

Working with the Disability Rights Commission

Bert Massie: CBI Annual Conference November 2001

Working with Business

Although the DRC is the newest of the British equality commissions, opening our doors to the public just over a year and a half ago, we have been working steadily within the existing legal framework towards achieving our key objectives. We have sought to work with business to help identify and disseminate good disability practice; and together, to eliminate disability discrimination. This partnership approach has been effective in raising awareness of the role of the DRC and in highlighting disability issues and tackling outdated stereotypes. The DRC will continue to ensure that business is aware of the services we provide, and the other ways in which we can promote the rights of disabled people. We will, in particular, contribute by publicising the Disability Discrimination and related Acts; informing individuals and organisations of the help and advice available from the DRC and elsewhere; and promoting policy, as well as legislative change, in key sectors of the economy and society.

DRC Services

In our first year, we have established a helpline that responded to 65,000. Out of the 65,000 calls made to our helpline, 20% were from employers and service providers, the majority of which were keen to know more about disability legislation generally, and more encouragingly, others believed that they may have been discriminating unlawfully and wanted our advice on how to change their policies and practices to prevent discrimination. We have created a team of caseworkers to unravel problems and

try to solve them. In their first year, they did so on over 2,000 occasions. Our preferred approach has been that of co-operation and conciliation. To that end, we have also funded an independent conciliation service to help disabled people assert their rights of access to goods and services.

Using the Law

We are pleased to say that we have helped both disabled and non-disabled people as customers, employees, employers and service providers gain a better understanding of their rights and duties under the current disability legislation. However, there are some companies that either as employers or as providers of goods or services believe they have the right to discriminate against disabled people. They will not be persuaded and the only language they know is that of compulsion enforced by law. We have therefore assembled a first rate legal team and in our first year initiated 41 actions in employment tribunals, county courts or in one case the Appeal Courts. When I spoke at the launch of the DRC I said that we would use the force of argument but if that proved ineffective we would not hesitate to use the argument of force. That remains our position.

The DRC will use its legal powers to support individual cases in ways that will have the greatest impact. This direct support comprises finance to meet the costs of legal representation by solicitors and barristers, as well as where appropriate representation provided directly by qualified DRC staff. The Commission aims to use these legal powers to clarify aspects of the DDA, which are currently untested or unclear, and to tackle widespread forms of discrimination. In deciding whether to provide support, the Commission has particular regard to whether the case in question addresses a point of principle, its chances of success in the Tribunal or Court, and the

individual's ability effectively to pursue the case, unaided or with support from another party. From 2001-02 onwards the planning assumption is that, taking one year with another, the DRC will support some 75 cases annually.

DDA Part III - Code of Practice

The DRC have just produced a new Code of Practice in relation to the Disability Discrimination Act for service providers. This is currently being considered by Government and should be published by early next year. We will continue to raise awareness among service providers of the major access provisions of the DDA, and the associated Part III Code, which come into force in 2004. This will particularly focus on what is known as the 2004 duties, that is those around considering what to do about physical features that are making it difficult for disabled people to use services. We will also be producing a wide range of supporting material for service providers. We will produce a practical guide for small service providers and we are currently considering what other information/guides would be helpful. At present, employers with fewer than 15 staff are exempt from the employment provisions of the DDA. In October 2004 the DDA Employment Threshold will be abolished.

The Economics of Diversity

Contrary to popular belief, disabled people will bring more to business than the cost of adapting your premises. The spending power for disabled people is estimated to be £40 billion per year. Can your business really afford to not take a share of the market? It is increasingly apparent that we have an ageing population. Who will no doubt demand the levels of service they were afforded in their younger days. Clearly, disability occurs throughout the age spectrum but what is absolutely clear is the exponential increase in disability rates beyond 50 years of age, such that by the

age of 80 there is over a 70% chance of becoming disabled (OPCS, 1988). So, if you don't die young, be prepared to join us! The astute among you will have, no doubt, identified the foundations of a business argument - it makes good business sense to build in the disability factor.

