Bert Massie Holocaust Memorial Day 24 January 2006

Reading by Bert Massie at the Holocaust Memorial Day, City Hall, London on 24 January 2006.

The forced sterilizations of disabled people, people with physical and/or learning impairments, together with those who had mental health needs, began in January 1934 under the Nazi ‘Law for the prevention of Progeny with Hereditary Diseases.’ Altogether an estimated 300,000 to 400,000 people were sterilized under the law, this included Roma and gay people, as well as other ‘asocials’ .

In October 1939, Hitler himself initiated a decree that empowered physicians to grant a "mercy death" to "patients considered incurable according to the best available human judgment of their state of health." The intent of the so-called "euthanasia" program, however, was not to relieve the suffering of the chronically ill. The Nazi regime used the term as a euphemism: its aim was to exterminate disabled people and those who had mental health needs, thus "cleansing" the "Aryan" race of persons considered genetically defective and a financial burden to society. In all, between 200,000 and 250,000 disabled individuals were murdered from 1939 to 1945 under the T-4 and other "euthanasia" programs.

As Henry Friedlander puts it in his book The Origins of Nazi Genocide:

Regardless of background, ailment, age, or nationality, the victims died at the hands of killers certified as physicians and nurses. They died in hospitals that were built to aid and cure but had been perverted into places to kill.

At the Hadamar [Murder Hospital] trial of October 1945, one of the first American war crime trials, Colonel Leon Jaworski, the trial judge advocate, described the murder of patients by physicians as follows: “Oh, what a vicious falsehood, what a terrible thing, what an evil and wicked thing to do to a person who is already suffering and carrying burdens, to build up the false hope that sunshine was to enter their hearts. They told them they were given medication that would help them. Oh yes, they were given medications, medications of poison that gripped their heart and closed their eyelids still; that is the sort of medication they were given.”

Keywords: Disabled people; Holocaust

Achieving equality and social justice a future without disability

Speech by Bert Massie at Westminster City Hall, 30th January 2006

"I’d like to begin today by welcoming you all to Westminster Central Hall.

This building has played host to many of the great leaps forward in human liberty, equality and social justice during the 20th century.

In 1914 the suffragettes met here.

Here in 1940 General de Gaulle announced to the world the foundation of the Free French movement.

Last year this building played host to events in support of ‘making poverty history’.

Perhaps most famously, Westminster Central Hall was the chosen venue for the inaugural General Assembly of the United Nations in 1946.

Prime Minister Clement Attlee welcomed the UN to “this ancient home of liberty and order”.

Yet it is only in the last few years that I, and others who use a wheelchair, have been at liberty to enter this building.

And even now our freedom is restricted.

But while I apologise for the rather convoluted route which some of you will have experienced in getting in today, on this occasion I make no apologies for our hosting this event here.

Because as I will set out today, this is where the issues I want to talk about belong.

At the very heart of Whitehall and Westminster.

Issues of liberty, equality and social justice.

People with impairments and long-term health conditions have always been with us and more than likely always will.

We need to accept this and meet the challenge of extending freedom and equality to all.

If we don’t, everyone suffers.

The inequality experienced by disabled people affects us all.

It stands between this government and the ability to achieve its core ambitions for Britain.

Despite positive steps in some areas, public policy is in danger of leaving disabled people behind.

Today I want to map out a way forward which could break the cycle of inequality and low expectations which have led us to this point.

My argument is that successive governments have failed to break the cycle of low expectations that hold disabled people back. There is a lazy fatalism that still too often shapes perceptions that politicians and the media in particular have of disabled people.

Things have got better for some disabled people; but in important areas the distance between the living standards, opportunities and life chances of disabled people and the rest of the population has widened.

This is manifestly unjust.

Bad for individuals and bad for society.

We have to change if we want a country that is genuinely committed to equality and social justice.

That means a new approach to public policy and a new emphasis on enabling disabled people to participate fully in the civic and political life of modern Britain.

Today I want to set out precisely what that entails for Government, individuals and the disability community.

The Good Society

When the Chancellor recently gave a major speech on Britishness, he claimed this issue was important because: “You cannot, as a country face up to the huge decisions that you've got to make in the modern world - unless you have a sense of shared purpose, an idea of what your destiny as a nation is.”

And I want to start the debate about where disability fits into our vision of ourselves as a country, where our diversity becomes a strength, where our differences do not divide us but enrich us as a nation.

Just as people met here in the past to agree their vision of the good society, so I want to begin today by setting out my vision of what life in Britain could be like for people with an impairment or long-term health condition - if we make the right choices about our future.

A future in which we accept that having an impairment or long-term health condition is a pretty ordinary aspect of human experience, not an extraordinary sign of human failure.

A future in which we break forever the link between having an impairment or long-term health condition and a life of restricted opportunities, poverty and unfulfilled potential.

A future in which we finally accept that discrimination and disadvantage in relation to a person's impairment or long-term health condition is as absurd as for gender or race.

A future in which society sees no alternative but to extend the practical means for achieving freedom and equality to all citizens.

In my vision of the good society, our response to people with impairments and long-term health conditions would be quite different.

We would not be surprised that a person can be a manic depressive and be at the top of their professional game.

That a person with a learning disability could make a brilliant parent.

That blindness is no barrier to holding high office.

That a child with special educational needs was heading towards high academic achievement at university.

And we would be in no doubt about the injustice of poverty, of people being left out, being denied dignity, being absolved of control over their own lives; of not being able to live their dreams or, through life’s struggle, having no time to dream at all.

That is my vision of the ‘good society’.

And it’s one in which we all have a stake.

The vast majority of us will be affected by disability at some point in our lives, directly through personal experience, or indirectly through our families, friends and colleagues.

So if someone asks you if you are disabled, and assuming you are not, the most honest answer you could give is “not yet”.

As you are listening today and perhaps thinking about your response, it might help to consider that it is very probable that you are thinking about your own future.

This is about our shared destiny.

I bet if you spend a few seconds now you will be able to think of someone you know who has an impairment or long-term health condition.

Perhaps it’s a colleague who has taken quite a bit of time off work with stress.

Or an older relative complaining that they can’t open jars anymore because of the arthritis in their hands.

Maybe it’s the child in your kid’s class at primary school who is autistic, or the mum with depression, struggling to get on to the packed bus in the morning.

It might be your uncle who has just found out he has diabetes or
the friend or celebrity with breast cancer.

You might even know one of the survivors of the bombings on 7 July who had their lives so dramatically changed on that terrible day, who were not disabled when they awoke that morning but who by sunset had a whole different life in front of them.

I say this not, as journalists such as Rod Liddle have suggested, in the hope that through some process of magical osmosis I will be able to convince you that ‘we’re all disabled now’ and this will of itself trigger some form of revolution.

Rather, I tell you this to underscore the fact that developing an impairment or long-term health condition **is** an ordinary part of life for most people.

Official statistics suggest it affects around 10 million Britons today.[1]

Yet, despite this, and for far too many, this life change still acts as a trigger for profound social and economic exclusion.

This is unnecessary and it must change.

Before I set out how change could be brought about, let me spell out the nature and the scale of the problem: why disability continues to exclude individuals socially and

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[1] Adults in Britain covered by the DDA. Source: Family Resources Survey 2002/3 DWP

economically, why it perpetuates deep inequality of opportunity and denies fair life chances for all.

How we arrived here: society’s perception of disability

It starts with our outlook as a society.

The legal academic Luke Clements has argued that many disabled people are still not considered fully ‘ripe for freedom’ in the same way as ”women, serfs and southern blacks once weren’t”.

How else can one explain a doctor placing a ‘do not resuscitate’ notice at the end of a disabled person’s hospital bed without their knowledge?

A judge granting permission for a disabled woman to be sterilised without her consent?

People with a learning disability not being able to determine where and with whom they live, simply because they can’t get the support they require where they want it?

I do not really believe it is widely accepted that disabled people have the capacity to be equal.

And for this reason we do not fully recognise disabled people’s circumstances as issues of injustice and inequality.

The disadvantage disabled people face is all the more ingrained and pernicious as a consequence.

It has quite simply become normalised.

It goes unquestioned.

If we do not recognise these circumstances as profoundly unequal, we do not respond to them in this way.

Despite recent developments, society still sees its best response to disability as care, welfare and charity - rather than equal rights, opportunities and citizenship.

Our instinct is to protect.

But in ‘protecting’ people we deny humanity rather than liberating it.

And in order to protect we can make people dependent.

To borrow from Amnesty International’s new campaign, we need to ‘protect the human’ by extending freedom, respect, equality and dignity.

Society has chosen to see having an impairment or long-term health condition as the point at which people should be exempted from the ordinary responsibilities of citizenship.

Sometimes this is motivated by a sense of compassion.

At other times it is an overt lack of confidence in disabled people’s abilities - for example in a particular job or to be a good parent - or because we are trying to protect ourselves or others.

But in doing so we have been oblivious to the impact this has on expectations and on access to the adjustments and support needed by many disabled people to actively participate in society.

Our historic approach to disability has institutionalised low expectations.

These in turn have institutionalised exclusion and fostered often inescapable dependency, compounding the low expectations which create such problems.

So when people develop an impairment or long-term health condition, their lives change dramatically.

Freedom is restricted. Control is lost. And status is diminished.

Poverty beckons. Well-being plummets. And social interaction lessens.

A sense of belonging decreases. The chance to develop and grow as human beings – and as equal citizens - slowly dwindles.

The social and economic costs to the disabled individual, and to society, are enormous.

The social and economic costs of exclusion

For example, someone on incapacity benefit is, contrary to the image generated by the media, living on a meagre £76 a week.

Four out of 10 people out of work are disabled.[2]

The rate of income poverty amongst working age disabled adults is double the rate for non-disabled adults. Thirty per cent are living in poverty – up 3 per cent in the last 10 years.[3]

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[2] Labour Force Survey, Spring 2005

[3] Households Below Average Income, based on the Family Resources Survey. DWP As quoted by Palmer et al (2005) Monitoring Poverty and Social Exclusion 2005. Joseph Rowntree Foundation December 2005

There is now a higher incidence of income poverty amongst disabled adults than either children or pensioners.

Conversely, the incapacity benefit bill has grown to £12 billion a year.

Although some things are getting better for disabled people, something is going seriously wrong.

It needn’t be this way.

The choice I put before you today is this.

In future, will we see the very existence of people with impairments and long-term health conditions in Britain as a sign of failure – something which undermines our notion of Britishness and which we would rather hide and deny? And in denying it fail to make provision so disabled people can play a full role in society?

Or rather, having finally accepted that human difference is human essence, will it be the exclusion and inequality experienced by people with impairments and long-term health conditions that we see as challenging our sense of shared purpose?

Our answer to this question will determine the course we now take.

In my view, the first option denies reality and causes untold damage.

For example, mental health problems are seen as the antithesis of British identity.

They are seen as weakness.

“Mustn’t grumble.”

“Can’t complain.”

The Government’s Social Exclusion Unit report on mental health quotes a respondent as saying: “I feel too afraid to admit I’ve a mental health problem. The stigma and rejection are too hard to face.”[4]

A MORI poll last year showed that a quarter of British workers would be afraid to ask their boss for support at work if they developed an impairment or health condition.[5]

There are people who qualify for protection under the Disability Discrimination Act who go to work every day terrified to reveal aspects of their identity, for fear of being found out and losing their jobs.

Every day there are disabled people, and not only those with mental health problems, who **are** found out and lose their jobs.

And there are plenty more for whom the fear of being open about their situation leads them to being less productive than they could otherwise be.

In denying that impairments and health conditions are an ordinary aspect of human existence, we are directly contributing to social and economic exclusion, the costs of which we all bear.

Can we really stay in denial about who we are and still succeed as a nation?

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[4] Mental Health and Social Exclusion. Social Exclusion Unit , 2004
[5] MORI/DRC 2005

The answer, clearly, is no.

Impairments and long-term health conditions are here to stay. They are part of the human condition.

They are a part of who we are and what shapes our lives individually and collectively.

Their nature may change over time, as science and technology develops, as environmental conditions change, as demographic patterns such as the age of our population shift, as humankind evolves.

But there is little chance of a future where they are not part of our lives in one form or another.

So let’s say we manage to accept that impairments and long-term health conditions are part of who we are.

We must now decide what we want them to mean, for us individually and as a country.

I have already alluded to the frankly obscene levels of poverty experienced by disabled adults, and the costs to the country of disabled adults being out of work and on incapacity benefit.

This situation is also a central factor in relation to child poverty.

Sixty-eight per cent of families where neither parent works include at least one parent who is disabled.[6]

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[6] Labour Force Survey Spring 2003 from Stickland H (2003) Disabled Parents and Employment background paper for the HMT/DWP seminar November 2003

Studies suggest that over half of families with disabled children are living in or at the margins of poverty.[7]

Eighty-four per cent of mothers of disabled children are not working compared with 39 per cent of mothers of non-disabled children.[8]

In the global economy, Britain's competitiveness increasingly depends on our ability to lead the world in relation to knowledge and skills.

By 2020, if current trends continue, 40 per cent of jobs will require a degree-level qualification.[9]

In 2005, disabled people accounted for over a third of those without any qualifications at all – a figure that has changed little over the last eight years.[10]

Are our efforts to build a knowledge economy reaching disabled people? Can we afford for them not to?

There are a million young people in Britain who are not in any form of employment, education or training – NEETs as they are called – a figure of understandable concern to ministers.

Disabled 16-year olds are twice as likely to be in this position as their non-disabled peers.[11]

What does the future hold for them?

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[7] See Disabled Children in Britain: a reanalysis of the OPCS Disability Surveys. Gordon et al (2000)

[8] Family Fund Trust, 2002 and General Household Survey 2002

[9] Projections calculated for the DRC by IPPR. Disability 2020 (unpublished)

[10] Labour Force Survey Spring 2005 Great Britain

[11] 15 per cent of disabled 16 year olds compared to 7 per cent of non-disabled 16 year olds. Source: DfES Youth Cohort Study: The Activities and Experiences of 16 Year Olds: England and Wales 2004

And if they're not at work or at college, what are they doing?

Does this depressing figure have anything to do with the fact that 60 per cent of those referred to youth offending teams have special educational needs?[12]

The Prime Minister recently launched the Government's 'respect' agenda.

I welcome all attempts to foster a culture of mutual respect and tolerance in our communities.

Successive studies have shown the disturbingly high rates of physical and verbal harassment disabled people, and in particular people with learning disabilities, experience in their daily lives.

A recent study found that the rate of physical attacks on disabled Londoners was twice that of non-disabled Londoners.[13]

Such experiences have profound effects on the well-being of victims.

Violence, or the fear or violence, circumscribes the opportunity to participate fully and live a fulfilling life.

Yet evidence, including the DRC's own report into hate crimes in Scotland, suggests that many disabled people have little faith in the institutions set up to protect them or to bring the perpetrators to justice.[14]

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[12] NACRO (2003) Missing Out

[13] Another Planet? Disabled and deaf Londoners and discrimination. December 2003. Greater London Authority

[14] Hate Crime against disabled people in Scotland: A Survey Report. 2004 Disability Rights Commission and Capability Scotland

Unemployment, child poverty, skills, youth, safer communities and respect – successfully addressing the key challenges of public policy today rests on successfully addressing the circumstances of disabled people.

Only by putting disability at the heart of public policy can public policy succeed both today and in preparing for the future.

My friend and colleague Jenny Watson, Chair of the Equal Opportunities Commission, recently pointed out that we continue to assume that the independence of older and disabled people relies on the unpredictability of unpaid work, provided overwhelmingly by female relatives.

This position is not sustainable in an ageing population where many women are choosing to live alone and not to have children.

She rightly asks who will undertake this task voluntarily in future and how public policy is changing to reflect these new realities.

Disabled people need personal assistance and support.

Women overwhelmingly provide that support in the absence of properly resourced social services.

That position is clearly unsustainable, and the goals of promoting gender equality and disability equality are increasingly entwined.

Just as disability is at the heart of dealing with the major challenges of today, it will have a huge part to play in shaping the future.

But for some reason, and despite all the facts, public policy makers are not generally thinking about disability.

It is something ‘over there’ for the specialists to deal with. Something to do with wheelchairs and ramps.

The Government is to be congratulated for the progress it has made in extending statutory duties to prohibit discrimination and promote equality of opportunity for disabled people.

These duties should help make the task of securing a more equal future and of embedding disability into mainstream public policy significantly easier.

But whilst we have established these duties on the statute book, there is still a major task ahead in translating them into everyday reality.

We have not yet seen progress in translating their approach across public policy.

In many of the areas I have outlined it is the failure, deliberately or by omission, to address disability which has led to the point where it now stands between Government and its targets.

By public policy makers failing to take disability to their hearts, disability is now, acknowledged or not, at the heart of public policy.

And whilst there have been some improvements in many of the areas I have highlighted – unemployment, child poverty, skills, crime – success has relied on going first for the lowest hanging fruit.

Millions of disabled people have been left behind by public policy and the costs to us all are far from negligible.

Flawed public policy

You can see this in the flawed reliance on institutionalised social care and the flawed approach to housing provision for disabled people.

Institutionalisation is already on the rise.

Since 1997 there has been an increase of 20 per cent in admissions to residential and nursing care for younger people with a learning disability; and 40 per cent for people with mental health problems.[15]

For some, our ambitions for their freedom are still circumscribed by notions born in the Victorian era.

Is it where you want yourself or your parents to end up?

Do we want a future in which many of us are left with no choice about where and with whom we live?

Or perhaps instead you will tolerate a system which allows you to stay at home, provided you are okay about having help getting up and going to bed only five days a week, or are content to go to bed at tea time?

A social services system which provides you with only life and limb support and no opportunity to participate and make a contribution to society?

A system that might keep you alive but not provide you with the means to live a life?

Is this just? Is it economically viable? Is it really the best we can do?

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[15] Health and Personal Social Services Statistics, National Statistics 2003 (data applies to the period 1997 – 2002)

The housing we are building now needs to meet the requirements of future generations.

We are taking decisions now, the effects of which will be felt for at least the next 70 years.

This is why the Government's recent rejection of calls to introduce what is called the 'lifetime homes' criteria into the regulations governing the development of new housing represents such a significant failure in joined up government.

Homes designed to this standard ensure optimum numbers of people can use them, including wheelchair users, and are designed to be easily adapted in order to mitigate changes in the life course without major costs.

Already, new housing in London must comply with this standard.

With an ageing population, why are we building houses that do not match the needs of the people who will live in them and which cannot easily be adapted as needs change?

How can this count as **sustainable** development?

Our future success is going to demand some far-reaching reforms and a change of approach in public policy across the board.

Breaking the cycle of lazy fatalism

We need to break this cycle of low expectations and neglect because it is this which continues to generate a lazy fatalism about the lot of disabled people in Britain.

We need to break this cycle for people like Anthony Ford Shubrook. Anthony is a wheelchair user who at 16 almost didn’t get into his college of choice to do an IT course because the college refused to make the classroom accessible. Every Briton needs the chance, like Anthony, to get in, get on and go to university.

We need to break this cycle so that fewer people like Gaynor Meikle, a teacher who lost her sight and her job, find that having an impairment or health condition spells an end to their ability to contribute to British society.

We need to break this cycle so that a school that fails disabled children is considered to be a failing school.

We need to break this cycle so that Home Office programmes to promote active citizenship stop characterising disabled people as simply the objects of others’ good deeds. Instead, disabled people need to be viewed as people who have a major part to play in improving our communities as active citizens themselves.

We need to break this cycle so that a non-disabled person without any qualifications doesn’t still stand a higher chance of finding a job than a disabled person with a degree.

We need to break this cycle so that when a disabled person has their children taken away from them without the offer of appropriate parental support from social services it is seen as scandalous.

We need to break this cycle so that journalists like Andrew Gilligan cannot write disabled people off as a dispensable minority in defence of keeping the inaccessible Routemaster bus.

Andrew, we need to go to work too and we need a bus we can use to get there.

Only high expectations can shine a light on injustice.

And this challenges all of us to choose a course and to stick to it.

That won't always be easy.

As last week's Welfare Reform Green Paper reminds us, opposition to changes in the benefits regime affecting disabled people has a long history.

In the past, we were right to oppose benefit cuts that would have impoverished disabled people whilst failing to provide new ladders to opportunity.

But we must have the courage of our convictions now, in holding the Government to account not only for its reform of incapacity benefit – only part of the story – but also for ensuring that the changes really do raise expectations. Reforms must enable more disabled people not only to get a job – whether low paid or not - but to enjoy full access to the education and training which lead people into careers.

Welfare reform on the cheap will only deepen the cycle of low expectations that has caused so much harm over the last century.

The choice: preserve the status quo or fight for change

We too face a choice as a movement.

Do we want to fight for change or to retain the status quo?

And are we prepared to take risks in moving forward?

Because the disability community has in my view a huge amount to offer in defining that way forward and should not fear progress.

The destination I want us to move towards is a high expectations culture with the support to enable those expectations to be met.

Where we focus on promoting personal freedom, choice and control above basic levels of social protection.

Releasing potential above managing dependency.

And recognising and challenging injustice and inequality wherever it exists.

I believe the ideas generated by the disability community are coming of age and finding currency in mainstream debates around equality, social justice and citizenship.

Let me begin by saying a little about our approach to equality.

The core mission of the disability movement: equality and social justice

As one of the Prime Minister's favourite political philosophers, RH Tawney, rightly said, equality is not about treating everyone in the same way. It is about responding to different needs in the different ways which best suit them.

We have never preached equal treatment, because to treat everyone the same is to ignore their essential differences - with the perverse effect of creating inequality.

Equality of results is more important than equality of treatment.

It can take different treatment to provide equal opportunities.

This notion of a substantive form of equality has guided the evolution of disability rights.

It is now guiding the future direction of public sector reform – choice, diversity of provision and personalisation, for example.

It is why our anti-discrimination laws in relation to disability require employers, service providers and educational institutions to make adjustments both at the individual and institutional level.

This approach will, at the end of 2006, be helpfully augmented by new positive duties on the public sector to actively eliminate discrimination and to promote equality for disabled people.

To do so requires that we offer people a more equal start in life - and mitigate the inequality that emerges during key life changes - such as the onset of an impairment or health condition.

It involves giving people the practical means to improve their own life chances and removing the barriers that might stand in their way.

A new philosophy of life chances for disabled people requires an entirely new approach to public policy.

We need to empower people by improving their capability to enjoy freedom and giving them the choice to pursue opportunities.

Let me set out how I believe this should work in several key areas in the future, touching on the benefits system, social services and strengthening social capital.

Building people’s capability

We know that poverty restricts freedom, choice and opportunity.

The poverty experienced by disabled people concerns not only a limited income but, on average, higher outgoings related to the costs of living with an impairment or health condition.

This financial poverty plays a major part in creating a poverty of experience – the inability to participate, to exercise choice and control, to live a fulfilling life.

