

User-led service providers need more support from the Government if its commitment to ‘independent living’ for disabled people is to be achieved

Many ‘vulnerable groups’ will be especially hard hit by public service budget cuts, none more so than disabled people. So an inquiry by the Joint Parliamentary Select Committee on Human Rights into the implementation of the right of disabled people to independent living is timely. [Peter Beresford](#) gave evidence to the inquiry and here discusses what more the government needs to do to support disabled people.



Through the Coalition Government’s emphasis on reducing the public deficit, many disabled people have felt particularly singled out for attack rather than support. This has been despite the Prime Minister’s early commitment to protecting ‘the vulnerable’ among whom he included disabled people. The strong message from disabled people’s organizations – on their networking websites and social media, and in their demonstrations and marches – has been that they have been particularly victimized by benefit reform policies, cuts in dedicated support services and in mainstream public provision. Given that social care services were already acknowledged to be in a state of crisis, with plans for fundamental reform of their legislation, funding and delivery, there can be little surprise if disabled people and their families have lately felt beleaguered, with both their rights and needs under direct political attack.

This political and policy context makes the [inquiry into the rights of disabled people to independent living](#) of the Joint Parliamentary Select Committee on Human Rights all the more timely and important. The Inquiry, chaired by Dr Hywel Francis MP has been seeking evidence, including from disabled people, in the context of the UN Convention on the Rights of Persons with Disabilities (the Disability Rights Convention), which the UK ratified in 2009. I was asked to give oral evidence, alongside two other disabled people on [28 June](#). They were John Evans, a pioneering member of the disabled people’s movement who has worked widely in Europe and Doug Paulley a residential service user and activist. I took part as a long-term mental health service user, chair of a national service user/disabled people’s organization and network, [Shaping Our Lives](#) and drawing on the work I do as Professor of Social Policy at Brunel University.

One of the powerful messages that came across from the evidence we gave was the positive framework for disabled people’s independent living and human rights that the UK has established over the years through legislation and progressive policy. It may not be perfect by any means, but it is still sadly ahead of many other western countries and is something the government both needs to be proud of and do as much as it can to safeguard. The three of us each offered our understanding of ‘independent living’ and goals like ‘choice’, ‘control’ and ‘increased opportunities’ were highlighted by all of us. For me, ‘independent living’, based on the social model of disability, means that disabled people have the real chance to live their lives on as equal terms as possible as non-disabled people and that this is ensured through them having the individual support they need and equal access to mainstream life and services.

However as a mental health service user I have come to realise that many other users and the psychiatric system itself are unaware of the idea and philosophy of ‘independent living’. Recently another idea has gained importance in this field, ‘recovery’. Unfortunately, this is often interpreted in a narrow and medicalised way and there is a failure to appreciate that mental health service users, like other disabled people, may still need support, even when they are contributing and taking on other responsibilities, alongside other people. Withdrawing support can then set them back and put them at risk.

Recently, we have seen some appalling instances of abuse of disabled people, notably with the scandal of [Winterbourne View Hospital’s](#) treatment of people with learning difficulties. However, the evidence of a four year UK research and development project (in which I have been involved) and which recently published its findings, the [Standards We Expect](#) project highlights the common failure of social care services to safeguard and respect disabled people’s rights and to meet their needs. While it did not identify any extreme examples of abuse or neglect, the routine ‘drip, drip’ kind of constraints placed upon people’s lives, especially those of residential and long term service users emerged as a major cause for concern. Our focus was particularly on developing person-centred support or personalization. But institutionalization and restricting disabled people’s opportunities, actions and choices are still commonplace in both domiciliary and residential settings and relate to unhelpful approaches, to practice, provision, policy and organization.

In my evidence I also stressed concern that while there was a growing awareness of the importance of

safeguarding people's rights and needs as social care service users, other policy in some cases seemed to be developing at odds with this. Most notably here is welfare reform policy, where the same people can be treated as 'scroungers' and dishonest. This seems to be affecting all groups of disabled people, including people at the end of life and perhaps particularly mental health service users, where no physical signs of impairment may be recognized and is reflected in harsh and arbitrary processes of assessment and medical review and determined efforts on the part of government agencies to force people off benefits. The [high level of successful appeals](#), for example, against cessation of Employment and Support Allowance, highlight justifiable concern.

The recent financial crisis surrounding Southern Cross, the largest independent social care provider in the UK also raises major issues for the human rights of disabled people, particularly older disabled people who have emerged as particularly vulnerable to the risk of such home closures and the erosion of quality and conditions. While successive governments have highlighted the importance of moving to a pluralist approach to providing support for disabled people, as yet, the private sector, which is associated with low pay, ever larger organisations and provision, now has more than 90 per cent of the market. Yet we know from the evidence, that disabled people particularly value services provided by local user-led and disabled people's organisations (ULOs and DPOs). These organisations are invaluable in supporting the empowerment of disabled people and helping to support arrangements for independent living and broader social change in line with the UN Convention. Yet they are currently vulnerable and underfunded and inadequately supported to take on the positive roles they offer as both employers of disabled people and service providers. There is a real need for a change in policy direction from government, which gives the same encouragement and support to these social and micro enterprises and mutual companies as it has given to the private sector.