives. In the UK organisations of people with learning disabilities are showing that they are able to advocate for themselves, sometimes with the support of a support worker. When disabled people begin to control their own service, those services invariably become more responsive to their own needs and usually at a lower cost.

Throughout the world disabled people are acquiring new rights. They have not come easily. A generation of disabled people have fought long and hard for those rights but it is becoming increasingly apparent that we need a new generation of disabled fighters to take the battle forward. There is still a great deal more that needs doing. Disability organisations in Malta and Britain need to work together to develop new agendas and to ensure that the needs of disabled people are never lost in broader agendas and campaigns. The Roman Empire, like many other empires failed only when it became divided.

So what are some of those new agendas? I think one might be review the concept of active citizenship. I believe that any society has obligations towards its disabled citizens. But we need to ensure that disabled people are never seen as passive recipients of other people's goodwill. Disabled people want to contribute to the well-being opportunities in which we live and are willing and able to do so. Indeed, looking back through history it is easy to see many disabled people have contributed. Next week in the UK we will commemorate the Battle of Trafalgar. A disabled man named Nelson led the British forces. Beethoven, who became deaf, wrote the anthem for the European Union. And who can forget the paintings of the Van Gogh having seen them. A leading player in ending World War II was Roosevelt who was also disabled. But we do not need to look to history for our heroes. There are many disabled people alive now fighting for the human rights and emancipation of disabled people. There are such people here in Malta and in many other countries. Let us join them in building the society that is to be fit for heroes even if they are disabled.

Thank you for listening to me and I wish you every possible success in your endeavours.

Keywords: Disability Discrimination Act; Disability Rights

Bert Massie BSI Conference London July 2005

Keynote Speech by Bert Massie - ‘Stopping Websites that prevent people buying: The case for accessibility’ at the BSI Conference on Defining and Developing a Profitable Web Accessibility Strategy in London on 7 July 2005

Good morning Ladies and Gentlemen, it’s a pleasure to be here today to discuss an issue that is very much part of our lives.

Tim Berners-Lee is the inventor of the World Wide Web and once stated that “The power of the Web is in its universality. Access by everyone regardless of disability is an essential aspect.”

Whether you’re aware of it or not, website accessibility is an issue for your business website. Today many businesses still fail to consider the needs of disabled people in gaining access to their websites. This is despite existing legislation and guidelines that define website design and development. The Disability Discrimination Act 1995 requires services available to the public to also be available to disabled people. It is a complex Act and to assist people in understanding it the DRC has produced a number of Codes of Practice that are not in themselves a statement of law but must be taken into account by courts and tribunals.

If a service is provided through a website, the site should be accessible to disabled people. Although this is an obvious part of the service that many companies offer the public, employers should also consider that disabled staff might need access to their internal intranet.

The Disability Discrimination Act makes it unlawful for employers, providers of goods and services, education providers and soon transport providers to treat disabled people ‘less favourably’ for a reason relating to their disability. It also requires that they take steps to remove barriers – physical, organisational and social – which might otherwise lead to disadvantage.

The Code of Practice has a specific example of using a website. Section 2.17 states: “What services are affected by the Act? An airline company provides a flight reservation and booking service to the public on its website. This is a provision of a service and is subject to the Act.” Although no cases have yet come to court in this country, two cases were supported by the RNIB. The organisations concerned settled out of court, which should tell us something. Furthermore, some cases are being considered by the DRC at the moment. So it’s a live issue, it is on people’s radar screens and it’s going to get bigger.

The DDA was enacted because Parliament agreed that we should have a society in which disabled people could participate fully as equal citizens. Historically, there have been many barriers to this. In fact, most social and economic activity actually takes place in the mind – by and large the senses are just ‘input/output devices’. However, in the physical world, we have constructed actual or metaphorical steps at every threshold. We have created a physically inaccessible environment.

The consequence of this is that people with mobility impairments have their mobility further restricted. Blind people or those with low vision are denied access to information and there are thousands of pre-lingually deaf people in this country whose first language, BSL, which has a different structure from verbal communication. For many of them written English can be almost as inaccessible as oral speech. One-to-one sign-language interpretation is expensive and in short supply, but the advent of intelligent speech recognition associated with avatar sign-generators could give BSL users unrestricted access to the spoken and written word.

Today, the PC isn’t just an indispensable business tool; it is also a gateway to information, services, entertainment and social interaction - facilities which enable economic activity and enhance quality of life.

Although untested in Courts, there is little question that it is illegal to provide a service by way of a website which it is unreasonably difficult for a disabled person to use, and that service providers have a duty to make reasonable adjustments to remove such obstacles. I am not convinced we are at the stage where we need further legislation but we are perhaps reaching the stage when current legislation might need to be enforced more vigorously.

One question I am often asked is how someone can tell that their website conforms to the DDA. People want an unambiguous test of compliance. Unfortunately, it is impracticable to provide this. Their duty is to achieve an outcome – usability. Usability is not absolute, like jumping red light; it is qualitative, like driving without due care & attention. As in most business decisions, this requires those responsible to acquire skills and exercise judgement.

What guidance can we give them to help them to stay on the right side of the law?

The ultimate responsibility and power to achieve change rests with site owners – the board of management of the organisation sponsoring the site. So the first and most important step is for every Governing Body to develop and adopt a formal policy for meeting the needs of disabled people.

The DDA calls for reasonable adjustments, not perfection. What is ‘reasonable’ depends on circumstances and, in the last resort, this will be decided by a Court or Tribunal.

I suggest that, to sustain a defence that all reasonable steps have been taken, site owners should be able to demonstrate that they have given serious consideration to the needs of disabled users, and examined how far they can go in accommodating them.

A documented policy would support this contention, and our research findings suggest that such a policy needs to include

- the target level of accessibility that the organisation is aiming for, and the minimum which it considers acceptable
- a requirement to verify that this is being achieved and maintained, inter alia by involving disabled people in testing
- a requirement that all specifications, ITTs and outsourcing agreements oblige developers to conform to the policy.

Adopting a policy is only the start: it must be accompanied by a process for applying it.

This is a compliance issue: as with other regulatory matters – Health & Safety, Data Protection, Consumer Protection – Boards can delegate, but not abdicate, responsibility for implementing policy.

Although not expected to understand the technical intricacies, they should

- define the outcome required – e.g. the ability of users of specified categories of Assistive Technology to make practical use of site facilities

- assign responsibility – who is personally accountable for delivery? Perhaps HR for systems used by employees or job applicants, but probably line management for service delivery systems;
- audit compliance – verify that the policy is being observed.

Given that a tick-box checklist is not feasible, we feel that the most useful tool would be a template: a model business process which can be adapted to the needs of individual organisations.

The people best qualified to develop this are the interested parties themselves, and the DRC is promoting the establishment of a consortium of stakeholders, facilitated by BSI, to formulate a procedure (not technical standards) which would ensure that relevant considerations are identified and taken into account at each stage in the commissioning, development, and maintenance process.

Government, and BSI committees, have a key role in raising awareness of the need for good practice in this area. I have touched on the moral and legal reasons but, although time doesn't allow me to enlarge on the topic, there is usually a good business case to be made as well.

However committed site owners may be, they are reliant on IT practitioners to translate their good intentions into practice. Most practitioners are aware of the WAI guidelines but are too often ignorant of their rationale and unaware of their limitations. Delivering a usable site calls for an insight into the problems which inconsiderate design can create. Too few practitioners have this insight. Here we face a major challenge. To equip those who develop websites we need to influence their training, but we are not sure how they acquire their training!

We are not dealing with a structured and regulated profession. Commercially run short courses on the use of proprietary software tools are probably more influential than vocational degree courses.

The DRC is not competent to tackle this issue itself. DfES and the Learning & Skills Council are likely to be better equipped to identify and influence the relevant training channels. We are looking for direction and active support from those quarters.

This training needs to be backed-up by guidance on best practice to be observed throughout the design/development/testing/maintenance cycle, and we would hope that this might be built into the BSI project to which I referred earlier.

All this will be in vain if disabled users themselves do not have access to the technology most appropriate to their needs.

The first step is assessment. We have recommended that those providing front line health and social care should have a basic understanding of the potential of information technology and of available sources of assistance - sufficient to enable them to provide a signposting service for clients who might benefit. We hope to develop these ideas with DoH.

The technology itself, and the associated training and support, may be beyond the means of many who could benefit from it. There are narrowly targeted grant schemes, such as Access to Work and the Communications Access Project, but they are not widely publicised, their capacity often falls short of demand, and there are large gaps between them.

Government should be aware that, a few years from now, the deprivation caused by inadequate IT will be as obvious

– as scandalous - as an unfulfilled need for a wheelchair or hearing aid.

One of the DRC’s powers is to conduct investigations to see whether disabled people are facing discrimination. In April 2004, we published the results of a Formal Investigation (FI) into the issues faced by disabled people when using websites. We looked at over a thousand websites and were surprised to discover that over 80% failed to meet even the most basic of access standards.