One of the ways we have sought to mitigate the extra costs of living with an impairment or long-term health condition is through Disability Living Allowance.

However, take-up of the benefit is notoriously low.

We need to identify why this is the case. It may be that people are not able to find out about and access the benefit.

Increasingly the frontline of public services are being automated, including creeping use of the internet as the primary point at which citizens are expected to access services and entitlements.

In 2004, 37 per cent of people receiving Disability Living Allowance – roughly one million people in Britain – had never used a computer.[16]

How many of those who are not taking up the benefit would, if only they could use a computer and had access to the internet?

Those of you in the room who have managed to crack the enigma code and access Disability Living Allowance will be only too aware of the complexity in applying.

Some of the most excluded people in our country including those with a mental health condition or a learning disability may require the support of an independent advocate in becoming aware of and accessing their rights.

Is this really all that different to the way many would use a financial adviser if they were shopping for a mortgage or pension?

In improving people's life chances we need to mitigate the costs of disability by improving take-up of Disability Living Allowance.

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[16] Electronic Government at the Department for Work and Pensions: Attitudes to electronic methods of conducting benefit business. DWP Research report 176

We therefore need to invest in IT skills and access to new technologies, and we need effective networks of independent advocacy, information and advice, which put choice and control into the hands of the individual.

We need to find ways to build people’s individual capability, including through the support available to them, to take control over their own destinies - if we are to expand the numbers enjoying real freedom and choice.

Disabled people in control of their own destinies

Doing so also requires a significant re-drawing of the contract between disabled people, the state and society.

The disability community can lay claim to having led the way on securing direct payments which allow people to take money in lieu of social services and to employ their own personal assistance and support.

Where successful, direct payments have transformed lives.

To quote Julia Winter, a disabled woman: “With direct payments, you can say, ‘It’s a lovely day. Let’s not worry about the housework. Let’s go out!’ You can be spontaneous. You can live.”

No longer grateful and passive recipients of care, faced with the unreliability of inflexible services.

Instead, the employer - free to define how to live your life.

Power and control in the hands of those previously relegated to being objects of care.

We need to build on this and find other ways to redistribute control to individuals.

One way the Government is looking to do this is through piloting ‘individualised budgets’ and we hope the pilots work well enough to convince the Treasury of their value ahead of the 2007 spending review.

I should add a brief caveat here – that being in control can also involve making the choice to relinquish control.

But that choice to give control to someone else is something all should enjoy equally.

We need to explore further options.

This is not simply about the way we access services but also about people’s security.

Disabled people are far less likely to own their own home, and so lack the financial security such an asset can offer.

How else can we increase opportunities for people to build assets, escape poverty and take control over their own lives?

Building social capital and transforming expectations

As I have said, to promote equality we need to transform expectations.

In 1984 a paper from the United Nations World Programme of Action on Disability stated that: “As disabled people have equal rights, so they should have equal obligations. It is their duty to take part in the building of society.”

Are we yet ready to say that along with equal rights come equal responsibilities?

To do so we need to be sure that our public policy and programmes are all seeking to promote disabled people's active participation in family, community, economic and cultural life.

That they are driven by high expectations.

Only through disabled people playing an active part across life will society's attitudes and expectations shift.

Taking on more responsibilities is part of the journey to equality.

Disabled people's active and recognised participation is part of the process of building support amongst the wider community for the re-deployment of resources towards this goal.

Participation also brings interaction between disabled and non-disabled people, which helps build the capacity of communities to extend membership to groups previously left out.

We need to think about the role the voluntary sector can play in this process.

Organisations of and for disabled people may be effective at bonding social capital – bringing individuals with similar experiences together to assert control over their own lives.

They must also contribute to 'bridging social capital' – breaking down the barriers that exist between disabled people and the wider community.

To help us on our journey towards equality we need to make full use of the tools that help us to challenge discrimination and inequality.

Equality at the heart of policy making

We need to shout when disabled people are left out and forgotten.

Like the deaf children who face inequality because the Government has decided to teach literacy in primary school using phonics.

Did it think about deaf children when it decided this policy?

How will it mitigate the impact of this decision for them?

Can we be certain that the Education White Paper won’t also create new inequalities?

The DRC would be more than happy to work with the Department for Education and Skills in ironing out any potential risk that this could be the case.

Our institutions have a major role to play in advancing equality and social justice.

As well as providing services to individuals, they are an expression of our shared purpose.

They embody and transmit the values of society.

As we design and develop new institutions – sure starts, extended schools, city learning centres, health walk-in centres – we must design, run and maintain them with the expectation and ethos that they are there to serve the whole community.

They are a place where people meet and interact with one another.

And the institutions we build now will echo our values down the generations.

Just as the institutions of the past speak of disabled people’s exclusion, so the institutions we build for the future should speak of their full inclusion at the heart of our society.

Disability in the CEHR

A major new institution to come is the Commission for Equality and Human Rights (CEHR).

This new Commission will replace the Disability Rights Commission, the Commission for Racial Equality and the Equal Opportunities Commission.

It is not, as some understand, a merger.

That is why we are so keen to set an agenda now – to ensure it builds on our work and can be a genuine step forward for disabled people’s rights.

And it is why we have fought so hard for a dedicated committee on disability, with executive powers, within the forthcoming CEHR.

Not, as some suggest, to keep disability outside of the Commission’s main business but rather to make sure that disability can never be left out.

The committee will be there to make sure the new commission does not fall prey to the low expectations culture I have talked of today.

Conclusion

We want to build an agenda that all can support and from which all can benefit:

- A new account of disability which accepts that having an impairment or long-term health condition is an ordinary part of the human condition.
- An end to lazy fatalism and the emergence of a high expectations culture.
- People equipped with the practical means and support to take control and play an active part in society.
- Discrimination and injustice laid bare and challenged wherever it exists.
- Communities with the capacity to include.
- Disability equality firmly embedded across public policy and our institutions, and a CEHR that builds on the DRC's achievements.

In the emerging consensus around the importance of social justice, the role disability plays needs to be fully acknowledged if policy and programmes are to succeed.

There has long been a phrase used by the disability movement – "nothing about us without us".

Yet too much of society has continued to evolve without our full involvement.

The sort of transformational change we need will only come if we redress the ability of disabled people to participate fully in the civic and political life of our country.

So today I want to finish by laying down three challenges to begin this journey.

That in order to increase the representation of disabled people in Parliament, our main political parties will introduce a rule that at least one candidate for all vacant seats has to be disabled.

That in order to increase disabled people's representation in public life, the Commissioner for Public Appointments will work towards a target that 20 per cent of public appointments should be disabled people or people with long-term health conditions – reflecting our representation in the community.

That in return for winning contracts to deliver public services, voluntary and private sector organisations must demonstrate how they will ensure disabled people are playing an active part in the leadership of their organisations.

Three steps on the way towards the sort of future I want.

A future without disability.

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

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

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

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

This is your future as well as mine.

It's time to choose.

Thank you.

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

Is Transport Open to All

Making the Connections Three Years on - Social Exclusion Report into Transport and Social Inclusion Leeds Town Hall 23rd February 2006

Speech By Bert Massie
"Is Transport Open to All?"

I am pleased to be in Leeds today to address a conference on an issue that is finally coming of age.

The Social Exclusion Unit Report into accessibility barriers to transport was a landmark report recognising the way in which the transport system in the UK presents barriers to many disadvantaged communities. For years the barriers faced by disabled people have been acknowledged, but this report represented an important step forward in documenting the breadth of communities which are disadvantaged in their use of transport services.

Transport as the vehicle to inclusion

Perhaps the hallmarks of an effective public transport system are the extent to which it can provide for both the routine of our daily life and for the spontaneity we need to feel free and alive.

It should help us to do the things we have to do without the stresses of having to worry too much about them.

And it should allow us to do the things we want to do in order to make life rich and enjoyable.

For millions in Britain, it defines the ability to participate effectively in social and economic life.

It defines people's horizons.

At the end of last month in London I made a major speech highlighting the way in which public policy in the UK inadvertently marginalises disabled people and perpetuates the disadvantage which they face.

Our transport policy has historically been an area of public policy which has kept disabled people at the margins.

And through that neglect, many disabled people's horizons have been severely restricted.

On every index disabled people suffer greater poverty than other members of society and the Government's admirable policies of eliminating poverty and promoting social inclusion will fail unless disabled people and their needs are at the heart of public policy.

The enormous costs of this exclusion are felt both by the individual and by wider society.

One dimension is the way in which rates of employment of disabled people are twice those of non disabled people.

The Government's recent Welfare Reform Green Paper sets out their proposals to tackle the high rates of economic inactivity amongst disabled people and the drag that this places on the UK economy. Yet nowhere does it address the problem of getting to work if you can't use public transport.

In 2003 the Leonard Cheshire Foundation published "Mind the Gap" a report on the transport barriers faced by disabled people. They found that 23% of disabled people looking for work had turned down a job because of inaccessible transport, and a further 23% had declined a job interview. 86% of people with a visual impairment said that transport barriers restricted their choice of jobs.

These same barriers also prevent disabled people from accessing the economy as consumers, from opportunities for leisure, recreation and social interaction.

Progress since the SEU report – More Accessible Vehicles

Since the publication of the SEU Report, the accessibility of public transport services in the UK has steadily improved. In the last report of the Department for Transport's Mobility and Inclusion Unit for the year 2004/5, 39% of all buses were low floor and accessible to disabled people. On the current trend we will exceed 50% within the next couple of years.

In London in December last year, I had the pleasure marking the introduction of accessible buses on the last remaining bus route operating the old Routemasters.

Predictably, the last Routemaster was preceded and followed by a tidal wave of sentimental nostalgia by many who not only gave no thought to the mobility of disabled people but attacked those with placards celebrating the demise of the routemaster.

As one enlightened journalist noted at the time, if we based our public transport system in London on nostalgia we would all be rowing boats down the Thames.

Things have to move on.

In reality, the disability dimension of the change in the bus fleet was overstated.

One of the main reasons for ending routemasters was, according to the man in charge, that they quite simply did not have the capacity to meet demand – they were not big enough.

As we moved to replace a fleet which could not meet modern-day demands in terms of capacity, it was only right that we should meet modern day demands in terms of the requirements of people needing to use the system.

While London is unique in achieving 100% accessibility, rates in many areas are climbing rapidly and it’s not just in urban areas that progress is being made. Dorset reported last summer over that 50% of all their buses were compliant with Part 5 of the DDA.

Over 4000 trains now in service are compliant with the Rail Vehicle Accessibility Regulations and there are many more that were introduced in the run up to these regulations which provide high levels of accessibility to the majority of disabled people.

The era of wheelchair users having to travel in the guards van is over.

Despite the uproar in the coach industry trade press in January last year when scheduled coaches came within scope of the Public Service Vehicle Access Regulations it is pleasing to see that some operators have now embraced the change.

National Express are to be commended for their commitment that all their fleet will be wheelchair accessible and compliant with the regulations by 2012.

It think this is an appropriate moment to pay tribute to Ann Frye’s work at the Department for Transport.

As Head of the Mobility Inclusion Unit and it predecessors for over 25 years until the end of last month, she worked tirelessly to promote accessible and inclusive transport. She has helped to overcome the initial view that it was impossible to accommodate wheelchair users on public transport vehicles to the point that many transport providers now acknowledge the business benefits of the extra income generated by operating accessible vehicles.

I well recall the meeting that we both attended in June 1980 under the chairmanship of the then Permanent Secretary of the Department of Transport, Sir Peter Baldwin. From that single meeting of disabled people, transport providers and intelligent and committed public servants almost every improvement in the mobility of disabled people can traced. We listened to the taxi trade saying it was impossible for wheelchair users to get into taxi and it was unnecessary because they could always use ambulances. The bus industry just shrugged their collective shoulders. British Rail had already begun make provision on trains and did much to support further work during the 1980s and beyond. The aviation industry was in parts positive.

In the more than quarter of a century since that meeting the change has been enormous. It has been led by a small number of Ministers and officials at the Department for Transport working with the transport industry and disabled people over that time. But now is not the time for the Department to sit back in the soft armchair of complacency and to downgrade disability issues. Instead we must all lift our sights and recognise a simple and basic fact.

It is this: unless the mobility of disabled people is at the heart of transport policy the Government will fail to achieve it policy objectives – in health, education, employment, on the high street

And it is no longer sustainable for the transport industry to view disabled people as a group of people over there who keep making unreasonable demands.

If you design your transport systems for athletic young people you will find that a rapidly diminishing percentage of the population will be able to use your services.

We, you, are getting older and as you do so, many will become more frail. Disability will be more common.

If you wonder for whom I seek inclusive transport I would reply that in part it is for you.

Of course we need more progress. The Public Service Vehicle Regulations don't require provision of audible and visual announcements on buses. For many blind and deaf people this presents a serious barrier. It is deeply frustrating that after an apparently successful pilot scheme in West Yorkshire was completed in 2001 we are still waiting for amendments to the PSVAR.

Now We Want Good Customer Care

But removing barriers excluding disabled people from public transport is not simply a matter of introducing accessible vehicles. All too often it is the behaviour of drivers, support staff and other members of the public which deter disabled people from using public transport services.

Sadly calls to our Helpline tell stories of people who have been humiliated by poor staff behaviour. Sometimes it s the member of station staff who has patronised someone with learning difficulties when supposingly helping them to locate the train they need for their journey. Even some of my more assertive staff grumble about being referred to as "I've picked up the wheelchair on Platform 3 and I'm taking them to the exit" shouted into the radio as if describing a parcel from a goods train.

On buses, problems can vary from the refusal to kneel the bus because the driver is running late, to the reluctance to ask the mother with their baby buggy in the space for wheelchairs to fold it up so a wheelchair user might use the service. At least the buggy can fold and the baby travel on their mother's knee: many wheelchairs users do not have the option to get out of their chair.

A member of the DRC's Mental Health Advisory Group tells us of a fellow user of mental health services who asked to use the front seat on a scheduled coach because they felt uncomfortable if they weren't seated near the exit. The driver's reaction was to tell him that nutters should travel at the back of the bus – with strong echoes of Rosa Parkes

And it isn't simply a matter of poor staff behaviour. Sometimes it's the inadequate levels of staff operators are willing to fund. You may have heard how recently I arrived at Euston station to find, not only was no-one from Network Rail able to meet me at the taxi rank as arranged, but the office couldn't find anyone available in time to assist me to catch the train on which I was booked. I was informed that if I missed the train, I would miss the train.

I find it impossible to fault the accuracy of this sage. I just wish be had been less wise and more helpful.

Fortunately on this occasion it was just a matter of waiting an hour. Had the limited number of wheelchair accessible spaces been booked on the next train I might have been forced to stay an extra night in London. Perhaps not a great hardship for someone in my position, but if you're travelling on a low income with low confidence this could be a financial calamity which could prevent you ever using the rail network again. In all fairness I should add that I normally receive a good service at Euston, but disabled people need to know that high quality service can be expected and predicted.

9 out of 10 people with a learning disability report harassment in their daily lives.

We want to stamp this out.

A significant amount of such harassment takes place on public transport – only by working with transport providers and the wider community can we achieve our aim of ensuring that disabled people’s opportunities are not circumscribed by fear.

Getting it Wrong Will Soon be a Breach of the DDA

It’s all too easy to deliver a talk like this highlighting examples of bad practice by transport operators.

Thousands of disabled people do travel every day without problem and are growing in confidence as the systems designed to assist them prove to be increasingly reliable.

This is good news not just for disabled people who benefit for these improvements, but also for those forward looking transport providers themselves.
From the 4 December this year transport providers who continue to stubbornly remain out of tune with the modern demands of their customers could find themselves in breach of the Disability Discrimination Act for failing to provide the support systems disabled passengers require.
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We hope that this will be the final incentive for transport providers to get it right when serving disabled passengers.

It is in their interests as well.

Disabled people are already a net income generator for transport providers

Widening the net of potential customers today will not only increase these revenues, but also help ensure that public transport providers can thrive in the ageing population we anticipate over the coming decades.

Concluding Remarks

It is the DRC's vision that disabled people are able to participate equally as full citizens in society.

Only through developing a transport system which everyone can use can this vision be realised.

The Social Exclusion Unit Report identified some important steps to achieve that objective. Measures taken over the last 3 years have made significant strides in the right direction.

With the rising numbers of accessible vehicles, and the removal of the transport exemption from the DDA, we are on the verge of a major breakthrough in creating a truly inclusive transport network.

But the progress remains vunerable.

Taxi drivers still often refuse to stop for wheelchair users and in some parts of the country it is almost impossible to locate and accessible taxi.

Some bus drivers still see disabled customers as a nuisance and make them feel unwelcome.

Transport providers still spend a remarkable amount of energy to find ways to justify discriminatory behaviour whereas the same energy would be better spent finding solutions.

I have already alluded to the approach I would commend to you and it really is very simple.

Look around you, not at the people in this conference, but at those you see outside.

Observe the richness and diversity of humanity and appreciate that there are 10 million disabled Britons.

One day you might be one of them.

At the top of your organisation think disabled people.

Get your middle managers to do the same and ensure your most junior staff also do.

And remember that if you get it right for disabled people your services will be more sensitive for all your customers.

And after all they are the people who pay your salaries.

Now is the time to give them true value for money.

Thank you

16 February 2006

Keywords: Disabled people; Inclusion; Transport

The Human Rights of Persons with Disabilities
Extending Freedom to all

The Disability Rights Commission: a positive approach to equality and human rights. Speech given by Nick O'Brien, Legal Director of DRC at LSE, 9 March 2006

One of the pleasing things about tonight’s event is its recognition of the journey taken by disabled people, a journey from welfare to rights, from a medical model of disability (that sees impairment as the problem) to a social model (which highlights instead the failure of the social, economic and cultural environment to accommodate impairment) and perhaps now from that social model to something like Amartya Sen’s and Martha Nussbaum’s capability model, which sees the aim of liberal politics as that of providing support for human need so that all human beings, including disabled people, can choose to function. But what sort of rights should we aspire to in this context? Are the anti-discrimination norms favoured by the domestic Disability Discrimination Act 1995 (the DDA) sufficient? Or is the very different-looking human rights approach (whether that of the European Convention on Human Rights now incorporated into the domestic Human Rights Act, or of the revised European Social Charter which at Article 15 provides for the ‘independence, social integration and participation in the life of the community’ of disabled people, or again the Draft UN Convention with its principled insistence on independent living and participation) a necessary complement to anti-discrimination law and in fact a better bet for achieving anything like substantive equality for disabled people?

More specifically, and from the perspective of the Disability Rights Commission (the statutory body established by government in April 2000 to promote and enforce disability rights, especially as enshrined in the

DDA, and, incidentally, the statutory body which has been expressly refused powers by successive Secretaries of State to bring stand-alone human rights cases on disability issues) I want to talk about three things: first, I want to draw upon the DRC's own litigation experience (and its observation of litigation in this area more generally) to suggest that in the context of disability rights a human rights framework does indeed complement and enlarge a narrower approach based just on conventional anti-discrimination law; secondly, I want to suggest that this complementarity has something to do with what might be described as the uniquely 'positive accent' in which disability rights law is enunciated, its distinctive requirement that employers and others do not just, in some crudely symmetrical and neatly rationalistic way, treat disabled people the same as everyone else but that they take positive steps ('make reasonable adjustments' to use the jargon) to achieve substantive equality for disabled employees, students and pupils, customers and clients; and finally, I want to suggest that it is precisely this 'positive accent' that gives us a clue to the sort of pivotal role that disability rights might have in the future development of anti-discrimination law more generally and within the practice of the planned Commission for Equality and Human Rights. This analysis suggests that, far from being the poor relation, disability is well placed to shape the future practice and discourse of anti-discrimination and human rights law.

The DRC's experience

So let's start with the DRC. The very existence of the DRC is a reflection of a profound shift, a shift that has seen the disadvantage experienced by disabled people become not so much a source of pity as of indignation, a matter of justice and rights rather than of charity and welfare, of participation and empowerment rather than of benefits and patronage. A tangible sign of that shift is the DDA, of which the DRC is in a sense the ‘guardian’. Although a major symbolic breakthrough, based largely on the Americans with Disabilities Act 1990, the DDA was greeted with some skepticism by parts of the disability movement: first, its ‘medical model’ definition of disability (in other words its preoccupation with what is wrong with disabled people rather than with what is wrong with the social set-up) opened the door to protracted litigation about who precisely is protected by the law (does it cover people with dyslexia, those with bad backs, those who are depressed for six-month spells but never quite for a whole twelve months in a row, and so on?); secondly, the balancing act between the needs of disabled people and the demands of business made for a relatively low ‘justification’ threshold and certainly for a useful negotiating tool when it came to settling cases before trial; and, even more importantly, the scope and reach of the DDA was heavily circumscribed by ‘block-booking’ exceptions from coverage, the most relevant in this context being the effective exclusion of all public functions (something only to be remedied in December this year). The result is that whilst the DDA has been a useful tool in certain employment and consumer disputes, it has left largely untouched whole swathes of public sector service-delivery, such as health, transport, social care and even education (covered by the DDA since just 2002), in other words, precisely those areas where protection is most needed if disabled people are to flourish socially, economically and culturally, and where anyway it would take something more positive than mere ‘non-discrimination’ (with its comparative dimension) to make a real difference.

In its early days, the DRC (and disabled people more generally) as a result found itself involved in cases that turned on just these issues: was the individual really disabled at all, and if so ‘prove it’; surely health and safety factors justify such and such an employment practice; can a tea shop in Harrogate really be expected to make room for a wheelchair; can non-disabled golfers in Surrey sleep soundly in their beds when they know the next day they will be pitted against a disabled golfer in a buggy instead of carrying his own clubs like them. Important though these issues were, the question inevitably arose: was this what it had all been about, all the campaigning, the lobbying and ‘sit-ins’? Did this relatively compressed employment and consumer agenda really do justice to the complexity of disabled people’s lives and to the real scale of the historical disadvantage encountered?

And so, enter human rights as one possible source of deliverance. By intervening in a series of human rights cases (not DDA cases at all but very often cases central to the independent living agenda) and by appealing to human rights principles (especially those developed under Articles 3 and 8 ECHR), the DRC has been able to reach beyond the DDA and its limitations. When two young disabled women wanted to challenge the decision of East Sussex County Council to take them into residential care because its health and safety practice entailed a ‘no-lifting’ policy in the home, it was human rights principles and not the DDA that came to the rescue; when Leslie Burke wanted to challenge the GMC’s guidance to doctors on the withdrawal of artificial nutrition and hydration it was to human rights principles that he instinctively turned for ammunition; and when a disabled child developed asthma and was effectively denied the necessary ventilation on ‘quality of life’ grounds, it was human rights principles which informed her parents’ determination to demand what was needed from another hospital and which enabled them to reach agreement with the first hospital about what had gone wrong.

