Nothing without us or nothing about us?

Neil Crowther

_____

'*as disabled people have equal rights, they also have equal obligations. It is their duty to take part in the building of society*'

Introduction

In 2007, 'disability rights' is at a crossroads.

Despite major developments over the last decade, far too many disabled people remain amongst the most disadvantaged in British society. Whilst a comprehensive disability rights framework has been established, it is unlikely on its own to fully transform many disabled people's life chances. Without urgent action, disabled people will be poorly placed to weather the projected social and economic upheavals of the coming decades, solidifying existing patterns of inequality whilst creating new challenges.

The legal and institutional infrastructure which has led to this point is undergoing radical change.

In October 2007, the Disability Rights Commission (DRC) will close for business, replaced by the Commission for Equality and Human Rights (CEHR) with responsibility for promoting equality, human rights and good relations in respect of race, religion and belief, gender, sexuality, age and disability. The new Commission is expected to be augmented by a single equality Act, replacing all existing equality statute including the Disability Discrimination Act.[1]

The Westminster Government has launched an 'Office for Disability Issues' (ODI) set up to secure delivery of the cross-Government strategy set out in the Prime Ministers Strategy Unit report 'Improving the Life Chances of Disabled People'. The ODI has promised innovative new models of involvement of disabled people in policy-making, including through the independent advisory body 'Equality 2025', made up largely of disability activists.[2]

Many organisations led by disabled people, central to delivering first the social model of disability and then the cultural, public policy and legislative changes which have flowed from this revolution in thinking are struggling financially to stay afloat, despite Government's commitment to establish a 'user-led' organisation in every locality by 2010.

The grand coalition forged around the campaign for civil rights and anti-discrimination legislation between organizations led by disabled people and the more traditional charities providing services for disabled people largely fell away after the first Disability Discrimination Act in 1995.

On 30th March 2007 the UK Government signed the UN Convention on the Rights of Disabled People. Hailed as a radical step forward by many British activists, in practice the Convention is unlikely to expand disability rights domestically - indeed it was the British Government's position to accept only provisions which did not exceed existing European law.[3]

With a clear case of 'lots done, lots more to do' how can the disability movement adapt to best meet remaining and future challenges? How might the disability movement build on its achievements over the coming decade? What form might the movement take? What are the challenges and where do the opportunities lie?

Where did it all go right?

In answering these questions it is sensible to begin by thinking about the history of disabled people's struggle for equality.

The history of the movement can be divided into distinct (albeit overlapping) phases – a *revolution* in thought and consciousness, the struggle for *recognition and representation* and the lobby for *human and civil rights.*

In the beginning came a revolution in thought and consciousness as disabled people, inspired by driven by an intrinsic sense of injustice and inspired by other civil rights movements began to identify and

challenge the constraints society placed upon their lives. As with feminism, this did not all begin in the 1960's and the beginnings of such approaches to disability can be found far earlier, but it was in the late 1960's and 1970's that a coherent analysis began to take shape.

From this revolution came the struggle for *recognition and representation* of disabled people as a group who were oppressed by society, not confined by their impairments or health conditions, which came to be known as the social model of disability. Through these shifts in recognition and representation came the campaign for human and civil rights, culminating with the Disability Discrimination Act (DDA) in 1995, which followed international developments including the Americans with Disabilities Act and Australian Disability Discrimination Act.

Whilst the DDA was for many a disappointment due to significant gaps in coverage, weak protection and inadequate enforcement provisions, nobody could sensibly dispute the remarkable success of the movement in the 10 years between 1995 and 2005. This period was book-ended by two Disability Discrimination Acts, and punctuated by the Disability Rights Task Force, Disability Rights Commission, the Direct Payments Act and the Special Educational Needs and Disability Act among other developments in relation to building regulations and planning laws. Each stage has seen significant steps forward in the extent and strength of the legislation, moving from a 'negative compliance' approach to one emphasising the taking of positive steps to promote equality. The conceptual approach to equality underpinning developments in disability rights, which unlike other equality statute requires that people are treated differently in accordance with their needs, rather than being treated in exactly the same way, is now leading debates about the wider approach to equality legislation in the run up to a single equality Act.[4]

