

# **Fighting for a slice, or for a bigger cake?**

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In 1996 I had the privilege of writing a book with Professor Michael Oliver called Disability Politics. In researching this book we discovered that it was too simplistic to suggest our liberation was 'learnt' or adopted from other civil rights movements.

The political movements on race or gender liberation certainly influenced the disability movement, but our journey was different as well as equal!

We discovered that our movement's emergence took a unique turn (as it developed slowly) through an organisational process where disabled people came together and formed their own pressure groups, or 'took over' those controlled by non-disabled 'paternalists'. Simply by breaking away from those who spoke on our behalf, and finding a space where we could beg the question: Why are we excluded from society? And how can we break in? we found the key that unlocked some of the fundamental principles of the Social Model of Disability that became the unique hallmark of our struggle.

At that stage we didn't even own a slice of society's cake; we just observed others eating it on our behalf. Like most movements it took an action to make the change. With racial activism it took a black woman to sit on the whites-only section of a bus. For disability it was a letter in the Guardian:

Wednesday September 20th 1972

*Sir, Severely physically handicapped people find themselves isolated in unsuitable institutions where their views are ignored and they are subject to authoritarian and often cruel regimes. I am proposing the formation of a consumer group to put forward nationally the views of actual and potential residents of the successors to the Workhouse.*

Yours faithfully, Paul Hunt."

"Nothing about us, without us", the slogan which described our politics of disability identity, can be traced back to this formative letter.

As a result of Paul Hunt's invitation, the Union of the Physically Impaired Against Segregation (UPIAS) was established and the social model of disability was developed by its disabled members. The social model is now regarded as 'the big idea' of the British disability movement (Hasler, 1993). The work of Vic Finkelstein (1980, 1981), Colin Barnes (1991) and particularly Mike Oliver (1990,

1996) gave the disability movement academic credibility, and Disability Studies became established as a discipline in its own right.

The social model played a crucial role in enhancing the collective consciousness of disabled people, and the emergence of the Disability Movement (Campbell and Oliver 1996). It gave disabled people a framework to distinguish between organisations, policies, laws and ideas which were emancipatory, and those which were oppressive or inadequate.

Most importantly, the social model enabled the identification of a political strategy, namely **barrier removal**. If people with impairments were disabled by society, then the priority was to dismantle these disabling barriers in order to promote the inclusion of people with impairments. Rather than pursuing a strategy of medical cure or rehabilitation, it was better to pursue a strategy of social transformation.

The social model had a significant impact on the identity of disabled people themselves. Replacing a traditional, 'medical model' view of disability (in which the problems arose from deficits in the body), with a 'social model' view (in which the problems arose from social oppression), was wholly liberating. As happened with feminist consciousness-raising in the late 60s, or lesbians and gays 'coming out' collectively in the 70s, disabled people began to demand a new identity. We challenged society's misrecognition of our identity, casting off labels of flawed, incomplete, tragic, brave, vulnerable and

victim, and demanding the creation of a society in which all disabled people could participate fully as **equal citizens**.

But a political consciousness does not in itself constitute a social movement nor does it necessarily bring lasting change. The latter requires an understanding of the lived experience and aspirations of disabled people, the creation of practical solutions and activities to deal with them, and the political skills to influence those in power to turn ideas into reality.

In Britain the Disability Discrimination Act 1995 was a major, albeit seriously flawed, early success in challenging this misrecognition, and securing legislation aimed at barrier removal.

The following decade saw a succession of legislative developments, including the Direct Payments Act of 1996; the creation of the Disability Rights Commission in 2000; extension of the Disability Discrimination Act to cover education from 2002; implementation of the Act's provisions in relation to physical access in 2004; the Disability Discrimination Act of 2005 which included new duties on the public sector to actively promote equality for disabled people; and finally, the Mental Capacity Act of 2006 which went some way to extending personal autonomy for people with learning disabilities or mental health conditions.

The Prime Minister's Strategy Unit report on the Life Chances of Disabled People in 2005 promised full equality for disabled people by

2025, placing the promotion of independent living - another innovation of the disability movement - at its heart. This was followed in March of this year by a 5-year strategy on independent living.

This same period also saw a growing awareness of the diversity of disabled people, reflected in the now very broad definition of disability in the Disability Discrimination Act. The act embraces not just those areas historically associated with disability, but now also includes long term health conditions such as cancer and HIV.

