

NUS Students with Disabilities Conference February 2002

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Introduction

Last week I had the pleasure of visiting Cleves primary school in Newham, East London. The school prides itself in its inclusive practice. In its view, every child has the right to belong to its local neighbourhood school, and the principles of incorporating diversity, of community, of co-operation, of choice, interdependence and equality are at the heart of everything it does.

And just from spending one morning at the school, talking to staff and children and observing the way all children - some with complex needs such as autism, were not simply "integrated" but involved, accepted, supported, welcomed and viewed as equals by staff and pupils alike - it was obvious that the school's culture, ethos and organisation greatly enriched the experience of everyone there.

But one couldn't help but feel sad about how all this groundwork could so easily be undermined as these children move through the education system - if the system does not undergo major change.

These disabled children will be increasingly separated as they move into secondary education, some unable to attend the same local school as their friends. Later, policies in further education might preclude them from attending the same classes, with disabled young people - instead having to attend specialist courses. And for those who are able to progress past further education, a traditionally unsympathetic higher education system emphasising "academic standards" which allow little scope for flexible patterns of learning and achievement will present even tougher barriers.

This is what we have to change. And the new legislation provides a stronger framework through which to do this.

What I'm going to talk about

I'm going to begin by providing an overview of the new duties for Post 16 education

Then I'm going to briefly go through a few of the loopholes in the legislation

Then I'll cover the Disability Discrimination Act (DDA) duties as they affect student union bodies

Then lastly I'll talk about how we might want to move forward and I'll share what the Disability Rights Commission (DRC) and others have in the pipeline.

The new duties

From September 2002, Post 16 education will begin to be covered by the Disability Discrimination Act (DDA), as amended by the Special Educational Needs and Disability Act (SENDA). These duties will make it unlawful for providers of Post 16 education and related services to discriminate in:

The admissions and enrolment of students

In the terms on which admissions and enrolment offers are made

By refusing or deliberately omitting to accept an application for admission or enrolment

In the provision of services provided wholly or mainly for students or those enrolled on courses - including courses of education, training, recreation, leisure and catering facilities or accommodation

Permanent or temporary exclusions.

Discrimination can occur in two ways:

When a "responsible body" treats a disabled person less favourably for a reason relating to the person's disability, than it treats or would treat a person to whom that reason did not apply.

For example:

A student with dyslexia applies to do a degree in English and is told by the university that they do not accept dyslexic students on English degrees. This is less favourable treatment for a reason relating to the person's disability and therefore likely to be unlawful.

A student who is deaf and also has a mobility impairment attends a specialist college for deaf people. She is told by the college that she cannot take part in an evening outing for the students because it would not be suitable for her because of her additional disability. This is likely to be unlawful.

A university makes an offer of a place to a student who is a wheelchair user on the condition that she finds her own living accommodation locally. No other students have this condition placed upon them and so this is likely to be unlawful.

Reasonable steps

Discrimination also occurs where a responsible body has failed to make a "reasonable adjustment", which has meant that a disabled person has been placed at a substantial disadvantage in comparison with a student who is not disabled.

This latter duty will come into force in three stages:

From September 2002 - adjustments will have to have been made to policies, procedures and practices.

For example:

A student who lip-reads has a lecturer who continues to lecture whilst simultaneously writing on a whiteboard - the student is likely

to be at a substantial disadvantage as a consequence of this failure to adjust practice and this is likely to be unlawful.

A further education (FE) college modularises its learning programmes so allowing learners with learning difficulties who might be able to access one part of a programme at a more advanced level but require another part at a more basic level to match provision to their needs. The college is anticipating reasonable adjustments that might need to be made.

From September 2003 there will be a duty to provide "auxiliary aids and services"

For example:

A university ensures that palantypists are present during lectures to ensure that deaf people can participate.

An FE college ensures that it can transcribe course materials into large print, on audio tape and braille.

A college ensures that it can call on specialist support workers for students with dyslexia.

From September 2005, there will be a duty to take reasonable steps to remove barriers to physical access.

A university arranges for an access audit of all its premises and develops an access policy and action plan to ensure that access is improved at every opportunity, such as during major refurbishment or during redecoration and during general cyclical maintenance.

An FE college begins a process of moving all of its technical classrooms to ground floor level.

All these duties are owed to disabled students at large and are therefore "anticipatory". That is to say, providers of Post 16 Education have to plan ahead and take reasonable steps to prevent discrimination occurring, not simply react to individual needs. It's

also important to remember that this duty is an evolving one - continuous review and improvement is essential.

What is "reasonable"?

The Act does not define what will or will not be reasonable steps to take - this will be a matter for the courts. However, whilst we now have the DDA extended to education, it's worth noting that the factors, which saw education's original exclusion from the Act in 1995, are factors, which will determine reasonableness now. These are not all unique to the education provisions, but issues such as the need to maintain academic and other standards, cost, health and safety and the interests of other students are factors in determining what steps will or won't be reasonable to take.

Redress

Legal action

A person who believes that they have been discriminated against may bring civil proceedings in a county court in England and Wales or a Sheriff court in Scotland. Court action must be brought within six months of the alleged discrimination.

Conciliation

The DRC will be setting up a conciliation service to promote the settlement of disputes without recourse to the courts. Conciliation will be made available locally around the country and disputes may be referred to conciliation if both the complainant and the responsible body agree.

Agreeing to conciliation does not prevent a complainant from pursuing a case through the courts. The time limit for bringing an action to court is extended by two months if the conciliation process has been used within six months of the alleged act of discrimination.

Codes of Practice and Guidance

The DRC will be publishing the Codes of Practice to accompany the Act in early May 2002.

A range of guidance is also being prepared.

The Association of Colleges will be publishing a 'toolkit' for FE Colleges in March 2002.

The DRC is working with Skill and a wide range of organisations in the Higher Education (HE) sector to produce a series of booklets aimed at different areas of HE provision - these will be published in May 2002, alongside the Code of Practice.

We are also preparing a fact sheet for students concerning their new rights, and this should be available from our Helpline shortly.

Outstanding issues

Firstly, the definition of disability in Part I of the DDA: the most likely things to change here are the definitive inclusion of specific conditions - in particular non-symptomatic HIV and Cancer.

However there are a range of issues where whilst the DDA's definition of disability might not include a particular persons impairment or condition, that person may experience substantial disadvantage in their education where adjustments are not made - a major area being mental health, where a persons condition is periodic to the extent of not fitting the DDA's requirement of "long-term". In those areas of Post 16 Education to which the Learning and Skills Act applies there is likely to still be scope for adjustments to be made and needs to be met and the DRC is working with the Learning and Skills Council to look specifically at how both the DDA and Learning and Skills Act can be used to lever change.

In the Higher Education sector, this is not the case. The DRC is currently undertaking a legislative review and will look at the definition in detail - we will be consulting on this from May this year.

Qualifying bodies - which govern entry into particular careers such as social work, teaching and various medical professionals are not yet covered by the DDA - their entry requirements can continue to discriminate against disabled people, so precluding them from professions which paradoxically are covered by the employment provisions of the DDA and so required to make adjustments for existing employees.

Examining bodies - most likely are not covered, meaning adjustments to examination arrangements are not a legal requirement - for example extra time to complete an exam.

The providers of work placements - which are becoming a more widespread requirement of FE and HE courses, are not covered by the DDA. Institutions will be required to make adjustments in the locating and allocating of work placements, but this leaves disabled students only partly covered.

Lastly, for now, an ex-student wishing to use a **careers service** would not be covered - only existing students.

Duties for Student Union Bodies

I now want to talk briefly about Part III of the DDA, which concerns the provision of goods, facilities and services, as this is the part of the Act, which covers student unions.

In terms of what providers of goods, facilities and services will be required to do, the duties are broadly similar to those for education, but on a different timescale.

Providers of goods, facilities and services have had a duty not to discriminate by treating disabled people less favourably since December 1996, and to make reasonable adjustments to policies, procedures and practices and in the provision of auxiliary aids and services since October 1999. The final part of the duties comes into force in October 2004 - the duty to make adjustments to physical features, which make it impossible or unreasonably difficult for a

disabled person to make use of a service. The DRC will be publishing the revised Part III Code of Practice on 26th February 2002. We have already published a practical guide for small businesses, which is available from our Helpline.

What does all this mean?

Whatever ones views are of the Disability Discrimination Act, this is an incredibly significant milestone and opportunity.

Unlike pre-16 education in which there have been evolving rights afforded to children with special educational needs, including disabled children, moving towards a greater emphasis on inclusion, this is the first time providers of Post 16 education have been under a legal duty to ensure non-discrimination in the provision of education and related services.

But the legislation, Codes and guidance are only the beginning.

We do not want Institutions to simply meet the duties. We want the DDA to act as a leveller and safety net, but ultimately we need a major change in the culture and ethos of those who shape and provide Post 16 education to ensure that the principles of equality and diversity become woven into the very fabric of everything that they do and seek to achieve.

To this end, the DRC will be launching its "Educating for Equality" campaign in May 2002, the same time as we launch the Codes of Practice.

We will be seeking to ensure that:

- Disabled people are aware of their educational rights, and are informed and supported so that they can exercise these rights, including via conciliation and taking legal cases.

- That key opinion formers, including Parliamentarians, the media, think-tanks, Central and Local Government,

employers, disability groups and those in the education sector become engaged in debate concerning disability rights in education, and for the DRC and others to add value to wider debates about the future of education (there are those who argue that the disability movement has been far too engaged in "special pleading", and that it should look at the big picture and seek to influence issues in the round as opposed to only its own corner - I think this is certainly valid in the area of education where influential think tanks like Demos are arguing that the education system is too knowledge based, that we need to learn to be able to learn, that being able to relate to people, to manage situations and manage information are what people need to live in the 21st Century, that a learning difficulty is a learning opportunity, that teachers should not be in the business of imparting knowledge, but should instead be learning coaches and others, particularly in the field of lifelong learning are arguing notions such as "stage, not age", putting development before chronology. In all these areas there are great opportunities for disabled people to contribute. There are other areas of mutual interest too. I don't think it's a coincidence that the advanced nature of Newham's education policies exist within an area of rich racial and ethnic diversity, and the vision of inclusion at Cleves primary school was as much about incorporating racial and ethnic diversity, as it was about disability.

That practitioners are aware of their duties and are able to access information and support to meet these - I mentioned the guidance earlier - practitioners also need to be able to be signposted to training, advice and expertise both within and outside their institutions.

To seek to map out and influence public opinion concerning the rights of disabled people in education. In December 2001,

we commissioned a survey of parent's attitudes to including disabled children in mainstream schools. There was broad support for such inclusion, but when we dug a little deeper we found that there was significantly less support for the inclusion of children with mental health conditions and learning difficulties than for children who were wheelchair users - we have to tackle these attitudes.

To keep the legislation and its implementation under review and propose amendments and action to improve the legal framework where necessary.

To work with a wide range of partners to seek to affect real change within education - including I hope the NUS.

Concluding remarks

So to conclude, the extension of the DDA to education is a significant milestone, but it can only be a catalyst for change, not a be all and end all in itself.

We need to work hard towards ensuring that the education system of the 21st Century is one which reflects the sort of values and principles to be found at Cleves primary school in Newham - one which values diversity, one which sees equal value in all people, one which is flexible enough to enable all people to develop to their own optimum potential, and most importantly of all, an education system which upholds and contributes to the DRC's vision of a society in which disabled people can participate as equal citizens.

Thank you.

Keywords: Disability Discrimination Act 1995; Post-16 Education

Civil Rights for Disabled People: Do OTs have a role?

Bert Massie College of Occupational Therapists Annual Conference June 2002

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Introduction

The Disability Rights Commission has a vision of a society in which all disabled people can participate fully as equal citizens. At the heart of that vision is the notion of independence and independent living

The DRC uses the term 'independent living' to refer to a state of affairs where all groups of disabled people have the same degree of choice, control and freedom as any other citizen in all aspects of their lives. This means much more than disabled people simply 'doing things for themselves'. Independent living in this context is seen as essential to achieving disabled people's full participation in

the social and economic life of their communities and enabling them to secure equal rights, choice and opportunities.

Do occupational therapists have a role in making this vision a reality? The answer is most definitely 'yes' and, potentially, it is one of the most important roles of all.

What is so important about independent living is that it underpins just about any aspect of participation and inclusion one could think of. As noted in the recent report - New Directions for Independent Living - from the Social Services Inspectorate:

"Independent living is the concept of empowering disabled people to control their own lives as far as possible and to have the freedom to participate fully in the community. It is not the name of a particular service or provision but should be the objective of services and provision. Support for independent living includes personal assistance, information, housing, education, access to public goods and services, employment and training and access to the environment and the political arena."

(SSI, 2000, p. 2)

The provision of high quality rehabilitation and support services is not, therefore, an end in itself but - fundamentally - a means to enabling independent living. Most importantly, without access to this support many disabled can be prevented from exercising any other rights they may legitimately expect to enjoy. A right to accessible transport for example becomes academic if you cannot get out of your house while lack of access to transport can in turn create a significant barrier to employment.

Current issues and opportunities for change

The principle of supporting independent living has moved higher up the policy agenda in recent years. As well as major reforms to health and social care services the other major plank of the

government's modernisation programme has of course been Welfare to Work - which is also seen as fundamental to underpinning opportunities for independence and inclusion.

Many of these recent developments have created genuine opportunities for promoting access to independent living and full social and economic participation. At the same time, there are still several obstacles to overcome before the vision of full social and participation becomes a reality for all disabled people. The key challenges now are to encourage the successful implementation of recent positive policy initiatives, and to remove the barriers that remain. As always the key to success is not merely the policies themselves, but whether they can be implemented successfully. And, it is here that Occupational Therapy potentially has a vital role to play.

The role of occupational therapy in meeting the challenge

The modernisation programme envisages an expanded role for Occupational Therapy in promoting independent living and social and economic participation. This will create both challenges and opportunities for the profession.

In Realising the Potential, your College (of Occupational Therapists) outlines the essential purpose of Occupational Therapy as promoting independence not only in terms of physical functioning but also in terms of all aspects of 'occupation', including paid or unpaid work, education, and participation in social and leisure activities. Most importantly, perhaps, Realising the Potential defines the role of OTs as "problem solvers who empower people to take control of their lives."

These definitions of the purpose and role of Occupational Therapy clearly sit very well with the concepts of independent living and full inclusion which are at the heart of the DRC's vision. However, there are a number of obstacles - many of which, I should stress, are not

of OTs own making - which so far have prevented the full enabling potential of Occupational Therapy from being realised.

Indeed, the 30 years since the Tunbridge Report was published have, in many ways, seen a narrowing of the role of Occupational Therapy.

Occupational Therapy resources are highly concentrated within acute general hospital services and pressure on those resources have meant that Occupational Therapists are able to devote less time than is needed on their steadily increasing caseloads. As a result, people are getting a lower level of service.

A recent inspection of independent living services by the Social Services Inspectorate (SSI) found that inter-agency and multi-disciplinary approaches appear to be working best in areas such as leisure, education, transport and housing. In particular the SSI report highlighted the key role of OTs in relation to improvements to housing access and housing adaptations. Examples of good practice in relation to other key aspects of independent living, such as personal assistance were harder to find however.

Although Occupational Therapists rehabilitation role remains well developed in some specialist settings like spinal injury units, their role within the acute general hospital setting is often limited to facilitating patient discharge in response to the pressure to reduce waiting lists and maximise bed occupancy levels.

As noted in a recent study by the Audit Commission, this often means that: "too many patients, especially older people, are discharged before their potential for rehabilitation has been optimised." (Audit Commission 2000, p. 66)

The Audit Commission report also highlights concerns - which are shared by the Disability Rights Commission and the College of Occupational Therapists - that these trends have resulted in too

much focus on quantity and outputs, at the expense of quality and outcomes.

The pressures on OTs resources have also had a detrimental impact on the re-deployment of OTs to work in the community as recommended by The Commission of Enquiry on Occupational Therapy chaired by Louis Blom-Cooper in 1989. Even now, 12 years on, there has not been any significant shift in resources to enable this to happen. (College of Occupational Therapists, 2002, p. 10)

This is not good news for disabled people and is significantly hampering the enabling potential of occupational therapy to contribute towards the promotion of independent living and inclusion. The situation is summarised very well in the College's own consultation document on strategies for modernising Occupational Therapy.

"Occupational therapists have witnessed the steady decline in hospital based rehabilitation and been unwilling (and often powerless) partners in people returning home with preventable levels of dysfunction and dependence. Many rehabilitation units have closed down. Traditional links with employment services to help adults with the potential to return to work (at one time a primary role of occupational therapy services) have diminished and the emphasis has moved to essential activities of daily living - or basic survival in self care. People with an illness or disability have lost out as a consequence of this reductionist model."

(College of Occupational Therapists, 2002, p. 8)

This summary of the current state of Occupational Therapy services shows quite clearly that OTs have valuable knowledge and resources which can be used to support disabled people's aspirations for independence and inclusion, but these need to be re-deployed in different ways to maximise the benefits.

So what needs to change?

Joint working

Given the interdependence between the variety of barriers faced by disabled people there is clearly a need for a much more sophisticated, co-ordinated and - dare I say - joined-up' approach to facilitating their removal. It is not surprising then that we have seen so much emphasis placed on joint working between various agencies - including Occupational Therapy and other Allied Health Professions - in recent policy developments. But translating this into everyday practice has so far proved challenging to say the least.

As Occupational Therapy - almost uniquely - cuts across the health and social care interface, as well as having a role in employment support, OTs are often particularly hampered by the generalised problems with joint working. A recent inspection of independent living arrangements for younger disabled people by the SSI found that inter-agency and multi-disciplinary approaches appear to be working best in areas such as leisure, education, transport and housing. In particular, the report notes that OTs have played a key role in relation to improvements to housing access and housing adaptations. Examples of good practice in relation to other key aspects of independent living, such as personal assistance were harder to find however.

The SSI report also emphasised the role of Occupational Therapy in promoting rehabilitation and independence but noted that there was little emphasis on rehabilitation outside of the OT teams they looked at. Most significantly, the report noted that: "the potential contribution of occupational therapy was often limited by organisational arrangements and by ambivalence and ambiguity about whether OTs were primarily assessors or providers." (SSI, 2000, p. 22)

Similarly, the Department of Health Joint Strategy Group on OT in 1997 concluded that::

"occupational therapy services need to be more fully integrated in the thinking and practice of social services departments the potential contribution of occupational therapy to policy and management was not fully realised in most of the inspected councils. Linking the thinking - the theme of a recent occupational therapy stakeholder conference programme - had yet to occur in most areas."

(SSI, 2000, p. 54)

Supporting employment

It is a similar story if we look at how other agencies work with OTs in the area of employment support for disabled people.