Conclusion

Even if we believe, perhaps naively, that societal attitudes towards disability will only improve. It may, for those disabled people who are already educated, employed and integrated into society. It may not for others who, still ignorant of their rights, are content to accept lower standards of service or being treated unfairly. There is an obligation on each of us, to reflect the values of the society we aspire towards, and to demand and end to prejudice, intolerance and exclusion, in whatever guise it manifests itself. Our success in achieving this aspiration depends on the effectiveness of our partnership with business.

Thank you for listening.

Keywords: Disability Rights Commission; business

Valuing Diversity; The Disability Agenda, We've Only Just Begun

Jane Campbell Bristol University November 2001

When Bristol University asked me to give a lecture on Diversity and Disability, I immediately thought of Adolf Ratzka, a seasoned disabled activist from Germany. He had the UK's disability movement splitting our sides with laughter and wonder when he presented his 'Crip Utopia' at one of our gatherings two years ago.

"Human diversity will be embraced when I read in the English Times of an elegant black woman who whizzed out of No. 10 Downing Street in a flashy power wheelchair".

"A Prime Minister who would, lead the 'United Minorities Party', whose major political thrust was to protect the human and civil rights of all their minority constituencies through detailed and tough laws.' Laws, which prescribed **Universal Design** as the guiding principle in all activities and interrelationships between individuals and entities, private or public.

Adolf dreamt of a Europe, where the United Minorities Party abolished physical Apartheid and the universal wheelchair sign was forbidden. Why? Because as Adolf rightly pointed out - it singles out:

"and stigmatises a particular group of citizens. By using this symbol of access you do yourself a disservice, because the symbol serves as an alibi for the accepted norm of inaccessibility, emphasising the exception rather than the rule."

Adolf's Utopia is appealing, amusing and many would say unrealistic. So wake up Jane, we're in England, post millennium, where the accepted norm is largely still in the

hands of those who do not experience the world as a disabled person.

And basically that is the nub of it - The gulf between Adolf's Minorities party and our social, political and economic status in society, has yet to be bridged. But good news! Bridges are finally being built....just watch out for the 'bridge too far'.

Some of the messages in this lecture today may seem obvious, but they continue to be uncomfortable for the majority. The messages demand a radical change in the way we include difference in our lives. How do we surrender power and control to those unfamiliar to us or to those we may even fear? How do we encourage this diversity to thrive and create?

If society is to value all disabled people, we need to find ways of making our collective minority **powerful** enough to influence the future. Shaping our future is something the Disabled People's Movement has been preoccupied with for decades. It is important for us to briefly revisit our history as a civil rights movement. For as Professor Oliver and I said in our book 'Disability Politics', "in order to be valued for who we are and what we want, we need to understand our history" .

In researching for our book, we felt the real watershed came in the mid 1970's when disabled people started to organise away from charities and statutory bodies who spoke on our behalf.

Breaking away from these self-appointed guardians, we made a space where we could beg the questions: Why are we excluded from society? How can we break in? The key was to unlock some of the fundamental principles of the Social Model of Disability that we hold so precious now. The Social Model had and has the potential to

transform our lives and yours. It has become the disability movement's tool for social inclusion.

The Social Model. This must be one of the most misunderstood concepts yet it constantly trips off the tongues of those who understand it least. Many find it difficult to believe in its transforming power because it argues that our problems derive from external circumstances and not our individual medical conditions. It demands an approach that wrecks the foundations of society's main solutions to our so-called 'problems', rehabilitation, cure, institutionalisation and death. If that sounds too heavy, just think about the recent press coverage of Diane Pretty's application for lawful euthanasia.

As I said, the Social Model was developed in the early 70s by a radical group of disabled thinkers. Our heroes, our leaders. Yes, we too have our gurus. Let me remind you of the fundamental principles of this philosophy. Although developed nearly 30 years ago, they have guided our struggle for rights ever since.

Disability is a situation, caused by social conditions, which requires For its elimination the following:

That no one aspect such as incomes, mobility or institutions is treated in isolation.

That disabled people should, with the advice and help of others, assume control over their own lives.

That professionals, experts and others who seek to help must be committed to promoting such control by disabled people.

These principles locate the problem of disability with society - **something we can change and improve**. How liberated I felt when I realised I was not the problem and no longer had to apologise for my existence!

