DISABILITY
and CIVIL RIGHTS
in the New Millennium

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5th April 2001

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27th April 1999

DISABILITY AND CIVIL RIGHTS IN THE NEW MILLENNIUM

INTRODUCTION

The lectures presented here were organised by the Strathclyde Centre for Disability Research and Glasgow City Council and took place between April 1999 and November 2000. The first lecture in the series, delivered by Professor Mike Oliver, launched the Strathclyde Centre for Disability Research. In the tradition of town-gown links, the lectures were intended to bring together activists, academics, service providers and any one else with an interest in developing the civil rights of disabled people. The lectures covered a wide range of topics and demonstrated, if nothing else, the interest and complexity of issues facing the disability movement and its supporters in the twenty first century. In the following paragraphs, some of the key issues are highlighted.

KEY ISSUES

Tensions between reform or more radical change

The disability movement, like other civil rights movements, has to make strategic decisions about how to achieve change.
Inevitably, different groups of people decide to tackle the system in different ways and there are strengths, as well as tensions, in using diverse tactics. Mike Oliver and Jenny Morris are critical of what might be described as the liberal wing of the movement. They both feel that the definition of disability enshrined in the Disability Discrimination Act is based on a notion of individual deficit, described in shorthand as the medical model of disability. Oliver feels that the Act should be repealed because its definition of disability is inadequate and its approach to social reform is piecemeal.
Bob Benson, on the other hand, provides a principled account of the work of the Disability Rights Commission. Through the enforcement of anti-discrimination law, Benson believes that the Disability Rights Commission will be a positive force for change. Working with government is clearly not without its problems, but, Benson argues, winning popular support for disabled people's rights is essential to achieving progress. The different positions adopted by Benson and Oliver illustrate a major dilemma. On the one hand, there is a danger that government may assimilate and contain radical energy, but on the other hand the law is a powerful medium in securing a better deal for people who have traditionally been treated as marginal citizens.

The social and political recognition signalled by the Disability Discrimination Act cannot be ignored or dismissed, but it may not be the complete answer.

The limits of rights

Connected with points raised above, throughout the lectures, questions arise about the nature of the civil rights which have been gained by disabled people and the limits of a civil rights approach. Pete Ritchie reminds us that, whilst the struggle for rights is of major importance, rights without power are of little use. This is well illustrated, he suggests, by observing social and political conditions in the USA, the home of civil rights. Whilst an individual rights approach is enshrined in US law, this is the country with the widest wealth gap between rich and poor in the entire western world. It is not simply a matter of according rights, Oliver and Ritchie suggest, but of ensuring that all citizens have the economic power to ensure that their rights are both meaningful and enforceable. Conferring rights without tackling poverty will bring about only superficial change.

Oliver and Ritchie also ask us to reflect on the extent to which new policies which promise change are actually able to deliver social improvements. The Adults with Incapacity (Scotland) Act 2000, for example, was heralded as a new approach to safeguarding the rights of people with the most significant learning difficulties and mental health problems. However, Ritchie suggests that issuing a **‘certificate of incapacity’** to individuals on the basis of two medical reports may be a step backwards rather than forwards. Yet again, he suggests, a social problem has been medicalised, and as a result the outcomes of the new law may simply replicate the problems of the old system.

Welfare and work: the basis of social inclusion

Throughout the lectures, questions are asked about the nature of both welfare and work for disabled people. The Government places great store on work as the basis for social inclusion, providing people both with a sense of purpose and identity as well as a means of earning a living. Whilst the disability movement generally endorses the importance of work and struggles against discrimination in the workplace, Oliver points out that questions remain about the benefits of the New Deal for Disabled People. Whilst discrimination in access to education and transport remains, disabled people will continue to compete on unequal terms in the labour market. In addition, as Beyer notes, the failure of Employment Service programmes to meet the needs of people with significant learning difficulties or mental health problems, along with perverse incentives built into the social security system, means that many disabled people who would like to work are deprived of the support they need to do this.

Welfare as right, not charity

A common theme running through all the lectures is the need to look afresh at the nature of welfare. Very often, as noted by Morris and

Ritchie, the provision of benefits and support to disabled people is seen as an act of charity rather than the delivery of a right. Disabled people tend to be characterised as dependent on the support of others, but this loses sight of the fact that they also give support to partners, children and their wider social network. Morris reminds us that understanding the nature of inter-dependence is a key message of feminism, although it has been forgotten in some feminist critiques of community care. Support is needed not just to meet disabled people’s physical needs, but, more importantly, to allow people to fulfil the social roles which they choose such as being a parent, a worker or a supporter of others. Legislation may change to give people rights to enter cinemas, but if disabled people are segregated together rather than able to sit with the person of their choice, little may have changed in reality. In addition, whilst a disabled mother may have the right to support to enable her to look after her children effectively, unless this support is available without a struggle and on her own terms, the entitlement will be of little use. Direct payments, which hold out the hope for disabled people of managing their own care, have thus far been introduced very slowly. It will clearly be important to monitor closely the nature of health, social care and benefits provision in the modernised welfare state which is to unfold over the next decade.

The uses and abuses of science

Finally, questions are raised in many of the lectures about the opportunities and threats associated with new scientific and technological developments. Clearly, science and technology may provide the means to overcome the effects of impairment, but at the same time their use within the military-industrial complex means that they are also major creators of disability.

The position of the disability movement towards the new genetics is particularly fraught. Shakespeare carefully disentangles some of the arguments, pointing out that genetics and eugenics are not the same, although they have sometimes been seen in this way by members of the disability movement. His view is that, on questions such as genetic selection, individuals have to determine their own moral position. Up to 24 weeks, the decision about whether to go ahead with a pregnancy should be made by the woman. It should not be possible, however, to abort an impaired foetus after 24 weeks when this is generally not allowed. Oliver, on the other hand, disagrees strongly with this view, suggesting that allowing abortion on the grounds of impairment implies a negative view of the social worth of disabled people.

In many ways the issues raised above encapsulate the purpose of the lecture series. The aim was not to gloss over differences of opinion, but rather to draw them out into the open so that the debates may continue. It is likely that people reading these lectures will adopt different positions on a whole range of issues, and will find themselves agreeing strongly with one writer’s position whilst disagreeing equally strongly with the views expressed in another lecture. Controversial questions include the following: How much faith can we have in the approach of the Disability Rights Commission to solve the problems of disabled people? Is work the key to social inclusion for disabled people? What are the downsides as well as the upsides of direct payments? How should we respond to the challenges of genetics? Such questions are of major importance to all of us, and if these lectures stimulate further discussion they will have been an extremely worthwhile venture.

Speakers’ biographical details

Professor Mike Oliver is Professor of Disability Studies at the University of Greenwich and Chair of the Research Sub-Committee of the British Council of Organisations of Disabled People. He is an executive editor of the international journal Disability and Society and a member of the Social Research Advisory Panel of the National Lottery Charities Board. He is an internationally recognised academic and political commentator, having participated in several major policy reviews in education, health and social services and published numerous books and articles on disability and other social policy issues over the last 15 years. He has also made many appearances on national and regional television and radio. His extensive knowledge of disability and community care issues has been built up through personal and professional experience, academic and research work, membership of various policy reviews and committees, and extensive contacts with voluntary organisations, statutory authorities and government departments. He remains an active member of the disability movement.

Major publications include the following: Social Work with Disabled People (1983), Walking into Darkness: The Experience of Spinal Cord Injury (with M. Moore, V., Salisbury, J. Silver and G. Zarb) (1988), The Politics of Disablement (1990), Ageing with a Disability: What do they expect after all these years? (with G. Zarb) (1993), Understanding Disability: From Theory to Practice (1996), Disability Politics: Understanding our Past, Changing our Future (with Jane Campbell) (1996), Disabled People and Social Policy from Exclusion to Inclusion (with Colin Barnes) (1998).

Dr Jenny Morris is a freelance researcher. Her publications include Pride against prejudice: transforming attitudes to disability (The Women’s Press) and Independent Lives? Community Care and Disabled People (Macmillans). Most recently she has been researching the experiences of disabled children and young people and publications include Still Missing? Disabled children and the Children Act (The Who Cares Trust) and Hurtling into a void: Transition to adulthood for young disabled people with ‘complex health and support needs’ (Pavilion Publishing). She is currently working on two research projects - one concerning disabled children and residential schools, the other social exclusion and young people with high levels of support needs.

Pete Ritchie is co-founder and director of Scottish Human Services Trust. A social worker by training, a philosopher by inclination and a social entrepreneur by accident, he has worked in various ways over the last twenty years to make human services more responsive and inclusive.

Dr. Stephen Beyer is Deputy Director of the Welsh Centre for Learning Disabilities at the University of Wales College of Medicine. After graduating with a PhD from Bristol University, and after a period in social services research in Bristol, Stephen joined the Welsh Centre in 1985. Since then he has carried out evaluation work on the impact of the All-Wales Strategy on services and clients, and on the impact of training in service development. He has been associated for many years with research and development in the context of supported employment, local authority day centres and in other forms of day provision for people with learning disabilities. Stephen Beyer is currently Chairperson of the Welsh Association for Supported Employment.

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DISABLED PEOPLE AND THE INCLUSIVE SOCIETY? OR THE TIMES THEY REALLY ARE CHANGING

COME GATHER ROUND PEOPLE

As we approach the Millennium the words inclusion and exclusion have become fashionable and are often used as shorthand to talk about a series of complex social processes. Like most words they have the power to create meanings of their own and they are often used to suggest a new approach by society to a variety of disadvantaged and disaffected groups - a new dawn in the treatment of such groups for the new Millennium. Whether these words really do represent a new approach or whether they are merely a cynical language game to misrepresent an unacceptable underlying reality which will continue into the Millennium and beyond will be considered fully in this public lecture.

A recent publication jointly produced by Disabled Peoples International, Inclusion International, World Blind Union, World Federation of the Deaf and World Psychiatric Users Foundation to commemorate the 50th anniversary of the Universal Declaration of Human Rights is provocatively entitled: **Are Disabled People Included?** In a foreword to the publication Mary Robinson, United Nations Commissioner for Human Rights states

…disabled persons frequently live in deplorable conditions, owing to the presence of physical and social barriers which prevent their integration and full participation in the community. Millions of children and adults world-wide are segregated and deprived of their rights and

are, in effect, living on the margins. This is unacceptable.
(DAA 1998.2)

The United Nations itself estimates that the above quote applies to some 500 million disabled people across the World and given that the UN Declaration has been in existence for 50 years, it is clear that large numbers of disabled people have suffered human rights abuses for a long time. The report documents many of these abuses and names the perpetrators (or perps as they are known in the American cop shows). The list of perps includes not just the usual suspects but also many of those Governments who are so fond of lecturing others about such abuses of human rights to the point of imposing trade sanctions, withdrawing economic aid or even bombing them into submission. Unable to resist the temptation to play language games myself, this report reveals that many of those who wish to appear as whiter than white could do with a good wash themselves.

I was delighted to be invited to give this lecture because it has given me the opportunity to think again about my own attempts to understand what has happened to disabled people, what is currently happening to us and what may happen in the future. Accordingly I wish to pay homage to the writer who has been the most influential in my own thinking and writing about the exclusion and inclusion of disabled people; not Karl Marx as those of you familiar with my work might assume but Bob Dylan. Some 40 years ago and for another troubled time he wrote a song called **‘The times they are a-changing’**. Like many great writers, his work is timeless and the message in that particular song is perhaps more pertinent now as we approach the Millennium than it was when he wrote it.In it he warned us all

> If your time to you
> Is worth savin’
> Then you better start swimmin’
> Or you’ll sink like a stone
> For the times they are a-changing’.
> (From the CD The Times They Are A’changin’)

DRAWING LINES AND COUNTING CURSES

My own deliberations on the exclusion of disabled people from modern societies unequivocally locates capitalism as the main villain. While I don’t think Bob Dylan ever used the term, in my favourite song of his **‘It’s alright Ma, I’m only bleeding’** he is clearly talking about capitalist society when he says

> . …the masters make the rules
> For the wise men and the fools.
> (From the CD Bringing It All Back Home)

And he sums up the central values of capitalism in one line, **‘money doesn’t talk, it swears’**.

Unpopular and unfashionable it may be in these (post) modern times to use such terms, but it does still seem to me that capitalism has a lot to answer for. For example, for 50 years the people of the Balkans lived fairly happy and peaceful lives until they were ‘liberated’ by the coming of free market capitalism. I do not make this point as a quick and easy comment on what is currently happening there nor as a cheap jibe at capitalism. But it is relevant to the theme of disability in that war is responsible for creating thousands of impaired people every year all over the world and using euphemisms like ‘collateral damage’ shouldn’t be allowed to obscure that fact.

But to return to the theme of the exclusion of disabled people rather than our creation, while a comprehensive history and anthropology of disability has yet to be written, it is clear from what evidence we do have that disabled people are not excluded from all societies. Accordingly exclusion is not an intrinsic part of the human condition of being disabled. Even in those many societies that do exclude disabled people, this exclusion varies with the economic and social conditions and the core values of the society concerned. Forms of exclusion range from death making through expulsion onto institutionalisation and finally denial. In our own society disabled people have and continue to face all these forms of exclusion. We know the Nazis killed 200,000 disabled people in Germany, but we still practice death making in the here and now and still hidden from view. Disabled children and elderly people are the main victims and we avert our eyes just like the Germans did all those years ago. I’m not suggesting that there are gas chambers out there, but there are things going on that we talk about in hushed tones using terms like euthanasia, mercy killing and termination.

We still practice expulsion by denying disabled people the right to live where and how they choose and we claim that we cannot afford to do otherwise. We still build and place people in institutions and attempt to salvage our consciences by calling them group homes, residential care or old peoples' homes. We continue to deny that these practices are happening and we even name these institutions after the perps of this exclusion; there are Cheshire homes all over the world for example, and in our own localities we glorify such places by calling them after the local politicians and bigwigs responsible for building them.

And we play yet more language games with our discussions of rationing and economic priorities and we invent code words like QUALYS and DALYS to disguise our unacceptable activities and the choices that are already being made, hidden from our eyes. Usually it falls to great artists like Bob Dylan to point to the realities underpinning these games. But this is not always the case; the power of words sometimes emerge out of profound experiences like the one Ann Macfarlane describes in her poem **'Watershed'**. Let's not play language games anymore.

> We were quiet, hiding our fear
> Knowing in our nine-year old hearts
> That we were about to witness something

Frightening and evil.
One cried quietly,
And we clutched inadequate towels around
our thin bodies
As Mary, pretty and small, passive and unmoving
Became the focus of all our attention.
They lifted her effortlessly
Into the deep porcelain tub
And then, without warning
Pushed her passive pale body under the water
And held her there.
We felt the fear through our ill clad bodies.

There was no shriek, no cry, no dramatic action.
The loud clock ticked on
A reminder that we had seen this before,
Had shivered and cried restlessly
And watched Mary come up again.
Now we were two weeks more knowing
And understood that we must not move,
Must not show what we felt.

Mary was dead.
Her body naked in the porcelain bathtub,
Tiny, frail, utterlessly lifeless.
Her long wavy hair over her face not pretty anymore.
She needed to be hugged, needed to be cared for.

But her bathers had no compassion.
The stood motionless over her, Eyes staring transfixed
Not seeing a human child, not seeing her.

Slowly their attention turned to us,
Unacknowledged, unwanted onlookers.
One by one we were wheeled back to our beds
Alone with our fearful thoughts.
No one spoke of Mary again.
It was if she had never been,
And yet she was our friend,
Part of our lives.

Nearly fifty years later, this scene comes and visits me.
Then we knew we must stay silent.
Now I speak it for all the Marys.
In institutions, in hospitals, in segregated schools
And for my nine-year-old self, who had no choice
But to sit and watch.

In face of the anger that such words stir, why did such things happen hardly seems an appropriate question but we owe it to all the future Marys to ask the question because, as Bob Dylan wrote in a song about the death of a poor black woman **'now ain't the time for our tears'**. My answer to this is that exclusion from the world of work is the most important factor in what happens to us and the way we are treated by society. The coming of industrialism shook many groups and individuals out of the labour force and consequently they came to be seen as burdens on society in general and the tax payer in particular. Hence, society had to do something about disabled people and it did; not being shy about using all the forms of exclusion mentioned above. However it needed people to sanction and carry out these exclusionary practices and it found the increasingly powerful medical profession and the newly emerging ideology of individualism willing supporters. I'm not, of course, arguing that disabled people are or have been treated better in other kinds of society, but I'm here to talk about us today and not others or yesterday.

This is obviously a very simplified version of a complex argument about exclusion which I published some ten years ago (Oliver 1990). It has not been without its critics and revisionists of one kind or another. You pay too much attention to work and not enough to culture say some. Society's hatred of us is because we are classed as **'other'**, not because we are unable to work say others. You fail to allow for the personal limitations that impairments bring with them say yet others. Pernicious social forces such as sexism, racism, homophobia and ageism are more important than work in our lives say yet more critics. And even if what you say is true, the coming of the welfare state and the development of community care will eventually ensure the inclusion of disabled people because they will be taken care of, so the final argument goes.

I do not deny the relevance or force of some of these arguments in shaping the lives of disabled people but ultimately I still believe, like Karl Marx, we are what we do, not what we think. On encountering a stranger for the first time and struggling for something to say, we usually open with the question **‘and what do you do?’**. To ask that same stranger **‘what are you thinking?’** would be liable to evoke a very strange response indeed. If you doubt my word, the next time you meet a stranger do what the American sociologist Harold Garfinkel used to encourage his students to do and disrupt the unspoken rules and norms of everyday life. Conduct your very own sociological fieldwork and start asking complete strangers what they are thinking. However please don’t write to me with the results or try to sue me if you get punched on the nose.