The SSI recently carried out an inspection of Welfare to Work (SSI, 2001) which found that:

councils were not generally engaged with 'employment-ready' disabled people and most did not see supporting disabled people in employment as a high priority;

existing employment schemes focused on people with learning disabilities or mental health problems with little attention to people with physical disabilities or sensory impairment;

provision of information to help disabled people wanting to work was generally poor;

health agencies did not pay much attention to employment as part of rehabilitation;

and, most significantly perhaps,

the limited success of local Welfare to Work schemes was more by chance than design.

(SSI, 2001)

The DRC would agree with the comment on the report from the College of Occupational Therapists that: "Sadly, there is little evidence that Welfare to Work has been grasped for what it is, namely an opportunity to restore to mainstream practice consideration of disabled people's occupational needs by improving their opportunities for employment." (COT, 2002, p. 14)

The Disability Discrimination Act protects people who meet the Act's definition of disability and obliges employers with 15 or more staff to make 'reasonable adjustments' in the workplace to accommodate the requirements of employees, or potential employees, who are disabled. This can involve adapting buildings or equipment or providing equipment. OT's have the skills required to advise individuals and employers about reasonable adjustments. What is now needed is greater use of OT's in helping disabled people retain their jobs and settle into new ones. You have the skills, now is the time to use them.

It is clear that there are difficult problems to overcome before the enabling potential of occupational therapy can be realised. One of the most important challenges will be to translate the principles of independent living and the holistic philosophy of rehabilitation into mainstream practice. The key to achieving this is to go back to where it all starts - the process of assessment.

Getting assessment right

Appropriate and quality assessment practice is the starting point for producing the kind of support disabled people really need. So much depends on getting assessment right and, as they are often closely involved at the coal face, Occupational Therapists have a crucial role to play in this.

Assessment needs to be focused on user involvement, enable informed choice, and promote the use of creative, client centred,

solutions to disabled people's support needs. We also need to encourage a greater emphasis on concrete outcomes - based on disabled people's own aspirations - rather than service inputs and outputs.

Most importantly we need to encourage a shift in focus away from limitations and problems with individuals towards looking at what external barriers people face and what opportunities they are being denied. In other words we need to adopt more of a civil rights approach to assessment. OT's are already playing a part in trying to bring about such change and the DRC welcomes and encourages their efforts.

One of the first practical problems which needs to be addressed is the lack of focus on rehabilitation and its importance in enabling social and economic participation.

Many Social Services OTs tend to work in separate specialist teams. There are advantages to this in terms of providing a specialist focus but such separation often contributes towards a lack of co-ordination and effectively sidelines some of the rehabilitation focus of their work from mainstream care management. (SSI, 2000)

This marginalisation of the rehabilitation focus of OTs work also contributes to a lack of unity and integration in the assessment process as a whole. As noted in the recent SSI inspection of independent living services: "Many assessments and care plans lacked a holistic approach, were insufficiently integrated with health and were still service rather than needs-led, failing to specify planned outcomes." (SSI, 2000, p. 7)

Another key obstacle to developing more enabling assessment practice is the reductionist model of rehabilitation that has narrowed the focus of occupational therapy to personal activities of daily living

or self-care. "This has often been to the exclusion of disabled and older people's wider occupational needs." (COT, 2002, p. 14)

Support for personal care, day to day functioning, basic life skills and health and well being are all important, but a wider range of support is needed to overcome the many barriers which disabled people face. This is recognised by the College of Occupational Therapists but the challenge now is to achieve a practical transformation in the ways in which OTs work.

Current government plans for developing single or unified assessments has the potential to help OTs here. The recent Department of Health draft guidance on single assessments - Fair Access to Care Services - proposes that there are four key factors in maintaining a person's independence:

Autonomy - which refers to the extent of choice and control people have over their own lives;

Health and safety - for both disabled people and others;

Managing daily routines - including practical support people need to meet their responsibilities to family members or other dependents;

Involvement - as well as involvement in work, education and learning, family life, social and community activities this also includes recognition of individual's broader social roles and responsibilities.

In future the plan is that single assessments should look at all of these aspects of independence in the round and assess the degree of risk - both currently and longer-term - attached to failing to meet an individual's needs.

The DRC welcomes this new emphasis on support needs that are essential to maintaining independence. We are concerned however that the overall balance between the various risk criteria outlined

are still heavily skewed towards a functional 'life and limb' approach. Factors such as health and safety and daily routine are given greater emphasis than autonomy and involvement in community life whereas, in reality, these are interdependent and are all equally important to disabled people themselves.

The DRC's view is that greater weight should be given to broader social factors such as supporting life goals - returning to, or maintaining employment, for example - and the risks of social exclusion generally.

Similar comments can be made about the International Classification of Functioning, Disability and Health (ICF), an adapted version of which has recently been endorsed by the College of Occupational Therapists.

The components of the ICF relating to social and economic participation and the interdependence between health or impairment and societal barriers have been greatly expanded compared with its predecessor - the International Classification of Impairment, Disability and Handicap (ICIDH). The addition of a completely new classification relating to civil and human rights is also a particularly welcome development.

The key will be how the new classification system is actually used as a tool for assessing the barriers to participation faced by disabled people and, consequently, the kind of interventions recommended.

Despite the expansion of the social and rights based components of the ICF it is difficult to avoid the conclusion that the overall balance of the new classification scheme is still skewed towards medical conditions and functional limitations.

This is not to say that functional limitations are irrelevant - that would hardly be either sensible or particularly helpful to the person being assessed. By the same token, using environmental, economic or other external barriers as a starting point without reference to the

individual is equally likely to fall wide of the mark in terms of identifying the barriers a person might face in their own lives. The real challenge - which the ICF has not really met satisfactorily - is to develop assessment practice that treats individual factors and external barriers as genuinely interdependent.

It is to be welcomed then that the College of Occupational Therapists have proposed that the ICF should be set within the wider context of the World Health Organisation's Ottawa Charter for Health Promotion. The Charter emphasises the of health professionals 'advocates', 'enablers' and 'mediators' as well as the crucial concept of 'enabling occupation':

"The Charter recognises as pre-requisites for health - peace, shelter, education, food, income, a stable eco-system, sustainable resources, and social justice and equity. Many of these are dependent on, or manifest by, people's occupations - occupation encompassing all manner of 'doing'. That raises the important notion of occupational justice which, in a broad sense, is about the just and equitable distribution of power, resources and opportunity."

(COT, 2002, p. 21)

The DRC would agree with the view of the College of Occupational Therapists that this approach represents a more creative and enabling way of looking at how occupational therapy might better address disabled people's needs and aspirations.

Supporting human and civil rights.

I've said that one of the key challenges for all the supporting professions will be to develop assessment practice that treats individual factors and external barriers as genuinely interdependent and that focuses on the outcomes disabled people aspire to. In the context of the DRC's vision of full participation for all disabled people, the underlying aim of assessment is therefore to support

disabled people in securing the same help civil and human rights as every other citizen.

Truly enabling assessment should be about exploring whole range of barriers which are preventing someone doing what they want to achieve:

"Assessments should identify: what someone wants to achieve, and what is getting in the way. Instead of asking 'What is wrong with this person', a needs-led assessment asks 'What is wrong for this person?'

Assessments should ask: Which human and civil rights are being contravened? Which need to be promoted, improved, or extended?"

(Morris, 2002, pp. 4-5)

Let me give you a couple of examples.

The first is a story about a 29 Year old woman called Jane. She lives in a residential home where only two care workers understand how she communicates. The home has two large buses but only one volunteer driver so Jane can rarely go out other than to the day centre twice a week when transport is organised by the local authority. Jane ceased her full-time education at the age of 19. Jane's parents live 100 miles away and can only afford to come to see her four times a year. Their home is not physically suitable for her.

Jane is being denied the following human and civil rights:

- Communication and freedom of expression

- Privacy and a family life

- Opportunities for socialising

- Opportunities for maximising her potential.

It is easy to see that this in fact also a list of Jane's needs. Seen this way, meeting her practical needs is exactly the same thing as promoting her human and civil rights.

The second example is a story that will be familiar to many of us here today.

Neil is 42 years old and works full-time. His aspiration is to continue working but he has a progressive condition and is having increasing difficulty with getting up and dressed in the mornings. He struggles to do this without help but has started to be late for work on a regular basis. He is currently applying for help with taxi fares through the Access to Work scheme but is having difficulty negotiating the bureaucratic process involved.

The barriers Neil is facing include:

- Lack of personal assistance at the times he needs it

- Problems with access to employment support

- Problems with bureaucracy.

These barriers clearly pose a threat to Neil's independence, as there is a risk that he will not be able to continue working.

Risk and risk taking

Consideration of the threats to independent living posed by disabling barriers also points to the need for a re-think about traditional approaches to risk. In the past, rehabilitation professionals - and the 'caring' services generally - have tended to adopt a narrow, restrictive and over protective view of risk and risk taking by disabled people. This is not compatible with the goals of promoting independent living and full participation. A more realistic and positive approach is needed.

Positive risk taking is an essential part of everyday life, which enhances independence and choice. There is currently too much

emphasis on controlling risk. Occupational Therapy has to be about enabling risk taking as well, starting from the premise that individuals are capable of taking risks unless there are strong indicators that this is not the case. Unreasonably denying disabled people the opportunity to take the same risks as anyone else is more than just over-protective - often it can amount to denying their human and civil rights.

Recent debates over the impact of the Health and Safety at Work regulations on lifting and handling for disabled people provide a clear example.

Several commentators, for example Professor Brian Doyle, have referred to health and safety as the last refuge for disability discrimination and this has certainly been borne out by the recent DRCs work in this area.

Many disabled people have recently been experiencing a number of problems with support arrangements that involve any manual lifting and handling. In several cases people have been told by their local authorities or care agencies that staff would no longer be able to perform any manual lifting and handling operations, or that such support would be restricted in order to comply with health and safety at work regulations. In many cases these restrictions have severely compromised disabled people's independence.

However, legal advice obtained by the DRC indicates there is no legal justification for the kinds of restrictions which some local authorities and care agencies have imposed, and that the interpretation of current regulations goes beyond what is required in the avoidance of risk to workers.

Consequently, in partnership with the National centre for Independent Living and others - the DRC has been working closely with the Health and Safety Executive on production of their new lifting and handling guidance for home care service workers. When we first became involved the first drafts of the guidance were far

from satisfactory in terms of balancing the health and safety needs of care workers with the requirement to support and enable disabled people.

Since then DRC has successfully negotiated a number of changes to the Health and Safety Executive guidance to address these problems. For example, the guidance now emphasises the importance of support services in terms of combating social exclusion and promoting independent living. Most importantly, we have secured inclusion of a key statement making it clear that any unreasonable restrictions on the design or delivery of support services may compromise disabled people's rights under the Disability Discrimination Act and the Human Rights Act.

There are still remaining concerns about the overall balance between protecting the health and safety of care workers and the rights of disabled people but there is a commitment from the HSE to work with DRC to make further changes to address these in subsequent guidance.

Again, while we have made real progress on this issue, the key challenge in the future will be to ensure that the guidance is actually implemented in an enabling way.

Resurrecting employment rehabilitation

As I've already said, employment is, for many disabled people, an absolutely crucial part of independent living. Disabled people have almost twice the unemployment rate and almost half are economically inactive (unemployed and either not seeking, or not available for work, or both) compared to 14 per cent of non-disabled people. There is also clear research evidence that disabled people want to work. According to data from the Labour Force Survey, disabled people make up half of those who are not employed but would like to work and one third of those classified as available to start within a fortnight. (Witcher, 2001, p. 12)

Of those who become disabled while in work, one in six lose their employment during the first year after becoming disabled. By implication, improving retention could make a substantial difference to overall rates of employment among disabled people. (Burchardt, 2000)

Also, although recent initiatives in which OTs have played a role have had some success in helping disabled people to return to work, the benefits of such interventions have not been distributed equally among all groups of disabled people. For example, people with mental health problems have unemployment and economic inactivity rates of well over 80 per cent. Occupational therapists are part of the multi-disciplinary teams serving this group and have a key role in supporting people to work.

So, what kind of occupational therapy do we need to help maximise disabled people's economic participation?

First, occupational therapy needs to address people's aspirations for real jobs with real salaries. All the evidence suggests this is far more effective than doing 'preparation for work' type activities such as social skills training, IT training and so on. The thing that helps people get the confidence and skills to return to employment is to start working in a real work situation, with lots of individually tailored support. Paid work is also usually valued more by disabled people than separate 'therapeutic' type activities.

Further evidence comes from the recent SSI inspection of Welfare to Work schemes that looked at a variety of 'occupational' schemes in areas such as light industrial manufacturing, horticultural and catering. Although these "provided a real sense of worth" for the people who used them, they produced "little success in enabling disabled people to move on to open employment." (SSI, 2001, p. 3)

Second, we need a more proactive approach employment support to try to ensure that as few people as possible have to leave work in the first place following the onset of disability.

One of the main flaws with Welfare to Work is that support only kicks in when people are already well and truly detached from the labour market. There has been little attention paid to job retention measures, although the new job retention pilots are a welcome initiative which we hope can be successfully expanded as soon as possible.

Once detached from the labour market chances of re-employment can diminish quite rapidly and, even if people are able to return to work at a later date, it can be difficult to regain the same level of skills, confidence and work discipline. All of this suggests there is scope for greater proactive OT involvement in the workplace in addition to supporting people who are already unemployed.

This also means that occupational health assessments must relate to the particular individual in the particular job and that OTs need to be working closely with individual employers to advise them on how they can best assist with retaining disabled employees. The DRC can help here as well by making sure that employers are aware of their obligation to make reasonable adjustments required by the DDA.

Finally, if we are going to stop people becoming detached from the labour market it is essential that referrals to, and interventions by, OTs are instigated as quickly as possible. The present situation where referrals and assessments can take several weeks or even months seriously weakens the effectiveness of occupational therapy support. OTs cannot resolve this on their own however. Greater awareness is needed among referring agencies (particularly GPs) and OTs themselves need to be adequately resourced if they are to be able to deal with all their case loads in a timely fashion.

The problems associated with awareness of, and speed of response to, disabled people's rehabilitation needs among GPs in particular often seems quite intractable. Professor Tunbridge noted more or less exactly the same concerns 30 years ago. The solution

proposed in the Tunbridge Report is also just as relevant today as it was then:

"Few doctors other than those specialising in rehabilitation can be expert in all the intricacies of a complete rehabilitation service but they should be made aware of the potentialities of such a service and be willing to seek and utilise the experience of those with specialised knowledge at the earliest opportunity."

(Department of Health and Social Security, 1972, p. 22)

At a time when there is such level of unmet demand for the kind of support that Occupational Therapists can offer it is, at best, curious that their services are still relatively underutilised in this way 30 years on from the Tunbridge Report.

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Promoting a Positive Response within Health Social Care Services

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RCN July 2002**

Promoting a Positive Response within Health & Social Care Services

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1. Introduction

Good morning ladies and gentlemen, may I start off by saying what a pleasure it is to be here today. Thank you for granting me the

opportunity to speak, representing the Disability Rights Commission (DRC).

At the outset, Madam President, I would like to acknowledge the work undertaken by the Royal College of Nursing (RCN) - for example, in setting professional standards, networking, awareness raising, policy and research.

2. Aims & Objectives

I hope that you will all leave today having gained greater understanding into the DRC's work, with confidence in our ability to impact on modern society - for the benefit of all, not just individual disabled people. Overall, the aims of my presentation today are to:

- gain commitment to disability equality; and,
- spread knowledge about the DRC's strategies for leading change.

In terms of learning outcomes, I hope you will go away today having understood:

- the DRC's role, functions and activities;
- the scope of the Disability Discrimination Act (DDA) 1995 and associated legislation;and,
- the agenda for legal reform and initiatives for developing best practice.

3. Areas to Address

The areas that I will cover today include:

- background to the DRC and our work;
- overview of legislation;
- review of the DRC activity;

current issues on disability, especially those relating to health and social care; and,

future strategies for tackling discrimination, including raising awareness and legal enforcement.

4. Scope

The DRC builds on decades of work by disabled people and their organisations. As a result, there is now a positive climate for change, with a greater determination to enforce rights, coupled by attitudes and practices becoming more inclusive.

The culmination of campaigning by disability organisations came with the DDA, although there were weaknesses with this legislation - not least with the lack of enforcement powers. Due to continuing pressure from disability groups and recommendations of a Government Task Force, Parliament approved the Disability Rights Commission Act (DRCA) 1999. On 25 April 2000, this new body - the Disability Rights Commission (DRC) - opened its doors for business.

5. Our Vision

There are 8.5 million disabled people in Great Britain. Discrimination and disadvantage are widespread amongst them. As a result, from the outset, the DRC has set itself the goal of achieving:

"A society where all disabled people can participate fully as equal citizens".

The DRC's vision therefore represents a very major programme of change, which will be taken forward primarily through advice, conciliation and where necessary, legal enforcement. The DRC will also deploy the other instruments available to it where these will

have a major impact, including publicity campaigns, standard setting, development of good practice and providing policy advice.

6. Context

In order to achieve our broad objectives, it is important to place the tasks ahead in context. So, where do we start? Lets look at some of the facts about the 8.5 million disabled people in Britain.

Disabled people are twice as likely as non-disabled people to have no qualifications.

There are 6.5 million disabled people of working age, less than half of them having a job - representing only 12 per cent of the workforce. The other half are on means tested benefits, not having worked for over a year.

The annual average household income of disabled people is around £16,000 compared to nearly £22,000 for non-disabled counterparts. This situation is further compounded by the extra costs incurred by having an impairment.

Nonetheless, the spending power of disabled people is estimated to be over 40 billion per year. Although 75 per cent of small and medium sized businesses recognise the commercial benefits of improved access, they tend to think of ramps for the relatively small numbers of wheelchair users (less than 5 per cent of disabled people), rather than enhancing lighting or providing a seat.

Surely society can draw more effectively on the talents and resources of disabled people. If we continue to ignore these untapped potentials, society will ultimately suffer from its failure to provide opportunities and reap the rewards. I suggest, hardly good business sense.

7. Legal Framework

Let us now look at the current legislative framework.

7.1 Disability Discrimination Act (DDA)

The DDA provides individuals with the right to challenge discriminatory behaviour through the courts or employment tribunals. However, it also allows discrimination in certain circumstances to be legally justified.

Discrimination, in its main sense, refers to unjustified ways in which disabled people are treated less favourably because of their impairment, compared to the treatment of non-disabled people in similar circumstances.

Part II of the DDA - employment - states that it is unlawful for organisations who employ more than 15 people to treat disabled employees, or potential recruits less favourably than other workers for reasons connected to their disability, unless they can justify this as being reasonable. The threshold of 15 employees will be removed in October 2004, as will the exemption for police, fire fighters and barristers. This is possible by virtue of the EU Framework Directive on Equal Treatment.