What had been separate, sidelined movements of people with learning disabilities, people with mental health conditions, and more recently those with neurological conditions, are now joined in the mainstream disability movement, where all demand better recognition.

But of course disabled people face more than oppression and disadvantage linked to their different impairments and health conditions. Many have to struggle against **other forms of oppression** including ageism, racism, sexism, and heterosexism.

Nasa Begum expresses the dilemma that people face who experience – as she calls it - *'simultaneous oppression' within the movement:*

[Nasa writes:]

*Many of us will identify with different bits of our identity at different times. It all has to be addressed when it presents itself. Sometimes*

*the appalling treatment I have experienced in hospital has come from being disabled; but some is around being black and there's this sexism crap they come out with because I'm a woman.*

As Nasa illustrates, many face compound disadvantages arising from the intersection of personal characteristics and circumstances. Other examples include disability and social class; or being one of the 260,000 disabled lone parents who are out of work; or being an older disabled person facing ageism; or a disabled person who is also a member of an increasingly stigmatised group - those on incapacity benefit.

The case of Sharon Coleman who, as the mother of a disabled child, is seeking to bring a case against her employer of “discrimination by association with a disabled person”, provides just one example of the way disability discrimination, as a phenomenon, affects not just the individual but also those with whom they share their lives.

The fact that one in three children living in poverty in Britain today has a disabled parent provides another example.

The development of the social model and its journey into the fabric of our communities through social, political and economic infrastructures, gave the disability movement the authority to say that we have emerged as a fully fledged civil rights movement. But only through our alertness to the diversity of the characteristics and experiences of disabled people, and to the causes of the barriers

which prevent equality, can we avoid three very real risks which will prevent us from moving forward:

- First, is an overly narrow representation of disabled people – **by other disabled people** – which denies the complexity of people's lives, the multiplicity of their identifications, and the cross-pulls of their various affiliations. The rich diversity of disabled people has too often been reduced to the wheelchair symbol.
- Second is the related difficulty that we could then have, in truly recognising, understanding and responding to the multilayered barriers and causes of entrenched inequality that people face. Can a person on a welfare-to-work scheme be both disabled *and* old? Or disabled *and* from a minority ethnic community? Or are they forced to choose between these administrative categories, thereby denying critically important aspects of their identity which are influencing their employment prospects?
- The third risk we face is the potential divisiveness that pure identity politics often manifests. So instead of coming together with others to collectively overcome the shared social and economic causes of inequality, such as poverty and under investment in public services, we end up fighting about whose needs are greater.

I am going to spend the rest of this lecture exploring why we need to (and how we can) avoid these risks. I will focus on a major challenge

that faces us – reform and investment in social care – as the vehicle to illustrate why we need to address discrimination holistically.

The accumulation of disability rights over the last decade or so has played out against a backdrop of public services which have failed to keep pace with demographic change. Public services which are essential to many older and disabled people's full participation in society have simply failed to materialise.

Whilst demand for social care has increased, social services have been cut back so drastically that many people would have fared better in the 1970's than they do today, in seeking even the most basic support. Over 70 per cent of local authorities provide services only to those whose needs are considered 'critical or substantial'. The rest are left, with their families, to go it alone. Whilst our politicians have adopted the language of the Independent Living Movement, users receiving services are lucky to get anything extending beyond being washed and fed.

The inadequacy of our current social care system therefore presents such a barrier to independent living, that without large scale reform and investment, we will never achieve this goal. Without significant re-evaluation, Government will not be able to deliver, as it has promised, "equality for disabled people by 2025".

Moreover, without transformative public services which enable disabled people more choice and control, we will never fully



overcome our social inequality. We will continue to be viewed as vulnerable people in need of care, instead of active valued citizens in charge of our own lives.

I do not believe it is the politics of identity and recognition which will win the redistribution required to secure the services we seek.

This kind of redistribution requires a different sort of politics, a **politics of participation and consensus**.

The challenges we face at the beginning of the 21st century demand that our slogan 'nothing about us without us' speaks to, and of, our diversity. We should constantly be asking and adjusting to who '**us**' is. It must now speak less of our separateness and difference, and more of our interdependence and connection with others. Critically it must be about seeking to **share** control and responsibility, not simply **taking** control.