The investigation discovered that many disabled people find websites difficult to use. What was interesting was that even websites that seemed to conform to WAI standards were often difficult for disabled people, and particularly blind people to use. One of our recommendations was that website hosts should not rely on automated testing but should go further and consult disabled people on the accessibility of the site. This recommendation, perhaps predictably, was not greeted warmly by some companies that earn their living selling such automated testing. But they should not have been surprised by the standard. WAI makes the same point as the DRC made. Many features of websites that can affect accessibility cannot be picked up by such tools. That is not to say that there is no role for automatic testing but it is only the start. For example, while tools can check whether each image in a website has associated ALT text (which provides descriptive text for visually impaired users as an alternative to an image or picture) by inspecting the page’s HTML code (which governs the structure and layout of a website), they cannot verify that such text is helpful or appropriate. In such cases automated tools can only give warnings highlighting those aspects that should be checked manually. We called for the tools to be improved but also for website designers to consult disabled people at an early stage of the design.

Websites are still fairly recent technology and is still developing. We suggested that the Government should consider a formal accreditation for web designers that would include some knowledge of the needs of disabled people.

When the DRC published the FI, we hoped that industry, commerce and the public sector would take the baton and progress things. Unfortunately that has not happened to a sufficient degree, so we have commissioned the British Standards Institute BSI to produce a Publicly Available Specification (PAS). This is only a guide, not a standard, but it is still rigorously researched and reviewed. Unlike a full British Standard it can be produced relatively quickly and it should be available later this year. It is aimed primarily at people who commission and own websites, it will explain the issues of accessibility, the importance of standards and will guide them in developing a properly usable and accessible website.
When we designed our physical world we choose to include many barriers to disabled people because we knew no better. Now we are having to correct those mistakes at some cost. We are still at the early stages of designing the cyber world. I hope we will not repeat the errors of the past but work together to ensure that the new cyber world is one in which we design out the barriers that prevent disabled people from full and equal participation.

Thank you.

Bert Massie

7 July 2005

Keywords: Accessible websites; Businesses; Formal Investigation; Standards

Bert Massie Annual General Meeting of the British Polio Fellowship September 2005

Keynote After Dinner Speech

May I start by saying how pleased I am to be with you this evening? Attending any meeting of the BPF is rather like being at home. I became a member of the Fellowship in the 1950's and have remained one ever since. I am also conscious that in the last year or so the Fellowship has undergone significant change and some of it has been controversial, to say the least. The names of the Lantern and the Northern Lantern Hotels bring back memories for most of us. But in a changing world we all have to change and that invariably causes some stress and conflict. The challenge for all of us is how we deal with it.

Some years ago I was a minor player in a very major change to public services. At one extremely heated meeting the chairman said that in his opinion conflict was a bit like sex in that in certain circumstances it was inevitable and like sex it should be thoroughly enjoyed! I'm not sure the debate to find a new way forward for the BPF was as enjoyable as all would have liked but I think a reappraisal was necessary and I congratulate our chairman and his fellow trustees, as well as the small staff team, for their efforts in producing the new strategy for the Fellowship. It seems to me to deal with all the main issues with which the BPF will have to deal in the future.

I suppose one major issue of concern to many of us is the late effects of polio. I think I would rather it was even later than it is, or even better, like Godot, fails to turn up at all. We might get the long pauses of Beckett's script but, alas, extra problems do turn up, so we are then faced with how to cope with them. I think this issue alone shows the changing role of the Fellowship. Like many I had assumed that all we had to do was deal with the current consequences of our impairments and anything else Fate throws at us. But no, we face new problems associated with the effects of polio. At the same time so few of our physicians know anything about polio so fail to spot the systems and therefore cannot act. I think the BPF has done a good job in bringing this issue to the fore, in much the same way as the Spinal Injuries Association has worked to ensure good medical treatment for their members. But given that the average age of our members is 65 there remains much to be done to ensure people are not dismissed as having problems because they are getting old when polio is the real cause of the problem.

It does, of course, mean that some of the resources of the Fellowship now needed to be directed towards research rather than supporting members directly. This is a dilemma for many organisations but, as the Multiple Sclerosis Society has shown, it is possible to square that circle. Who knows, we might discover a magic pill that will enable me to play for Liverpool!

Some of the issues that have been concentrating the minds of trustees have also been exercising the minds of the DRC Commissioners and our very able staff. The DRC was conceived in 1999 but was born in 2000. During the past five years I think we have made a significant difference to the lives of millions of disabled people, and I'll say more about that in a few minutes. We have now reached the age when, if we were a child, we would have just started school. We will not be allowed to leave our primary school intact because in 2007 the DRC will be abolished and replaced by the Commission for Equality and Human Rights. We have been successful in persuading the Government that a section of the new body must be dedicated to the needs of disabled people and a committee on which at least half the members are disabled will determine disability policy. Alas, this arrangement is possibly only for five years.

It is remarkable how even today many non-disabled people think they know what is better for disabled people than we do. We could therefore face a future in which disability policy on equality and discrimination is set by people who believe that the blue parking badge really was designed for people who have no problem walking for miles and at great speed, because that is the type of person they see parked in the disabled motorist's bays in our supermarkets and elsewhere. As you know, there are over 2 million blue badges on issue at the moment. You will be relieved to know that detailed research shows that some of them have actually been issued to disabled people. Guard them with your lives. I'm told they fetch thousands of pounds on the black market as our "walky talky" motorists seek the rights the badge brings. Come to think of it, a bit more walking would be good for them.

One of the reasons that progress has been made over the years is that politicians of all political parties began to listen to the views of disabled people rather than those who had no personal experience of disability. Those who live with an impairment every day of the week, and for every second of those days, must surely be the experts in defining our needs and how to meet them. From day one the DRC has drawn its strength from disabled people and the disability community.

I hope that the CEHR will prove to be sufficiently sensible to work with disabled people in creating and enforcing equality laws that affect us and does not allow disability issues to slip because some other issue has a higher political profile at the time. However, at the DRC we need to decide what sort of legacy we will leave to the CEHR to inherit, and if our departure leaves a gap, who will fill it. To that end we have initiated what we are calling the Disability Debate and I hope that the Fellowship and its members will take a thoughtful and vocal role in it.

Our starting point is to recall what has been achieved. Only ten years ago disabled workers had no rights in respect of their impairments, apart from the neglected quota scheme. Unemployment amongst disabled people of working age was about 70%. The Disability Discrimination Act created new rights and the DRC has ensured they are enforced. The unemployment rate of disabled people is now 50%, still too high but a move in the right direction. Employers are beginning to take disability issues seriously. In Employment Tribunals last year, of all the cases they considered, the highest average awards went to disabled people. What do we need to do to ensure that 60% of disabled people of working age are able to do so? It is a figure we should be able to achieve providing we ensure people have the skills for the jobs available and we eliminate discrimination.

At one time the major problem for many disabled people was gaining access to public transport. The DDA built on improvements that started in the 1980's and now virtually all of London's buses are accessible for wheelchair users. So are all new trains and most of the old ones. We even have access to toilets on the trains, so as you can see we are flushed with success! But in many parts of the country we still can't use the taxis and, even when we can, we sometimes need the diplomatic skills of the United Nations to get the driver to stop for us. That will change with new laws coming into effect next year. Just as a shop-keeper cannot refuse to service us without very good cause, nor will transport operators be able to.

However, airlines and ferry companies are still excluded. Should they be? And, if not, what is it reasonable for them to be required to do. You might know that the DRC was heavily involved in legal action regarding charges for a wheelchair that were imposed on disabled Ryanair passengers. That has now been resolved but how can we avoid disabled people feeling like second class passengers?

Disabled people are now able to play a far greater role in the society in which we live. Well can I recall being banned from nearly everywhere because I was supposed to be a fire risk. I had thought that when I died I would be banned from Hell for the same reason, but if the DDA applies there I should be able to demand rights of access. As you see, sometimes laws have unintended consequences. However, our rights to the same services as non-disabled people is a huge step, or in my case a huge roll, forward. It will, of course, still take some time before all services, shops, hotels etc are fully accessible but if we look back 20 years it is possible to appreciate the enormity of the changes that have been achieved.

As many of the barriers to our inclusion are dismantled, I think disabled people will be viewed differently and, equally importantly, we will view ourselves differently. In the past we knew that the many obstacles that society placed in our path meant that we were not able to contribute as much to society as we would have liked. We were denied education, employment and as a consequence, financial resources. That is why the BPF has had to assist members with heating bills. Despite this, the history of our country is liberally decorated with examples of disabled people who have made a magnificent contribution and some of them have been members of the BPF. I think of Sir Peter Large and Mary Greaves who were pioneers in fighting for our rights. In the branches of the Fellowship up and down the country there are many more people making their contribution.

We are moving into a new age. It is one in which the welfare state as we know it is under attack. Government increasingly wants a contract with the people it assists. In return for state assistance, whether it be civil rights or financial support through the social security system, the Government wants us to accept our responsibilities as active citizens. This really is what the Disability Debate is all about. How do we make the transition, if there is one to be made, from being recipients of state aid and support to being active and involved citizens who are noted not only for the support we receive but for the contribution we make?