Unfinished business

Despite these achievements, research, discussion and debate underpinning the DRC's Disability Agenda demonstrated that whilst this decade of progress has undoubtedly created more opportunities for many disabled people to participate and fulfil their potential, disability continues to remain for too many a passport to deep and

persistent social and economic exclusion.[5]

This is largely because at the same time as these rights and opportunities have arrived, the infrastructure of public services and entitlements which many disabled people and their families require to make full use of them has become threadbare at best, and is often poorly organised and inefficient. A lack of reform and investment has meant that what is available is not calibrated towards the same goals of equality and participation. As DRC's Chairman Sir Bert Massie commented during his speech to launch the Disability Agenda 'Many disabled people have been invited to look up to the stars…only to find the ground opening up beneath them.'[6]

Such disadvantage acts to confirm (and is confirmed by) the very low expectations held by many disabled people of their own life opportunities, and by society at large of what disabled people are capable of being and doing in their lives.[7]

Whilst more disabled people work and overall disabled people may be better off than a decade ago, more disabled people of working age now live in relative poverty, meaning they have not benefited equally from the widening prosperity that characterized the period.[8] For example, of all children living in relative poverty, 1 in 3 has a disabled parent.[9]

The employment rate of disabled people has risen from around 43% in 1997 to 51% in 2005, compared with 80% of the working age population overall.[10] But progress has been incredibly uneven. For people with mental health problems the employment rate is 20%. For people with a significant learning disability it is 25% - though other sources report it to as low as 17%[11]. When in work disabled people are disproportionately in low paid, low status jobs and earn on average 10% less than their colleagues. [12] Of all disabled parents living in poverty, one quarter (100,000) already have jobs[13].

Whilst independent living is now endorsed as Government policy and the ideas of the disability movement are shaping reform, access to social care has become severely restricted with most English local authorities providing services only to those with the very highest levels of assessed need.[14] As a consequence, debate about the

future of 'care' increasingly focuses on support for unpaid carers, without any guarantees that this will deliver human rights and citizenship for disabled people.

The Government has increased the amount it spends on supporting children with special educational needs and extended the Disability Discrimination Act to cover the education system, yet 27% of disabled 19 year olds are outside of any form of employment, education or training – three times the rate of non disabled 19 year olds.[15] At a time when the number of jobs requiring low or no qualifications is diminishing rapidly, of all people without formal qualifications in Britain, over one third are disabled.[16] The one group not to have seen employment rates increase in recent years is those without recognized skills.[17]

Despite some major breakthroughs such as the campaigner Baroness Campbell of Surbiton entering the House of Lords and the widespread voluntary activism and support of disabled people, disabled people are underrepresented in public and community life. Only 5% of public appointees are (self-declared) disabled people, and where disabled people are in public appointments a disproportionate number relate to disability issues specifically.[18] Only 6% of formal volunteers are disabled.[19]

Perhaps initiatives such as Valuing People and the 'No Secrets' scheme are the reason a succession of inspectorate reports have identified what many had long suspected – that disabled people are being attacked and abused in institutions claiming to provide 'care', and the perpetrators have been able to carry on in such a fashion without fear of being caught and prosecuted.[20] The criminal justice system appears not to extend its reach past the front door of such institutions.

Even some of the most important legislative gains are proving difficult to translate into practical change on the ground. For example, it is not without irony that many disabled people have been unable to make claims under Part 3 of the DDA in relation to accessing goods and services because the County Court system is itself so impenetrable. Rights have no value if they cannot be exercised.

It is difficult to conclude that disabled people's human rights are secure when, during the DRC's formal investigation into health inequalities we were advised of a case where the first words to a grieving mother by a GP attending to the death of her daughter, who happens to have Downs syndrome, from meningitis, were 'Well it's probably for the best, isn't it?'[21]

Completing the job

It is abundantly clear then that there remains much still to achieve and that this requires a strong and effective movement behind it. In the next phase *reform and redistribution* will be the twin goals to ensure disabled people have access to the high quality public services needed to deliver equality of opportunity for themselves and their families.

