

The Lorraine Gradwell Memorial Lecture

BROKEN PROMISES

Looking back on 'Improving the Life Chances of Disabled People'

by **Dr Jenny Morris** (film presentation)

Friday 8 March 2019

3.30pm to 5pm (3pm doors)

Friends Meeting House, Mount Street, Manchester M2 5NS

followed by a discussion and questions

All welcome

British Sign Language

Full access

Organisers include:

Breakthrough UK

Greater Manchester Coalition of Disabled People

Broken Promises: Looking back on ‘Improving the Life Chances of Disabled People’

In 2004, a group of civil servants working in the Prime Minister’s Strategy Unit came to Manchester to visit Breakthrough UK. Lorraine had organised the visit for them to see how Breakthrough delivered employment support for disabled people. They heard how Breakthrough advisors - most of whom were disabled people themselves - helped to address a range of barriers, how they challenged employer’s attitudes and assumptions, and how they acted as advocates for the disabled people they were working with.

I was with that group of civil servants. As a freelance consultant I was working with them on what became a 25 year strategy, published in 2005 called ‘Improving the Life Chances of Disabled People’.¹ I had been brought in to lead a section on independent living, which became the main thrust of the whole strategy - mainly because I was able to introduce the civil servants to the ideas, the organisations and the individuals who had been fighting for so many years for our rights to choice and control in our lives.

Tony told me that Lorraine saw the Life Chances report as a ‘policy high point’. It was certainly well received generally by the disability movement. It was a moment of hope, a moment when we thought that government had finally understood the nature of our lived experiences, the barriers we face, and the kind of solutions that would make a real difference. Although, perhaps inevitably, the policy proposals didn’t go far enough the general feeling was that, to coin a phrase, ‘things could only get better’.

¹ HM Government, 2005. *Improving the Life Chances of Disabled People*. <https://webarchive.nationalarchives.gov.uk/20130402160115/https://www.education.gov.uk/publications/eOrderingDownload/1968-2005PDF-EN-03.pdf>

Indeed, Life Chances was followed by the setting up of the Office for Disability Issues - a cross government unit with the aim of promoting disability equality across all government departments - and the Independent Living Strategy (which I also worked on and which again Lorraine influenced).

There were two commitments set out in Life Chances which the disability movement particularly welcomed. The first was one which said that, by 2010, every local authority area should have a user-led organisation modelled on existing Centres for Independent Living.

The second was a cross-government approach to providing disabled people with the resources - money, services, adaptations and equipment - which enable choice and control and social inclusion. This was to be initially delivered by piloting individual budgets, which were to include not just social care funding, but also continuing health care, employment support and disabled facilities grants.

Both these commitments were taken forward in the context of the Office for Disability Issues being set up to work across government departments to deliver the Life Chances strategy.

But the financial crisis of 2007/8 came less than three years after the publication of Life Chances, and we were only two years into the five year Independent Living Strategy when the Coalition government took over in 2010. And things changed.

Like me, Lorraine was struck by how quickly the public and political discourse separated disabled people into who was to be categorised as 'vulnerable' and who was a 'scrounger'; how quickly government's emphasis seemed to be entirely on reducing the numbers of people on out-of-work disability benefits;

how the gains we thought we had made, and the opportunities we thought there were for further progress, seemed to disappear almost overnight.

But actually - looking back on the hope associated with Life Chances - it is possible to see that there were other policy developments happening at the same time - before the financial crisis - which sowed the seeds of what was to come under the Coalition and then Conservative governments in the years since 2010.

It is also possible to see, with hindsight, that we should have been much more ambitious in our proposals concerning independent living.

To take the first point - other policy developments at the time - the Life Chances strategy included a chapter on employment but it was what was happening on this issue in other parts of government which had a more profound impact on disabled people.

The disability movement during the 1980s and 1990s framed employment opportunities as a civil rights issue, arguing for the right to work and for an end to employer discrimination and other barriers to employment. Recognition of discrimination in the context of employment was a key part of the campaigns for disability anti-discrimination legislation.

The employment chapter in the Life Chances strategy was written by a civil servant on secondment from Treasury. Although the chapter did refer to discrimination and barriers, it also framed the problem as there being “little incentive or assistance for people to move off benefits and into work”. It

made assertions such as work being “a component of good health”, “work as a positive driver for good health” and emphasising the “beneficial health effects of work” - almost as if employment was a treatment for ill health. Lorraine herself, in commenting on Life Chances, raised a concern that the proposals seemed to conflate impairment and ill health, leading to a possibility that people who were ill would yet still be expected to work.