In the East Sussex case, the judge, Mr Justice Munby, placed the argument firmly within the jurisprudence developed by the European Court of Human Rights when he remarked,

> ‘True it is that the phrase [human dignity] is not used in the Convention but it is surely immanent in Article 8, indeed in almost every one of the Convention’s provisions. The recognition and protection of human dignity is one of the core values – in truth, the core value – of our society and, indeed of all societies which are part of the European family of nations and which have embraced the principles of the Convention...The other important concept embraced in the “physical and psychological integrity” protected by Article 8 is the right of the disabled to participate in the life of the community…This is matched by the positive obligation of the State to take appropriate measures designed to ensure to the greatest extent feasible that a disabled person is not “so circumscribed and so isolated as to be deprived of the possibility of developing his personality”.’

The ‘positive accent’ of disability rights law

What these human rights cases had in common was the desire to get public authorities to accept that they have positive obligations towards disabled people. This was not just a matter of human rights as a series of ‘keep out’ notices to Church and State, a manifestation of a narrow ‘civil liberties agenda’. Instead, this was something more positive, entailing a sense of positive value and the need for certain positive interventions that would be necessary if the disabled people in question were to have any meaningful freedom of choice, any meaningful prospects of social inclusion and participation. The fact that they were not always completely successful in their arguments is not the point: human rights principles (more than black-letter human rights law, still less black-letter anti-discrimination law) provide a language and framework within which the arguments could be articulated and given their due weight.

And, as it happens, such an approach sits well with, and builds upon, the most productive and distinctive parts of the DDA, its ‘reasonable adjustment’ provisions. It is those provisions that recognize, albeit imperfectly, that for disabled people equality is not about formally equal treatment at all, not about some neatly symmetrical notion of equality of opportunity, but in fact about something more ambitious, about difference of treatment to achieve something a little more like substantive equality. Baroness Hale made the point well when in the recent House of Lords DDA case of Archibald v Fife Council she said that unlike the Sex Discrimination Act and the Race Relations Act the DDA does not see treating everyone the same as the answer but instead accepts, realistically, that different treatment is actually the path to real equality; and the same ‘positive’ approach emerges too in the new Disability Equality Duty which will come into force on public authorities from December this year and provides that they must take account of disabled people’s situations even where that involves treating disabled people more favourably than others.

In fact, it is recognized that both the SDA and RRA also need the inclusion of more positive provisions if they are to have real impact. The Race Relations Amendment Act 2000 already, in response to the Stephen Lawrence inquiry, introduces a positive duty on the public sector, and the Equality Act, passed just a couple of weeks ago, paves the way for a similar duty on gender. Elsewhere, in Canada for example, the ‘reasonable adjustment’ duty has been applied to all the prohibited grounds of discrimination, with the human rights concept of ‘dignity’ being used as a ‘moderator’ that avoids a comparative approach and instead tests against a common substantive benchmark.

Disability, equality and human rights

So where does this leave the future of equality and human rights law? This coalition of positive human rights obligations and what I have called the positive accent of the DDA (its reasonable adjustment provisions and the new public sector duty) is not just of parochial interest. The government's decision to review discrimination law and to create a new Commission for Equality and Human Rights raises fundamental questions about the purpose and effectiveness of anti-discrimination law, about the relationship between human rights and equality, and about the sort of equality that might carry positive value and not just pleasingly neat and formal symmetry. Last week we heard that the Commission on Women and Work had confirmed what everyone knew, namely that after twenty-five years of the SDA the pay gap is still huge. Yet what the Commission failed to conclude (albeit controversially) was that the problem lies primarily with individual discriminatory acts on the part of employers, with breaches of the well–established and much-litigated law in this area. What I have suggested here is that the DRC's experience invites the conclusion that the achievement of substantive equality for disabled people will entail the continued interpretation of anti-discrimination law within a human rights framework, informed and enlarged by human rights principles and perhaps even occasionally by human rights law; that the lessons do not stop with disabled people but provide pointers for all seriously disadvantaged social groups to the sort of strategies that might help; and that such a positive approach does not lead in the direction of some sort of politically correct tyranny but instead to the only version of liberalism worth having, a liberalism that is not about negative freedom, about freedom from discrimination and irrationality but about something more ambitious, about dignity and equal worth, about the positive freedom to flourish and participate. To realize the human rights of disabled people in that case simply is one way of furthering equality and that positive liberty for everyone, whether disabled or not. And that, in my view, is an opportunity not to be squandered lightly.

9 March 2006

Keywords: Disability rights; Equality; Human rights; Law

From Paupers to Citizens Independent Living and Human Rights Paper presented at Human Rights Transforming Services conference QEII Centre London 27 March 2006

Gerry Zarb
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Disability Rights Commission

Introduction

In this short paper I want to examine the relationship between human rights and independent living for older and disabled people in the context of current reforms in public services and the future equalities agenda. The paper focuses in particular on the extent of exclusion that older and disabled people face as a result of limited rights to independent living. It also examines the prospects for achieving legally enforceable rights to independent living and promoting Independent Living as a human and civil rights issue, particularly in the context of the forthcoming Commission for Equality and Human Rights.

What is Independent Living and why is it a civil and human rights issue?

I want to start off by explaining briefly what we mean by the term 'Independent Living' and why the DRC and others believe it is central to making a reality of disabled people's civil and human rights. I'll come on to the formal definition shortly - and you can read all about it at your leisure anyway in our recently published discussion paper, copies of which are available on the DRC stand.

But, before that, I want to tell you a story that I hope will illustrate very clearly exactly the sort of problems that older and disabled people face and why we believe rights to independent living are the solution.

I don't know how many of you are married, or have long-term partners - probably quite a few I would guess. I have a partner of nearly 15 years who I love very much, who is my best friend, my advisor, and who looks after me when I am unwell, as I do her. We have been together for quite a few years now, but nowhere near as long as my partner's parents who - like many of their generation - have clocked up more than 60 years of marriage so that it seems impossible to picture them as anything other an indivisible partnership.

In reality I know that nature dictates that one day they will be separated, as will my partner and I. Death is always extremely sad and sometimes very cruel in the way that it arrives. But it is unavoidable so we just have to prepare for the separation it brings as best we can.

Imagine for a moment though if we had the power to hasten that separation; to take partners away from each other after more than 60 years of marriage; in effect, to sentence their partnership to a heart-rending 'living death'.

What could possibly justify the legal exercise of such a power?

How about being sent to prison? Unfortunately, yes - even though one of the partners may be entirely innocent of any wrongdoing.

Terminal illness requiring permanent hospitalisation perhaps? It's arguable that this could be avoided by access to palliative care at home. But unfortunately that isn't always practical so, however sad, it's difficult to portray separation on such grounds as infringing any fundamental rights.

Another reason might be that one of the partners does not meet the criteria for support from public services such as housing or social care. But surely, that's just a technicality.

No fair minded, democratic, society would sanction use of such a power.

True this was a regular occurrence in the Poor Law era when pauper families were regularly split up for no other reason that they did not meet the criteria for being supported by the parish. But in the 21st century? Surely not. Surely, common sense and basic compassion would override the use of such power. After all, we have human rights now don't we? We don't treat our citizens like paupers any more - or do we?

Regrettably, as the recent story of the Cheltenham couple, Beryll and Richard Driscoll shows - we have not managed to rid ourselves of the legacy of the Poor Law just yet.

As reported in The Guardian last month, the couple had been separated for the first time in 65 years because social services refused to put them in the same care home.

Burma veteran Richard Driscoll cannot walk unaided and relied on his wife to help him get around, while Beryll Driscoll is blind and was accustomed to using her husband as her eyes. But they have been forced to spend the last seven months apart. A place in a care home was found for Mr Driscoll after he fell ill but social services will not pay for his wife to stay with him. She is having to be looked after by other relatives and the couple, both 89, meet only twice a week.

Mrs Driscoll said: "We have never been separated in all our years together and for it to happen now, when we need each other so much, is so upsetting. I am lost without him - we were a partnership.

"It has been such a struggle without him. He was my eyes. Since I went blind 16 years ago he has done everything for me. I am so depressed. I just want to be with Richard but I am told I don't fit the criteria. I think it is very cruel."

And, as one of their sons has said:

"They had a great passion for each other, which makes me so angry that they have been torn apart. A lot more compassion should have been shown towards them both."

Indeed! This isn't Thomas Hardy's 1830s Wessex, nor Charles Dickens Victorian London - this is in Gloucestershire 2006. So how can it be that one of our most basic human rights can be overridden in this way?

There is nothing unique about Gloucestershire social services and - technically - they have done nothing wrong. Indeed, the professionals involved in the case were very sensitive to the anguish that the decision had caused and I'm glad to say that Richard and Beryll are in fact together again today and their 7 month ordeal is, for now at least, at an end.

But, even the fact that they have been reunited displays the fundamental problem with our current public support services as that has only been possible through another bureaucratic technicality, rather than by virtue of any inalienable human or civil rights.

As outlined in our discussion paper on independent living, there are a number of fundamental problems with the existing legislative framework for social care:

1. The framework places duties on local authorities to provide services, rather than giving rights to individuals to receive support. If it had been the other way round then clearly the starting point for Richard and Beryll's assessment would have been how to support them to stay together.

2. There is no entitlement to live at home instead of in institutional care. Again, if we had such rights it would have been impossible for Richard and Beryll to become separated in the first place.

3. It does not adequately cover assistance to participate in leisure activities, work, relationships, or looking after children/other family members. In the Driscoll's case, clearly the system failed completely to support their right to family life for example.

4. There is no legal entitlement to advocacy except in very limited circumstances.

5.Enforcement of existing entitlements involves negotiating an inaccessible legal system with inadequate support. It is stating the obvious that the Driscoll's would clearly have benefited greatly from being able to access appropriate independent advocacy to help them negotiate their way through the system that forced them apart.

So, what is Independent Living and why is it the solution to these problems?

While there are numerous variations in the way Independent Living has been defined, they all tend to focus on four key values, namely choice, control, freedom and equality.

As Camilla Parker's recent analysis has shown there are several points of overlap between independent living principles and the key values of dignity, autonomy, equality and solidarity, or participation, which underpin human rights.

These values are all reflected in DRC's formal definition of independent living, based on principles defined by the Independent Living movement, and which has been adopted wholesale in the Prime Minister's Strategy Unit

2005 report on Improving the Life Chances of Disabled People:

"The term independent living refers to all disabled people having the same choice, control and freedom as any other citizen - at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations and should address the practical barriers to participation that they face."

Even if they do rely on support in their day to lives, this should not define the parameters of disabled people's identities, or the extent of their rights. In reality, disabled people are customers, workers, students, parents, taxpayers and voters, and community members. The purpose of any form of support should, therefore, be to enable people to overcome the practical barriers they face to participating in all of these roles and activities.

The DRC believes that there should be a basic enforceable right to independent living for all disabled people. Although some people assume that this already exists, the DRC knows it does not – and that many, many disabled people are denied independence on a daily basis. That is why we are supporting Lord Jack Ashley in introducing an Independent Living Bill in the current session of parliament aimed at establishing legal entitlements to a range of support, including advocacy and communication support, that we believe to be essential to enable disabled people to participate in the social and economic life of their communities on a par with other citizens.

The extent of disabled people's exclusion

The over-arching goal for establishing rights to independent living is to create a level playing field by entitling people to a minimum level of support necessary to participate in the range of social and economic roles and activities that most citizens take for granted. Even the most cursory examination of the evidence on the extent of disabled people's exclusion can leave no doubt as to the justification for such rights.

Disabled people have very few rights to services that would guarantee assistance to enable independent living. What minimum rights there are do not guarantee very much more being washed and fed.

A particularly important issue for DRC is that of enforced or inappropriate institutionalisation. While there is no central monitoring on this, there are numerous anecdotal accounts from organisations such as NCIL of people who are either stuck in residential care or afraid of being forced into residential care, because of rigidly applied budget rules in their locality. They include a women in her early twenties, wanting to get on with her life, who can not get out of residential care because her estimated care package is £80 a week more expensive than a local care home. Also, the case of a woman more than 100 years old, wanting to end her life in her own home, who can not stay there because her estimated care package is higher than the costs of a placement in a care home.

And we read about other ways of restricting people. People with learning difficulties and a label of challenging behaviour, sent to a privately run residential institution, where they will be locked in, shielded from the outside world and utterly isolated from it.

These individuals can not exercise their ordinary human rights, can not participate in daily life on a basis of equality. Independent living support, including advocacy, would enable them to change their situation.

There are no positive rights in existing legislation to enable people to choose where they live or who with and no legal protection against disabled people being forced to live in institutional care against their wishes. Nor are any such rights proposed in the recent white paper on the future of health and social care. Indeed, a specific proposal for such a right from DRC has, so far at least, been resisted by the Department of Health. It will nevertheless feature as one of the key proposals in the Independent Living Bill.

It is difficult to square this response with the rhetoric of government's 'choice and voice' agenda. Surely it is neither fair or logical that statutory care standards make it mandatory for people to have a say over things like what colour paint they have in their room in a care home, yet gives them no rights to say whether or not they want to live there in the first place.

The British Government's lukewarm approach to institutionalisation is in marked contrast to the situation in the US where the Olmstead ruling by the Supreme Court decreed that forcing people to live in institutions is a form of disability discrimination and ordered that federal states had to pay for IL support.

Another very important way that rights to independent living could underpin older and disabled people's ability to exercise their civil and human rights is by tackling head on the state of institutionalised dependency that our current public services often do more to maintain than to challenge.

Common perceptions of the nature and purpose of social care - among both service professionals and the general public - essentially portray disabled people as passive 'recipients of care', rather than active citizens facing practical barriers to participation in the social and economic life of the community.

Indeed, it is very telling that policy and practice has traditionally been placed under the nomenclature of 'care' rather than 'support'. The difference between the two is much more than a matter of semantics however. The way in which the essential purpose of public services is defined has a huge practical impact on how those services are organised and delivered and, consequently, the kind of outcomes people can expect to receive. Outcomes based on care tend to maintain and reinforce dependency. Outcomes based on support, on the other hand, clearly imply an expectation of participation and active citizenship.

In his recent speech ‘Achieving equality and social justice – a future without disability?’,the DRC Chairman, Bert Massie, highlighted how, despite recent developments such as the Disability Discrimination Act:

"Society still sees its best response to disability as care, welfare and charity - rather than equal rights, opportunities and citizenship … Our instinct is to protect. But in ‘protecting ’ people we deny humanity rather than liberating it.

And in order to protect we can make people dependent. To borrow from Amnesty International ’s new campaign, we need to ‘protect the human’ by extending freedom, respect, equality and dignity."

The Prime Minister ’s Life Chances report made a similar point:

"Historically, disabled people have been treated as being dependent and in need of ‘care ’, rather than being recognised as full citizens."

The result of this deeply embedded dependency culture is that policy and practice on supporting disabled people's participation and inclusion is becoming increasingly out of synch with the modernising aspirations that characterise the current political agenda. It might well be that disabled people have moved from being 'undeserving' to 'deserving' paupers in the slightly more benign 21st century manifestation of the Poor Law, but they remain paupers all the same.

As society has come to expect disabled people to accept the ordinary obligations of citizenship, for example to work or to be good parents, so a new light has been cast on existing systems of entitlement and support which are failing adequately to provide disabled people with the means to do so.

This gradual realisation has coincided with wider debates concerning public sector reform which emphasise extending greater choice and control to all citizens over the design, delivery and evaluation of services.

Such an approach to public service delivery has been pioneered through ‘direct payments ’ to users of social services, with evidence of mutual benefits to both service user and provider, including a more effective and efficient use of resources over time.

However, there remains a persistent culture of categorising some disabled people as inherently ‘vulnerable’, at risk and without sufficient competence to manage their own affairs. When combined with public authorities ’ ‘duty of care’ and a culture of risk aversion in areas of the public sector, opportunities for disabled people to assume greater control over their own lives too often remain extremely restricted.

Human Rights, Independent Living and Equality

In the final part of this paper I want to consider how the Independent Living and Human Rights frameworks might interact and reinforce each other and the prospects for using both as tools for promoting equality and citizenship.

Section 6 of the Human Rights Act 1998 requires all public authorities to act in a manner that is compatible with the European Convention on Human Rights. But the HRA is not just a legal mechanism. It is also intended as a tool for promoting a culture of respect for human rights.

With that aim in mind DRC, working with SCIE and NCIL, recently commissioned Camilla Parker to explore how the HRA could be used to influence practice compatible with promoting rights to Independent Living.

Her analysis identified a number of ways in which independent Living, human rights and public support systems - particularly social care - can be linked in practice.

First, independent living can be seen as essential to enabling disabled people to fully exercise their human rights: For example, disabled people living in residential care homes will face a range of restrictions on their private and family life and their opportunities to engage in society.

This is a particularly important issue for DRC because, while there has been an overall decrease in the rate of permanent admissions to residential and nursing care, for some groups of disabled people - particularly people with learning disabilities and mental health conditions - the numbers are still on the increase.

There are also important questions to be asked about the potential incompatibility between institutionalisation and protecting people's psychological integrity, as required by the HRA.

Secondly, Independent Living is a process of empowering people to exercise their human rights: Ensuring that disabled people can live ‘ordinary’ lives provides them with the opportunities to exercise their rights. Independent living is an important means of enabling people to access their human and civil rights.

Thirdly, the failure to respect human rights has an adverse impact on Independent Living. For example, a routine of providing breakfast to residents while they are sitting on their commode has a severe impact on the individuals’ independence, dignity and autonomy. Again, there also questions to be asked about whether such practices are compatible with the principle of protecting people's psychological integrity.

In practice however current policy and practice on meeting older and disabled people's support needs does not adequately reflect either the spirit or the legal requirements of the European Convention on Human Rights (ECHR). With the exception of the Bournewood judgement legal cases that have highlighted Human Rights failings in existing community care arrangements (e.g. East Sussex and Enfield) have not resulted in any corrective measures in either legislation or statutory guidance.

As Help The Aged have highlighted in relation to older people - although their findings apply equally to disabled people - the very system by which support is currently organised and delivered can actually put people's human rights at risk.

For example, eligibility for support is often so tightly rationed that people are left in deteriorating circumstances until such time that their situation is deemed critical enough to warrant support. Similarly few services go beyond very basic 'life and limb' support to address the range social, psychological or emotional needs, which may be essential for sustaining the level of dignity and integrity required by the ECHR.

Most importantly perhaps, as the story of Richard and Beryll Driscoll so graphically illustrates, people's rights to respect for private and family life under the ECHR are completely overidden when they are required to leave their homes and families against their will - either because they do not meet local eligibility criteria or because it is deemed more cost effective to place them in residential care rather than provide adequate support at home.

The HRA has, so far, been little used for cases related to independent living specifically (with the major exception of the Botta vs Italy case). However as we have already heard, recent cases in the UK have shown encouraging signs of the potential for using Convention rights in ways that are supportive of at least some important elements of independent living.

For example, in the recent lifting and handling case supported by DRC, the high court ruled that organisations providing community care services must take proper account of people's dignity, independence and human rights under the Convention. In particular the court ruled that the way services are delivered must respect their "rights to participate in the life of the community". Another landmark case, in Enfield, concerned a woman who, because of unsuitable housing could only use the downstairs rooms in her family home. In this case the courts ruled that the local authorities failure to provide adequate housing adaptations created a breach of her right to privacy and family life under article 8.

It is hoped that these developments can be built on in the future.

On the broader horizon, we have the revised European Social Charter which at Article 15 provides for the ‘independence, social integration and participation in the life of the community’ of disabled people. Although still some way off, there is also the Draft UN Convention with its principled insistence on independent living and participation.

On the domestic front, of course, there are now just 18 months before the Commission for Equality and Human Rights opens it's doors for business. The duties of the new commission will include:

- Encouraging awareness and good practice on equality and diversity
- Promoting awareness and understanding of human rights
- Promoting equality of opportunity
- Working towards eliminating unlawful discrimination and harassment
- Promoting good relations between different communities
- Keeping discrimination and human rights legislation under review

The Disability Rights Commission welcomes the Equality Bill, which establishes the new Commission. It marks a new approach to equality and human rights, which we believe has great potential to transform the life chances of disabled people and other marginalised groups in our society

As DRC's Legal Director - Nick O'Brien - has pointed out, the Equality Bill marks a sea change in the approach to tackling discrimination. The new Disability Equality Duty switches the focus from individual acts of discrimination to the positive actions that public bodies need to take to tackle discrimination, and to promote equality at an institutional level.

He further argues that this new duty takes us way beyond existing anti-discrimination legislation in that, rather than simply aiming to level an uneven playing field, the duty explicitly recognises the need to take positive steps to remove barriers to participation and inclusion:

"the refusal to acquiesce in equal treatment and the willingness to transcend that limited strategy by insisting on ‘going the extra mile’ (as it were) to make the positive interventions that will actually deliver substantial equality of outcome rather than merely formal symmetry."

Concluding comments

Achieving independent living demands a universal refocusing of public policy and services towards the goals of promoting choice, control and participation amongst disabled people. This will require the commitment and shared action of different national and local government departments, and shift in culture which moves on from categorising disabled people as inherently vulnerable and which allows the sharing of risk between service users and providers.

Applying human rights principles to the question of promoting independent living and inclusion also highlights the need for some significant changes in the ways we have traditionally viewed provision of support for disabled people. For example:

- Promoting community living in place of institutional care.
- Providing support which facilitates social inclusion and participation.
- Ensuring that the delivery of social care and other support services maximises choice and control.

Accepting that the ultimate aim of any support system should be to address barriers to social inclusion and participation.

In particular, we need to question why, in the 21st Century, it is still seen as acceptable for disabled people to be living in institutions against their wishes, to be denied access to basic support to enable them to enjoy a family or social life, and to be guaranteed no more than the bare minimum services for day to day survival.

For all the apparent complexity in achieving independent living, its goals are fairly unremarkable. It is essentially about disabled people accessing the freedoms and life opportunities they should expect as British citizens – nothing more and nothing less.

However, while independent living is already a reality for some disabled people, for many others it is a distant dream.

Having put in place anti-discrimination measures to remove the barriers and create a more ‘open road ’ for disabled people, the next step in the journey towards equal citizenship is to provide people with the more equal start that independent living represents.

For many, progress towards the goal of equality absolutely depends on it.

Keywords: Equality; Human rights; Independent Living

Bert Massie ACAS Diversity Symposium Tower of London New Armouries Meeting Suite

Speaker's Brief: 'Influence the diversity agenda to look at one of the major challenges of the changing demographic climate, that of moving from an agenda on 'individual rights' to one based on opportunities and workplace modernisation'

Abstract: 'Success comes from putting disability at the heart of British life, of public policy and of organisational strategy'

Not so long ago, most organisations, private or public, linked the subject of equality and diversity to legal compliance or perhaps simply to 'doing the right thing'. Today, many organisations – including government itself - are finding that putting disability equality at the heart of their strategies and policies is the key to success.