This question is of course contentious. Many disabled people, as I have said, are already making a contribution and those of you in this room are amongst them. Moreover, it could be argued that it is unreasonable to expect disabled people to contribute when so much of the support we need is absent. Many of you will know of the nightmare of trying to get basic adaptations done to your homes. Or the exhausting hassle of trying to get disability equipment and this can even include wheelchairs. A friend of mine is usually offered vouchers instead of a wheelchair but they do not cover the full cost of purchase and maintenance of the chair he needs. It is like being told you can buy a car with the grant that is given but discovering it only buys three of the four wheels. It makes for a bumpy ride!

Increasingly many people who have had polio for most of their lives need more assistance around the house and with personal functions. The old home help service has long gone. Local authorities have increased the threshold at which they agree the person has a need for assistance so those who would have been helped in the 1970’s no longer receive assistance. Care plans can be resource rather than needs led. The Government has announced that it proposes to increase provision of direct payments and that is most welcome. But first you have to get through the assessment that you need help and, if so, how much you need. The potential for conflict is huge but the power lies with the local authorities rather than with disabled people.

Despite all this disabled people complain to the DRC that they are prevented from contributing by rather silly rules. For example, the Government has a target to increase the number of disabled people sitting on its various advisory and executive bodies. This is good news because it would enable disabled people to influence policy across a whole range of government activities, including those that are not obviously related to disability issues. Many of these positions allow the people appointed to claim a small fee, usually less than £200 a day for about 10 or 20 days a year. But if a disabled person so appointed claims the fee they could find their disability benefits threatened. As a result, disabled people are discouraged from applying. The DRC has made representations to the Government about this and I hope they will change the rules.

There is, however, a debate to be had about the extent to which state support should be conditional and I hope Fellowship members will take part in that debate. We need to debate what we mean by active citizenship and assuming it is desirable what do we collectively, and the government, need to do to make it a reality. If disabled people were involved in all aspects of national life I have no doubt that Britain would be a better and stronger country because this country’s disabled people have so much to offer.

To some extent none of this is new to the BPF. It is an organisation that from its earliest days in 1938 has been run by and for the members. It has seen its childhood members grow up and become adults and then older adults. Yet it has supported campaigns to eradicate new cases of polio in other parts of the world. It has supported its members and it took hold of the issue of the late effects of polio when others said it did not exist. In its field it has been a leader. It has never flinched from a challenge and as we look ahead we can see new challenges. Some are as awesome as those of the past. The successes in the fields of civil and human rights cannot be consolidated until we also have full access to health and social care. We also need to ensure that as our average age increases that we remain relevant to younger people in our country who contracted polio when living overseas. As a Fellowship we must continue to live up to that title and work with other disability organisations, as we have with Baywatch and other campaigns.

I strongly believe that the BPF has a future as bright and purposeful as its past. I take some comfort that when the DRC is no longer around to defend disabled people as we have and to fight for the implementation of the rights for which we all fought so long, that disability organisations such as the BPF will still be here using the experience and skills of its membership to ensure that the opponents of disabled people are never able to take the flag from our mast. I hope that in the short term you will go to our website at www.drc-gb.org and lend your thoughts to the Disability Debate so the DRC can leave a legacy of which you feel proud. In the even shorter term, I suggest we move as soon as we can to the bar so we can make our contribution to the brewing industry.

Thank you for you attention.

Bert Massie
Aug 2005

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

Bert Massie A Modern Transport System September 2005

Bert Massie, A Modern Transport System, QEII Centre, 29 September 2005. Speech entitled 'Meeting the Needs of all Passengers'

'Meeting the Needs of all Passengers'

I would like to say how pleased I am to be here today. I say this not as a polite introduction, although I hope it also serves that function. But it does occur to me that it is easy to overlook the simple fact that consideration of the mobility needs of disabled people at mainstream transport conferences is a relatively new phenomenon. When many others and I first began campaigning for a public transport system that disabled could use our ideas were seen as slightly cranky. It is to the credit of disability organisations, a series of government ministers and the Mobility and Inclusion Unit of the Department for Transport that so much has been achieved in about 25 years. I acknowledge the contribution of those players and thank them for their efforts. I also wish to thank the transport industry. Some have resisted change but significant numbers have embraced it and their expertise has enabled accessible taxis, buses and trains to be designed and built. When the DRC was created we inherited all this effort that preceded us.

However, the battle to make public transport physically accessible to disabled people was just one phase in the quest to give disabled people access to public transport. And it is not yet won. Some aviation and maritime companies still too often design aircraft and ships that are inaccessible and are hostile environment for disabled people. The choice is theirs. They can put their house in order or the demand for legislation to require them to do so will be unstoppable.

As increasing numbers of accessible vehicles come into service on our roads and rail network the UK is well on track to have a highly accessible transport network. This has helped create new and exciting challenges the most important of which is to improve the experience of those using the public transport system.

1. The New DDA Transport Duties

Accessibility isn’t all about design and engineering.   Good customer care has a key role to play in removing barriers faced by disabled people.

From the end of next year additional parts of the Disability Discrimination Act will apply to the UK’s public transport system and it will make unlawful much of the behaviour which still creates barriers for disabled people and discriminates against them. Sadly the DRC still regularly gets calls to our Helpline from disabled people who have had bad experiences while using the transport system:

> Wheelchair users who have been turned away from the bus by drivers who simply say they don’t have time to lower the ramp.
>
> People with learning difficulties regularly tell me, and the staff of the DRC, how they find the impatience of transport staff so upsetting that they try to avoid travelling by public transport if at all possible.
>
> And elderly people frequently complain that they have given up using the train network because the assistance they have requested to help them with their luggage just doesn’t turn up.

All of these examples illustrate that disabled people face attitudinal barriers as well as physical ones when they try to use the transport network.   The key to removing these barriers is not a matter of design or engineering, it’s about changing staff attitudes.

Earlier this year RNID produced a report about the experiences of deaf people using public transport in London. Some of the findings related to technical issues such as induction loops at ticket offices not working, but again the message came through strongly that it was staff attitudes, which were frequently the biggest barrier. The older publication by RNIB “Travellers Tales” makes many of the same points. Yet putting this right is hardly rocket science. As someone who regularly uses public transport I have had some pretty dreadful experiences but mostly I am treated rather well. So if some staff in the transport system can get it right, can we help the rest to do so? It is important that all of us succeed in doing so. If people are treated badly they will lose confidence in using public transport. Increasingly in the future they will seek redress through the courts.

The changes to the DDA will make unlawful much of the poor behaviour I have described and give disabled people new rights to challenge it in the Courts. The DRC is here to ensure the law is followed and we shall use our legal powers to protect disabled people from discriminatory behaviour. Part 3 of the DDA covers disabled people’s right to goods and services. This will apply to people using public transport so the current exemption will go. But the DRC does not see litigation as necessarily the best way to stop discriminatory behaviour. We hope to see transport operators investing in training and reviewing their policies to get the message across to everyone in their organisation that bad behaviour towards disabled customers must stop. Bus drivers too busy to deploy the ramp or to bother communicating with a deaf passenger do credit to neither themselves nor their employers.

It won’t always be obvious which customers are disabled. No one will fail to recognise me as a disabled customer who needs assistance, but the passenger who asks for help lifting their luggage may have no visible symptoms of the heart condition that means he mustn’t lift heavy items.

It would be convenient if everyone who might need assistance were overtly disabled. But disability isn’t like that. Many impairments are invisible, and many people are (quite naturally) reluctant to tell strangers the details of their condition. This is a challenge for all of us. As many as half the people who qualify as disabled under the DDA do not view themselves as disabled. For example people with facial disfigurements or a history of mental health problems can face discrimination but might not need additional assistance. Others with respiratory impairments might. Therefore, it seems sensible to design services so they are customer friendly in every sense. Never forget that the population is aging and so are your customers.

Some of those who have responded to the recent consultation on the DRC’s Draft Code of Practice have expressed concerns about the issue of hidden disabilities. They seem concerned that people will claim to be disabled in order to get assistance to which they are not entitled. I suggest we need to get this issue in perspective. Do you really think there are large numbers of perfectly healthy people who are so idle that they will claim to have a disability just to get assistance, particularly on the railways when they should have booked it 24 hours in advance, and will need to turn up early at the station? Compare that with how frequently you see elderly and disabled people struggling to step onto a bus, or carrying luggage over the footbridge at the station because they are too proud to ask for help, or they don’t know of the services that might assist them? Where do you think the greater problem lies?

Many transport operators have addressed these issues and have drawn up positive policies to assist disabled customers. But judging from the calls we get at the DRC there are too many gaps between the policy and the practice. We think that the new duties under the DDA will provide the stimulus to operators to ensure that staff implement their policies, and give a sharp wake-up call to those transport providers who have not got policies in place.

