# Controversial Speech by British Activist: Have Disability Rights Gone Too Far?

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(Editors' Note: Reprinted in Disability World with permission of Colin Low, this presentation was made in early April to City University in London, and based on some lively exchanges on disability listservs, seems to have caused quite an uproar in the British disability community. It is reprinted here in its own right-a frank and historical assessment of the disability movement in Britain by one of its senior members-but also for its insights about a current international development, the publication this spring of a new and controversial version of the World Health Organization's International Classification of Impairments, Disabilities and Handicaps, known as ICIDH-2.)

Vice-Chancellor, ladies and gentlemen,

I was naturally flattered to receive the Vice-Chancellor's invitation, but also a little taken aback. "Dear Clive" it began, presumably mistaking me for Prof. Clive Holtham, who preceded me not only chronologically, but also alphabetically in this series. Sorting out the University's mail-merge system still left me with a certain sense of apprehension however, since I realised that I am probably one of those academics whom J. K. Galbraith rumbled about all those years ago as having built a successful career on their unpublished works, and I figured this must be a cunning ploy of the Vice-Chancellor's to check up on what I was doing. Still, there seemed nothing for it. The Vice-Chancellor wanted something fascinating in topic and delivered with panache, and anyway, it would give me a welcome opportunity to acknowledge publicly the link of now some two decades' standing which has existed between City University and RNIB. In the 1980s, the University validated the course for blind physiotherapists which we ran at that time. The establishment of the Volprof Centre in the Business School under the direction of our Director-General, Ian Bruce, broke new ground in the application of the systematic study of management to the training of staff to work in the voluntary sector, and some 150 students have graduated from the Centre in the last ten years. More recently, there has been a fruitful relationship with Mike Floyd's Rehabilitation Resource Centre where I have been based. The Centre has evaluated a number of our programmes, and Doria Pilling in particular has undertaken significant literature reviews of the employment and post-school educational experience of visually impaired people, as well as of the links between visual impairment, low income and poverty. And now just this year, in a potentially fruitful collaboration between our Eye Health Unit and City's Department of Optometry, there is the Certificate Course for eye clinic link officers which promises to deliver a step change in the amount of knowledgeable and understanding support people receive at a critical juncture in anyone's life - that of losing sight. All this bespeaks just the sort of partnership relationship to be looked for from forward-thinking institutions in the academic and voluntary sectors at the beginning of the 21st century, adding the values of academic rigour and objective study to those of social relevance and concern.

As Michael Howard used to say whenever he visited a prison and was asked to address the inmates, I'm delighted to see so many of you here tonight. But if it's not too invidious to say so, can I say what a particular pleasure it is to see Prof. Donald West of the Cambridge Institute of Criminology, who was my supervisor there more years ago than probably either of us cares to remember. And before I go any further, I should also like to express my appreciation to the King's Fund, the Baring Foundation and the Esmee Fairbairn Charitable Trust for helping to create the space at City University for me to think about the matters I want to discuss with you this evening.

#### Title of the lecture

I thought long and hard about the title of this lecture. At length I came up with "of disabilities, models and monoliths". But when I gave this to the External Relations people at City, they thought for a moment, then said: "how would you feel about `have disability rights gone too far?" " - you can see their point! To judge from the little flurry of interest on the Internet, some consider the very question inadmissible. But I don't

think so. It will be one of the leitmotifs running through this lecture that the disability movement needs to be more self-critical - self-aware even - about the positions it takes. Closed systems of thought which regard themselves as self-validating and cut themselves off from any internal self-questioning or external challenge are not ultimately built on very sure foundations. Des Wilson always used to stress the importance of giving full weight to the arguments of your opponents before you could hope to be any use as a campaigner. So I said I could go with the title as a peg on which to hang a lecture. The models and monoliths will remain important to the answer, but they will have to yield pride of place to the question. And that's as it should be. People should wait for the answer before condemning the question.

And so, with such panache as I can muster, "have disability rights gone too far?" At one level, of course, the answer is obviously "no". The disabled are clearly one of the more disadvantaged and under-privileged groups in our society. \*1 The disablement Income Group in the mid-60s and Prof. Peter Townsend when he founded the Disability Alliance in 1973 established that by common consent and placed disability firmly on the social policy agenda for the first time, and things are not substantially different today. At the last count some seven times more likely to be unemployed and on benefit than non-disabled people, \*2 disabled people are clearly, in the language of today, the victims of social exclusion. Over half of all disabled people have incomes that are below the poverty line, and amongst disabled people with children, this rises to 60%. \*3 Disabled people are twice as likely as non-disabled people to have no qualifications, \*2 and only 40% of disabled people of working age are in paid employment. Parents of disabled children are less likely to work, and when they do, their earnings are lower than those of parents as a whole. Homes with chronically sick or disabled people in them are amongst those with the highest deprivation rates, and parents with disabled children have a lower socio-economic profile than other families. \*3

So for the avoidance of doubt in view of what I shall later say, I believe that disabled people do have rights - importantly the right to be treated as equal citizens, given equality of opportunity and not discriminated against. Furthermore, they have the right, as far as possible, to fulfil themselves in mainstream activities, by receiving mainstream services delivered in the normal way, as part of the mainstream of society. I believe that these rights are sufficiently unfulfilled that they need to be backed by law, and that we have some way to go before law, practice and understanding have developed to the point where these rights can be said to be fully delivered in practice.

#### Complexity of disability phenomenon

I can beat the drum in support of this position as well as anyone. I could make out that the title of this lecture was just a Socratic device for introducing another ringing endorsement. But that would be disingenuous, and honesty compels me to be more up-front. For while I do unreservedly subscribe to the rights agenda as an important component of disabled people's struggle to be recognised and given a fair deal, it also seems to me that the civil rights paradigm for addressing the problems of the disabled has serious limitations. In truth we here encounter the first of our monoliths - often distilled in the slogan "disability is a rights issue" - which inevitably means in my book that it will itself be disabled. For it is the central contention of this lecture that monolithic or one-dimensional analyses and prescriptions are inherently unable to do justice to the complexities of the phenomenon that is disability. As for this one, flawed in its philosophical underpinning, it both proceeds from and reinforces a particular cast of mind - negative and adversarial. As it sweeps all before it, it throws whole orphanages out with the bath-water, and its excoriation of alternative perspectives leads to error in its policy prescriptions. And all these features conspire to produce an intellectual and campaigning style which is repugnant. In short, it stakes out a position which in the Communist Party was always identified as being on the ultra-left. It is a sad fact of equality politics generally that liberals and mainstream progressives have been so variously bemused, beguiled and intimidated by the blandishments and menaces of the left that they have been all too ready to engage in appeasement with it. The politics of disability are no exception. But i don't see why the radical ground should be ceded to the Red Guards of the disability

movement. My answer to the question at the head of this lecture is therefore "no", but my contention is that there is need of a good deal more subtlety and sophistication in the way rights are pursued than we commonly see at the moment. The creation of some space for a mainstream radical position, largely by means of a critique of the pseudo-radical position just identified, will therefore be the work of the rest of this lecture.

#### **Terminology**

Turning first, then, to the philosophical under-girding, we run slap into the second of our monoliths, the so-called social model of disability. If I had to give one tip to anyone dabbling in the field of ideas, it would probably be never to refer to anything as the "so-called" model or school of anything. I've probably got into more trouble over the years for this than anything else. People always assume it has a pejorative connotation, but in truth I just mean "here's an idea which may be new to you and this is what it's called"; and that is how I should be taken to be using the expression whenever I use it again in this lecture.

The social model of disability is a conceptualisation which the disability movement has developed over the last three decades or so in contradistinction to the so-called medical model of disability. In order to understand these distinctions fully, it is necessary for me to subject you to a short excursus on terminology, which is very complicated, confusing and confused in this area. Most of the difficulty stems from the ambiguity with which the term "disability" is used. Unfortunately, it is used in no less than four different senses: First of all, it is used non-technically, in the way that it is used in general parlance today, to refer to the global phenomenon, disability, the particular form of disadvantage we are dealing with. But since most people are agreed that that global phenomenon is a compound phenomenon, it is also used in a technical sense to refer to just one strand of that global phenomenon. The analysis of the global phenomenon in commonest use today is that of the World Health Organisation, who in 1980 came up with an International Classification of Impairments, Disabilities and Handicaps (ICIDH). Recognising the scope for confusion in using "disability" to denote both the global phenomenon and a sub-strand of it, they used the term "disablement" as a "generic descriptor" as Prof. Philip Wood, the Classification's author has called it, for the global phenomenon.