To be constantly and consistently denied the opportunity to work, to make a material contribution to the well being of society is to be positioned as not being fully human, indeed in my view, is the root cause of us being labelled as **‘other’** or **‘useless eaters’** as the title of Simon Smith’s CD suggests. And our culture only allows us to be Christopher Reeve or Christy Brown precisely because we are not fully involved in working in all those industries which produce images about us. Racism and sexism further separate us from our humanness when they attempt to deny a disabled woman of the right to mother the child she has given birth to or a young black man the wish to have his hair groomed the way he chooses. Finally, the welfare state tells us not to worry because even if we are a burden on carers, we will still be cared for; by that vast professional army or our loved ones who work tirelessly on our behalf rather than allowing us the dignity to work for ourselves and indeed to become ourselves.

Will it all be different after the Millennium?
Are the times really changing for disabled people?

Prophesies of the pen

To return to the main theme of this lecture, that of inclusion, it is certainly something that the new Labour Government has discovered. Led by the nose to it by one of their (alleged) gurus, Professor Tony Giddens who in his new book called The Third Way suggests that **'The new politics defines equality as inclusion and inequality as exclusion'** (Giddens 1998.102). And he further suggests that **'Equality must contribute to diversity, not stand in its way'** (Giddens 1998.100). Personally I prefer my own guru's thoughts on the little matter of equality.

> A self-ordained professor's tongue
> Too serious to fool
> Spouted out that liberty
> Is just equality in school
> 'Equality', I spoke the word
> As if a wedding vow.
> Ah, but I was so much older then,
> I'm younger than that now.
> (My Back Pages from the CD Another Side of Bob Dylan)

The Government of course, despite Tony Blair's claim to be an old rock and roller, prefers to listen to their own guru rather than mine and have recently published their own thoughts on exclusion and inclusion.

The causes of social exclusion are varied and complex and often cut across traditional Government boundaries. Many of the individuals and communities affected by social exclusion are on the receiving end of many separate public programmes and professional services. The poor rarely have the chance of helping to determine the programme of action for themselves. These programmes are rarely integrated; most deal with symptoms rather than causes; and most have been driven by the structure of existing Government machinery rather than by the needs of citizens. Not surprisingly, these approaches have often been ineffective. (HMSO 1998.63)

Can we take them at their word 'as if it were a wedding vow'?
Their claim, for example, to provide a 'joined-up' approach to tackling the problems of exclusion cannot be squared with their failure to repeal the Disability Discrimination Act. How can outlawing discrimination in some areas and not in others be joined-up? How can disabled people compete properly in the labour market if they continue to be denied an education which gives them the necessary qualifications so to do or they are unable to get to work once they have found a job?

Mrs Hodge, the new Minister for Disabled People, offers no more hope. In her new regular column for Disability Now, the disability newspaper that passes for the disabled version of the Sun, she makes no promises to provide fully comprehensive and fully enforceable civil rights legislation but instead promises to permanently change the climate of opinion towards disabled people by fully involving a combination of newspaper moguls, business, the Royal Institutes, one legged models and fading television personalities, many of whom most of us thought were dead. Haven't we heard all this for the last 50 years and hasn't it proved to be an abject failure?

As far as I know Bob Dylan has never met Margaret Hodge but he once wrote a song about another woman who got up his nose in the way she gets up mine.

> I see you got your brand new leopard-skin pill box hat
> Well, you must tell me, baby
> How your head feels under something like that
> Under your brand new leopard-skin pill box hat
> Well you look so pretty in it
> Honey, can I jump on it sometime?
> (Brand New Leopard-Skin Pill Box Hat from the CD Blonde on Blonde)

There is one area where the Government's very own guru does agree with me, and that is that work serves many important purposes both for the individual and society and that we must create a proper balance between work and non-work.

Involvement in the labour force, and not just in dead end jobs, is plainly vital to attacking involuntary exclusion. Work has multiple benefits: it generates income for the individual, gives a sense of stability and direction in life, and creates wealth for the overall society. Yet inclusion must stretch well beyond work, not only because there are many people at any one time not able to be in the labour force, but because a society too dominated by the work ethic would be a thoroughly unattractive place in which to live. An inclusive society must provide for the basic needs of those who can't work, and must recognise the wider diversity of goals that life has to offer. (Giddens 1998.110)

The Government agrees and in the White Paper A New Contract For Welfare they promise a new 'welfare to work' deal for disabled people and suggest that up to a million disabled people can be moved off welfare and into work, thus substantially shifting the burden away from social security and thereby enabling these disabled people to pay taxes instead; to refer back to my earlier comments, to re-position themselves as citizens rather than to continue to be seen as burdens on the state. A noble aim which has been somewhat tarnished in its implementation: while the Government intends to lop £750 millions off benefits for disabled people immediately, at the time of writing only 50 disabled people have found jobs under the New Deal. Personally I'd settle for 750,000 disabled people into work and

£50 million off social security benefits. Expecting a combination of vested interests, charities, cripples and the near dead to sort all this out really does seem to be little more than ‘blowing in the wind’.

The problem is that the Government’s plans to get disabled people into work are focused around 2 initiatives: a small number of special schemes and job coaches for individual disabled people. At a conservative estimate, there are a least one million disabled people of working age who are employable and such trifles are unlikely to have any significant impact on the unemployment rate amongst disabled people. They also claim that they will address the issue of equality of opportunity in the workplace but they have no plans to introduce fully comprehensive civil rights legislation and the new Disability Rights Commission will only have an enforcement role in the small number of cases where issues of principle are at stake.
If equality (of opportunity) is indeed a wedding vow for the Government, it’s indeed fortunate that disabled people are ‘so much younger now’ and we know that the politicians are playing language games of their own.

Giddens, in the above quote, recognises that work may no longer be available for everyone who requires or wants it and that a genuinely inclusive society must provide for the needs of those who don’t work, for whatever reason. Others, notably Zygmunt Bauman - one of the gurus of postmodernism, have gone further and suggested that, into the Millennium and beyond, society will be driven by the consumption ethic rather than the work ethic (Bauman 1998). While I remain to be convinced about this, when discussing this proposition with my friend Merav recently, she assures me that she is no longer what she does but what she shops and that she only does what she does so that she can shop.

To put this sociologically, if consumption rather than production is to become a basis for identity formation into the Millennium and beyond, then Governments may need to adopt some radically different social policies. Bauman suggests that the decoupling of income from employment is one such policy. Disabled people in Britain will recognise an earlier version of this policy when in the late 1960s and early 1970s the Disablement Income Group and the Disability Alliance proposed a national disability income available as of right to all disabled people. This proposal was not simply attacked on the grounds of cost but disabled people themselves argued that such a proposal would serve as a basis for the further exclusion of disabled people from other parts of society (UPIAS 1976); if disabled people didn't need jobs, why bother to educate them or given them the means to travel - so the argument went. Were governments to adopt decoupling policies, not just for disabled people, but for everyone else as well, then clearly the basis of the arguments around a national disability income would shift considerably. But until then, while participation in the world of work remains the main mechanism for social inclusion, disabled people will continue quite rightly to demand a full and equal share of it.

The link between work and exclusion is clearly important as far as older people are concerned, many of whom are disabled for, as Tony Giddens notes (1998.120). **'A society that separates older people from the majority in a retirement ghetto cannot be called inclusive'**. More than one in six older people will spend the last years of their lives in these **'retirement ghettos'** and as I grow older every year, I get more and more scared that such a fate awaits me.
As usual Bob Dylan expresses this so much better than I can.

> The ghetto that you build for me is the one you
> end up in.
> (Dead Man Dead Man from the CD Shot of Love)

Small wonder that the Direct Action Network (DAN) can claim that **'residential nursing home beds are on the increase, abuse in institutions is rife and our people are paying through the nose for it selling their homes for nursing profits'. They warn that they 'are going to build a freedom railroad out of the institutions and into the community'.** If they need a song to support their non-violent civil rights action, as most successful social movements do, then they could do worse than adapt the following

> I see my light come shining
> From the west unto the east
> Any way now any day now,
> I shall be released
> (I Shall Be Released from the CD Basement Tapes)

HEADING FOR THE HIGHLANDS

Will indeed any of us ‘be released’ with the coming of the Millennium? Bob Dylan aficionados will note that so far I have drawn on his early work but his most recent CD includes a eulogy to Scotland **‘where the Aberdeen waters flow’**, his words not mine. However, like most of his work it is about much more than Scotland; it is about that special place that we all have in our hearts or heads to which we give a variety of names - heaven, utopia, home, socialism and on. In the song he claims

> I’m already there in my mind
> And that’s good enough for now
> (Bob Dylan - from the CD Time Out Of Mind)

The decline in religion and the demise of state socialism have dented somewhat our faith in the existence of both heavenly and earthly utopias and if we do have a vision for the future, it is to science, technology and medicine that we look for our salvation. Science will provide us with the knowledge to change the world, technology the means to accomplish it and medicine will ensure that we are healthy enough and remain alive long enough to enjoy it.

At the interface of these worlds of science, technology and medicine is the issue of genetics. Its promoters say it will eradicate all illnesses and impairments and will prolong life for us all, or rather for all of us

who are genetically perfect. The rest will be genetically engineered out of existence, for their own good as well as that of society.
It sounds a familiar story, doesn't it? Disabled people will be confined to the history books and occasionally in the new Millennium films like the Elephant Man will be made about our wretched lives and their makers will probably win the 21st century equivalent of oscars. Everyone will live healthy, pain free lives and life expectancy figures will continue to increase.

Not everyone sees this as heading for the highlands, of course. Some see it as heading for the lowlands (not in this instance the place where the sad eyed lady Bob Dylan once wrote about came from) both because of the global ecological crisis that has been created by science and technology as well as the concern over what genetically perfect individuals will really mean for society.
Many disabled people fear that our disappearance from the future will not be a matter of progress but one of bitter regret, for society as well as for ourselves. When nearly twenty years ago in the pages of The Guardian I claimed that my disability was the best thing that ever happened to me, I was metaphorically burned at the stake by being grilled by Dr Miriam Stoppard on live television. Fortunately since then a positive politics of personal identity has emerged and more and more disabled people don't want to change the way we are anymore.

This identity politics does not merely provide a personal plea to allow us to stay alive but suggests that difference makes a positive contribution to the ultimate health and well being of society. Let me give you a historical example. One of the conditions it is claimed that will be eradicated by the appliance of genetic science is that of Huntingdon’s chorea. If that technology had been available, say 100 years ago, one Woodrow Wilson Guthrie would not have been born. In that case he would not have inspired Bob Dylan to produce the work he did and as a consequence of that, I would not be here before you now, giving this public lecture.

Some of you will undoubtedly say **‘good thing too; that’s the best argument for genetic engineering that I can think of’** but that would be to miss the serious point that when we tamper with such things, it affects us all. Even the heir to the British Monarchy has recently fuelled the current moral panic about genetically modified food by pointing to its potential dangers. I await the day when he will express similar concerns about genetically modified people. It would perhaps be too cynical a commentary on modern politics to suggest such a question will never be asked because the power of the medical establishment is so much greater than the farmers’ lobby these days. Nevertheless ask yourselves what scares you most - a genetically modified carrot or a cloned person?

THE SLOW AND THE FAST

However it is not just cynicism that is bringing about a decline in peoples’ faith in modern politics and its institutions. It is also fuelled by greedy, selfish and hypocritical politicians themselves as well as the failure of the state to deliver programmes based upon the democratic wishes of the people. How else can we account for the fact that it took the British political system more than 15 years to deliver anti-discrimination legislation (albeit in a watered down form) when everyone including the general public, leader writers in the Sun, elected politicians and disabled people were in favour of it.

What's more this failure will not be resolved in my view by finding **'a third way'** between state socialism and market freedom; the decline in modern politics is much more serious than that.

Once again Bob Dylan puts it much better than I could.

> The line it is drawn
> The curse it is cast
> The slow one now
> Will later be fast
> As the present now
> Will later be past
> The order is rapidly fadin'.
> And the first one now
> Will later be last
> For the times they are a-changing'.
> (The times they are a-changin' from the CD The times they are a-changin'.)

They certainly are for disabled people. In the last 30 years we have begun to shake off the dead hand of charity that has kept us oppressed and excluded for more than 150 years and to confront all those politicians, policy makers and professionals who have offered us little but patronising benevolence while continuing to build their own careers. In so doing we have built a political and social movement that does offer us the very real possibility **of 'changing our futures'** (Campbell and Oliver 1996). This possibility is based upon the bedrock of three big ideas which have emerged exclusively from our movement and have been based entirely on our own experiences; the ideas are, of course, the social model of disability, independent living and civil rights.

We are already seeing some of the benefits of this in terms of service delivery with the establishment of independent living schemes and centres, the coming of direct payments and the acceptance in principle, if not in practice, of the idea of civil rights. As a consequence more and more disabled people are escaping from institutions, others are regaining some semblance of control over such mundane things as when to go to bed and get up, what to eat and when and yet others are taking back control over their lives completely. We should not however be fooled into thinking that these are the majority of disabled people either here in Britain or elsewhere throughout the world.

While we may be **'heading for the highlands'** there is still a long way to go and many barriers to face. Most recently for example, we have seen some changes to the leadership in some of the organisations who make up the disabled people's movement in Britain and this has been seized upon by our enemies to suggest that somehow the whole movement is in crisis. We have to remember that those organisations who seek to dance on the grave of our movement are those very organisations who in the past kept us excluded and oppressed and who now seek to pass off our big ideas as if they were their own.

I doubt if Bob Dylan ever experienced the **‘charity’** of all those organisations who have spoken in our name for the past 150 years but their track record can best be summed up by the opening verse of another of his songs.

> Nothing was delivered
> And I tell this truth to you,
> Not out of spite or anger
> But simply because its true.
> (Nothing Was Delivered from the CD Basement Tapes)

THE CHIMES OF FREEDOM

It would not be appropriate for me to end this public lecture organised by the Strathclyde Centre for Disability Research without some reference to the role of the academy in ensuring the inclusion of disabled people in the third Millennium. From small beginnings more than twenty years ago disability studies has secured a hard won place on the agenda and in the curricula of some universities and we can be confident that from these small beginnings will emerge a vibrant force for educational and social change. We can be confident about this because disability studies, in Britain at least, is developing as a genuine partnership between disabled people and the academy and as a consequence of this, the voice of disabled people will be heard far louder than it otherwise might.

While the relationship between the academy and disabled people will not always be an easy one, nonetheless I believe it will be fruitful. If nothing else it will allow the voice of disabled people to be heard in fora where otherwise it would not and I am confident that the Strathclyde Centre for Disability Research will play a role in giving the disabled people of Strathclyde a voice. It is not however, only academics who give voice to the voiceless in pursuit of freedom but great artistes as well. I will end where I began with the words of Bob Dylan who in this verse manages to acknowledge the difficulties and the potential of giving voice to the voiceless as well as specifically mentioning disabled people.

> Through the wild cathedral evening the rain unraveled tales
> For the disrobed faceless forms of no position
> Tolling for the tongues with no place to bring their thoughts
> All down in taken-for granted situations
> Tolling for the deaf an’ blind, tolling for the mute
> Tolling for the mistreated, mateless mother, the mistitled prostitute
> For the misdemeanour outlaw, chased an’ cheated by pursuit
> An’ we gazed upon the chimes of freedom flashing.

(Bob Dylan - Chimes of Freedom from the CD The times they are a-changin')

Let's make sure the chimes of freedom really are flashing for disabled people in the third Millennium.

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Jenny Morris

25th May 1999

THE MEANING OF INDEPENDENT LIVING IN THE THIRD MILLENNIUM

INTRODUCTION

I’ve used the opportunity of preparing a paper for this lecture to reflect on where we are at in terms of **‘independent living’** at the end of this millennium and what barriers and opportunities we face as we go into the next millennium.

The concept of, and demand for, independent living grew out of the experiences of people who were incarcerated in residential homes. One of the features of the post-second world war period in Britain was the development of charities, often named after the individuals that founded them. These charities were motivated by a very real concern that society and government were not making proper provision for disabled people. They thus became service providers themselves, and because the prevailing attitude was that people who have physical or sensory impairments, or learning difficulties need looking after, the most common service provided was residential care.

One of the things we have to beware of in the development of the Independent Living Movement is the tendency for progressive ideas to be watered down, at worst completely distorted, when put into practice. It is worth bearing in mind the humanitarian intentions of Leonard Cheshire, the founder of what is now the largest organisation providing institutional care for disabled people. The Leonard Cheshire Foundation’s Mission Statement commits itself to **‘unquestioning**

recognition of (disabled people's) full human rights'. Yet that is not the experience of many people who use its services.
The Independent Living Movement faces a similar danger of its radical ideas being turned in practice into something different from the original intentions.

It was in the 1970s that a group of people in one Leonard Cheshire Home, Le Court in Hampshire, came to a key understanding about their experiences: namely an understanding that, just because they needed help with going to bed, this did not mean that they had to be put in their pyjamas at 6 o'clock in the evening. This is what the social model of disability is about: that it is not impairment in itself which restricts what someone can do, but the lack of suitable assistance; it is not impairment in itself which separates someone from society but the attitude that segregation is an appropriate response to their needs. People living at Le Court started to object to the way that society was spending large sums of money to keep them in a situation where they could not choose when they got up, when they went to bed, whether they went out to the local pub, whether they had sexual relationships, and so on. Such a situation separated them from society, denied them opportunities for employment, a home of their own, a family - in other words denied their human rights.