In the same year that Life Chances was published, the government also published a document called ‘The Scientific and Conceptual Basis of Incapacity Benefits’. This report had been commissioned by the Department for Work and Pensions and was to form the basis for what became the Work Capability Assessment. The document argued that in order to reduce the numbers of people on out of work disability benefits the social security system needed to bring about a “fundamental transformation in the way sick and disabled people see themselves”.²

This “fundamental transformation” involved separating disabled people out into two main categories: those “with severe medical conditions and permanent impairment” and those with what they call “common medical conditions”, who they thought make up two thirds of those claiming out of work disability benefits. They argued that it was only the former group who the welfare benefits system was supposed to provide for. Those with ‘common health conditions’ they identified as having “mild / moderate mental health, musculoskeletal and cardiorespiratory conditions” and experiences of these conditions were said to be “subjective”. It was therefore people’s “attitudes and motivation” which were the main barrier to employment.

² Waddell, G. and Aylward. M. 2005. *The Scientific and Conceptual Basis of Incapacity Benefits*

Instead of seeing the lower rate of employment amongst disabled people as a civil rights issue, governments of all persuasions have presented the numbers of people eligible for out of work disability benefits as the problem. The focus is therefore on 'getting people off benefits', instead of delivering equal opportunities for employment; the focus is on scrutinising whether people are 'fit for work', not on what changes to working conditions might make employment possible; the focus is on people's supposed attitudes and motivations instead of on whether suitable work is available in the local labour market.

Worse than any of that, is the denial of people's own experiences of illness and/or impairment - unless you can be categorised, by a measurement devised by the DWP, as having a severe and permanent condition then your experience is considered to be contentious. Thus the Work Capability Assessment gives assessors the power to determine a person's level of impairment or their experience of ill health - treating as irrelevant not only medical diagnosis but also how people themselves experience their impairment or illness and its impact on them.

No wonder that, particularly since 2010, disabled people's organisations have been forced to focus on illness and impairment in defending people's right to an income if they are not able to work. Work is framed not only as an obligation but increasingly as a response to ill health - to such an extent that the 2017 White Paper on work and disability was jointly published by the Department of Health and the Department for Work and Pensions, and urged healthcare professionals to see "work as a health outcome".³

Disabled people welcomed the way the government had formally adopted the social model of disability in Life Chances. But what

³ DWP and DH, 2017. *Improving Health: The future of work, health and disability*.

we hadn't realised was how the model would be misused. At the time of Life Chances, the disability movement had spent almost 30 years emphasising how it was social, economic and attitudinal barriers not impairment or illness that held us back. But this meant we were caught on the back foot when, at the heart of the reforms to welfare benefits, was a denial of people's experiences of impairment and illness.

It's not surprising therefore that it has often been people with chronic illness who have made the most vocal challenges to the Work Capability Assessment, and also to the replacement of Disability Living Allowance with Personal Independence Payment. In 2012, the Spartacus report ⁴ about welfare reform, written by a group of social media activists - many of whom couldn't leave their homes because of chronic illness - hit the headlines and helped to bring about a series of defeats for the government in its legislation to reform Disability Living Allowance. ⁵ Since then a movement has grown of people with chronic illness who seek to apply the social model to their experiences. They have developed and enriched our understanding of the social model, a lot of this now happening through the Chronic Illness Inclusion Project, whose website I highly recommend - inclusionproject.org.uk.

Life Chances would have been a better strategy if these groups and their experiences had been involved in the disability movement in previous decades, and particularly if they had been consulted in developing the Life Chances proposals on employment.

It wasn't just that those of us working on Life Chances didn't pay enough attention to what was going on elsewhere in the policy

⁴ Diary of a Benefit Scrounger et al, 2012. *Responsible Reform: a report on the proposed changes to Disability Living Allowance*. http://www.ekklesia.co.uk/files/response_to_proposed_dla_reforms.pdf

⁵ <https://www.theguardian.com/society/2012/jan/17/disability-spartacus-welfare-cuts-campaign-viral>

jungle. We also made a fatal error in our proposals on independent living.

Yes, it was great that the Life Chances strategy adopted the disability movement's definition of independent living - the recognition that independence comes not from doing things for yourself, or living on your own, but about having assistance and support how and when we choose. And the commitment in Life Chances to pilot individual budgets laid the foundation for what became personal budgets for social care - the intention being that self-determination would be achieved by giving people control over the resources needed for their support.

But personal budgets have not generally delivered self-determination. Instead, in the context of significant cuts in funding for social care, the level of resources has too often been reduced to only providing the most basic personal care. Most importantly, there remains an unequal relationship between disabled people and social services professionals because it is local authorities who have the ability to determine - through the assessment and resource allocation process - what kind of life we can lead.