Turning to the components of the Classification, "impairment" refers to a loss or abnormality of psychological, physiological or anatomical structure or function. "Disability" refers to the consequent inability to perform normal activities. Thus "impairment", at the lowest level of analysis, is concerned with specific functions of the body or mind. "Disability" is concerned with compound functions or activities, such as walking or seeing. "Impairment" refers to the various mechanisms which give you the power to move your legs purposefully in an upright position and the fact that they are not working. "Disability" refers to your inability to walk. "Handicap" refers to the disadvantage resulting from the interaction between a person's impairment or disability and their environment. \*4

So far so good. The only snag is that "disablement" has never really caught on as a generic descriptor, and a significant section of the disability movement prefers a twofold classification which distinguishes simply between impairment", corresponding broadly to the WHO's "impairment" and "disability", and "disability", which corresponds broadly to the WHO's "handicap", except that in the latter case there is a difference of emphasis between the WHO and the disability movement - for the WHO it is the individual who is ill-adapted to fit into the environment, whereas for the disability movement it is the environment which is ill-adapted to accommodate the individual. The upshot of all this is that the meaning of "impairment" is reasonably clear-cut. It refers to physical and mental functions, simple or compound. But the meaning of "disability" is not. On the one hand it is used to refer to the global phenomenon, or disadvantage, with which we are dealing, and on the other to the disadvantaging interaction between an impaired individual and his environment. To cap it all, it is often used loosely and interchangeably with "impairment" in this latest sense,

the disability movement's "impairment/disability", when it would be more accurate and less confusing to stick simply to "impairment", as when we talk about "learning disabilities" or "disabilities of sight". Confusion reigns supreme when we talk of "multi-disabled visually impaired" or simply "MDVI" children! Got it? I shall try to confine my use of "disability" to the global phenomenon and the disability movement's antithesis with "impairment", or if you prefer "impairment/disability". But I fear I shall probably slip into most of the other usages at one time or another, so I shall just have to hope that the context will make clear on each occasion which I am using.

The medical model of disability can take a variety of forms depending on whether it emphasises biomedical abnormality per se (ICIDH impairment) or the consequent functional limitation, such as the inability to walk, see, etc (ICIDH disability)notwithstanding the fact that it is called the medical model of disability, the key organising concept for the medical model is, for the disability movement at any rate, impairment. The dominant consideration in disability is mental or physical defect, giving rise to a very negative stereotype of the person with a disability. This too is a monolith. People with disabilities, especially those with the same impairment, are lumped together, all viewed in terms of their impairment as passive, helpless, tragic victims and not as ordinary human beings at all. Impairment, not humanity, comes to construct the identity of the person with a disability, and people with disabilities come to be seen as pathetic objects of pity and care and not as conscious actors in their own situation.

#### Medical or individual model

There are just two points I want to make about the medical model - it is neither exclusively medical nor a model. The essence of the distinction between the social and the so-called medical model is that the latter sees disability as fundamentally about something to do with the individual - as principally a function of the person's individual characteristics. These will often be medical, but they need not be. Even more to the point, the typical response suggested by this way of thinking is to seek to change the individual in some way. This may be by treating his medical condition, but by no means necessarily so. For example, it might take the form of training in something or other, such as mobility, or living skills or in using access technology. You can see why this whole orientation to disability has attracted the medical label - from the key role doctors have had in mediating it - but for all these reasons, I prefer to think of it as an "individual" rather than a specifically medical model, in that the focus is on the individual rather than society as the locus of a range of problems, not necessarily all medical, and because of the concern to transform the individual rather than the environment in which he or she is placed by a variety of means, not just medical.

The medical or individual model is not a model in the sense that it has ever been consciously constructed as such. Of course we all know doctors whose horizons do not extend beyond the door of their consulting-room. But it is doubtful how far the medical model has ever really been espoused as such or in pure form. Even those who have tended most to the view that disability arises out of a medical condition of some sort have usually recognised the social dimensions of the problem in some degree and sought to address them. As Jerome Bickenbach has put it, the medical model is really the default position - more part of the mental furniture of commonsense than something consciously constructed by anyone. \*5 In fact it would probably be nearer the truth to say that it has been constructed by advocates of the social model as a kind of Aunt Sally against which to elaborate their own theories. All the same, it reflects a reality in the experience of disabled people.

#### The social model

To this medical or individual model, then, as I have said, disability activists have counterposed a social model of disability, which sees disability not as something to do with the individual, but rather as something to do with society, maintaining that disability is a function of social, not medical or individual factors at all, such as prejudice and discrimination. These are often referred to as barriers to full participation in society

erected against disabled people by society itself, and can be attitudinal or material - physical, economic, social, cultural or political. As the Union of the Physically Impaired against Segregation Editorial Collective declared in 1981: "it is the way our society is organised that disables us"; and again: "disability is not something we possess, but something our society creates." \*6 As Rachel Hurst, a leading disability activist, has put it: "disability is something that happens to you, not something you have." \*7 This is why the disability movement insists on referring to "disabled people" rather than "people with disabilities", which is a medical model formulation. Even more pointedly, other writers have spoken about disability being "caused" by unsupportive social and physical environments. For example, Vic Finkelstein, a leading thinker about these matters, has written: "the cause, then, of disability is the social relationships which take no or little account of people who have physical impairments." \*8

#### Four possible interpretations

There are at least four ways in which one could understand statements like these. First, one could think of the conditions of society, for example if they were particularly harsh, as literally causing the medical conditions which give rise to disability. A good example of this was contained in an article by the Anti-apartheid Health Committee in June 1981, which was headed "Apartheid disables". It stated that it was apartheid policy which was responsible for so much disability in South Africa. "The very diseases which disable" it said, "tuberculosis, polio, malnutrition, trachoma, are rife in the black population because of the poverty and appalling living conditions of apartheid." Finally it cited statistics for death and permanent disability as a result of industrial accidents some four to five times higher than in Britain, though the population of South Africa was half as great. \*9 More recently, a team of optometrists from City University had considerable success in relieving the scourge of visual impairment which had afflicted the population of Albania for many years because of the lack of facilities for manufacturing spectacles under the Communist regime. \*10 However, it is doubtful whether proponents would acknowledge this as a legitimate construction of the social model of disability. In a paper given a few years ago to a conference convened to celebrate the tenth anniversary of the journal "Disability and Society", the disabled sociologist Paul Abberley denied the contemporary relevance of Engels' use of similar kinds of evidence to criticise the inhumanity of the industrial revolution, on the ground that this colludes with a negative valuation of disability in line with the values of industrial capitalism. Talking of the withering away of impairment with the State in a society progressively abolishing the injurious consequences of production for profit, he says "Of most significance for disabled people today, it is an issue whether such a situation, could it occur, would be desirable. As long as there is a general eugenicist consensus between left and right that impaired modes of being are undesirable, disabled people must challenge such views as in essence genocidal." \*11

Second, disability can be seen as a function of social definition. We can say that disability is "socially constructed" in that just when a person deviates sufficiently from the norm to be regarded as disabled, what constitutes normal activity, and just when an impairment becomes a disability, are all matters of definition presupposing social norms. In this incarnation, the social model of disability has much in common with labelling theory in the sociology of deviance, which famously asserted that "Deviance is not a quality that lies in behaviour itself but in the interaction between a person who commits an act and those who respond to it"; or again even more famously "Deviant behaviour is behaviour that people so label". \*12 Some people question this, however, and insist that disability has an objective quality, unlike behaviour - homosexuality say or the behaviour which is considered to constitute crime - which is infinitely capable of interpretation. There are certain fixed points in the real world which are non-negotiable against which at least the central cases of disability inevitably become a departure from the norm. \*13 "Not so" cry the social constructionists, "the inability to walk is only a disability in a leg-dominated society"! \*14 Many will remember Vic Finkelstein's celebrated picture of the society almost entirely made up of people in wheelchairs where everything - both the physical environment and social relationships - is structured in line with their needs and perceptions. In such a society, Finkelstein argued, it is the conventionally able-bodied who would become

disabled. \*8 I have come across an anthropological study of a small island community where all the inhabitants were deaf which seemed to bear out Finkelstein's fantasy, \*15 and of course most recently there is the "Talk" video with which the Disability Rights Commission launched its "Actions Speak Louder Than Words" campaign, which illustrated the relativity of conventional norms by depicting an able-bodied person in a variety of situations where disabled people were in control. The point to note, however, is that the first and third of these examples were imaginary and the second was a one-off.

Third, disability can be seen as a product of the way human beings have chosen to construct their environment, arrange their society and conduct their affairs, e.g., by using steps to make changes in level in a way that excludes people in wheelchairs, the spoken word for communication in a way that excludes deaf people, and the written word in forms that exclude blind people.

Fourth, disability can be seen as the result of the way disabled people are treated by non-disabled people - shut up in homes, sent away to special schools, turned down for jobs, and so on.

## Achievements of the social model approach

The social model represents what is often called a paradigm shift in thinking about disability. To give credit where credit is due, it has done much good in providing a vehicle for disabled people to combat the legacy of segregation, custodialism, enforced dependency, discrimination and denial of citizenship rights in the form of a proper say in their own affairs. In forcing the principal focus away from impairment and on to the discriminatory attitudes, rank prejudice and inaccessible schools, workplaces, transport systems, information systems and leisure facilities disabled people have to contend with every day of their lives, the social model has projected into the foreground the rights, normality and ordinary humanity of disabled people. In this it has served a strong expressive as well as an instrumental function: it has enabled disabled people to feel better about themselves. But all revolutions go too far and stand in need of correction. I shall return to the expressive dimension in due course, as it possibly accounts for some of the social model's worst features in practice. But for the moment I wish to concentrate on an examination of its logical basis, for here two fatal flaws immediately become apparent.