The DRC's Disability Agenda, supported by the Disability Equality Duty, aims to provide a blueprint for action and a case for investment, reform and culture change in our public policy and services - support for families, investment and reform of social care, tackling health inequality, widening access to education and training, increasing employment opportunity, ensuring equal access to personal security and criminal justice, improving housing choices and conditions, ensuring CEHR optimizes the opportunity presented by its human rights remit and securing progressive equality statute through a single equality Act. It is about complementing the more 'open road' being engineered by anti-discrimination law by securing a more equal start. It aims to take the struggle out of simply seeking an ordinary life. Its objective is to put more power and control into the hands of disabled people and their families, ensuring disabled people reap equal benefits from high quality public services and enabling people to make a positive contribution. Importantly it is about challenging the low expectations which continue to underpin so much of the disadvantage disabled people face.

The Disability Agenda is founded upon the independent living principles of self-determination, participation and contribution, and it applies these to the real world challenges of today and the coming years. It is designed to help take us to what might be the next frontier in disabled people's struggle: *realization* of DRC's vision of 'a society

in which all disabled people can participate fully as equal citizens'.

Nothing about us without us

The clarion call of the disability movement has long been 'nothing about us without us'.

This principle of self-determination has underpinned every phase in the history of the struggle for equality and human rights. It was the driving force for the direct action of the residents of Le Court residential home in the early 1970's who broke the early evening bedtime curfew to go to the pub in their pyjamas and discuss disability politics, just as in 2005 it was the driving force behind lobbying to secure in the Equalities Act provision in the new Commission for Equality and Human Rights for a statutory Disability Committee.

It has helped begin to re-shape disabled peoples' relationship with public services from 'passive recipients' to 'co-producers' - for example through direct payments and individual budgets and the emphasis on involving disabled people in the new Disability Equality Duty.   It is the foundation stone of independent living - now Government policy.

The principle of 'self-determination' is what made a disabled people's movement make sense, providing through solidarity a powerful voice to gain first recognition, then rights. It is what had led Government to set up the 'Equality 2025' advisory group.

But as the movement moves into the next phase, and seeks the reform and redistribution necessary to realize its vision, difficult questions need to be asked about exactly how self-determination shapes strategy and action.

Towards a 'mutuality model'?

In moving to the next phase, a long forgotten and (by some) unfairly dismissed publication by the thinktank Demos, commissioned by DRC's predecessor the National Disability Council called 'An inclusive future? Disability, social change and opportunities for

greater inclusion by 2010' is worth returning to.[22]

The report recommended that for the disability movement to continue to have relevance and success, it should seek to be future facing, should broaden its horizons to think not just about 'disability questions' but to contribute to national debates and developments, and should forge strategic alliances, becoming expert advisers and partners to a range of other sectors.

There are strong examples of such alliances forming and yielding successes. For example, a broad alliance under the banner 'Housing for All', and in particular an alliance between disability and age organizations, won an early concession from the (then new) Labour Government when it extended Part M of the Building Regulations to cover new-build housing in 1998.

It is highly unlikely that the disability movement can secure the reform and redistribution (and joined up Government) it now requires to realise its aims by going it alone, or with arguments constructed solely around individual or 'group' rights. A new approach based on the 'mutuality model' Demos proposed is likely to be of major benefit. This requires the movement to increasingly think about the case for the investment and reform it seeks not simply from the perspective of its own needs and requirements, but through identifying others who either may share such an interest or who might be persuaded of the benefits to them through 'enlightened self-interest'. Out of this re-appraisal should come more powerful arguments and broader coalitions of interest.

It is around such an approach that the DRC's Disability Agenda has been built, and through this approach that it will hopefully be implemented.

Who are 'disabled people'?

In moving towards such an approach it is perhaps useful to start by asking whether the modern disability movement is itself sufficiently inclusive of 'disabled people'.

Disabled people are a heterogeneous group, and the specific issues

which shape their life opportunities are just as diverse.