The good news from other businesses who have been subject to duties under the DDA for nearly 10 years now is that good customer care for disabled people means good customer care for all. Staff who are trained to assess and respond to the needs of disabled customers apply the same principles to all their customers and businesses see a rise in customer satisfaction.

2. Public Functions and the Disability Equality Duty

As the number of accessible vehicles in service continues to rise another area receiving increasing attention is the interface between modes of transport. Poor management of the pedestrian environment generally, and particularly at transport interchanges, can undermine much of the investment in accessible vehicles. In December of next year an important provision of the 2005 Disability Discrimination Act will come into effect. This will require public authorities to go further than not discriminating. They will have a duty to promote the equality of disabled people and this will demand a review of all their policies. This could result in a major improvement in the way in which public services are delivered.

One of the points made most strongly in response to the consultation on the DRC’s the Code of Practice is the concern of bus and coach operators that they will be in breach of the DDA if obstructions prevent them getting their vehicle to the kerb, and as a consequence disabled passengers cannot board their vehicle, or equally problematic, are unable to get off.

I can reassure them that they have nothing to fear. The reasonableness principle, which underpins the DDA, means that transport operators will not be held liable for circumstances outside their control.

While some of my more militant staff would like to argue that buses should be fitted with 'bull bars' to push obstructions out of the way, I can't see any Court deciding that is a reasonable adjustment!

However, Those Councils and Police Forces who fail to respond to persistent complaints from disabled people about obstructed pavements and highways which prevent them carrying out their normal activities may find themselves in breach of the DDA because as public agencies they will have a duty to promote the equality of disabled people.

3. Concluding Remarks

In recent years the UK has made some important steps towards a modern public transport service, which is widely accessible to disabled people. Our challenge now is to ensure that the investment achieves its purpose, which is to enable more people to use public transport. To achieve that the transport industry needs to ensure that all of its staff are trained to welcome and assist disabled passengers. The best already do so. There is therefore no need to create new systems just follow the best of your competitors. More broadly we must ensure that the outdoor environment, as well as bus and rail stations, are designed to enable you to do your job and disabled people to travel with ease. That is the challenge for today and tomorrow.

Bert Massie

September 2005

Keywords: Disability Discrimination Act 1995; Disability Equality Duty; Disabled people; Transport

Bert Massie Duncan Guthrie Memorial Lecture October 2005

National Information Forum Annual General Meeting, Duncan Guthrie Memorial Lecture delivered by Bert Massie on 19 October 2005

The nature of memorial lectures is that they are so often about people whom one has never met and who died before the lecturer's birth. It is a particular pleasure and an honour to be asked to present this lecture because Duncan Guthrie was a man I knew, although not well, and whom I admired. Long before I met him I knew of him because for those of us involved in disability politics in the 1960's and 1970's Duncan was one of the giants of the time.

He had an interesting history and during the Second World War served in Churchill's secret army, the Special Operations Executive. He came into the disability field because his daughter Janet contracted polio in 1949 at the age of 18 months. As I also contracted polio in 1949, it was clearly a vintage year! Duncan was appalled at how little was known about polio, even though a great deal of research was taking place in the United States. Duncan was not a man to sit around when he could act and using savings of 7s 6d (that is 37 ½ pence in today's currency) in 1952 he founded a new charity, the National Fund for Poliomyelitis Research. That became Action Research for the Crippled Child. The name is dated but we are going back a long way and Duncan was always ahead of his time. The work of the National Fund helped speed the introduction of the polio vaccine in the UK.

He was quick to spot the value of celebrities and used sportsmen to raise funds. Many of the stars of the day such as Jimmy Hill and the test cricketer Jim Lake were involved and went under the heading of SPARKS or

Sporting Aid Medical Research for Kids. They raised a great deal of money for the National Fund and are now an independent charity.

While Duncan was Director of Action Research he was also for many years the Director of the Central Council for the Disabled, which is now known as RADAR. He was therefore heavily involved in supporting Alf Morris, now Lord Morris, in getting the Chronically Sick and Disabled Persons Bill through Parliament in 1970. It was while he was in that post he started the first campaigns to promote access for disabled people to buildings. It is possible to trace the trail that resulted in the Disability Discrimination Act 1995. In his latter days at the Central Council George Wilson, who became its Director in 1971, assisted him. This gives a link to Duncan’s international work.

George was teaching in Uganda when he met Duncan. Recognising a similar soul he persuaded George to work with him in setting up rehabilitation centres in that country. They also worked to eradicate polio in Uganda with considerable success. The event of Adi Amin as President of Uganda undid so much of the work that had been done.

Duncan was a doer. As such it was inevitable that he would upset a number of people – and he did. In 1962 the wife of the then Lord Mayor of London, Lady Hoare started a fund to assist disabled children. Duncan was asked to contribute to it and offered £50,000 but, it seems, only after a row. He was overheard suggesting that Lady Hoare’s surname had been mis- spelt! The Lady Hoare trust went on to do a great deal of good work and is now part of the charity Contact a Family.

On another occasion Duncan was unable to get to a drinks reception in Whitehall but one of his foes did attend but collapsed in Whitehall after the event. Duncan was telephoned with the news and after a few seconds pause his deep tones replied “Nothing trivial I hope.”

The Duncan Guthrie I recall did have a ready tongue but he was a great fighter for disabled people. He could see through cant instantly and he supported anything that would assist disabled people and opposed anything that made our lives more difficult. He would have thoroughly approved of the work of the National Information Forum and I believe would support what I propose to say later about new obstacles being placed in the path of disabled people in the cause of a risk free culture.

The National Information Forum is an important organisation because so little is possible without information. It is sometimes said that information is power. I’m not totally convinced of the wisdom of that cliché because although Noah knew a flood was due he would have drowned if he had not built his ark. In this case the information was the spur to action but it was the action that saved his life and ensured the future of London Zoo.

In the disability community gathering information generates particular problems. For a start, people can and do become disabled at any time of life. Often they lack even the vocabulary to articulate the questions to which an answer is needed. For example, a newly disabled person might worry about whether they will be able to keep their job but they are unlikely to ask if they might be entitled to Disability Living Allowance, Middle Rate Mobility Component. We need to get information to people who yesterday did not need it and did not seek it. Such people often do not know where to start.

Then we need to consider the needs of individual disabled people. The way in which a deaf person can receive and process information is different to a blind person who, in turn, has different information needs to a person with a learning disability. The gateway to much information these days is the internet but, as the DRC Formal Investigation showed, most websites are difficult and some impossible for disabled people to access. If people are denied information they are denied the benefits that information could enable them to obtain. Yet in the disability world there are any number of organisations that claim part of their role is providing information. Clearly there is a need for people to work together and co-ordinate their efforts and the Forum plays a major and important role in doing just that. I congratulate and thank Ann Darnborough who has made this life's work. We all have much to be grateful to her for.

The DRC has also allocated considerable resources to ensuring that the information we can give is readily available. Since we started 5 years ago our helpline has dealt with over a half a million enquiries, mostly from disabled people and their families and friends. Many of our publications are available in a variety of languages and in different formats. We have started including pages in sign on our website and, of course, we have pages in easyread. We must ensure this continues when the DRC disappears in 2007. As many of you know, the Government has decided to create a new organisation called the Commission of Equality and Human Rights that will, amongst other things, take over the functions of the DRC. Despite ferocious resistance, the DRC has successfully fought for a Disability Committee with executive powers to be included in the primary legislation. This will last for at least five years but I'm pleased that the Government has agreed that when the future of the Committee is reviewed the views of disabled people will be taken into account.

However, if the new body will not be established until the end of 2007, five years beyond that takes us to 2012 which gives us some time to mould the agenda so it does serve disabled people. I think the DRC has had considerable achievements during its short five years of existence. I have listed these in a number of other speeches and will not repeat them today. If you go to the DRC website you can read the various speeches. However, we still have much to do. Next year the Disability Equality Duty in the public sector will be introduced. It will change the approach of public bodies throughout the country. They will have to ask what can we do to promote the equality of disabled people and not merely how can we avoid discriminating against them. The right to service will apply on public transport so that no longer can the driver of the accessible bus refused to accept a disabled passenger. The gaps in the original DDA are slowly being closed.

The DRC's legal team this year won the Lawyer Magazine "Best Employment Team of the Year Award" fighting off competition from the big city firms. That related to a case that we supported to the House of Lords. We have many more legal cases to fight and win. We also need to fight for more changes to the DDA and we think their might be opportunities to do that later in this Parliament. But what of the longer term? Where do we want to be in 10 or 20 years time? Are there new issues that we need to address? To help us address these issues the DRC has started the Disability Debate. At its core it raises some fundamental questions. Disabled people do not just want to be free of discrimination. That, surely, is only the starting point. Disabled people tell us that they want to be a full part of society and play their role as active citizens. That cannot be achieved unless we move beyond discrimination law to a much broader canvas.

Access to information is part of this broader picture. How do we get all organisations in society to make their information available and accessible? How do we promote independent living? How do we ensure that instead of only 50% of disabled people of working age being in work, we get the figure to 60% at least? What needs to be done to support disabled people to control our own lives? These are big questions and the DRC needs to know what you believe the answers to be. While looking ahead we also need to be vigilant of new problems arising, often for honourable reasons but which, nonetheless, inhibit the independence that people seek.