# Considering discrimination

The first is the tendency of the social model to make itself true by definition. In the last two senses in which disability was said to be caused by society - when disability was portrayed as the result of environmental and social arrangements and adverse treatment by society - disability is pictured as a product of what is often termed discrimination or oppression. Increasingly, however, those who use "disability" in this way display a tendency to equate disability with discrimination. Sometimes they do so explicitly, as when the Union of the Physically Impaired against Segregation says: "We are led . . . to recognise . . . first, we are members of a distinct group with our own particular physical characteristics (physical impairment); and second, that society singles this out for a special form of discrimination (disability)." In other words, disability is defined in terms of society's response, so that disability is not just something brought about by discrimination, but discrimination is incorporated into the very meaning of disability itself - discrimination is just what disability is.

This conflates concepts which ought to be kept separate. Disability is something logically distinct from and prior to discrimination. How else could one talk about discrimination on grounds of disability? Discrimination is a matter of fact to be established, not something inherent in disability. One has to have independent criteria for the two. It is as if one were to confuse race with racism.

This conflation of the notions of disability and discrimination makes of the social model of disability a tautology. It is necessarily true given the meanings of the words and not as a matter of empirically verifiable

fact. This is a use of what H. L. A. Hart called the "definitional stop" \*16 to prevent enquiry into that which one most wants to know about, namely, the inter-relationship between the two. It begs the all-important question how far the disadvantage disabled people experience stems from the way they are treated by society or the medical condition they suffer from. This remains the central question in disability theory today, though largely unappreciated as such. When Finkelstein writes: " . . . the single factor that unites us together in our struggles is that it is our society that discriminates against us. Our society disables people with different physical impairments", we think he is making a contribution towards resolving this question with a claim of fact which is capable of being tested empirically. But if these two sentences simply mean the same thing and add nothing to one another, the argument is no further forward. One cannot settle questions of this kind with a definition.

#### Disability discrimination legislation

This is not just a piece of arid logic chopping. It has consequences in the real world. The disability movement has been very keen over the years to get full-blown social model definitions of disability into disability discrimination legislation. Some statutes have succeeded in including elements of the social model. The Americans with Disabilities Act famously includes perceived disability. Our Disability Discrimination Act did not go that far - though it did include severe disfigurement as a nod in the direction of the social model - and the Disability Rights Task Force set up by the present Government to recommend improvements to British legislation failed to find a way of doing so.

More significant, however, is the way the Task Force came to grief over its attempts to find a full-blooded social definition of disability that was operable in practice. We played around with formulations like "a physical or mental impairment or health condition, the consequences of which are that a person is substantially restricted in his or her ability to participate in any aspect of society", but all such attempts were inevitably doomed to founder on the logical reefs to which I have drawn attention in the last few minutes. A brave attempt to do something similar is to be found in the recommendations of the Irish Commission on the Status of People with Disabilities (1996). It ran: "a person with a disability means a) a person with a physical, mental, intellectual, emotional or sensory impairment and who, due to a lack of receptiveness and adaptability in existing social structures and otherwise, encounters obstacles to the participation on equal and equally effective terms with all others in all aspects of the life of the community ..". Needless to say, this did not find its way into the legislation which followed shortly afterwards and in fact the definition enacted was about as medical as they come. This ought to be an object-lesson to all would-be social reformers: if you come up with recommendations which are off the wall, you are likely to end up with something worse than the number you first thought of!

One slightly mischievous observer has commented that the problems are largely semantic and that we could get round them by simply dropping the terminology down a level. Instead of talking of discrimination on grounds of disability, we could talk of disability on grounds of impairment. Strictly speaking, we would then have the Impairment Disability instead of the Disability Discrimination Act, but as the meaning of that might not be immediately apparent to an expectant public, it could instead be called the Impairment Rights Act, or IRA! All the same, it should be observed that this just substitutes one problem, a much larger one, for another so far as the disability movement is concerned. For a piece of mystification which whisks the individual element from view by sleight of hand we would have substituted a formula which left it plain for all to see.

## Interactive models of disability

The second fatal flaw confronting the social model of disability is its exclusivity, its monolithic or unidimensional qualities and its colonising tendencies. At its most extreme, it maintains that disability has nothing to do with the individual whatsoever, but is instead a condition of society which operates in such a way as to exclude people with physical and mental impairments from participation in the mainstream of social activity. It will be recalled from our discussion of the World Health Organisation's Classification of Impairments, Disabilities and Handicaps that disability, in its global sense, is inescapably a compound phenomenon to which individual and social elements are both integral. The last word on this has probably been said by Jerome Bickenbach, who has spelt out a number of features which characterise what he calls interactive models of disability - the only ones he sees as viable: \*5

- Disability is a complex phenomenon, neither solely an attribute of a person, nor a creation of the social environment;
- There are different dimensions of disability (eg body level, person level, societal level);
- Dimensions of disability are distinct, and no dimension is fundamental;
- No two dimensions can be reduced to just one;
- They represent different perspectives on the same phenomenon;
- Trying to reduce disability to just one dimension will always distort it;
- Disability is an outcome of an interaction between features of persons and features of the environment:
- The nature of the interaction between person and environment will differ depending on the dimension of disability.

Interestingly, in view of what was said earlier about the social model tending to assume its own conclusion and make itself true by definition, Bickenbach goes on to say that models are theoretical constructs for organising and interpreting information and shaping research hypotheses. We shouldn't push too much theory into them to start with and then look to them for answers. We should beware causality in a model, and above all, models should not be used to determine or pre-empt the results of empirical investigation.

In face of all of this, I don't see how it is possible to defend the social model of disability - at least in strong form. On that analysis, there would be no place for hearing-aids for deaf people, glasses for people with poor sight or wheelchairs for people who cannot walk. That is not to say that I would necessarily endorse every medical intervention that has ever been suggested. That would be to make the mistake of social unilateralists. Individual and social models are not mutually exclusive. Indeed individual and social dimensions are both essential to the construction of an integrated model of disability, which must be the common task of disability theory today.

# An "Aunt Sally" position?

Of course it will be objected that I am constructing an Aunt Sally position which nobody actually holds simply in order to knock it down. All that the social model is doing, it will be said, is denying that there is only an individual dimension to disability, and asserting the need for the social dimension to be taken on board as well. To be sure, the social model does have weaker or more moderate forms. But it is hardly rocket science. As I have said, it is doubtful whether the individual model has ever been expounded in strong form. Organisations concerned with improving the situation of disabled people - certainly organisations concerned with improving the situation of the blind - have always seen the need to campaign for a better social response to the individual circumstances of disability. I have never heard anyone insisting that disability is only an individual affair. But it is undoubtedly the case that the assumption that disability is an individual condition, to be addressed by intervening to change the individual, has underlain much professional practice and commonsense public consciousness. To that extent, efforts to reassert social dimensions of disability at the expense of the individual have been justified. However, these have usually taken the form of mistakenly, in over-reaction, asserting the social model in one or other of its stronger versions. In a kind of reductionism, "not only individual" has become mistranslated as "only social", and "the individual is not everything" has become "the social is everything". \*17

I want to say some things about the stronger forms of the social model in a moment, but first we should be aware that they often come disguised as one or other of the weaker versions of the model. Thus social model theorists have increasingly taken to insisting that they do take account of impairment. But if they do, this is either purely formal, or else it is incoherent, disingenuous or not a version of the social model at all. In a purely formal sense, adherents of the social model are obliged to take account of impairment, in that an individual dimension is inextricably involved, for disability is a form of social oppression visited uniquely on impaired people - not just anybody. The individual circumstance of impairment is thus intrinsic to the social condition of disability. Remember what the man said: "Our society disables people with different physical impairments". That's just what disability is. As stated, this is a purely formal point, but there are nevertheless good substantive reasons for making it. Sometimes it is suggested that the sort of barriers disabled people face, such as steps and inaccessible transport, constitute barriers or forms of discrimination against other people too, such as women with prams. If one wants to single out disability discrimination as a distinctive form of discrimination, as advocates of the social model normally do, it is therefore essential to ground it in impairment.

#### Conceptions of disability or impairment-based discrimination

One could argue that disability discrimination should not be distinguished from other forms of discrimination in this way, but I can think of at least two good reasons for doing so. The first is that disability is not a clear-cut category like other grounds of discrimination such as race or sex, so that you either have it or you don't. It is a continuum, and judgments are required as to where the line falls between having it and not having it. The second argument is even more telling: in most conceptions of disability discrimination, it is obligatory not just to refrain from treating disabled people less favourably than non-disabled people, but also to make reasonable adjustments in order to accord them access to employment, services and so on. In this, disabled people are being accorded a form of social response not generally accorded to other subjects of discrimination, and for this reason alone, a separate category of discrimination, based on impairment, would seem to be essential.