When we were developing our proposals for independent living in Life Chances, we didn't pay enough attention to the growing resistance within the Department for Work and Pensions to the Independent Living Fund. The ILF was perhaps the most successful independent living policy there has been in this country but it happened entirely by accident and DWP as a department was never reconciled as to why its budget should be their responsibility rather than that of social care.

We should have recognised that the ILF had more potential to deliver a right to independent living than any reform to local

authority social care. The origins of the ILF were important - it was set up in 1988 to replace the Domestic Needs Allowance, a social security payment which covered the additional costs of those people who needed help with what was called 'ordinary domestic tasks' like cooking and cleaning. It was thus part of a system based on entitlement – if you met certain criteria you had the right to a certain amount of money. Although this principle of entitlement was undermined by the gatekeeping role that local authorities played in accessing ILF money after 1993, there was plenty of evidence of the empowering role that the ILF played before it was abolished by the Coalition government.

When we looked at the problems with social care at the time - in particular at the varying practices and policies across local authorities, the difficulties disabled people had moving from one area to another - the obvious question arose as to whether independent living should be funded on a national basis and taken away from local authorities. We floated this idea but the response was that this would undermine the local accountability which was achieved by leaving it with local authorities.

Instead of accepting this argument, we (but especially me in the role that I had) should have challenged it and put the case for an independent living system, nationally funded and based on the principle of entitlement.

We should have done this because the social care system does not, unlike the NHS, deliver support on the basis of need but instead delivers it on the basis of the resources available. And while local authorities have the legal responsibility for social care, it is central government that determines what level of resources are available.

Life Chances did not tackle this fundamental problem. Neither did it address the impact of the privatisation of social care services which had been steadily taking place since the 1990 NHS and Community Care Act. By now it is clear that the 'market' in social care services, created by that legislation, has failed in that both home care and residential care providers find it increasingly difficult to make a profit because of the squeeze on the amount that local authorities will pay. The associated low level of pay for care workers means that care providers have difficulty recruiting and rely on migrant workers - yet this will become much more difficult after Brexit and the proposed immigration policy which would require people coming into the country to be earning in excess of £30,000.

The self-determination that personal budgets were intended to deliver has, mostly, failed to materialise. Life Chances had pointed out that delivering independent living "would require a cultural shift so that social care professionals are working to promote self-directed support". Some people working in social care try hard to support people's self-determination, but they can only struggle against an inherently disempowering relationship. Three quarters of people over the age of 65 are on local authority managed budgets, with little or no choice of who provides their care. Even amongst people with physical impairments under the age of 65, only half receive their budget as a direct payment - and there is increasing evidence that local authorities are placing more and more restrictions on what direct payments can be used for, for example by insisting - contrary to the Care Act guidance - that people have to use a prepayment card rather than have money paid into a bank account.

Article 19 of the UN Convention on the Rights of Persons with Disabilities sets out "the equal right of all persons with disabilities to live in the community, with choices equal to others".

The current social care system is incapable of delivering this right.

Its total failure can be seen in the fact that social care fails to support young people with learning disabilities and/or autism to live in their local communities, leading to incarceration for years in institutions, many of which are now run by private companies.

The Reclaiming Our Futures Alliance - an alliance of a range of disabled people's organisations in England - recently published their proposals for making independent living a reality. They include a national independent living service, funded from general taxation, free at the point of delivery, and delivered locally in co-production with disabled people. This is what is necessary to deliver our Article 19 right to independent living.

One final point, one of the things that Life Chances did get right was the proposal for a national network of disabled people led organisations, modelled on the existing Centres for Independent Living. The Department of Health, together with the Office for Disability Issues, set up a programme for delivering this commitment but it was never fully realised and since 2010 many local disability organisations have had their funding cut and have found it increasingly difficult to hold onto existing contracts to provide direct payments support services. Such local organisations are a vital part of any nationally funded independent living service.

It's at the local level and amongst disabled people ourselves that we will develop innovative ways to enable people to live ordinary lives. It's amongst disabled people and their allies that we'll find different ways of delivering support.

This relates to an issue which is of concern to the majority of the population and not just to disabled people: how to design and deliver services that are responsive to the wishes of individuals, that are accountable to their users (rather than to shareholders or to a professional group whose culture is one of 'we know what's best for you').

What we need from government is investment in the infrastructure which enables us to develop our own responses to making Article 19 of the CRPD a reality - to enable "the equal rightto live in the community, with choices equal to others". And I know that that's what Lorraine would also have considered a priority. While she had a key influence at a national level, it was in her own city that she helped build organisations which make a difference to disabled people's lives and that's what we must continue to do.

Jenny Morris
8 March 2019