With assistance from the Leonard Cheshire Foundation, three individuals - John Evans, Liz Briggs and Peter Wade - pioneered the development of independent living by persuading their social services departments to fund the personal assistance they needed in their homes, rather than through purchasing a place for them in residential care (Hampshire Centre for Independent Living, 1986). At the same time, in other parts of the country, other people such as Maggie Hines and Ken Davis in Derbyshire, were successful in persuading social housing providers and social services authorities to make it possible for them to move out of residential care.

However, moving out of residential care did not guarantee control over your life. As long as people remained dependent on services over which they had no control they still could not choose when they got up and when they went to bed, and so on. So the growing disabled people’s movement and the increasing number of Centres for Independent Living put pressure on local authorities to provide more empowering services and, in particular, to give disabled people the cash so that they could purchase the help they needed themselves. By 1990, although the 1948 National Assistance Act prohibited local authorities from making cash payments in lieu of services, almost one in four social services departments were actually making direct payments to disabled people so that they could employ their own helpers and a number of others were making **‘indirect payments’** through voluntary organisations (Morris, 1993, p.26).

The whole idea of disabled people being enabled to purchase their own assistance was boosted by the establishment in 1988 of the Independent Living Fund, a government funded charity set up with an initial budget of £5million to make cash payments to people so that they could pay for their own personal assistance. This was offered in response to disability organisations' opposition to changes in the benefit system in the late 1980s which same terms as everyone else. When the first civil rights bills were introduced into Parliament as private members' bills during the early 1980s, the common reaction was that anti-discrimination legislation wasn't needed for disabled people because we didn't experience discrimination - everyone wanted to be nice to disabled people because they felt sorry for us and if we couldn't get employment it was because we were unable to do a job, not because of prejudicial attitudes.

We moved a long way over the course of 20 years or so towards a more general acceptance that there is discrimination and that employers and service providers should make adjustments to accommodate us. The Disability Discrimination Act reflects a victory in that it does attempt to address discriminatory attitudes and disabling barriers but it remains only a partial victory for reasons which have been well articulated by BCODP, not least because it remains based on a medical model of disability and excludes crucial areas of discrimination - transport and education.

So, as we go into the next millennium we face a situation where, although we have achieved a lot in the last 20 years, there is yet more to be done. What I want to do is to explore some of the more fundamental barriers we face in furthering the principles of independent living, of disabled people having choice and control in their lives.

THE DENIAL OF A LANGUAGE TO DESCRIBE OUR OPPRESSION

The government recently commissioned Demos, a think tank, to do some work on **‘ways in which genuine progress can be made in the coming decade to overcome the many barriers that affect the rights and quality of life of people facing disability’**. Demos wrote a briefing paper as the basis for a **‘symposium’** held in London in April this year. While the paper’s title was **‘An inclusive future? Disability, social change and potential opportunities for greater inclusion by 2010’**, its authors failed to take on board the starting point for our movement’s analysis of our social exclusion - namely the difference between disability and impairment. According to Demos, **‘disability as a concept covers a wide spectrum of medical impairments’.**

The disabled people’s movement does not use the word disability to mean impairment. Our political theory is based on the separating out of impairments - the functional limitations of someone’s body or mind - from disabling barriers: the prejudicial attitudes and unequal access which result in our social exclusion. We are disabled by what society does to us: therefore disability, like racism or sexism, is the word we use to describe our oppression. One of the most excluding things you can do to a group of people is to refuse to acknowledge the language they use to describe their experiences of inequality. Unfortunately, it is very common for policy-makers and professionals these days to say that they understand the social model of disability, and yet continue to use the language of the medical model. This is not mere detail, it is a fundamental undermining of our struggle for equal access to a decent quality of life, as I shall show.

THE NEED FOR FULL CIVIL RIGHTS LEGISLATION

The importance of getting the language, and thus the analysis of inequality, right is illustrated by the inadequacies of the Disability Discrimination Act which, in its current form, can only promote independent living and civil rights for disabled people in a very limited way. The DDA uses a medical model of disability in that it says **'a person has a disability...if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities'**.
Anti-discrimination legislation should focus on discrimination, not on the characteristics of the person being discriminated against.
The current DDA is similar to having an anti-discrimination law covering race focussing on how dark someone's skin is, or how **'foreign'** their accent, in determining whether they are protected against discrimination. Instead of being offered full protection against discrimination, the DDA asks **'is your impairment significant enough to give you access to fair treatment?'**

The problems with this medical model definition of who is covered by the Act are also related to the limitations of what is covered. The DDA does not cover disabling barriers created by social organisations.

It cannot because, by definition, the focus of the legislation is on limitations caused by impairment, rather than limitations caused by social organisations (the disabling barriers).
It therefore does not provide protection from, for example, the institutional discrimination resulting from the way education is delivered, or public transport provided. Neither does it provide protection from unequal access or outright denial of health care.
For example, the largest group of children who have heart disease in Britain are never, ever considered, or even assessed, for a heart transplant. This is because they have Down's Syndrome.
When asked to defend this policy, the medical director at Harefield Hospital, which carries out more heart transplants than any other centre in the world, said **'It's not just Down's we are seemingly discriminating against. It is anybody with any disability. We take, when faced with a choice, the person who is the most whole, as it were'.** (The Guardian Weekend, August 10 1996, p.18).

A failure to understand the importance of separating out disabling barriers and impairment is also key to the next barrier we face in our struggle for independent living.

THE RELATIONSHIP BETWEEN HUMAN RIGHTS, CIVIL RIGHTS AND ENTITLEMENTS

Disabled people insist that we are human beings and that we should therefore be accorded our human rights; we also insist that we are

citizens, like everyone else, and that we should have access to everything that all other citizens of this country have access to.
But in order to access our human and civil rights, in order to be able to do the same things as non disabled people, we also need entitlements to the additional things we require to have equal access: we need entitlements to physical access, to communication assistance, to personal assistance, to accessible information; we need legislation to protect us from prejudice. When the pioneers of the Independent Living Movement were asserting their human rights to freedom of movement, to form relationships, their civil rights to equal access to employment, to housing and so on, they were clear that in order to access these human and civil rights they needed specific action and assistance. In other words, in order to be the same as everyone else, we need our difference and our specific needs to be recognised.

We need human rights and civil rights but we also need specific entitlements. Three statements illustrate the differences between these and the relationship between them:

'Disabled people have the right to have children'. This is an assertion of a human right - it is about our common humanity, what we share universally with all human beings, although of course many disabled people don't have access to this human right.

'Disabled parents have the right to sit with their children in the cinema'. This is an assertion of a civil right - again it is about what we share in common with others, but in this case as citizens of this country: we should have access to the things that non disabled people have access to on the same terms as them. We need our civil rights in order to access our human rights. This particular right should be protected under the DDA but we will continue to have difficulty accessing it when new cinemas continue to be built - like the new IMAX in London. - which segregate wheelchair users from other members of the public.

'Disabled parents have the right to assistance with looking after their children in their own homes if they need it.' In order to look after their children disabled parents may need additional assistance, adaptations or equipment. If we don't have an entitlement to these things then we will not be able to access our human and civil rights to be parents. Ultimately, the promotion of our human and civil rights therefore is based, not only on a recognition of what we have in common with all human beings and all citizens, but also on a recognition of our difference and what we need to happen in order that we have access to the same rights as everyone else.
Disabled parents do in fact have an entitlement under the Chronically Sick and Disabled Persons Act 1970 to **'practical assistance in the home'** although it is notoriously difficult to get access to this entitlement.

What the pioneers of the Independent Living Movement were struggling against, and what we continue to struggle against, is the reality that when our difference is recognised, it is recognised in ways which segregate us, which demean us, which discriminate against us. Independent living can only be promoted - and thus our human and civil rights achieved - if the way difference is perceived is transformed. We don’t want to deny our difference but to ensure that it is recognised in a way which acknowledges the additional things that we need in order to access our human and civil rights.

Incidentally, this is why the government’s intended advertising campaign which uses the slogan **‘see the person not the disability’** is so wrong. This is not only an attempt to deny the feelings that people have about difference, it is also to deny that we are different - it is a denial of the prejudice we experience, a denial of the things that we need to happen in order that we can access our human and civil rights.

THE MEANING OF DEPENDENCY

We have to confront what our difference means. We have to confront the fact that most nondisabled people, when faced with the prospect of significant impairment, would rather be dead. This is why one of the things that the Independent Living Movement has struggled against has been the meaning of dependency, and the meaning of independence, in Western culture. Dependency is associated with being helpless, powerless, vulnerable. It is also associated with being a child, a woman and being old. Independence, in contrast, is associated with being in control, in charge, with capability. It is also associated with being a man and being young.

The Independent Living Movement has tried to break the relationship between having choice and control in your life, and being able to physically do things for yourself. Fear of physical dependency is a very real thing: in surveys of older people the most common reason given for support of voluntary euthanasia is not fear of pain but fear of having to rely on others for physical help. The Independent Living Movement has challenged the idea that to rely on others for physical help inevitably means a loss of choice and control, an experience of inequality, a loss of human dignity. This may have been how relying on others for help is traditionally experienced, but this is because of the social context, because of the unequal power relationship between those giving the help and those receiving it.

One of the most illuminating experiences I had recently was of running a training course for disabled people who live in residential homes. These are people who in their daily lives have no sense of an entitlement to the assistance they need, who are forever being made to feel a burden and demanding, who have to wait to go to the toilet, have to fit in with the Home’s routines for mealtimes, bedtimes and getting up times, who have to rely on the goodwill of others if they want to go to the cinema or down to the pub.

The two day training courses are residential and are run in four star hotels. During the course of two days in a hotel, the disabled people received a service from the hotel staff which was delivered in a spirit of their entitlement as customers. The training we were delivering was about empowerment but probably the most empowering thing for them was the experience of being asked by the hotel staff what they would like, being asked whether everything was satisfactory, of being treated with respect. The staff at the hotel, of course, may have had the same prejudices as anyone else about disabled people, but their 'customer care' training did not allow them to express this. Perhaps this same training should be provided to those working in residential homes and local authority home care services.

The Independent Living Movement aims to fundamentally change the experience of receiving assistance. Giving people the purchasing power is the most direct way of redressing an unequal power relationship, the most effective way of turning someone from a **'dependent'** into someone who decides who delivers the help they need, how and when.

Yet there are experiences of dependency which the Independent Living Movement has not yet really touched, and indeed there are growing numbers of people with these experiences (Morris, 1999a). Increasing numbers of children who have a combination of physical and sensory impairments and learning difficulties are surviving into adulthood. At the same time, there are increasing numbers of young people with significant brain injury as a result of surviving accidents which would previously have killed them. And of course there are increasing numbers of frail older people, particularly those with dementia. These are the new **'customers'** of the private and voluntary organisations providing residential care. The most disabling barrier many of them face is the assumption that significant communication and/or cognitive impairment means that they cannot make their preferences known and they cannot make choices.

We have to extend our critique of the meaning of dependency to people in this situation. This will also mean developing new ways of ensuring that people have choice and control. CILs are currently exploring how direct payments can be used by people who do not want to employ their own personal assistants. For example the West of England Coalition of Disabled People are seeking funding for a Partnership Operated Personal Assistance Scheme, where the scheme will act as the employer but the disabled person will be involved in recruiting and will have responsibility for managing the personal assistant on a day to day basis (Morris, 1999b, p.35). In the new millennium we will need to go further and seek ways of extending choice and control to people whose cognitive impairments require us to redefine involvement in deciding who gives you help, what kind of help and how it is delivered. We need to learn about different ways of understanding how people communicate their preferences and their experiences, for example from the pioneering work done by the consultancy Triangle who work with children with **'complex needs'** (Triangle, 1999a, b), from the work that Phoebe Caldwell has done with people with significant learning difficulties (Caldwell, 1996,1998) , and from developments in services for people with dementia, such as dementia care mapping - which uses close observation to understand experience.

THE SOCIAL CONSTRUCTION OF ‘CARERS’

One of the key barriers that the Independent Living Movement has always faced has been the assumption that the main source of receiving personal assistance will in fact be within personal relationships, within the family. The social construction of dependency has also had significant consequences for how these relationships have been defined. Over the last 20 years or so, researchers, policymakers and social and health services professionals have defined family members and friends who provide help to older and disabled people as **‘carers’** and those they **‘care for’** as **‘dependents’**. The 1980s saw a plethora of studies of so-called **‘informal carers’** where the role of **‘caring’** was defined as a **‘taking charge’** of the person who needs practical assistance and the voices of the **‘cared for’** - and the rights of disabled and older people to adequate support which would give them choice and control in their lives - were obscured.

Ironically, carers as a pressure group started off as a self-help, grass roots organisation, with a strong relationship with an organisation of disabled people, the Spinal Injuries Association, and with the aim of giving women the support and confidence to refuse to act as unpaid helpers. Its aims and purpose became subverted into a professional, national organisation, funded by government, whose aim is to establish informal caring as a career, with a carers’ income, protection of pension and other benefits (Morris, 1993, pp.31-40). In so doing, campaigners, together with the researchers in this field, have colluded with the government’s position that public resources will never be adequate to provide the support needed by older and disabled people and their insistence that, to quote a government white paper published in 1981, **‘Care in the community must increasingly mean care by the community’** (Department of Health, 1981, paragraph 1.9).

The ‘**carers’** issue of the 1990s has been the identification of children of disabled parents as ‘young carers’ and the way this has happened illustrates the ideological battles disabled people face (Keith and Morris, 1996).

The research studies of, the campaigning on, and the media interest in **‘young carers’** have tended to repeat two things which were common to the earlier debate on carers generally. They have defined and named a role, ‘**young carers’**, which until the children and young people came into contact with researchers or professionals, was not how they described themselves. And secondly, the main policy issue has been defined as providing services to **‘young carers’** which would ease the **‘burden of caring’**, rather than providing assistance to parents which prevent them having to rely on their children.

One of the factors which most seems to fascinate researchers, policymakers and professionals is the notion that there is role reversal going on where the children of disabled parents take responsibility for their parent and the parent becomes the **‘cared for’** party in the relationship.

A juxtaposition of the fundamentally different ways of seeing this relationship illustrates the way that disabling attitudes get in the way of recognising disabled people’s human and civil rights, and lead to a denial of the entitlement to additional assistance required.

Disabling attitude	**Disabling rights perspective**
People who need help with the physical tasks of daily living are dependent.	Independence is not about doing everything for yourself but about having control over how help is provided.
If your child helps you put your shoes on, this involves a reversal of roles - you have become the child, and your child becomes your parent.	The need for help with daily living tasks does not undermine your ability to love and care for your child.
We need to recognise the role of ‘young carers’ so that we can support these children in their ‘caring responsibilities, experiences and needs’.	Disabled parents should not have to rely on our children for help as we have statutory rights to ‘practical assistance in the home’ and to the adaptations and equipment we require.

We need research on how many **‘young carers’** there are.	We need research on whether disabled parents are able to access their entitlements, etc.

The disabling attitudes held by researchers and professionals lead to a failure to recognise the additional things that disabled people need to access their civil and human rights and to deliver these as entitlements. In contrast a disability equality perspective redefines the problem as a civil rights issue. In the new millennium we will particularly need to address the undermining of our entitlements which followed the House of Lords ruling known as the **‘Gloucestershire Judgement’** - which enabled local authorities to take levels of resources into account when assessing need for assistance. The previous and current government’s resistance to redressing this situation is a reflection of their failure to recognise or address the Independent Living Movement’s demand for a level playing field. This is also a factor in the current struggles over welfare reform and the funding of the community care system.

MEANS-TESTING AND THE EROSION OF THE UNIVERSALIST PRINCIPLE

The principle of univeralism is about creating a level playing field and it is a particularly important principle for disabled people. At the moment, the social security system makes a small recompense to those who incur extra daily living costs because of mobility impairments or personal care needs - in the form of disability living allowance. These payments are not means-tested because they are to pay for costs over and above what other people - who do not have mobility impairments or personal assistance needs - incur.

Unfortunately, the principle of universalism is not strongly enough applied and is currently under attack anyway. This is one of the biggest struggles that we face in the new millennium, to get politicians to understand the concept of a level playing field and the relationship between entitlements and human and civil rights.

The Labour government has dug itself into a hole by promising not to raise taxes - and yet to increase expenditure on health and education. So far, it has actually managed to raise taxes by stealth in order to finance this expenditure but in the medium to long term it knows that it has to cut the social security budget, particularly the numbers of people claiming incapacity benefit. It also has to keep a lid on the potential expansion of resources needed for enabling people to live in the community.

Means-testing is the solution to this dilemma: local authorities are forced more and more into means-testing services (which includes means-testing direct payments); ILF grants are means-tested; and, having abandoned fundamental reform of the social security system, the government is trying to force through means-testing of incapacity benefit and a reduction in the number of people who will receive it.

The charity ideas about disabled people are still very strong - if we conform to the stereotype of the poor disabled person who is forever dependent on others then we can expect some help from the state and the taxpayer. But we can only expect a safety net to prevent us falling through into utter destitution, we cannot expect a level playing field which would enable us to aim for the same quality of life as those who do not need assistance in their daily lives.

The whole debate about the future of the welfare state is dominated by a failure to understand what disabled people need in order to access human and civil rights. We experience disabling barriers which non disabled people do not face. We experience higher costs of daily living - created by a need for personal assistance, sign language interpreters, supporters, mobility equipment, communication equipment - which non disabled people do not face. Unless we have a welfare state which gives us an entitlement to resources to tackle these barriers and to provide this assistance then we cannot achieve our human and civil rights.