Over the past 30 years, disabled people have used the 'Social Model Principles' in our campaigns for comprehensive civil rights, anti-discrimination legislation and independent living. Institutionalised discrimination against disabled people was finally, grudgingly, accepted after we gave overwhelming evidence in 1991 - published in our fine book - 'Disabled People in Britain and Discrimination'.

The social model gave disabled people the confidence to campaign for rights in a way that was un-compromisingly based on social oppression. Not one off instances of prejudice as in the cases approach that had gone before. I have no doubt that this has greatly influenced the vision and values of the Disability Rights Commission. The DRC was established by this Government to tackle discrimination. A core value in the DRC's strategic plan says,

"The DRC will be guided by the social model of disability. Our philosophy and approach are underpinned by the social model of disability. We believe the barriers that exclude disabled people from full participation in society are the result of the way the social and built environments are constructed, and society's attitudes towards disabled people, rather than just being the result of individual impairments. A key part of our work will be to address, in a strategic way, those social structures and attitudes that have a disabling effect. The social model of disability is the most suitable model to adopt in our work."

This is quite a statement from a body born, not of the Movement, but the establishment. It is an indication of our power to influence and a demonstration by those with power, of recognising the experts. Such alliances are not without their problems, but as I said: we've only just begun. The Disability Rights Commission has much to

learn from those who have been developing and using the social model as a tool for change for many, many years.

The work began this year with the Commission visiting organisations of disabled people around the country to see how they wanted to be included in a common agenda of furthering and protecting disabled people civil rights. The terms of engagement are very important if we think back to the fundamental principles: **That professionals, experts and others who seek to help must be committed to promoting such control by disabled people.**

But will all be well with the world if we perfect the DDA?

Well not until we grasp the nettle that still denies that all life is of equal value. The DRC's vision is of "A society where all disabled people can participate fully as equal citizens". And this is where the squirming starts. Despite the DRC's vision and a growing international awareness of disability as a human rights issue the notion of elimination of our specific diversity is supported.

In the words of Mike Oliver:

"We know the Nazis killed 200,000 disabled people in Germany but we still practise death making in the here and now and still hidden from view. We avert our eyes just like the Germans did all those years ago. There are no gas chambers but there are things going on that we talk about in hushed tones using terms like 'euthanasia', 'mercy killing' and 'termination'".

Having a right to access the built environment, employment and education are easy for society to confront in comparison to disabled people's right to life. It is a sad fact that the majority of general public, think disabled lives are flawed or simply not worth living. In a

recent Daily Mail poll 68% of said they would want to abort if they found they were carrying a disabled child.

If we are to really value the lives of disabled people, we have to confront our own personal ghosts. This can only be done by listening to and involving those who experience that which we wish rub out. Not as most do - ask a Dr.

I want to give you a painfully graphic example, which may demonstrate why I have particular concerns as to the ability of society to make rational judgements about the value of our lives. We have a so called RIGHT TO LIFE (ARTICLE 2) of the Human Rights Act and yet in 1999 an eighteen month old child, ('Baby C'), with Spinal Muscular Atrophy (SMA) was denied ventilation to help her through her chest infection. It was deemed her "disability was too terrible to live a quality life". In addition she would need "total bodily care for the rest of her life" and this would be a "burden on state resources and family support" . The family did not accept this decision and took the hospital to court. The judge ruled for the hospital having received advice from a range of Doctors, all who stated quite categorically that no one with this diagnosis lives beyond the age of 2 years old and that if they did, life would be a living hell. The baby died as a result of being denied this routine health care offered to non-disabled babies with severe chest problems. Adults with SMA, including me, could tell a very different story.

Why do we put a value judgement on difference?

Logically, if it is said that the Baby Cs of this world are so different that they would be better off dead then the same should be said of Me.

We have a very topical case at the moment, where sadly the disabled person herself, sees no option other than euthanasia as her release from disability. Whilst I

understand her personal wishes, my outrage at the predominant social response to her situation knows no limits. So much so that a friend and I penned a letter to the Guardian.