The legislation also requires employers to take reasonable steps to prevent disabled people from being disadvantaged, when compared to a non-disabled person, as a result of any arrangements they might make or because of the physical features of their premises. So, when recruiting a Medical Secretary, for instance, you may need to use a sign language interpreter in an interview or adjust some of the job tasks amongst the team to effectively address the needs of an individual disabled person. These would be reasonable steps.

Some people suggest that the costs of making reasonable adjustments are prohibitive. Yet, the evidence speaks for itself. We have found that 64 per cent of employers making adjustments incurred no extra costs; whilst 40 per cent of those making changes spent less than £1,000 to that end.

Bearing in mind the developing debate on joint equality initiatives, it is worth noting that "reasonable adjustment" is a concept unique to disability legislation. This may well suggest having a continued focus on disability through a separate Commission.

(S10) DISABILITY DISCRIMINATION ACT - ACCESS TO SERVICES

Part III of the DDA - Goods, Facilities and Services - applies irrespective of the size of the service or of whether payment is required.

Since 2 December 1996, providers of goods, facilities and services have no longer, unless this treatment can be justified, been able to treat a disabled person less favourably than other customers.

Since 1 October 1999, providers have had a duty to make reasonable adjustments by changing policies, practices and procedures that make it unduly difficult for disabled people to use the service. As a medic, you may need to advise a blind person of some confidential information. In terms of the DDA, you don't have to send a Braille letter as they may prefer, but impart that information in some other means, such as by telephone. The confidential service is provided, but in a different way and which is reasonably suited for all parties concerned.

From October 2004, service providers will be required to make reasonable adjustments to physical features if they create barriers to access. Our recently revised Code of Practice incorporates these new duties.

I trust health providers and professionals have been planning for these changes. The evidence might suggest otherwise, as disabled people find it up to five times more difficult than non-disabled people to use primary health care services.

7.2 Special Educational Needs & Disability Act

Meanwhile, the DRC has been working with the Government to extend the terms of the DDA (Part IV) to cover education. Royal assent on 11 May 2001 for the Special Educational Needs and Disability Act (SENDA) was a significant step forward in civil rights for disabled people. Addressing education at all ages, this legislation will have long-term implications for developing and promoting equality and inclusion for disabled children and young people.

We have been working in tandem with this legislative development, to produce two Codes of Practice. These Codes deal with School and Post-16 Education. I anticipate this authoritative statutory guidance will be widely available in the next few days.

The DRC believes that growing diversity in our schools and colleges will enrich learning and that academic standards will not be adversely affected. We do however, recognise many of the procedural concerns on "statementing" set out in a recent Audit Commission report.

Whilst an institution is required not to discriminate in admission or examinations, its freedom of action may be constrained by the requirements of a professional body. This is precisely why the DRC supported legal action against the General Medical Council (GMC), who used technical grounds to defend their failure in recognising adjustments for a wheelchair user, Heidi Cox. However, we are pleased to note that the GMC has now indicated willingness to enter into discussions about support for prospective and practising disabled doctors. We anticipate that future legislative reform will remove the exemption for qualifying bodies.

7.3 Human Rights & Equality

On 2 October 2000, The Human Rights Act (HRA), 1998, came into force. We have asked the Government to establish regulations,

providing the DRC with powers to take action under this new legislation. However, some form of future joint equality body may well encapsulate the human rights dimension.

The Hepple Report, published within months of the DRC being founded, floated the idea of merging the existing equality commissions. The findings reflected many of the DRC's concerns about such a change. In particular, a body of this kind would be quite diverse, control would be lost by disabled people and we, unlike the other commissions, are at the beginning of our journey to tackle discrimination.

Obviously, the DRC will be collaborating with the Cabinet Review on equality enforcement and looking to secure strategic gains for disabled people, not least by strengthening legislative protection and rights.

8. Services

Anyhow, we have to operate in today's climate, facilitating best practice and enforcing legal requirements where necessary. To this end, the DRC has established six main services: Website, Helpline, case working, conciliation, legal enforcement and practice development.

Nurses and carers have massive contact with disabled people. You are in a prime position to inform disabled people about their rights and how to secure them - if your clients or colleagues are facing disability discrimination. If you would like to keep in touch with developments in our services and news of a range of disability discrimination issues, visit our website and subscribe to the DRC's regular email bulletin.

8.1 Website

Our Website came into operation in autumn 2000. It provides a guide to the DRC, its powers and services; together with information

on good practice and legal outcomes. In 2001-02 some 288,030 visits were made to the DRC website.

8.2 Helpline

During the course of our first year, the Helpline received in total over 65,000 contacts, moving on an upward trend in the second year to 78,000 calls. Demand has been amazingly high, substantially above Government targets. During this period calls also expanded in terms of complexity of the matters raised, but many "quick wins" have been achieved - for example, applying occupational health assessments. Disabled people and their advisers make the majority of calls, with a further third or so by employers, service providers and their advisers. In the last financial year 1,255 or 11 per cent of calls came from the health sector. Furthermore, Helpline satisfaction levels are very encouraging - 87 per cent of disabled people and 95 per cent of professional callers would use the service again.

8.3 Casework

Turning to Casework, this in-house service considers more complex individual cases referred to it. The service aims to secure solutions to the difficulties and discrimination experienced by a disabled person with an employer or service provider. In many cases it is possible to resolve the difficulties through discussion and sharing of good practice. Outcomes secured by this service have included a local authority changing the venue of its Council meetings, a telephone company changing the format of bills for a blind customer, an employer being informed of how to adjust a steering wheel for an employee with a prosthetic hand and a building society making backdated provision to enable a woman with learning difficulties to secure the benefits of a share issue. Last year our Casework team supported 2,800 individuals, 870 having been carried forward from the 2,200 cases referred in the DRC's first year. Thus, a total of 4,190 cases have been handled in this two-

year period. Some 40 or 6.2 per cent of cases last year came from the health sector.

8.4 Conciliation

Through Mediation UK, we have established a conciliation service on DDA goods and service cases. Meanwhile, The Advisory Conciliation and Arbitration Service (ACAS) handles DDA employment disputes, settling around 40 per cent of cases referred to it.

8.5 Practice Development

The DRC wishes to build partnerships with key stakeholders, to help spread good disability practice. Our work involves the developing quality standards for widespread application, as well as programmes supporting practitioners to promote change.

8.6 Legal Enforcement

The DRC wishes to use its legal powers to support individual cases in ways that will have the greatest impact. We aim to use our legal powers to clarify aspects of the DDA that are currently untested and to tackle widespread forms of discrimination. We intend to support around 75 cases this year, following 41 taken forward in our first twelve months and a further 61 cases last year.

The DRC has already taken forward a wide range of cases, closely linked to our strategic priorities and aimed at testing the boundaries of the law. Issues covered have included:

- the dismissal of a local authority accountant with a history of depression (successful before the Court of Appeal);

- denial of DDA protection to an applicant for the post of asylum support adjudicator (case rejected by the employment tribunal at first instance, as it was deemed to be an Office Holder);

refusal of hospital to consider reasonable adjustments for a nurse of 18 years' service who developed arthritis; and, failure of a golf club to permit use of motorised buggy by a man with reduced mobility.

9. Reform

Case law has played a major part in developing our proposals for further reform - for example, removing exemptions for statutory office holders and qualifying bodies.

From the outset the Commission has called for implementation of all 154 DISABILITY RIGHTS TASK FORCE (DRTF) recommendations. The DRC has accordingly welcomed the Government's response to the DRTF ("Towards Inclusion - civil rights for disabled people"). In its response, the Government undertook to legislate on the great bulk of the recommendations, many requiring amendments to the DDA and other legislation. On the other hand, it has invited the DRC and others to take forward the Task Force's non-legislative proposals. This represents a significant programme of reform for disabled people.

So, drawing on the DRTF, case law and numerous representations made to us, the DRC is currently publicly consulting on a range of measures that may effectively strengthen disability legislation. We hope that the RCN and others here today will take the opportunity to respond on proposals that include:

the public sector should have a duty to promote equalisation of disabled people;

the justification for failing to make a reasonable adjustments should be removed; and,

the tax system should support organisations to make premises accessible.

We intend to submit proposals for reform to the Government during Autumn 2002. The Government has already accepted many of these proposals, yet it is now time for it to translate pledges into action.

10. Thematic Plans

Like most organisations, the DRC has been in danger of being swamped by a multitude of legitimate concerns. We have consequently focused our work around a dozen thematic areas, namely:

- an effective legal and statutory system;
- accessible and more inclusive education;
- a fully accessible built environment;
- responsive health and social care;
- fully accessible transport; and,
- opportunity in employment.

11. Responsive Health & Social Care

I now wish to concentrate on one of these priorities. So, let's look at where you - as health professionals - can make a real and lasting impact: namely, health and social care. Don't dismiss the other thematic areas as these do still have relevance to the health and social care sector - for example, education and employment of disabled nurses, accessible primary care practices and hospital transport services.

11.1 Health and Social Care Policy

The DRC's goal in this field is:

"Equal and fair treatment of disabled people in health and social care services - as customers, patients and employees".

Whilst many disabled people receive excellent service from health and social care staff, there is nonetheless worrying evidence of discrimination being experienced. Far too often assumptions are made about the quality of life for a disabled person, meaning that albeit subtly, we are given less opportunity for treatment than our non-disabled peers.

The DRC has also found evidence of children being excluded from decent education, just because there is nobody to dispense their diabetes medication at lunchtime or to take them to the toilet. We are working actively with teachers, parents, disabled students and others to promote examples of "what works" in inclusive education.

It is evident from the media coverage of the Miss B and Diane Pretty cases, that there is still a widespread view in our culture that the life of a severely disabled person is a life not worth living. We want to challenge that assumption - to ensure that severely disabled people are supported to make the choice to live, not only the choice to die. The NHS can set the lead by, for instance, having non-discriminatory "do not resuscitate" policies. We are currently gathering evidence on these and aim to support and spread the best work we find.

Social care services are ideally placed to support the dignity and independence of disabled people - for example, by enabling them to employ personal assistants to facilitate at work, enable them to go out socially - or otherwise live their life as any non-disabled person would expect. Consequently, we plan to produce policy proposals to reduce inequality in direct payments and aim to secure national central and local government commitment to equitable access.

The DRC, working in partnership with the National Centre for Independent Living (NCIL), has successfully negotiated a number of changes to the Health and Safety Executive (HSE) guidance

concerning the manual lifting and handling of disabled people. This includes a clear statement to the effect that, the HSE does not advocate "no lifting" policies and there is no justification for any unreasonable restrictions on support provided to disabled people. Guidance has undoubtedly improved, but not yet sufficiently enough. The HSE is committed to work with the DRC, NCIL and the Department of Health on the production of further guidance, to fully address outstanding concerns about the balance between the health and safety of care workers and the rights of disabled people.

Prior to the HSE Guidance, some organisations had policies that resulted in blanket bans on lifting being imposed. Frankly, using risk assessments to diminish disabled people's rights is unacceptable.

Unhelpfully, this has been exacerbated by the RCN's "Green Book". Although focusing on hospital settings, it has been applied rigidly in relation to support provided for disabled people living in the community. Ultimately, in our view, although it is laudable to have rules about people being safe at work, they should not unreasonably curtail life choices of disabled people.

As a result, the DRC has given expert evidence in a case concerning two sisters seeking judicial review on their Council's decision that prevents carers from lifting. This case has now been held over for a hearing in September 2002, but interim support arrangements have been put in place - stating that where equipment is not a practical solution the sisters will be lifted manually by their carers. In situations like this equipment can help, but as the Audit Commission reported last week, support is generally of poor quality and availability is quite patchy.

During the Court hearing the DRC worked with the local authority to create a policy that complies with the current HSE guidance and finds a balance between the rights of carers and those of disabled people. Sure, there is a difficult balance to strike here. Nonetheless, we hope that nurses and carers will now apply the HSE guidance

when working with disabled people in their homes, rather than taking the RCN's more restrictive approach - as I said, dealing with hospital situations rather than community living.

11.2 Health & Social Care Practice

Disabled people also find that staff are often not trained to communicate with them effectively - for example, a deaf person may be told no British Sign Language interpretation is possible; or, a person with learning difficulties is given information leaflets on their physical condition that they cannot read and have no way of understanding. The commitment in the NHS Plan to ensure all health staff are trained in communicating with patients provides an excellent opportunity to put this right.

The NHS is the largest employer in Europe - since the disbanding of the Red Army. The NHS could lead the way in demonstrating best practice in employing disabled people. Many people say to me, when disabled people are colleagues or indeed bosses, that really transforms culture. But, currently the NHS isn't in that leadership position.

It is disappointing to note that policies and practices still frequently discriminate against disabled people. Considering pressure experienced by health services today, it is shameful that skills of many disabled people are being cast aside. Frequently, occupational health screening dwells on the conditions and dismisses skills of disabled people. Many health professionals perceive us as passive recipients of care, instead of being active citizens with ability to contribute to society. So, yes, it is possible to employ disabled people in more than stereotypical roles - for example, Nikki Heazel is a nurse at Birmingham City Hospital, where she practices successfully - working with one arm.

Health providers currently lack creative approaches to the recruitment, progression and retention of disabled people. Instead

of having a dialogue on possible solutions, they all too often impose a position. According to Income Data Services, DDA claims are relatively low in the health sector, probably due to under-representation in the workforce. However, claims that do emerge are proportionately more likely to reach Tribunal, because of the inflexibility of Health Trusts.

The Government is committed to introducing a positive public sector duty - similar to that under the Race Relations Act - and we'd like to see health and social care services thinking now about what that will mean for their services. To sum up, we would like health and social care providers to clearly conceptualise their role as fundamentally about supporting social inclusion and independent living - for example, nurses could be at the forefront of ensuring that treatment and care are not ends in themselves, but ways of enabling people to pursue their own goals.

In terms of delivery, the NHS Plan and the Modernisation of Social Services aim to transform the relationship between professionals and users. This transformation could be harnessed, to ensure disabled people are treated with dignity and respect. Unsurprisingly, therefore, we are keen to raise disability equality up the Government's modernisation agenda. Next year we aim to ensure that disability rights are included in the Business Plans and methodologies of at least three of the new health and social care standard setting and review bodies.

In our quest to secure "responsive health and social care", the DRC will work with the Department of Health to raise the profile of disability equality. Besides joint action to take forward the DRTF Recommendations, we will encourage the integration of disability equality into key areas, including:

- Primary Care Trust development;

- valuing people (especially advocacy);

producing publications and personal information in accessible formats;

providing translation and interpreting support;

giving professional training; and,

improving communications between health professionals and disabled people.

These are indeed challenging issues for the sector to address. We do not expect health and social care professionals to deliver against an impossible agenda - there is already plenty of pressure in the system. We want to ensure that health services have specialist training to deal with the realities of work and the right resources to achieve this vision.

12. Strategic Approach

12.1 Awareness and Enforcement

The DRC has a key role to play in raising awareness of disability and in tackling outdated stereotypes. Effective communication of significant legal cases and of the application of good practice can both have a powerful and persuasive effect. The Commission wishes to raise awareness of the DRC itself and in particular of our services and the other ways in which we can promote the rights of disabled people.

The DRC aims to shift attitudes, lastingly. We have to this end already produced award-winning materials, such as our first Annual Review and the promotional video - "Talk". These demonstrate how organisations can communicate inclusively.

The central challenge for the DRC takes the form of transcending the individualism that underlies the legal process so that existing legal rights can be realised more widely. If the legal resources available to the DRC are to be used most effectively, their

application must be strategic, informed by broader policy and communication interests, rather than merely reactive.

Consequently, the DRC is striving to get the right balance between raising awareness and legal enforcement. We prefer change by consent, but will use legal tools at our disposal if necessary, including powers of formal investigation.

12.2 Priorities

So let's now turn our attention to the DRC's overall strategic direction. Between now and 2005 our work will be directed to meeting five strategic objectives:

- all disabled people to secure comprehensive rights in practice;

- all organisations - employers and service providers - to apply best disability practice and meet statutory requirements;

- in key sectors (including education, employment, the built environment, transport, health and social care), bring to an end the legal, policy and practical barriers, which disadvantage disabled people;

- shifting public attitudes to inclusiveness and equality for disabled people; and,

- building a high-performing and exemplary organisation.

12.3 Implementation

We intend taking forward this ambitious agenda by:

- delivering high quality services;

- providing leadership and an authoritative, objective and independent voice;

- taking a comprehensive approach, concerned with all disabled people, at all stages of their life and in all communities; and,

working closely and in partnership with disabled people, as well as our wide range of other stakeholders.

13. Conclusion

Chair, ladies and gentlemen, I hope that you feel encouraged by the strategic direction of the DRC and that some of the information given today has been useful. Many thanks for your time and attention. In drawing to a close, the DRC wishes you well with continuing to spread best practice. The Royal College of Nursing has often backed rights for disabled people. This support is appreciated.

Let's briefly recap. I have sought to explain the background to the DRC and activities undertaken in our first two years. We have also cantered through some contemporary legislative and policy issues, not least in the health and social care field. Finally, attention has been given to the DRC's strategic direction.

On that note, to recount, our goal is a society where all disabled people can take part, having a fair chance of succeeding at whatever we choose to do. Yes, we want a society that stops wasting the talents and energies of 8.5 million disabled people (nearly one in eight of the population); where the fact that disabled people are seven times more likely to be out of work than non-disabled people - as is the case in 2002 - would be unthinkable in the future; where neglect or abuse of disabled people in institutions would be rooted out very soon.

It is a huge task to end discrimination against disabled people and to secure meaningful inclusion. However, the DRC is determined to succeed. Much has been achieved since the Commission was established in April 2000 and some firm foundations have been laid for the future. We cannot be complacent, there is still much for us to do. Building on this, and through our longer-term strategies, the

DRC looks forward to working in partnership with disabled people and those public services that work to empower them.

This is an exciting and challenging time, as the DRC begins to dismantle the wall of discrimination faced by disabled people. The Commission intends to make a difference to the lives of disabled people. We have consequently embarked on a long journey, supported by a wealth of partners, working to achieve change. The DRC is striving for "a society where all disabled people can participate as equal citizens". We invite you to join us in that endeavour, and to do so with passion!

Keywords: Disability Discrimination; Disability Rights Commission; Health & Social Care; Legislation; Nursing

Speech by Jane Campbell AGM DIAL UK October 2002

Jane Campbell MBE

I would like to start by thanking colleagues from DIAL UK for inviting me to address you this afternoon in Bradford. I would also like to congratulate the network on its 21st birthday. Whilst the network and its services to disabled people came of age many years ago, it is important to recognise your milestone and to recognise the valuable contribution your member organisations made in helping the foundation of the Disability Rights Commission.

DIAL UK has grown from one small group to a thriving network of 140 member organisations serving, in the last year, over a quarter of a million clients with nearly half a million enquiries. That is a huge achievement of major significance to disabled people.

For disabled people, information is power. DIAL UK and its member organisations have provided disabled people with advice on matters ranging from welfare rights through employment and education issues. Armed with this information, disabled people can secure rights and lead independent lives.