We particularly need to get the message through to the government that its policies of creating opportunities for disabled people in the labour market will not work unless the community care system stops means-testing the provision of services and direct payments. There are many people who currently use direct payments and ILF grants for whom paid employment is out of the question because it would just not be economically viable. There are others, currently in paid employment, who have benefitted from Independent Living Schemes set up by local authorities which do not currently means-test them. Yet the pressure to means-test is growing stronger and will be a key struggle for the Independent Living Movement over the next few years. We can only hope to win this argument if we can get central and local government to understand the concept of a level playing field.

INVESTMENT IN PROFESSIONALS RATHER THAN DISABLED PEOPLE

The post-war development of the welfare state saw huge resources go into the training and employment of people who apply their **'expertise'** to our lives. This went along with identifying our needs as **'special'** which therefore have to be met in ways which separate, segregate us from the mainstream. One of the key things that the Independent Living Movement has done is to insist that our needs are not 'special' at all, we want the same things as everyone else, it's just that we need particular kinds of assistance in order to achieve this.

Over the years, I have been to a number of meetings in the role of advocate or friend where someone is trying to get the help they need out of the health and social services system - and in the research I have done I have interviewed many people undergoing the same struggle. It never ceases to amaze me that the professionals and services with which people engage are often unable to provide the only things which would make a difference to their lives. My friend who was facing discharge from a psychiatric unit knew that she needed someone with empathy to be with her - not all the time but at crucial times when she was vulnerable to emotional distress. A friend who had just given birth knew that she needed someone to come into her home to help her with the tasks she needed help with at the times she needed the help. Yet, in both situations, we sat in a room with people - whose combined salaries cost the taxpayer more than £150,000 per year - to hear them tell us that this kind of help was precisely what was not available, while the help which was available was dis-empowering, dehumanising and often more expensive.

What disabled people want are advocates, training in self-advocacy, access to mentors and peer support. We want help with sorting out what it is that would make a difference to our lives and access to support which is delivered in a way which enables us to be included in society. The Personal Assistance Support Schemes developed by CILs are a model for providing self-advocacy, advocacy and peer support. In the new millennium we need resources to go into these kinds of services rather than into local authority social work and care management.

THE ROLE OF CHARITIES

Another factor which threatens to get in the way of the promotion of independent living is the role of charities like the Leonard Cheshire Foundation, MENCAP, Scope, etc. In the past, these organisations have been both service providers and have sought to speak on behalf of disabled people, using their position as service providers.

The disability movement has significantly undermined their credibility as a voice of disabled people and organisations such as Scope and MENCAP are gradually involving more and more disabled people in the running of their organisations.

However, many of these organisations still have large amounts of capital tied up in buildings. This particular use of capital inevitably means that it is used to separate disabled people from their communities because it is about taking them into buildings, whether they are residential homes or day centres, which are solely for disabled people. This generates jobs in segregated settings, creating a need to raise revenue to pay people's salaries, thus the need for fundraising and contracts with local authority purchasers. The jobs of those throughout the organisation are thus dependent on continuing to segregate disabled people from the rest of society.

Some of these organisations have of course seen the writing on the wall and are entering into contracts with local authorities to provide so-called independent living schemes and to develop services such as the Leonard Cheshire Foundation's Care at Home scheme.

Of course, there are people within these organisations who have a genuine commitment and understanding of independent living.
But there are also those who use the rhetoric to sell themselves in the new contract culture. In this kind of situation, one of the most important things that the wider disability movement can do is to seize

any opportunity available to make contact with people who live in residential care or who use services which institutionalise them within their own home. One example of this is the Empowerment Project run by Clare Evans. This resulted from a successful Lottery application from Leonard Cheshire Foundation to run empowerment courses for its service users. When they appointed Clare Evans as the co-ordinator they got a disabled woman with enormous experience of working to change organisations, of working in empowering ways to enable people who use services to determine how those services are run.

There was some criticism of her and those of us, like myself, who she employed as freelance trainers. But we need to sieze opportunities like this to work with disabled people who are in the most oppressive situations. It has been the most difficult work I have ever done, because the level of disempowerment amongst the participants on the training courses has been so great. Yet it has also been the most rewarding because the potential for making a real difference to people’s lives is enormous.

In the new millennium the Independent Living Movement needs to reach out to people who are in residential care, to people who, while they are living in their own homes, are yet institutionalised within them by services over which they have no control. One of our aims must be the demolition of all those buildings - many of them hidden away in the depths of the countryside - where disabled people are segregated from society. And we need to work with local authorities commissioning officers to ensure that the services they purchase on our behalf give us choice and control over our lives.

INDEPENDENT LIVING AND HUMAN RIGHTS

The European Convention on Human Rights, and now the Human Rights Act 1998 - which will be implemented in the year 2000, sets out everyone's right to be free from 'inhuman or degrading treatment'; the right to 'liberty'; to 'respect for private and family life'; to 'freedom of thought' and 'freedom of expression'. These are the standards against which any service should be measured.

In the work I've been doing recently, I have met people who are subject to **'inhuman and degrading treatment'** - people whose so-called **'incontinence'** is caused by having to wait for help to go to the toilet, people who are helped to eat in the most insulting and disrespectful manner, who are talked about in front of them as if they are not there, who have decisions made for them, who are treated as if they are not full human beings.

I have met people whose **'right to liberty'** is curtailed by a lack of ransport, drivers and escorts, who cannot choose to meet friends, go to the cinema, go for a walk round the block.

I have met people who experience no **'respect for their private and family life'**, whose mail is opened, who are denied the opportunity to have sexual relationships, who are separated from their families.
I have met people who are denied **'freedom of thought'** and **'freedom of expression'** because they do not have access to the support they need to communicate. This is perhaps the most fundamental denial of human rights because if someone is denied communication they are denied the opportunity to make choices, denied the most essential human interactions.

Independent living - as defined and campaigned for by the disabled people's movement - is not an optional extra. It is about promoting and protecting people's human rights. This is the most important thing that any social movement, any individual, can do. Let's hope we continue the progress we've made in the last decades of this millennium into the next millennium.

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12th October 1999

FROM HERE TO INCLUSION: DISABLED PEOPLE AND CIVIL RIGHTS IN THE NEW MILLENNIUM

INTRODUCTION

Much of the progress to date on civil rights for disabled people in the UK has been achieved by disabled people’s organisations and by leaders such as Mike Oliver and Jenny Morris who gave the first two lectures of this series. This lecture is intended to complement and build on the points they made earlier.

I want to start by summarising my key points.

First, I will be saying that in the last quarter of this century there have been significant improvements in the social situation and civil rights of disabled people in Scotland, the UK, Europe, and the other rich countries of the world.

Second, I will be saying that we have a long way to go.I will talk about equality issues where progress in Scotland has been slow or absent, and suggest some reasons why this is the case.

Third, I will be guessing at some major social changes in the coming century which are hard to predict but which will certainly challenge our ideas of right and wrong, of fair and unfair.

Fourth, I will be describing some strategies for achieving and maintaining a more equitable and inclusive society in Scotland over the next 20 years

But if I have one key message it is that we should not rely on individual rights to achieve social justice.

PROGRESS

The roots of the struggle for equal civil rights for disabled people go back at least a century to the British Deaf Association and the National League of the Blind. These organisations were unequivocally rights-oriented, campaigning on behalf of their members.

However, the main form of service provision then and for most of this century was segregated living and working arrangements for disabled people. Dozens of charitable institutions were set up between 1850 and 1950 - special schools, residential homes, villages, workshops - all with the good intentions of grouping and gathering people on the basis of impairment and providing them with something **‘special’**.

The 1913 Mental Deficiency and Lunacy Act (Scotland) was a massive curtailment of disabled people’s rights. This Act gave local authorities both powers and duties to identify and segregate anyone regarded as **‘feeble-minded’**.

For the next 60 years in Scotland the state-run institutions flourished as the centrepiece of the care system. They trained the staff, they provided so-called **‘respite’** for people living in their own homes, they often functioned as the administrative hub of the whole local system, they were the places from which the professionals did ‘outreach’ to the local community.

The period after the Second World War saw an unprecedented explosion in the welfare industry, with new professions, charities and bureaucracies emerging and flourishing. The words **‘help’** and **‘disabled’** became inextricably linked. Disabled people - especially those people who conformed to the conventional stereotypes - were the deserving poor, and the people who helped them were simply marvellous.

The pattern of services which developed combined an individual-medical understanding of disability with an administrative/prescriptive model of service organisation. Despite the growth in other professions and the expansion in local authority services in the 1960s and 1970s, the service machine continued to be dominated by medical doctors, psychiatrists and psychologists. Clinical status and quasi-judicial authority continued (and continue) to go together.
It was not until the 1960s and then increasingly in the 70s and 80s that the movement of disabled people was able to make its voice heard above the noise of care and welfare. There were two major issues - the specific campaign for entitlement to income and services and the broader campaign for recognition, respect and rights as equal citizens.

There are inevitable tensions between these approaches. Individual entitlement to benefits and services is based on the idea that a disabled person needs more help and more money to live a decent life than a non-disabled person, and that society should either pay for this help or give the disabled person extra money. So discussions of what counts as a disability or impairment move to centre stage, and people are expected to emphasise difference, difficulty and incapacity as a way to demonstrate entitlement.

The broader campaign for equality has been based at least in part on emphasising common humanity rather than difference, and capacity rather than incapacity - and on making services and society more inclusive for everyone.

The social model of disability developed by Vic Finkelstein and others shifts the focus of discussion about disability, from individual impairment to social exclusion and oppression.

Using this model, disability is no longer something **'in the person'** but something constructed **'out there'** in society by people's attitudes, the built environment, the health and welfare system, and institutionalised inequity.
Some versions of this model appear to some disabled people to deny the felt experience of impairment and to minimise rather than celebrate difference. The model does not work quite as well for people with learning difficulties and people with significant mental health problems.

But the model has helped a generation of people in Scotland, the UK and internationally to see themselves in a new light, to see themselves as OK and ‘the problem’ out there, to demand equity not charity, access not annexes, choice and control for themselves rather than care and control by professionals.

The disability movement has two major policy results in the last half of the last decade of this century.

The Direct Payments Act confirms the powers of local authorities in Scotland to put money directly into disabled people’s hands so they can pay for staff and other services directly. In theory, this could shift the balance of power within the service system from service providers to service users. In practice, the shift to date has been marginal in the UK and especially in Scotland. Nevertheless, this legislation provides one important foundation for reworking the relationship between disabled people and the welfare system. A major achievement of the disability movement was to insist and ensure that the scope of the DPA included all adults under 65 including people with learning difficulties. I will say something later about why the DPA has been such a damp squib in Scotland.

The Disability Discrimination Act (despite its awful title and its serious flaws) and the Disability Rights Commission are also an important step forward, even if they do emphasise how far back we started. Sitting in a bar on October 1st 1999 and knowing we had a right to move some chairs so we could all get round the table was a small pleasure but a very practical one. The provisions on employment and especially on housing will make a real difference over time.

At the same time, though, we should recognise that the improvements in service provision in the last 25 years owe little to the concept of individual rights. The **'right'** to an assessment under the Community Care Act is a good example of a right to nowhere.
The institutional closure programme and the community living movement did not come about because of people's civil rights but because of new values and new ideas shared by dissident professionals, disabled people and families.

I will say something a bit later about the broader strategies for equality and justice, but first want to talk about the specific issues facing disabled people in Scotland at the end of the 20th century.

PROBLEMS

Before focusing on Scotland, I want to acknowledge the situation of disabled people in the poorer countries of the world. This is not to say that disabled people here should count themselves lucky, but simply to point out that the struggle for liberation and decency does not stop at the Tweed or even at Gibraltar.

In 1995 UNESCO1 estimated that in the South 90% of young disabled people die before the age of twenty and 90% of children with learning disability die before the age of five. Of the 2 million blind children in India, only 15,000 receive any form of education. Millions of people become disabled every year through landmines, malnutrition and industrial accidents. Even when the political will is there, a country which has to spend 70% of its foreign currency earnings on debt repayments will struggle to tackle these problems. Despite this, there is brilliant work going on in some countries - for example in the field of inclusive education - and there are great opportunities for international collaboration.

Back in Scotland, we are struggling with difference, diversity, inequity and power. Having the English to blame has made it easier to obscure our own class system. Graham Leicester describes Scottish society as made up of three groups - comfortable Scotland, unsettled Scotland and excluded Scotland.

Most disabled people find themselves in excluded Scotland - much less likely to work, much less likely to have their own home, more likely to be harassed, and - particularly for older disabled people - at risk of being placed against their will in an institution. There are more disabled people over 65 in institutions now than at the start of community care policy, while there has been no significant increase in the availability of home care services. There are still more people with a learning difficulty in long-stay hospital than there were in 1915.

The main social role of disabled people continues to be **'recipient of charity'.** We are constantly told that disabled people need our help, need a minibus, need our unwanted goods, need us to ride a bike round Peru for them. As one small example, the Herald on Sunday last weekend headed a short piece about a guide to businesses on Part 3 of the DDA as **'help for disabled'**. For what other group would the establishment of a legal right to fair treatment be regarded as **'help'** rather than **'justice'**?

I would like to live in a society where people gave each other time and where health and social services were funded through the tax and benefit system.

Specifically in the field of civil rights, there are still major inequalities. Employers with less than fifteen employees are still allowed to discriminate unfairly - and these make up the majority of private companies.

Schools and education authorities are allowed to exclude children from their local school simply on grounds of impairment. As a result, despite the rhetoric of inclusive education, the number of children in segregated schools and units has not declined over the last ten years. Some schools are doing a great job of including all children - but far too many children and their parents still have the choice between welcome and resources in a special school and a constant struggle for access and acceptance in mainstream.

People with learning difficulties in longstay hospitals are locked in illegally. This is reported on by the government's own inspection teams. It is not seen as a major issue.

Disabled people over 65 (i.e. most disabled people) have fewer rights and entitlements than people under 65. Ageism is no more acceptable than any other form of prejudice and discrimination.
The concept of retirement was useful at the start of this century but is now past its sell-by date.

We are also about to see a backward step in the civil rights of people with a learning difficulty. The Adults with Incapacity (Scotland) Bill (now Act) means that 'certificates of incapacity' will be issued in relation to people with a learning disability judged not able to make a decision, on the basis of two medical reports.

Again, a social issue is being medicalised. But more importantly, while people with a learning disability and other cognitive impairments will lose civil rights by being declared incapable, they will not gain any right to individual representation or advocacy.

I am also concerned that the impact of this legislation will not be an investment in imaginative ways to help people understand, make and review decisions but an increase in defensive practice where professionals and agencies become less inclined to share risks with a disabled person in case there is a subsequent challenge to the person's capacity.

Direct payments have failed to ignite. Since 1996, a few hundred people have converted from indirect payments, but in most local authorities only a handful of **'new'** people have been awarded direct payments.

SHS is just starting on a short study commissioned by the Scottish Executive of direct payments in Scotland, and this will give us more information about the detail of implementation, but it is already clear that some local authorities and voluntary sector provider agencies have been less than passionate about making it happen.

Certainly, disabled people's organisations can set up more assistance centres to help people use their direct payments, but without a commitment from local authorities to redirect significant amounts of money as direct payments and to set up the infrastructure of local agencies which people can pay, direct payments will continue to be a safety valve rather than a serious alternative to traditional dependency-creating services.

Finally, our neighbours in England have just announced the setting up of 100 **'neighbourhood prison hospitals'** to lock up people with a personality disorder who have not yet committed an offence - but who have been certified as dangerous by two doctors. At least that could never happen here!

LOOKING AHEAD

No millennium lecturer can resist the temptation to speculate about the future. In the week of the 6th billionth person, it is comforting to know that the doomsday projections of population growth are all being rapidly revised downwards. The social predictions I make here are more likely to be wrong than right. However, three technical developments **will have an impact** in the next 20 years:

First, quicker and cheaper genetic testing will increase the pressure from insurers and employers to reduce their risk by discriminating against people on the basis of predictions from their genetic make-up.

It is possible to envisage a growing minority of **'genetically excluded'** people - people whose greater likelihood of a stroke, or cancer, or dementia makes them untouchable.

The Council of Europe's Convention on BioMedicine states **'Any form of discrimination against a person on the grounds of his or her genetic heritage is prohibited'.** But it will take courage to hold this line. We live in a risk-averse society where government is under huge pressure to play safe: if in doubt, lock them up; if in doubt, vaccinate. It will take courage - as it did with HIV testing - to say that not testing will result in some people dying younger because we found out too late, but that testing everyone would be worse.

Pressure for extending eugenic screening will grow over the next ten years with arguments about our overstretched health service and what society can afford. We need to have our own arguments ready.

Second, better repair and replacement of tissue and organs will mean that more physical and sensory impairments can be reduced or removed altogether. More spinal cord injuries will be treatable, more people will have vision or hearing restored, semi-artificial kidneys and livers will make transplants more widely available. Some single gene therapies will be used successfully in the womb. All this will come at a cost - and rationing decisions will continue to discriminate against older people and people with intellectual impairments.

While the distribution of impairments will change - as it already has for example in relation to rubella and polio - we will continue to create disability. In recent years, we have constructed dementia, challenging behaviour and attention deficit disorder as new empires for professionals, and have seen a rapid growth in asthma, dyslexia, dyspraxia, anorexia and anxiety. These conditions are socially constructed in the sense that they have been moved into the sphere of professional-controlled intervention, even if these interventions are not particularly effective.

It is difficult to know how many people living with these conditions will choose to identify with the disabled people’s movement.