"Your article about Diane Pretty (front page Saturday) raised some important concerns for us as disabled people. We both have a muscle condition, use electric wheelchairs and need a high level of personal care. We fully respect Diane Pretty's individual wish to end her life. However, it seems to us that she has given the press a real gift, tragedy on a plate and she has been rewarded for this by maximum coverage, none of which has ever questioned, even fleetingly, her suicidal tendency. One sure thing, the general public could be forgiven for getting the idea that anyone with a substantial level of disability will inevitably be deeply depressed and pre-occupied with thoughts of dying.

"We find this worrying, and feel somehow obligated to tell the world that we and many others like us are lucky enough not to be in that unhappy emotional state. However, we are pre-occupied with the low level of provision made to disabled people for care needs by social services and other bodies. Our vigorous campaigning on sometimes outrageous systemic injustices over the years has never been rewarded with more than tepid press interest. The message we get from this is that a pecking order of human rights concerning disability is emerging. The right to assisted suicide, which implies no expense to society and has high human emotional impact, is right at the top of the heap. The right, for example, to go to the loo when needed, which may have some cost implications and packs absolutely no emotional punch whatever is currently seen to be very much the poor relation."

Sian Vasey
Jane Campbell

We seem content to consign Mrs Pretty to the Graveyard, yet no one would dare think the same of Stephen Hawking. Logically, if we say that the Mrs Prettys of this world are so different that they should be better off dead then we should say the same of Steven Hawking. Or do we want Hawking to live because of his intelligence? Where do we draw the lines?

I believe that acceptance and celebration of our diversity at this level, is absolutely necessary for our own emancipation and feelings of self worth.

Rachel Hurst, in her plea to the Bioethics community at their 5th World Congress said,

"It takes a particular sort of courage to rise above these negative impacts and have a faith in your own worth, or the worth of your disabled family member. It takes courage and a clear understanding that disability arises from the social barriers of attitude and environment to your impairment, not the impairment itself. A similar sort of courage and understanding has been needed by women as they overcame the discriminatory images of subservience and earth mother or the courage and understanding that has been needed for black people to overcome slavery and apartheid. Just as we all recognise that society need the difference of women and people of different races and backgrounds, so society needs people with impairments".

So if we get through the hurdles of staying alive are we then accepted and included, now we have our anti discrimination legislation?

Well not quite, because there's always those sticky issues of cost and, O yes the industry that depends on our dependency.

How can we value diversity if we continue to incarcerate disabled people who are simply regarded as too diverse to support in the community? We do it in the name of cost, which somehow in our consumerist society makes it all right. Placing people in institutions is not recognised as a denial of human rights in this country, and yet how can it be not when....

An adult man and woman who live in a residential care home were prevented from becoming engaged to marry and denied access to privacy so they might form a close and loving relationship, by the home's staff. The staff refused to take them (they needed personal assistance to move) into a jeweller's shop to buy a ring and used various methods to keep the couple apart.

Right to marry and found a family (article 12)

I want you to know that after three years of this torment the couple persuaded some friends 'outside' to help them escape for the day and they married in a registry office in 1997. They are now living in a supported living flat employing personal assistants

Control over what happens in our lives on a personal day to day level, lies at the very heart of what we disabled people claim for ourselves. We call this simple philosophy - Independent Living. It is a state of mind rather than something we can physically or mentally accomplish in comparison with non disabled people. It is an entirely emancipatory philosophy which, if put into practice in the way we envisage, will empower us to make choices about how we want to live our lives and ultimately gain personal control.

Institutional settings, however well intentioned, can never be compatible with this philosophy. Their very existence relies on the notion that there will always be some disabled people who are incapable of making choices and controlling their lives, in a way that is 'safe' and 'realistic'. **Risk and economic reality** (i.e. if it costs too much to support you in your community) are the most commonly used arguments to deny disabled people the fundamental right to the same freedoms enjoyed by the rest of society.

A handful of disabled residents collectively developed an escape plan back in the 70's (Project 81) which, did force a change in social policy making it possible for disabled people to receive personal assistance in the community under their own direction. Hence the ILF. and later Direct Payments.

However Direct Payments and the ILF are not in themselves 'independent living'. Even though these legislative changes have made it possible for many disabled people to stay out of residential care and build inclusive lives, for those incarcerated today, the route is far less easy and direct. This is especially true for disabled people with high support needs who, as we discussed earlier, are less valued by a society.