We have seen this developing for some time. Forward thinking employers, such as those who are members of the Employers Forum on Disability, are already reaping the rewards of understanding the changing demographics of the workforce. Embracing its diversity whole-heartedly – whether that is ensuring flexible working arrangements for parents, recognising religious and cultural issues affecting migrants who come from outside the UK to work here, or acknowledging that we live in an ageing world - and that the incidence of impairments and long-term health conditions increases with age. Responding positively to these facts as opportunities not threats is crucial for any business.

Most big organisations are also now aware of the importance of corporate social responsibility – the expectations that consumers and the wider community have of how they do business: who they employ; how they treat their customers and suppliers.

Disability equality is increasingly at the heart of these responsibilities – not just in a legal sense. It is no longer acceptable or useful to consider including disabled people as an add-on, fitting us in on an individual basis where you can. The effective way, and increasingly the law reflects this, is to consider how organisations can ensure disabled people can be enabled to be equal consumers and contributors in British society.

The government's plans to get a million people off long-term sickness and disability benefits and back into the workplace will only have a limited impact unless a lot more is done to encourage employers to take on disabled people and people with long term health conditions in the first place.

There are 6.8 million working age disabled people in Britain, half of them (3.4 million) are in work, 1.2 million disabled people without work but want to work and 2.5 million disabled people are out of work on state benefits .

Over the next two decades, employment rates amongst older men and women below state pension age will continue to rise significantly. By the year 2010, 40 per cent of the UK population will be over 45 – the age at which incidence of disability increases.

A report from City and Guilds suggests that 16 to 25 year olds will comprise just 11 per cent of the workforce in 2020, compared to 16 per cent today – a plunge of nearly 1 million. Offsetting factors will need to incorporate bringing ‘economically inactive’ adults into the workforce.

The workplace will have to look very different in 20 years’ time if this programme is to be a success. But that changing workforce picture is just as crucial to the British economy and to the pensions situation as it is to our aspirations at the DRC or the Government’s concerns about incapacity benefit.

Workforce and Customer issues

Investment in a diverse workforce helps organisations develop better understanding and care for their customers. Sharing the knowledge, expertise and understanding staff have of barriers disabled people face in the workplace enhances an organisation’s ability to respond positively to disabled customers and to identify where you may not be reaching potential customers.

And disabled people, including people with long-term health conditions, form a significant market - around one in five of the population, with a total spending power estimated at between £80 billion.

Investing in the expertise already present in an organisation’s workforce results in a smarter, more responsive and intelligent organisation that can meet the needs of its customers. This isn’t just about in-work training but about tapping into schemes that develop disabled graduates and support those disabled early in life to overcome low expectations of what they can achieve; it’s about redeploying and supporting employees who develop impairments and long-term health conditions – retaining valuable expertise and experience and demonstrating to all employees that they are valued. In larger organisations, supporting and developing disabled staff groups is one way of harnessing the intelligence.

Much has been said about the cost implications of employing disabled people and people with long term health conditions. The reality is that cost is minimal.

Studies show that 80 per cent of employers found it easy or very easy to make adjustments enabling disabled people to join or stay with their business, with 65 per cent stating that there were no financial costs at all. Where adjustments were necessary, the average cost was below £200.

Government grants, through Access to Work for example, are available to cover the cost of many reasonable adjustments in the workplace. Sometimes the cost is an imaginative and flexible approach to getting the best out of people - something every organisation would do well to cultivate.

Of those employers that have made changes for disabled staff, 71 per cent cited as a reason that benefits would outweigh the costs.

Getting services and policies right from the beginning

A shift to citizen-focused approaches and a renewed impetus to challenge institutionalised discrimination means that employers must place equality and diversity centre stage. New national and European legislation and requirements on equality and diversity provide an opportunity for employers to radically overhaul their policies and practices.

Our response at the DRC has been to help shape the new agenda by involving all interested parties in our Disability Debate - about what is happening now and how we can influence the government and organisational agendas to help get it right.

People with impairments and long-term health conditions have always been with us - and more than likely always will.

We need to accept this and meet the challenge of extending freedom and equality to all. If we don’t, everyone suffers. The inequality experienced by disabled people affects us all. In fact, it stands between this government and the ability to achieve its core ambitions for Britain.

Things have got better for some disabled people; but, in important areas, the distance between the living standards, opportunities and life chances of disabled people and the rest of the population has widened. This is manifestly unjust - bad for individuals and bad for society. We have to change if we want a country that is genuinely committed to equality and social justice.

That means a new approach to public policy and a new emphasis on enabling disabled people to participate fully in the civic and political life of modern Britain. Despite positive steps in some areas, public policy is in danger of leaving disabled people behind. Government is increasingly recognising that tackling disability equality is the key to tackling some of the biggest questions facing Britain today. Whether it is whether we can reach full employment without tackling the low expectations that trap people on incapacity benefit and have harmful knock-on effects that keep children in poverty.

Disability equality duty

The Disability Discrimination Act was amended in 2005 to place new duties on the public sector to promote disability equality; to enshrine the proactive approach that works for Government, public services and business in tackling disadvantage and barriers to disabled people's contribution and involvement in British life.

Public authorities can now tackle disability discrimination in a practical way by introducing policies that actively promote opportunities and so prevent discrimination taking place. By taking an organisation-wide approach, public bodies can achieve tangible outcomes and improvements for disabled people.

This new approach will demand that public sector employers develop accessible workplaces and flexible work patterns; and revise unequal and biased work systems which discriminate against disabled people.

Successful organisational change should be as much about changing the way people think and behave as about overhauling how they work. These changes should begin to change the lazy fatalism about the disadvantage disabled people face; raise disabled people's aspirations for themselves and raise the expectations of others.

At the heart of Government and organisations' agendas

I have touched on the impact of:

changing demographics
the business case in recruiting, retaining and developing disabled employees
the proactive change approach to disability equality embodied in the new disability equality duty.

All of these paint a picture of where we are moving to. Clearly, there is still a long way to go for employers to embrace genuine diversity, but I hope these brief remarks have at least indicated the intersection of interests between disabled people, Government and the successful delivery of business, whether in the public or private sector.

Keywords: Disability rights; Diversity; Public policy

National Welfare Reform Conference
Westminster Briefing
‘National Welfare Reform Conference: Providing Support and Realising Aspirations’. 22 June 2006. London
Reflections on Incapacity Benefit & Welfare Reform

Westminster Briefing

‘National Welfare Reform Conference: Providing Support and Realising Aspirations’. 22 June 2006. London

When the word ‘disability’ is mentioned people still often think of a minority of people, often visibly impaired - such as a wheelchair user – whose problems are to be dealt with through ‘special’ policies and programmes. Despite ten years of the Disability Discrimination Act, we have a system of welfare benefits and social care specifically for disabled people which is narrowly focussed on their ‘dependency’ rather than an investment in supporting us to participate and contribute – in work, education, community and family life.

The legacy of exclusion and the design of our welfare state has meant that many disabled people have lacked opportunities to develop their potential, leading to the institutionalisation of low expectations, low status and disadvantage.

This cycle of disadvantage has led to what I have called ‘lazy fatalism’; low expectations of disabled people creating the conditions where human potential and contribution are denied.

The DRC has a different vision – of a society in which all disabled people can participate as equal citizens.

What equal citizenship means for disabled people, and how it can be achieved, is fundamental to the DRC's 'Disability Debate and Agenda'. We launched the Disability Debate earlier this year to generate wider discussion about the role of disabled people in society and to ensure that, when the DRC closes its doors, the new Commission for Equality and Human Rights continues the momentum towards equal citizenship.

The DRC's approach to welfare reform

Equal citizenship has also formed the basis for our approach to welfare reform. From this starting point we have developed three key principles:

The first principle is that there has to be a fair balance between individual responsibility and the responsibilities of others, notably employers. So for example it would be unfair to require individuals to make more efforts to return to work unless employers are also prepared and equipped to employ them. Too many employers are still not meeting the basics as required by the Disability Discrimination Act, accounting for over a third of calls to the DRC's Helpline. In one case (Gaynor Meikle) failure to make a simple adjustment – giving her written materials in a large enough font size – led to her being off work for so long that her sick pay was reduced. This was discrimination and cost her employer almost £200,000. As Gaynor's case shows, much more needs to be done, a point I will return to later.

The second principle is for a more flexible system of financial and employment support that enables disabled people to participate. This refers to both incomes and opportunities, including during periods when paid work is not possible. At the moment benefit rules can disadvantage people who want to take up public appointments, and whilst we recognise there has to be a balance between encouraging paid work and public life for people on benefit, the balance has to be tilted sufficiently to allow people on benefit to participate to their fullest potential.

The third principle is for comprehensive support to be available and accessible to individuals so that they can take part in work-related activities and day to day activities. So for example it would be unfair to require individuals to make more efforts to return to work unless they have the right kind of support to do so. In the absence of such support someone may be unable to exercise their rights or carry out their responsibilities.

Why is work important

It will probably be obvious by now that the DRC shares the government's stated aim of higher employment rates, and reformed public services. We do so because of the importance of paid work to disabled people's inclusion; over a million disabled people without work want a job.

Having a paid job is important to disabled people. It is a major source of income, a means of making friends, building self confidence and learning skills. Having a job also means that you are in a better position to save and to gain a pension in later life.

But paid employment is more than that. Being in a job brings with it the chance for interaction with non-disabled people. And educating those who know little about disability or long term conditions is important in making the wider cultural change that is necessary for a more equal society.

We know from the DWP's own research that employers who have successfully employed a disabled person are more willing to do so again. Familiarity breeds confidence. So helping one person into a job can help to generate opportunities for others. This means that job brokers and providers of employment services for disabled people may need to be more focused on engaging employers. They should also be ensuring that individuals are helped into a job which is the right one for them, and supported to stay in and progress in work.

Employers are the missing link

We have supported the main thrust of the Green Paper and the aim of getting a million disabled people off benefit within a decade. It should go without saying that without employers there will be no jobs for people to go into. But we agree with the recommendation of the recent Work and Pensions Select Committee report that the DWP should do more to change employers' attitudes in order to meet this goal.

I mentioned earlier that the DRC hears about employers who are failing to make the right adjustments for disabled people. Research that we did with the Health and Safety Executive showed that health and safety has sometimes been used, inappropriately, as a reason for not employing a disabled person. A common assumption is that someone is too big a risk to employ, though this assumption is often made unencumbered by knowledge of the DDA and reasonable adjustments that could be made to reduce any real risk.

People on Incapacity Benefit are regarded as even more of a risk by employers. Research from the Chartered Institute of Personnel and Development has shown that many employers are resistant to take on people from incapacity benefit, a third saying they exclude people with a history of long term illness or incapacity when recruiting.

To tackle this Jobcentre Plus could adopt and promote the systematic approach advocated by the Employers Forum on Disability. ‘Recruitment that Works’ draws on a partnership between the employer, Jobcentre plus and intermediaries to work together in putting forward individuals for job preparation programmes tailored to the employers needs.

Here too the DDA could be strengthened to outlaw pre-employment medical questions asking for details about someone’s health or periods in hospital, which can open up difficulties for people with mental health problems in particular. Instead questions should be limited to the kinds of adjustments needed to help someone do the job.

A further DDA duty could be introduced to for employers to anticipate the needs of disabled people (rather than just reacting when an individual complains). This anticipatory duty already exists for service providers but extending this to employment would give further impetus for employers to look at their recruitment process strategically and remove any barriers that disabled people may encounter.

Access to work

However if employers are to have more responsibilities in this way then it is only right and proper that they as well as individuals should have support to do the right thing.

In this respect the successful Access to Work scheme is crucial in enabling disabled people with support needs to participate in paid employment. Access to Work can help someone get to work and do the tasks involved in the job. The DWP’s evaluation of Access to Work has found that most people getting Support Workers and Travel to Work would not be in a job without this support.

We hear that from October this year, Access to Work provision will be withdrawn from central government departments (though advice will not). This has been on the cards for a while and was recommended by the Prime Minister's Strategy Unit in its 'improving the life chances of disabled people' report as a means of freeing up more resources for small and medium sized businesses. However this was subject to the proviso that the impact of withdrawing Access to Work should be evaluated and that there should be no negative impact on the employment of disabled people.

We already know from the government's research that Access to Work is used much more in the public than in the private and voluntary sectors, and particularly in central government. We also know that these public sector users were somewhat more likely than others to have a bigger package of Access to Work supports but were less satisfied with the extent to which Access to Work met their needs. What we do not know is if those needs would be met if Access to Work is removed.

We believe that the planned withdrawal of Access to Work should be evaluated before it goes ahead. As required by the new disability equality duty, an impact assessment would help to identify potential consequences. We already know that Access to Work can make it possible for disabled people to be in a job where it would have been unreasonable to expect the employer to make an adjustment. To give up this mechanism at a time when we expect more disabled people to participate in paid work would be extreme folly if to do so would result in slowing the rise in employment rates or limiting an individual's progression in work.

This brings me to a key point in the Disability Debate and Agenda overall.

Putting disability at the heart of public policy

Earlier this year we called for disability to be put at the heart of public policy. This is not just self interest on our part. Disability affects everyone and is central to meeting government targets.

Quite simply if we want to achieve goals like full employment, eradication of child poverty, stronger communities, a better skilled workforce, disability must be put centre stage. None of those government priorities can be met unless the needs of disabled people are at the core of policy making and delivery. We cannot tackle child poverty unless we do something about the one million workless disabled parents whose children are living in poverty, and disabled 16 year olds who are twice as likely to be out of work, education or training as their non-disabled peers.

Indeed the Prime Minister's Strategy Unit report on the life chances of disabled people recommended that arrangements should be put in place for the participation of disabled people in policy design and delivery at all levels. Four key departments - Work and Pensions, Health, Education and Skills and the then ODPM, signed up to this report and its recommendations as government policy.

To this end the incoming disability equality duty on the public sector points to the way forward on involving disabled people. This duty provides a framework through which government and public authorities, in partnership with disabled people, can identify new solutions to existing problems.

In a few months time the Disability Equality Duty will be in force and we hope – expect – that DWP and Jobcentre Plus, and its contractors, will be exemplary in meeting this new duty. The duty is a real opportunity to tackle your key priorities in a strategic way by meeting the needs of disabled employees and customers. Your chance to make your contribution towards equal citizenship for disabled people.

BERT MASSIE. JUNE 2006.

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Keywords: Disabled people; Employment; Incapacity benefit; Welfare reform

Bert Massie - A way out of poverty?

Speech by Bert Massie:'A Route out of Poverty? Disabled People, Work and Welfare Reform'. Delivered to a Child Poverty Action Group reception at the House of Commons, 26 June 2006

CPAG reception to launch ‘A Route out of Poverty? Disabled people, work and welfare reform

26th June 2006, 7p.m. House of Commons

The DRC’s commitment

I’m very grateful to CPAG for inviting me to speak this evening and for the opportunity to contribute the preface to this important publication.

The DRC is fully committed to ending all child poverty.

Child poverty predicts significantly poorer life chances.

It damages families, narrows horizons, depresses aspirations and constrains opportunities.

It lays waste to human potential and sets in train a lifetime of disadvantage with enormous costs to both the individuals concerned and to society at large.

A child who lives in poverty is less likely to succeed educationally and more likely to be unemployed and live in poverty when they are an adult, often setting in train the same pattern for their own children.

We must break the cycle.

Child poverty is not affordable to the children or families concerned or to Britain.

Disability at the heart of the challenge

We will not break this cycle and end all child poverty unless the particular challenges facing families with disabled parents or children are addressed at the very heart of the strategy moving forward.

A quarter of all children living in poverty have a disabled parent, and research suggests that over half of all families with disabled children live in or at the margins of poverty.

The risk of a child living in a poor household is almost double the average for children living in a household receiving Incapacity Benefit.

Only 16 per cent of mothers of disabled children work, compared with 61 per cent of mothers of non disabled children.

If we are serious about ending child poverty, then our strategy has to be one which mitigates the risks of child poverty ever emerging again in Britain.

And there has never been an opportunity quite like now to try and get this right.

Ensuring welfare reform delivers

The long-awaited Welfare Reform Bill is imminent.

Whilst work is not the answer to everything it is going to be critically important to this strategy.

Parents require effective support not just in the move from benefits to jobs, but in the move from benefits into realistic and manageable employment and career development opportunities.

In-work poverty is fast growing, and it will be little accomplishment if parents only find their way into low paid, insecure jobs and become stuck there. We need to consider how people can be supported not just to get into work, but to get on at work.

But we also must not advocate a strategy which robs Peter to pay Paul.

The Government's Every Child Matters strategy aims to ensure that all children are healthy, safe, make a positive contribution and achieve economic well-being.

Ending child poverty is instrumental to achieving these goals, but the methods selected to end child poverty cannot be at the expense of the other goals outlined – they must come hand in hand.

We understand that Incapacity Benefit reform is to distinguish between two classes of recipient - those who are required to do work related activity in return for benefit and those who are not.

Whatever category disabled parents fall into their income from benefits and tax credits must be sufficient to ensure that they or their children are not left living in poverty.

Evidence strongly suggests that Disability Living Allowance has a particular role to play, being payable for the costs of impairment, whether or not someone is in work.

In March 2006, Secretary of State John Hutton announced that with the DRC, the Government would subject its welfare reform proposals to a disability equality impact assessment.

Today I want to announce that within that process, and working with partners including CPAG, the DRC will undertake and publish an assessment of the likely impact of the proposals on achieving an end to child poverty amongst families with disabled parents or disabled children.

This will be the first such assessment undertaken of any Government policy in Britain and should provide a significant contribution to the development of DWP's child poverty strategy, expected in the autumn.

A comprehensive strategy

The DRC believes that an effective strategy must focus on three key strands:

The way child poverty is measured, recognising the extra costs of impairment and disability;

Optimising household incomes;

And ensuring both that families can access specific services and support to help them out of poverty, such as childcare or access to work;

And that mainstream goods and services, such as housing or leisure opportunities, do not throw up barriers which contribute to the extra costs which drive families into poverty, even where their incomes are above the poverty line.

Every disabled child matters

On the issue of services, the second major opportunity we have to shape the way forward is the Treasury-led cross-Departmental review.

I hope that the commitment to families with disabled children which Ed Balls demonstrated whilst a backbench MP is carried through into his role at the Treasury in leading this work.

It is critical we ensure that families with disabled children can access the services and support which should be their entitlement, and which are going to be instrumental to eliminating poverty.

We warmly welcome the Government's policy shift towards achieving better long-term outcomes and improving life chances for all children.

By all children we must mean all children.

Every disabled child matters too.

Investing in our children's future

A survey DRC commissioned in 2003 found worryingly low expectations among young disabled people.

They expected that they would get a worse job, earn less money, that they were not listened to by Government and that in many respects they would have a less rewarding life than their non-disabled peers.

Ending child poverty will be a major milestone.

But our ultimate test is to turn around this culture of low expectations and in its place create a culture of high expectations - where young disabled people's hopes and aspirations have not been ground down by poverty, disadvantage and discrimination.

If we want to end child poverty, then we have to insure ourselves against its re-emergence in years to come.

That means investing now in all our children's futures.
Building a mass movement for change

In the preface I refer to an African proverb which says: 'it takes a village to bring up a child'.

Ending child poverty cannot be achieved by Government alone.

It requires commitment and action at every level by all of us in this room and many many people out there.

Civil society needs to recognise child poverty is something which blights Britain and be persuaded that ending it is a critically important investment, not just for the children and families concerned but for UK plc.

Regional and local government have a pivotal role both in improving the economic and social well-being of their areas and in ensuring that resources and opportunities are distributed in a fashion which contributes to our goal.

The voluntary and community sectors have a vital role to play, especially in innovating, nurturing and supporting action from the ground up, and in sharing best practice across the country.

If just one major newspaper took up child poverty as its core campaign it could make a massive difference.

Parliamentarians – it is your duty to ensure this issue is never out of the red boxes of Ministers or that a day goes by without its mention in Parliamentary debate.

It is too important an issue.

Making child poverty history

Together I believe we can build a strategy which has wide support, is achievable within a generation and which removes the scourge of child poverty from Britain.

Disability is at the heart of that challenge.

I look forward to working with you to make child poverty history.

Ends

Keywords: Disabled children; Disabled people; Employment; Poverty; Welfare reform

The Role of Scope in Promoting Human Rights: Past and Future

Presentation by Bert Massie, Chairman, Disability Rights Commission, to Scope manager's conference, London 7 July 2006

I am very pleased to be here today because I think Scope is an organisation that has improved the lives of many disabled people over half a century. It is, I believe, an organisation of which you can all feel proud to be a part.

I have benefited from your services in a number of ways. When I was an impoverished student I needed an electric typewriter (this was long before the days of word processors and personal computers) but was unable to afford one. Scope, under its previous name, operated a scheme to give reconditioned IBM typewriters to disabled people. I was thus able to obtain the typewriter at no cost to me.

Every night as I travel to my flat in north London, I am reminded of the work of Scope. I live in Moira Close which is owned by Habinteg Housing Association, of which I am a trustee. 25% of the dwellings are designed for the use of wheelchair users. The Close is named after Habinteg's founder chairman, Alex Moira. Alex was, of course, also one of the four parents who set up the Spastics Society in 1952. It was Scope that identified the need for accessible housing in the community and in 1970 established a housing association to provide it. Habinteg is at the forefront of the campaign to have building regulations changed so that all new housing should have disability friendly features and I am sure that that particular campaign will be won. But it was Scope that started the ball rolling.

Those who travel by air might well use the British Airways on board wheelchair. The older models are indeed getting old but they were made by Newton Products which was a supported factory in Birmingham that was part of Scope but closed some years ago.

Time moves on and things change. There is nothing new about that. It seems to me that some of the changes currently happening at Scope can be roughly divided into those which, whatever the publicity, are little more than the continuous change and renewal that has always been part and parcel of Scope. The closing of residential facilities are an aspect of this.

Others seem to be fresh initiatives. At one time it would have been surprising, to say the least, that 17% of the staff should be disabled people. I understand that the target is 20% and when you achieve that it will be a well won feather in your cap. It is also significant that disabled people are at all levels in the organisation and that there is no room for tokenism at Scope.

I think many people, and I am amongst them, welcome the moves Scope has made to become an organisation of rather than just for disabled people. I appreciate that Scope was founded by parents and because we still fail as a society to give to sufficient support to the parents of disabled children as we should, it is important that Scope finds the rather difficult balance of handing power to disabled people while simultaneously protecting the rights and interests of parents.

The last few years have not been easy for Scope and I shall refer to some of the tensions in a few moments. But the choppy water has left in its wake a strong management team and a clear vision of where Scope is heading. This is an essential basis if Scope is to maximize the contribution it can make in the future.

A future in which the DRC will not exist but the Commission for Equality and Human Rights will.

A future in which human rights will have a higher profile.

A future in which pressures on social and health care might result in a lowering of the already poor service that disabled people currently receive all too often.