A number of disabled writers, particularly women, have stressed the importance of impairment, while professing still to be strongly wedded to the social model. This is incoherent, as is the response of those who have affected to take their point. No less a person than Mike Oliver, a leading disability theorist, has himself toyed with the idea of a "social model of impairment", \*18 but as Janet Read of Warwick University has argued, such a notion is unintelligible. \*19 If people do genuinely take on board impairment in anything other than a purely formal sense, their model ceases to be a distinctively social model at all. I recently had a conversation with a representative of the Joseph Rowntree Foundation, who said that all their research had to be based on the social model of disability. I suggested that as well as looking at barriers to employment in the workplace, it would be useful to look at the difficulties in doing different kinds of jobs to which different impairments gave rise. She insisted that that kind of thing was fully encompassed by their social model approach, which leaves me wondering if there is anything distinctively social left in the approach at all. If the social model of disability can incorporate this it can incorporate anything.

A further way in which seemingly weak versions of the model are really stronger versions in disguise is encountered when advocates of the social model tell you that individual and social factors both play a part in disability - it is just that social factors are the more important. Sometimes this concession is so grudging and minimal as to be worthless. "Perhaps 5% individual if you insist" is about the size of it. I don't see how you can say a priori what the precise balance of individual and social factors will be. Surely that requires the sort of empirical investigation modelling is not supposed to pre-empt. It seems to me that the relative importance of individual and social factors will vary from person to person and situation to situation, depending on the severity of the individual's impairments and the social response to them.

A variant of this argument does not deny that individual factors have their place - it just maintains that it is social factors its proponents are most interested in exploring. This often turns out to be disingenuous, as the exploration leaves little room for individual factors, and is at pains to make plain the malign effect which an interest in them has had in the past. Thus anything with the faintest whiff of medicine about it is denounced as being completely wrong-headed and banished to outer darkness. Ideas of prevention and cure are anathema, and even the term "rehabilitation" is suspect. Some years ago, RNIB developed the innovative concept of Rehabilitation Leave, by analogy with Maternity Leave, to enable those who became disabled at work to undertake the adjustment and retraining necessary for them to carry on in work. But the idea bombed with the disability movement until it was renamed Disability Leave. You can imagine the obloquy which our poor Rehabilitation Resource Centre attracts!

#### Social dimension of disability

Of course the protestations of simply wishing to focus on the social without denying the importance of the individual may be genuine. Perhaps that is the case with the Joseph Rowntree Foundation. Perhaps their position is a genuinely weaker version of the social model and I was wrong to dismiss it as no longer a social model at all. But in that case I think it would be less confusing if they were to say that they were particularly interested in the social dimension of disability rather than that they espoused a social model, for the term "model" is inherently holistic and inclusive. If someone offers to show you a model of a house, you don't expect just to be shown the west wing! One case where a claim that their adoption of the social model is dictated by their role is undoubtedly genuine is that of the Disability Rights Commission (DRC). That is their role - to promote and enforce the rights of disabled people under disability discrimination legislation. So I had no difficulty subscribing to that - well not too much anyway. But I still could have wished they had called it the social dimension of disability.

#### A continuum between individual limitations & social barriers

To finish with the social model once and for all, there are just three final points I would wish to make. First - and this is another formal point - one should probably think of the individual and the social as a continuum. It can be difficult to tell whether something is an individual limitation or the result of a social barrier. Is someone's failure to learn the result of individual inadequacy or the absence or poor quality of teaching, or a bit of both? Is someone's difficulty with mobility or self-care a function of their impairment or the unavailability or inadequacy of training? There is virtually no physical or mental limitation which could not be reconceptualised as proceeding from some deficiency in the social environment or in social provision. \*20 My interlocutor from the Joseph Rowntree Foundation sought to work this trick by maintaining that every disadvantage was social because it gave rise to a right that it be remedied. But you cannot make the individual social - make black white - simply by describing it as the subject of a right. In any case, we should be reluctant to set off down this track, first, because it will conduce to greater clarity of thought and action, eg in deciding who is responsible, if we call a spade a spade. If I fail to provide you with a hearing-aid, I am not socially disabling you but failing to alleviate your impairment. And second because, remember, we should not be using models to pre-empt enquiry into the very issue which is at stake, namely, the relative importance to be attached to individual and social factors in any given situation?

The second point is this: At the end of the day it all comes down to whether or not you accept that an impairment as such is a disadvantage. As my friend and colleague Bill Poole has pertinently observed with respect to blindness: "to believe that it is a handicap that is socially imposed and does not arise out of the condition of blindness itself . . . seems to me to lead inescapably to the view that cure and prevention are unnecessary or diversionary, and infliction unobjectionable." \*21 No-one would choose blindness if they could avoid it. It is something endemic, affecting every aspect of life. For as far ahead as anyone can possibly see, nobody would choose to work or study by the methods blind people use if they had the option. Even when every accommodation that can be conceived of has been made, there still remains an irreducible

minimum of disadvantage attributable to the individual circumstances of disability which has to be contended with. That is not of course the same as saying that this is an insurmountable catastrophe.

There is just one final dug-out in which the implacable social modeller can be found. It is sometimes asserted that a concentration on the social is justified - is all that is possible even - because the individual dimensions of disability are private - something those looking in from the outside as opposed to the individual concerned - cannot know anything about - or at any rate cannot do anything about. But that is surely nonsense. In the first place, it does not deny the importance of the individual dimension, it just says there is nothing that can be known or done about it. But that is not true. People speak and write endlessly about their disability - how they feel about it, what they can and cannot do, how it has affected their life, blighted their life, enhanced their life and so on. And regardless of what disabled people tell us, there is much that we can discover for ourselves - by observation and research for example. The assertion that there is nothing we can do about the individual circumstances of disability is true only for those fixated, as those who make it often are, on political and collective action. The options of medical intervention and training would be obvious to anyone not committed to ruling them out in principle. \*22

## Summing up on the social model

So to sum up this long disquisition on the social model, if propounded in strong form it is wrong, and if in one of its weaker versions, it is what I think it was C. Wright Mills described as "trite but true". \*23 Either it defines impairment out of the global phenomenon, disability disadvantage, we are considering, and is thus true by definition, or it doesn't, in which case it can only be valid in weak form. In the Commission discussion we had on the subject, one of the Commissioners said he agreed with some of what I said, but that, as he saw it, the social model was just commonsense. In any case, he added, it is necessary to exaggerate in order to compensate for the previous over-emphasis on the medical. I can accept that too. But I would have to say that, if the social model is just commonsense, then so is the medical. The social model of disability is what I call a heresy. By that I mean a doctrine which, while undoubtedly containing important truth, also contains significant falsehood which, despite having deceptive attractions and being an understandable reaction against previous error, is yet significantly distortive of reality in ways that are potentially damaging to disabled people. There is a lot of agreement round a social perspective on disability. But if people continue to maintain that it's exclusive, they will not connect with the common experience of ordinary people - disabled and non-disabled alike.

The social model has made a permanent difference. We will never think of these things in the same way again, and that's in many ways a good thing. But it doesn't mean that there is nothing of value in the ways we had of thinking about them before. I am very interested in music. There has been a similar revolution in our lifetime in the way we understand, think about and above all play and listen to baroque, classical and even to some extent romantic music which has uncanny parallels with the debates in the field of disability I have been talking about this evening. The Messiah as played today is no longer the same piece of music as that laboriously ground out by a cast of thousands in our youth. After it has had the attentions of a Gardiner, a Norrington or a Harnoncourt, we will never listen to Bach and Beethoven with the same ears again. But that does not mean that the great luminaries of the past no longer have anything to say to us - Beecham, Klemperer, Furtwangler, Karajan - well perhaps not Karajan!

My view of these things tends to be one of horses for courses and of rendering unto Caesar those things which are Caesar's. If your boss refused to let you bring your guide dog to work, I imagine you would send for a Disability Rights Commissioner in preference to a doctor. But If you suffered a massive heart attack, I doubt if the first thing you would want to do would be to send for an expert on the social model of disability. In the Association of Blind and Partially Sighted Teachers and Students, when wrestling with the Department of Education and Science, as it was then, over the Medical Fitness to Teach Regulations, we were always at

pains to insist on a proper division of labour. A doctor can say whether you are blind or not, we would maintain, but not whether or not you are able to teach.

You may feel that I have laboured these points inordinately, but I felt it necessary to do so because they underlie so much of the rest of what I want to say, and also because I have been making them for nearly two decades now, and nobody seems to be listening. I remember when I first got on to this about 1983 saying to my great friend and mentor, Martin Milligan, to whose memory I should like to dedicate this lecture, that I thought thinking about disability was taking a wrong turning. "Yes" he said, "things always go too far but they correct themselves in time". Nearly two decades on, I see no sign of this happening. In fact they seem to me to be getting worse.