So what are we to do? Well firstly we have to acknowledge that independent living is a human rights issue. Secondly, we have to learn not to retreat from the nettle even though it pains us. We must learn not to dismiss the voice of the so-called radicals that dare to tell it how it is. Society must include us at the heart of debates about where and how we want to live our lives. We must address the immoral argument put forward by the Minister for Disabled People in a commons debate in 1994, that "there are situations when the cost of supporting a disabled person in the community becomes too great" . £500 was the ceiling set. 6 years on that glass ceiling has

been raised to £650. I was stuffed then, I am now. It is only the enlightened discretion of my own authority that keeps me from that I most fear. Prison without locks. Until independent living becomes a statutory right, I will not accept my diversity is truly supported or even wanted.

Disabled people have created our own arts culture to cut through some of the raw prejudices I have brought to you today. Instead of shocking and alienating those we want to reach, I think poems like the one I'm about to read, help convey messages of how we survive in a world which has so much to learn from our diversity and satiric take on life. Simon Brisenden wrote this poem in 1987.

Vegetableism

**I am a child of the earth
I've been a vegetable since birth**

**I went to a school for vegetables
And learnt how to go with meat
I grew up and wore the stigma
Of being something people eat**

**And in my very early vegetable days
I went through a religious phase
And asked god why he had made me Just to drown in
a pool of gravy
But his answer was not detectable
So I became a Marxist vegetable
And bringing in elements
Of a feminist critique
I formed a vegetable
Liberation clique**

**The vegetable is political I said
And tried to undermine the state
We advocated passive resistance
To the knife the fork and the plate**

**And now I am writing a history in three volumes
(From a post-structuralist point of view)
Of all the anonymous vegetable victims
Who have perished in hot-pot or stew.**

This poem exemplifies my experience of daring to move out of my accepted sphere of expertise and experience.

I want to tell you about my interview for this wizzy job as Chair of the Social Care Institute for Excellence (SCIE). There was I daring the establishment to consider me, a service user, for one of the top jobs in social care. I sat there facing four men in grey suits who were quizzing me about my capacity to respond to a sector that I was not a part of? Would I understand their needs? How would I balance my campaigning background with a situation where balance and objectivity was required? How did I think the social care sector would take me seriously? And I said without thinking, "What you mean is when they find out the cabbage has got a brain?" They reeled back in their chairs and I kicked myself all the way home for being so blunt. I am convinced two years ago that would have clinched my rejection. But do you know what? I think it's one of the reasons why I got the job.

There is a readiness out there to try something different and to break the mould. This is sector where our diversity is most needed and, therefore has the potential to be most valued. Who else can change the nature of the relationship between those who give and receive support?

Disabled people have built an incredibly strong political and social movement. It must be strong to have sustained the constant under funding and attacks from the mighty charitable institutions and medical interventionists. It's a bit like that song by Labbi Siffri: The higher you build your barriers - the taller I become. And it's so true. I believe the time is right.

The disability movement has emerged with solutions to our collective experience of exclusion. Yes, don't forget. Non-disabled people lose from our exclusion. These solutions are based on, as Mike Oliver puts it: "three big ideas", which have emerged exclusively from our movement and have been based entirely on our experiences. The first, of course, is the social model of disability. Full Civil Rights is another and independent living is the third. In order to value diversity society needs to resource these three solutions . Power will have to change hands.

We want to contribute - not as a rung on someone's ladder to a charitable heaven - but in our own right, with our uniqueness recognised and our diversity celebrated.

Jane Campbell

Keywords: Disability rights; disabled people; diversity

DRC National Conference 3 December 2001

Bert Massie

Welcome to speakers, special guests and participants.

Importance of the event:

This first national conference marks the beginning of a key new phase in the DRC's work.

After a successful first 18 months, the DRC has an impressive range of services in place, for disabled people as well as employers and providers; and has delivered on a major policy programme which we inherited.

The DRC is now embarking on a radical and demanding new agenda, which in large part the DRC must decide for itself in conjunction with as many stakeholders and partners.