As part of the Disability Debate the DRC has published a number of papers that you can read on our website and let us have your views. I hope you will because your views are important. One paper we have published concerns attempts to avoid all risk and I would like to spend a little time on this because it is a monster that is growing and I think we might need to slay it or at least send it back to its cave.

No rational person is going to put disabled people or anyone else at risk if it can be avoided. However, we do not live in a world in which risk can be eliminated. Getting up in the morning involves risk: we might fall. Staying in bed is also risky: we might get pressure sores and, if we fail to get to work, we might get the sack. We know that being unemployed is a major health risk. Our starting point therefore must be that risk cannot be eliminated in every aspect of life. It needs to be assessed and managed but in such a way that the management does not create more problems than it solves. We must also be wary of allowing so called risk assessment to be used to permit managers to avoid the fundamental issues. Like many disabled people, I have often faced the frustration when Risk that has been called from his cave to limit my life opportunities or to ensure I paid more for them.

I cannot recall how many times I have been refused access to a cinema or theatre because, it seems, I was a fire risk. It was always my habit to ask the various managers to explain the risk. This was invariably amusing. They confused access with egress. They hadn't read the fire regulations that they claimed to quote. It was simply easier for them to say no. Risk was used to discriminate against disabled people. I can also recall buying travel insurance and the broker 'phoned me to say that there would be a loaded premium. On asking why, I was informed that it would take me longer to cross the road. I think I was then in my 30's and I told the broker to go back to airheads in the insurance company and ask them did they really think I would have got to my current age without being run over if I did not know how to cross a road. The loading was dropped.

The risk adverse culture which is seeping into all parts of life is producing tales so bizarre that a competent novelist would dismiss them as too improbable to include in fiction. Our paper on risk draws attention to some of them. When I heard of the local authority that withdrew napkins from its meals on wheels service in case people choked on them my initial thought was that the food must be so dreadful that they must think people would prefer to eat the napkins. But no: it was in case disabled people accidentally put the napkins in their mouth and then choked. There is only one such recorded case and it involved a baby who survived. However, hundreds of people die from choking on food so it would have been more rational to have withheld the food although that creates the risk of malnutrition.

There is ample and growing evidence that unemployment is bad for your health. Most disabled people who can work are better off if they are working. Yet the DRC has had cases where people have been in danger of losing their jobs because Health & Safety Officers were too inflexible. Of course, they have a dilemma. It took trades unions many years to secure legislation that protects the health of the work force. However, we must always assess how great a risk is and accept that sometimes seeking to eliminate it is even more undesirable for the people the legislation seeks to protect.

This year we mark the 200th anniversary of the Battle of Trafalgar and, of course, the role played by Nelson. Given that Nelson was blind in one eye and had an arm missing we can be sure that if he had been subject to a risk assessment he would not have been allowed near his ship Victory, let alone instructed to command the entire fleet.

Is it not time that we stopped suffocating disabled people in so much safety cotton wool that they are unable to breath? Those of us who are disabled live with our impairments every day of the week. We can evaluate risk for ourselves. Nobody wants to undermine sensible safety laws and regulations but when they start creating other dangers it is time to ask questions. Let me give you another example.

Many disabled people take tablets. A very common impairment is arthritis which often affects the figures. In case a child should open the tablets they come in childproof bottles: bottles that disabled people can’t open. Answer: smash the bottle with a hammer and leave the tablets in a saucer. Then blow the glass off the tablets before eating. The DRC is currently working with a major retailer to find a way around this problem.

Another example from our paper: a local authority refused to fit a stair lift in case the person fell off. As a result the person risks falling down the stairs and having an early death. But while all hell is let loose if a child dies, an elderly disabled person falling down the stairs is unlikely to get a mention in the local newspaper. The person concerned was fully able to use a stair lift but the misuse of the concept of risk ruins her life.

In the press last week we read of an airline that threw blind people off an aeroplane because they already had three disabled passengers. Yet other airlines have no difficulty accommodating larger numbers of disabled people. I suspect safety and risk were being used as a false reason to discriminate against disabled people. The airline was Ryanair and I read with interest their press release that justifies their action. They claim that when I was Director of RADAR in 1995, RADAR agreed that the limit should be four disabled people and that the DRC had taken over RADAR's functions. This came as a surprise to RADAR and indeed to me. So let's have a few facts. In the mid-nineties Ryanair was a small airline and they banned all disabled people from their flights. We had no legislation we could use to force them to change their policy but I did meet with Kell Ryan to see if we could resolve the ban. We eventually agreed that they would take up to four wheelchair users at no extra charge. A higher number would have been better but we could not get it. This related to wheelchair users who needed assistance. It did not relate to all disabled people and nor could it. Ryanair do not give people medicals as they board their aircraft. There is no reason why they should have ejected the blind people and I deplore the policy. Ryanair benefit from the use of British airports, customers and security. They should accept that there is a right and wrong way to treat disabled people and last week they chose the wrong way. The Disability Discrimination Act 2005 does empower the Government to bring aviation into the DDA. Discrimination in air travel is now widespread. That is why I have today written today to the Secretary of State for Transport calling on the Government to include aviation in the DDA. Rational argument will not work with some airlines. Only law will produce change.

Of course, we do not just seek to protect disabled people from risk. Those who assist us must also be protected. It is difficult to disagree with sensible risk assessment and management. The DRC is not in the business of creating disabled people who were not disabled until they assisted a disabled person. But again, have we gone too far?

It is the nature of impairment that some disabled people need to be lifted in and out of their wheelchair; or a bath or bed etc. For hundreds of years this was not a major problem until the European Lifting and Handling Directive came along and was swallowed whole by the safely industry. The result is that no-one can lift anymore and on that basis disabled people where left in their wheelchair for weeks on end because they could not be lifted out. People left in their bath for hours while others thought how to extract them! The DRC intervened in a legal case in which it was ruled that blanket bans on lifting people was unlawful. Instead each case had to be assessed on its merit. You would think that would sort out the problem but not a bit of it.

Take the case of Nick. He weighs less than 6 stone and has brittle bones. He fell out of his wheelchair, broke a few bones so ended up in hospital where none of the staff would lift him. They were prepared to use a hoist to lift him but that was of such a poor design he would have broken more bones using it. How did he cope? Well, he has his own Personal Assistant who had to stay with him in the hospital and do the lifting. For the avoidance of doubt, I want to stress that his PA is human and of the same species as the other 1.3 million people who work for the NHS. This is the same NHS that has an annual budget of over £65 billion a year but all this cash and over a million people could not lift a man of less than 6 stone without injuring him. Yet one PA could do it.

To the NHS Nick was a risk. They were wrong. Let’s add the letter T. Now we have it, “Nick was at risk” because staff had to avoid risk. In the NHS Nick was the customer and the NHS was the provider. They failed to provide.

Yet they bought the hoist that was dangerous for Nick to use. When the order was being placed did any one consult disabled people who suffer these devices? Did the hospital go back to the supplier and tell them a redesign was needed. I rather doubt it because the risk culture here is for the staff and not disabled people.

A risk free world is a fantasy. Equally, we do need to manage risk and that involves risk assessment. That risk assessment needs to look at all sides of the issue so that people can choose to take risk if it does not endanger other people. We must train people so they can lift disabled people without risk to their backs. If we are to use assistive devices then we must involve disabled people in designing them. Although health trusts and local authorities are often the buyers, the users are usually disabled people who often wonder what fool designed the equipment! If disabled people are to enjoy full civil and human rights we must push back the suffocating tide of safety officials who gold plate every safety rule that has ever been created. Disabled people will support and conform to rational safety rules but will resist those that are ill thought out and limit our independence and life opportunities.

A number of disabled people and others have already contributed to the debate on our website. One lady wrote "I am 76 year old born with cerebral palsy. I am so glad my mother encouraged me to take big and bigger risks all my life. Otherwise I would not be able to live happily on my own and taking the biggest risk if my life and thoroughly enjoying my self in every way. Woe betides anyone trying to stop me for my own safety. Leave me alone to take all the risks I want. She then makes the point that every day people cross the road – what's the difference?" Others have suggested that much so-called risk assessment is about protecting the service providers from any hint of litigation.

I do not think we can move to a society in which we ignore risk assessment, but we should perhaps examine the pro and cons more carefully. Nor can we really argue that disabled people should be able to judge their own risk and act accordingly. Our judgements will affect others and so contributors to the debate have said that because of their impairment they do not feel able to make such judgements. Some people with learning disabilities might think the same. So we need to find a balance which enables disabled people to live outside of the strait jacket that risk perception can impose while avoiding harm to ourselves and others. But it is surely not unreasonable that when non-disabled people make safety assumptions about disabled people that they should first stop. Then they should think through the issue. They should consult the disabled people concerned about the best approach. And then they should adapt before they act.