Redressing injustice still requires a politics of recognition, but this should no longer be reduced to a question of group identity or allegiance: rather, it requires a politics aimed at overcoming the barriers which prevent all *individuals, families and communities* participating as full members of society; it requires a politics aimed at overcoming the misrecognition people *individually* face.

Disabled people who are or have been associated with disability politics and have been active in the movement – and I include myself amongst them – must accept that what is ultimately important to the individual is their own and their loved ones' life chances; not those of the group one is considered to belong to. It is little comfort to an unemployed Bangladeshi woman with mental health problems - among the most disadvantaged of all people in Britain - to know that disabled people's employment rate has improved by 8 percentage points over the last decade. This is especially so when it is clear that neither the disability movement nor the social policy programmes aimed at improving disabled people's employment opportunity, have gone anywhere near recognising and responding to the complex barriers she is likely to face. Why should she feel part of a movement in which she is invisible?

The politics of participation aims to ensure that the **genuine nature and causes** of discrimination and disadvantage that people face, are more likely to surface. It also seeks to engage those who might otherwise be or feel overlooked. It also aims to engage those who may see themselves as separate and uninvolved.

In his book *The Politics of Hope* (2000) the Chief Rabbi Jonathon Sacks argues:

*'The universality of moral concern is not something we learn by being universal but by being particular. Because we know what it is to be a parent, loving our children, not children in general, we understand*

*what it is for someone else, somewhere else, to be a parent, loving his or her children, not ours. There is no road to human solidarity that does not begin with moral particularity - by coming to know what it means to be a child, a parent, a neighbour, a friend. We learn to love humanity by loving specific human beings. There is no short cut.'*

If we bring our attention back to social care, it is clear that our social care system presents a major barrier to disabled people's participation. And it is a barrier that is not just felt by individuals with impairments or health conditions identifying themselves as 'disabled'.

Older people now and in the future will probably never identify with the disability movement but they are equally impoverished, isolated and misrecognised as a consequence of our social care system's failure to support them to participate as full citizens. And what about the families with whom they share their lives, including those providing unpaid support - many of whom are misrecognised as carers? The social care system is a barrier to their participation too.

**All these groups face the same barrier to participation - namely an inadequate social care system.** But are they working together to overcome it? Sadly the answer is no.

In Britain today we have three almost entirely separate debates going on with regard to social care: the first is about how we fund long term care for older people; the second is about how we support carers; and the third is about promoting independent living for disabled

people. Even within each of these debates there are fiercely competing groups, each seeking recognition.

And whilst each fights for a slice of the cake, we are failing together to fight for the bigger and different-flavoured cake all of us need.

These three debates should be one debate, one question. Namely: How do we deliver a support system where people's human rights are enshrined and everyone's life chances are equally valued and supported?

This dares us to meet head on the greatest and perhaps hardest challenge we face - engaging, listening to, debating and finding common cause with others. Others who, though not a part of the common struggle for disability rights (and even those who may have opposed them at one time), nevertheless might share an interest in working together to overcome shared barriers.

Working alongside some groups will be challenging and at times even counterintuitive. Let me explain. Let's take those described (or perhaps misrecognized) as carers. It is not uncommon to hear of disabled people who have long struggled to be free of over paternalistic family carers. Indeed, the disabled people's independent living movement was partly borne out of that dynamic. So why on earth would I be suggesting we now join with those who have in the past appeared not to share our dreams of independence, choice and control?

My reason is twofold

First because I believe many carers now wish to challenge the assumption that they are an endless supply of unpaid support. Just as many disabled people complain of paternalism, many carers feel overwhelmed by the demands placed on them by those they support. Surely overcoming the paternalism disabled people experience, and releasing carers from the demands which overwhelm them, go hand in hand?

Moreover, many carers wish to re-establish or assume an ordinary family relationship with the person they support - to be a parent, a husband or wife, a child. In essence *they too* are striving for independent living. Existing policy denies them this right just as it does the disabled people they support.

Secondly, I believe our position as disabled people is fundamentally different to what it was 20, 10, or even 5 years ago. I believe we have a powerful voice and are now in a strong position to sit down with carers to help us all understand our common goals.

Reciprocal relationships of support could flourish if public service provision was genuinely geared to offering all people in such situations the practical means to optimise their life chances.