Not so long ago, someone told me, in terms which suggested she felt sorry for me more than anything else, that nobody thought the way I did any more, and by way of helpful illustration, she added that my disability was not something I possessed - "like my stubbornness or my pig-headedness"! The social model, and the errors in thinking it begets, seem to have spread like a poison through the sector. You can't turn round without encountering them, and no day goes by but what I do. Go to any discussion on disability, and you will find that it is sufficient just to label something as medical, often incorrectly, to dismiss it. We have seen how the Joseph Rowntree Foundation looks for all the research it funds to be conducted within a social model paradigm. At a seminar I ran to discuss these topics a few years ago, the idea that all research on disability should proceed from the social model as its foundation premise seemed uncontentious. To pick an example at random from the masses that litter my files: the NUT, in its response to the DRC's recent consultation on the Code of Practice on Part III of the DDA, said: "The Union regrets the reference in the Act to an impairment which has 'substantial and long term adverse affects [sic] on a person's ability to carry out normal day to day activities. The Union believes that it is not the impairment which has an adverse affect but rather the inadequate environment which fails to accommodate a wide range of people including those with disabilities." "But this is no worse than the bad old days when the medical model held sway" you will say. No indeed! They are as bad as each other. I didn't spend my youth contending against medical heresies to be saddled with social ones in my old age.

Even in my own organisation, RNIB, the virus is out of control in certain parts of the organisation. Only the other day I caught someone calling for a social model definition of blindness. This suffers from the same incoherence as Oliver's call for a social model of impairment to which I have earlier referred. The trustees don't want this. We've taken committee reports making clear that this is not our position. But it doesn't seem to make a blind bit of difference. Officers just carry on their sweet way as if nothing had happened. So you can see why I feel the need to speak a little louder.

# Historical beliefs about impairments

How is it that such a half-baked notion has taken such a hold? Here we are inevitably in the realms of speculation, but I think it goes back to the fundamental question I posed earlier about whether you accept that an impairment as such is a disadvantage or at any rate something negative. I don't think the adherents of the social model, at least in strong form, can accept this. In this they are the victims of a piece of word magic which, however, as so often reflects some kind of archetypal reality. Disabled people, in their impairment, it is often said, have something wrong with them. In a more primitive age, stretching back to the dawn of consciousness, when people were even less conversant with the fact-value split than they are today, this sense of wrong was often also taken to connote a moral wrong, and people with imperfections were often thought of as incarnations or visitations of evil or the focus of other superstitious beliefs. As we know, such beliefs have not entirely died out to this day - but then, football is a fertile breeding-ground for superstition. In parentheses, we should note that impaired people were often also seen as the repository of mystical or superhuman powers. Such people obviously exemplified the need for a radical separation of good and evil in

primitive thought. The ambiguity of "wrong", though it may largely have disappeared from official representations of disability today, is obviously still at work at an unconscious level, informing the uneasiness which still persists about disability and contributing to the oppression disabled activists discern. It's always risky to engage in amateur psychology, but it seems to me that disabled people internalise this oppression, or negative valuation, focused on their impairment. This they find difficult to live with, and so they deny the impairment and project the problem outwards onto society. This has two consequences - an unrealistic valuation of impairment and a very negative stance towards society.

## Cure, prevention & bioethics

Thus people are unphased by Poole's "inescapable conclusion" that cure and prevention are "unnecessary or diversionary" - though I have never actually heard anyone recommending infliction as unobjectionable. This is another piece of mistranslation: "prevention and cure are not the be-all-and-end-all" (correct), becomes "prevention and cure are inadmissible" (wrong). This mistranslation is in turn based on another: You remember my saying that the fact that there is an irreducible minimum of disadvantage attached to impairment is not the same as saying that it is an insurmountable catastrophe. That's why prevention and cure are not the be-all-and-end-all. But in the social model, "not necessarily devastating or the end of the world" gets translated as "actually positive or a good thing". Sometimes one gets the impression it's the best thing since sliced bread. \*24 Thus a recent conference on disabled people, bioethics and human rights declared: "We believe that a society without disabled people would be a lesser society. Our unique individual and collective experiences are an important contribution to a rich, human society. We demand an end to the biomedical elimination of diversity . . . or bio-diversity." I am not in favour of getting rid of disabled people, but I do think there is some confusion here. We can probably come by the richness contributed by disabled people by other means. But even if we couldn't, I suggest that that richness, and the reason for valuing disabled people, has more to do with their humanity than their disability. If this were not so, there really would be an argument for infliction. The case most often cited in this connection is that of Beethoven. But surely Beethoven's value lies in the fact that he was Beethoven, not that he was disabled.

Hand in hand with efforts to construe impairment positively goes the rejection of anything which might appear to reflect negatively on impairment. You remember Abberley's rejection of the fact that it created impairment as a ground of criticism of industrial capitalism because that would be to collude in a negative valuation of impairment. This is the source of the suspicion of prevention and cure. Thus a participant at the conference just referred to stated: "Terminating a foetus that is potentially disabled diminishes the lives of people who have that particular disability [sic]". This does not follow, and it certainly puts feminists in a difficult position. Sometimes one gets the impression that you can have an abortion for any reason except a good one; and if the medical model of disability is an evil doctrine, as I have seen it described, then I would have to say that so is a doctrine that would withhold cochlear implants from young children who could benefit from them.

# Wagons round the campfire & confrontational stances

All these arguments exemplify what I have earlier termed the expressive function of the social model - they enable disabled people to keep at bay the fault they feel has unfairly been imputed to them personally. That is why one can so often hear disabled people saying with such determination "at all costs we must hold on to the social model". I am glad if such a defence mechanism enables people to feel better, but my analyst always used to tell me that such devices were ultimately a fragile bulwark against reality and they always crumbled in the end. I'm not so sure about that, especially if they can find reinforcement in social/political/intellectual groupings that provide mutual succour for one another. Even then, they can prove quite precarious, as when reality breaks in the form of one of the group displaying an unfortunate tendency to independent thought. This leads to the luckless offender being driven out into the desert and the wagons being drawn into an ever tighter circle round the campfire, as has lately happened to Dr. Tom Shakespeare

after he wrote (but had difficulty publishing) a courageous article in which he changed some of his views about the social model, and tried to develop an objective critique of developments in genetics instead of one just based on emotion.

Another factor giving life to the social model is the frisson of radicalism it gives to soi-disant progressives among non-disabled people who think of themselves as agin the Government. (Soi-disant is the French for so-called, by the way.) Well, take it from me, you don't have to believe it!

As I have said, the social model mind-set begets a confrontational stance towards the rest of society. The following is not untypical: "Disabled people know only too well they are not welcomed in society"; and again: "Medical intervention in reproductive technology and genetic engineering (and genetic counselling) are all geared towards eradicating disability . . . Society is not prepared to build access to buildings for wheelchair users, provide information in braille/large print, provide sign language interpreters and teach sign language as a standard second language for all. Everywhere there are architectural barriers designed to keep us out of society". \*25

As can be seen, this has both an attitudinal and a structural component. Both seem to me to be over-done. I often go on holidays abroad with groups of anything up to thirty complete strangers. I have been very struck of late by the matter-of-fact but helpful response my disability elicits. I think the worst thing that ever happened was probably when someone remarked to my wife "He's really quite intelligent when you get talking to him, isn't he?" I won't tell you what my wife replied. At all events, I think I encounter as much incomprehension from other disabled people as from the able bodied.

#### Progress in recent decades

On the structural front, though everything in the garden may not be lovely, it is hard to maintain that it is all bad when disability is on the agenda of public policy and provision as never before. The Government will now meet the extra expenses you have as a student. It will pay for the special equipment and support you need to do your job. The accent is now on educating disabled children in mainstream schools if at all possible. So much information is being produced in an accessible form I haven't a house big enough to store it all. When I go to a meeting (in a subsidised taxi), I will have had the papers beforehand in a form in which I can read them. When I go to the theatre, I can have a commentary on what is going on. None of this was the case when I was starting out. To cap it all, the European Union has undergone a complete transformation in philosophy and policy towards disability in the last ten years: Where before it was all a question of specialist help and support, now the accent is firmly on removing social barriers, mainstreaming and combating discrimination.

# Examples of negativity of social model approach

The essential negativity of the social model's approach was never so forcibly demonstrated to me as when I had the job of chairing the steering committee for a National Disability Council project to try and tease out what opportunities might be disclosed for disabled people by Labour's modernisation agenda. The work was carried out for us by Ian Christie on behalf of the think-tank Demos and the great attraction of the project was that it was, in the words of one of the steering group members, "solutions focused". But this was not a commendation in the eyes of the representatives of the social model perspective whom we were keen to have on the group. One declined to join and the other soon walked out on the ground that the report did not focus sufficiently unrelentingly on the irredeemably dire situation of the disabled. What was even more extraordinary, though perhaps not in view of what I have earlier said, was that the representative from the Joseph Rowntree Foundation, a great philanthropic institution, walked out in sympathy with them. From that day to this I have been at a loss to understand the poor reception which Christie's report has had, extending from unconcealed hostility on the part of the card-carrying members of the disability movement, in spite of

his bending over backwards - too far in my view - to take on board the insights of the social model, to lukewarm suspicion on the part of the big charities. I can only conclude it is because he did not go through the motions of recycling the tired old litany of gripes that those in a position to change anything must have long since tired of hearing. I have to question whether this is wise, however, for I have to tell you that No. 10 is paying much more attention to Christie than it is to any of you. Christie owes nothing to the disability movement. I suppose on reflection that's his problem. But it seems a great pity that his analytical skills and influence should be lost to it.