Exactly where we should draw the line is one of the issues the Disability Debate needs to address. That is why I invite you all to take part in the debate. Let us draw the map for the next ten years so when the CEHR is formed it will inherit and clear map of its way forward and a map that has in a large part been created by disabled people.

If Duncan Guthrie was here to hear some of the examples I have given today, I think he would say “This is bloody nonsense. Let’s do something about it.” And so we must.

Thank you.

Bert Massie

October 2005

Keywords: Accessible information; Disabled people; Disability Rights; Duncan Guthrie; Polio

Bert Massie UK Presidency eAccessibility Conference October 2005

Bert Massie gave the keynote speech 'Overview of eAccessibility issues in the UK' at the eAccessiblity Conference at The Landmark Hotel, London on 21 October 2005

Good morning Ladies and Gentlemen, it's a pleasure to be here today to discuss an issue that is very much part of our lives. I'm pleased that as part of its Presidency activities the British Government has chosen to focus on a truly international phenomenon – the World Wide Web and its accessibility for disabled people.

Before I speak about access to the Web I should like to outline the approach in Britain that I know is shared by other countries, in enabling disabled people to play a full and fulfilling role in society. The Disability Discrimination Act 1995 built on a number of measures designed over the years to remove the obstacles disabled people face in our every day live. The Act defines disabled people and creates employment and education rights, amongst other measures. Of relevance to our discussion today is the duty on those in both the private and public sector who provide goods or services to the public, regardless of whether they are paid for or provided free, to ensure that those goods or services are accessible to disabled people. It is unlawful to refuse a service, to charge more, or to offer disabled people a lower standard of service on grounds of their impairment. In addition, reasonable adjustments must be made to ensure disabled people can use the service. The word reasonable is important. The DDA is not about putting people out of business.

The Disability Rights Commission was established by Parliament in 2000 as an independent body to ensure the Act is enforced and also to promote the equality of disabled people. The Government has provided us with appropriate funding of just over £20 million this year and we have about 200 staff plus outsourced Helpline and Conciliation services. We also have a range of legal powers we can use to prevent discrimination against disabled people or to seek redress following a case of discrimination. Today there is no time to tell you in detail about the work of the DRC but, rather appropriately, you can read about us on our web site at www.drc-gb.org or just put Disability Rights Commission into a search engine and you will find us.

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

Tim Berners-Lee, the inventor of the World Wide Web, once stated, “The power of the Web is in its universality. Access by everyone regardless of disability is an essential aspect.”

Because of the universal nature of the Web we can sometimes assume that it is accessible to all. I will argue that it is not and that this is a significant cause of concern because increasingly the Web is not a toy to be visited for mild amusement but is a way through which goods and services are provided and sometimes is the only way to access those services. Under the provisions of the DDA, websites should be user friendly for disabled people.

For those here who have a legal frame of mind, the relevant part of the DDA is Part 3. If a disabled person is unable to access a website because of their impairment they might be able to take legal action against the organisation whose website it is and thus gain compensation. The DRC has a range of legal powers to help eliminate discrimination and these include funding legal action that disabled people want to take. On average we initiate legal proceedings about once a week. However, we prefer to prevent the discrimination occurring in the first place. One way in which we do this is to publish Codes of Practice, which are not definitive statements of law but provide advice on how the law is likely to be interpreted by the courts. We have issued a Code on the application of Part 3 and are currently consulting on a revised version.

The current Code of Practice has a specific example of using a website. Section 2.17 states:
"What services are affected by the Act? An airline company provides a flight reservation and booking service to the public on its website. This is a provision of a service and is subject to the Act."

Although no cases have yet come to court in this country, two cases were supported by the RNIB. The organisations concerned settled out of court, which should tell us something. Furthermore, the DRC is currently supporting a case against an airline that does not permit disabled people to book their tickets on their website but then makes an extra change for ordering them via the telephone. So it's a live issue, it is on people's radar screens and it's going to get bigger. The debate is not confined to this country. At the time of the Sydney Olympics, it was held in Australia that the Organising Committee had been in breach of the Australian DDA by failing to provide a website to which a visually impaired man, Mr Maguire, could have access. In the USA, the 1998 amendment to Section 508 of the Rehabilitation Act has been highly effective in requiring all federal agencies to ensure that their technology is accessible to disabled people.

Over the years we have received a number of complaints from disabled people about the accessibility of websites.

This does of course raise another issue, which is how to determining precisely what an accessible website should look like. The DRC is not the first to address this issue. The World Wide Web Consortium (WC3), a Web industry co-operative, has recognised the need for universal accessibility and gsince 1999 its Web Accessibility Initiative (WAI) has published the Web Content Accessibility Guidelines to reduce potential difficulties. As with all W3C recommendations compliance is voluntary. The recommendations comprise a set of checkpoints or design practices. These checkpoints are ranked into three categories, defined by the WIA as priorities 1, 2 or 3, according to its view of their relative increasing importance in enabling Web access by disabled people.

A number of commercial products have been developed to detect checkpoint violations automatically. However, the guidelines emphasise that such tools cannot identify all accessibility issues and recommend the involvement of disabled people in a manual review process. The use of WAI "declaration of conformance" on a site relies on self-assessment and does not guarantee that this recommendation has been observed. Within the European Community, the Euro-Accessibility Consortium launched an initiative in 2003 to foster European co-operation towards a harmonised methodology for evaluating the accessibility of websites.

One of the powers that Parliament has given to the DRC, and to which I have not yet made reference, is to conduct formal investigations, or FIs. These can either be into the conduct of a particular company or organisation, or they can be more general. In March 2003 we decided to conduct a formal investigation into websites and their accessibility. This work was undertaken under the leadership of my fellow Commissioner Mr Michael Burton. There is clearly insufficient time to go through all the detail of that investigation but I think the headlines provide a sufficiently clear picture.

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

As I have already indicated, the people who devised the WAI guidelines readily acknowledged that the checkpoints alone were not a guarantee of usability and that websites should be user tested by disabled people. We therefore established a panel of disabled people in the following impairment groups: blind, partially sighted, dyslexic, physically impaired and hearing impaired. The panel evaluated 100 websites selected from the original sample of 1000. The results were that 76% of the attempted tasks were completed successfully but, by definition, 24% of the tasks were failed. But this success rate was unequal depending on the panel member’s particular impairment. For example, people with physical or hearing impairments succeeded in 85% of the tasks and the rate among people with dyslexia was only 2% lower. Partially sighted people succeeded with 76% of the tasks but this dropped to 53% for blind people.

Not surprisingly, when we compared the time taken by blind people to complete a task successfully with a control group of sighted users there was a clear difference. If a site had a high degree of accessibility the control group took 36 seconds to perform the tasks, whereas blind people took 114 seconds. If the site had low accessibility the control group took 52 seconds and blind people took 173 seconds. These figures reveal two important things. Firstly, the badly designed sites took 50% longer to navigate, whether the user was blind or sighted. Secondly, whilst the sluggishness of a poorly designed site may just irritate some users, task completion times can be so long as to render it practically useless to someone who relies on screen-reading software. This part of our study reveals another figure that should be of concern to every organisation that has a website or employs staff who use websites. If we use a baseline of 100 for the control group for a high accessibility web site, the figure for blind users will be 321. For a low accessibility website the figure for blind people is 486. However, the figure for the control group was 146. It therefore takes 1 1/2 times as long for non-disabled people to use a low accessibility site compared to one with high accessibility. The conclusion is clear. Low accessibility websites are inefficient, wasteful of time and bad for business; and that is before you have considered the needs of disabled people.

Our investigation enabled us to identify the problems different groups of people experienced when using websites. Blind people were frustrated by the incompatibility between screen reading software and Web pages. This meant that assistive technology was unable to detect some links or it proved impossible to highlight text using text-to-speech software. Cluttered and complex page structures created difficulties as did the failure to provide ALT text for images.
Partially sighted users complained of inappropriate use of colours and poor contrast between content and background. They also identified incompatibility between Web pages and accessibility software used, for example, for magnification. Poor layout of pages and confusing and disorientating navigation mechanisms were also difficulties. Predictably graphics and text sizes that were too small were also problems.

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

I mentioned earlier that WAI drew attention to the limitation of automated testing tools. Of the hundred websites evaluated by the user panel, we tested either the whole site or the first 500 pages encountered in the site. This made a total of nearly 39,000 web pages tested. The number of checkpoint violations and the instances of violations were then compared with results of the user evaluations. The number of checkpoint warnings, or instances of warnings do not relate statistically to any of the user evaluation measures. Regrettably then, automated tests alone do not predict the experience of disabled people using the websites.

The user evaluations revealed widespread accessibility and usability problems. Although 55% of these related to checkpoints, 45% were not an explicit violation of any checkpoints and would not have prevented a site from claiming WAI conformance at any level. Of reported problems that were covered by the checkpoints, as few as 8 checkpoints accounted for 82% of all explicit violations.