Thus we can immediately observe the crossover between the work of the Disability Rights Commission - the DRC - and DIAL UK. We have, in many ways, a joint agenda and a similar mission - in the DRC's words, achieving "A society where all disabled people can participate fully as equal citizens".

At your AGM two years ago you heard about the emerging priorities and services of the DRC. Statistics can of course tell all sorts of stories and I will use them shortly to show how the demand on the

DRC's public services demonstrates the levels of discrimination still being experienced by disabled people across Great Britain.

But before I do, one of our most recent success stories gives a perfect example of how rife discrimination continues to be. Whilst we will help business, service providers and now schools achieve not just compliance with the law but, ideally, best practice, this case shows how the DRC will support disabled people in litigation if necessary.

Mary, a young woman with learning difficulties and hearing and visual impairments was refused service in a public house, and then asked to leave the premises. Further investigation revealed that two of her friends who also have learning difficulties have been refused service in the same pub. All three, with their support workers gave evidence during the three-day county court case funded by the DRC.

The judge found that the defendants had acted unlawfully and also awarded Mary £3000 in compensation for injury to feelings, an award which is comparable to some amounts that have been awarded in the employment tribunals in recognition of the distress caused to the claimant.

Mary was just one of more than 150,000 people who have made contact with the DRC Helpline since we opened our doors for business in April 2000. The call trends at our helpline have risen from 65,000 in our first year to a forecast 110,000 in this current financial year. Of course not all of those callers have been disabled people and it is important to note that a good third of our contact is with employers and service providers seeking to secure best practice.

What is very important in the operation of our Helpline is a guarantee about the quality of the service being offered and I am interested to see that you work shopped quality standards in DIAL services today. The DRC Helpline is accredited by the Community

Legal Services and is independently audited by both RICA Ability and the Central Office for Information. We expect to have our Caseworking service similarly accredited and tested within the next year. I am delighted that both our organisations are striving to offer services of excellence to our clients.

Of course, there are some people who cannot be assisted by the help line for a number of reasons. For example, some callers raise issues that are not within the remit of the DRC, some of whom we will signpost to, for example, DIAL UK members. In other cases a more detailed investigation is necessary. In the first two years of the DRC nearly 5,000 cases were referred to our casework team.

We have a team of about 20 caseworkers spread across our various offices. Caseworkers will work through a new case with clients and establish if the facts of the discrimination enable us to take the matter forward. In some cases a letter from the DRC produces a solution. For cases involving access to goods or services we have established a free and independent conciliation service. This is still small scale but growing. If disabled people use the conciliation service and fail to reach an agreement they still have recourse to legal remedy. We have found that in many cases this approach has produced better results than we could have achieved through litigation. It is almost always faster.

However, this does not mean a simple return to the old hearts and minds arguments. Many of the agreements we achieve are only possible because people know the law is there in the background and we are willing to use it. Without that law I think much of our work would be unproductive.

We have also established a legal team. In our first year they initiated 45 legal actions and in the last year this grew to 65. To make the best use of our resources we need to take the difficult test cases although there will always be pressure on us to accept any case in which a disabled person has faced discrimination. We have

had some notable successes as well as disappointments. We clarified the definition of mental illness, showed that some aspects of school life were covered by the DDA, although that has been overtaken by the Special Education Needs and Disability Act, and proved beyond doubt that blind people do have the right to take their guide dogs into restaurants regardless of the religion of the restaurant owner.

Defeats have shown the major limitations of the DDA which, whilst disappointing, is still useful in providing ammunition for debates we conduct with Parliamentary colleagues. So, for example, The General Medical Council and other qualifying bodies can prevent disabled people studying medicine as the Heidi Cox case demonstrated, even though, in her case, Oxford University has accepted her onto the course.

That's the sort of discrimination currently not afforded redress by the DDA that we hope our legislative review will help to solve. The consultation period for the review is now complete and we hope to publish the final version shortly.

In tandem, we continue to press the Government to legislate for the majority of the Disability Rights Task Force recommendations. We were expecting the Government to begin honouring its manifesto commitment in the next Queen's Speech. You will have read about our bitter disappointment in having to give way to other priorities. However, the Government does have other legislative tools that it can use to introduce change and we believe that it is going to use them.

Looking further ahead we have the various challenges of more business generated by the Education amendment to Part IV of the DDA - we already have over thirty cases up and running; 2004 and access to the built environment; the lowering of the employment threshold and, of course, the European Framework Directive, which

is partly responsible for the Government's review of the status of the three existing equality commissions.

The DRC has not yet brought a formal investigation. We intend to put that right shortly. We have studied the investigations launched by the Commission for Racial Equality and in particular the challenges they have faced. It is already clear that there exist some rather bright lawyers who are skilled in ensuring that formal investigations do not succeed. We will need to draft the terms of reference with enormous care. One issue is identifying the subject of such an investigation and who the target should be. We are just beginning to unearth a small number of repeat offenders who might well need a formal investigation if they are to follow the DDA. The DRC is open to any suggestions you might have. Our first formal investigation will be relatively modest as it will help us gain experience to fight bigger battles later

Additionally, we must meet targets set by our themed work - Education, Employment, Continuous Improvement, Transport, the Built Environment, Legal & Statutory Framework and finally, Health and Social Care.

Each of these themes are generating key pieces of work that we believe will lead to a real change in society. To demonstrate the type of targets and outcomes we envisage, I'll briefly talk you through some of our current Independent Living - Health & Social Care thematic priorities, of which I am one of the sponsor Commissioners.

We have worked extensively with the Health & Safety Executive and organisations such as the Royal College of Nursing to enable the removal of draconian bans on the lifting and handling of disabled people. To that effect we appeared as an interested party at the Judicial Review of a local authority's policies with regard to lifting and handling.

Colleagues at the Commission are working in depth with the Department of Health to ensure that the provision of access to direct payments becomes mandatory for local authorities, rather than the current permissive situation that means that not all disabled people - particularly, for example, people with learning disabilities - are getting right and proper access, and therefore independence, to direct payments.

Within our Life and Death project work we are now researching the use of do not resuscitate notices placed on disabled people's notes with neither their consent nor their knowledge. Interim findings suggest we have much work to do on developing models of best practice. We will need to work closely with the medical professions to embed and monitor that practice.

Now, looking to the long-term future, the DRC is and will continue to be at the forefront of the debate on any proposed single equality body. Whilst we will be constructive and work with our colleagues in the Equal Opportunities Commission and the Commission for Racial Equality, we will be seeking to safeguard and build upon civil rights for disabled people. The DRC will want to see the levelling up of legislation before the creation of any similar such body. We will also want to be reassured that specialist disability teams will continue to function in a new overarching body.

So, you can see, we have much to challenge us over the coming years. Today's theme is all about Connecting the Network. The Disability Rights Commission is a relatively small, national organisation with, as I have already discussed, a substantial agenda. On our own we cannot expect to achieve the change we all desire. Together however, through formal and informal networks, we can meet those challenges.

We need to reach out to and involve organisations networked into entities like DIAL UK. That is why I and my colleague

commissioners have approved a one year pilot exercise in Partnership Building.

I'm delighted to be here in Bradford today to tell you more about our Partnership Building programme. The project will commence in January 2003 and will be piloted in the Yorkshire area defined by the Yorkshire Regional Development Agency.

Yorkshire has been selected for a number of reasons, but particularly, it has a high concentration of people from black & ethnic minorities. Like all public bodies, we have a positive duty to promote racial equality. Take up of our public services, particularly at the Helpline, is not as high as we would like. We will therefore be testing models in Yorkshire that will better enable people from black & ethnic minorities to be informed and thus to exercise their rights.

The DRC recognises that, being a relatively small national organisation it needs to connect with local and regional organisations, particularly those run by disabled people. We need to gather and learn from grassroots opinion on both our services and wider legislative and policy issues. The Commission is aware that it cannot possibly meet all of the huge demand for services. Neither can it possibly hope to inform all of general public on disability rights and responsibilities.

That is why we need to partner with regional organisations that know their users and are trusted by the same. We need to tap into and feed into the networks supported by those organisations. I hope that, by January 2004, we will have demonstrated models that meet our mutual aims and benefit, ultimately, disabled people leading to sustained changes in society.

At the same time we will be building more bridges with our key national partners - DIAL UK included. We will encourage you to join us and help promote key issues - how to use our mutual services; what 2004 means to disabled people; how to challenge discrimination; learning from each other's experiences.

If I have a challenge to you today it is to join us in proactively promoting rights and responsibilities, to empower individuals to gain their own redress to discrimination and, ultimately, to remove the barriers that stop disabled people from participating in society, fully, as equal citizens.

October 2002

Keywords: Disabled People; Disabled People's Organisations; Disability Rights Commission; Partnerships

Trade Union Congress 11 September 2002

Bert Massie

I should like to start by thanking you for inviting me to speak to you today. I should also like to thank the trade union movement throughout the country for the support you have given to disabled people in our battle for civil rights. Throughout the last twenty years you were at our side giving moral, financial and other practical support as we fought for comprehensive and enforceable civil rights. The Disability Discrimination Act of 1995, though far from perfect, was at least a start. The incoming Labour Government of 1997 recognised the limitations of the DDA and in its Manifesto promised comprehensive and enforceable civil rights. So how has the Government done?

The 1997 administration did extremely well. Within months of achieving office the Disability Rights Task Force, chaired by a Minister, was established with representation from disabled people, employers and, of course, the trade union movement. It made over 150 recommendations when it reported in December 1999. The Government had already acted on one recommendation that was also in its Manifesto: that was to create the Disability Rights Commission. It also took forward the recommendations on education and introduced the Special Educational Needs and Disability Act that came into effect last week. With reference to that, I should like to acknowledge and thank the unions representing teachers for their help when the DRC was drafting the Codes of Practice and in helping their members to understand the Act. The Act can only work with the support of teachers and other people who enable such good education services to be delivered.

The Government within the next year will introduce regulations to enact other recommendations by the Task Force. These will relate to employment. The shameful situation in which over 80% of

employers, those employing fewer than 15 people, are exempt from the employment provisions of the DDA will end. We will also see an end to the situation whereby the General Medical Council can refuse to allow a disabled person to study medicine for no other reason than they are disabled. The DRC very much welcomes these changes. They will change the lives of many disabled people.

However, and it's a big however, many of the Taskforce recommendations cannot be introduced without primary legislation. Disabled people need a new Act of Parliament to amend the DDA and I call today on the trade union movement to support us in demanding new legislation. There has been enormous progress in making buses and trains accessible but it remains lawful for a transport operator to refuse access to a disabled person even if the bus is accessible. They could not refuse someone for the colour of his or her skin or because of their gender but they can do so on grounds of disability: and they sometimes do. One airline charges disabled people for assistance in airports and believes that is fair. There is discrimination in housing and many other areas. We need to extend the definition of disabled people to include people diagnosed as having cancer or who are HIV positive but are asymptomatic. The Government has agreed these changes but has given no indication when they will introduce legislation. It seems certain it will not be this year. How much longer must disabled people wait? It is said that some people have the patience of Job. Compared to disabled people he was a non-starter but that patience is wearing thin. It will snap. Given the age of many disabled people, they will die before they receive the civil rights we were promised in 1997. That is why I call on your support for new legislation to amend the DDA. The Government must turn promises into action and do it soon.

The Disability Rights Commission is just 2 ½ years old. We have a huge task ahead of us and we need to focus on that. However, we must now address the issue of whether there should be a single

equality body to replace the DRC and the other Commissions and to also cover the three new strands that will be given new employment rights. We very much welcome the extension of new rights to cover age, sexual orientation and beliefs. There are common battles to be fought but there are also major differences that need to be recognised and accommodated. It is difficult to have a definitive view on the merits or otherwise of a single equality body because much will depend on the nature and structure of such a body and, from the viewpoint of disabled people, whether it will be able to promote the civil and human rights of disabled people. However, it is difficult to see how such a body can be more advantageous for disabled people than the current arrangements. Moreover, if it is introduced, it will take some years to establish and further years to settle down. This could result in a significant pause in the campaign to improve the rights of disabled people. Once established the proposed SEB will, on current proposals, be serving groups of people who have different rights and facing a hierarchy of oppression. If any new body is to have even a chance of success it must be built on firm and strong foundations. Before creating a single equality body, and I stress the word 'before', the Government must introduce a Single Equality Act.

What do I mean by a Single Equality Act? Well, first we must upgrade the rights for all the groups to be covered by the SEB so all enjoy at least the best available to other groups. It is outrageous that people will face lawful discrimination in the provision of goods and services on account of age, sexual orientation or belief, as the new laws will only cover employment. In the disability field we need to do more than equalize rights. We need the extra rights recommended by the Disability Rights Task Force. The Task Force recommended disabled people should have equal rights to pensions. A recommendation the Government has not even accepted. The current Private Members Bill being promoted by Lord Lester does not go nearly far enough and the Government has shown little indication of interest in a Single Equality Bill. If a Single

Equality Body is established to enforce the current dog's dinner of equality legislation it will force the new body to spend its early years fighting for changes that the Government should introduce long before such a body is established. Without such a Single Equality Act there must be serious doubts about the commitment we as a county put on creating an equitable society for all our citizens.

I think therefore that trade unions and your members must think long and hard about any proposals that emerge from Government. If we can upgrade people's rights and ensure that the proposed SEB is truly able to represent the various groups including disabled people, and enable disabled people to control our destiny, the new body could have a future. If not, we should be wary of seeking neat and tidy solutions to our difficulties, which in the longer term will be unable to meet our needs and could represent a significant backwards move in the fight to create a society in which disabled people can participate fully as equal citizens. There is little point in moving the deckchairs of current Equality Commissions while ignoring the iceberg of discrimination that blights our lives. Let us attack the iceberg first.

The Union movement has done much to assist disabled people and your disabled members. Your concern and support is shown by some of the motions you are considering this week. With your help we can all continue to make progress and today I call for that help.

Thank you for your attention.

Keywords: Disabled people; trade unions; legislation

Disability and the Future

Bert Massie AGM of the Association of Disabled Professionals October 2002

I would like to start by thanking the Association of Disabled Professional (ADP) for inviting me to address you today. I give many speeches each year but this one is rather like a home match because I have been a member of the ADP since the early days of the Association and served as a member of the Executive Committee for a number of years. I recall the days when Mary Greaves and Peter Large established the ADP, which was inspired by a French organisation. I think its name was the Association of Handicapped Intellectuals, a title that would never work in this country. In its thirty year history the ADP has influenced many of the disability policies in this country.

Before the concept became fashionable, disabled people controlled the ADP. The members of the ADP have been and remain significant figures in the disability community. In any objective study on people who have influenced legislation to the benefit of disabled people, there would be several chapters on your Parliamentary Advisor, Sir Peter Large. He is a remarkable man to whom I owe a great deal. Sue Maynard Campbell has also made a significant contribution. I could as easily mention other members of the ADP and the only reason I shall not do so is that the list would be so long. It is an organisation that has made a difference.

I have been asked to speak to you about the future of the Disability Rights Commission (DRC). This is encouraging because it presupposes that we have a future. I think we have, but the issue of whether the DRC should be subsumed into a single equality body (SEB) is one to which I now have to devote an increasing percentage of my time. However, before looking to the future I think it would be helpful if I first reflected on the past.

It has long been recognised that disabled people in this country face unjustifiable discrimination. The Disabled Persons (Employment) Act 1944 established the quota scheme whereby employers that employed more than 19 people should ensure that 3% of their workforce were registered disabled people. This is not the time to analyse the success or otherwise of that law but to recall that the Government of the day recognised the discrimination disabled people would face when the war ended.

The next significant piece of legislation was the Chronically Sick and Disabled Persons Act 1970. This introduced the Orange Badge Parking Scheme, improved some social service provision for disabled people and said that public buildings should be accessible, in so far as it was reasonable and practicable. A recent DRC survey showed that 30 years later most local authority buildings in Wales are still inaccessible.

In the late 1970's Lord Snowden's report showed the many areas of life in which disabled people faced discrimination. In 1977 the then Minister for Disabled People, Alf Morris, established the Silver Jubilee Access Committee chaired by Peter Large. The inspired title of its report was " Can Disabled People Go Where You Go?" I leave you to guess the answer. This was followed by another investigation by the Committee on Restrictions Against Disabled People, again chaired by Peter Large. This reported in 1981 and was the major study that placed discrimination firmly in the structure of society; a concept that guides much of our work today. The British Council of Disabled People did much to sell that concept to a disbelieving world. It then took another 14 years before the Disability Discrimination Act 1995 (DDA) was passed by Parliament, and even then only after a campaign that left scars on most of us.

No one believes that the DDA was the comprehensive legislation that was required but it was the best that could be obtained at the time. Since then it has been amended but many more changes are needed if disabled people are to enjoy protection from

discrimination. However, one battle has been won. For so many years we heard from Government that discrimination could be ended by persuasion and all we had to do was to win people hearts and minds. There is now a broader recognition that it is much easier to win those hearts and minds when the force of law backs the argument.

The DDA established the National Disability Council, which under the chairmanship of David Grayson did more than anyone could have expected. But it had no powers of enforcement. Its replacement by the Disability Rights Commission provided the Commission for which disabled people had fought for so long and so long. The Special Educational Needs and Disability Act 2001 brought education within the DDA.

When the Labour Government was elected in 1997 it entered office with a manifesto commitment to introduce comprehensive and enforceable civil rights legislation for disabled people. It established the Disability Rights Taskforce, which reported at the end of 1999. Most of its recommendations remain no more than recommendations but some have been or will be implemented: at least I believe they will.

The DRC opened its doors in April 2000. We are approaching 2 ½ years old so it is reasonable to ask whether the DRC has met expectations or indeed made any difference to the lives of disabled people. Let me first describe the structure of the DRC.

At the top of the Commission are the Commissioners. Including myself, we number 15, 10 of whom are disabled. So, all major areas of policy are determined by disabled people. The Chief Executive is Bob Niven, who is known to many of you. He has a team of Directors who run the organisation on a day-to-day basis. We have over 150 staff and four offices that are located in London, Manchester, Edinburgh and Cardiff.

The way to contact the DRC is through our Help-Line in Strafford upon Avon. In the first year we received about 65,000 enquiries and last year this rose to just less than 85,000. I expect this will increase to 110,000 or more this year. We pay for external monitoring of the help-line and there is a high rate of people who are satisfied or very satisfied with the service they receive.

However, there are some people who cannot be assisted by the help line for a number of reasons. For example, some callers raise issues that are not within the remit of the DRC. In other cases a more detailed investigation is necessary. In the first two years of the DRC about 5,000 cases were referred to our casework team. We have a team of about 20 caseworkers spread across our various offices. Their job is to determine whether the person is disabled under the terms of the DDA. If so, were they discriminated against as defined by the Act? If so, was the discrimination on account of their impairment? If so, was it justified? If it is believed that the person did face unlawful discrimination, we need to decide what action to take.