One effect of the DDA has been to transform our idea of who disabled people are. 20 years ago we would not have counted in people with HIV, diabetes or heart problems. People with a learning disability were at the periphery of the disabled people's movement.[23] People with mental health problems were not included at all.[24]

Now anyone who fits the description of being 'a person with an impairment or health condition with a substantial and long term adverse effect on their ability to perform normal day to day activities' has rights under the DDA, and is by its definition a 'disabled person' with protection from discrimination should they require it.[25] The Government estimates that there are 'around 10 million' such people in Britain.[26]

Since the early stages of the disability movement Britain has become far more ethnically and culturally diverse, with disability and ethnicity increasingly significantly the risk of disadvantage for some groups. For example, children in Bangladeshi families where there is a disabled parent face an 83% risk of growing up in poverty compared to 36% in white families with a disabled parent.[27]

The most significant increases in the numbers of disabled people will come from the ageing population. The vast majority of disabled people are over the age of 60 and most developed an impairment or health condition late in life, including conditions such as dementia. We are also seeing a rapid increase in the numbers of children with impairments and health conditions, including 'neuro-diverse' conditions such as autism and children who through scientific advances are surviving into late childhood and early adulthood with complex and severe impairments when not so long ago they would have died.[28]

Across almost every indicator of progress it is people with a mental health problem or a learning disability who are being left behind, followed closely by people with a visual impairment. Whether we are talking about income and work, educational opportunity, health or personal security, people with these impairments and conditions are among the most disadvantaged in our society.[29]

Other characteristics or circumstances have a major bearing on the life chances of people with impairments or health conditions. There are over a quarter of a million lone parents who are disabled and living in poverty. Where disabled people live in Britain has a bearing on opportunities and levels of disadvantage. Past educational achievement, employment and social class all have a major bearing on disabled people's social and economic position.

The DRC has advocated changes to the definition of disability under the DDA, moving away from an approach which entitles people to protection on the basis of the degree of impact of their impairment or health condition, yet avoiding the risks of a very broad definition diluting action by encouraging public authorities to focus on promoting equality for people with impairments or health conditions who are experiencing substantial exclusion.

When the disabled people's movements holds up a mirror to itself can it say with confidence that in its representation, culture, practices, language and priorities it has modernised to encapsulate the diverse experiences of those experiencing substantial exclusion? Does it speak to and of minority ethnic communities? Does it speak to and of people with HIV/AIDS, or mental illness? Does it speak to and of working class disabled people? Does it speak to and of the young or the very old?

Do they belong to the movement?

If not, is it not a far weaker movement than it has the potential to be? And how can its leaders say with confidence and in all honesty 'nothing about us, without us' when the 'us' is not representative of the whole?

Whatever people say I am that's what I'm not

A particular challenge for the movement remains the fact that the majority of people with rights under the DDA do not consider themselves to be disabled, and nor do the people who encounter them in their everyday lives.

According to research by the Department of Work and Pensions (DWP), around 52% of people covered by the DDA do not employ the solidarity-driven clarion call 'nothing about us without us'[30] instead preferring a motto resurrected by the rock band the Arctic Monkeys: 'whatever people say I am, that's what I'm not'[31]. They reject being identified as disabled. A number of pieces of research have demonstrated that this is more prevalent among younger people, suggesting that the numbers proactively identifying as disabled may be shrinking.[32]

Some in the disability movement have in the past argued this is tantamount to self-expulsion - that by choice such people have put themselves beyond rights to support and assistance. Even if the DRC shared that view privately - and it does not – its statutory duties to promote equality demand that it find ways to reach out to all citizens with rights under the DDA. That is why the DRC followed up the research by the DWP which identified this group to find out just how, if people did not see themselves as disabled or actively rejected such an identity, did such people self-identify?

Like much of the general public, many of the 52% think disabled people are wheelchair users. Few identified with disabled people as a group to which they belonged preferring instead to identify with others who shared their impairment or condition if they felt the need to at all. Few liked the word 'rights' preferring instead words like 'fairness'. And none liked the word 'Commission'. Overall the research created a communications headache for the DRC![33]

If over half of those covered by disability rights legislation do not associate themselves with it, then what is the answer? Some in the movement argue that these people just need to take the step of self-identifying as disabled as their predecessors did in order to liberate themselves. They argue that this is where it is all going wrong, and efforts should be made to encourage such self-identification.