Third, we will have better assistive technology. Robots that do something useful, voice-driven cars, computers that do what you think or respond to touch - all of these will assist people's autonomy, at a price.

But the big issues are not the technology, or even civil rights, but wealth and power. If we are lucky enough to avoid global catastrophe, Scotland will be at least 50% richer in twenty years time. The question is how far we are prepared to use this extra wealth to tackle social exclusion in Scotland and to reverse the last twenty years of growing inequality.

In the UK, the unlinking of wages and pensions has impoverished older people and the basic level of benefit income is among the lowest in Europe. Most disabled people rely on a pension or on benefit income, and are excluded by poverty as much as by prejudice.

WHAT NEXT?

The current government has made a commitment to ensuring **'comprehensive, enforceable civil rights'** for disabled people. The heart of this is equality and fairness - equal civil rights for disabled people and non-disabled people.

There have been important parallels and differences between this struggle and the struggle for gender and race equality. We have gone down the same road of seeking to specify what is fair and unfair discrimination, direct and indirect discrimination, reasonable and unreasonable adjustments to accommodate difference.

The way civil rights will be upheld in practice will be through guidance notes and codes of practice which place obligations on employers and service providers, and court cases where individuals make claims of discrimination against specific agencies.
As a recent Disability Rights Taskforce (October 1998) report notes, however:

> The danger in going down this route alone, however, is that the broad principles may be lost in the detail of compliance.

Establishing procedural rights requires behavioural change in certain contexts. It does not in itself lead to either a change of attitude or to equity of life circumstances.

Equal civil rights provide some protection to individuals against unfair treatment on grounds of disability, gender, or race. They do not deliver equality of opportunity or equality of outcome. In the USA - the country which brought you civil rights - the life expectancy of black men is under 50 in many states and 60 million people are without proper health care.
25 years of the Race Relations Act have not cured us of racism, and nor has the Equal Opportunities Commission cured us of sexism. While the Disability Rights Commission will make a difference, it will

not be enough on its own to cure our society of disablism, nor to ensure a decent quality of life for disabled citizens.

If one more example is needed, we can just think about the Disabled Person’s (Employment) Act of 1944 and the 3% quota which (last time I checked) almost no local authority, NHS Trust or other public body in Scotland (including the Parliament) has achieved after 55 years.

Establishing equal rights under the law for disabled people and non-disabled people is one strategy for tackling the oppression of disabled people. But it has a narrow scope. Many major reforms - such as the abolition of slavery and child labour, the provision of universal education and the Geneva Convention - do not rely on the creation of individual rights but on the prohibitions of certain transactions or the establishment of social duties.

Rights legislation also generates a huge weight of lawyers and enforcement mechanisms, and could easily become a major energy sink for the disabled people’s movement. When we are working on the small branches of technicalities and definitions we may be missing more important events happening at the scale of the forest. So if as allies of disabled people we profess a commitment to social justice we need to think carefully about our other strategies for change.

First and above all, we need to change social perceptions. Shifts in social perceptions since the War have run in parallel with the emergence of the rights movements. While oppressed groups make the claim for equality and justice, there also have to be enough people in the wider society who support this claim. Laws and policies which outrun social perceptions by too great a distance are empty rhetoric.

If we want to move beyond a more or less grudging acceptance of equal procedural rights to a much broader commitment to equity for disabled people, then we have to keep shifting social perceptions, changing mindsets, developing our philosophy.

There are two elements to the argument for equity for disabled people. First, that people should be treated fairly. Second, that disabled people are people.

The argument that people should be treated fairly raises very broad questions about the sort of society we want to build. I think that a Charter of Human Duties (rather than human rights) would include a generalised duty of treating people fairly, not simply in the context of certain defined roles as employee or customer, but simply as people. And treating people fairly does not mean treating people the same. But we have to recognise the difference between a moral claim to fair treatment and a partisan claim to special treatment. Those of us who support the claim of disabled people to fair treatment must also be conscious of and concerned about the unfair treatment of other disadvantaged groups in society.

Just as important, though, is the argument that disabled people are people. There are still many people - and just as many who work in the service system as who work outside it - who still don’t get it.
The way we run our schools, our news stories and TV programmes, the way we train professional staff, the way we design services - all of these reinforce a sense, not just of difference, but of not-like-us-ness, of strangeness, of distance, of alien objects of curiosity.

I believe that values training makes a contribution to changing these perceptions, and more and better work of this sort needs to be done.

We should stop trading on charity and pity. We have colluded far too long in presenting disabled people as sad, dependent and needy. Organisations which provide services to disabled people should concentrate on the quality of their service and not on the moral high ground of their charitable status and their good intentions.

We should start welcoming diversity. While compliance with rights legislation is important, there is a danger of seeing this compliance as simply another regulatory burden - something organisations and businesses have to do to stay within the law. We (in particular employers and trades unions) need to emphasise diversity and inclusiveness in who we employ and who we serve as good business ethics and good business sense.

We should stop segregating children in education. We should see inclusiveness as a key indicator of quality in schools and design it in to arrangements for teaching, teacher training, school organisation and school inspection.

We should make significant and strategic investments in assisting disabled people to get employed and stay employed. A recent Hester Adrian survey found only 4% of people with a learning disability in employment. Given that 70% of jobs are not advertised, we should not expect too much from the DDA in the short term. Our models for supported employment also have to change so that we respond to and support the disabled person's choice, direction and initiative rather than assess and place.

We should support and fund initiatives within the disability movement both to develop leadership and expertise and to broaden the base. For example, there are leadership opportunities in the parliament for young disabled people to be trained and employed as researchers for parliamentary committees. The DDA creates a huge opportunity for disability equality training and access consultancy and there is a shortage of trained and experienced disabled people.

If we are committed to inclusive and participatory models of research, we need to give disabled people proper opportunities to develop research skills. We should support initiatives to bring young people into the movement, and initiatives which connect different groups within the disability movement and create new dialogues.

We should support the development of disability culture - the recent funding by Scottish Arts Council of a disabled performers' initiative is very welcome here. Scottish survivors' poetry is another positive example of this culture in action.

We should dis-invest in special needs housing and make housing subsidies available to individuals not to landlords. We should encourage the development of neighbourhood generic agencies with disabled people on the board and properly trained, properly supported staff which can provide a responsive and reliable service for cash or contracts.

We should de-medicalise and de-professionalise disability, and prune back the areas in which clinical opinion becomes judicial authority. We should increase the involvement of lay people and disabled peers in issues of assisted decision-making, inspection, safeguards and standard-setting.

We should continue to recognise that while equal civil rights provide some protection against discrimination and poor treatment there are still thousands of disabled people in Scotland who are highly vulnerable and isolated, and we should help principled independent advocacy to flourish.

CONCLUSION

To sum up: We have made significant progress in equalising civil rights for disabled people in Scotland at the end of the 20th century. The agenda for the 21st century is achieving social justice for disabled people as part of creating a fairer and more inclusive society.

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27th April 1999

THE VALUE OF SUPPORTED EMPLOYMENT FOR DISABLED PEOPLE

INTRODUCTION

In the light of recent government proposals over changes in Incapacity Benefit entitlement, much of the debate in the media and among lobbying groups has been about the right of disabled people not to work if it isn’t feasible. It is ironic that so much effort is being put by the government behind moving people out of benefit when, still, so little has been done to make it possible for people to find jobs, to qualify for them, to get from home to them, to learn and keep the job and to make it economically viable for them so to do.

The motives of governments can be misunderstood when policies that are undoubtedly desirable socially, such as the New Deal for Disabled People, are also financially convenient for the Treasury. We could, and probably still will, debate whether it is sensible for some disabled people to take up paid employment, and on whose terms they should enter work. What is, I think, less controversial, is that paid employment can have major benefits for disabled people.

1. Paid employment is an aspiration for the majority of the adult population

2. It can yield significant benefits financially and materially, while of working age and, increasingly it can yield benefits in retirement, as the State Pension is eroded and there is a push towards company pensions and private pensions planning.

3. For better or worse, a job plays an important role in defining how we are viewed by others, and the formation of our own identities.

4. Employment, and a career, provides one source of personal development and growth.

5. And employment is a mainstream arena for social interaction and the development of social networks.

So, it remains terribly important that disabled people have the support that they need to enter paid employment if they so wish. It has, of course, been recognised that disabled people face discrimination at a number of levels in obtaining paid work. This has been acknowledged in a number of countries through the passing of anti-discrimination legislation, notably in the US with the Americans with Disabilities Act, and our own Disability Discrimination Act, both of which have significant elements dedicated to employment.

However, we don’t have to go too far back in time to find that large groups of disabled people were regarded by governments, government agencies, employers and society at large as incapable of paid employment. For people with a learning disability we only have to go back 30 years to find they were regarded as incapable of education, let alone employment. Despite the introduction of the DDA, and progressive benefits such as the Disability Working Allowance and the Tax Credit that has taken its place, this assumption of incapacity remains deeply engrained in our legislation and social policies, particularly our welfare benefit policies. The basic premise of our welfare benefit system is black and white:

You are either disabled and cannot work, or you can work and therefore cannot be disabled. Most reforms as yet have only been patches to obscure this basic premise.

Those involved in government employment rehabilitation programmes in the UK work hard to refine their schemes to meet individual need. However, their programmes are, at their core, based on the premise that there is a thing called a job with fixed skill and productivity requirements that, as a disabled person, you either have or do not have. If you do not have these, then you may go to a special place and job where the environment and productivity arrangements are tailored to your ability (a sheltered workshop) or an employer must be financially compensated for your inherent inability to meet productivity requirements (the Supported Placement Scheme). These are, I am sure, false premises.

I am of course sensitive to the situation of people with learning disabilities because of my professional association. I do think that they do pose a very significant challenge to traditional rehabilitation systems, and they have played a pioneering role in some aspects of the chase for an alternative. This quote by Lou Brown does show that 15 years ago we could challenge with confidence assumptions of **"employability"** for people with learning disabilities, already based on 10 years of demonstration work in the US showing that even people with severe learning disabilities could be employed:

For too many years it has been hypothesised that extremely few adults with severe mental handicaps could perform meaningful work, and that even those who could would only be able to do so in segregated environments. As a result they have been devalued, under taught, their life spans tragically constricted, and many generalizations have become embedded in the minds and hearts of millions of experientially deprived non-disabled persons. The label 'severely intellectually handicapped' is not an exemption from the real world of work. On the contrary, those so labelled have the human right to be given every reasonable chance and resource to learn to perform in integrated environments. (Brown et al., 1984 quoted in Mcloughlin, Garner and Callahan, 1987, p10-11)

So much that has happened over the last 30 years has showed us, time and time again, that people with undeniable and, at times, very significant physical, sensory and intellectual impairments or enduring mental health problems can become successful, valued employees in the general workforce. The key to large-scale success has not been the accumulation of disabled people's 'heroic' efforts to overcome their own impairments. It has been the ability of society, and its agencies, to re-organise themselves to deliver support in a variety of flexible forms to each individual and their employer that has enabled large numbers of disabled people to enter paid employment.

This has often meant employers and workplaces being flexible, negotiating over the way that tasks are carried out, over productivity levels and quality targets. It has also meant disabled people's abilities to work being regarded not as fixed, but changeable through skilled and specific training, environmental adaptation, personal and technical aid, and part of a more dynamic negotiation where both person and job can move to accommodate each other and enable a match to be achieved.Supported Employment, sometimes called the Job Coach model, has, I would argue, made a significant contribution to assisting disabled people into paid employment. It is not the only model of assistance. Nor, where it has developed in North America, Australia, the UK, and increasingly in Europe, is it anywhere near the largest form of provision. But I believe it has contributed in a much more significant way than its size would suggest, to our understanding of what support should mean, and to our thinking about what level of problems can be overcome in the workplace.

I believe Supported Employment can give us the clearest picture of what employment possibilities might be like for disabled people in the new Millennium.

SUPPORTED EMPLOYMENT - WHAT WAS IT AND WHAT IS IT BECOMING?

Supported Employment in the UK is defined as **‘real work in an integrated setting with on-going support from an agency with real expertise on finding employment for people with disabilities’**. This is the Association for Supported Employment (AfSE) definition. There is often confusion with the government’s own Employment services, Supported Employment Programmes which offer places in sheltered workshops, of which Remploy is the largest example, and the Supported Placement Scheme, which provides the disabled worker with a wage through an agent and to which the host employer contributes a sum based on the agreed productivity level of the worker. To understand this mode of Supported Employment, one has to recognise its first clients were people with learning disabilities in the US. First called the Place, Train and Maintain model, it came out of a recognition that work preparation training for this group was not working. People moved through various segregated centres, sheltered workshops and various levels of training too slowly to ever make it into open employment. Often the training was not powerful enough to enable people to make the jump from one sheltered environment to a new place and a new job. The workplaces, the routines and the jobs differed in a hundred small ways from the training environments, and people with learning disabilities find it difficult to adapt to these changes without help.

The key then, was to start by finding the right job, then training the person in situ, with adequate skill and power, and then assuming a monitoring brief over time to help overcome any subsequent problems. **Place - then Train - then Maintain**. The sophistication of the model developed apace after it was seen to work and gain US legislation approval and funding in 1984. It was imported to the UK around 1985.

In the US there were actually 4 models of Supported Employment specified in the legislation and funding, three of these being group placement models:

Work Crews Models: Originally up to 8 disabled people working together on paid contracts, commonly involving office cleaning, hotel maid service or grounds maintenance, often with Job Coach worker ratios of 1:8.

Enclave Models: Again of up to 8 people working together, often on one function within a company, such as the post room, assembly teams, or packaging groups, with Job Coach ratios of 1:8 again.

TABLE 1: Outcome for different models of Supported Employment

EMPLOYMENT MODEL

Outcome	**Individual**	**Enclave**	**WorkCrew**	**Total**
Average Hourly wage	$3.51	$2.63	$ 2.69	$3.02
Average Hours worked	87	77	65	80
Annual Income	$1,912	$1,554	$1,393	$1,692
Average Tax withheld	$263	$212	$178	$233

Entrepreneurial Models: This was not so often used but basically was a small business outside of a company doing sub-contract work, often high value such as circuit board assembly or wiring businesses for computing or car industries. Sometimes the Model has been associated with people who have complex disabilities or challenging behaviour, with higher staffing ratios and intensive learning methods.

As **Table 1** shows, the early data on wage outcomes for individual placements were superior to group models, and from 1985 onwards in the UK it was the individual model that was taken up. By 1993 105,000 people had been employed through these Supported

Employment models in the US. By a similar time, 17,000 had been placed in Australia, and 5000 in the UK. Growth slowed, however and by 1999 130,000 had been placed in the US and an estimated 7,000 in the UK. We have seen national government funded Supported Employment services emerge in Norway, the Netherlands, and seen significant growth in Portugal, Spain, Germany, Italy and Ireland.

We have also seen the people served by Supported Employment broaden **(Table 2)**. People with Learning Disabilities now make up around 70% of those using Supported Employment in the US.

Many people with enduring mental health problems are using the model, as are people with Cerebral Palsy, others with physical and mobility impairments, people who have sustained traumatic brain injury and a smaller number of people with sensory impairments.

With the broadening of the client base of Supported Employment we have also seen changes in emphasis within the model. The powerful work based training has been de-emphasised for people who have no real Learning Disability. Instead there may be more emphasis on helping people to find their own jobs, or on physical adaptation to the workplace for people with physical impairments: more time spent outside worktalking over issues and strategies with people who have enduring mental health problems, or perhaps more emphasis on creative job negotiation to assist with the problems that the cyclical nature of some conditions generate. In the UK in 1996, 90% of people using Supported Employment were people with a learning disability. With a shift to smaller unitary authority with smaller funding bases, and the increasing awareness of Supported Employment, there has undoubtedly been a growth in services to people with other impairments over the last 3 years which will continue.

One of the key assumptions Supported Employment has brought to employment has been the assumption that anyone can be employed if they want to - we just have to get the support right. This is known as the **“Zero Reject Philosophy”.**

TABLE 2: Disabled people served by Supported Employment internationally

Primary Disability	**GB ’96**	**Norway ’96**	**Australia ’95**	**USA ’93**
Learning Disability	90.3%	31.0%	54.9%	70.3%
Mental Illness	6.3%	19.2%	17.5%	19.3%
Sensory Impairment	0.55	12.6%	8.4%	2.6%
Physical Impairment	0.3%	-	12.0%	3.3%
Head Injury	0.6%	-	3.5%	1.5%
Other Disorders	2.0%	37.2%	3.7%	3.0%

By shifting the emphasis from the ability of the person to the means of support the Zero Reject Philosophy puts the onus on the supporting agencies and by implication society to improve their performance rather than for the disabled person to shoulder the responsibility for change. This is better, because society has more resources at its disposal to improve support than does the individual.

The philosophy also asks for research and for assessment to concentrate on the effectiveness of the support system, not on quantifying the weaknesses of the person.

Finally, the Zero Reject Philosophy involves a shift from norm referenced vocational evaluation - seeing whether people fit the average profile for an employee in any particular job - to criterion referenced evaluation - what the job and workplace actually need. This means knowing the person well and what kind of job and situation they need; finding a potential job and making sure it is a reasonable fit to their requirements (which may include negotiating a job of parts in which real tasks are carved from other jobs to make a specific job for a person to mutual advantage of worker and employer); and bridging gaps between competency and job requirement through support - which may include training on the job, aids, adaptation, personal, social and emotional support or transport help or even financial incentives - we will return to this later.