In some cases a letter from the DRC produces a solution. For cases involving access to goods or services we have established an independent conciliation service. This is still small scale but growing. If disabled people use the conciliation service and fail to reach an agreement they still have recourse to legal remedy. We have found that in many cases this approach has produced better results that we could have achieved through litigation. It is almost always faster. However, this does not mean a simple return to the old hearts and minds arguments. Many of the agreements we achieve are only possible because people know the law is there in the background and we are willing to use it. Without that law I think much of our work would be unproductive.

We have established a legal team. In our first year they initiated 45 legal actions and in the last year this grew to 65. We could take up to 75 a year, but we should choose the cases carefully. To make

the best use of our resources we need to take the difficult test cases although there will always be pressure on us to accept any case in which a disabled person has faced discrimination. We have had some notable successes as well as disappointments. We clarified the definition of mental illness, showed that some aspects of school life were covered by the DDA, although that has been overtaken by the Special Education Needs and Disability Act, and proved beyond doubt that blind people do have the right to take their guide dogs into restaurants regardless of the religion of the restaurant owner. Defeats have shown the major limitations of the DDA. The General Medical Council can prevent disabled people studying medicine. The Government can discriminate against disabled people when filling statutory posts.

It inevitably took some time to establish the DRC but that has been achieved. Now we must build up our expertise so we can be more effective and serve disabled people better. We will shortly announce our first formal investigation. It will be relatively modest but it will provide us with the experience to take and win more difficult cases in the very near future. We have started to make use of judicial reviews especially in the area of lifting and handling, where an over rigid interpretation of new regulations could push back the support severely disabled people receive for personal care to an age we thought was lost in a disreputable history.

We have set up a policy team to help us follow our statutory function of advising the Government, the Scottish Parliament and the Welsh Assembly of the working of the DDA and changes that might be required to it. A study of the cases we have investigated, the report of the Disability Rights Task Force (DRTF) and our own legislative review, convinces us that further legislation is not only desirable but vital. Some of it that is related to employment is likely to be introduced to enable the Government to meet its obligations under European law. The employment threshold of 15 will go and so will the current exemptions on the uniformed police and fire

service although the armed forces will remain outside the scope of the Act. We are, however, working with the Ministry of Defence on a voluntary code that should help. These new laws should come into effect in 2004.

Also in 2004 service providers must ensure their services are accessible to disabled people. This does not mean that all buildings must be accessible although that will often be the most sensible solution. 2004, a mere 27 years after the Silver Jubilee Access Committee was formed! One can hardly accuse the UK of acting with excessive speed in granting civil rights to disabled people. However, I expect there will be major legal battles in 2004 and beyond as people seek to weaken the law. The DRC is determined to be ready to fight those battles. They are always on two fronts. The first to preserve the victories of earlier battles and the second is to win new rights. While we fight those battles we also continue to work with employers and service providers to help them understand and follow the law. We have already published three codes of practice and our Practice Development Team is working with major organisations so they implement best practice. But still new laws are needed.

At the last election the Government accepted some, not all, of the DRTF recommendations. We were very hopeful that in the Queen's speech this year a new Disability Bill would be announced. We were bitterly disappointed to learn that yet again disabled people had to give way to other priorities. The Government does, of course, have other legislative tools available to it and we wait with interest to see if any shall be used. But only primary legislation, ie an Act of Parliament, can plug the gaps that enable transport operators to discriminate at will even if the transport vehicle is accessible. One day disabled people will have full access to the rail network that is paid for from our taxes. There have, of course, been major strides in making public transport accessible but we need to finish the job.

In addition, a law is needed to fulfil the Government's promises in other areas including housing, public appointments, and a positive duty on all public bodies actively to pursue disability equality

The question on my mind is whether the DRC will exist to finish the job. Even before the DRC was created there was a lobby to merge the equality commissions, so the arguments are not new. They are also in some ways seductive. Surely it makes sense to join the commissions as this will prevent duplication and save money. It would be able to handle multiple discrimination because we all have multiple identities. And if a new body is created, surely it is madness for disabled people to be outside of it. Part of inclusion is for all groups to work together. All these arguments have to be taken seriously. The DRC has not so far opposed in principle the idea of a Single Equality Body (SEB) - the Government has not yet said it will definitely create one nor what sort of shape and structure it favours. I would say however that I detect fatalism and perhaps even defeatism by those who think we should accept the inevitable and merely seek the best deal possible. That is not my style. The disability movement should be active in seeking to shape the debate - we have much to offer. Then we must see what the Government proposes and as the new body, if it is created, might be intended to represent disabled people, it does not seem unreasonable for disabled people to have a say about it. Let's us hope and press for meaningful consultations by the Government with disabled people.

Under European law protection against discrimination in employment will be granted to people on account of age, sexual orientation, and beliefs. It clearly makes little sense to create a further three equality commissions. Using perverse logic some seem to have reached the conclusion that putting the three current commissions and the three new strands into a single commission is the obvious answer. It is neat and easy and everyone will be happy. At least that is the theory.

At the DRC we are working with the Commission for Racial Equality and the Equal Opportunities Commission to offer advice to the Government on the strengths and weakness of any SEB. We can all agree on a future of a world without discrimination and in which we all live in harmony. We can agree that there might be new ways of preventing discrimination that a new SEB might develop. But before we go skipping merrily to collect our pot of gold from the end of the rainbow, I have a duty to ask whether there are any negative aspects or risks to this that might affect disabled people.

The ADP and the DRC have at least one thing in common. Disabled people control both. Would this be possible in a SEB? In some models there is the possibility of control by disabled people but if the Northern Ireland model is chosen it would be impossible. If the SEB merges all groups, including the three new strands, it would be impossible for any group to dominate the governing council. Disabled people would have to compete for resources and influence and there might be only one disabled commissioner. We would return to the bad old days when disabled people spent much of our lives trying to get non-disabled people to understand even the basics about life as a disabled person. Our needs are much more complex than the other strands: we can get killed by people trying to be good to us as well as those who wish us ill. If you doubt that statement, I suggest to speak to those disabled people who have survived well meaning but ill informed doctors putting "Do Not Resuscitate" notices at the foot of their hospital bed. Some groups look to macro-economic figures to prove discrimination against them. Disabled people can do that but we also need to get our wheelchairs through doors. If the door is too narrow the effect is the same as being banned: we can't get in. We can be discriminated against by a single millimetre.

The DRC has agreed, therefore, that we would oppose a SEB that was established entirely on cross-cutting "functional grounds" (ie. with an internal structure based solely on such general features as

"Policy", "Legal" or "Media" without any dedicated Divisions or units specialising in disability or, I would suggest, in the other types of discrimination - gender, race, sexual orientation etc.). Under a purely function-based model, our needs would be lost.

If disabled people can retain control of the agenda there are some models that could be more helpful. Could each strand be in its own silo, allowing the silos to leak so there is cross fertilisation? The people it seeks to represent could control each Silo. An advisory "umbrella body" could be created while retaining the identities of existing Commissions and representative bodies. Might the new strands be merged with the current commissions? That would ensure they are being effectively represented much more quickly than establishing a new organisation. There are a number of other options that could be considered. From our point of view, the role of disabled people is critical.

We would need to ensure that the resources the DRC spends on serving disabled people are not diminished. It is easy to see how a SEB might be under-funded and the funds currently available for disability related work are raided for other work. How can we protect against that?

The DRC and the other commissions have called for a Single Equality Act to be passed before a SEB is created. There are excellent reasons for this. At the moment each of the proposed strands will enjoy different rights even within the SEB. The three new strands will not have any rights in relation to goods and services. If we, as a country, are truly committed to civil rights for our citizens we cannot allow this dog's dinner of equality legislation to remain unamended. Any SEB would be at odds internally and its external credibility would be reduced. The question is how much do we really believe in equality.

Many of the recommendation of the DRTF remain no more than recommendations. We need to bring them into legislation. As any

reputable SEB is likely to spend its first years fighting for basic rights for the three new strands it will not have much time for disability legislation. It is imperative, therefore, that the disability legislation is enacted before, not during or after, but before a SEB is created. Moreover, the legislation must have time to settle down and be tested by the DRC before it is allowed to have a low priority in a SEB. The earliest such a bill could be presented to Parliament is next year. If it passed in 2004, it might be implemented by 2006. Two or three years to settle it down takes us to 2008/9. On this timetable a SEB in 2010 might make sense. If the DRC is dissolved before then there will be a price to be paid and I suspect disabled people will do the paying.

If despite the above arguments the Government goes ahead and creates the wrong type of SEB, disabled people will need to be very vigilant. I shall give just two examples. We supported the Education Act 1981. You will recall it abolished the old definitions of disabled children and created the much broader label of Special Education Needs. Some disabled advocates feared that because this would cover up to 20% of children that disabled children might face resource restrictions and that, of course, is what happened. There is evidence today that some local authorities permit their resources to influence the content of disabled children's statements and hence the support to which they are entitled. My next example is the orange or, as it is now known, the blue badge scheme. When it was created in 1971 the eligibility criteria was tight and it was a helpful scheme for severely disabled motorists. Today badges are issued with such generosity that many severely disabled motorists are unable to park where they need to as the spaces are occupied by people with a very minor or no impairment. I draw the moral that there are times when it is better for disabled people and disability to remain distinct. Will a SEB filled with non-disabled people appreciate this? We could even have a situation where, for what appear to be good reasons, the SEB argues against the interests of disabled people.

Having said that, let us await the Government's decision. I expect some type of consultation document in the Autumn. Disability organisations must respond to it. With the right structure, the right timing, and appropriate disability legislation passed in advance, a SEB could work. But what if the Government chooses all the worse options? It is in our interest to ensure the SEB is as effective as possible and we must work towards that, even if we suspect it to be a lost cause. Further, organisations like the ADP must be ready to provide the leadership and the inspiration to ensure that the battle for civil and human rights continues to be influenced by disabled people and is not allowed to be lost in a broader picture. Even in large pictures, the detail is important.

I have raised the issue of human rights for the first time. The DRC has called for the creation of a Human Rights Commission. Whatever the Government does, it is critical that as disabled people we are fully involved in the life issues that affect us. There will be huge debates over genetics. Many learned people will have their say and once again disabled people could be subject to procedures that limit our life opportunities. When the ADP was founded there was much to do. Much has been achieved but the battle is far from over. While the DRC is here we will share those battles with you. We are not a lobby group, like some charities, but we do work with a wide range of stakeholders and the needs and views of disabled people must always guide our work. We are after all the Disability Rights Commission and we believe in rights. Let's work together in achieving and exercising them.

Thank you for your attention.

Bert Massie

October 2002

Keywords: Disability Rights Commission; Disabled professionals; single equality body

AGM British Council of Disabled People October 2002

Bert Massie

I should like to start by thanking you for inviting me to address you today. I intend to outline the work of the Disability Rights Commission and explore some of the issues that concern us. I will look towards the future and discuss the changes I believe we need to achieve. I also want to discuss and to gain your views on the current proposals for a Single Equality Body to replace the DRC and the other equality commissions. Before doing so I should like to acknowledge the critical role BCODP has played in promoting civil and human rights of disabled people and, equally importantly, in empowering so many disabled people in this country and contributing to the disability movement throughout the world.

The wisdom of the slogan "Nothing about us without us" has been well demonstrated in the field of disability. In the late 19th century the National League of the Blind and Disabled was formed as a trade union and was perhaps the earliest organisation run by disabled people. In 1922 the Disabled Drivers Motor Club was formed and in the 1930s successfully opposed measures to ban disabled drivers from holding driving licenses. When the DDMC was originally formed drivers did not require a driving license. The years following World War II saw the creation of a number of organisations controlled by disabled people. These included the Disabled Drivers Association and the Infantile Paralysis Fellowship, now the British Polio Fellowship. These organisations were formed for people with a specific impairment or to deal with a specific need. In the early days of the Disabled Drivers Association it promoted the use of the invalid trike and it was in the late 1960s that it started to campaign for the trike to be replaced by a car. This was for social reasons and showed the use of social model thinking, although at the time it was not analysed in such a way. It was only when social arguments failed that safety was brought into the equation.

The 1977 Silver Jubilee Access Committee called for laws to make buildings accessible, and later the Committee on Restrictions Against Disabled People produced the first Government Report to show that most of the barriers faced by disabled people were environmental. During the 1970s the seeds of the disability movement were already growing through the work of people like Paul Hunt and Vic Finkelstein and this resulted in BCODP. The new organisation made its case well and Colin Barnes' book *Discrimination in Great Britain: the case for Anti-Discrimination Legislation* changed many perceptions. I think it became clear that education and persuasion would never work on its own and that comprehensive and enforceable legislation was necessary. That led to the campaign through the 80s and 90s for such legislation. The Disability Discrimination Act (DDA) was, of course, a shadow of the Act we all wanted but there was never a chance the Government of the time would do more. Indeed, nearly half the 1994 Cabinet thought the DDA went too far! So, that fight continues today even though the Disability Rights Commission Act 1999 and the Special Educational Needs and Disability Act 2001 have amended the DDA. We do, of course, need further primary legislation.

I think the most significant change in the last 20 years has been the role played by disabled people. In the 1970s there were a very small number of disabled people in some of the charities who were consulted on policy affecting disabled people. That has changed. Disabled people demand to be consulted and have the systems available to enable effective consultation. However, after so many years of being on the sidelines many disabled lacked the self-belief and confidence to assert themselves. The manner in which BCODP and its members worked with disabled people to give them the confidence they needed has changed not only the way in which the world sees disabled people but also the way in which we view ourselves. I think it is impossible to overstate the magnitude of that achievement because it underpins almost everything else that makes the disability movement as strong as it is.

I have no doubts that without BCODP many of the rights we enjoy would not exist. Without BCODP the Disability Rights Commission would not exist. Two thirds of the Commissioners are disabled. That does not startle us today but 25 years ago it would have been surprising. From its first day the DRC has sought to build and maintain close links with the disability community even though we are not a campaigning organisation in the same sense as BCODP. We must work with employers, service providers and Government. But unless we are serving disabled people the other stakeholders become unimportant. I find it amusing when I am criticised by some for calling for additional rights for disabled people because such calls are unhelpful! Why do they think we exist? If we discover areas where law is inadequate we have a duty to seek to put that right.

The DDA is a complex piece of legislation and many people find it difficult to understand. One of the first things the DRC did was to establish its help line. In its first two years it received over 144,000 calls. On current trends we expect about 100,000 to 110,000 calls this year. We can expect a significant increase in 2004 as the new duties on access to goods and services and on small employers come into effect. The old DDA help line, run by DARAS, had been subject to some criticism from disabled people and I think that was largely due to the restrictive brief they were given by the Government of the day. We arranged for staff to be retrained and also placed a number of DRC staff at the help line to ensure the operators had skilled advice readily available. While I cannot claim that we always get it right, we do monitor satisfaction rates carefully and use external agencies to do this to avoid internal bias. About 97% of the users of the help line are satisfied or very satisfied with the service. This does not, of course, mean they are satisfied with the outcome. In some cases we have to tell people that they are not disabled under the provisions of the Act or that although it appears that they are disabled and have experienced discrimination the Act does not protect them. We also monitor those occasions when we

are unable to help because they influence our advice to Government on changes needed in legislation. Indeed, we are drawing on this data in our negotiations with the Government concerning a new disability bill.

On some occasions it is difficult or impossible to tell whether a person has faced unlawful discrimination. We therefore established a casework service to investigate cases of alleged discrimination. When the DRC was established it was anticipated that we would have about 200 such cases a year. In the first year we had 2,200 such cases. We had over two thousand new cases in our second year.

Our caseworkers, many of whom are disabled, come from a variety of backgrounds but a number of them are legally trained and are solicitors in their own right. They do not simply investigate but also seek to resolve. In some cases they have obtained higher levels of compensation for disabled people than they would have got had the case gone to court. In other cases the simple fact that the DRC is involved results in a discriminator altering their policies and treating disabled people in an appropriate manner.

We also established a conciliation service for Part 3 cases. Again this has resulted in some significant successes that we could not have obtained through the British legal system. For example, one hotel chain changed its policies throughout Europe. This will result in many disabled people not facing additional charges for their personal assistants.

However, this approach has been criticised and we need to reflect on those criticisms. It has been suggested that the DRC should simply focus on enforcing the law; everything else is a diversion. I will return in a few moments to how we do indeed enforce the law. As I see it, our role is to promote and enforce the rights of disabled people. To do so we must use all the weapons in our arsenal. We always have at least two clients in any particular case. The first is

the individual disabled person and the second is the wider disability community. Their interests are sometimes but not always identical. The individual often wants a quick solution to the discrimination they have experienced and the courts are never fast. Conciliation can often provide a fast and effective method of achieving a just settlement. It is not second rate justice but, as EEOC Commissioner Paul Miller discovered in the USA, conciliation can provide better solutions. It is not second class justice.

The disadvantage of this approach is that it does not help develop a body of case law that other disabled people can draw upon. Moreover, there are some people and organisations that believe they have a right to discriminate and will not respond to any pressure if they do not have to. That is why the DRC has a strong legal service. In the early days of the DRC we were criticised for not bringing enough cases and we still face that criticism today. Charles Dickens' Mr Bumble said the "... the law is an ass...". He could have said it is a slow and stubborn ass. I do not have legal training so I was astonished at how slowly the legal process moves. Delays of up to a year are not uncommon. That was one of the DRC's frustrations in the first year; we were dealing with cases but had to wait to get them into a tribunal or courtroom. Today we have our legal service has intervened in over 150 cases and we take on average just over one new case every week. I would like to give you a flavour of some of those cases.

Under the DDA it is clearly unlawful for a restaurant to refuse to admit a blind person accompanied by their guide dog. A number have done so. In one case the blind person accepted compensation of just £500 but the restaurant then agreed to accept equality training from the person concerned. In another case the restaurant owner argued that as a Muslim his human rights to follow his religion overruled the DDA and he could therefore refuse a person with a guide dog. I doubted his interpretation of the law was accurate and we decided to fight it. However, we also contacted the

Shariat Council for the UK and Europe who were extremely helpful. They made a ruling that although Muslims must not keep pets they have a duty to promote independence and, as the guide dog helps a blind person to be independent, Muslims not only have no right to refuse access to a guide dog when it is working for a blind person but they have a duty to admit it. Once this judgement was shown to the restaurateur concerned he withdrew his objection and paid compensation. Of course, we must be sensitive to people's belief systems but I do not believe that any religion would promote discrimination against disabled people.

We have taken one case to the Court of Appeal to clarify the definition of mental illness under the DDA. That case resulted in a disabled person receiving compensation of £120,000. We have fought against the "no lifting" policies that risk increasing the dependency of disabled people. We have fought one such case against a local authority and are currently fighting another one against a health authority. In these two cases we are using powers to seek Judicial Review, as the issue is not covered by the DDA in the conventional way.