This is a high-risk strategy for the future of the movement. For many the process of re-claiming and re-articulating their identity as a person disabled not by their impairment or condition but by society has been truly liberating, and of course these personal revolutions have provided the energy for the movement at large. But evidence

does not support the argument that without this step people fail to recognise injustice when they encounter it, nor can an identity be said to be emancipatory when it is imposed against an individuals will or made a condition of participation. The very real risk is people turning away from the movement precisely because it has created a closed shop. As Jane Campbell cautioned in 1997:

'A political consciousness does not itself constitute a social movement and an awareness of the culture and dreams of its constituency and creating activities as a result are what the British Council of Disabled People constantly needs to engage in'[34]

It is also a high risk strategy for achieving its goal of improving the life chances of disabled people. If a lone parent with mental health problems out of work and living with their child in poverty does not access disability benefits or the New Deal for disabled people because they do not self-identify as a disabled person, do we genuinely think the answer for Government and others is to encourage the parent to self-identify as disabled?

The practical question facing the DRC has always been: How do we communicate with people to let them know they have rights without alienating them in the process? The practical questions facing the disability movement is: how can it remain relevant to an evermore diverse group of people in order that it can claim with credibility to speak on their behalf?

One for all and all for one

Disabled people's disadvantage is strongly interrelated with the disadvantage faced by others and undermines national social and economic well-being.

If we look at disability-related disadvantage in the context of a three generation family for example we can see that the economic disadvantage of disabled adults is playing a central role in driving child poverty – in 70 per cent of low income (workless) couple households with children at least one parent is disabled.[35]

We see that the threadbare state of our social services is robbing

millions of people, who feel compelled to step in to fill the gaps left, of their own economic, social and physical well-being. There are currently estimated to be 6 million unpaid carers in the UK.[36] Children as young as 6 are providing substantial levels of care to their families, and women overwhelmingly providing care and support which in turn undermines progress towards gender equality, as well as adding pressures on family life.

We see a future where the numbers of people over 85 will increase by a third in the next decade, meaning many more people between the ages of 40-60 will have parents who are still alive and who may require support in the absence of statutory services.[37] In doing so, new patterns of intergenerational disadvantage may emerge. Older disabled parents without the money to pay for the support they require will call on their adult children who give up work to provide it. In turn they spend their retirement in poverty and call on their own children for support and so on.

If we look at the disadvantage of disabled people in relation to employment and skills we recognise that when a third of all people without formal qualifications are disabled, disability disadvantage stands in the way of achieving the levels of competitiveness Britain is going to need in the coming decades. When we acknowledge that 40% of all those out of work are disabled, then we recognize that disability disadvantage severely undermines economic growth.[38] When we realize how many people will have to leave work to care for a relative if we choose not to invest in statutory support services, we recognize Britain faces tough choices about future levels of immigration to fill the job vacancies left.

When we start to view the disadvantage disabled people face from this perspective, we begin to see how new and more powerful cases can be made for reform and investment and the very broad coalition that might be built in support of it - far wider than what we now think of as the 'disability movement'.

Reaching the tipping point

How might the movement for change develop?

Michael Gladwell's influential book 'The Tipping Point' identifies three dimensions of successful 'social epidemics' – that is, bringing about social change. He calls these 'the law of the few', 'the stickiness factor' and 'the power of context'.[39]

The 'law of the few' relates to the argument that social changes are more often than not driven first by very few people, but that those few people possess special characteristics which cause change to happen precisely because they are influential and are listened to. When such people come together, change flows. The chief characters need to include people who are trusted and respected experts in their field, people who are well connected and act as a communication and influencing 'hub', and 'sales-people' who possess strong skills in persuasion and negotiation.

The 'stickiness factor' relates to the specific issue or product at hand and the way it is communicated and understood. What is it that popularizes (or makes unpopular) an idea or product? What is its most potent intrinsic value? Why should people buy into it or reject it? Have we learnt to market our proposals in this way or are we under-selling what could be a very popular idea?