This incident also illustrates well the intellectual arrogance of the leaders of the disability movement. We held a conference to discuss Christie's report at which we naturally invited the leading thinkers of the disability movement to speak. Mike Oliver, positively oozing smugness and hauteur, came along and dismissed Christie's efforts with Olympian disdain. Picking on a careless reference to "the social model of impairment" in an earlier draft, he excoriated the report's authors for their third-class understanding of the social model of disability, and for setting up an Aunt Sally version of it, "which no-one has ever held", simply in order to knock it down. But hang on a minute! Wasn't it Mike who earlier appeared to endorse the idea of a social model of impairment himself? \*18 And wasn't it Mike who said "disability is wholly and exclusively social" \*17 and "disablement is nothing to do with the body - it is a consequence of social oppression"? \*26 I was reminded of a literary friend telling me of the propensity of post-modern critics to keep changing their position and then disowning in the strongest possible terms what they themselves had said only a short time before. As an illustration, he cited the critic Terry Eagleton, who was in the habit of saying things like "no-one could possibly hold such-and-such a view", or "no-one could possibly say a thing like that" or "I know of no-one who has ever advanced a position like that", to which the appropriate response was usually "well yes, Terry, actually you did - a couple of years ago"!

I had encountered a similar kind of obscurantism a couple of years earlier at the Disability and Society conference, when the stock response of the leaders, sitting up at the back, to anything they disagreed with seemed to be "well what can I say? Crap is crap"! You may gather that I entertain a not dissimilar opinion of many of the views I have been discussing this evening, though I would hope to have been able to express it with a little more delicacy and depth of analysis.

#### **Problems with WHO's ICIDH revisions**

I hope you can see where all this is leading. If you believe that the essence of your problem lies with a malformation of society and has nothing to do with you, you will naturally tend to see yourself as no different from other people and entitled to the same as them as a matter of right. We are therefore getting close to the matter of rights. But I must first briefly acknowledge certain implications, or at any rate applications, of the social model which can be productive of wrong turnings in policy if we are not careful. The first is the attempt to revise the WHO's Classification so as to substitute the terms "activity limitation" and "participation restriction" for "disability" and "handicap" respectively in a vain attempt to avoid all negative associations, and to decouple the levels of "impairment", "disability" and "handicap" completely. There are two things wrong with this: In the first place, as will readily be apparent, it abandons the formal link between disability and impairment, so that the discriminations and oppressions experienced by disabled people are no longer distinct from those experienced by anyone else. Thus the difficulty a person has in washing himself due to paralysis becomes indistinguishable from that experienced by his brother in Botswana who does not have a plentiful supply of clean water; or the difficulty I have in reading becomes indistinguishable from that of my American cousin when the lights go out in California. The second thing wrong with the ICIDH-2 is that it underwrites the disinclination of administrators since the days of the Warnock Report to classify people in terms of their impairments, most recently evident in the work of the Tomlinson Committee on further education.

It is no doubt the case that classification by impairment category was too rigid and inflexible in the past. Noone should suggest that there is a one-to-one correspondence between a person's impairments and their needs. But it surely goes too far in the opposite direction to suggest that there is no relationship at all, and that it is quite immaterial whether someone is deaf, or blind, or obliged to use a wheelchair.

The down-grading of impairment begets another tendency of the social model, namely, the drive towards genericism. As little as fifty years ago - forty even - the concept of "disability" hardly featured on the social policy agenda. That is not because it wasn't given enough priority, but rather because it scarcely existed. The blind, the deaf, the mentally ill, the mentally handicapped - these were all completely separate categories of social concern, and people would as soon fly to the moon as lump them all together. Now things are very different, and it suits administrators' book to deal with us all together. Indeed we often have to band together into coalitions of ill-assorted bedfellows in order to get a hearing. The social model materially assists this tendency. The reflex equation of impairment with the medical means that it is instantly dismissed from the case. Impairment-specific organisations such as RNIB whose business it is to represent the needs of a particular impairment group tend to be somewhat suspect. This is disastrous. The needs of the blind and the deaf are as different as chalk and cheese. The fiasco of generic social services departments ought to be enough to make us wary of going any further down that route. It is not even coherent. There is no earthly reason why the social model should not be capable of encompassing impairment-specific barriers. But as I say, the knee-jerk equation of impairment with the medical seems to preclude it. The height of absurdity was reached when the DRC was recently contemplating commissioning some research on the costs and benefits to service providers of making different kinds of adjustments for disabled people. Until I intervened, it was proposed to omit any questions about adjustments for different impairments on the ground that that might medicalise things too much. This is not just nonsense - it's nonsense on stilts. Without such questions, one wonders what exactly they would be researching into.

#### Realities of discrimination

I now come to the concept which lies at the heart of the civil rights agenda - discrimination. I am certainly on board with the reality of discrimination. I myself have been discriminated against. The clearest case occurred when I was working at the University of Leeds. It emanated not from Leeds but from a nearby university to whose Social Administration Department I had applied for a job. At the interview they asked me three questions: how would I make the transition from teaching under-graduates to teaching mainly post-graduates? How would I make the transition from teaching Law to Social Administration, and how would I manage with my handicap? I was able to answer, reasonably persuasively I thought because it was the truth, that I already taught more than my fair share of graduates, that I thought my main subject, Criminology, had many affinities with Social Administration, and I told them how I did my work as a blind person. That was on a Friday afternoon. On the Monday morning, I received a letter which said that they were very sorry they weren't able to offer me the job, because they just didn't feel that I would be able to make the transition from teaching under-graduates to teaching mainly graduates; that I'd be able to make the transition from Law to Social Administration, and they didn't think I'd be able to manage with my handicap!

This story has a couple of tail-pieces to it. Some time later, when I was sitting on a committee on discrimination, we got as evidence a letter from the selfsame lady, the Head of Department who had turned me down for this job in the terms I have described. I can't remember the context, but I clearly remember her saying that people's different characteristics justified their being treated differently. By way of illustration, she continued: "I, for example, could not reasonably expect to be employed as a ballet dancer. Similarly, I once had to interview someone who was blind who had applied for a job in this Department, but we had to turn him down because it is perfectly clear that no-one who is blind could possibly cope with a subject like Social Administration with the vast amount of reading involved." I can only say that I agree with the premise but not the conclusion!

The second sting in the tail came when we all had to send in, anonymously, to this selfsame committee on discrimination, examples of discrimination of which we knew. We then had a meeting at which we all sat round considering these cases to see which we considered were valid cases of discrimination in order to determine whether the existence of discrimination was substantiated and whether they were possibly suitable for inclusion in the report as illustration. Imagine my chagrin as I sat there listening to my colleagues coming up with 101 spurious reasons why my case was not a case of discrimination! I agonised whether to come out fighting in support of my case with chapter and verse, but in the end, I'm afraid, I settled for rather half-hearted advocacy with one hand tied behind my back. I remarked to someone afterwards on the perversity of my colleagues' conduct and wondered what he thought they could have been playing at. "Oh!" he replied. "I just think they all knew it was you"! Who needs enemies with friends like that?

I am probably as gung-ho as anyone on the DRC's Legal Committee, but I do think there are certain things one needs to bear in mind in relation to claims of discrimination. You sometimes get the impression that they are regarded as self-validating:

## Discrimination can also be positive

First, as regards general claims of discrimination, it is important to remember that discrimination can be positive as well as negative. Writing of how the matter strikes him personally - and in this his observations are not greatly at variance with my own - Selwyn Goldsmith, the disabled architect, says: "My experiences do not tally with the images fostered by disability rights activists, that disabled people are an oppressed minority in society, that they are victimised, and that they are subjected to widespread and unwarranted negative discrimination . . . I am not as a rule averse to privileged discriminatory treatment, and in my experience as a building user with a disability the benefits of positive institutionalised discrimination outweigh absolutely the constraints of the negative. I am a regular customer of shopmobility schemes which give me at no cost a scooter to ride around in. The orange badge on my car brings with it massive advantages that I readily exploit; on urban streets I can usually find a convenient place to park with impunity, without paying and with no fear of wheel-clamping. I welcome the reduced prices that come with being in a wheelchair on visits to Covent Garden and other theatres. I do not mind being patronised by Wandsworth Council; their decree was that registered disabled people should not have to pay to go swimming, and I know that if I were to argue the issue with the friendly staff at the Latchmere in Battersea they would feel offended. I do not protest if, when in a wheelchair, I am moved to the front of a queue. This has happened on numerous occasions in Britain."