As I shall describe very shortly, the theme of education - and our Educating for Equality Campaign launched today - is a prime example of all that. But, first, a quick pen-picture of the DRC - what we exist for, what we have achieved and our plans.

The DRC so far:

Today is primarily about looking forward. However, it is worth noting briefly the DRC's

achievements to date on which we shall now build:

65,000 calls handled by our Helpline, set to rise to 80,000 this year;

2,200 cases handled by our caseworkers last year, and likely to total some 2,500 this;

DRC support already for 100 important legal cases under the Disability Discrimination Act, with dozens more likely to be under way by the end of 2001-02;

A Conciliation Service established last March to deal with goods and services cases under the DDA;

Other major activity to identify and disseminate good disability practice among employers and service providers, as well as DRC Offices in Scotland and Wales operating effectively in the devolved context there;

The preparation of a major new statutory Code of Practice concerned with disabled people's rights to access to the Goods, Services and Buildings (Part III) provisions of the DDA. This is of course major importance to all providers of goods and services, as well as those who own or rent buildings. I am delighted to say this Code was laid [last week] before Parliament, and should be published in February;

Successful completion of a policy agenda which included advice to Government on abolishing the exemption for small organisations (with fewer than 15 employees) from the employment provisions of the DDA;

on British Sign Language; a much sought after report and analysis of the implications of the Human Rights Act for disabled people; and expert advice and comment on relevant Government consultation exercises; including on charging for social services, social care provision and transport.

Shaping the Future:

However, we have only just begun and we have a huge canvas to work on.

Under the Act which established the DRC, the Commission is obliged to tackle discrimination against disabled people; to promote equal opportunities for them; to disseminate good practice; and to advise the Government of the day on legislation.

The Commission has set the vision of "a society where all disabled people can participate fully as equal citizens".

To progress towards that vision, the DRC will focus on seven key themes in the coming period:

- As you can tell from today, accessible, more integrated education; an effective overall legal and statutory framework of rights;
- An accessible built environment; · responsive health and social care;
- Accessible transport;
- Greater opportunities in employment;

and ensuring continuous improvement in the DRC, particularly in our services to disabled customers and as an employer.

This is a major set of objectives, and we shall be focusing closely with key partners in each case on those actions which will have greatest benefit for disabled people. For example, our top priorities for the coming year include:

Encouraging the Government to legislate soon to implement its Manifesto commitment to major extensions of the Disability Discrimination Act;

Begin our first Formal Investigation into a key area of difficulty for disabled people;

Ensuring that the rights coming into force under SENDA apply in reality for disabled people when they come into force from September next year.

Why the emphasis on Education: What will the DRC do?

Education is of crucial importance to disabled people, of all ages.

Access to education is the most powerful influence on subsequent employment, economic well-being and quality of life for the individual.

Greater integration of disability into education offers a powerful means of influencing non-disabled people's understanding of and attitudes to disability.

The education professions - whether teaching, support or administration - represent very large area of employment where disabled employees and groups have much to offer.

Major new disability rights are being extended to education where virtually none existed before. The major provisions of the Government's very welcome Special Education Needs and Disability Act (SENDA) come into force next September and progressively over the succeeding few years; Over the last 9 months, the DRC has led a major consultation exercise to prepare statutory Codes of Practice on SENDA - for schools and for post-16 respectively. We are on target to meet the demanding timetable to deliver these to the Secretary of State by 18 December, for laying before Parliament. The Codes are likely to be formally published by next April;

We are also announcing today the DRC's Educating for Equality Campaign - a sustained programme of action and change to make a reality of their new rights and of equal opportunities for disabled people throughout education.

A description of the Campaign is in the Conference packs. The Campaign includes the DRC's plans not only to boost awareness of the Codes and related guidance, but also new helpline support, a conciliation service, targeted legal work where necessary, and greater mainstreaming of disability into the curriculum and teaching materials.

Working with all partners concerned, the Campaign marks the DRC's determination to ensure we all seize the golden opportunity represented by the new, breakthrough legislation.

The DRC is delighted therefore to welcome you to this first National Disability Conference and to make education the centrepiece.

Thank you for attending today. I hope you will find the Conference useful and enjoyable

Keywords: Disability rights; DRC; Education