Finally, the 'law of context' refers to how our understanding and response to situations is shaped by the context in which we operate or in which things happen. A phenomenon Gladwell calls 'fundamental attribution error' is one all too familiar to the disability movement - when it comes to interpreting other people's behavior, human beings invariably make the mistake of overestimating the importance of fundamental character traits and underestimating the importance of the situation and context. Obviously the response of the disability movement to this phenomenon has been the social model of disability.   In the context of campaigning for change it is important to have an appreciation not simply of the value we ourselves attach to our goals but also of the wider social, political and economic context in which we are seeking to secure them, and to respond to and take advantage of the context we are in. By not doing, claims can be viewed as being out of tune and irrelevant.

Independent living - a case in point

There exist many opportunities for collaboration between disability organizations and others. For example, stronger engagement with mainstream consumer organizations could help promote implementation and enforcement of Part 3 of the Disability Discrimination Act, so widening access to goods and services, where existing enforcement mechanisms are failing.

To illustrate how such approaches might work in practice, this article now focuses on one major priority of the disability movement – independent living.

Lord Ashley of Stoke's Independent Living Bill, which the DRC helped to write, sought statutory rights to independent living.[40]

To make these rights a reality will require significant reform, culture change and large scale investment in key public services across national and local Government, across different professions, across the voluntary sector, the media and wider public.   There are lots of people to convince, priorities to compete with, thinking to be done, practical solutions to be developed and cases to be made.   This includes the daunting task of making independent living a national spending priority.

Taking Gladwell's analysis of achieving 'the tipping point' and the recommendations offered by the Demos report, how might this be achieved?

First we need to understand the drivers of spending decisions, and the primary drivers of policy in the core area of social care. This is the context in which we are operating. We then need to understand who has greatest influence over such decisions and who is listened to by those who take them - this is the law of the few. Finally we need to understand what is going to be most persuasive in making the case for investment - the stickiness factor. With this information to hand, we can begin to build alliances and contribute most effectively to national debates.

Government spending decisions on public services and its reform agenda now and for the foreseeable future are based on achieving 'invest to save' through creating what has been called an 'active

welfare state'. That is, public services which can be counted as a social and economic investment, such that they give people the tools to escape 'dependency', improve life chances and opportunities, and through doing so contribute to widening prosperity and economic growth. Optimising the numbers of people participating in paid employment is a primary objective. Alongside broader efforts to encourage individual responsibility, this goal underpins Government objectives including ending child poverty, promoting gender equality, ending pensioner poverty, promoting 'active ageing', strengthening families and promoting community cohesion. The political banner for these various initiatives is 'support for hard working families' - in return for greater individual responsibility, citizens can anticipate rights and opportunities.

Childcare became 'sticky' because it came to be seen in this way and this resulted in the Government's childcare strategy being billed as 'the new frontier of the welfare state'. Childcare is central to promoting employment participation amongst parents and reducing benefit dependency. It is critical to ending child poverty and promoting children's life chances through access to resources such as 'Surestart' and parenting classes. Expanded childcare helps to promote gender equality. Critically, childcare is seen as important to achieving widened prosperity and economic growth. The campaigns which helped secure childcare as a major government priority involved campaigners for children's rights, parents, gender equality as well as a vital ingredient, business and employers. It is seen clearly as part of the new 'active welfare state'.

Independent living is not. Yet given what is beginning to drive the debate around social care there is every reason that it should be. The major driver of the social care debate concerns the sustainability of relying on unpaid carers in the context of increased demand from an ageing population, and the relative responsibilities of individuals, families and Government.   Decisions about the future of adult social care will play a central role in shaping issues of major national importance. These include balancing the goal of full employment against increased reliance on informal carers, achieving gender equality, promoting healthy work-life balance, supporting children and family well-being, questions about sustainable levels of immigration required to fill labour shortages, and last but not least the

opportunities for disabled people of all ages and their families to achieve independence and more equal life chances.

Investment and reform to promote independent living can be made 'sticky' if it is seen as creating an active welfare state to help Britain deal sensibly with all these issues.   Independent living is unlikely to be won if it is seen only as a costly way to deliver the 'rights' of a minority.