About two thirds of our legal cases relate to employment issues. In one case a woman with epilepsy had a job offer withdrawn once the employer knew of her impairment. We obtained compensation of £4,000. Another woman had spent a short time in hospital being treated for depression. When her work colleagues discovered this they taunted her. As a consequence she had to take sick leave and was then sacked. She was awarded £17,000. In a case where an employer failed to make a reasonable adjustment for a visually impaired man he was paid compensation of £23,000. However, none of these payments can turn back the clock. The discrimination should not have taken place and we hope that a growing number of employers will take note that we will enforce the law and they should implement policies that prevent discrimination taking place. Sometimes employers have blanket policies that discriminate but do

not appreciate the fact. That is another reason why we need to work with employers and service providers.

I've mentioned the amounts of compensation paid for a purpose. It is to draw attention to the different amounts paid for Part II and Part III claims. In Part II employment claims the compensation is calculated on the hurt to feelings, the loss of wages and other benefits and the action taken or not taken by the employer. There have been a small number of payments of over £100,000. However, when we look at payments under Part III they are much more modest. One case that hit the media concerned Tom White, a schoolboy who has diabetes. This case was significant because it helped establish that recreational school trips were covered by the DDA. He received only £3,000 in damages and that was one of the larger awards. With such low sums being awarded, some disabled people are questioning whether it is worth pursuing cases for Part III cases and I can understand that point of view. It has led to some criticism of the DRC for not agreeing to fund cases where people think they should receive compensation of £10,000 or more. The current law appears to be unhelpful to us.

I have another anxiety about the low amounts of compensation paid under Part III. When the new access duties come into effect in 2004 some service providers might find it less expensive to pay compensation to individuals rather than improve services for all disabled people. We could use some of our other powers, such as a formal investigation to deal with such discriminators but I think we do need to address the issue of inadequate compensation to disabled people who have been the victims of discrimination.

The DRC has not yet brought a formal investigation. We intend to put that right shortly. We have studied the investigations launched by the Commission for Racial Equality and in particular the challenges they have faced. It is already clear that there exist some rather bright lawyers who are skilled in ensuring that formal investigations do not succeed. We will need to draft the terms of

reference with enormous care. One issue is identifying the subject of such an investigation and who the target should be. We are just beginning to unearth a small number of repeat offenders who might well need a formal investigation if they are to follow the DDA. The DRC is open to any suggestions you might have. Our first formal investigation will be relatively modest as it will help us gain experience to fight bigger battles later.

While seeking to enforce the law the DRC believes that we also need to work with industry to help them get their policies and practices right. That is why we established our Practice Development Team. It has enjoyed some success in working with local authorities on the production of guidance. It is currently working with the Ministry of Defence. The Government has made it clear that it is determined to ensure that the armed forces remain outside the scope of the DDA. Personally, I believe that exemption is unnecessary, but I have failed to persuade the Government. Therefore, we are working with the MoD on the production of a voluntary code or guidance, which we hope will result in the MoD following the principles of the DDA even if they do not have to.

The DRC has now published three Codes of Practice. These documents do not set down the law but they must be taken into account in tribunal or court cases. The first we issued concerned the new rights of access coming into effect in October 2004. The other two relate to the Special Educational Needs and Disability Act that started to come into effect in September. We are currently drafting a fourth Code which will update the current Code of Practice covering the employment duties of the DDA and will take account of the fact that small employers will be covered. So will the uniformed police and other services. It will help plug another of the DDA's many holes.

We all know that the DDA is far from perfect. When I launched the DRC's first Annual Review I called on the Government to commit itself to a new Disability Bill. I appreciate that many believe that the

best way forward would be to repeal the DDA and introduce new legislation. While I understand that viewpoint I do not detect any appetite within Government to do so. We therefore need to explore whether the DDA can be amended via a Disability Bill. The Disability Rights Task Force, on which members of BCODP were prominent members, recommended a number of changes to the law. The Government is moving forward through regulations on some of the employment recommendations. But many of the recommendations can only be implemented through primary legislation. That is why the DRC has expressed its profound disappointment that the Government decided not to have a Bill this year. This means that the next opportunity will be in 2003 and if we miss that opportunity the next general election will be upon us

I hope that the Government will agree to a Bill in 2003 and during the next year the DRC, the disability movement, and the Government can work together to determine what should be in the Bill. I hope the Government will go beyond the promises made in the Manifesto for the last general election. The DRC is currently finalising its own recommendations for new legislation following our analysis of the responses to the consultation document we issued earlier this year.

One of the areas in which our powers are severely curtailed relates to human rights. Many people with very severe impairments need access to health and social services but it is difficult for the DRC to represent them because our powers are limited. I have asked the Government to use the powers available to it to extend our remit. There is a joint committee of both Houses of Parliament investigating human rights legislation but we have no idea when it will report and whether the Government will accept its recommendations. Meanwhile time passes by and in many crucial areas of disabled people's lives the DRC is unable to offer the support we should be giving. There needs to be a change in the law.

I want to turn now to the future. As an immediate task we need to ensure that the Special Educational Needs and Disability Act is implemented properly. This Act will not result in the closure of all special schools but I think it will result in the closure of some of them. We must ensure that disabled children are able to attend a mainstream school if that is what they wish. We must also ensure those schools have the resources to do the job effectively. The resources need to follow the child and not be reserved within the special education system.

The DRC's major current campaign is called Educating for Equality. This concentrates on the new Act. The Heidi Cox cases shows how important this is. You might know that the General Medical Council prevented her studying medicine because she was disabled. We need to ensure that no disabled person is denied education at any stage of their life.

In 2004 new duties will come into effect. I have already spoken about the employment provisions. I now want to consider the provisions on access to goods and service. It is important to understand what the DDA does and does not require. The Act requires the service to be accessible, not necessarily the building from which the service is normally provided. We might, therefore, learn of some rather creative ways of providing service. I suspect that in many cases physical access will be the only way of linking disabled people with a service. We will then move to a new phase of the campaign for civil rights. So far most of the discrimination covered by the DDA can be summarised as people being beastly to disabled people. In 2004 they will have to change more than their attitudes; they will have to change their buildings and that will involve spending money. That creates the danger of a negative reaction against disabled people. We already see some signs of this. On at least two occasions the Radio 4 Today programme has run features lamenting the fate of village halls that will have to make themselves accessible. It seems, if the Today programme is to be

believed, that the access requirements of the DDA will result in village halls throughout the country having to close and that they are such important local facilities. So important, it would seem, that it does not matter if disabled visitors are unable to use them! It appears to me that disabled people are simply the scapegoats because the halls have not been maintained in the past. We can expect much more of this. Disabled people will be called unreasonable and every plague that hits the country will be blamed on us. We need to be ready to respond.

I think that as disabled people we need to be cautious about those consultancies that inform industry of the changes they must make but gold plate those changes so much that the alterations suddenly become unreasonable because of cost. One of the many things that the Disability Living Movement has taught us is that good provision does not always need to be costly.

The DRC is now just over two and a half years old. As result of the new employment rights being introduced to cover discrimination on account of age, sexual orientation or beliefs the Government has proposed to merge the current equality commissions and create a single equality commission. The DRC welcomes the new rights and does not in principle oppose a single equality commission. But before we can give it a warm welcome we need some assurance that it will not result in a reduction in the rights of disabled people or the support available to us in enforcing those rights. I think BCODP also needs to think carefully about its position.

I have mentioned several times that we need new legislation. The DRC is fighting for that legislation. If a Single Equality Body is to be effective it needs to be underpinned by strong equality legislation. That is why the DRC has called for a Single Equality Act. What do I mean by a Single Equality Act? Well, first we must upgrade the rights for all the groups to be covered by the SEB so all enjoy at least the best available to other groups. It is outrageous that people in the new strands will face lawful discrimination in the provision of

goods and services on account of age, sexual orientation or belief, as the new laws will only cover employment.

All the strands need to be covered by the public duty rights that apply in the case of race. The new Act must also bring in the recommendations of the Disability Rights Task Force. We need this doing before the SEB is established. That would enable the new body to work from a firm and solid base. It would prevent it from having within it a hierarchy of rights and of oppression and thus also help prevent internal infighting as each group seeks to press their own important agendas.

The Government has indicated that it does not want to introduce a Single Equality Act. If they hold to that position and still want to create a SEB they will create enormous difficulties for the new body.

We do not yet know what the structure of the new body will be. I think it would be unacceptable for disability policy in the SEB to be determined by people who have no person experience of disability. There might be ways in which the influence of disabled people can be ensured. I am convinced that although there will be common strands of discrimination between the various groups and we all have a multiple identity, there are issues that are specific to disabled people. We need disabled people to help resolve them. That is why the DRC has already rejected a SEB based on the functional model used in Northern Ireland. We need to be more creative.

Whatever happens regarding the proposed SEB, I am convinced that the role of BCODP and its members will become increasingly important. Disabled people will not control the new SEB but the view of disabled people must also be made to Government and others. Organisations of disabled people will need to be ever vigilant and ensure those views are made. You must also ensure the new SEB is aware of your views. The Government will listen to the SEB and if they do not understand disability issues they might

argue against you. You have fought long and hard in the past. I think you will need to do so in the future. Your proposal for a Parliament of Disabled People could provide a way of giving disabled people a platform. Whatever path you choose to follow the role of BCODP will be critical if the battle for comprehensive and enforceable civil and human rights is to be won for disabled people.

Thank you for listening.

Bert Massie.

October 2002.

Keywords: Disabled people; disabled people's organisations; disability discrimination legislation; single equality body

Universities UK Conference 29 October 2002

Bert Massie

I would like to start by thanking Universities UK for inviting me to speak today and for their work in promoting awareness and understanding of the new duties that are now part of the Disability Discrimination Act 1995. Last year I found myself in a hotel bedroom listening to Radio 2. The program was about the life and works of the duo Flanders & Swan. Those of you of a certain age might remember them. Younger people might at least know part of their famous song "Mud, Mud, Glorious Mud". Michael Flanders was a university student at Oxford when World War II intervened and he was called up for the Naval Reserve. He then contracted polio and used a wheelchair. When he tried to return to his studies after the war he was informed, and I quote, "We don't take cripples." Let's not be deflected by the choice of words. What is more important is that until September of this year it would have been perfectly legal for any university in this country to have used the same words to a disabled student. That has now changed.

The introduction of Part IV of the DDA means that disabled students finally have the right to challenge discrimination in their education and provides clear legal impetus for those institutions that do not have a sensible, progressive approach to get their house in order.

Happily many higher education institutions have already made major inroads into widening access and participation, with innovative policies, procedures and practices enabling disabled people to participate and achieve alongside their non-disabled peers.

Unfortunately, there are still numerous instances where lack of forethought, neglect, low expectations, ignorance or just plain prejudice deny disabled people educational opportunity - and so

sets in motion a life of unfulfilled potential and social exclusion.

A recent National Audit Office report found that a disabled person aged 18 is less than half as likely to enter higher education as a non-disabled 18 year old. The reasons for this are complex and include early disengagement from education, poor educational opportunities prior to higher education, lack of confidence in higher education as a realistic option and difficulties in securing financial support.

Partly as a consequence of poor educational opportunities, working-age disabled people are twice as likely to be out of work than non-disabled people.

The DRC wants to change all this. We believe that disabled people should have the same right to a lifetime of educational opportunity as anyone else. Equality in education underpins all of our aspirations for a society in which disabled people can full participate as equal citizens.

Whilst we have the legislation in place, there is still a major job to be done: transforming expectations of what disabled people can achieve and contribute and of what can be done to help achieve this.

Ask yourselves this: could you make provision for a severely disabled student who needed help with most physical activities, used a powered wheelchair and communicated through a machine? Would you have ensured physical access to libraries, lecture theatres, laboratories and the dining room? Would you have ensured that lecturers had disability equality training and made appropriate adjustments in lectures and tutorials? Would you have addressed his communication needs? Would you have made adaptations for the submission of essays or the sitting of exams?

Would you have seen all these things as a worthwhile investment? If he said his name was Stephen Hawkins, would you tell him to

take his brain elsewhere? Or would you recognize talent and accommodate the person with it, even if they were disabled? Some of you can clearly answer in the affirmative but can you all?

Where the new duties and the principles underlying them are met with a particularly begrudging response it suggests one thing in particular - that it is not viewed as a worthwhile investment. This begs the question of why. Is it because we have low expectations of disabled people? Do we see them as a cost rather than an asset? Equality of opportunity does not just happen: it has to be planned and worked for.

Experiencing diversity enriches our understanding of the world we live in.

The DRC believes that not only is it wrong to deny disabled people educational opportunity, it is just as wrong to deny students access to the diverse range of personal experience and insight available in our society that can be brought to learning. Disabled people are part of society and contribute to its richness.

In short - disabled people have much to bring to education.

In September we launched the Commission's first major campaign: [Educating for equality](#).

In the course of the coming year we are working with a whole range of organisations representing students, lecturers and the universities themselves to ensure that this law has the impact that it needs to have. We are also seeking to promote the very positive contribution that disabled students make to each school, college and university across the country.

Our campaign is seeking to involve all stakeholders in bringing real and meaningful change - helping those with duties to meet and exceed them; assisting disabled people to challenge discrimination and assert their rights; stimulating debate and seeking to raise awareness of disability rights throughout society generally. Showing

what goes right where a little effort is made and highlighting what can go wrong and the consequences.

For example:

Lindsey Brown enjoyed her course in physiotherapy and student life until the Easter vacation when she developed epilepsy. Her department asked her to attend an occupational health appointment and doctors stated that they had full confidence that Lindsay's condition could be controlled with medication.

However, shortly before she was due to sit exams, she received a letter stating that her department concluded in a meeting that due to her medical condition it was considered unsuitable for her to study any longer. The University Disabilities Co-ordinator wrote a report explaining how reasonable adjustments could be made to accommodate her disability, and feeling understandably angry and hurt, Lindsay appealed the decision. But the appeal failed.

Minded of her experience, Lindsay decided to embark on a course in Law at the same University. Her experience could not have been more different - the support offered was second to none.

Lecturers took time out to re-assure Lindsay and her family that everything would be okay. They organized everything so that she could concentrate on her course, and on one occasion went with her to hospital when she was ill and also met her requirements for sitting exams. The University's Disability Services Team provided a 'Study Skills Mentoring' scheme - a unique learning strategy enabling Lindsay to continue studying while helping to tackle any barriers faced regarding her impairment.

Lindsay graduated with a 2:1 earlier this year.

This was one University with completely conflicting approaches in separate departments - it really highlights the need for those who are legally responsible for the duties - Vice Chancellors - to lead their Institutions and to ensure whole-Institution approaches to

equal opportunities.

It is difficult to underestimate the importance of leadership. Some of you here today are leaders. Others of you might become so. Whatever your individual role, you help to set the tone. It is Vice Chancellors, Principals and Senior Management who determine the direction in which your university travels.

In many cases, the adjustments needed don't need to be complicated and merely require creative thinking on the part of the university or the individual member of staff.

Just a few examples:

Lecture notes could be provided to a student who cannot take notes because of their dyslexia.

A university could put in place a procedure in case a student with epilepsy has a seizure during a lecture.

A student with a mobility impairment could have their lessons timetabled on the ground floor.

These minor simple adjustments cost little or nothing but a little flexibility and thought and yet make the world of difference to the individuals concerned.

Of course there are some adjustments that will require greater investment. Foresight and planning is the key here. Costs of physical access adjustments will always seem misleadingly high if they are separated off. But we do not develop, refurbish and manage buildings in this way. Making accessibility an integral objective of all capital building works is the way forward, in the same way health and safety considerations or environmental impact assessment are now commonplace.

Where adjustments are factored in to general capital expenditure projects, costs diminish, and the cost-benefit ratio is significantly

weighted towards the benefit.

The law only demands that universities do what is 'reasonable'. An issue we know is of concern is maintaining academic standards. The law does not demand that academic standards are lowered. However, what is meant by academic standards should be carefully scrutinised.

From 2004, qualifying bodies will be covered by the DDA and this will require scrutiny of the entry requirements into certain professions and consequently admissions criteria and academic standards for associated courses of education.

We have a serious anomaly whereby a person practicing in a particular profession has rights under the DDA in the area of job retention to have adjustments made to allow them to continue practicing, and yet a person with the same requirements wishing to enter that profession can be excluded for the very same reasons.

We need to analyse carefully what we mean by academic standards to be sure that these are not simply unnecessary institutionalised barriers to disabled people, as opposed to meaningful and necessary precursors to entering particular areas of employment.

The Disability Rights Commission is the body set up to enforce the new rights. We provide a help-line and a free conciliation service to institutions and individuals who want clarification of the law and advice on how to make adjustments. We are here for you as well as for disabled people. Wherever possible we want to find simple solutions to issues with a satisfactory outcome for both parties where conflict has arisen. But we will provide legal support to individuals wishing to take cases against Universities. And we have a number already lodged with our casework team.

I want to finish by setting each of you here a challenge. Go back to where you have come from today and find out about something really positive that is going on in your Institution to ensure your

disabled students are fully involved or find out about the positive contribution that one of your disabled students is making.

If you find something - shout about it! Publicise it and tell us and other colleges and universities about it.

If you can't find something, put something in place that will ensure that disabled students achievements are celebrated and that there are practices and procedures in place to ensure that disabled students are being involved in the life of the university. Again, publicise your achievements and show other institutions what they can be doing too.

Throughout the course of the year, our campaign will take on many different activities. We will be speaking at events such as this, we will be holding our own events to take the debate forward, we will be issuing publications that will clarify the law, and we will promote good practice, and stressing the fundamental importance of ensuring that disabled students get equal access to education.

Public opinion is behind us. We commissioned research in September which shows that the public supports disabled pupils and students having the same opportunities as others. The argument has been won - almost everyone accepts that disabled students should have exactly the same opportunities as anyone else within the whole of educational life from nursery, through school, further and higher education and lifelong learning. But it is those who deliver education who have the toughest task, which is to turn the new laws into practical reality. I hope you and the DRC can work together to this happen and give future generations of disabled people the opportunities previous generations were denied. That is a goal worth scoring.

Bert Massie

Keywords: Disability Discrimination Act; Post -16 Education; Universities; Reasonable adjustments

Skill AGM November 2002

Bert Massie

May I start by thanking you for inviting me to speak to you today? In 1974 I attended the inaugural meeting of what was then known as the National Bureau for Handicapped Students. I was nominated to serve as a Trustee but was not elected. The wisdom of the electors at that meeting has been shown by the subsequent success the organisation, now known as Skill, has enjoyed in the intervening years. It is a remarkable story of achievement and I offer you my warmest congratulations on it.

I would like to acknowledge and celebrate the partnership and collaboration which has evolved over the last two years between SKILL and the DRC. When the DRC was established in 2000 we knew that we could only achieve our objectives by forming such partnerships. We share the same goals in seeking equality, educational opportunity and a society in which disabled people can participate fully as equal citizens.