Kevin Carey puts the point even more sharply when he asks: "How far do people want to be equal and how far would they really prefer to be privileged? I put this question every time my wife and I go to the English National Opera and sit in the best seats for £25 the pair because I'm registered as disabled." Perhaps this is the sort of speculation which can only afford to be indulged in by opera buffs! Incidentally, in preparing this lecture, I came to realise that there are four reasons why work is neglected: The first, as in Shakespeare's case, is because it is suppressed. The second, as in Christie's, is that it is wilfully misconstrued. The third, as in Selwyn's, is because it isn't read; and the fourth, as in my case, is because it hasn't yet been written!

Secondly, sticking with claims of generalised discrimination, one frequently comes across statements like "disabled people are twice as likely as non-disabled people to be unemployed, under-qualified" or whatever it might be - indeed one has come across them in this lecture - as if that by itself proved that disabled people are discriminated against. Here it is crucially important to remember the difference between disability and race and sex discrimination, where the disadvantages are such more a matter of imputation than substantive difference. There is of course the matter of reasonable adjustment, but it will not always be possible to cancel out all the effects of disability which make for a legitimate difference. This is why impairment remains so

important.

Third, sometimes an adjustment is so novel and comes as such a breakthrough, that its presence seems more like a bonus than its absence does a piece of discrimination. This is probably a personal reaction, but it's how audio-description in the theatre still strikes me today. At all events, it serves to show that discrimination is context-dependent. To take an absurd example, you couldn't say that blind people were being discriminated against by not being given information in braille before braille had been invented.

Fourth, turning to individual claims of discrimination, it is important to be prepared to test the claimant's story. It cannot always be taken at face value. Sometimes what unquestionably feels like discrimination to the person on the receiving end is less obviously so on a more objective consideration. As somebody recently said, when people don't get a job and claim that it's because they're disabled, sometimes it is and sometimes it isn't. One has to remember, too, that if patriotism is the last refuge of the scoundrel, discrimination is often the first. One has to be alert for claims of discrimination being used as a cover for stupidity and incompetence.

## Civil rights agenda and education

Turning to the impact of the civil rights agenda on two of the more important areas of policy, its pernicious effects can be seen in the Special Educational Needs and Disability Bill which is going through Parliament as we speak. I have been a campaigner for more inclusive education for disabled children all my adult life, but it has never seemed to me a likely prospect, in the present state of our education system, that we would be able to dispense at an early date with special schools for a hard core of children with particularly severe and complex difficulties. As Prof. Brahm Norwich said in his inaugural lecture at London's Institute of Education, special education is pre-eminently an area of policy where multiple values are in tension, and the balance has constantly to be negotiated between those of inclusion and an effective education for the individual child. A mixed economy is indeed the Government's policy, and the legislative framework which has been in place for nearly a decade now contains a number of safeguards against inappropriate inclusion to do with the needs of the child, the needs of other children and the efficient use of resources. There are those, however, unencumbered by the burden of competing values, who would like to see inclusion the invariable rule as a matter of right. They have long campaigned to have the safeguards swept away, and in the present Bill, they have almost got their way. One proviso is left - if inclusion is incompatible with the needs of other children. To prefer the needs of the other children to those of the disabled child in question seemed so perverse, I was initially inclined to think the Department had made a mistake - but not so. That has been left in to placate the unions concerned about an influx of children with emotional and behavioural difficulties. But the lobby for inclusion at any price has got its way, and the safeguard for the needs of the child has gone. What is worse, the responsible middle-of-the-road Special Educational Consortium comprising all the major interests in the field of special education, has connived at this, with the exception of RNIB. There are weasel words about the safeguards already being there in the fabric of the legislation, but this cannot disguise the fact that the safeguard has been removed from the face of the Bill, and neither the Government nor the Consortium has had the guts to face the extremists down.

Provision in mainstream schools is still very patchy. As American experience shows, things like the teaching of braille can easily become a casualty. I am prepared to lay money that, if the drive for inclusion continues to hurtle along at its present pace, in twenty years' time they will be saying "where have all the special schools gone?" Just as in the case of mental health services, they will have to start bringing specialist facilities back. Not in exactly the same form of course. But I wouldn't mind betting more money that they will then look with more favour on the blueprint the National Federation of the Blind came up with for the education of the visually impaired in the 1970s - not individual integration into neighbourhood schools, but a network of centres of excellence in selected primary and secondary schools throughout the country

specialising in the education of the visually impaired.

The civil rights agenda has also had an unfortunate influence on the debate about remedies. Students in further and higher education are to be offered an action in the county court, which we know from goods and services cases is expensive, difficult and does not work. RNIB's suggestion of an educational remedy in the revamped Special Educational Needs and Disability Tribunal, which follows a much less adversarial approach, would have answered to the need much better. Similar considerations underlie the clamour, so far unsuccessful, for the new tribunal to be able to make awards of financial compensation. The punitive animus of some civil rights activists can be seen in a comment by Rachel Hurst on the launch of the DRC's conciliation service: "It will mean that some more cases will be settled out of court, but what we really need are high profile cases where the providers of goods and services are fined a considerable amount of money."

## **Employment**

About employment I can be even briefer. The "give us the jobs and we'll do the rest" mentality of the social model leaves the elitist and one-club nature of the rights approach cruelly exposed. It is fine for the able, articulate person capable of asserting their rights, but it leaves those less well cut out to flourish in the open market and in need of something more supportive poorly served. In his foreword to RNIB's forthcoming strategy report "Gaining and Retaining Employment", Fred Reid, Chair of our Education and Employment Committee, puts the point bluntly when he says: "It will call upon Government to develop more supported employment for disabled people who cannot cope in the open labour market. The report is critical of Government for placing an exaggerated value on 'progression'" in supported employment. Such thinking is based on a false paradigm, leading to the unrealistic conclusion that all disabled people are capable of working as productively as non-disabled people. They are not, and the provision of supported employment - which need not take the form of traditional 'sheltered'" employment - is an urgent priority if we are to make significant in-roads into the scourge of disabled unemployment."

If you have stuck with me through the long trek up the lower slopes, you will now be poised for an assault on the summit. It's not that disability rights have gone too far, but their pursuit has too often been simplistically mis-focused through too narrow a concentration on the civil rights agenda, and the manner of pursuing them can easily be counter-productive. All I can do here is point to some of the complexities that need to be taken account of in a few brief propositions:

# Considering complexities of benefits, services & rights

First, we need a mixed economy of benefits and services as well as rights. We cannot fudge this by saying that we need rights to benefits and services as well as the benefit of rights. The values of care and support for the vulnerable should not be lost amid the clamour for rights. Those who see welfare to work as the solution to all disabled people's problems and consider that a regime of benefits undermines the drive for equality, forget that work is not an option for two-thirds of all disabled people who are over retirement age and heavily reliant on benefits. \*31 Similarly, there need to be services in place to make a reality of rights. Anyone who knows the history of deafblind people's campaign for communicator-guides will understand the force of this given the Government's view that this demand goes well beyond the scope of reasonable adjustment.

Second, Rights are not absolute as often portrayed. Sometimes it seems as if it is enough to say I have a right to something - information in my preferred medium, sub-titling on television or to vote in person - to establish that I must have it now. But other considerations come into the reckoning, such as how much it will cost in relation to the benefit, and whether there are acceptable alternative means of achieving the same end. If we wanted to go to Dublin we might not have started from here. But we are here, and we have to work out the best way of getting there by the optimum route in the optimum time and at the optimum cost.

Third, It is not just that the disabled are disadvantaged and everyone else is all right, Jack. Too stark a dichotomy is posited between the disabled and the rest of society. The steps up to the front door are not the only reason it's not possible to get into the Ritz Hotel. Its focus on mutuality and commonality of interest between groups of disabled and non-disabled people was one of the strengths of the Demos report. Disabled people need to considered the impact of their having their rights on other people, as well as what they can do to engineer an optimum way forward, as opposed to just waiting for a pre-conceived package which may never be delivered.

Fourth, as for campaigning, I don't have a problem with people who say the glass is half full. My quarrel is with those who continue to make out that it's completely empty. Sooner or later this runs out of credibility. Campaigning which is limited to moaning, whingeing, complaining, shouting, hand-wringing and breast-beating doesn't cut much ice. It provides some useful background noise and gives serious campaigners something to threaten recalcitrant ministers and civil servants with, but not much more. As for serious campaigning, I can't do better than commend RNIB's Stephen King's paper on influencing strategies for achieving an accessible information society for visually impaired people presented to an Information Society Advisory Group Summit on 5 April last year. I can't do justice to this here, but suffice it to say that the key is presenting solutions not problems, and being resourceful in finding levers to pull and buttons to press. All too often one comes away with the impression that the only weapons the disability movement knows are the blindunderbus and the battering-ram.