These arguments are developing and already winning support from diverse interests, working collaboratively with DRC. The disability movement needs to capitalise on such developments and make efforts to make alliance including with organisation's campaigning for gender equality such as the Fawcett Society, carers organisations such as Carers UK, older people's organisations, children's organisations, think-tanks like Demos and the Institute of Public Policy Research (IPPR) who are embarking on work in this area, professional bodies such as the Association of Directors of Social Services, networks such as the Local Government Association, trade unions, politicians and journalists. Getting business and employers behind independent living would mark a major step forward.

It is critically important that such an alliance is led in a fashion which cannot be characterised as partisan - it must be a broad and inclusive church.

Harnessing the future of equality and human rights

The CEHR's statutory Disability Committee has a critical role to play. To quote Bert Massie the Committee is 'not, as some suggest, to keep disability outside of the Commission's main business but rather to make sure that disability can never be left out.' A primary task of the Committee is to ensure that the distinct flavour and challenges of promoting disability equality are at the heart of the new Commission's work. In turn, the Commission provides a significant opportunity to mobilize credible arguments and alliances in pursuit of those goals the disability movements shares with others. For example, the Commission is committed to promoting independent living, but its goals demand that it does so in a fashion which moves forward

equality, human rights and good relations as a whole. Given independent living already enjoys widespread support from a number of the stakeholders outlined above this is a major opportunity to put independent living right at the heart of the Commission's work. By doing so, and with the right expertise on board, the CEHR will play a central role in showing the value of independent living to a broad community of interest and in doing so clearly articulate its centrality to a wide range of social and economic objectives.

As it moves into the next phase of its development, the disability movement needs now to ask itself what matters most in relation to securing a future and in building powerful movements behind the changes disabled people still seek. Should it keep itself to itself, a coalition forged along lines of a political class of people who share a narrative of oppression and emancipation, or with looking outwards, participate in the development of new coalitions forged around the shared interests of people who whilst having multiple and fluid identities, nevertheless share similar goals which joint working will bring closer?

The risk of the former approach is that such a shared narrative may increasingly preclude new members who do not recognise it from their own experience or feel that it fails to meets their aspirations, and can, like all belief systems, obscure facts, pitch it needlessly in competition with other groups who share its aims and lead it towards extinction. The very real risk of the latter approach is compromise and what some may view as a loss of self-determination and dilution of purpose.

Conclusion: Nothing without us or nothing about us?

In considering its own answer to this question, the disability movement might think again about the next frontier of the journey it has embarked upon - realisation of equal citizenship - and recall the words of disabled people back in 1981 during the UN International Year of Disabled Persons in describing what achievement of this goal would look like:

‘*as disabled people have equal rights, they also have equal obligations. It is their duty to take part in the building of society*'[41]

If the disability movement is going to continue to deliver life-changing results for disabled people, the next stage requires active participation in broad communities of interest, collaborating together in the building of the 'good society'. Retreat into a narrow and isolated community of identity is very likely to result in being left out in the cold without the power or leverage to achieve its goals.

'Nothing about us' is the risk ahead if productive partnerships are sacrificed on the altar of ideological purity, and isolationism shapes action. As we seek to meet the challenges of the coming decades and finally realize our vision of a society in which all disabled people can participate fully as equal citizens, 'nothing without us' needs not just to be a motto, but our primary measure of success.

References

[1] See www.cehr.org.uk

[2] See http://www.officefordisability.gov.uk/

[3] See http://www.un.org/disabilities/convention/

[4] For more discussion on the approach to disability rights read: http://www.drc.gov.uk/about_us/commission_for_equality_and_hu/accentuating_the_positive_d.aspx

[5] See www.disabilityagenda.org

[6] See www.disabilityagenda.org/news/speeches/speech_by_bert_massie_at_launc.aspxhttp://www.disabilityagenda.org/news/speeches/speech_by_bert_massie_at_launc.aspx

[7] For example see Burchardt, T (2005) The education and employment of disabled young people. Joseph Rowntree Foundation; Abrahams, D and Houston, D (2006) Results from the 2005 National Survey on Equality, Diversity and Prejudiece in Britain. University of Kent

[8] Guy Palmer et al (2006) Monitoring poverty and social exclusion 2006. Joseph Rowntree Foundation

[9] Lyon, N., Barnes, M. and Sweiry, D. (2006) 'Families with Children in Britain: Findings from the 2004 Families and Children Study', Department for Work and Pensions Research Report 340.