The British and many other governments have a policy of encouraging people to use the Internet as a way of accessing public information and services. This admirable policy will fail unless the websites are designed in such a way that they can be used by all of the population including those who are disabled. This must certainly apply to websites controlled by government departments or their agencies but as government work is increasingly outsourced to private companies it is also important that the websites of those companies are fully accessible. As the DRC investigation has shown, although Public Sector sites are not the worst offenders, two thirds of them fail to meet even most basic accessibility requirements.

One effect of the Disability Discrimination Act is that many governmental agencies and private companies are adapting their buildings to ensure disabled people can get into them and use them. Every country in Europe has many modern buildings, some of which were designed to be accessible to all. In Britain all new buildings to which the public are admitted have been required by law to be accessible and this has been the case since 1985. However, in common with other European countries we have many buildings which are hundreds of years old and a few that are 1000 years old. It is hardly surprising that the needs of wheelchair users and other disabled people were not taken into account when those buildings were built. The folding wheelchair, which has given people unable to walk so much out-door mobility, was not invented until 1937 in United States. Countries are now spending enormous amounts of money ensuring those old inaccessible buildings are able to meet the needs of today’s people, including those who use wheelchairs.

But what is the excuse for the accessibility of so many websites? The World Wide Web is only 10 years old. It is only in the last five years it has become universally used yet already we are repeating the mistakes we made in relation to the built environment. Just as so much of the physical world remains inaccessible we are permitting the owners of websites to make the cyber world inaccessible. Yet, as with the physical world, better access for disabled people means better access for all. We cannot rely on Web designers to do the right thing any more than we could rely on architects to design accessible buildings unless the law forces them to do so. The message for national and European wide government is clear;

persuasion on its own will fail unless it is supported by law. However, law on its own will not resolve the problem. We need to train web designers on the needs of disabled people, as we have had to train architects. We also need better guidance material and I am pleased that following our research the British Standards Institute will be producing new guidance (a ‘publicly available specification’) in November to enable the effective delivery of website accessibility. In particular, the BSI specification will, with the benefit of advice from the DRC and other key stakeholders, outline good practice in managing the design of websites that are accessible and usable by disabled people. It will cover the management of the entire process and give guidance on applying the existing voluntary guidelines, on involving disabled people in the development process and on using the current software-based compliance tools that can assist with this. The guidance will equip those who are responsible for commissioning and managing the development of websites the tools and knowledge to ensure their agents deliver genuinely accessible websites rather than merely pay lip service to the ideal." I hope it will be widely used in the public and private sectors alike.

We also need to look beyond the Internet. Television is also part of most people's lives. It is possible to have subtitles on every programme so that deaf people can also enjoy television programmes. I'm pleased that some programme makers are also including sign language. The technology already exists to screen television programmes with audio description so blind people have access to television. The battle to extend these services has already started.

While I believe we should welcome the possibilities of new technology I also believe that nothing in history can reasonably encourage us to believe that those developing the technologies will take the needs of disabled people into account. Equally, when governments become involved and give disabled people the right to accessible services we improve those services for everybody. I believe the challenge for all of us is to act sooner rather than later to ensure that the access restrictions on the physical world are not reflected in the cyber world and I hope those who are here today will accept that challenge.

Thank you.
Bert Massie

Keywords: Accessible websites; Disability Discrimination Act 1995; Disabled people; Technology

Bert Massie Annual General Meeting of the Multiple Sclerosis Society October 2005

Speech at the Hilton Hotel, National Exhibition Centre, Birmingham on 23 October, 2005.

I should like to start by saying how pleased I am to be here as I have known of and admired the work of the MS Society for very many years, and a number of my friends have been members over the years. I would also like to congratulate Tony Kennan on his election as your new chairman. He will bring many attributes to the task. Perhaps the most important is that, like me, he is from Merseyside, even though he now lives on the opposite side of the country. As well as experiencing MS within his own family, he has a wide knowledge of disability issues and did more than anyone to promote the construction and use of buses and coaches that were suitable for wheelchair users and other disabled people. At the time he was a member of the Disabled Persons Transport Advisory Committee and it was my privilege, as a fellow member of that Committee, to be able to watch how he turned the hostile views of the bus industry to a positive approach to the whole issue of accessible transport. It was the work of Tony and others that helped to pave the way for the transport provisions in Part 5 of the Disability Discrimination Act 1995. The MS Society is already successful but I anticipate yet further success under his leadership.

Today I will say something of the effects of the DDA and of the work of the Disability Rights Commission. I want to look ahead to how civil rights law is evolving and what disabled people can expect from the proposed Commission for Equality and Human Rights that is expected to replace the DRC in 2007. Of course civil rights are important but for many disabled people human rights are at least equally important. I will therefore say something about the human rights agenda and also deal with an issue that is difficult and which divides disabled people because it is so personal and important. I refer to the debate on the right to life and the arguments put forward to change the law to permit physician assisted suicide. Finally, I think we should accept frankly that even if disabled people won full civil rights many would always need access to health services and social care. These are not covered by the DDA but are a growing concern to the DRC because they have a direct impact on our objective of enabling disabled people to benefit from independent living. Far too often disabled people find themselves placed in residential institutions because as a society we are not prepared to support them to remain within the community. These are heavyweight issues but they affect the extent to which those of us who are disabled are able to direct our own lives.

When the DDA was passed in 1995 its critics claimed that it was a toothless Act. I recall commenting at the time that its teeth would grow but until then it had fairly strong gums. In fairness to its critics, when the Act was approved by Parliament it was much weaker and thinner than it ought to have been. It has been strengthened since then by three major Acts of Parliament and by minor amendments elsewhere. First, the DRC was created to enforce the Act and replaced the National Disability Council that had only advisory functions. Education was added to the Act and just this year the transport parts of the Act were improved and a new law will require public bodies to promote the equality of disabled people. This will be known as the Disability Equality Duty. The DRC keeps the working of the Act under constant review and makes recommendations to the Government of changes that are required.

I’m pleased to say that the Government has listened and even more importantly has acted. One of the difficulties people with MS experienced was that some employers discriminated once they knew a person had MS even if at that stage the symptoms were fairly minor. The reason was that to gain the protection of the DDA a person had to have an impairment that had a significant affect on their day to day activities. The DRC recommended that people diagnosed as having MS should be able to enjoy the protection of the DDA from that day. From December 2005 all people diagnosed as having MS will be covered by the DDA, as will those diagnosed as having HIV.

It could be argued that such people, at least at that stage, are not really disabled. But the important point is not the extent of their impairment but the degree of discrimination they might otherwise experience. The purpose of the DDA is to prevent discrimination against people on grounds of their impairment, so the change in the law is consistent with the intention of the Act.

The DDA is also designed to prevent discrimination in the field of employment and the DRC has supported many cases to enable disabled people to seek redress following discrimination. Trade Unions and other organisations can, of course, also support people. The DRC seeks to clarify the law and we tend to put our muscle behind those cases that will do this and in which a victory could help many disabled people rather than just the person we are representing. One such case concerned Susan Archibald who was employed as a street cleaner by Fife Council. She became disabled and could no longer continue in her current job. Instead of identifying another job within the Council that she could do, her employer argued that they were making a reasonable adjustment by allowing her to apply for other jobs but ensuring that the person who was in their view the best applicant was appointed. Mrs Archibald was rejected for over a hundred jobs even though it was obvious she could do many of them. The DRC argued that the Council should have offered her one of them. They disagreed and the case was heard in various courts until it ended up in the House of Lords where it was judged that the DRC’s view was accurate. This case was widely reported in the legal press and was an important clarification of the law. Also, incidentally, it won the DRC legal team the Lawyer Magazine Best Employment Legal Team of the Year award this year.

It has been a long wait for people with mobility impairments to be able to expect to shop as other people can, or to be able to expect hotels to be accessible, or not to be turned away from restaurants for reasons of access. The final section of Part 3 of the DDA came into effect last year. You might be forgiven for not noticing because so many shops and restaurants remain inaccessible but we now have recourse to legal action and the DRC has already supported one man who has brought a case against Debenhams because the mezzanine floor was inaccessible. We still have a long way to go before disabled people can take the spontaneous decisions our fellow citizens take for granted.

I am pleased that the DRC has done so much to promote the civil rights of disabled people. I had hoped we could finish the job but, alas, that cannot be because in 2007 the DRC will be replaced by a Commission for Equality and Human Rights. We have been successful in persuading the government that there should be a least one disabled commissioner and a disability committee with executive powers, with most of its membership comprising disabled people, should be included in the primary legislation. The disability committee will be reviewed after five years but I am pleased that the Government has agreed that disabled people must be consulted as part of the review and that this requirement will become part of the law.

These provisions are important because the main strength of the DRC has been drawn from our close links with disabled people. The view of the DRC is that disability policy should be driven by the views of those with personal experience of disability. So, given that the CEHR has to serve many groups of people and not just those who are disabled, how can we ensure than it serves disabled people at least as well as the DRC? One way is to ensure that the DRC leaves behind a strong legacy and it is with that end in mind that the DRC has initiated the Disability Debate. We believe that disabled people want to be active citizens and contribute to society in many ways. I hope you will all take part in that debate and will go to the DRC website at www.drc-gb.org. and let us have your views. Last month, when I spoke at the Annual General Meeting of the British Polio Fellowship, I outlined the reasons for the Disability Debate especially in relation to civil rights for disabled people. If you are interested in that speech, you can read it on the DRC Website.