Let us consider then, what Supported Employment has achieved, focusing primarily on British data. **Table 3** shows several aspects of outcome and the performance of British Supported Employment agencies of 1996/97. Just under half were assessed by agency managers as performing at between 80 - 100% of the productivity of non-disabled workers in the same company. 44% were operating at 30 - 80% productivity at a rate that, if confirmed by the employment service, would make them eligible for wage subsidy or a sheltered workshop place under the government Supported Employment

Programme. Indeed, 19% of those in the Britain sample already received Supported Placement Scheme funding in addition to Supported Employment agency support. The rationale for Supported Employment Programmes is that people cannot compete in open employment. Supported Employment Agencies appear to be achieving just that for similar clients. The largest job sector for British Supported Employment is cleaning or work in restaurants and kitchens. This is lower than the US where fast food jobs and cleaning contracts have formed the backbone of Supported Employment placements for many years. In Britain we see many more jobs relatively in retail and clerical industries - a welcome diversification of the employment base.

TABLE 3: Selected outcome measures for British Supported Employment

Outcome measure	**Percentage of supported employees**
Productivity	
100% - 80%	49%
80% - 30%	44%
Supported Placement Scheme	19%
Jobs	3
Cleaning and food	5%
Hours	
1 - 15 hrs per week	50%
16 - 30 hrs per week	25%
30+ hrs per week	25%
Wage rates	

£3.00-£3.99	48%
No pay	13%
Earnings	
£1 - £15 per week	32%
Income increased	32%
Increase 80% - 400%	7%
Integration	
Excellent	40%

In terms of the hours people work here, 50% work 16 hours a week or more, opening up the possibility of significant income increases over basic welfare benefit incomes and opening up the possibility of Access to Work funding for workbases support. A disappointing number (half) worked only part-time, mainly due to the need to stay below an income level where the means tested Welfare Benefit Entitlements would be withdrawn. Linked to this, around a third of Supported employees took home between £1 and £15 extra per week through employment. This again equates to the level of income disregarded for benefit purposes if workers are regarded as working for therapeutic reasons. More encouraging, 79% experienced some increase in income through their employment, 7% having significant rises in income. As we shall see, welfare benefit regulations remain a significant barrier to the growth of employment through Supported Employment in the country.

A job can be a means to a more integrated life in the community. 40% of supported employees were said to experience **'excellent'** integration into the workforce. While a crude measure, this is encouraging non the less. There is research evidence which supports this view. **Table 4** compares data for supported workers from one Supported Employment Agency and their immediate co-workers. Engagement is a measure of the proportion of time people were spent actively engaged in meaningful activity, this being split into being engaged in tasks of the job, non-task engagement (such as breaks, talking to supervisors) and the conversational elements of task and non-task activity. This shows that supported workers were engaged in general for the same proportion of time as their co-workers (87% against 88%). It shows they were engaged in the tasks of their job for more of the time than colleagues (78.9% against 67.8%). They appear to be working in the same way as co-workers. Their conversational patterns are different however. Time spent in conversation about the job is well under a half that of colleagues, whereas conversation about topics other than work tasks is about a third of colleagues. In frequency terms, supported workers started interactions much less frequently, and were talked to much less frequently than colleagues. So, while people work well and typically, their social integration is not complete, and there is some work for services to do to assist in making integration more successful.

TABLE 4: Comparison and engagement and interaction for Supported Employees and there co-workers

	SUPPORTED WORKER	**CO - WORKER**
	Mean Percentage Time	**Paired T-Test**

	A	**B**		**A**
Engaged	87.0	88.0	-0.61	ns
Engaged on - task	78.9	67.8	4.93	<0.001
Engaged off - task	7.9	20.3	-4.76	<0.001
Engaged in on - task conversation	4.6	11.2	-4.46	<0.001
Engaged in off - task conversation	7.8	20.5	-4.75	<0.001
	Mean Number Interactions			
FROM person to all sources	4.8	9.4	-5.85	<0.001
TO person to all sources	4.9	7.6	-4.85	<0.001

TABLE 5: Employer rating of supported worker performance

	1 NOT AT ALL SATISFIED **3 SATISFIED** **5 Very SATISFIED**	**1 TO SELDOM** **3 USUALLY** **5 ALWAYS**
Attendance	4.46	4.75
Arrive leave on time	4.46	4.54
Breaks on time	4.29	4.49
Quality of work	3.78	4.49
Work speed	3.17	-
Safety	4.10	-
Accepting authority	3.97	-

Performance compares to non-disabled workers	-	3.98

Shafer, Hill, Seyfarth & Wehman (78 firms) Shafer, Kregel, Banks & Hill (125 firms)

The employer is another important customer of Supported Employment. Research tends to show positive reactions to the performance of supported employees on the part of employers (**Table 5)**. They appear to be highly satisfied on average with the performance of supported employees in many key areas of employment activity. The lowest ratings are for **"work speed",** but even here the average rating is a little above satisfactory.

Supported employees also appear to be at least as consistent in their attendance as co-workers, and if anything appear to have les time off sick, for treatment, or for unforseen circumstances, as **Table 6** illustrates.

Taxpayers ultimately foot the bill for Supported Employment, as they do for other mainstream employment services. From the perspective of tax payers Supported Employment can be a cost beneficial model as it often provides significant input early, and then fades to much

TABLE 6: Employer comparisons of supported employee and co-worker attendance

		CUMULATIVE YEARS
Unexcused absences	Supported employees	0.03
	Colleagues	0.07
Sick leave	Supported employees	0.02
	Colleagues	0.03
Excused absences	Supported employees	0.01
	Colleagues	0.01

Mertin et al, 1985

lower, and therefore less costly input over time. Resources released allow for more people to be placed and for unit costs to be reduced over time. To achieve this, fading must take place. The result is a reduction of cost over time, compared with institutional forms which have static or increasing unit costs.

THE IMPACT OF NATURAL SUPPORTS

Over recent years people have recognised that there is a dilemma in the role of the job coach. A job coach may be needed for some people to ensure they can do the job, but a job coach can also get in the way socially, marking the person out as different. We have seen the social disruption caused by the job coaches in our research. However, recent research by David Mank and colleagues, has revealed other impacts also. In a recent study he compared wage and interaction outcomes achieved in placements where jobs were found and trained as any other job in the firm was (typical), and in jobs where the process was totally different (non-typical).

Mank found that wage rates were related to the way jobs were found, the more typical the job finding approach, the higher the wage and that social interaction was related to wage. Mank and colleagues also found better outcomes in wage rate and integration where informed work in disability awareness has been done with immediate co-workers rather than at company level. In a similar study of six agencies we have found similar results. This indicates that the way we approach job finding can have a significant effect on outcome for supported workers, and that increasing subtlety is required by supported employment agencies.

WHAT MIGHT THE FUTURE OF EMPLOYMENT HOLD?

Those of us working within Supported Employment are often stretched and have to keep our eye on the ball, keeping close to developments with individual supported workers. Unfortunately we might find that while we keep our eye on the ball, someone is busily moving the goal posts or even remodelling the pitch and stadium around us. Business is changing and the long-term trends hold both threats and opportunities for Supported Employment. The time span between the development of a new product, whether it be in manufacturing, insurance or media is falling fast. Those companies that can react to markets and changes in technology swiftly are at an advantage. The implications for jobs are that people’s jobs will change more frequently, they will be required to adapt quickly and re-train more frequently. The skill level of jobs and range of duties may increase. This may cause a problem for people with learning disabilities who have traditionally gone into low skill, entry level jobs. However, this trend may highlight the importance of new support technologies which concentrate on creating independence and adaptability, or place a premium on jobs that require mutually dependent working rather than high degrees of personal flexibility.

As skills change rapidly, they may have become more specific to firms and industries, and require more training in-house or on quick response external training. This may lead to jobs becoming of shorter duration interspersed with periods of re-training. It may also lead to companies gearing up to train quickly and effectively to train in-house. This may suit people with learning disabilities, with more structured and specific requirements; it will be easier for them to learn jobs from in-house trainers rather than the specialist Supported Employment Agencies.

Connected to the trend for more specific training requirements is the trend for companies to look to establish secure pools of labour they can train themselves, or who may have some of the skills they require. This may lead to stronger links between industries and firms and local schools and colleges, with opportunities for some work experience to take place within factories, and for greater communication between teachers and company trainers. Opportunities for firm links with local industry may help in effective school transition for disabled people, particularly people with learning disabilities.

There has been a great deal of publicity in recent years over the potential of internet or e-commerce to develop a new style of business. This may lead to an increase in people buying outside of their area or their country. From the company point of view the access to global markets may offer viability to small firms that would not have once survived in local markets, and make location less important than before. This may increase the number of jobs in small businesses and improve job prospects for disabled people whose skills are as diverse as computer skills to packaging and distribution - key aspects of the distribution industry.

Technology is also promoting the growth of out-sourcing , the formation of companies that would once have been large in-house operations, but are now based on networks of interconnected smaller contracting firms. This may provide new opportunities for groups of mutually dependent disabled and non-disabled people to come together in supportive Social Firms to provide services in wider networks. We will discuss the relationship between Supported Employment and Social Firms in detail in due course.

We must not overlook the downside of globalisation - competition. With Asia still a major player in the world economy (if a little shaken in the recent years as in the case of Japan and Korea) and with China emerging as a world force in manufacturing, our share of global markets may fall. With this would come higher unemployment and increased pressure on jobs. If that does happen we are all in the mire and disabled people would be hard placed to make up ground in these circumstances, particularly as the great gains in the US were in the 1980s, a period of stable and low unemployment.

Two other trends are likely to be positive in any respect, however. The concern of an increasing number of middle and large size firms with TQM (Total Quality Management), and their increasing desire to respond to the needs of a diverse work force for efficiency purposes. In TQM, the emphasis is on team working, reducing costs and stabilising quality by progressively removing error from production processes. Mank and others have written on the way that TQM procedures have been used to address the requirements of the Americans with Disabilities Act. TQM teams looking at how company production can be made more efficient can go hand in hand with exploring how procedures can be modified to enable disabled people to take up jobs within the company.

Also firms are increasingly waking up to the fact that they already have diverse workforces. Talk to any personnel manager about the range of personal issues they normally have to deal with in a year! It makes the effort needed to accommodate a disabled person seem tame in comparison. Getting, training and keeping good staff requires more effort to meet their needs, creating personal support, supervision, work schedules and support packages that can cope with the range of issues generated by a diverse group means that catering for the needs of disabled people can become much easier for the company. For example, ensuring all furniture is height adjustable can serve a number of people, not just disabled people.

Catering for the range of learning styles and educational abilities in the general workforce can stimulate effective teaching strategies that help people with memory loss, physical impairment or learning disabilities. Having staffing rotas which cope with children being sick, family and emotional crisis can also accommodate people with cyclical health conditions or some mental health problems.
Both TQM or other quality assurance approaches, and diversity management are likely to progress whatever the other trends in business.

In either respect, business does seem to be more open to working with Supported Employment organisations to assist the former in meeting their responsibilities under the DDA. A recent survey we carried out in South Wales showed employers still under-prepared for implementing the DDA, significant numbers reporting they had inadequate knowledge of the Act. One of the most commonly stated forms of help they felt they required was having an organisation they could contact to help them deal with individual issues of people being disabled to ensure job retention, or to help them understand the needs of possible disabled applicants.

THE FUTURE OF SUPPORTED EMPLOYMENT?

It is likely that we will see a continued broadening of the clients served by supported employment to include **"disaffected youth"** where many of the techniques used are also relevant. This reflects the falling funding base in learning disability and the increased awareness of the potential of Supported Employment. We may see increasing selectivity in parts of the process applied, because of the need to control costs. We are likely to see links to sheltered workshop and SPS conversion projects to further progression from these projects. We hope we will see government funding through SPS spread to cover the job coach model of supported employment with **“conversion”** funding with the retention of a wage Natural support approaches and employer led supported employment will see continued growth. The concern with independence will also lead to the emergence of self-determination as a dominant set of techniques in supported employment with the following factors coming into use more often:

- Job tryout with consumer-led decision-making built in
- Assisted job finding
- Self-instruction for people with learning disabilities

- Self-monitoring and goal setting in key performance areas
- Diversified support model for people with high support needs

(Support co-worker; Job share; Productivity subsidy)

We are likely to see diversification in the employment models within the Supported Employment family of approaches to include self-employment, social firms, the Club House model. If any of this is to happen we need to see changes in the following areas of policy:

- Funding

The Employment Service needs to find a funding stream for the job coach model of supported employment.

The outcome of the Employment Services discussion document on the future of the Supported Employment Programme is crucial

- Welfare Benefit reform
  - Partial participation needs to be recognised
  - 16 hour rule scrapped
  - To work and to be disabled fully recognised as OK

- Tapered progression from benefit to paid employment, and vice versa

- Supported Employment skill base recognised and responsibility for training located

- Employment seen as a school transition goal and links to Supported Employment made.

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Bob Benson

Disability Rights Commission

5th October 2000

DISABILITY RIGHTS COMMISSION IN SCOTLAND: A NEW FORCE FOR CHANGE

INTRODUCTION

I would like to thank the Strathclyde Centre for Disability Research for inviting me to give this lecture. I'm also very pleased to be in Glasgow again addressing an audience who have well supported the previous lecture programmes underlining the considerable interest in disability equality and rights issues for all who are concerned about discrimination and who wish to see changes in both attitudes and awareness, better access and improved services.

So, why is it so important that these issues are addressed and change made? Our own recent commissioned research shows that many people feel that disabled people are not getting a fair deal. Over half of all people from a recent survey of some 2,300 adults in Great Britain say that disabled people are not treated fairly in society. Around 41% say that they are not treated fairly by employers. Only just over a quarter feel that enough is being done to make goods and services accessible for disabled people. A sizeable minority (22%) feel that it could be justified to treat disabled people less favourably than others (BMRB Omnibus Survey September 2000). With the establishment of the Commission we have a massive opportunity and task to change things for the better, for the 8.6 million disabled people in Great Britain - in Scotland almost 800,000:

- To counter massive disadvantage and discrimination;
- To tackle low public awareness;
- To challenge the difficulties through a range of different approaches.

It seems appropriate for your new programme and for year 2000 to be talking about the establishment of the Disability Rights Commission and how its work will bring about change.

I will cover a number of areas in my presentation including how the Commission came into being, its functions and duties and the expectations it has through its broad strategy, objectives and targets and how it will monitor its effectiveness to make change. I have specifically focused on the impact of new legislation and our research work and suggested some Scottish themes.

HOW WAS THE COMMISSION SET UP?

On the 27th July, 1999, the UK Parliament in Westminster passed the Disability Rights Commission Act 1999 to establish a Disability Rights Commission thus bringing into being a body which disabled people and disability organisations had campaigned and fought for many years to see established to ensure that the Disability Discrimination Act 1995 was fully implemented and enforced. The Commission had been a Labour Party Government manifesto commitment which was supported through the work of the Disability Rights Task Force set up in late 1997 which reported to Government in the spring of 1998. Following the consultation exercise published in the White Paper entitled **'Promoting Disabled People's Rights, Creating a Disability Rights Commission fit for the 21st Century'**, the Bill finally became law in 1999. The impact of the establishment of the Disability Rights Commission will have a profound effect on disabled people, employers and service providers and indeed society as a whole.

The Commission has a number of general functions including the following duties:

- to work towards the elimination of discrimination against disabled persons;

- to promote the equalisation of opportunities for disabled persons;

- to take such steps as it considers appropriate with a view to encouraging good practice in the treatment of disable persons;

- to keep under review the working of the Disability Discrimination Act 1995 and the DRC act itself.

> In addition, it has powers to make proposals to any Minister of the Crown as to aspects of the law or changes of the law or similarly to government agencies and other public authorities, it can also arrange for or support (financially or otherwise), the carrying out of research or the provision of advice or information.

It has extensive legal powers to ensure that the Disability Discrimination Act is being enforced through investigation and taking action in discrimination cases and providing a conciliation service. Critically it has powers to financially support disabled people who wish to bring complaints and claims about unlawful discrimination under Part 2 and 3 of the DDA. The introduction of the Human Rights Act across the whole of the UK from the 2nd October has potential implications which I will return to later.

On the 25th April 2000 the opening of the Commission was formally launched. We now have an independent non-departmental public body (NDPB) which is funded by the government. It is the third major commission to be established since the Equal Opportunities Commission and the Commission for Racial Equality.

The Commission only operates in England, Wales and Scotland.

An Equality Commission has been established in Northern Ireland incorporating all these functions and bodies. It has been suggested that this could be a future model for Scotland but this is probably some time away in the future.

The Commission has 15 Commissioners, 10 of whom are disabled people, including the Chairman Bert Massie. The Commissioners come from a wide variety of interests and backgrounds; from disability organisations, the business sector, trade unions, as well as specific Commissioners with special knowledge of Wales and Scotland. Elaine Noad is the Commissioner with special knowledge of Scotland. They have a key role to ensure that the overall strategic direction and objectives are set and achieved. It's ironic with hindsight to consider how far we have come. I remember clearly as a Disability Rights Task Force member the debate we had about whether a majority of disabled people should be Commissioners and whether this would lead to tokenistic appointments. We are lucky to have the calibre of Commissioners we now have, many of whom give considerably more than their allotted time (2 days a month) to the Commission's work. It's inconceivable that black people or women would have been seen as less than fit people for the other two commissions, but it underlines that disabled people are discriminated against not just because they are disabled but must also be seen to be better performers, producers and fit enough to do the job.

WHY IS THE COMMISSION SO IMPORTANT?