Over the past 18 months you worked with the DRC to prepare a Code of Practice for providers of Post 16 education. The Code has now been published and has been widely welcomed and praised. You have joined with us to prepare detailed good practice advice for higher education institutions and I am confident that will also have a significant impact. Moreover, SKILL has been a source of valued advice and support in all that we are seeking to achieve and you have been excellent colleagues with whom to work.

Currently DRC staff are working alongside SKILL to support the Learning and Skills Council in implementing the DDA in the further and adult education sectors. I know that your staff and mine frequently share platforms at conferences and events to ensure that the duties and underlying principles about the new Act are known

about and, equally important, understood. It is a valuable partnership and long may it continue.

I recall that in the early years of SKILL a great deal of time was expended finding out which university courses were held in accessible buildings. There was limited information on the support services which different educational institutions offered to disabled students. As a consequence many disabled people chose their college or university not on the basis of the quality of the academic courses but on more fundamental criteria such as "can I get in the place?". It is sad to reflect that until September of this year it remained perfectly legal for any university, college or LEA to discriminate against disabled people. Prior to then section four of the Disability Discrimination Act could be summarised rather crudely. It was this: further and higher educational institutions needed to have a policy on disabled students. If that policy was "we don't like disabled people", that was perfectly legal and the law was fulfilled. That has now changed. The Special Educational Needs Disability Act was not the same document which began life as a Bill. It was largely thanks to the efforts of SKILL and others that the Act was a much more useful document. Indeed, SKILL played a major role in persuading the Government that new legislation was necessary. In 1994, when the DDA was being drafted, it was the view of the Government that no further legislation was necessary in the educational field because the Education Act 1993 covered everything. Those concerned at the time argued that viewpoint was mistaken. SKILL can take some pride in its role in filling that original gap in the DDA.

Although we now have the legislation in place, there is still a major job to be done. Constant discrimination lowers people's expectations. We must transform the expectations on what disabled people can achieve and contribute and consider what can be done to facilitate this. It is a major part of the DRC's mission.

On Monday of this week the DRC held its second National

Conference. It was in Manchester and was aimed at young disabled people. Prior to the conference we commissioned research to discover the expectations of disabled people in the 16 - 24 age range. It appears that expectations are growing but nearly half of disabled people still expected to be earning less than non-disabled people by the time they were 30. Nearly a third thought they had faced discrimination on grounds of disability when seeking a job. However, they were ambitious, they want access to education and young disabled people want to make their contribution to society. Clearly, it is self evident that disabled people should have the same rights to a lifetime of educational opportunity as everybody else. Equality in education underpins all of our expectations for a society in which disabled people can participate fully.

Whenever the new duties and the principles underlying them are met with a particularly negative response it suggests one thing in particular - that it is not viewed as a worthwhile investment. This immediately begs the question of why. Is it because we have low expectations of disabled people? Do we see disabled people as a cost rather than as an asset? Equality of opportunity does not just happen; it has to be planned and it has to be worked for. Vigilance is always necessary. Perhaps one of the major faults within our society is that we believe we are rather good at calculating the cost of doing something. We can work out how much it will cost to make a building accessible. We can calculate the cost of providing information in alternative formats for visually impaired people or in plain English for people with learning difficulties. We can calculate how much support services will cost. What we are less good at doing is calculating the benefits. We sometimes see cost as wasted money rather than an investment. If we as a country can give disabled people the opportunities to achieve the maximum benefit of education all of society benefits. And we should not measure that success merely by the number of degrees or academic qualifications people get. Not everybody has the ability to obtain a university degree but few people lack the ability to benefit in some

respect from education and to improve their life opportunities as a consequence. Indeed, within further education many people are benefiting even though not achieving what is normally regarded as academic success. Not only is it wrong to deny disabled people educational opportunity, it is also wrong to deny students access to the diverse range of personal experience and insight available in society that can be brought to learning. Disabled people are part of society and contribute to its richness. In short disabled people can not only extract a great deal from education but also bring a great deal to education.

In September we launched the DRC's first major campaign: Educating for Equality. In the course of the coming year we are working with a whole range of organisations in Post 16 education, students, providers and staff to ensure that this law has the impact that it should have. We are seeking to promote the very positive contribution that disabled students make to each school, college and university across the country.

Our campaign is seeking to involve all stakeholders in bringing real and meaningful change: helping those with duties to meet and exceed them. We want to assist disabled people to challenge discrimination and assert their rights. We want to create debate and raise awareness of disability rights throughout society generally. Showing what goes right where little effort is made and highlighting what can go wrong as the consequences are important aspects of this.

In 2004 further rights will be introduced. These will ensure that there should be no discrimination on work placements. Qualifying bodies will not be required to lower their academic standards but they will be required to ensure that they do not discriminate against disabled people. Earlier this year the DRC supported a disabled woman who brought a case against the General Medical Council because they refused to allow her to study medicine. We won in the lower court but lost our appeal. Without going in to the details of the case, the

important point is that we were not allowed to investigate whether there was discrimination because they are excluded from the Act. That changes in 2004 and this will inevitably produce greater opportunities for disabled people to study for a number of different professions.

The Disability Rights Commission is a body established to enforce the new rights. We provide a helpline and a free conciliation service to institutions and individuals who want clarification of the law and advice on how to make adjustments. It is important to emphasise that we also want to help further and higher educational institutions. About a third of the calls from our helpline are from employers and service providers. Wherever possible we want to find simple solutions to issues with a satisfactory outcome for both parties where conflict has arisen. However, we recognise that there are occasions when the law is ambiguous and clarification would be helpful.

We will bring cases to the courts to test the law and help clarify it. Some of you will know that earlier in the year we supported a school pupil in a case against Clitheroe Grammar School. This is not the time to go in to the ins and outs of that case but there was some uncertainty about whether extra-curricular activities were covered by the Act. The school clearly thought they were excluded and we thought they were included. The eventual judgement supported the DRC's position but until that point there was some doubt in the minds of some people about what the law really meant. Clarification was therefore helpful. Of course, since then the position has been more than clarified by the introduction of the Special Educational Needs and Disability Act. The DRC will provide legal support to individuals who believe they have been discriminated against by universities. A number have already been lodged with our casework scheme and we are investigating whether there is a case for our intervention.

It is widely recognised that the Disability Discrimination Act was an

imperfect piece of legislation. SENDA and the Disability Rights Commission Act did much to strengthen it. There is however much more which needs doing. Part 5 of the Act gives the Government powers to issue regulations requiring physical access to certain forms of transport. However, it remains perfectly legal for a bus driver driving an accessible bus to refuse to admit disabled people simply because he or she does not like disabled people. We need to change that. There is little point in making our educational institutions accessible if people cannot get to them.

There is a strong case for enhancing the definition of disabled people. Public bodies already have a duty to promote racial equality. Surely there should be a similar duty in the field of disability. The DRC is therefore seeking a new Disability Bill to strengthen the DDA. We were disappointed that such a Bill would not be introduced this year but there have been welcome assurances from the Government that they will fulfil their election manifesto commitment. When they do, important new rights for disabled people will be introduced.

Whenever a Bill is introduced it will take time to implement its provisions. The new employment provisions coming in to effect in 2004 are nine years after the DDA became law. There is now a question mark on whether the DRC will still exist to help lay the ground for new disability laws. Many of you will be familiar with the Government's consultation on whether there should be a Single Equality Body to replace the current Equality Commissions and to cater for the three new strands of age, sexual orientation and beliefs. I hope you will all participate in that debate. The DRC has already rejected the option of a totally integrated functional organisation such as they have in Northern Ireland. We believe disabled people will experience severe disadvantages under such an arrangement. There are other options which we could consider. However, before any Single Equality Body is created I believe it is important that the new Disability Bill is passed through Parliament

and is given time to settle in. In any new arrangements we need to ensure that we do not return to the old days when non-disabled people determined policy on behalf of disabled people on the assumption they knew what was good for us. It didn't work then and it will not work in the future. We need to ensure that in any new arrangements disabled people will be served at least as well as the DRC serves them. We should not accept arrangements which will disadvantage disabled people but which are otherwise administratively neat. The DRC has not yet finalised its position. It is an important debate and I hope you will all take part in it.

Whatever the future of the DRC what is certain is this. We are slowly moving away from the days when disabled people were routinely denied opportunity and were marginalized within society. Disabled people have and continue to demand the right of equal citizenship. Society, Government and educational institutions are responding to that challenge. That is a major step forward. SKILL has played its role in the past and I am confident will play an equally important and positive role in the future. The DRC looks forward to working with you to create that better and more just society for disabled people and by implication for all our citizens.

Thank you for listening.

Bert Massie

October 2002

Keywords: Disability Discrimination Act 1995; Disability Rights Commission; Post- 16 Education; SKILL;

DRC National Conference 11th November 2002

Tanni Grey Thompson

Thank you - great pleasure to be here today... I am not sure if I am honoured to be at a conference talking about disability rights, or whether I am still grateful to be included at a conference that is talking about "young" people.

The strange thing is that as an athlete is that everyone becomes very age obsessed, and I am no different. I think it is because I went from being one of the youngest members of the British Team, which I was very proud of, to when I was in my twenties no one really cared. When I went to compete in Sydney I faced all the usual questions, mostly "you don't mind me asking how old you are do you?" When I told them I was 31, it was met with indrawn breath and a few mutterings, accompanied by "how long do you think you can last?"

It does seem a very glamorous lifestyle being involved in sport, a little bit like being a Miss World contestant because I get to travel the world and meet nice people.

But in seriousness, the way I am treated varies considerably... if I am recognised as "that woman who does the marathons" then generally I am treated with respect, but the rest of the time I am treated like a disabled person, sometimes OK but also sometimes I have to face discrimination.

I would generally say that I have been very lucky and not experienced a lot of problems with me being a wheelchair user. I think a lot of this relates to the fact that I have fairly stropky Welsh

parents who believed in me as a young person and wouldn't generally be walked over.

I think that I was also lucky in many ways in that there were other medical difficulties in my family, my sister was born with a heart condition and a few other problems, but we were never ill at the same time. After I was born I didn't seem to exhibit too many outward symptoms of Spina Bifida, so Mum and Dad got on with things because they had to, and that is the way that they have always been - just there and supportive.

I grew up in a sports mad family and that had a big impact on what I wanted to do, and I am naturally a very competitive person. I was the sort of child that would want to have a race about putting my socks on...

I could walk until about the age of seven, and I don't really remember when I stopped walking because I don't think it was that important to me. I probably felt the most "disabled" when doctors were obsessed with me walking and trying to keep me on my feet by making me walk in callipers and crutches.

When I had my first wheelchair, I finally felt free and was able to do all the things that I wanted to do, but that doesn't make up for the number of times I have had to answer questions like "How did you catch Spina Bifida", and that was just from the doctors!

I remember when I got actively involved in sport, and watching the men's Great Britain Basketball team play. I knew that was what I wanted to do, and decided that I too wanted to play Great Britain level, but there was a slight problem in that I couldn't throw, catch or shoot!! Which is a hindrance if you have grand ambitions. My basketball career was short lived and because of that I found athletics.

I was lucky that my parents realised at a young age that education was the best way forward for me and fought very hard to get me in

to mainstream education. I had attended a mainstream primary school with an element of luck; my sister had gone there so I did too. It was only when it came to my secondary education that we realised things were different. I was originally accepted at my sister's school, only to find out that the Headmaster changed his mind when he realised I was a wheelchair user. There then followed a protracted battle, which involved my parents quoting various sections of the Warnock report at people until they listened!

I mentioned before that I find that I am treated very differently depending on whether I am recognised as an athlete or not and this has changed through the years. In Seoul (1988) I was described as "elfin-faced", which is as much to do with the way female athletes were treated at the time, but also as "crippled", and a "Spina bifida sufferer".

From Barcelona onwards things started to change and by the time we got to Sydney in 2000, there was more talk about sport rather than disability, but with recognition from the media that they did need to talk about impairments, as people were interested but not to dwell on the negative side of it too much.

In my life where I am treated like an athlete then the support that I have received has been on the same level as non-disabled athletes, even when sometimes it is a bit strange. I have had a giraffe named after me at London Zoo (apparently a great honour as they only name their Giraffes after sports people), and in 1992, two females were born, so one was named Sally (Gunnell) and the other Tanni (Grey).

I have also been on programmes like A Question of Sport (been on one of the biggest losing teams ever) and They Think It's All Over...

In my other side of my life, and it does feel like the two are separated out, I am treated like a disabled person. I have not had to deal with widespread discrimination - more often than not it was smaller difficulties along the way. Sometimes I wonder whether that

is because I grew up with a disability and don't always notice when people are treating me differently. Certainly my husband, who had a spinal cord injury at the age of 21, notices more when it happens to him - I think because it is more of a change for him. I do know a lot of people who experience quite direct discrimination, but because that is the way that they have always been treated then they don't realise that it is occurring. It is not just the attitude of the wider world that we have to change but also disabled people so that they recognise when they are not being treated properly but more importantly are prepared to do something about it.

When I became a mother I faced some of the most open questions that I could ever have imagined. Several people came up to me and asked how I had become pregnant, which I wasn't really sure how to deal with. After several times awkward situations I decided that I would have to think of something to say and replied "through my ear". Those people who have asked were either too embarrassed to question me further or just thought that I was mad. I am not sure how being a wheelchair user automatically gives people the right to ask personal questions but in most situations I try to have a sense of humour about it.

The one question that I am asked more than most is how I felt at the BBC Sports Personality when in 2000 I came third but there was no ramp for me to get on stage. How I really felt was excited, and thrilled and it was a dream come true. I didn't need to get upset because the BBC are better than that - they had after all been at the forefront of showing disabled athletes on the TV and everything else I had done with them had been thought out. I think it was a mistake on the night, and to be honest I was more pleased with the fact that the BBC had so many complaints about me not being able to receive my award on the stage. We decided that the best way forward was to issue a joint statement with the BBC to try and rectify the situation, and ensure that something good came out of it. The media coverage was huge, and for me one of the most positive

things is that four years ago I wouldn't have been voted in third place let alone had so many non-disabled people think that it wasn't right.

For the short term, even old as I am, I intend to keep training and competing for a few more years and see where it takes me. Hopefully beating Ian my husband in a race (he is a Great Britain level athlete) and keep going until I no longer want to do it any more.

Ends

Keywords: Disability rights: Sport

DRC National Conference 11th November 2002

Maria Eagle MP Minister for Disabled People

I am very pleased to be here in Manchester today and I am very pleased to be able to tell you a bit about the Government's role in empowering young disabled people to achieve their aspirations.

There are many things I want to emphasise.

Young disabled people have goals, dreams and aspirations in life that are no different to any one else's.

Educators and employers, service providers and Government need to expect the best from young disabled people and not make assumptions about what they do or do not want, what they can or cannot do.

Government's role is to set the framework of law to prevent discrimination, to encourage achievement and to facilitate the solution to problems and barriers that exist.

Society in Britain is changing and disabled people are beginning to take their rightful place. In Government, in business, and in science, high achievers with disabilities are all competing on equal terms with non-disabled people. On the sports field too, for the first time this year, in the Commonwealth Games here in Manchester, world class disabled sportsmen and women have competed alongside their able bodied counterparts. So progress has been made.

But there is more to do.

There are still more barriers in your way as young disabled people. Barriers put up by society. Physical barriers, as well as barriers of ignorance and misunderstanding.

You've only got to look at the DRC's legal cases to see the overt discrimination that can still exist - whether it's deliberate or not, it still hurts and it is still a barrier.

It is our role in Government to break down barriers. We are determined to end discrimination against disabled people so that everyone has the opportunity to play a full and active part in society. To achieve the best they can. This country will not achieve its full potential without including everyone. So this makes sense if we want to remain a prosperous country.

Access to education and employment opportunities are two vital elements of equality. That's what I'd like to focus on today. The action we are taking to strengthen disabled people's rights and give them greater protection from discrimination. As well as the practical support we're providing so that disabled people can make the most of the opportunities out there.

The Special Educational Needs and Disability Act (SENDA) became law last year. This is a huge step forward for disabled pupils, students and adult learners.

The Act strengthens the right of children with special educational needs to be educated in mainstream schools alongside their non-disabled peers though it does not prevent the continuation of special schools. It also means that schools, colleges and universities cannot treat disabled students less favourably than non-disabled students.

Post-16 institutions must make reasonable adjustments to the way they deliver their education and other services to ensure that they are accessible to disabled students. This is not just about teaching and learning. It is also about things like accommodation, careers advice and leisure services. And in three years' time post-16 institutions will need to make reasonable adjustments to physical features of premises to improve access for disabled students.

But legislation alone is not enough. It is important that education providers understand their legal obligations.

Two Codes of Practice - one for schools and one for the post-16 education sector - were published by the DRC in July this year. They provide practical advice and examples on things like making reasonable adjustments to make the law easier to understand.

And in September the DRC launched a major campaign - Educating for Equality - to promote awareness of the new legal duties and codes of Practice. The role of the DRC is vital in spreading equality and inclusion throughout the education and employment worlds. Because laws alone are not enough.

Of course legislation is a key issue but we are also helping turn legal clauses into real improvements by providing financial help.

The Schools Access Initiative provides capital support for projects to make mainstream schools accessible to pupils with disabilities. For example, it can be used to install lifts or ramps, provide specialist IT equipment or induction loops for hearing impaired children. £220 million is available over the three-year period 2001 to 2004. £50 million has already been allocated to LEAs and this represents a five-fold increase in the funding available in 1996/97.

And for the first time, funding of £172 million is being provided over this financial year and next to improve access for disabled students and learners in further and higher education institutions.

For disabled students in higher education, we have increased Disabled Students' Allowances. These allowances are paid on top of the standard support package for students to meet the extra costs that are incurred as a result of a disability. We have dropped the means test in the Disabled Student's Allowance for full time students and we have extended the allowance to part-time and postgraduate students.

Expenditure on Disabled Students' Allowances has risen from just under £1 million in 1990/91 to over £45 million in the last ten years. There has been over a 40-fold increase in the number of Disability Students' Allowances awarded from 710 in 1990/91 to over 29,000 in 2000/01.

All this clearly will help.

And for those who are looking for information and advice, there is Connexions. Launched in 2001, Connexions is the Government's new support service for all young people aged 13 to 19 in England. It can offer you practical help with choosing the right courses and careers and also help you get involved in broader developmental opportunities like sport, the performing arts and volunteering activities. A lot of people have used it already - over 1.25 million interventions to help young people have been made and over 85,000 personal development opportunities have been supported - so we know it is popular. And of course, it applies to you.

The second key area where we are moving forward is employment.

Currently it is unlawful for an employer with 15 or more employees to discriminate against disabled people. This means they cannot treat any disabled employees or job applicants less favourably than others unless such treatment can be justified. Covers all aspects of employment - recruitment, selection, promotion, training etc.