If, in our lifetimes, we are to see social care become a national priority; to witness a major uplift in investment; and to see its reform transfer control into the hands of disabled and older people and their families; then we have to be brave enough to form these partnerships and have these discussions

To achieve **independent living**, we need to engage in the **practice of interdependent living**.

We have to learn how to appeal to other people's experiences, dreams and expectations. We have to relate to the particularity of their lives, not simply demand they engage with ours.

And let's not stop at those with an immediate and obvious current interest in social care. These interdependencies extend far and wide. Social care policy and practice influences (and will have ever greater influence on) the strength and quality of **family life** in Britain. For example, when my independent living support is dramatically reduced, say when a PA falls sick and my husband fills in, I require the services of Relate within about two weeks! Were this the status quo, as it is in so many families, I very much doubt my husband and I would stay the course. And yet I consider our love for each other as strong as most who want to stay together the rest of their lives and support each other.

Leaving people to fend for themselves forces people into relationships of support which subvert ordinary family life, and

increase the risk of abuse or family breakdown. Do we seriously believe it is right to leave a frail older person to cope alone in supporting their partner with advancing dementia? That is not about promoting care; it is the absence of care. Not the caring society, but the go-it-alone society.

Carers UK estimate that the numbers of unpaid family members providing support to relatives will increase from 6 million to 9 million people over the coming two decades as our society ages.

Can our economy sustain so many people being outside the workforce to support their ageing relatives in the absence of publicly funded services? Can people afford to leave work to provide support and still pay their mortgages, their children's university fees, all the while providing for their own pensions and their own future care needs? Can we afford to pay for the ill-health that so many carers experience?

And what of the impact on women's equality? Jenny Watson, the last Chair of the Equal Opportunities Commission, named independent living for disabled people as one of her four top priorities for Government in addressing gender equality.

So you can see that the barrier disabled people face is shared by countless nondisabled people, directly or indirectly. And I hope you can also see that through participating in wider coalitions of interest, we may finally begin to realise the ambition laid out by our forebears during the International Year of Disabled Persons in 1981 who said:

*'As we gain equal rights, so we have equal responsibilities. It is our duty to take part in the building of society'*

By the time Government merged all the gender, race and disability equality commissions together into the **Equality and Human Rights Commission** last year, many disabled people like me felt ready to join forces with other groups, other movements; ready to move on to the next phase of our liberation as multifaceted human beings contributing to the broad enterprise of equality and human rights for all.

At the same time, as Chair of the Commission's Disability Committee, I feel a tremendous responsibility not to lose all that we have gained as disabled people. Some of my disabled colleagues and friends warn that the strength of the social model, the articulation of reasonable adjustments and the well articulated demand that a disabled person's life is of equal value, will be lost or watered down in the mix.

**An alternative view** is that the ideas of the disability movement - barrier removal; reforming public services to give people greater control over their own lives; and equality legislation based on accommodating difference rather than ignoring it – that these are the blueprint for the next stages of promoting equality and human rights overall.



Rather than claiming these ideas for ourselves, the opportunity ahead is, I believe, to offer them to the wider world, as solutions to a range of social and economic inequalities. Indeed, such ideas have already had a profound impact on progressive and liberal thought in Britain, in particular demonstrating how to transform the state from an instrument of paternalism to an agency of empowerment that gives people greater choice and control over their lives. The disability movement has increasingly engaged in - and is indeed winning - the battle of ideas in this country. Not every injustice has been conquered - quite the contrary - but the tide is turning in our favour.

I'd like to draw to a close with another quote from Jonathon Sacks. He wrote for Holocaust Memorial Day 2007, on the theme of the dignity of difference, that:

*'Difference keeps us apart for many legitimate reasons, but precisely because of that, we have to make a conscious effort to know each other better – and no longer put it off for another time [just] because it takes time and real effort.... Making changes to the way we live together may be inconvenient and time-consuming [but] exclusion does not respect time, it exploits it.'*

[end of quote]

The ultimate objective of equality and human rights movements is not about dividing up finite resources among competing interest groups, but deciding priorities through debate and democratic argument. It is

about genuinely involving people in the decisions that affect their lives.

Sitting side by side with the other equality strands, the ideas and approach of the disability movement, far from getting lost and devalued, are one step closer to being found.

Thank you.