A future in which the Government will look to the not for profit sector to provide more services on behalf of the State.

A future in which organisations in the not for profit sector will need to work with rather than against each other.

Perhaps one question to resolve is whether Scope is to be all things to all people. Is it primarily for people with cerebral palsy or it to be a pan disability organisation? Or a bit of both? Is it a service provider or a campaigner? Or both?

Each choice involves tensions. Cerebral palsy is a complex impairment. Babies who would have died twenty or ten years ago are now surviving but with multiple impairments and in which the traditional view of CP is but one. In this context it seems legitimate for Scope to claim to be pan-disability. But can Scope speak for people who are blind but have no other impairment? Or for people like me who have had polio? Or for people with spinal cord injuries? As the Royal National Institute for the Blind, the British Polio Fellowship and the Spinal Injuries Association are all run by disabled people through a free and democratic vote, members of those organisations might be rather surprised if Scope were to claim to speak for them. Equally, Mencap and People First might believe they are more able to speak for people with learning disabilities. Yet some of the difficulties people with CP have are applicable to many other disabled people: discrimination in education, employment, leisure activities and mobility, to name just a few. Success in these areas would benefit very many disabled apart from your members.

Part of the strength of an impairment specific organisation is that it can focus of the particular needs of a group of people who would be overlooked by wider society, even in the field of social provision. Indeed, it was this very situation that led to Scope being established. As I look at social provision for disabled people today, it does seem that those with the greatest and hence more expensive needs are likely to receive a service that is barely adequate. The lowest hanging fruit is the easiest to pick and thus meet the artificial targets chosen in ways that mystify many of us. But this does not help people with the greatest support needs. I am sure it is wise for Scope to seek to assist this group of people who, of course, now cover all age ranges. It is also critical to support the parents of people with CP. Back in the 1970’s Alf (now Lord) Morris observed that a disabled person is part of a disabled family. Helping individuals is as important as the social campaigning.

Scope has always been a good campaigning organisation. I can recall the “Save a Baby” campaign of the 1970s, headed by Peter Mitchell and Mary Holland. It won you many friends in both Houses of Parliament and made the Government reconsider much of its policy. Today there are new campaigns related to civil and human rights and there is a huge role for Scope to play.

However, I doubt that even Scope can win major long enduring successes on its own. But the disability community collectively can do so. I sense that in recent years Scope has not endeared itself to other disability organisations and that has cost you the value of a large external army that could have helped with your battles. This is not the time to debate the causes of those ruptured relationships but they are not beyond repair. If, as Scope says, it is to be a campaigning organisation it will need to regain friends who have become perhaps a little disillusioned. This will not produce easy and fast headlines but, as the past year has shown, publicity is not always positive.

If the disability community is not united then it will be weaker than it would be if it worked in harmony. I appreciate that all disability organisations need publicity to assist with their fundraising and to enable them to continue the battle. Nonetheless, internal strife and competition in our community has resulted in poorer results than would otherwise have been achieved. I am astonished at how many organisations, including Scope, are selling disability equality services to public and private organisations. How are they to choose from so many charities? Yet a collective effort could produce a service far superior than many of those sold in the private sector. It is in the not for profit sector that many of the highest developed skills and knowledge resides. Disunity sells the sector short.

Some of the press coverage Scope has received recently seems to imply that the organisation is closing all its direct services. That is, of course, nonsense. Scope started life providing services and it still does so. I suspect in the future it will provide more although you will no doubt wish to insist that a charity is not expected to subsidise the Government. Charities can provide excellent services but we need to be cautious about provision that is currently provided from the public purse being offloaded onto charities at bargain basement prices. The latest figures from the National Council for Voluntary Organisations show that in 2003/4 47% of the sector’s income was earned with 43% being voluntary income. The remaining 8% came from investments. The public sector accounted for 38% of charity income in the same year.

Scope is a significant player in the provision of services for disabled people. In the provision of such services it might well be appropriate for Scope to serve a larger group of people than those with cerebral palsy. However, like all charities, you stand the risk of the nation seeking to pass its financial responsibilities on to you or, at least, expecting you to subsidise them. This seems to be a dangerous path that could lead to grief. If, through inadequate funding, you have to reduce or close a service, the blame will fall on Scope and not the public authorities that refuse to fund the service adequately. If you succeed, it will not be too long before the private sector argues that charities provide unfair competition for services they could provide at a profit. Yet, can charities sit back while support services deteriorate as so many have. Disabled people are perhaps the only group of people using the welfare state that are still subject to means testing and charging and many cannot afford the services they need.

This wider role of Scope has been demonstrated by your newspaper Disability Now (DN). I can recall its earlier life as “Spastics News”. I was a fairly typical in-house journal that dealt mostly with internal matters and gave a bit of disability related news. I think it was Admiral Sir John Cox who initiated the move to DN when he was your Chief Executive. It was a bold move and one that illustrated the self confidence of the organisation at that time. Under the editorship of Mary Wilkinson it became the disability newspaper that all the major players read. It was feisty and independent and contained a certain amount of gossip as well as hard news stories. On occasions it even criticised Scope. And, over the years, it said a few odd things about me. But to my mind it suggested that Scope was a strong organisation that could host such an independent newspaper.

I have been an avid reader of DN for many years and I detect with sadness a change in editorial policy. There is nothing dramatic but a slow drift towards being a journal to sell Scope and criticism has all but disappeared. It is as though there is a higher hand slowly reviving Spastics News. It is, of course, perfectly valid for Scope to do this. It is your journal. But such a change is not without risk.

At the moment DN rightly sells itself as the “must have” newspaper. If it becomes an in-house journal it will lose that claim and will lose readers. That will affect advertising and revenue. I believe there is a need and a role for a newspaper like DN. But if the current drift continues, and a member of the House of Lords has written in a national newspaper about it, then Scope will have an excellent in-house journal but there will be a vacancy for an independent disability newspaper that will be filled by some other publication. It will also cast a shadow on claims to be pan-disability.

In the future there will be much for DN to report. The fight for civil rights for disabled people has been long and bloody. Some of our greatest fighters have died along the way. 1995 saw the passing of the Disability Discrimination Act. It was not as fulsome as many of us would have wished but, as I said at the time, it was a start and it could be amended later. That is what happened. In 2000 the DRC was created. Later the education provisions were improved and other provisions widened. The 2005 Act made further changes and as a result the Disability Equality Duty will come into effect in December of this year. This will require public authorities to promote equal opportunities for disabled people and in doing so to involve disabled people in drawing up policies. Involve is a powerful word. It does not mean just to consult. Involvement is a much greater commitment.

The Act does not specify how to involve disabled people. There might be a role for Scope both nationally and locally. If people with CP, working with other disabled people, can influence policy formulation then the policies will be much more sensitive to the needs of disabled people than many policies current achieve.

We need to ensure than disabled people have the skills to take on this new responsibility. Scope has excelled in helping disabled people through your leadership programmes. We need to ensure than we turn the stream of such people into a river and we need to debate how we achieve that. I recently attended a dinner of senior players and head hunters to discuss ways of taking this agenda forward. I am sure there is a major role for Scope.

We certainly need a new generation of disabled people to assume leadership of the disability community and to lead disability organisations. But we must not limit our horizons to that. We need disabled people in all areas of life to take leadership positions but to know enough about wider disability issues that they can use their influence in a way that promotes the independence of disabled people and the elimination of discrimination.

I think the DRC has played a significant role in ensuring that the DDA was not allowed to gather dust. We have tried to help industry understand the Act and what is required of them. We have clarified the meaning of the Act through a series of high profile legal cases in the Court of Appeal and the House of Lords. On average we support about 50 legal cases a year or around one a week. We have monitored the implementation of the DDA and made recommendations for changes to the legislation, many of which have been accepted and implemented by the Government. I think the impact of our work is beginning to be felt, although another ten years should make a huge difference. However, the DRC will not be here in two years, let alone ten. The Commission for Equality and Human Rights is expected to open its doors in October 2007. So, what are the implications for disabled people and the disability community? What role might Scope consider playing as part of your determination to end discrimination?

The time is past to ask whether the CEHR is a good or bad development. It is going to exist so we need to make it work for disabled people. It will only be able to do that if it works for all the groups of people it is intended to serve. So, we need a strong, vibrant organisation that can provide excellent services but fight as hard for the rights of disabled people as the DRC has done.

It will start with some strong legal weapons. Many of the wrongs experienced disabled people violate their human rather than their civil rights. We see this in social and health care. It cannot be right that disabled people can be forced to live in residential accommodation because that option costs their local social services department less money than it would to support them in the community. The nation would be outraged if this enforced incarceration was imposed on any other section of society than disabled people. Quite rightly, prisoners are given a discharge date from their incarceration but disabled people can be placed in residential homes until they die and never given a release date.

The CEHR will have powers to protect people's human rights and in a complex world we need to ensure that it uses that power to support disabled people as well as other groups would have their rights violated.

The CEHR will be charged with protecting people's rights on grounds of race, age, gender, sexual orientation and belief systems as well as disability. The current equality commissions estimate that the CEHR will require a budget of about £120 million pa but it will receive a budget of about £70 million. It will therefore have to determine its priorities very early. This raises the possibility that disability will receive a lower priority than the DRC has been able to give it. I shall be giving a speech later this year in Northamptonshire on how I think the CEHR might operate most effectively. Today I shall just outline what the DRC has done to ensure that the disability agenda does not suffer and the role that Scope and other disability organisations might be able to play.At the DRC we have had three main strategies. The first is to ensure that we leave a strong legacy and clear sense of direction for the future. We are currently conducting what we call the disability debate and I urge you to take part in that. Early next year we shall publish the outcome of that debate as the Disability Agenda. This will guide the DRC's actions until we are abolished. It will also, I hope, offer the CEHR a clear programme of action that they can inherit and adopt. When the DRC was first set-up we found it extremely helpful to inherit the work of the National Disability Council, under the chairmanship of David Grayson. We also inherited the Disability Rights Task Force Report which did a lot of the ground work for us. Let us hope we can give the CEHR the same start.

Our second strategy has been to seek structures that would enable the CEHR to operate effectively and at the same time ensure it meets the needs of disabled people and involves them in determining their policies. We originally proposed that there should be a review of equality legislation, then there should be a Single Equality Act, and finally there should be a joint commission. For reasons better known to the Government, they did everything in reverse! It explains many of the problems this project has faced.

We then suggested that the CEHR should be structured on a strand based or federal model, so the work on each strand could be guided by the people most concerned. That was rejected but we were able to argue with success that it was wrong to expect disabled people to hand over the disability agenda to non-disabled people. As a result there will be at least one disabled commissioner who will also head a disability committee, half of whose members will be disabled people. The committee will have executive functions and should be able to take forward the work of the DRC as well as developing new activities and contributing to the CEHR as a whole. These arrangements are subject to review in 2012. There will also be a transitional commissioner for a few years from each of the three current equality bodies.

I hope these arrangements will contribute to the success of the CEHR but we cannot be sure. So, our third strategy is to ensure that even if the CEHR is a disaster, the impact on disabled people will be minimised. When we closed our case work service a year ago we enhanced the support that could be given by our helpline so that more people could be helped. We improved our website so it contains much more information to help disabled people to assert their rights themselves. We are arranging for the website to outlive the DRC but I urge you to use it and learn from it. We have also funded DDA legal officers in a number of organisations that offer free legal advice to disabled people. This is to help build up the experience and skills of those organisations so they can support disabled people to bring legal cases when the DRC is no longer here.

To recap: we are setting a future agenda, working hard to make the CEHR effective, but if it is not, ensuring there is external capacity that will be independent of the CEHR and will outlive the DRC.

However, this will not be enough. Even an effective CEHR will not be able to do everything. It will be under funded and under huge pressure. If we are to ensure the end of discrimination against disabled people it will be crucial for voluntary organisations such as Scope to measure levels of discrimination and to produce the research reports that make the case. You will also need to be prepared to support disabled people to bring cases in employment tribunals and the courts. Education and persuasion are important but, as the DRC has shown, some discriminators will only respond to legal action. And, of course, it is sometimes the only way for people to get compensation. I hope the CEHR will fund the expensive test cases that help to clarify the law. But the simpler cases could be taken by voluntary organisations.

The CEHR will have many contacts with the media but it can only highlight a limited number of stories. You, with your media experience, will have a role ensuring that positive stories appear rather than negative ones. We have not yet won the media war. I continue to be surprised at how often non disabled journalists are eager to criticise the DDA and how it is all “political correctness gone mad”. When a village hall closes because no money has been spent it for 50 years it will not prevent the closure being blamed on disabled people and the DDA. It is perhaps a sign of our collective success that disabled people are no longer to be patronised but used as the scapegoat. Fine, let’s be ready to fight back.

I am sure that Scope will continue to provide direct services. They are important. You might expand them and take over services from public authorities. But with the abolition of the DRC I think you also need to continue your campaigning. Poster campaigns are helpful for a number of reasons but I hope we will also see Scope in the courts defending people with CP from discrimination and working with other organisations to ensure that the baton that the DRC passes on is never allowed to fall or falter.

I wish you every success with your battles ahead.

Bert Massie
7 July 2006

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

Presentation by Bert Massie, 3rd International Forum on Disability Management, Brisbane, October 2006

3rd International Forum on Disability Management,
Brisbane, Australia, 8-11 October 2006

Applying Human Rights Principles to Disability Management.

I am pleased to be in Brisbane at this conference to discuss ways in which we can further promote the full inclusion of disabled people into all aspects of society. It is an opportunity to review progress and consider whether we have the right tools in our tool-kits.

In 1995 the UK Government passed the Disability Discrimination Act. I do not intend to discuss the detail of that Act today other than to point out that it drew on the Americans with Disabilities Act and the Australian legislation. These three countries, and many others throughout the world, have based their legislation on the premise that even after rehabilitation, disabled people are held back by various forms of discrimination, whether it be people's behaviour or badly designed infrastructure, laws or regulations. It is argued that if discrimination and barriers are removed, disabled people will be able to compete on equal terms, be able to contribute to society and enjoy the full benefits of citizenship. It is recognised that reasonable adjustments might be necessary to enable barriers to be removed and in this sense an element of positive discrimination is appropriate.

Looking around the world, including the UK, it is clear that this legislation has had a positive impact. In the UK the employment rate of disabled people has risen from 30% to 50%. That is an increase of 66% in ten years. An increasing percentage of our buildings and transport system is accessible. For example, in London every bus and every taxi can now carry wheelchairs users in their wheelchair and a growing number of cities will soon achieve this result. One consequence will be that people with mobility impairments will have improved opportunities to travel to work. We can, with justification, say the Disability Discrimination Act 1995, and its subsequent amendments, has been successful. The question, however, is not whether the Act has been successful but whether it has been sufficiently successful and whether it has reached all disabled people. We must also ask the simple but tough question of whether our current laws are truly giving disabled people control over our own destinies to the same extent as other people.

Although we have achieved an employment rate of 50% for all disabled people, the figure is not so good when we start dissecting it. The employment rate for the rest of the working age population is 80%, so we still have a gap of 30%. The employment rate of people with mental health conditions is just 20% and only a little higher for people with learning disabilities. In one UK survey 30% of employers stated that they would not employ anyone who has a history of mental illness, even though such discrimination is unlawful. This suggests there is still much to do.

One of the features of the Disability Discrimination Act is that we measure the extent to which a disabled person has experienced discrimination by comparing it with how a non-disabled person would have been treated in similar circumstances. In this sense the non-disabled person becomes the comparator. Yet there are many areas of life in which there is no obvious comparator. What do we do about those situations?

Another feature of disability equality legislation in many parts of the world is that before a disabled person can gain redress they must first experience the discrimination.

Compensation, where paid, is in respect of the loss or hurt experienced. How much better would it be not to experience the discrimination in the first place? Could we develop polices that prevent the discrimination occurring?

The Disability Discrimination Act in the UK was recently amended to impose on public agencies a duty to promote the equality of disabled people. This is much stronger than merely not discriminating. They have to take positive action and in preparing their policies and statements they are required to involve disabled people. Involve is a much stronger commitment that simply consulting disabled people. Disabled people must be in at the beginning and not just invited to comment on the final draft. We hope that the Disability Equality Duty will enable public bodies to review all their services to ensure that they do serve disabled people. If services are better for disabled people they are also likely to be better for all people and the DED should therefore be seem as a management tool to improve public services.

There remain other areas of life where the current legislative framework fails to provide the protection that disabled people need. In many parts of the work disabled people receive inadequate support in the provision of health and social care, and the UK is no exception, as our recent report on primary health care for people with mental health issues or learning disabilities shows. Why is the health of disabled people seen as less important than that of non-disabled people? Why does our social care system sometimes force disabled people into residential institutions because it is less expensive than supporting them to live in their own home? Apart from convicted criminals, and in some countries political prisoners, who else is denied the right to family life? In many parts of the world the human rights of disabled people are regularly and systematically violated. The proposed UN Convention on the Rights of Disabled People is an important step in the right direction but it is only a step. The challenge for the future is to extend the acceptance of civil rights into an acceptance of human rights. The right to life. The right to family life. The right to be valued as a unique person in our own right and the right to social support and respect to enable every disabled person to live in dignity and with self respect and pride.

In Europe we have the European Convention on Human Rights, which was incorporated into UK law through the Human Rights Act, and it has been by using this that the Disability Rights Commission has been able to reach beyond the DDA and its limitations. When two disabled young women wanted to challenge the decision of their municipal council to take them into residential care because its health and safety practice entailed a “no-lifting” policy in the home, it was human rights principles and not the DDA that came to the rescue. When a man with a deteriorating impairment wanted to challenge the UK’s General Medical Council guidance to doctors on the withdrawal of artificial nutrition and hydration it was to human rights principles that he instinctively turned for ammunition. And, when a disabled child developed asthma and was effectively denied the necessary ventilation on “quality of life” grounds it was to human rights principles which informed her parents to demand what was needed from another hospital and which enabled them to reach agreement with the first hospital about what had gone wrong.   I find it interesting how many people with no personal experience of disability consider themselves to be experts on the “quality of life” of disabled people.

In the case of the two young disabled women, the senior judge, Mr Justice Munby, was clearly drawn to the human rights principles. He said “True it is that the phrase [human dignity] is not used in the Convention but it is surely immanent in Article 8, indeed in almost every one of the

Convention’s provisions. The recognition and protection of human dignity is one of the core values – in truth, the core values, of our society and, indeed of all societies which are part of the European family of nations and which have embraced the principles of the Convention….The other important concept embraced in the “physical and psychological integrity” protected by Article 8 is the right of the disabled to participate in the life of the community….This is matched by the positive obligation of the State to take appropriate measures designed to ensure to the greatest extent feasible that a disabled person is not “so circumscribed and so isolated as to be deprived of the possibility of developing his personality”.”

If we view the rights of disabled from a human rights perspective we have a set of principles that can form the bedrock for practical measures. Whereas civil rights can seek to create parity with non-disabled people they offer little support when a situation is unique to disabled people and where there is no comparator. The principles of human rights provide the absolute standards which humanity demand we honour for all our citizens. Without such rights we cannot claim with justice to be a civilised society.

If we want the inclusion of disabled people to be more than shallow rhetoric we must thread the concepts of human rights like a golden thread through all our equality legislation and end forever the days when anyone believes it is acceptable that disabled people can be viewed or treated as less than full citizens with all the rights that status implies. This conference can discuss the issues. Disability Management, in the sense in which the phrase is used in this conference, is not just about what can be done to assist disabled people in the work environment. It also involves wider principles concerning the support to give to disabled people to enable them to assert their civil and human rights across the broad spectrum of life’s activities.

Thank you.

Keywords: Disabled people; Human Rights

The CEHR: new beginning or dead end?

Speech by Bert Massie, Chairman of the Disability Rights Commission at Northampton University, 16 October 2006

Northampton University, 16 October 2006

Bert Massie, Chairman of the Disability Rights Commission

I am honoured to give this keynote speech at your annual One World Week within the University of Northampton and to support the very good work of Paul Crofts and Judith Glashen within the Equality and Diversity Unit here.

I am not a complete stranger to Northampton. It was my pleasure some years ago to address the Northamptonshire Guides Association on the topic of the International Year of Disabled People. I mentioned in passing then that over the years it had always struck me that the guides did rather better than the scouts when it came to food at summer camp. Although denied admission to the guides for fairly obvious reasons, I was touched to be presented at the end of my talk with a girl guides badge and honorary membership. I hope you won’t think my equality and diversity credentials are scotched for ever if I reveal to you now that I have always lived in fear of being asked to wear the full uniform.

I am especially pleased that by inviting me today you have acknowledged how central a place disability rights now have in the equality and diversity field. Even 10 years ago that would not have been the case. The DRC itself has of course been around only since April 2000, and the Disability Discrimination Act (the substantive law in this country on disability rights) did not see the light of day until 1995. You might just about remember those last days of the Major government, when William Hague, destined for greater things, was the Minister for Disabled People with responsibility for the Bill. It seems like another era, and yet it means the DDA is little more than a decade old. Compared to the laws on gender and race, which go back to the 1970s, this makes the DDA something of a late developer.

Of course the DDA was far from the start of the story. For at least a generation or more, disabled people had been fighting for legal recognition in this country. When that recognition finally took legislative reform, it was shaped by a wide range of factors – social, political, and jurisprudential. At the social level, there had been a huge shift in the post-war period away from approaches to disability that concentrated on welfare, and towards a new 'social model' that put the emphasis on the shortcomings in the social set-up instead of the physical or mental impairment of the individual person. As a result, the plight of disabled people began to elicit indignation rather than pity, and the language of rights replaced the language of charity as the dominant medium.

I like to think that a major catalyst was the success of the Vietnam veterans in putting disability on the civil rights agenda in the USA in the late 1960s. Certainly, it was the Americans with Disabilities Act 1990, more than any domestic or European legislation, that gave new impetus to the political struggle here in the 1990s.

When it finally emerged, the DDA showed all the signs of the political buffeting that were so typical of the uncertain years spanning the eclipse of Thatcher and the epiphany of Blair. A medical definition of disability, a relatively low threshold against which discriminators could justify their discriminatory acts, and a myriad of exclusions (from education to transport, private clubs to the uniformed services) left many disabled activists feeling distinctly dismayed.

Yet amidst the political compromises the DDA retained a jurisprudential pearl of true value in the shape of the distinctive provisions on ‘reasonable adjustments’. These provisions were more or less a straight lift from the ADA. There was nothing like them in any other domestic or European legislation. In fact, in the beer tents of Europe, legal nerves still jangle at the mention of reasonable adjustments, with their hint of positive or affirmative action, the bugbear of US academia in particular. If equality means treating people differently, not the same, where does that leave all our much-cherished equal treatment legislation, so carefully honed since the 1970s? For that matter, where does it leave Western Civilization if not teetering on the brink of a Dante-esque precipice sign-posted, ‘Abandon all hope, all ye who enter here: political correctness gone mad, this way’? Political correctness gone mad is a term used by journalists who are too idle to look deeper into a story.