Employers may also have to make reasonable adjustments for disabled people. For example, providing special equipment like a text phone for someone who is deaf. Or changing working hours, like allowing someone with a mobility impairment to start later to avoid rush hour traffic.

We are committed to extending these provisions by introducing legislation by October 2004 that will mean that all businesses, whatever their size, are covered by the employment provisions of the Disability Discrimination Act.

Most disabled people are able to make very effective use of mainstream employment and training programmes. However, some people who are looking for work might find that their disability represents an additional obstacle in their search for work. This is why we sponsor specialist programmes to help them find, keep and train for work. Through Jobcentre Plus we plan to spend over £260 million this year on specialist programmes for people with disabilities. Programmes like Access to Work, Workstep, Job Introduction Scheme and Work Preparation. These are all designed to help you.

The New Deal for Young People is aimed specifically at young people aged 18 to 24 who are looking for work. By the end of June 2002 it had helped nearly 380,000 young people into jobs.

One further area that I would like to touch on briefly is transport. Having a place at college or a job are not much use if you can't get there.

We are committed to providing an accessible public transport system so that disabled people can enjoy the same opportunities to travel as everyone else. We have introduced new laws, which require all new buses and coaches providing local and scheduled services and new trains to be fully accessible to disabled people.

In addition, the Department of Transport will be consulting soon on proposals to ensure that disabled people are not discriminated against when they use these accessible buses, coaches and trains and to improve the accessibility of existing trains.

We are committed to ending discrimination against disabled people.

I've set out some of the measures we are taking - legal as well as practical. I believe these will make a real difference to the lives of young disabled people and help them to achieve their potential.

Government can set the framework, but we cannot transform attitudes and society alone. The DRC and other stakeholders have a key role to play.

Together we can go forward to a better world, where disabled people are included, where the barriers they face are minimised whilst the contribution they make is valued.

That's what we are aiming at. That's what we are going to do with your help.

Ends

Keywords: Disability rights; Disabled young people; Legislation

DRC National Conference 11th November 2002

Bert Massie

I want you to imagine a room perhaps as large as this, filled with a sample of disabled people from this country. Who would be in that room? Well most of them would be women as there are more disabled women in this country than men. Two thirds of them would be of retirement age, about five per cent would be under the age of 20 to 25, and given that disabled people represent the rest of the community, about 10 per cent would be gay or lesbian and we know about five per cent would be from ethnic minorities.

Now that you have this room, with all these people in it, then you look at how long change takes. Lets just look at how things do change. With regards to transport - the first time a seat was taken out of a train, so that someone in a wheelchair could travel in the coach and not in the guards van was in 1979; on current projections all trains will be accessible in 2030.

The Labour Government changed the law a couple years ago to make new housing accessible; in 50 years time half the housing in this country will be accessible; and in 95 years time over 90 per cent will be accessible. The campaign to make buildings accessible started in 1965. The new laws of the DDA require current buildings to be made accessible - if that's what is needed, this will come in 2004. That's the timescale it takes for the kind of changes that we are looking for.

When you look at how the DRC is working, and the kind of world we are trying to create, it's a world where young people will have to live. This puts a great deal of responsibility on those of us who are talking to Government and influencing policies to make sure that the

world we are trying to create suits not only our needs but those of young people. And that is what today is all about. The DRC is conscious of saying that we mustn't just listen to the people who have set the agenda of the past, but we must look for new agendas and that will come from young people.

We commissioned some research and we found that with 16 to 24 year olds by the time they reach the age of 30, nearly one in three of young people expect to earn less than other people because of their disability. If you earn less, then when you retire, your pension is less, and less money means fewer choices - it is as simple as that.

Nine out of 10 young people think it's harder for disabled people than non-disabled people; that's despite all the changes with the law over the years. That is the perception. One in six said they've been turned down for a paid job, and they've been told that the reason relates to disability or ill health. Now that might actually be illegal, but people still think it's happening! The encouraging thing was that 85 per cent said that they had not experienced that. Now in the 1970's you would never have had 85 per cent of people saying that so clearly there has been some progress there. 18 per cent said they'd been turned down for a job and told it was not for a reason related to their disability but they thought it was, so there may be place for examination.

What do young people do? Well, a third of young people said they are not able to do the things their friends can do and be with their friends - that's social isolation. That's 2.5 million disabled people that are being excluded. However two-thirds of people said they could join in, which is positive. Yet social isolation is a real problem and something we need to look at.

When we look at transport, almost half of those questioned said that they have experienced problems in using public transport, which in turn made it difficult for them to participate in activities that other

people their age take part in. All new buses are required to be accessible - however we will have to wait till 2017 for all buses to be made accessible. Not all taxis in the country are accessible either, although often there are accessible taxis in some of the major cities. Eight out of 10 people said they are unable to use buses and seven out of 10 young people said that they are unable to use trains. Now given what's happening, it's unlikely that those figures are accurate, but that is what people think so we're not giving people the confidence to use the transport systems. And two-thirds of people said that they could not go to concerts because of transport problems.

Over a third of young disabled people felt that the Government did not listen to them at all; whilst a third believe that the Government listened to them a little.

And so what we have to do at the DRC is to use our influence to do what you want us to do. And so when you go in the workshops, we will be listening very closely to what you are saying. And today is an opportunity for young people to say to the DRC what we are doing right and wrong and what issues you want us to raise on your behalf. We'll take that back and that will influence our programmes over the next year. So for us here at the DRC this is a very important conference and the most important people here are you - you are the experts, you are the young people. Tell us what you want - we're listening.

Ends

Keywords: Attitudes; Young Disabled People

Lakhvir Rellon at the expert seminar

Prepared by Jill Stewart Policy Manager Health and Social Care

The Disability Rights Commission has a Vision of "A society where all disabled people can participate fully as equal citizens."

Health staff are absolutely central to achieving this vision through:

being responsive to the needs of disabled people;

promoting the social model of disability;

ensuring that the lives of disabled people are valued equally;

ensuring disabled people have equality of access to health services.

In addition health services and professionals have a vital role as educators, advocates, opinion formers and agents for change in wider society.

Nowhere is this more essential than when reaching decisions on whether to withhold or withdraw treatment. This truly is a matter of life and death and disabled people must be sure that they will be safe, that their views will be taken seriously, and they will have the maximum possible choice and control when entering hospital.

To this end we have asked you to take part today, to pool your experience and share insights from different sectors (including medicine, disabled people, law and ethics), to address the issues and agree the way forward.

Scope's survey by Lamb B and Layzell S (1995) Disabled in Britain: Counting on Community Care, Scope, London

Reports that already many disabled people do receive an excellent service as one person put it:

"I have received the utmost care, support and consideration from the medical profession, including psychiatric doctors and community nurses and hospitals, and above all, I am most appreciative of the efforts of the local GP, without whose encouragement and support I would not be able to keep going."

The same report however shows that others have not found the service so responsive and indeed have faced assumptions about their quality of life, or their abilities.

"I have often been 'talked over' without being consulted. In fact I was 50 years old before I saw a doctor who talked to me and not my carer."

"As far as the health service goes I have had to fight for everything. Firstly I was told my daughter was going to die, when she didn't I took her home ... (getting) her to see a heart specialist and an orthopaedic surgeon for her feet was a fight, as the doctor thought it was a waste as she was going to die. She is now six."

The vast majority of health staff however want to treat disabled people fairly and have their best interests at heart - of course there may be exceptions (where the DRC will be prepared to take action). The main problems are not intentional discrimination, but unquestioned assumptions that disabled people have a lower quality of life, and institutional barriers such as policies and practices which do not take account of their needs. For example some services do not train staff in resuscitation techniques for neck-breathers.

This has resulted in patients lives being put at risk for example: A young doctor in a recover ward placed a plaster over the laryngectomee's stoma thinking that by placing the mask over his mouth and nose the patient would get more oxygen - fortunately an ENT trained nurse in the ward who rushed to help when the patient

was convulsing violently, spotted immediately what was wrong.
(reported by the National Association of Laryngectomee Clubs)

Some graphic clinical evidence highlights inadvertent discrimination:

The National Clinical Sentinel Audit into Epilepsy Related Deaths showed that every year 1,000 people die as a result from epilepsy. The report found that poor clinical management had resulted in a substantial number of epilepsy deaths where 39% of adult and 59% of children's deaths were considered to have been potentially or probably avoidable. Often patients are not even made aware of the increased risk of premature death.

Clinical evidence shows higher mortality rates among people with learning difficulty and also people with schizophrenia. There may be multiple reasons for this: life-style (smoking, nutrition), suicide risk etc. - but one factor certainly is differential access to a) screening and b) treatment. Mind's survey Not Just Sticks and Stones, London 1996 found that one in four respondents had been turned away from primary care when they needed help. One person reports: "I suffered from general health problems for several years - on-one would listen and everything was put down to my mental health problems. I eventually received help when I was severely ill on holiday. This time I was immediately listened to and my problem diagnosed. This resulted in major abdominal surgery (much more major than if it had been if diagnosed earlier)."

Mencap's report The NHS - Health for all?: People with learning disabilities and health care, 1998 showed evidence of discrimination in access to general health services. 1825 disabled people and 1478 families and carers took part in the research. The research found disturbing evidence that health promotion/prevention initiatives not reaching people with learning disabilities. For example breast screening uptake is 76% for women in the UK (ONS 1998), but between 17% (family care) and 52% (formal care) uptake by

women with learning disabilities. Whilst uptake for cervical screening for women 18 and over was 3% (family care) to 17% (formal care) for women with learning disabilities compared to a UK figure of 85% of women between 20 and 64 years who had had a smear test in the last five years, in the year 1996/7 (Department of Health 1997).

There are however some excellent examples of how this can be overcome. Professor Sheila Hollins of St George's has undertaken work to overcome the low uptake of cervical screening by woman with learning disabilities. A woman with learning disabilities was trained to explain to other women with learning disabilities what this is and why it matters. Take-up improved dramatically.

Another major barrier is lack of access to information and communication needs, which can result in disabled people not being consulted or listened to. Mind's survey of 418 people who had experienced ECT) Shock Treatment - A survey of people's experiences of Electro-Convulsive Therapy (ECT), London 2001, found that: 34% were not aware that they could refuse to give consent to the treatment; 61% were not, as far as they remember; given any information about possible side effects; 30% were not told why they were being given ECT; and only 41% were told how the treatment would work. Only 15% of those who received ECT in the last two years had the opportunity to consult an independent advocate before making a decision about ECT.

Here the Disability Discrimination Act can act as a driver for change. The DRC amongst others can provide information and guidance on the law but also on good practice. The health service is the largest employer in the UK and yet disabled people are vastly underrepresented. The NHS initiative on diversity should lead to increased numbers of disabled staff throughout the organisation. This has the potential to change the whole culture. It is harder to patronise disabled patients or make decisions inappropriately on

their behalf when other disabled people are your colleagues ... or your boss.

As a service provider the NHS has a duty to make their services accessible through for example information in different formats Braille, cassette, large type, and to provide auxiliary aids such as induction loops and other communication aids such as sign language interpreters, or possibly for some people the use of advocates.

A major barrier to equality is the attitude of others to disabled people. Decisions around whether to withhold or withdraw treatment are made against a backdrop of negative views and assumptions about the value of disabled people's lives. This negative view can be fuelled by the way in which disabled people are portrayed in the media for example a broadsheet reported on the BMA's guidance on withholding and withdrawing of treatment under the headline 'Doctors can let hopeless patients die'. Words used to describe disabled people include freak, moron, deformed, cripple, retarded, deranged, unsightly. 312 out of 796 stories about disabled people in local newspapers were to do with charity. A typical story portraying disabled people as hopelessly dependent and reliant on charity reported how pupils of Greentrees Junior School raised money from a sponsored walk to help 'John who is a 25 year old and suffers from muscular dystrophy. Before this cruel disease affected him, John was an active sportsman and keen footballer. Sadly John has lost his mobility and without help will soon be confined to bed.'
(Cooke et al 2000 STOP PRESS - How the press portrays disabled people, Scope, London)

The language and assumptions used in judicial rulings again reinforce these views. The courts have developed a test in which it is only acceptable to deny life-saving treatment, where the individual is terminally ill or where their life is going to be 'demonstrably awful', 'full of suffering', or 'intolerable'. The law rules

that the impact of some people's disabilities are so serious that it is in their 'best interests' - and therefore lawful - to withhold life saving treatment. This will apply even where the individual is "neither on the point of death or dying." Put bluntly, the law regards some people, including some young children, as better off dead.

Other judicial decisions, in the criminal law field, reinforce this picture of disabled people as burdens, and their lives as intolerable.

One recent example reported in The Daily Mirror October 2002 under the heading - 'Mercy Kill Axe dad goes free: A man who beat his wife and severely disabled daughter to death with an axe walked free from court yesterday. Judge Sir Rhys Davies accepted that dad-of-six acted in desperation to end their suffering. Manchester Crown Court heard that Frank and his wife had devoted their lives to caring for their daughter aged 33 who was virtually wheelchair bound because of physical and mental problems. As they grew older Frank realised that Fiona might have to go into a home and be sedated. He decided the only way his wife and daughter would finally be at peace was to kill them. He waited until they slept at home, whispered he loved them, then killed them. "It was my way of solving the problem" he told police. I loved them to bits and wanted them to be at peace." He wept as he was freed after admitting manslaughter on grounds of diminished responsibility. The judge jailed him for nine months but he was released because he had been in jail since May.'

There are some very successful practical initiatives taking place in medical schools aimed at redressing the balance through training. Bristol University has reported on its initiative aimed at improving training of medical students. The Disability and Rehabilitation Panel (Co Chair Dr M A Byron) Department of Clinical Medicine report that disabled people have taught on the Bristol Medical School Disability course since its inception in 1993. The social model of disability now underpins teaching at Bristol and disabled people lead as teachers e.g. communication workshops are led by people with

specific communication impairments: visual, speech, hearing and learning difficulties. The university has developed a module concerned with Disability Equality as a part of a Diploma or Masters in Medical Education. The aim is to embed the underlying philosophy throughout the whole of the medical course.

All of these issues around possible discrimination and disabled people can affect decision-making on withholding and withdrawing of treatment. It is difficult to quantify the exact extent of any problems but cases continue to be reported.

A charity helpline was contacted by a care worker concerned that a client's right to life had been compromised. The client was a mature adult with Cerebral Palsy who had been taken into hospital with a respiratory infection. At first treatment with antibiotics went well (administered in intensive care). Later the patient suffered further complications and was put on life support. At this point the patient's closest relative requested that they be taken off life support, as the family did not think the patient had any quality of life. The care worker was concerned because the person had explicitly expressed a desire (in front of witnesses) to receive full medical treatment.

The very fact that the issues are complex, and that each person and their circumstances can be very different, present dilemmas which are difficult to resolve. For example the case - reported in the Guardian in April 2000 - of a woman who had stomach cancer who was admitted to hospital after a tube used in her chemotherapy treatment became infected and she developed septicaemia. She eventually discharged herself because she was unhappy with her care and demanded to see her hospital notes. A doctor had written on the top of the records: "In view of the underlying diagnosis (cancer), in the event of cardiac arrest or stroke, resuscitation would be inappropriate." The note also said "Do not ring 555" - the hospital number for the resuscitation team. Mrs Baker said: "When I read this I was absolutely horrified. They were going to let me die. My

husband broke down in tears." Nine months later she was still alive and enjoying good quality of life.

One medical professional points out that CPR success rates are approximately only 15% in hospital, and there is significant morbidity for the survivors. In addition there are certain clinical features - which may well have been present in this case - which indicate minimal chance of surviving. He asks if doctors were in fact making a decision not to overburden her with a futile intervention, rather than going to let her die?

This shows graphically how difficult it is to identify whether decisions have been made in the best interests of the patient or if unintentional discrimination has taken place.

The question of 'Quality of life' is not easy to define. There will even be differences of opinion between disabled people with the same level of physical and mental function. A lifestyle that one person considers good quality another may find intolerable. The case of Miss B who refused treatment because she did not want to spend her life reliant on personal care from others, brought forth testimony from disabled people with similar needs who expressed great satisfaction with their quality of life. Each case has to be treated on an individual basis.

The main problem however - highlighted in all the cases we have found - was the lack of consultation with the patient (or where appropriate their family). Mistakes can be made with the best of intentions. For example there is some feeling that the need to consult with patients about DNR notices may be upsetting for the patient. However, the guidance is very clear that wherever possible patients must be consulted. Also research has shown that, in the main, patients welcome discussion. Morgan et al, BMJ 1994;308:1677-1678 (25 June) found in their research with elderly patients (98 out of 100) and their relatives (95 out of 100) that most

people did not feel uncomfortable discussing their resuscitation status but welcomed it.

The BMA and GMC have both recently issued guidance on withholding and withdrawing treatment, which is helpful. Medical professionals are still however left to envisage what is meant by 'severe pain or other distress' or 'profound disability'. Other guidance relies on interpretation of 'such a degree of impairment that it would not be reasonable to expect him or her to bear it' or an 'impossibly poor life'.

It is difficult to unravel whether discrimination has taken place or if in fact the appropriate decision has been arrived at, following strict guidelines and protocols. However there is enough evidence - both clinical and anecdotal - of disabled people being denied access to general health care, together with specific cases where DNR notices have been placed without consultation with the person, (or where appropriate their family), for there to be real cause for concern.

The cases we have found show that the problems often arise through lack of policies and protocols to support the process. Sometimes they exist but staff are not aware of them.

A resuscitation audit of two hospitals found that correct documentation of DNR status was found in only 23% and 10% of cases in patients identified as "Not for CPR". A survey by students at one hospital found that out of 72 doctors only 54% had read the Trusts guidelines.

A search of CHI clinical reviews of NHS Trusts shows that of 19 reports regarding DNR, 3 Trusts have a policy, in 3 trusts policies are being reviewed or have plans to review, 3 trusts have detailed policy and practice guidelines, and reports on 10 trusts show concerns, some serious.

However there are examples of good practice and one trust is highly praised:

'The trust has recently developed comprehensive do not resuscitate (DNR) and consent policies. All patients who are admitted to the hospital are designated category A, meaning they will be resuscitated if at all possible, until their consultant has discussed the matter with them. The trust is clear that it is the responsibility of the senior medical staff to talk to the patients about their DNR status. These discussions often take place with a nurse present. CHI is impressed with the actions taken by the trust to develop and implement the DNR policy.'

Some of the questions that all of this raises are:

What support do medical professionals need when facing these complex situations?

How do we help doctors who may have never had experience of working with a disabled person?

Do medical professionals receive sufficient training to enable them to communicate? Are there sufficient support mechanisms, for example access to signers/advocates?

How do we ensure that disabled people receive equality of access to health services.

Ends

Keywords: Disabled People: Health services; Medical staff : withholding treatment