#### Disability movement as monolith

So finally, what of the disability movement which has provided so much of the matter for this lecture. Well I feel about them a bit like the Duke of Wellington surveying his troops before the battle of Waterloo - "I don't know what they do to the French but they frighten the life out of me"! We have already referred to elitism, negativity, arrogance and obscurantism, but the charge-sheet doesn't end there. The disability movement is also a monolith, in that it's not enough to be disabled to be a member - you have to think a certain way on pain of ex-communication. They wouldn't have me, for example, which I suppose invites a sort of inverted Groucho Marx response. The movement has a strong vein of illiberality running through it. The stock response to perceived oppression is suppression. The way Glenn Hoddle was hounded out of his job, for instance, was a scandal. I can't now remember exactly what he said, but it struck me as more loopy than offensive. In any case, even if it had been, it is a strong liberal principle that merely causing offence is not sufficient grounds for subjecting someone to sanctions.

I have experienced this myself. A few years ago I ran some seminars with the aim of bringing the ideas of the disability movement into dialogue with some of the more traditional disciplines, such as Philosophy, Jurisprudence, History and so on. The disability movement staged a boycott and wrote to the ESRC in an attempt to get the funding stopped - I think because my flyer referred to the "so-called" social model of disability, and because it was feared someone might say something with which they disagreed. They also pressurised one of the speakers into withdrawing with the threat that they would withdraw cooperation from his research. I must say that Rachel Hurst deserves credit for bringing the two sides together and bringing people back into the discussion. The movement is also venal. Impatient with the rigours of the examination process at City University, they take their theses down the road to a more compliant university with the encouragement that they will be fast-tracked.

Some may find my words harsh. I once mentioned to a colleague that I regarded the social model as a heresy. "Mmm!" she reflected, "people used to get burned at the stake for heresy." In my experience it is orthodoxy that more readily attracts that fate today. But in any case, it is my experience that if I do not speak as I find, nobody will. Another thing my analyst told me was that disability has a very high blackmail factor. Faced

with an articulate disabled person making progressive-sounding demands, non-disabled people find it very difficult to say boo to a goose, even if it's disguised as an emperor penguin without any clothes. In any case, they're all so concerned about not being thought to be out of line with one another. There was obvious nervousness at the top of the DRC (Disability Rights Commission) and the RNIB at the prospect of this lecture. Perhaps I could just put out some extra publicity to reassure people it wasn't going to be as bad as all that; or make sure I ended up with a ringing declaration that disability rights hadn't gone too far. I regard such reactions as craven. I think it would be an insult to the level of analysis attempted in this lecture to say that the question admitted of a simple yes or no answer. I believe that questions were even asked in Parliament, and it is greatly to the credit of Bert Massie, Chair of the DRC, that he responded a) that Commissioners have a life outside the DRC; b) that the title had a question-mark after it; and c) that the disability movement ought to be strong enough to withstand some freedom of debate.

Disabled people are too readily intimidated by the claims of a spurious solidarity. For myself, just this once, I do not wish to play that game. If you don't like the message, for heaven's sake shoot the messenger. Don't blame the RNIB, and certainly don't blame the DRC.

The reaction to the announcement of this lecture was entirely predictable. Dead on cue, or rather about four weeks ahead of the queue, the following heart-warming greeting headed "Colin Low - The Tiny Tim of the Disability World" was received at City University from one Bob Williams-Findlay, who describes himself as a disability rights campaigner: "Good to see Colin Low has maintained his long held priority of self-interest and feathering his own nest. Have Rights gone too far asked the Rehab man? I suppose it depends on who you are and where your situated. Most disabled people are not comfy middle class brown noses who snuggle up to New Labour while cotton wooled inside an ivory tower. Maybe there's a cure for Colin - but it might be hellish painful."

Ladies and gentlemen, I rest my case. I don't think it could be said that I have gone out of my way to ingratiate myself with anyone in this lecture. It would obviously be unfair to tar all disabled people with this distasteful brush - though Bob's organisation does claim to speak on behalf of several million. All the same, I think disabled people need to take care that their activist leaders do not represent them in such a way as to incur the scorn of the late Auberon Waugh: "My grand philosophical conclusion at the end of the day is that humanity does not divide into the rich and poor, the privileged and the unprivileged, the clever and the stupid, the lucky and the unlucky or even the happy and the unhappy. It divides into the nasty and the nice. Nasty people are humourless, bitter, self-pitying, resentful and mean. Saints may worry about them and even try to turn their sour natures, But those who do not aspire to saintliness are best advised to avoid them whenever possible and give their aggression a good run for its money whenever it becomes unavoidable. "Ladies and gentlemen, I hope you may feel that I've given them a reasonable run for their money this evening.

#### Notes

\*1 I may use terminology which offends against what has become known as disability etiquette. Opinions differ as to what are and what are not the right terms in which to refer to disabled people, but on one point everyone is apparently agreed - the one term by which it is not appropriate to refer to disabled people is "the disabled". I don't agree. If one is making a statement such as "the disabled are an excluded group", one is referring to a category, like "the French" or "the Christians", and not to disabled people as people at all, and so "the disabled" is arguably the most appropriate expression.

- \*2 Disability Rights Commission: Disability Briefing, November 2000.
- \*3 Figures supplied by Disability Alliance.

- \*4 "Handicap" is nigh on universally rejected by disability groups today as a term for referring to the situation of disabled people on the entirely spurious ground that it derives from the expression "cap in hand". In fact as connoting a disadvantage as opposed to a complete "disability" it is in many ways preferable to "disability".
- \*5 Bickenbach, J., "Conceptual Changes to the Original Model of Disability", Presentation to Stakeholders' Conference, ICIDH-2, London, 21 April 1999.
- \*6 Union of the Physically Impaired Against Segregation, "Fundamental Principles of Disability", 1976.
- \*7 Hurst, R., "The View of Disabled People", Presentation to Stakeholders' Conference, ICIDH-2, London, 21 April 1999.
- \*8 Finkelstein, V., "To Deny or not to Deny Disability?", in Magic Carpet (New Year 1975) vol. xxvii, no. 1, pp. 31-38.
- \*9 Anti-apartheid Movement flyer.
- \*10 City News, 13 February 1995.
- \*11 Abberley, P., "The Limits of Classical Social Theory in the Analysis and Transformation of Disablement", in Barton, L. and Oliver, M. (eds.), Disability Studies Past, Present and Future, Leeds, The Disability Press, 1997, p 25 at p. 28.
- \*12 Becker, H., "Outsiders: Studies in the Sociology of Deviance", Glencoe, the Free Press, 1963.
- \*13 Jackie Leach Scully, on Disability Research discussion list, October 1997.
- \*14 Gregor Wolbring, on Disability Research discussion list, October 1997.
- \*15 Groce, N., "Everyone Here Spoke Sign Language", Harvard UP, 1985.
- \*16 Hart, H. L. A., "Punishment and Responsibility: Essays in the Philosophy of Law", OUP, 1968, ch1
- \*17 See, for example, Oliver, M. in Barnes and Mercer (eds.), Exploring the Divide: Illness and Disability, Leeds, The Disability Press, 1996, p. 41: "disability is wholly and exclusively social" (my emphasis).
- \*18 In Barnes and Mercer (eds.), op. cit., pp. 47-49.
- \*19 Read, J., "Individual Change and the Social Model of Disablement", Disability and Society, 1997.
- \*20 cf. Oliver, M., "Understanding Disability: from Theory to Practice", Macmillan, 1996, p. 33: "It is not individual limitations of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation" (my emphasis).
- \*21 Poole, W. B. L., Review of "On Blindness: Letters between Bryan Magee and Martin Milligan", British Journal of Visual Impairment, 1996.

- \*22 Echoes of a number of these positions can be found in Oliver, M. in Barnes and Mercer (eds.), op. cit., pp. 47-49.
- \*23 Mills, C. W., "The Sociological Imagination.
- \*24 See, for example, Rock P. in Disability and Society, March 1996: "Terminations of pregnancy are easy to get and encouraged by the medical "experts". Many mothers are pressurised to consider themselves irresponsible parents by contemplating going ahead with the birth. The knock-on effect is to give a message to that family that the birth is not a time for rejoicing. People say little and shake their heads when the disabled child is born. Doctors see it as "breaking bad news", and only rarely are informed advice and positive attitudes to be found in assisting the mother to celebrate the birth of her disabled child."
- \*25 Rock, op. cit.
- \*26 "Understanding Disability: from Theory to Practice", Macmillan, 1996, p. 35.
- \*27 Goldsmith, S., "Designing for the Disabled: the New Paradigm", Architectural Press, 1997, pp. 138-40.
- \*28 Carey, K., "Design for Life", Presentation to DFEE/NDC/Demos Seminar, 29 April 1999.
- \*29 Norwich, B., "Special Needs Education, Inclusive Education or just Education for All?", London, Institute of Education, 1996.
- \*30 Quoted in Disability Now, January 2001.
- \*31 See Caroline Daniel, "Radical, Angry and Willing to Work", New Statesman, 6 March 1998.
- \*32 Quoted in Neil Clark, "Auberon Waugh, Hero of the Left", in New Statesman, 29 January 2001.