

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

PUBLIC LECTURE

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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 found 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, 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 to 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.
They 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 as 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 Mary's 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
To 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 of the labour market and not in education or transport by 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 upto 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, so far 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, its 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 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 Huntington'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 too miss the serious point that when we tamper with such things, it effects 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 peoples 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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