Of course, the answer was that it left us in rather a better place than before, especially if you were disabled. And since something like 10 million of us in this country already are disabled (or if we’re not, we probably will be some time quite soon, unless we die before we make it that far), that means just about everyone should have an interest in this stuff. Let’s face it: when even the judicial bench of the House of Lords gets it, you can be pretty sure that the walls of the political establishment are hardly likely to fall around our ears any time soon. It was Baroness Hale (so nice these days to have law lords called Brenda) in the leading case of Archibald v Fife Council (DRC-funded and run, I hasten to add) who put it so eloquently and so bluntly:

[In the cases of the Sex Discrimination Act and Race Relations Act] men and women or black and white…are opposite sides of the same coin. Each is to be treated in the same way. Treating men more favourably than women discriminates against women. Treating women more favourably than men discriminates against men. Pregnancy apart, the differences between the genders are generally regarded as irrelevant. The 1995 Act [the DDA] however does not regard the differences between disabled people and others as irrelevant. It does not expect each to be treated the same way.

In essence that's the concept of reasonable adjustments. Now whilst this might not exactly leave all right-minded people quaking in their boots, the notion of reasonable adjustments does draw a potentially radical sting. In a legal context, it invites an approach to equality that is not so much about neatly symmetrical processes and results as something far more valuable and elusive: being allowed to feel you count because you have a worthwhile part to play and a realistic chance of playing it. In a broader, extra-legal context, it challenges our notion of citizenship, of what it is to be an active member of a democratic society. And of course that in turn challenges our notion of what it is to participate in civil society itself, in all those institutions that lie outside the reach of the political State, from professions to youth clubs, bingo halls to, yes, even the girl guides.

Of course, this apparent celebration of 'difference' looks like bad news for a political class that is increasingly inclined to ditch multiculturalism, to nail its colours to the mast of a common culture based on values that are thought to be quintessentially British and a final bastion against the havoc wreaked on geographical and cultural insularity by an ever-encroaching tide of globalisation. Where Hitler, Napoleon and Phillip II of Spain failed, the Web and the global market have surely succeeded. Multiculturalism for disabled people is not dead. It is very much alive and it must influence future policy. Broad brush policy can easily overlook the needs and aspirations of disabled people.

Certainly when the idea of the CEHR was first seriously floated in 2002 by the then Minister for Women and Equality, Barbara Roche, and the DRC had the temerity to assert that ‘disability is different’ (not completely different in every way, but significantly different in some important ways), when we responded to this vacuous paper it invoked the disdain of the political establishment, itself by that stage disenchanted with what it saw as identity politics and favouring instead a new drive towards what it politely called social cohesion and what others impolitely pilloried as compulsory assimilation to a white, liberal, Anglo-Saxon norm. The DRC’s campaign to make sure that a new single equality body (or CEHR, as it soon became) was at least as good for disabled people as the DRC looked to some like special pleading, a reversion to the now unfashionable identity politics, an unfortunate manifestation of self-interest on the part of those disabled people who should know better, be grateful for what they already had and not spoil the show for all those others who simply wanted ‘to get along’ together. Just like in ‘Alice in Wonderland’ everyone got prizes, even though no prize was worth having.

The trouble is that the track record of those others in letting disabled people just get along together is really not that great. In the admittedly rather parochial world of comparative quango studies, the lessons from Australia and closer to home in Northern Ireland have not persuaded disabled people that integrated equality bodies often leave the disability agenda with a fair slice of the organisational cake. I have just been in Australia and New Zealand visiting the equality commissions there. The disability representatives there think that we are mad getting rid of the DRC. They believe that they could achieve more with a strong ‘DRC-like’ component within their commissions. That’s why the DRC pressed so hard for (and got) an Equality Act that requires the CEHR to have at least one disabled Commissioner on its Board, a

Disability Committee for at least five years (perhaps much longer) with a majority disabled membership, and enough money and staff for the Committee to do its job properly. Those protections were the essential condition of the DRC's continuing support for the CEHR. Any last-minute government reneging on that would be nothing less than a flagrant breach of faith – in which case, 'I predict a riot' (as they say), always assuming Part 3 of the DDA is working well enough to let disabled people get out on to the streets in the first place. This message is not just to the Government, but also to the leadership of the CEHR.

But it's not just quangos that have ostracised disabled people; it's everyone else too. Let's look at a few facts. 9 out of 10 people with a learning disability come across harassment and bullying as a regular feature of their daily lives, whilst 8% of all disabled people in London suffered a violent attack in 2001/2 compared with 4% of the non-disabled population. The impact on daily life can be huge: 1 in 4 disabled people live in fear, too scared to go out in the dark, compared with 1 in 10 non-disabled people; and a third have had to avoid specific places and change their usual routine; 1 in 4 has gone so far as to move house as a result of an attack.

When the government published its 'big design' for children and families called 'Every child matters', a consortium of disability organisations was moved to respond with a campaign called 'Every disabled child matters'. We know for example that families with disabled children are 30% more likely to be in temporary, poor or over-crowded accommodation. Conversely, the Child Poverty Review found that 25% of children living in poverty have parents who are long-term sick or disabled, and in almost 70% of households with children where both parents are not working, at least one parent is disabled. The Government talks about abolishing child poverty but this can not be achieved without tackling disabled child poverty. The Government will fail to meet their targets if they do not take disabled people's needs into policy decisions.

When it comes to education, things are just as bad: at 16, disabled people are twice as likely not to be in any form of education, employment or training as their non-disabled peers (15% compared to 7%); 21% of disabled people aged 16-24 have no qualifications compared to 9% of non-disabled people of the same age; and young disabled people are only 40% as likely to go into higher education at 18 as non-disabled 18-year olds. To an extent, some of these figures can be explained. A student with a severe learning disability may not be expected perhaps to go to university. However, how many colleges are there in this country that are still physically inaccessible? From examples such as these, you can begin to draw out the conclusions.

And that conclusion is stark: across the board, whether it's in paid employment or voluntary service, public appointments or access to health services, school or further and higher education, disabled people are consistently at the sharp end of things, to be found wherever the going is toughest and the life chances skimpiest. This is the reality for many disabled people and their families in this country now. They would love just to get along with everyone else, but they simply don't get the chance.

Now perhaps you can see what the government at first did not see in 2002 with its initial blueprint for a CEHR: of course the DRC cannot simply allow itself to disappear without trace and without an unalterable guarantee that the CEHR itself will carry on the good work on disability. This was not an ideological stance, a politically inspired manoeuvre or a Machiavellian plot: it was plain common sense. If disabled people are to get along with everyone else, we must be given the chance to join in on terms that give us a fair crack of the whip. And having a fair crack of the whip will in the end be about not just organisational design or governance structures within the CEHR; more than that, it will be about the ability of the CEHR to deliver on a disability agenda that contains 10 distinct priorities for action.

Let me spell out those priorities now so no one is in any doubt:

- Increasing disabled people’s active participation in public, civic and community life
- Closing the employment gap, including a successful outcome on welfare reform
- Ensuring no one is obliged to live in an institution or in a particular living arrangement against their will.

Why does our social care system sometimes force disabled people into residential institutions because it is less expensive than supporting them to live in their own home? Apart from convicted criminals, and in some countries political prisoners, who else is denied the right to family life?

- Securing rights and entitlements which facilitate independent living across the life course
- Creating safer communities by tackling hate crime, harassment, bullying and negative stereotypes
- Improving disabled people’s housing rights, opportunities and conditions
- Ending child poverty, disadvantage and other barriers to children’s and young people’s life chances
- Enhancing vocational and personal skills
- Tackling health inequalities

The DRC has just published a study for on the primary healthcare of people with mental health problems and/or a learning disability. We looked into why members of these groups are dying younger than other members of society, and dying from curable diseases. We looked into 8 million health records and found that many people are unable to even access the services and once they do are often victims of 'diagnostic overshadowing' or not offered the same kind of tests as other patients.

> Ensuring that future legal and institutional arrangements on equality and human rights really do secure disabled people's rights.

It is to an aspect of this last priority (the institutional set-up) that I now want to turn. What will it take for the CEHR to deliver the goods not just for disabled people but for everyone else whose life might be enriched by living in a world that takes equality and human rights seriously? Because let's make no mistake about it, we are all in this together. The fact that disability is indeed 'different' does not in any way detract from the reality that what is good for disabled people will almost invariably be good for us all. If the CEHR cannot serve disabled people, it stands little chance of serving anyone else properly in the long-run either. Conversely, it matters to disabled people that it does the business on human rights, race equality, sexual orientation and all the rest, since disabled people are just as much touched by injustices in these areas as anyone else. Disabled people too have a race, a belief, a sexual orientation.

There are three critical things which must happen if the CEHR is to stand a chance (and let's be honest, even after four years of planning, the jury is still very much out on whether it's going to make it): first the CEHR must be 'owned' by the right people; secondly, it (and everyone else) must know why it is there; and thirdly, it must know what it has to do and how to do it. This much is obvious. Yet finding shared answers and then making it happen are endlessly elusive tasks.

So, first of all, who should own the CEHR? I don't mean which individual personalities should hold the purse strings, design and sell the strategy (although, heaven knows, that issue has generated enough heat and smoke already). What I mean is, whose interests must be paramount in setting priorities, in determining what the CEHR gets up to, in setting the tone for its way of going about things? The answer seems to me to be obvious (and I here I draw quite deliberately and literally on the purposive clause in the Equality Act itself): the CEHR must first and foremost be for those whose ability to achieve their potential is most strikingly limited by prejudice or discrimination; those individuals whose human rights, dignity and worth are least respected; those whose opportunities to participate in society are most seriously curtailed; those groups who suffer most from the lack of mutual respect and understanding that are so essential for a society that seriously aspires to value diversity and achieve shared respect for equality and human rights.

That has a number of consequences. It means that those with non-executive positions on the Board (in other words, the Commissioners) cannot just be representatives of special interest-groups but insiders with the experience and insight to listen attentively to what people on the street tell them, to understand the nuances of the grass-roots movements that can claim with some legitimacy to be the real representatives of those who are marginalised, and the ability to translate those messages into action that is independent and authoritative yet so in touch with its roots that it does not quickly lose its salience and all too soon look like betrayal. To put it in quango-speak, what this means is that the CEHR must be 'consultative'; it must find ways of including in its plans all those who are least likely to find their way to the negotiating table on their own; it must recognise that its 'stakeholders' (more quango-speak) are more than just the usual suspects. It is this sort of approach that has led the DRC to consult extensively on its plans and projects, to set up advisory groups on mental health, on learning difficulties, on neuro-diversity, and on BME issues, as well as keeping in close touch with the major organisations of and for disabled people, whilst providing space for the expertise of its own Commissioners to blossom.

It also means that those with executive positions (in other words, the staff) must have or very quickly acquire the expertise to speak the language of the marginalised, whilst retaining the ability to influence the powerful and win the political support without which the CEHR will be stranded and ultimately impoverished, both literally and metaphorically. A generation ago, the shaping of public policy might not have been a priority. Those naïve days have gone and the need for the CEHR to be a serious political player is plain for all to see. That takes expert knowledge not just of equality and human rights, of disability and gender, race and religion, but of the ways of Whitehall and Westminster, of Holyrood Palace and the Welsh Assembly, of the political and popular media in all its increasing variety.

And here is the sting for the CEHR. Whilst the DRC, and no doubt the CRE and EOC too, have worked long and hard to cover both bases, to win grass-roots support and sustain political commitment, the CEHR project is notably devoid of both. I challenge you to find any grass-roots movement clamouring for a CEHR in the way the disability movement demanded the DRC. On the contrary, grass-roots BME and other organisations have largely been conscripts to the entire process, at various stages threatening to strangle the thing at birth or even at conception. And when did you last see a Cabinet Minister or other senior member of the Government capture the headlines by championing the CEHR and actually mean it?

Secondly, if it is owned by the grass-roots but with the benefit of high-level political commitment, the question of purpose answers itself. The purpose must be to achieve social change of a sort that will significantly benefit those who are marginalised, denied opportunities, subjected to prejudice and exposed to human rights abuses. There may be a business case for doing the right thing, and there may even be businesses which need to hear it before they are stirred into action. There will certainly be laws to enforce against those who remain oblivious to any case for change, whether business or otherwise. But none of these things can be an end in themselves. A predominantly ‘service’ ethos which sees its ‘stakeholders’ as ‘customers’ (however defined) will simply miss out much of what the CEHR needs to be about. This cannot be just another piece of government machinery, inward-looking, dogged by crudely quantitative measures of value. Yes, of course it must be effective and efficient, responsive to individual need wherever possible, alert to whatever the next phase of ‘modernisation’ throws up in the way of managerial vogue. But the day any of this becomes detached from its broader purpose, an end in itself, will also be the day the game is finally up for the CEHR. Success for the CEHR will not be about press headlines but will be about impact, real and beneficial impact in the lives of those who have most to gain and least to lose, impact that is seen as such by those on the receiving end. Anything less will be a scandal.

Thirdly, and very much linked to this, the CEHR must know what it is doing and do what it knows best. Of course it must provide uniquely authoritative and compelling advice and information, produce codes of practice and other practical guidance, support litigation and other legal interventions, but it will do none of these things as ends in themselves but instead as means to a larger societal end. The CEHR can never afford to become just a service-delivery machine, a processor of claims or a producer of leaflets. It must use its distinctive powers in a way that only it can to mobilise the forces of change and produce results on the ground. Again to resort to quango-speak, that means the CEHR must be ‘strategic’ in all that it does, not to the exclusion of all opportunism and the ability to react swiftly and incisively when necessary. But if it’s not too paradoxical to say so, the CEHR must be strategically opportunistic, alert to opportunities to maximise impact, a close reader of the signs of the times, whatever form they take.

Let me point to developments that have emerged since Barbara Roche’s announcement in 2002 and which already suggest something of the way in which the CEHR will need to go about its business. First of all, there is the proliferation of public sector duties which effectively turn discrimination law on its head, shifting the emphasis from supposed ‘victims’ and individualised forms of remedial redress to potential perpetrators and collective prevention. We have had the Race Relations Amendment Act since 2000, with its public sector duty on race as a response to the Stephen Lawrence report. Something similar on disability will come into force in December this year as part of the amended DDA. The Disability Equality Duty will impose on public agencies a duty to promote the equality of disabled people. This is much stronger than merely not discriminating. They have to take positive action and in preparing their policies and statements they are required to involve disabled people. Involve is a much stronger commitment that simply consulting disabled people. Disabled people must be in at the beginning and not just invited to comment on the final draft.

And now as part of the CEHR’s Equality Act, the government is introducing a public sector duty on gender too. It can only be a matter of time before the scope is extended even further, no doubt as an integral part of any single equality act initiative to which the government has also belatedly, but sensibly, turned its attention with its current Discrimination Law Review.

Secondly, there is the rather late, some would say reluctant, inclusion of human rights within the proposed CEHR domain, the promotion of a new ‘human rights culture’ emerging as a frontrunner as the informing ideology of the new institution. The precise theoretical linkage between equality and human rights is contentious, but one example of what it means in practice can be gleaned from those human rights cases which touch upon disability rights, cases heard in Strasbourg and since the Human Rights Act came into force in October 2000 in this country too, cases about the participation of disabled people in social and cultural life, about the provision of health and care services, about equality and human rights as they touch upon matters quite literally of life and death for disabled people. What is striking about these cases is the way they articulate what commentators have called the ‘third wave’ of human rights thinking: not so much the ‘negative liberty’ enshrined in the individualistic eighteenth-century first wave with its ‘keep out’ notices to Church and State, or even the more communitarian second wave associated with the 1948 Universal Declaration of Human Rights, but instead the European Convention’s emphasis on the positive duties imposed by Article 8 (the right to private and family life) and Article 3 (the prohibition on inhuman or degrading treatment), duties which ensure that disabled citizens are not prevented from developing their own personalities, from developing social relations and from engaging in society more generally as equal citizens. The point was well put by the judge (Mr Justice Munby) in the recent East Sussex case on manual handling regulations in which the DRC intervened. In addition to emphasising the centrality of the concept of ‘human dignity’ to the ECHR, he remarked that ‘the other important concept embraced in the ‘physical and psychological integrity’ protected by Article 8 is the right of the disabled to participate in the life of the community...This is matched by the positive obligation of the State to take appropriate measures designed to ensure to the greatest extent feasible that a disabled person is not ‘so circumscribed and so isolated as to be deprived of the possibility of developing his personality’.

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

Since I am privileged to speak to you today in a place of learning, let me by way of conclusion inject a little academic flavour. Where will all this position the CEHR in the debates about equality and diversity, multiculturalism and diversity? Academic commentators talk of there being four models of equality. First and most familiarly is the individual justice model, with its emphasis on redress for individual victims of irrational prejudice and disadvantage. Here the keyword is ‘discrimination’ and of course this is the model that lies behind the gender and race legislation of the 1970s. Second is the group justice model, with its recognition that there is a social dimension to inequality, that individual instances of ‘discrimination’ are embedded in social practices and institutions and so inform the experience of entire groups of people who share a common fate of social disadvantage, and here the keyword is ‘redistribution’, redistribution that is of social goods and benefits. Third is the identity model, which recognises the cultural dimension of disadvantage and seeks to remedy the experience of cultural exclusion by celebrating diversity and embracing difference, and here the keyword is precisely ‘diversity’ as the cornerstone of multiculturalism. And finally there is the participatory model, with its emphasis upon social and civic inclusion and the recognition that the achievement of flourishing individual persons and groups entails their ability to participate in the dance of a fully integrated social life, and here the keyword is ‘participation’, the rather Olympian notion that it’s the taking part that really counts.

Clearly there are tensions between these four models and it would be rash to argue that any one model captures all the richness that the concept of equality denotes. Indeed elements of all four models are ever-present in actual debates about public policy. But if I had to pick out the two that come closest to what I see as the spirit of the CEHR project, I would choose redistribution and participation. It is the linkage between these two models that grounds the government vision of a new human rights culture that can in turn disclose a truly participatory experience of citizenship. It is also this linkage that transcends the more limited notions of discrimination and identity. I suggest that if that vision is to be turned into practice the distinctiveness of disability rights must play a pivotal and vitalising part, sitting as they do at the crossroads between the old and the new. In that way the role of the CEHR as a guardian of equality and human rights legislation, and as a resource for the effective mobilisation of the law (not just its enforcement or promotion, the one at the expense of the other), will stand the best chance of realising the sort of social change, refreshed configuration of citizenship and new culture of human rights that the underlying vision so prizes.

There has been much talk of ‘the light touch’ approach to regulation that will underpin the CEHR’s work. If that light touch is not all too rapidly to make the CEHR a soft touch, we must finish the job on disability rights, and finish it in

such a way that not just disabled people, but indeed all people, disabled or not, can reap the considerable rewards that lie uniquely in that direction. Anything else would be to squander a once in a lifetime opportunity that the CEHR presents. The CEHR will be a new body that seeks to promote the equality of opportunity and human rights, to challenge discrimination and promote citizenship and social cohesion, but its success is not guaranteed. If it does fail, the work that the DRC and the other Commissions have been doing will be imperilled. Thus, the CEHR will only work if we all try to ensure its success. That is the challenge awaiting all of us.

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

Participation - Have we got an attitude problem?

Speech by Bert Massie to the National Disability Research Conference, Dublin, 16 November 2006

Introduction

Rudyard Kipling said it matters not whether you win or lose in the great game of life, it’s how you play that game.

But for many disabled people, just getting the chance to participate at all is the problem.

I believe that attitudes to disability are the major barrier to disabled people’s full participation.

From pity, awkwardness and fear to low expectations about what disabled people can contribute, stereotypical and negative attitudes hold people back.

We often see the impact of negative attitudes in how one person treats another. But negative attitudes are also the foundation stone on which disabling policies and services are built. Harmful attitudes that limit and restrict are institutionalised in policies and services and so maintain the historic disadvantage disabled people have faced.

I’m going to talk today about the nature and the impact of these harmful attitudes and how they restrict disabled people’s participation.

In doing so, I do not intend to imply that changing attitudes simply through educating or persuading people to think differently is the sole answer to increasing disabled people’s opportunities to play their part. Campaigns of that kind play their part and the Disability Rights Commission has invested in them.

However, they are only part of the solution. As Martin Luther King put it, we cannot legislate for what is in people's hearts but we can legislate for what they do about what is in their hearts.

Because negative attitudes have tended to infect law and public policy, changes to law and public policy are also needed to deliver the future that we want.

That vision of the future is summed up by the DRC in our mission statement:

The creation of a society where all disabled people can participate fully as equal citizens.

There are three main tools that the DRC has chosen to deliver that future: influencing change to law and policy; strategic use of litigation; and leading thinking on disability away from negative assumptions and stereotypes towards the concept of disabled people as equal citizens.

I will talk in turn about each of those tools for change.

Attitude Problem

But first I want to talk about the nature and the impact of the negative attitudes faced by disabled people.

The National Disability Authority's survey of attitudes to disability in the Republic of Ireland conducted in 2001 found that large numbers of people in Ireland identified some prejudice against disabled people. For example, just 42 per cent thought that people with mental health difficulties are treated fairly. And the British Social Attitudes Survey of 2000 found that 35 per cent of the respondents think there is 'a lot' of prejudice again disabled people; 51 per cent think there is 'a little' and only 3 per cent think there is 'no' prejudice in the society.

Yet, few people are willing to admit that they themselves are prejudiced and so it is difficult to measure. However, evidence from different scenarios – from the classroom to the bus stop - illustrate a wide range of unhelpful or aggressive attitudes towards disabled people, which often vary according to type of impairment or health condition, and according to ethnic origin, age and gender.

They include harassment; sometimes misplaced and stifling pity or admiration; perceptions of low competence and being an economic drain; and fear that the person will harm themselves or others.

For example, people with significant disfigurement or amputations have to deal with others' awkwardness. People with HIV encounter ill-informed fears of 'catching something'. People with mental health problems are viewed as unreliable, unpredictable, lacking judgment and potentially dangerous.

But possibly the most damaging consistent response to disability is simply the low expectations that we have of disabled people and for them – and, as a consequence, that many have for themselves.

We don't expect that people with significant levels of impairment will work, so when such people present themselves for a job, the experience is novel and employers naturally worry about their productivity; the likelihood of lots of sick leave; whether they will disrupt normal working practices; or put the customers off.

Of course the expectation creates the reality – the apparent absence of disabled people from board rooms and public life fosters low aspirations and expectations. 'How could I ever climb that high?' This is both because people who have obvious visible impairments often aren't there and because people with invisible impairments have the rather dubious luxury of hushing it up. But at what personal cost?

Yet inequality for other social groups – the pay gap, the ‘male and pale’ nature of most corporate boardrooms – is pretty universally now seen as socially constructed; the product of historic disadvantage and prejudice. Not as something that is an inevitable consequence of being female or black.