In that speech I said that if we are to win the right for disabled people to be active citizens then we must deliver on civil rights. However, I also emphasised that civil rights could not be achieved if we did not also ensure disabled people had full access to social care and support services and were able to exercise their human rights. I would like to explore this further today.

It is already obvious that some disabled people can only work if they have assistance to get up in the morning. Without that help they stay in bed. Yet the agenda to help increase the number of disabled people in work does not address the social care agenda. It is a classic case of disjointed government.

In fairness to the government, it is seeking a way forward. The Strategy Unit report on the Life Chances of Disabled People was one of the most thoughtful and profound documents the government has produced on disability issues but even that report seems to accept that disabled people can be placed against their will into residential care homes if it is less expensive to do that than support them in the community. Even a felon gets a trial before being incarcerated against their will. They can then appeal and, if they lose, they will have a release date and might earn remission. All of this can be denied to disabled people who can be incarcerated for life against their will. So will the CEHR, with human rights as part of its title, be able to assist? It seems the answer is no because it will not have powers to represent disabled people, or indeed anyone else, on human rights grounds. What it will be able to do is promote human rights in a general sense. In other words, to talk about human rights. That will not be the greatest comfort to disabled people wondering where their human rights went.

I am old enough to recall the days of the early 1970s when, following the passage of Alf Morris's Chronically Sick and Disabled Persons Act, cash was available to promote the independence of disabled people. Today the independent living movement are working to give disabled people the power and the resources to control their own lives. It has successfully promoted direct payments and this is now government policy. I welcome that but I am concerned when I read the Government's plans for the reform of adult social care. The Government says they must be cost neutral. This will be at a time of a growing elderly population with higher support needs. The effect will be a reduction in expenditure per head. We can therefore expect local authorities to set ever tighter criteria for people to meet to qualify for help. Many disabled people with high support needs will not get the support they need. And if they do, they will be terrified of moving home in case their new local authority sets even tighter limits. People who fail the eligibility test will not qualify for direct payments and will be unable to buy the support they need. This failure of the social care system to support disabled people has a strong impact on the ability of disabled people to become active citizens and thus enjoy the civil rights that have been so hard won.

Being independent does not mean doing every thing for yourself. In that sense nobody is truly independent because we all rely on someone else to supply our electricity and water, to grow and deliver our food to the shops etc. What is important is that we can control our own lives. That might mean using equipment or it could mean using a personal assistant to give personalised support under the control of the disabled person. This can be costly but there is a huge cost in doing nothing. We need a social support system that helps people with low as well as high support needs. Such a system should not make the gateway so narrow that people who need support cannot get through it. And it should not be means tested in such a way that cost deters people from using it. Is it not odd that parents are not expected to pay for social services provision for their children, prisoners are not charged for their time in jail but disabled people are charged for social services provision? Some might call that discrimination.

Independent Living is therefore an important part of the Disability Debate and I urge you to join that debate because your views matter. Some of the issues raised around independent living are fundamental if we are to have a society that recognises the human rights of disabled people. Perhaps one of the most basic human rights is the right to life itself. Yet there is a growing army of people who seem to have limited concern for disabled people’s right to life but are extremely active in promoting the right to die. And, they say, if we cannot kill ourselves the law should be changed to allow others to assist us to die. Some disabled people support this view and they are embraced by the right to die proponents.

This has created something of a dilemma for the DRC because there are strong arguments on both sides. Some disabled people have written to me demanding that the DRC support the measures to enable disabled people to ask others to assist them to die. It could be argued that as the DRC supports the right of disabled people to determine their own future, we can not logically seek to deny disabled people the right to assisted suicide. However, the DRC does not support this position and I would argue that our position is not a contradiction but a paradox.

My first question is always this: why do disabled people want to die? I have read the accounts of relatives who have taken disabled people to Switzerland to have their live ended. The same theme emerges time and again. They say the person felt a burden. I repeat: they felt a burden. That is different from being a burden but we must take such people's views seriously. My second question is this: why did they feel a burden and what did we, as a society, do to share the task of supporting the person? It is clear that the failure of social care to which I referred earlier is a major contributing factor in the decision of some to end their lives. People want to die because we will not support them to live. That is outrageous but it is an aspect of the debate that receives far too little attention. If the Voluntary Euthanasia Society and its supporters put the same effort into giving people the support to live as the right to die their case would be more credible.

Many religions have as part of their creed that people must not end their own lives. The DRC understands that view but because we are a secular organisation it does not influence our views. Instead our approach is much more pragmatic. We do not say that we would always oppose Physician Assisted Suicide but before we can support it we would want disabled people to first have the right to live. We are a long way from having such a right. So often the lives of disabled people are judged to have a lower value than the lives of non-disabled people and this influences the decisions that are made by doctors and others about the extent to which they should strive to preserve our lives. Let me give you a couple of examples.

One of the DRC's Commissioners, Jane Campbell, was admitted to hospital a few years ago. Jane has high support needs, has physical impairments but an agile brain, and is a great campaigner for disabled people. She has a more than full time job and is making a significant contribution to the life of this country. Yet all the doctors saw was a severely disabled woman and they said that "if you stop breathing you will not want us to resuscitate you, will you?" This was an invitation to collude in her own death. She insisted on being resuscitated but for 48 hours she was afraid to sleep unless she was denied treatment. She survived and continues to make her contribution. Had the doctors had their way she might have died. Why did the doctors behave the way they did? It is hard to be sure but part of the reason must surely be that they think the lives of disabled people are so dreadful that we would be better off dead. We therefore need to be very wary of promoting any public policy that further diminishes the status of disabled people and colluding with policies to legitimately end the lives of disabled people would do just that.

I spoke a few moments ago about the right to live. This is no abstract concept. The DRC intervened in the dispute between Lesley Burke and the General Medical Council regarding guidance that they had produced. In summary it said that it was for the doctor to decide whether to offer a patient artificial nutrition and hydration if they were unable to take nourishment in other ways. Mr Burke argued that as a consequence of his impairment he would still be mentally alert but might be physically unable to express his wishes. He knew that if he said he wanted no further treatment the doctors would have to respect his wishes but if he said he wanted ANH the doctors could ignore his wishes. He therefore wanted the guidance changed so his wishes would be respected. The Appeal Court ruled that while Mr Burke could express his wishes the doctors must provide the nutrition but once he could not express his will the decision would be for the doctors.

If Physician Assisted Suicide affected only the people concerned the DRC approach might be more relaxed but it does not. It helps to create a culture in which it is seen as normal that the lives of disabled people are inferior and an early death is humane. This was the policy of Nazi Germany. Long before the Jewish people were slaughtered in their millions, disabled people were used to test the gas chambers and to be spared the burden of life. The DRC is not insensitive to the views of those disabled people who do demand a change in the law so they can choose the timing of their deaths. But only when we give full support to people to live can we feel confident that the right to die will not become the duty to die.

I am told that a new law would do no harm because it would merely regulate what is happening already. Doctors, I am told, already assist people to slip away quietly. Of course, doctors do not say much about this because to do so would expose them to a charge of murder. The logic of the argument is that if doctors are killing people anyway they best way forward is to regulate it so it is legal. If motorists dive at 60 mph through an area with a 30mph limit, we do not respond by increasing the limit; we prosecute the motorists.

I have dealt with this issue at some length because it is of interest to all of us. But we are hardwired to live and survive and most disabled people are, by definition, fighters and survivors. Every day we deal with difficulties beyond the comprehension of many non disabled people. Yet, as I have shown, we are not afforded the same dignity in life as others and too many people with the power of life and death believe we would be better off dead – in our own interest you understand. I and the DRC are fully prepared to review our position on the right to Physician Assisted Suicide but only after society and the law of the land give us as many rights as the rest of the population to live, and have our lives valued as unique and sacred. We must then have a totally reformed social support system that makes independent living a reality and not a distant dream. We must banish for ever the feeling some disabled people have that they are a burden. They are not. They are citizens and assets of this country and we must offer collective support. The fourth largest economy in the world surely cannot argue that we cannot afford it.

I talked earlier about the Disability Debate. People with MS are an important part of the disability community. You have already shown through the campaigns of the MS Society that you can fight your corner to get the right drugs and treatment. You know from your daily lives the discrimination that disabled face. We have made much progress in the last 25 years but we are not there yet. Join the Debate. Let us know your views. Play your role in ensuring that when the DRC is no longer here the battle will not stop because the disability community will provide the troops to ensure there will be no surrender but only a laying down of arms when the battle for both human and civil rights is won.

Thank you for listening.

Bert Massie

Keywords: Civil rights; Commission for Equality & Human Rights; Disability Discrimination Act 1995; Disability Rights Commission; Multiple Sclerosis