The Commission was established after years of campaigning by disabled people and disability organisations to set up a body that would enforce disability rights legislation to deal with the un-acceptability of discrimination against disabled people and to work towards equality of opportunity. This discrimination is well-documented, for example, the following information has been drawn from the Labour Force Survey (Winter 1999-2000, Great Britain):

- **Disabled people are around 7 times as likely as non-disabled people to be out of work and claiming benefits.** There are over 2.6 million disabled people in Great Britain out of work and on benefits: over a million of them want to work. However, many of them would not be able to start work straight away, mainly due to health reasons. They are also more likely to receive in-work benefits.

- **Disabled people are twice as likely as non-disabled people to have no qualifications.** This difference is consistent across all age groups.

- **Disabled people are only about half as likely as non-disabled people to be in employment.** There are currently around 3 million disabled people in employment: they make up 11% of all people in employment.

- **Employment rates vary greatly between types of disability.** They are lowest for people with mental illness and learning disabilities.

- **ILO Unemployment rates for long-term disabled people are twice as high as those for non-disabled people, 10.7% compared with 5.2%. Their likelihood to be long-term unemployed is also higher.**

- **In Scotland, only 37% (225,000) of disabled people of working age are in employment and some 52% (323,000) are on State Benefits and not in work. Base: all people of working age (men 16-64, women 16-59). Estimates from Labour Force survey (winter 1999 - 2000 Great Britain).**

These statistics refer only to employment but similar discrimination also occurs in education, housing, health and social work. We exist to knock down the barriers to inclusion and ending discrimination - prejudice, ignorance, behaviours and imbalance of power.

SETTING UP THE COMMISSION

By the end of the financial year 2000-2001, the Commission will have up to 150 staff with offices in London, Manchester, Cardiff and Edinburgh. The Scotland office will have 15 staff covering areas such as legal, casework and development services, policy development and promotional work.

CORE VALUES

Below are the core values which will inform our work and by which we will be judged:

- A commitment to disability equality
- A determination to make a difference and to deliver change effectively
- To be inclusive and consultative and to share good practice
- To be independent, open to change and creative in identifying solutions
- To always seek to improve
- Respect for everyone as an individual
- Awareness and respect for difference and diversity
- Creating an organisation which is empowered, accountable and constantly challenging itself
- Openness and honesty with no hidden agendas
- Support for each other, including constructive feedback

How these core values are embedded in our work and practice is of great importance to our credibility and how our stakeholders will judge us at the end of the day.

Our vision is to achieve a society where all disabled people can participate fully as equal citizens. Each word says a lot about what we want to achieve, for example, the emphasis on **'society'**, **'all'**, **'can'** and **'citizens'** refers to our commitment to rights and citizenship.

‘Participate’ and **‘equal’** provide ways of measuring whether progress is being made. All that we want to see is a level playing field for disabled people to obtain equal access to the opportunities which are available to non-disabled people.

OUR KEY STAKEHOLDERS

Everyone has a stake in the work of the Disability Rights Commission - our task is concerned with the whole of society. Within that context there are some groups that we have identified as key partners in our work to bring about change:

- Disabled people and disability organisations
- Business and employers
- Government departments and public and non-profit organisations including trade unions
- Local Authorities and enterprise companies and enterprise forums
- The media (particularly as a crucial point of contact with the general public).

RANGE OF APPROACHES FOR CHANGE

On our information leaflet you will see that we wish to make change by means of advice, conciliation and legal enforcement. These are our key approaches but there are other ways by which we seek to make change. Public relations is another approach particularly through the media where we hope to influence public awareness around disability and why rights are so important.

Similarly we wish to develop capacity in all sections where individuals and organisations are working from a more informed position through developments of networks and in key areas of policy and practice. Training, for example where disability awareness/legal rights and best practice are involved could be an area of focus. We will develop partnerships with other organisations to implement shared initiatives where this is appropriate.

Finally, where the law is found to be weak or inadequate, we will make recommendations to change the law. These various instruments for change highlight why the DRC can make change in a more holistic way and not just through legal enforcement, which some people tend to regard as the only role of statutory commissions.

We have identified the following five key strategic objectives for the organisation to enable us to achieve our vision. These are:

- To ensure disabled people are secure in their rights and have equal opportunities
- To enable individual employers and service providers - private, public and voluntary - to apply best practice and to meet their legal obligations
- To remove the barriers which disadvantage disabled people in key sectors of society and the economy

- To shift public attitudes and awareness towards lasting inclusiveness and equality for disabled people
- To ensure a high performing and exemplary DRC

TARGETS AND MILESTONES

Achievement of our broad objectives will be underpinned by a set of short, medium and long term targets and milestones. We have identified a considerable number of those through external consultations on the strategy of the Disability Rights Commission. For the sake of brevity, I have focused on a limited number of targets to be achieved between 2001-2002. Each target is discussed in turn below.

- **Provide a comprehensive set of high quality advice, conciliation and other services for disabled people, employers and other organisations.**

The DRC runs a helpline which is projected to take some 50,000 calls a year, answering questions on everything from information on the Disability Discrimination Act to advice on discrimination at work and transport issues. Each month they distribute roughly 40,000 leaflets and information packs. We will establish a new National Call Centre which will be fully operational within the year. This will provide a much higher quality of information and advice for all of our stakeholders.
A new conciliation service is planned in 2001 to deal with cases arising in relation to Part 3 of the DDA (access to goods, services and

facilities). This service will operate on a similar basis to ACAS for employment. Future plans will be drawn up for education conciliation services in relation to the SEN and Disability in Education Bill which will become law by 2002. In Scotland, the extension of the DDA raises some interesting issues as education is devolved to the Scottish Parliament and the policy framework is different; for instance, we have no local Education Tribunal services similar to those in England and Wales.

- **Help with problem-solving through casework on issues ranging from expectations that clients will pay for use of a wheelchair on an airline, to tackling complaints about local authority services.**

In the first six weeks of operation, over 200 cases were taken and future estimates suggest there will be up to 1800 per year. Currently some 40-50 new cases are being referred every week. The Scotland office will be operational from the end of October 2000 when caseworkers will be in post.

I would strongly urge everyone to look at the DRC Web-site **www.drc-gb.org**. The site has received very positive responses from users particularly about its accessibility.

- **Effectively disseminate codes of practice and other supporting materials and information on Part 3 of the DDA, disability and education, and any changes to the employment provisions of the DDA**. In 2001, the new Part 3 code on access to goods services and facilities was published. The new code takes into account different building regulations in Scotland and will ensure that premises are physically accessible by 2004. There will be a considerable amount of work for casework and legal services to clarify what is meant by reasonable adjustments in terms of duties and practice and where less favourable treatment or failure to make reasonable adjustments can be justified. I'm under no illusions about the challenge that faces us in implementing the Code, however experience from other Commissions suggests that most cases are satisfactorily dealt with at casework and conciliation stage. We have also conducted a small pre-consultation exercise this month on the means and timing for reducing the threshold with regard to the size of organisations covered by the employment measures of the DDA. [N.B. Following this consultation, in March 2001, the Minister announced that employers with two or more employees (rather than 15 or more) would have to comply with Part 2 of the DDA from 2004.] Advice has also been provided to the Minister for Disabled People on recognition of British Sign Language.

We conducted a consultation exercise on the Special Educational Needs and Disability Bill which will remove the barriers which disabled people face in securing good quality education. The law will extend the right of non-discrimination to disabled students at school, college and university. We urged Government to make some amendments to the Bill to ensure that disabled children themselves had a voice on plans for their education and that the legislation did not give out the message that mainstream schooling was likely to be very expensive, or cause disruption to other pupils' learning.

Finally we wish to address discrimination and human rights abuses in health and social care services. Through our programme of work we will identify the major issues facing disabled people and work with health and social work agencies to ensure fair and accessible services. In doing so, we will be implementing the following specific recommendations made by the Governments Disability Rights Taskforce which reported in December 1999, whose recommendations the DRC supports. (See Government response to the DRTF **"Towards inclusion - civil rights for disabled people"** March, 2001)

- **Support legal cases to clarify key aspects of the legislation and address wide spread blatant discrimination and strategic recourse to formal investigations.**

Where the law needs testing, we take cases to court or tribunal. Our first success was in support of Mr Kapadia, who had been dismissed from his finance job following absence due to depression. The employment tribunal judged that he was not disabled under the DDA Act because they could not detect problems with his concentration during the hearing. But this ignored medical evidence and the obvious point that mental health problems fluctuate, so the employment appeal tribunal decided he was disabled. But his employer appealed to the Court of Appeal, where the DRC supported Mr Kapadia and won. This judgement was important for people with mental health problems who can be placed in a catch 22 situation whereby. If they make a strong and coherent case, this can be used to argue their problems are too slight for them to be disabled.

Mr Kapadia himself could not have afforded to go to the Court of Appeal without the Disability Rights Commission. This case also highlighted some of the very real issues for disabled people particularly in health areas where they do not wish to be defined as disabled because of the stigmatisation of certain conditions even where successful cases have been won in the past. The price for disabled people and their families can be very high in such cases both in terms of finance and stress. Other cases where employees choose not to disclose if they have had mental health problems to their employers raises important issues. The main point at issue is whether lack of candour about a disability on the part of a potential employee provides a defence of justification to an employer who subsequently treats that person unfavourably. Referring to the successful Court of Appeal action, our Chairman, Bert Massie, said, **'When we have been unable to succeed through the force of argument we are then compelled to use the argument of force'.**

For children, discrimination in ordinary activities also occurs.
Tom White, a fifteen year old, has diabetes and quite recently went on a school skiing trip. Unfortunately, he had a hyperglaecymic attack whilst away and the school took the view that the attack was a result

of his mismanagement of his diabetes. The school therefore banned him from any future school trips. There were two future trips in the offing, one to Germany and one to France. The German trip appeared to be exclusively educational; the French trip, on the other hand, was a canoeing holiday and so arguably recreational.

The question of what amounts to **'education'** and what does not needs to be tested. If the canoeing trip is educational, the boy would not be protected by Part 3 of the Disability Discrimination Act, although he would be covered by the forthcoming SEN and Disability Act. The School was asked by the DRC to change their policy or face going to Court.

- **To promote the relevance of the Human Rights Act to Disabled People, and to press the Government to implement regulations enabling the DRC to support relevant legal cases under the Act.**

The Human Rights Act comes into force across the whole of the UK on 2nd October 2000. The DRC, like the National Disability Council and Disability Rights Task Force before it, believes the Act has important implications in particular through its provisions on the rights to life, privacy and family life as well as to freedom from abuse and degrading treatment in institutional care and the restriction of medical services. Organisations representing disabled people hear constantly of cases of unfair or degrading treatment. Until now there has been very little legal remedy in some situations. Under the HRA disabled people have the right to expect public authorities to treat them with dignity and respect.

The Commission has just published a report prepared for the Disability Rights Commission and the Royal National Institute for the Deaf by Rowena Daw on the impact of the Human Rights Act on disabled people. It will inform disabled people about their rights under legislation and is likely to lead to legal challenges to public authorities where people suffer discrimination.

The Human Rights Act contains significant new rights for disabled people. The Act is intended to create a **‘cultural shift’**, with rights enshrined in the European Convention of Human Rights permeating the decision-making of government, public authorities and legal systems at all levels.

INDIVIDUAL RIGHTS AND THE HUMAN RIGHTS ACT

Article 14 is critically important because it prohibits discrimination against people, including disabled people, in their enjoyment of Convention rights. This means that if someone is denied one of those rights on the grounds of their disability - i.e. a disabled person is potentially denied the right to life because of a ‘not for resuscitation’ notice to their medical notes - then it is open to the individual to bring a challenge under the Human Rights Act, in the British courts.

Article 2 - the right to life

This article will have a significant impact for disabled people trying to get treatment from health services. The refusal of treatment solely on the grounds of someone’s disability, or on assumptions about ‘poorer quality of life’, will breach this article, for example, a child with Down’s Syndrome being refused a transplant because of their quality of life. The use of ‘Do not resuscitate’ notices could also breach Article 2.

Article 3 - Prohibition of inhumane and degrading treatment

There are many examples where disabled people have been neglected, abused or treated with cruelty in residential and nursing homes, hospitals and prisons and cases where the standard of community care has been seriously deficient. This Article may affect many public authorities and private organisations that carry out social service functions on their behalf.

Article 5 - the right to liberty.

It is relevant to people with mental health problems who are compulsorily detained and to other disabled people in institutional or community care. Article 5 will pose dilemmas for the courts and for public authorities in balancing an individual’s safety (for example in cases of potential suicide), or more rarely public safety, with individual rights. It may affect the procedures for detaining people under mental health laws and for their release.

Article 6 - rights of due process in criminal and civil cases.

It imposes standards in social security disputes and may affect complaints procedures in the NHS and social services. It will possibly give greater rights to legal representation benefiting, for example, people with mental health problems or learning difficulties, who have at times been unable to secure justice because they are deemed to be ‘unreliable witnesses’, or because there is no advocacy support.

Article 8 - the right to private and family life and
Article 12 - the right to marry and found a family.
These articles will have the most widespread implications for disabled people and will challenge the current policies and practices of local authorities, which often have the effect of making it virtually impossible for disabled people to have and raise children. Rights to fertility treatment,the sterilisation of young women with learning disabilities, the rights of severely disabled people to live independently, and rights of adoption are among relevant issues.

Article 8 should help protect disabled people from invasion of their privacy and from intrusive and insensitive treatment. It should:

- help with claims to live at home rather than in residential care
- give better access (especially for people with learning difficulties) to medical records and other information in the hands of public authorities.
- provide redress for the worst abuses in the management of public housing.

Article 10 - freedom of expression
Disabled people who find difficulty in accessing information held by

public authorities.

Protocol 1 - protects rights of property, of education and the right to participate in elections.

The Protocol will help to outlaw practices which marginalise disabled children in schools and deny them access to further and higher education. Since currently disabled young people are twice as likely than non-disabled people to leave school without qualifications, these

measures could bring significant improvements in life opportunities. The **right to property** may have implications for the treatment of the property of disabled adults in care and to their receipt of welfare benefits. It should help in ensuring a speedy determination of their claims for benefit.

The DRC is not currently empowered by statute to assist disabled people challenge in the courts potential human rights abuses. In contrast, the Disability Rights Taskforce recommended the DRC should have the power to represent disabled people in legal action under the European Convention of Human Rights. This would strengthen disabled people’s ability to secure their rights at law, be wholly consistent with the remit of the DRC, and help to ensure consistency in the development of case law as it affects disabled people. It is also the only recommendation of the Disability Rights Task Force regarding the establishment of the DRC that the Government has not as yet implemented.

The DRC Act contains provisions that enable the Government to introduce regulations to give the power to the Commission and, when the Bill was debated in Parliament, the Government indicated that it wished to consult and introduce the regulations at a later date as appropriate. The Commission has urged the Secretary of State for Education and Employment to introduce quickly the regulations to enable the Commission to support disabled people in such cases. This would represent a further major step in its commitment to strengthen the effective rights of disabled people and would be warmly welcomed by them and their organisations. The proposal is strongly supported by the Northern Ireland Equality Commission Disability Committee given their responsibility for disability issues there. The Government has so far refused to change the regulations that would empower the commission to support such cases.

In the study of the Human Rights Act, the report's author stresses that change brought about by the HRA should be as positive as those which the DDA is bringing about. It cautions however that :

Change cannot occur by being forced upon reluctant and unprepared public authorities through expensive court challenges. Disabled people should be realistic in their expectations. A constructive dialogue needs to occur so that the complex issues that arise can be resolved in accordance with a shared ethical framework that the Human Rights Act is designed to foster. (Daw R, 2000)

- **Establishing the DRC’s programme of long-term research and dissemination on trends, successful practice, and impact of disability legislation.**

  The key aims and priorities of our research and evaluation will contribute to achieving the aims of the organisation and to its efficient operation. There is a need to establish authoritative data against which future improvements in which the position of disabled people in these areas can be monitored and this is one of our key aims for this year. In addition, there is a need for reliable information on the way the Disability Discrimination Act (DDA) is working and the views and experiences of those affected by it, to allow us to assess its impact and effectiveness and outline the case for further guidance and/or legislation. However, the programme also aims to assist in achieving real progress with regards to disability rights and independent living of disabled people, by proposing a public consultation and a series of papers and guidance studies. The programme will focus on the Commission’s choice of priority policy areas, i.e. education, employment, access and health and social care. These broad areas will be covered by a variety of in-house and external projects.The theoretical framework for the research programme is essentially a pragmatic one: research methods will be chosen as appropriate for the questions to be addressed. Base line information (numbers, key facts and figures) will need to be collected through survey research and statistical analysis, whereas taking forward the theoretical debate and giving a voice to disabled people will need a

> different approach, one that is based on an in depth exploration of the salient issues. Although it is important to have a clear focus on achievable objectives, it is also important to be mindful of the bigger picture andlonger-term objectives. The DRC should be seen as a main provider of high quality, reliable research and briefing, informing public debate and having a high visibility in doing so. It should be exemplary not only in designing relevant, cost effective programmes of research, but also, in disseminating them efficiently by a variety of means and providing concise, accurate briefing to policy makers, opinion formers and the public. Disabled people will be involved in the design and conduct of DRC research, rather than just being at the receiving end of it.

DRC research and evaluation needs to be funded and managed within the resource constraints of a new, relatively small public body whose research funding is limited relative to that of Government departments. It is therefore particularly important to obtain best value-for-money and ensure that Commission work does not duplicate that carried out elsewhere. There are a range of external studies in which we are involved, which include on-going DFEE-funded projects on how employers and service providers are responding to the DDA and attitudes to and experiences of disability. These two projects will provide good baseline information on disabled people, employers and service providers. We also produce a quarterly statistical briefing pack, using the Labour Force Survey (LFS). This is along the lines of the former DfEE Disability Briefing, but with added information on ethnicity and age, to provide a fuller picture.