While the disability movement has made relatively rapid progress in the past 30 years in extending this approach to the issue of disabled people’s disadvantage, my suspicion is that the argument is by no means yet won.

People may say the right thing nowadays but I suspect that the unspoken assumption is still that disabled people should just not expect the same outcomes as others - because they, or indeed we, are flawed as individuals. It isn’t really worth investing in levelling the playing field – if you are disabled you just are going to lead a limited life.

If we do not recognise the circumstances that disabled people find themselves in as avoidable, caused by the way the world has been organised, we do not respond to them in this way. We apply minimum standards to compensate for the tragedy of disability. We do not respond with outrage in the way that we would if someone who wasn’t disabled faced the same set of circumstances.

How else can one explain a doctor placing a ‘do not resuscitate’ notice at the end of a disabled person’s hospital bed without their knowledge?

Or a judge granting permission for a disabled woman to be sterilised without her consent?

A couple who have lived together for 50 years forced to live apart because one of them needs support with the dressing and eating?

I sometimes describe the lack of outrage at these situations as ‘lazy fatalism’; an unthinking acceptance or complacency about the inequality that disabled people face. And in some ways I think this lazy fatalism or complacency is the most damaging attitude of all.

Despite recent developments, society still sees its best response to disability as care, welfare and charity - rather than equal rights, opportunities to participate and citizenship.

Our instinct is still to protect people. To absolve them of the responsibilities that other citizens have – as workers, earners, parents, civic and political leaders.

But in ‘protecting’ people we institutionalise dependency and we send a powerful message to those we seek to protect that we expect very little of them. How, then, can they expect much of or for themselves?

Sometimes this protective approach is motivated by a sense of compassion.

At other times it is an overt lack of confidence in disabled people’s abilities - for example in a particular job or to be a good parent - or because we are trying to protect ourselves or others.

Sometimes it is even motivated by a sense of social justice: we cannot expect disabled people to work and make other contributions to family and public life until all the barriers have been brought down.

But in thinking we are letting people off the hook in this way, we overlook the impact this has on expectations.

If we take the attitude that disabled people should be expected to participate in the ordinary activities of life, and, with support, to make the contribution they can, we put in motion the beginnings of the very participation that can help to transform that lazy fatalism. Demonstrate the achievements of disabled people large and small. And raise expectations among disabled people themselves - of what they can experience, achieve and contribute.

What impact does lazy fatalism have on disabled people themselves?

Does it make them lower their sights? Hide aspects of themselves? Miss out on adjustments and support that could help them to reach their full potential?

I suspect that all too often low expectations of people’s capacity to participate saps confidence and self esteem and affects how people behave. As a result of fear of prejudice and discrimination, for example, many people with mental health conditions and people with HIV keep silent about their condition.

The term ‘time immemorial’ might have been invented for the historic segregation of many disabled people, through being educated separately, through worklessness or segregated housing. And when asked what comes to mind when people hear the term “disabled”, it is a very narrow image of isolation and dependence. As the Irish playwright Brian Friel said: “It is not the literal past, the ‘facts’ of history, that shape us, but images of the past embodied in language.”

As a result, many disabled people do not enjoy a strong sense of connection to the wider community. Some are acutely isolated – in separate places of learning, work, recreation or living.

Many people with learning disabilities, for example, have few non-disabled friends. People with severe and enduring mental health problems and learning disabilities are at particular risk from physical or verbal abuse. What does this do to their social skills? Their capacity to interact with others, particularly people they don’t know well? Once again, the danger is that poor communication skills and unusual behaviour are put down wholly to their impairment or health condition.

I’ve already said that while some of us have little chance but to announce our disability status to the world, where people can they often hide their condition.

There are people who qualify for protection under the British Disability Discrimination Act who go to work every day terrified to reveal aspects of their identity, for fear of being found out and losing their jobs.

Every day there are disabled people who are found out and lose their jobs. Since last December, when the law changed to protect people with cancer against discrimination from the point of diagnosis, the DRC has received two calls a week about problems at work, with cancer survivors being sacked and refused time off for treatment.

There are a million young people in Britain who are not in any form of employment, education or training. Disabled 16-year olds are twice as likely to be in this position as their non-disabled peers.[1]

What does the future hold for them? And if they’re not at work or at college, what are they doing?

By age 26, young disabled people are more than three times as likely as other young people to agree with the statement: “Whatever I do has no real effect on what happens to me.” Initiatives aimed a promoting social responsibility and active citizenship are more likely to characterise disabled people as objects of volunteering, rather than participants.

Does this depressing figure have anything to do with the fact that 60 per cent of those referred to youth offending teams have special educational needs?[2] It's easy to see how low aspirations and a lack of opportunity shapes behaviour and becomes a self-fulfilling prophecy. Why would you want a young disabled person on your course or in your workplace? They're trouble aren't they?

Attitudes institutionalised in policies and services

I have already mentioned that I believe negative attitudes are not just a matter affecting how one individual behaves towards another. I believe that they infect and are institutionalised in policies and services.

For example, black people with mental health problems are eight times more likely than the overall population to be in high security psychiatric hospitals. Evidence suggests that this is because of service providers' stereotypical fears of people being "big, black and dangerous" and that black people fear services and so miss out on early intervention.

Parents are routinely expected to have a termination in the case of a positive test for Down's syndrome.

Social service cultures are risk averse: they would rather try to avoid any risk at all to people deemed 'vulnerable' than ensure lives of dignity, choice and independence. As a result, many people have no choice other than to live in institutions.[3]

Rehabilitation services fail to suggest that those who experience strokes or other sudden onset of disability will ever work again.

And adult learning services in Britain, according to a recent inspectorate report, see "compassion . . . as not only sufficient, but as a justification for restricting ambition and growth”.[4]

The DRC has recently published a study on the primary healthcare of people with mental health problems and learning disabilities in England and Wales. We looked into why members of these groups die younger than others and die from curable diseases. Looking at 8 million health records, we found that many people are unable to get basic access to services and once they do their physical health conditions are often dismissed as “all in the mind” and they are not offered the same kinds of tests and treatments as other patients.

Since 1997 in Britain there has been an increase of 20 per cent in admissions to residential and nursing care for younger people with a learning disability; and 40 per cent for people with mental health problems.[5]

Looking at the attitudes within the healthcare system – policy-makers and service-providers – the DRC concluded that there is an overriding complacency about the poor health of people with mental health problems and learning disabilities. The prevailing view is that they “just do die” younger – and perhaps the unspoken assumption is that this really doesn’t matter very much. Not so much lazy fatalism and fatal fatalism.

Yet disabled people are underrepresented in the public sector, particularly in strategic and management positions. They are underrepresented where decisions about policy and service provision are taken.

And despite the considerable achievements of disabled people in developing voluntary organisations, people who are disabled or have long-term health conditions officially constitute only 6 per cent of formal volunteers and around 4.3 per cent of public appointments in Britain. On the whole disabled people are not in the places where decisions about policies and priorities are made.

Lazy fatalism on disability holds us all back

And assumptions about disability don't just affect disabled people themselves. For example, we continue to assume that support for older and disabled people can rely on the unpaid work, provided overwhelmingly by their female relatives.

This position is not sustainable when we consider the challenge of an ageing population, where many women are choosing to live alone or not to have children - and where not being in full-time paid work can mean being trapped in poverty.

Change and Responsibilities

So, the disadvantage disabled people experience is rooted in low expectations; this is institutionalised in our services and there is inertia - the lazy fatalism I have talked about. This affects not just disabled people but their families indirectly.

What can we do? How can we tackle such low expectations head-on? How can we remodel public policy and services to break this cycle of actual second class status, feeding low expectations, maintaining second class status?

The impact of legislation

When I and others were campaigning for the UK's Disability Discrimination Act in the 1980s, the standard response was that a law wasn't necessary to deal with the problems disabled people faced. If discrimination existed, it was based on individual prejudice and education and persuasion were the answer.

I have mentioned Martin Luther King's pretty trenchant views on that point already.

The DDA and its enforcement have a crucial part to play in promoting participation and indeed in transforming attitudes.

The Disability Discrimination Act is an increasingly strong piece of legislation and it has a crucial difference from other forms of anti-discrimination law.

The Act's approach is to recognise that equality is not about treating everyone in the same way. It is about responding to different needs in the different ways that best suit them.

The DDA is not about equal treatment, because to treat everyone the same is to ignore their essential differences - with the perverse effect of creating or sustaining inequality.

It can take different treatment to provide equal opportunities.

This notion of what's called by the legal academics a substantive form of equality has guided the evolution of disability rights.

It is why our anti-discrimination laws in relation to disability require employers, service providers and educational institutions to make adjustments both at the individual and institutional level.

This approach is being usefully augmented in Britain next month by new positive duties on the public sector to actively eliminate discrimination and to promote equality for disabled people. The duty means that public authorities must work to promote equal opportunities for disabled people; must promote positive attitudes towards disabled people; and must support disabled people’s participation in public life.

And when I say “support”, fortunately, I do not mean simply saying that these are good things. No. Public authorities will need to publish action plans that show exactly how they are going to deliver these things. Potentially a very powerful tool to create change.

They must involve disabled people actively – participation is another word for it – in setting priorities and targets, not simply consult with them.

Human rights

They DRC has also used Britain’s Human Rights Act to challenge the policies built upon low expectations and low estimation of the value of disabled people’s lives.

For example, we supported Les Burke, who has cerebella ataxia, when he challenged the General Medical Council’s guidelines on withholding and withdrawing artificial food and water in a judicial review under the Human Rights Act in 2004.

Les was concerned that his condition meant he would reach a stage where he was no longer be able to swallow or talk and could lose capacity for decision-making. At that point, doctors could decide to withhold or withdraw food and water. He could die of starvation and dehydration and be aware of what was happening to him.

The court of appeal in 2005 upheld the right of a competent patient to autonomy and self-determination. It emphasised that disabled people should be “treated properly and in accordance with good practice and that they will not be ignored or patronised because of their disability”.

The DRC also intervened in a case against East Sussex County Council that demonstrated how policies and services institutionalise lower expectations for disabled people. The case involved two disabled women affected by the introduction of the council's blanket ban on care workers manually lifting and disabled or older person. The court emphasised the need for a balanced approach to health and safety and the avoidance of a "no risk" regime.

So we can challenge the attitudes that limit participation by using the law and by shaping public policies and services in ways that liberate potential and root out historic, entrenched disadvantage.

Cultural change

That is what I meant when I said that changing attitudes is a means to an end but that education and persuasion through exhortation are not the only means to that end.

Cultural change can only be achieved through challenging low expectations and aspirations by promoting actual active participation by disabled people in all aspects of public and private life. Not just by demanding that it must happen but by demonstrating that it can be done and celebrating when it is.

When we look at major figures in public life who have experienced disability or poor health, until very recently, if they could, they hid that fact away. The US President Franklin D Roosevelt was only ever photographed in ways that hid the impact of polio. Kennedy's disabling back condition was hidden. Churchill's depression - hushed up. When Tony Blair's heart condition became national news, it had to be played down – and we had the dubious pleasure of being entertained and informed by footage of him working out in the gym.

Instead of just telling people to change their attitudes to 'let in' disabled people to play their part, we can equally consider how engineering participation in families, organisations and communities changes attitudes.

Where there is evidence on what changes attitudes, it centres on the impact of contact between disabled and non-disabled people. This seems to work more than any other method – more, for example, than big communications campaigns. However, contact must be on at least equal terms.[6]

It is nearly 50 years since Gordon Allport published 'The nature of prejudice', where he expounded the 'contact hypothesis': "Merely by assembling people without regard for race, colour, religion, or national origin, we can thereby destroy stereotypes and develop friendly attitudes".

And Miles Hewstone recently conducted analysis based on 516 studies to determine whether the hypothesis hold true. His findings confirmed that the more contact under specified conditions, the less prejudice. All rather obvious, perhaps. But looked at from the other end of the telescope, it is it is the lack of interraction that breeds unease and misconception – the very opposite of familiarity breeding contempt.

So, to overcome mistrust and misconception in a still largely segregated society, we must engineer and promote interaction. Herman, now Lord Ouseley's report for the British Commission for Racial Equality, on fighting in the streets between white and ethnic minority communities in Oldham, is instructive. He claimed that: "If left to their own devices it seems people will retreat into their own separate comfort zones, surrounding themselves only with people like themselves."

The DRC's own research found that the group with highest DDA awareness and the most inclusive attitudes about disability are people who 'know someone who is disabled at work'.[7] Inclusive schools also influence non-disabled children to hold more accepting attitudes towards disabled children.[8] Contact on equal terms can also be achieved through training, and evidence shows that training led by, for example, people with mental health problems, impacts on attitudes and that this change is sustained over time.[9]

Policy-makers should use this evidence to develop policies and programmes on education, democratic engagement or leisure that actively support participation and 'contact' on equal terms.

The presence of people willing to talk about their experience of disability or health issues in leadership positions – as teachers, local and national politicians, board members and senior managers – also shift mindsets. This is why giving disabled and non-disabled children opportunities to learn and play together is so important.

In fact, every public institution and every person elected or appointed to represent others shares a responsibility to promote equality, including by fostering positive attitudes towards all citizens affected by disability or long-term health conditions.

Cultural change requires significant leadership by public institutions, such as central government departments, institutions such as the BBC and the NHS.

And private businesses are in some cases demonstrating leadership in mainstreaming equality into organisational culture. There should be a growing expectation that this is part of corporate responsibility.

There are evidence-based approaches to changing organisational culture. These include board level visibility of people who are disabled or have long-term health conditions and are prepared to acknowledge this in an equality context; board level champions; a whole-organisation approach where equality is written into plans and the responsibilities of all managers; and an anticipatory approach to including disabled people, and those with long-term health conditions.[10]

Communications messages and campaigns can provide an effective backdrop to ‘contact’ and help reinforce change. For example, small businesses respond well to messages that support existing good practice and retention. They trust messages that come from the intermediaries (accountants, bank managers, solicitors, trade associations) with whom they currently deal. This approach can help to avoid backlash.

Transforming expectations

As I have said, to promote equality we need to transform expectations.

In 1984 a paper from the United Nations World Programme of Action on Disability stated that: “As disabled people have equal rights, so they should have equal obligations. It is their duty to take part in the building of society.”
I hinted at this point earlier. Are we yet ready to say that along with equal rights come equal responsibilities?
To do so we need to be sure that our public policy and programmes are all seeking to promote disabled people’s active participation in family, community, economic and cultural life.
That they are driven by high expectations, rather than institutionalised complaceny.
Only through disabled people playing an active part

across life will society's attitudes and expectations shift. We cannot rely on the promised land being created first. It may not be fair, but I believe that taking on more responsibilities is part of disabled people's journey to equality.
So, the DRC's approach is to use the law, change law and policy, shift mindsets through tackling assumptions and complacency. We believe that transforming the expectations and aspirations of disabled people and the expectations others have about disabled people is central to our vision.

A future in which we all accept that having an impairment or long-term health condition is an ordinary aspect of human experience.

A future in which we no longer assume that having an impairment or long-term health condition automatically, as a direct consequence, means a life of restricted opportunities, poverty and unfulfilled potential.

And, in this topsy turvey future, we would not be surprised that a person could be a manic depressive and company secretary of an international firm.

That a person with a learning disability could get GSCEs, have a responsible and interesting job or be a good parent.

That someone with very significant impairments, needing support to get up, to eat, drink and breath, could be the chair of a national public body.

We do not have all the evidence we need on what creates change. But at the DRC we believe that we have made a start. We will be publishing in February a new Disability Agenda outlining our recommendations on public policy. And Britain's new Commission for Equality and Human Rights, which succeeds the DRC in October of next year, will forge a new approach. It will provide a forum to give consideration to how prejudices overlap. How we can be at ease with the diversity of modern societies.

It will consider the new challenges. Such as an ageing population. The transformation of women's roles at home and work. The medical and technological developments that are supporting more people with complex impairments to survive and thrive. The continuing rise in the incidence of depression and anxiety conditions in Britain and other of the world's wealthier countries.

The evidence base, and the exchange of research across borders, will be crucial to the success of the new commission for us in Britain. The work of the National Disability Authority will be part of that and I hope we can continue this important dialogue on the transforming power of disabled people's participation.

End Notes

1. 15 per cent of disabled 16 year olds compared to 7 per cent of non-disabled 16 year olds. Source: DfES 'Youth Cohort Study: The Activities and Experiences of 16 Year Olds: England and Wales 2004'
2. National Association for the Care and Resettlement of Offenders (2003) 'Missing Out'
3. Better Regulation Commission (2006) 'Risk, Responsibility, Regulation: Whose Risk Is It Anyway?'
4. Adult Learning Inspectorate (2006) 'Greater Expectations: provision for learners with disabilities'
5. Health and Personal Social Services Statistics, National Statistics 2003 (data applies to the period 1997 – 2002)
6. Hewstone, M. (2003). 'Intergroup contact: Panacea for prejudice?' The Psychologist, 16, 352-5.

7. DRC (2002)
8. Gray (2002)
9. Thornicroft and Huxley (2003) ‘Social inclusion, social quality and mental illness’
10. Employers Forum on Disability; Equal Opportunities Review; Manchester Metropolitan University (2002); IRS (2005)

Keywords: Attitudes; Disabled people; Equality; Human rights; Legislation

DaDaAwards - opening address

Speech by Bert Massie at the North West Disability Arts Forum's DaDaAwards, as part of DaDaFest 2006, on Thursday, November 30 2006 at the Crowne Plaza Hotel, Liverpool.

North West Disability Arts Forum

DaDaAwards as part of DaDaFest 2006

Thursday, November 30 2006, Crowne Plaza Hotel, Liverpool

Opening Address by Bert Massie

I’d like to start by saying how pleased I am to be back in my home city of Liverpool and to congratulate everyone involved in DaDa Fest. What was once a small local event has become the largest disability arts festival in Britain.

It is also no longer local but now includes Manchester and it is good to see the growing cooperation between these two great cities.

Liverpool has many dates that we want to remember but one of the blacker days was 29 May 1985, when part of the Heysel Stadium collapsed during the European Cup

Final in which Liverpool was playing Juventus. 39 Juventus fans died that night.

I recall the night well. I was in Edinburgh watching the game on TV. The following day I took part in the Scottish launch of the Attenborough report on Arts and Disabled People.

In preparing for this evening I re-read that report. I was a member of the committee that wrote it and my first thought was that I had been appointed not as a token disabled person but as the token philistine. I think I was the only person there who spelt Picasso with a “K”!

But it is worth considering how far we have come. The clear message from re-reading the report is that we have moved a long way in the right direction.

In 1985 there was no requirement that arts venues should be accessible and there was no funding available to those who wanted to improve access. One result of the report was the establishment of the ADAPT trust, which provided funds to arts venues to improve access. That closed this month when it distributed its final £150,000. Today, organisations that want lottery funding for the arts have to ensure that the needs of disabled people are considered and addressed or they will not get funding.

We called for greater involvement of disabled people in the arts. DaDa Fest shows that that call has met a response.

The work of the disability arts movement has achieved a great deal, and has mirrored the progress made by the disability rights movement as a whole. Both began in the 1970s, both were based around disabled-led grassroots organisations and both included a strong element of activism.

Then, as today, disability arts reflected what was happening in the lives of the people who where making it. It was about their experiences as people disabled because of the barriers of attitude, policy and environment that society had erected or failed to dismantle. At its simplest, disability arts is the creative expression by disabled people of what it is to be a disabled person. By creating art through painting, sculpture, film, music or performance, disabled people have taken back their own subjectivity.

It's inevitable – and important - that representing disabled people's experiences in art will sometimes involve powerful expressions of anger. Installations like Tony Heaton's 'Shaken not Stirred', where he threw an artificial leg at a seven foot high pyramid of charity collecting cans. The names of some of the exhibitions of work – 'Defiance', the first major public exhibition of disability arts to tour major public galleries and 'Unleashed, which featured Heaton's 'Great Britain from a wheelchair', are evocative examples.

As well as the visual arts, many disabled artists use drama, song and humour to get their point across - to move, inform and entertain us. Graeae – the first professional theatre company for disabled people – has been joined on the scene by many more.

Film can also be a particularly potent way of sharing disabled people's current experiences and their history. Of course, DaDa Fest's Lifetime Achievement Award winner, Julie McNamara, is a previous Director of the London Disability Arts Forum and created the internationally successful Disability Film Festival.

And I was delighted that we were able to have the writer and film director Liz Crow to a DRC staff away day earlier this year. She shared her film 'Nectar' with us – which was beautifully shot. Set in the 1930s it evoked that time from the perspective of a deaf man very effectively.

Liz’s work demonstrates that the power of graphically portraying disabled people’s reality. Policy papers and campaigns are important but through the arts we can expand people’s thinking and help them to envision a different future. We can break down all sorts of awkwardness, ignorance and pity and replace the abiding images of disabled people with more realistic portrayals.

But of course film is an expensive medium and all disability art forms need funding. Liz has also been very effective at lobbying to improve funding criteria so that equality is built in.

Funding bodies like the Arts Council do have funding schemes like Programming Innovations for individual artists, and fund annual festivals this one, the Disability Film Festival and the Xposure festival.

And the DRC was delighted to fund Shape Arts and David Hevey two years ago to produce the exhibition ‘Giants’ featuring archive material on the history of disability and empowering photographs from David. We have also collaborated with Alison Lapper, whose image in Trafalgar Square caught the public imagination and put a spotlight on her work exploring issues of identity and sexuality.

Disability arts has run alongside important efforts to encourage more involvement by disabled people in the arts as viewers and listeners.

Over the last few years there has been an emphasis on access, as the Disability Discrimination Act has given more power to disabled people. Public venues and galleries are being encouraged to include British Sign Language and audio-description to make their shows and exhibitions accessible to deaf and blind people.

The Disability Equality Duty that comes into force next week is a new duty for all public bodies. It should provide added impetus to public arts bodies to consider further their role in opening up the arts to disabled artists and audiences.

We know that far more needs to be done to invest in disability arts, as performers, film makers and artists have to struggle for funding and the infrastructure often isn't there. There is no shortage of creativity or ideas for how investment can build the networks needed to make sure that disabled artists can both portray and change the experiences of disabled people, as tonight's awards demonstrate.

I am delighted to be part of this evening's ceremonies. It is a fantastic showcase of talent and achievement and I congratulate all the winners.

Keywords: Access; Arts; Disabled people

DED Day: Are you ready?

Speech by Bert Massie at Westminster Central Hall on Monday 4 December 2006.

Westminster Central Hall, 4 December 2006

Welcome and Overview by DRC

You have heard something earlier today about where the DRC is going next on the disability equality duty – after all the work that we have done to promote it through codes of practice, our conferences and events and extensive guidance.