[10] Labour Force Survey, from Disability Rights Commission (2006) 'Disability Briefing March 2006'

[11] Disability Rights Commission (2006)

[12] Disability Rights Commission (2006)

[13] Households Below Average Income 2007

[14] For example, according to the Society of County Treasurers/Local Government Association in 'Social services finance 2005/06, a survey of local authorities, research briefing 1.06 March 2006', nearly 70 per cent of local authorities in England only provide social services to people assessed as meeting the highest levels of need

[15] Department for Education and Skills, op. cit.

[16] Disability Rights Commission (2006)

[17] Freud, D (2007) Reducing Dependency, Increasing Opportunity – options for the future of welfare reform. Department for Work and Pensions

[18] Public Bodies 2006, Cabinet Office, http://www.civilservice.gov.uk/other/agencies/publications/pdf/public-bodies/publicbodies2006.pdf

[19] CSV:RSVP, 2000 Disability need be no handicap London:CSV

[20] For example, Commission for Social Care Inspection and Healthcare Commission (2006) 'Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust'; Buckinghamshire County Council (1998) 'Independent Longcare Inquiry'; Commission for Health Improvement (2000) 'Investigation into the North Lakeland NHS Trust'.

[21] Disability Rights Commission (2006) 'Equal treatment: Closing the Gap, a formal investigation into health inequalities experienced by people with learning disabilities and/or mental health problems'.

[22] Demos (1999) 'An inclusive future? Disability, social change and opportunities for greater inclusion by 2010' http://www.demos.co.uk/publications/inclusivefuture

[23] See Campbell, J (1997) Growing Pains – Disability Politics the Journey Explained and Described

[24] See Sayce, L (2000) From Psychiatric patient to citizen: overcoming discrimination and social exclusion

[25] See: http://www.drc-gb.org/the_law/legislation__codes__regulation/guidance.aspx

[26] Family Resources Survey 2004/5

[27] Platt, L. (2006) 'Ethnicity and Child Poverty, Research for the Ethnic Minority Employment Task Force', data derived from Households Below Average Income statistics.

[28] DRC/IPPR (2007) Disability 2020: Opportunities for the full and equal citizenship of disabled people in Britain in 2020

[29] See www.disabilityagenda.org

[30] Grewal, I et al, (2003) Disabled for life? Attitudes towards and experiences of disability in Britain. Department for Work and Pensions

[31] The title of the debut album by Sheffield rock band the Arctic Monkeys is taken from a line delivered by Albert Finney in the 1960's

kitchen sink drama 'Saturday Night and Sunday Morning'

[32] DRC (2007) My school, my family, my life: Telling it like it is

[33] Market research (2005 unpublished) ORB on behalf of DRC

[34] Campbell, J (1997) Growing Pains – Disability Politics the Journey Explained and Described

[35] Stickland, H (2004) *Disabled Parents and Employment,* Background paper for HMT/DWP seminar, 24th November 2003 Hugh Stickland, Lone parents, Older workers and Disability Analysis Division, Department for Work and Pensions

[36] Carers UK estimate there are 6 million unpaid carers in the UK and project this to grow to 9 million over the next 20 years

[37] Wanless, D. (2006) 'Securing good care for older people – taking a long term view'

[38] Labour Force Survey, as quoted in Disability Rights Commission (2006) Disability Briefing. Labour Force Survey

[39] Gladwell, M (2000) The Tipping Point: How little things can make a big difference

[40] see http://www.publications.parliament.uk/pa/ld200506/ldbills/122/200612 2.htm

[41] UN World Programme of Action concerning disabled persons – objectives, background and concepts (1981) http://www.un.org/esa/socdev/enable/diswpa02.htm