There are several priorities for forthcoming work within the 2000 & 2001 time period which arise from the DRC's work programme and information needs. They are:

- Authoritative base line study of disability issues
- Monitoring the impact of the DDA
- Focus studies on topics of particular relevance

Baseline Study on Disability Issues

This should cover disabled people, employers and service providers as well as non-disabled people and their perception of disability, to provide a baseline for gauging progress in the wider inclusion of disabled people in society.

The extent of Disability in Britain: Sources and Projections

One important area which is not explored by current research is the question of whether numbers of disabled people are increasing and what the likely future trends are in this respect. Estimates of working-age disabled people, obtained from LFS, have consistently risen over recent years. Reasons for this may include an ageing population, an increasing awareness of different types of disability and a greater willingness of people to identify themselves as disabled. It would be useful to establish from existing data sources what, if any, the real rise in numbers of recent years has been and project future trends from this. This would afford a reliable base for developing DRC strategy and policy and alleviate the problem of inconsistent disability estimates being used in public debate.

In order to establish the nature and size of the disabled population and produce future projection, it will be necessary to look at information from a variety of longitudinal data sources, such as the Labour Force Survey (LFS), General Household Survey (GHS), the Census and others. Such a study would aim to reconcile different estimates, taking into account the different disability definitions and different age coverage of the various surveys and derive a set of standard estimates over time. The study would also make comparison to other European countries, to explore national differences and/or the statistical capture of disability.

The DRC 2000

It will also be important to collect a base line of public views on disability and the DRC in particular, against which progress can be measured. An omnibus survey is planned of some 2000 people, collecting their views on disability issues, integration of disabled people in society and awareness of the DDA and the DRC. It will be repeated at regular intervals, with a mixture of standard questions and topical add-ons. Using an existing omnibus survey by a market research company allows us to tap into an existing, very frequent survey and receive results after fieldwork all for a relative small outlay.

Consultation on DRC Strategy and Research

It is also proposed to carry out a wider consultation on the DRC's strategy and research to see whether there are other topics, in addition to the immediate operational priorities which others feel the Disability Rights Commission should explore. This will allow us to get a clearer understanding of what disabled people and others feel we should be concentrating on and to take this into account when agreeing our forth coming priorities. This would involve consultation with a wide range of disability organisations, as well as employers, service providers and others with an interest, to outline the shared agenda for DRC action and research in education, employment, access and health and social care. The project would also include a public workshop and discussion, findings of which will feed into its final report. Particular care will be taken to ensure that all strands of the disability movements in Britain will be given a voice and a say in this consultation, to arrive at a shared agenda for action.

Monitoring the impact of the DDA

This strand of work will consist of continued monitoring of DDA cases and the effect of this on the legislation and also of gauging the potential impact of extending DDA coverage in line with recommendations by the Disability Rights Taskforce (DRTF).

There are a range of relevant projects in DFEE and DETR such as **“Monitoring the DDA - Stage 2”** which will continue the long-term evaluation of the effectiveness of the DDA and will update and maintain the existing database of all cases brought. We will also liaise with DETR on some of their research into building regulations covering access and facilities for disabled people.

Statistical briefing will include regular up-dates from the Employment Tribunal Service on numbers of Part 2 cases brought and decided. This will allow us to monitor cases more closely than by relying solely on interim reports from the current DFEE project.

Impact on Small Business of lowering the DDA Part 2 Threshold

Research is required to explore the impact of lowering the DDA Part 2 exemption threshold on businesses with 15-19 employees. It will also examine the potential impact of lowering the threshold further by investigating smaller organisations’ current policies and practices regarding the employment of disabled people and what information, advice and support would be useful to them if the threshold were lowered further.

Costs and Benefits to Service Providers in making reasonable adjustments in response to Part 3 of the DDA

This research will aim to identify and measure the range of costs and benefits to service providers when making reasonable adjustments for people with disabilities, in line with Part 3 of the DDA. This study will use a case study design, involving in-depth interviews with representatives from relevant organisations. It will help to monitor and evaluate the impact of the new duties under Part 3.

Other studies, for instance, concerning equal opportunities for voluntary workers are also currently being considered.

Focus Studies on topics of particular relevance

In addition to the core areas of collecting base line information and continued monitoring of the DDA and its impact, there are specific topics which are of particular interest to the Commission, such as the effects of multiple disadvantage and how best to meet the needs of people with mental illness.

There are number of relevant studies commissioned by external organisations and Government departments, which include DFEE projects on disabled jobseekers and assessing the organisation and provision of sign language interpreters.

Research by other organisations includes a study of disability benefits, work and social inclusion, funded by the Joseph Rowntree Foundation, which uses information from a range of large-scale data sets to outline trends in the labour market, income distribution and the benefit system as they affect disabled people in Britain.

In addition, the LFS can be used to provide briefing on particular topics, such as education and qualifications of disabled people and numbers of disabled students. We will also aim to monitor findings of other disability research as they emerge and produce a regular directory or findings, with an assessment of their reliability.

DRC research will include a series of comment papers, with the aim of taking forward conceptual thinking and discourse, e.g. with regards to defining disability. These should be original, fresh and innovative pieces of work, rather than merely reiterating established views.

We will also be issuing a number of DRC discussion papers, commissioned from experts in a wide range of areas. The aim will be to introduce a fresh angle and provide added food for thought to public debate. Comment papers should be brief and to the point, to ensure that they reach a wide audience.

The Commission may also publish guidance about what would help disabled people lead more independent lives. A series of studies would also provide research to inform on DRC guidance which would cover for example efficient sign-posting and office layout as well as things to bear in mind when designing or up-dating accommodation.

All outputs from DRC research and evaluation will be published in a DRC series, to improve public awareness and to show value for money is obtained from Government funding. Summaries will be published free of charge and put on the DRC Website. Reports which will be likely to be of particular interest to media and outside observers will be highlighted by a press release.

The DRC disability briefings will be sent out to disability organisations and others with an interest free of charge (including fax and email); they will also be put on the Website. In the longer term, we will also look to publishing at regular intervals, a digest of research findings which augment ours and other organisations' research to give a fuller picture. I would hope that this would include the work of the Strathclyde Centre for Disability Research.

Research into quality assurance and evaluation of our effectiveness will be the real measure of our performance and future credibility over the next few years. We are already committed to at least 10% growth in public awareness of the DRC; at least 5% growth in the awareness of the DDA; increasing levels of support for action to combat discrimination against disabled people and at least 65% satisfaction with the DRC among key stakeholders and customers by 2002.

We will be looking for example to see how we can mainstream disability equality into parliamentary, central and local government policy, planning and decision making. We would wish to clarify Schedule 5 of the Scotland Act to see the extent to which equal opportunities for disabled people can be strengthened and promoted in Scotland. We will monitor for example the use of exclusion clauses against children with special educational needs who wish to gain access to mainstream schooling under the Standards in Scotland's Schools etc. Act 2000.

CONCLUSION

To summarise what I have said above, we will work in partnership with a whole range of Scottish based organisations, across all the stakeholder groups, supporting networks and building capacity.
We will create a clear identity for the work of the DRC in Scotland focusing on the uniqueness of our country's geography, people and cultures and operating within a new devolved Parliamentary system, sustaining campaigns on disability related issues and responding pro-actively when discrimination arises. We are a new force and we are here to stay to bring real change for the better in disabled people's lives.

REFERENCE

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Dr Tom Shakespeare
Policy, Ethics and Life Research Institute, University of Newcastle
28th November 2000

GENETICS: A SPIRALLING PROBLEM

INTRODUCTION

The year 2000 has been the year of genetics. Every Millenium broadcast and article at the beginning of the year highlighted genetics as the big story of the next century. The announcement of the first draft of the Human Genome Project in the summer was heralded as a giant leap for mankind by Clinton and Blair. Since then, we have had a wave of stories about designer babies, about wonder drugs, about cloning and stem cells and all manner of biotechnological marvels. We are undoubtedly entering the century of the gene.

Before I start asking some questions about what this means for disabled people, I want to point to a paradox. I believe that at the turn of the century, we are also at another important stage in human history. For the first time, being disabled need not be a problem, if our society has the resources and the political will to do something about it. We have medical care which ensures our survival, whether we are born prematurely, or break our backs, or develop degenerative diseases. We have the potential for a welfare state which can get disabled people into work, promote independent living and give us a quality of life equal to any non-disabled people. But at the same time that disability need not be a problem, genetic science, if you are to believe the hype, is promising to remove disability from the world. This is the ironic coincidence which keeps some of us awake at night. But I am not here to make a political speech. Our current genetic problem is that the debate is polarised between biomedical hyperbole on the one hand, and the hysteria of pro-life and extreme disability radicals on the other. Both approaches are unhelpful, in my view. My job is to try and disentangle the rhetoric and look at the evidence and to work out whether genetics is a spiralling problem, and if so, why. So, in the rest of this talk, I will ask three key questions. Is genetics the same as eugenics? Will genetics increase discrimination? Will genetics cure disabled people?

IS GENETICS EUGENICS?

The biggest current impact of genetics is in prenatal testing and screening, and it is this which has enraged and alarmed those people who believe that life begins at conception, and those people who believe that selective abortion is a conspiracy to eliminate disabled people from the world. Sometimes, people who have this intense political and emotional reaction use words like extermination plan, or Nazism, or eugenics. I think this is unfortunate. As soon as you call a geneticist a Nazi, you have lost the argument. I do not believe that genetics is the same as eugenics, and I will explain why.

The eugenic policies of the first half of the twentieth century were distinguished by two main elements. First, they were designed to improve the quality of the population. Second, they were implemented through coercion, as well as consent. Contemporary genetic policies operate at the level of individual women and families, and often respond to their own fears and demands. The ethos of contemporary medical care is patient autonomy, and no genetic programme in the western world relies on coercion.
Individual women and men are deciding to have prenatal screening and to terminate pregnancies affected by impairments such as Downs syndrome, and that is the reality with which people have to come to terms.

Let's look at bit more closely at this decision to terminate. I should point out at this point that there are 180,000 terminations in UK every year. Only about 1% of those are on the basis of foetal abnormality.
I support a woman's right to choose and I do not consider that conception is the key moment for personhood. I would call for a limit of 24 weeks for termination, unlike the present discriminatory situation where pregnancies can be terminated up to birth in the event of severe handicap.

When women and men make the difficult decision to terminate a wanted pregnancy, are they passing judgement on disabled people? Are they saying our lives are less valuable, or we are unworthy of life? I do not think so. There are four reasons I can think of to have a termination on grounds of disability. First is the eugenic reason about wanting to avoid disability, or regarding us as less valuable. Second is the eugenic reason of avoiding cost to society. Third is the desire to avoid the suffering associated with impairment. Fourth is the reason to avoid the stress and pressure on families affected by impairment. I do not think these two reasons are inhumane. I think we need to show that many disabled people can have a good quality of life, and that the real problems of disabled people are social arrangements, not their impairments, but I do not think we can blame women and men for wanting to avoid the birth of children with impairments who will suffer or die prematurely of their genetic or developmental conditions.

So I do not think we live in a society with eugenic policies, and I do not think that the reproductive decisions of women and men are eugenic. However, I do not think the problem ends there. If we are to support the idea of choice, we need the choice to be a proper choice, and I think there is plenty of evidence that it is not a proper choice. Let me cite three dimensions of this. First, women are not given full and balanced information about impairment and disability before making decisions about tests and terminations. Second, doctors and professionals sometimes influence the decisions which pregnant women make, explicitly or implicitly. There is an absence of proper counselling or non-directive support. Third, the conveyor belt of routine testing and antenatal care removes the possibility of informed consent, and drives people towards decisions which they may not have wanted to make. We need radically to improve our screening programmes if we want to achieve proper reproductive choice, and above all we need to support disabled children and adults to achieve inclusion, independent living and a good quality of life, because otherwise, the decision to terminate pregnancy will not be on the basis of impairment, but it will be on the basis of disability. We will be solving the problem of disability by removing individuals from the population, rather than by removing barriers from society.

WILL GENETICS INCREASE DISCRIMINATION?

Sometimes, disabled people say that genetics discriminates against us. I am not sure about this. I do not think that selective abortion discriminates against me, or against disabled people. I do not think the argument **'I would not have been born'** has any logical weight. I think it is perfectly possible to try and avoid impairment, while still respecting and supporting disabled people. For example, we try to minimise cerebral palsy, but this does not mean treating people with CP with less respect. We take polio vaccines, but this does not mean treating polio survivors with less respect. The disability movement has to get to grips with impairment prevention which, on a global scale, is a vital issue.

However, I do worry that genetics will cause problems. For example, there is evidence that women who choose not to use screening are blamed for having disabled children. Disabled people may be seen as a problem which should have been prevented in future. There is also a danger that disability will be again reduced to biological or genetic factors, and the role of society will be ignored. There is a dangerous process of geneticisation, whereby social problems are redefined as genetic problems, and the emphasis is shifted from society or structural factors to individual and biological factors. It is particularly dangerous when this happens with behaviours like homosexuality or aggression or depression or alcoholism, but it is also a danger for disabled people. We do not want to be be seen as an avoidable genetic error, we want our civil rights and acceptance in society. There is also a specific problem of genetic discrimination.

For example, there is the situation of insurance companies demanding access to results of genetic tests, and their claim that genetic information is no different to other medical information.

There is also a danger of employers discriminating against people on genomic grounds. While some people argue that genetic knowledge will increase occupational health, in fact, unless it is covered under anti-discrimination legislation, it will lead to more cases like that of Terri Seargent, an American fired from her work because of alpha 1 antitripsin deficiency, at least where medical insurance is part of the employment package, as in the US.

WILL GENETICS CURE DISABLED PEOPLE?

Genetics is often presented as the solution to the disability problem, or the cure for disabled people. Some disabled people radically reject this suggestion, because they argue that curing a problem by removing the individual is a drastic solution. Other disabled people live in hope of cures, and argue strongly for more genetic research. I think we have to respect the fact that disabled people, like society as a whole, are deeply polarised on this issue. But we can make some important observations.

First, all disabled people's lives are made harder by discrimination and prejudice, and we should all be campaigning to make society more inclusive and supportive of people with impairments, whether genetic or acquired. Second, not all impairments are the same. This is not to say that some disabled people are more valuable than others, but to make the obvious point that some impairments restrict life far more severely than others, and that in particular degenerative impairments are different from static ones. I respect the desire of people suffering from nasty genetic conditions for a cure. We need to distinguish between interventions which are normalising - which are about making disabled people less different - and those valuable interventions which are about alleviating suffering and degeneration.

But the third point is that a lot of the hype around cures is inaccurate. To date, there is only one gene therapy trial which seems to have been successful. The majority have failed, and some people have died as a result of this experimentation. For most conditions, there is no immediate prospect of a cure. There may be discoveries which make life a bit easier for people, but researchers who promise fantastic solutions around the corner are manipulating patients and public opinion. The major immediate application of genetic research is diagnosis and screening, not therapy and cures.

Finally, there are two important provisos about genetic research and cures. Faced by terrible diseases or personal suffering, there is a natural tendency to think anything is better than this, and that the end of cure must justify any means. However, I think there are important ethical and financial constraints. I think there are certain key ethical principles which should not be infringed, whatever the potential benefits. I am deeply concerned about embryo experimentation, about cloning, about germline gene therapy, and about other techniques which may promise benefits, but at the cost of our ethical principles. Hard cases make bad law and worse morality.

Many people dislike the metaphor of the slippery slope, because it implies that we cannot halt scientific developments: I prefer the idea of the camel's nose, which shows how difficult it is to prevent the extension of genetic and reproductive technologies, and the way that establishing a precedent may pave the way for unforeseen applications and consequential problems. The second provisio is of course the financial priorities of the health service and of society. With so many people in poverty and suffering, both nationally and particularly globally, there are difficult questions about how we can invest to improve the lives of the many, not of the few. Much of the genetics debate is about profit, not about principles. We should be very careful about how we intervene: prevention and social change may be a better route than individual or medical solutions.

WHAT IS THE PROBLEM WITH GENETICS?

So let me conclude. The problem of genetics is not just about the technologies themselves, but about the discriminatory social context in which they are applied. I do not think disabled people should oppose prenatal testing, but we should oppose the way it is introduced, and the social values it reflects. We should uphold the value and contribution made by disabled people, and show what we can achieve, in a society which is committed to our rights. Opinions on genetics are very polarised. Disabled people, like everyone else, will have different views. For every radical opponent, there is a strong supporter. We need to educate ourselves about the science and the practice of genetics, and not believe the hype on either side of the debate. We should be very cautious of being used as alibis or scapegoats or otherwise manipulated by vested interests, whether that is the pharmaceutical companies or the medical profession, or the anti-abortion movement or anyone else.

In particular, there are crucial ethical issues which affect everyone, disabled and non-disabled alike. When it comes to genetics, we are all impaired, we all have four recessive genetic conditions and many more genetic predispositions. One in four of us will get cancer, many of us will develop degenerative conditions. These facts show that what some people call the **‘genetic cleansing philosophy’** is fundamentally unworkable. Disabled people will make a crucial contribution to our society, if we can show the need for caution and careful deliberation before accepting any particular genetic technology as a straightforward solution to a perceived difficulty. The role of the sociologist is to provide empirical evidence of the impact of genetics and disability on the lives of ordinary people, and to show that we need to understand these problems at all levels, rather than resorting to unreflexive rhetoric, or ivory tower philosophising. Genetics is too important to be left to the professionals. We all need to have our voices heard. But we have a responsibility to become informed.