I want to say a little more about why the DRC believes the duty matters so much; what the DRC's vision is of what it can achieve; and why it is now over to you to deliver.

My key message to you is that life after today, DED Day, is not going to get easier but tougher; but that action to promote disability equality will ultimately benefit all of us.

Why?

There is no doubt that the lives of many disabled people have altered radically in the last 30 years - particularly in the last five to 10 years, with the first Disability Discrimination Act in 1995 and the setting up of the DRC in 2000. If I look back on my experiences as a child and young man who was disabled, it is clear that many young disabled people today will have a very different experience.

Yet disabled people remain second class citizens in Britain. I believe that this results from the very low expectations that we still have of disabled people and for their expected quality of life – and, as a consequence, that many have for themselves.

We don’t expect that people with significant levels of impairment will work. So when such people present themselves for a job, the experience is novel, and employers naturally worry - about their productivity; the likelihood of lots of sick leave; whether they will disrupt normal working practices; or put the customers off.

Of course, the expectation creates the reality – the apparent absence of disabled people from board rooms and public life fosters low aspirations and expectations: ‘How could I ever climb that high?’ This is both because people who have obvious visible impairments often aren’t there and because people with invisible impairments have the rather dubious luxury of hushing it up. But at what personal cost?

Inequality for other social groups – the pay gap, the ‘male and pale’ nature of most corporate boardrooms – is pretty universally now seen as socially constructed; the product of historic disadvantage and prejudice. Not as something that is an inevitable consequence of being female or black.

Yet when it comes to disability, my suspicion is that the argument is by no means yet won.

People may say the right thing nowadays but I suspect that the unspoken assumption is still that disabled people should just not expect the same outcomes as others - because they, or rather we, are flawed as individuals. It isn’t really worth investing in levelling the playing field – if you are disabled you just are going to lead a more limited life.

If we do not recognise the circumstances that disabled people find themselves in as avoidable, caused by the way the world has been organised, what policies and services we put in place, we do not respond to them as avoidable.

If we do not start from the assumption that disabled people have something to contribute – as workers, volunteers, family members, politicians, entrepreneurs, artists, sportspeople – we do not put a premium on action to release that potential.

We do not respond with outrage to the disadvantage disabled people face in the way that we would if someone who wasn’t disabled faced the same set of circumstances.

Having an impairment or long-term health condition is a pretty common experience. Indeed, the leader and the likely future leader of our two main political parties both have sons with long-term health conditions. Yet governments and public authorities have regarded disabled people as so different, so special, they have often absolved them of the responsibilities that other citizens have – as workers, earners, parents, civic and political leaders.

But in ‘protecting’ people, we institutionalise low expectations and dependency; we rob people of a voice and of the right to ask for more than the most basic minimum in terms of quality of life.

The DRC believes that this can change. Indeed, that it must change.

We should expect disabled people to participate in the ordinary activities of life, and, with support where it is needed, to make the contribution they can. To do so is to put begin the active participation that can ensure that disabled people become equal citizens.

To do this, we have to unpick the policies and services that maintain dependency. Some of you may have seen the series ‘How Clean is Your House?’ Well, to use that cleanliness metaphor, I believe public authorities need to roll up their sleeves. They need to disinfect the policies and services that have institutionalised low expectations about disabled people’s achievements and about the quality of life that they can attain.

I’ll give you just two examples of the low expectations culture infecting services. According to a recent inspectorate report, adult learning services see “compassion . . . as not only sufficient, but as a justification for restricting ambition and growth”. And our health formal investigation looking at the experiences of people with mental health problems and learning disabilities concluded that the prevailing view is that these people “just do” die younger than others. With perhaps the unspoken assumption that this really doesn’t matter very much.

Changing this requires a profound shift in culture as well as in the mechanics of how policy is developed or services are delivered.

This is why the Disability Discrimination Act, in the sense of protecting individual disabled people from individual acts of discrimination, was never going to be sufficient to delivery disability equality. And why a duty on you, on the whole of the public sector, is so crucial.

It is crucial not just for disabled people themselves but for their families and the economy. Low expectations don’t just affect disabled people themselves. We continue to assume, for example, that support for older and disabled people can be delivered via unpaid care work, provided overwhelmingly by female relatives.

This position is not sustainable when we consider the challenge of an ageing population, where many women are choosing to live alone or not to have children. And where not being in full-time paid work can mean being trapped in poverty.

These themes – the rights of disabled people; the impact of inequality on them and their families and on Britain as a whole – are the subject of a new ‘Disability Agenda’ which we will be launching in February.

So, no excuses. I don’t want to hear about bureaucracy or things not being clear enough.

Reflect on where the biggest barriers to equality lie and what is within the gift of your organisations to change. Have a look around your metaphorical house and see where the dirt is; where low expectations have infected your policies and services; and at how disabled people are, as a consequence, second class citizens.

You have a new form of democracy to deliver, involving some of the most excluded of our citizens. Government departments. The health sector. Local authorities. Schools. These are institutions that shape most people's lives and have the power to affect how we live.

You will have involved disabled people in the preparation of your schemes. Maintain that important dialogue. Respect and reward that participation. You will encounter anger and frustration. Of course. You will need to consider other sources of evidence about where action is best taken. Of course.
You won't be able to deliver everything that is asked of you. Of course.

But remember that the DRC will be watching. We will be undertaking enforcement action, and after us the Commission for Equality and Human Rights, including its Disability Committee, will be taking enforcement action.

Not because we don't understand that you have heavy burdens to carry already. Not because we don't understand the pressures on you. We do. But disabled people cannot wait any longer. The parents, children, siblings and partners of disabled people cannot wait any longer. And with 10 million adults meeting the definition of disability in the Disability Discrimination Act – half of them not in paid work, many of them living in poverty - Britain cannot wait.

So the going is going to get tougher not easier. Today is an important day. A day to mark. A day to celebrate. But it isn't the end of the journey. It is simply the end of the beginning.

Keywords: Disability Discrimination Act 1995; Disability Equality Duty

Carers versus cared for?
Challenging assumptions
Speech
By Neil Crowther, Head of Policy
December 2006

the disability agenda

Disability Rights Commission

Speech delivered to Carers UK Conference 'Great Expectations' Royal College of Nursing, 6 December 2006

Introduction

I'd like to begin by thanking Carers UK for inviting the DRC to address today's conference.

You were supposed to be hearing from Gerry Zarb. Gerry sends his apologies. He is a member of the DWP's Independent Living Review and they scheduled a key meeting today with the Minister for Disabled People and Minister for Care Services, so he asked if I could step in. And I have to tell you it was only after I agreed that I learnt that the issue Carers UK wanted us to address was 'carers versus cared for'.

Gerry claims not to have known this. Come to think of it, I haven't double checked that there is actually a meeting of the Review today. But it's too late now!

So, carers versus cared for. I could use this platform to start a phoney war. It might be a good way to get some headlines: 'Disability watchdog attacks carers' lobby for oppressing disabled people.' And of course there are some in the disability lobby who would applaud me for saying that. Who consider that lines have been drawn and who refuse to enter into dialogue with the 'enemy'.

That is not the position of the DRC. At the DRC we recognise that there is a critical difference between working to advance human rights and equality for all, and simply seeking to secure your own rights and opportunities at the expense of others.

We recognise that many carers are themselves disabled people, and that the life chances of disabled people will not be improved by impeding or failing to improve the life chances of those with who they share their lives.

We recognise that the pot would be calling the kettle black to berate government and public authorities for their failure to adopt a joined-up approach to public policy and services, and then fail to do so ourselves.

So, let me be absolutely clear before I go on. The DRC believes that carers should anticipate an equal level of access to dignity and respect, freedom and opportunity as those who require support and assistance in their lives.

Carers and people who are disabled or have long term heath conditions share the same goal of securing choice and opportunity.

The DRC also believes many of the barriers faced are the same, and that while there may appear to be competing claims to recognition, power and resources, in reality the solution is the same.

It is on the task of overcoming these barriers and securing this solution that I am going to focus today.

The DRC’s position on the rights and opportunities of carers

I want to start by setting out what DRC believes is required to advance the rights and opportunities of carers. And I do so not simply because it seems politic but because we recognise that if there is a division between carers and cared for, most often it isn’t along the lines of disabled and non-disabled people.

Many people with mental health problems, for example, offer support at times of crisis to friends experiencing the same thing.

Very recently, I was on the tube and noticed an older couple being helped off the train by their daughter who had Down's syndrome. There are 70,000 adults with a learning disability who live with parents aged over 70. Discussion on that issue tends to centre on the support parents provide to their children. I suspect that in reality it is much more of a two-way street.

Many older carers have impairments and health conditions. There are very many disabled parents. And for the most part in this discussion we are talking about the well-being of whole families, not just individuals.

Public policy must strengthen the capacity of families to function in a way that improves the life chances of all their members.

Disabled people's life chances will not be improved if we do not improve the life chances of those with whom they share their lives.

How can we do that? Well, first, the DRC believes that caring responsibilities should be recognised in future anti-discrimination law as a specific ground; a belief we share with Carers UK and the Equal Opportunities Commission.

A single equality act must generate a better balance between work and family life by widening opportunities for people to improve their social and economic well-being. This is crucial to secure the prosperity and economic growth Britain needs in the face of rapid demographic and world economic change.

To support this aim, the DRC is also funding a discrimination case which will test whether claims of disability discrimination can be brought by non-disabled people on grounds of their association with a person who is disabled – in this case, the mother of a disabled child who believes she has been treated less favourably by her employer.

We also believe there should be stronger rights to flexible working. In time, we believe rights to flexible working should be available to everyone. In the short term we believe existing rights to request flexible working should be strengthened by making them available from the point of recruitment -rather than six months into a job - and by requiring employers not to unreasonably withhold consent to such requests.

Finally, and this is what I am going to focus the rest of my remarks on today, we believe that carers could benefit considerably from major reform and investment in our social care system.

As many of you will be aware, the DRC has worked closely on this issue of reform and investment with Carers UK and the Equal Opportunities Commission. Both of them have supported Lord Ashley's Independent Living Bill, which the DRC helped to write.

And to go back to the title of this speech, this is the area where perhaps the most difficult challenges lie and where historic divisions have kept those lobbying on behalf of disabled people and of carers apart.

From objects to citizens

I think it might be useful at this point for me to say something more about the position of some disability activists and why they have seen the interests of carers and disabled people in opposition.

The pioneers of the disability movement in the 1960s and 1970s included people living in institutions who had no choice about being there and no choice about what they ate, who they saw, what they did and when they went to bed.

In some cases, the people who made that choice for them were their parents and they had no power to disagree or to decide for themselves, even as adults. Others lived outside residential care but not in their own home. They were unable to move out of the home of their parents or foster parents and again found themselves subject to their parents' decisions.

These activists began publicly to reject the very notion of being 'cared for', because they believed that kindly sounding phrase was being used as cover for their incarceration, and the complete denial of respect, dignity and choice.

For the advocates of what later came to be called 'independent living', the set of functions and activities we tend to call 'care' had become an end in themselves, and that end was mere containment. Carers, whether members of the family or paid for by the state, were often viewed as oppressors.

As such, campaigns for greater recognition, rights and status for the function of 'care-giving', where they did not simultaneously try to secure rights to independent living for disabled people, were viewed as part of the problem.

It can be argued that such campaigns actually stand in the way of disabled people securing full citizenship, which hard-pressed carers themselves – through no fault of their own I hasten to add - are unable to guarantee within the current social care settlement.

I have given an extreme account of how some disabled people have viewed carers as in direct competition for rights and resources. I should say that the DRC’s Learning Disability Action Group overwhelmingly views family carers as strong allies and facilitators of their rights.

Nevertheless, in moving forward it is important to consider the power balance in some caring relationships, which may not bear the obvious hallmarks of oppression, but which can still act to restrict freedom, choice and opportunity. And some people do feel that they have little control or power to do anything but accept the bare minimum offered to them.

However, we believe where discord exists it is a product of the settlement we currently have – the current system is so limited, and rights and entitlements so threadbare, that different groups are forced to fight their own corner to compete for attention and resources.

Much of public policy as far as disabled people are concerned remains founded upon notions of care, welfare and charity - rather than rights, opportunity and citizenship.

We have had over a decade of developments in disability discrimination legislation – an acceptance that disability is a social rather than medical challenge. Yet our welfare state – from the benefits system through to social care – remains stubbornly rooted in an approach that undermines rather than aids progress towards equality.

Support where it exists too often fosters dependency and does little to aid well-being. For many it doesn’t exist at all. In England, for example, almost 70 per cent of local authorities’ social services only deliver any support at all to those with the very highest levels of need. Since 1994, the proportion of older people receiving home care has almost halved, as resources are focused on those with the highest levels of need.

Clearly this isn't just the concern of disability activists. This situation creates a huge reservoir of unmet need. And just as public policy on social care rests on outmoded assumptions concerning the place of disabled people in society, so it also rests on increasingly outmoded assumptions about the capacity and willingness of others to fill the gaps.

And it is here I believe that the interests of the cared for and the carers really collide. Millions families and individuals are often struggling to provide support, at great expense to their own well-being, for millions of others who would choose something else were it available. Were there an alternative, I believe we would all welcome it.

A democratic mandate for change?

Earlier this year, the DRC, the Equal Opportunities Commission and Carers UK commissioned a survey of the British public's attitudes and expectations of social care. It found that people have high expectations of the support available should they become disabled.

Ninety per cent want to be supported to stay at home; 83 per cent want support to visit family/friends; and 78 per cent want support to take part in local activities. Women are still expected to provide more support than men but a third of both women and men say they are unwilling or unable to provide informal support now or in the future. I think most of us here know enough to realise that those expectations could not be met within the current system.

But there is an appetite for change. Those polled were willing to pay higher taxes for better social care by a ratio of two to one.

In our ageing society, I believe the question of ‘who cares?’ is one of the big three, alongside environmental and security concerns, for any political party looking for electoral success.

I believe by coming together we have the opportunity to provide a new account of the shared costs we face and to chart the potential shared benefits for carers, the cared for and the whole of British society of a new settlement on social care.

The costs of inequality

So, what is the cost we face and why is it important to define it? The shared cost is disadvantage and inequality. And this costs not just the individuals and families concerned but society at large.

It is critical that we define these costs in this way, because otherwise the change and investment we seek is not viewed as a solution but just another problem to add to the pile.

The cost includes the poverty that blights the lives of disabled people and those with whom they share their lives. There are twice as many disabled adults living in poverty than non-disabled adults. One in three children in poverty has a disabled parent. Amongst Bangladeshi families where there is a disabled parent, the risk of child poverty is 83 per cent compared to 36 per cent in white families.

Many carers live in poverty, including many women who spend their retirement impoverished because they have provided unpaid care earlier in life, often not by choice but because statutory services were not available. Many rely on benefits as their primary source of income.

This continues to have a marked impact upon gender equality, most keenly felt in relation to incomes in retirement, but also in respect of pay and advancement during women's careers. Many mothers and carers work part-time for low pay – they cannot find higher productivity work that they can combine with family responsibilities. Around half of all people paid less than £6.50 an hour are women who work part-time.

Nearly four in ten carers providing 50 hours of support or more a week have never worked or are currently unemployed. A recent report by the charity Barnardo's calculates that there are 175,000 young people – many between the ages of 13 and 15 providing substantial levels of care to their parents or other family members. Their social and academic development suffers, as does their health. To allow this situation to continue strikes us as indefensible.

Adults caring 50 hours or more a week are twice as likely to be in poor health than those not. Many young carers develop mental health problems.

The cost of residential care has risen steeply in recent years, partly in response to rising expectations and standards. For example, in Scotland the average weekly cost of residential care for people with learning disabilities rose by £100 between 2003 and 2005. And the availability of home care has, as I said earlier, diminished considerably.

Of course, alongside the impact on carers' work opportunities, the way that social services support is, or rather often isn't, offered means that no paid work is possible for the person requiring support. As a consequence, the situation we find ourselves in impedes prosperity and economic growth. And we know, as our society ages, that many more will be in a similar situation without radical change.

And how do carers feel about their lot? Well, according to Princes Royal Trust for Carers, over half have felt like walking away from being a carer. A recent survey found that:

- 71 per cent of carers said they were stressed
- 83 per cent of carers are frustrated by their caring role
- More than half feel overwhelmed, angry, depressed and taken for granted
- four in ten carers feel they never had a choice in deciding to care
- about a third feel sad about the loss of the previous relationship they had with the person they now care for.

It is clear to me that disabled people and carers have a common interest in turning this situation around. It is also clear to me that together we can make a powerful and compelling case for investment and reform.

Escaping the black hole

But first there is something we have to deal with. I have just spent the last few minutes charting the enormous cost to individuals, families, society and the economy of maintaining the existing status quo, with the hope that we can begin to build a new case for investment in adult social care.

But chances are this will all be drowned out. Why? Because the carers' lobby has inadvertently created a huge black hole at the centre of this policy galaxy. And what is this black hole? It is the argument that carers provide a service free of charge of the same, if not greater, financial value as the NHS. An argument raised to gain recognition and secure access to resources. An argument that has played a part in securing rights to flexible working, tax credits, assessments and in relation to pensions.

As a political tool we can admire it but equally it is an argument that says two things to any government. First, don't ever seek to replace what carers do with statutory services – an utterly unaffordable option. Rather, make it a bit easier for them to do and seek to lessen the impact. Second, their voice is politically more important than the people requiring the support and so it is around them that we should build policy.

Both outcomes of course undermine the campaign for investment in independent living services to which I referred earlier. I am also unconvinced that the savings argument is helping to achieve what carers really want.

In preparing this talk today, I googled the words 'childcare and public investment' and I got about ten pages of links. Was it the financial value of the childcare that parents provided which won the case for investment in childcare? Was it the fear that parents might walk away from their responsibilities?

No. Investment in childcare came to be seen as a politically attractive investment because the case was made that it would widen opportunities for parents, and in particular mothers, to work; it would reduce the benefits bill, improve the life chances of children, alleviate child poverty, extend prosperity and promote economic growth. What's more, it would be popular amongst important sections of the electorate – particularly women.

What had traditionally been seen as a private family matter became a major issue for public policy. In short, the costs of the status quo were spelt out and the argument in favour of public investment won the day.

I then googled the phrase 'adult social care and public investment'. And I got nothing. Adult social care, unlike childcare, is not yet regarded as an investment. It is seen as deadweight expenditure – a cost and nothing much else – no real outcomes are foreseen and no real value is attached to it.

This brings into question whether the modest gains made on the back of the argument that carers save the state £57 billion a year are in fact a product of the government's genuine recognition of the value of what carers do or simply an expression of relief that they do it.

Just as pity for disabled people has unhelpfully shaped responses to them, perhaps gratitude is a similarly harmful response to the situation of unpaid carers?

A new model for social care in a 21st Century welfare state?

So, if we share an interest in reform and investment in social care, are we able to come together to make a new case for change? And how might this look?

The DRC believes social care needs to be re-modelled around the principles of independent living. The primary measures of success would be the choice, control and participation those requiring support and those with whom they share their lives were able to achieve.

The Independent Living Bill, which the DRC helped Lord Ashley to write, includes safeguards to ensure that decisions made about support for disabled people should not be to the detriment of other family members or carers.

The DRC believes there should be minimum outcomes, at least equivalent to those for children under the ‘Every Child Matters’ outcomes.

We believe government – national and local – should be required to produce strategies demonstrating how they will promote independent living and meet these outcomes.

We seek to extend choice and control through expanding access to independent advocacy, introducing self-directed assessment and promoting a navigator model for social work.

The degree to which choices are met should be a core area of local authority performance measurement. So should measuring the degree of control people have and how easy they find it to take part in family, social and economic life – as parents, active citizens, workers, consumers.

We support individual budgets and want more such initiatives, to help people assume greater control and gain greater flexibility in the services they use.

We believe people moving from one part of the country to another should be guaranteed their support package in the area they move to, at least for a fixed period before re-assessment.

We believe families should be offered mediation where disagreements emerge between members - for example, where a person is refusing an assessment to accept support from anyone other than a family member who is unable or unwilling to do so. This is a clause in the Independent Living Bill.

That is the model we seek and we believe it chimes with the vision politicians of all colours are beginning to chart out for a 21st century welfare state. One which:

- delivers dignity and respect
- is Empowering
- extends choice and control and fosters independence
- expands opportunities for people to work when they can and or to play an active part in the life of their communities
- improves health and well-being
- invests to save – for example by preventing poor health, welfare dependency or admission to residential care
- is 'joined up'
- provides value for money
- and contributes to economic growth and widening prosperity.

I believe we can together make a case as powerful, if not more so, than the one that has secured childcare as the 'new frontier of the welfare state'.

Carrying forward the debate

I expect some of the things I have said today you may have found challenging. I expect there are things I said today for which there are equally powerful counter-arguments.

Whatever you have thought, I am still glad to have had the opportunity to have this dialogue with you, and I hope it will develop and continue through the remaining life of the Disability Rights Commission and into the life of the new Commission for Equality and Human Rights. We stand to gain far more from talking than from not talking.

And I would like to set a particular challenge today for the new Equality 2025 advisory group of disabled people, to be announced by the Minister for Disabled People Anne McGuire tomorrow.

This group has been set up to assist government with the process of expanding disabled people’s life chances by providing advice through the new Office of Disability Issues. It is a powerful expression of the principle ‘nothing about us without us’ – of the direct involvement of disabled people, absent for so long, in policy-making.

My challenge for that group is that it joins this debate and recognises that there need be no conflict between the interests of carers and those requiring support – between disabled people and the family and friends who support them.

Conclusion

Before I close, I want to show you a short film produced by the DRC as part of our ‘Are we taking the dis?’ campaign. It ran in cinemas earlier this year.

The film was shown at the event and will be available on DRC’s website in the new year: http://www.drc.org.uk/health_and_independent_living.aspx

The film is based on a real case that came to the DRC’s attention last year of a couple who were forced apart when the husband was no longer able to provide the support his wife required, and social services were unwilling to support in the place they wished: their own home. They both suffered as a consequence. He fought and won and they are now back together

The reason I wanted to show you that is because we mustn’t ever forget that fundamentally this debate is about people and relationships. It is about the shifting nature of interdependencies that exist in families at different points throughout life. Between mothers and daughters, wives and husbands, sons and fathers, brothers and sisters. Between us and those with whom we share our lives.

And that includes disabled adults who receive support in their lives and who become givers of care as their parents age, they have children of their own or have friends that need help.

One day, the question of ‘who cares?’ affects us all. And we have somehow to harness that fact and use it to build popular support for reform and investment in public services that promote the dignity, well-being, and independence of everyone involved. Which recognises that this is not a matter of ‘carers’ or ‘cared for’. It is about all of us, whatever side of the coin we find ourselves on.

The investment and reform I have proposed today is an investment in all our lives. I hope we can work together to turn these ideas into reality. Thank you.

Keywords: Carers; Disabled people; Independent living; Poverty