

LAG Community Care Conference: Bringing Rights Home conference.

Jane Campbell

Bringing rights 'into' the home

'It then occurred to me that the right to be the same ...and the right to be different ...were not opposed to each other. On the contrary, the right to be the same in terms of fundamental civil, political, economic and social rights provided the foundation for the expression of difference through choice in the sphere of culture, lifestyle and personal priorities.'

Justice Albie Sachs

I am pleased to be here today speaking to you about 'Bringing Rights Home'. I am aware that in the legal world, this phrase is a reference to the UK 'incorporating' the European Convention on Human Rights – a treaty inspired by Winston Churchill but not applied here before the millenium - into UK law through the Human

Rights Act so that individuals can enforce their rights through their own courts.

However over the years politicians and the public seem to talk about human rights as though they have been imposed on us by the European superstate; and they only serve the people who deserve them least! I hope today, I can encourage you to keep the faith and not succumb to this pessimism. Nowhere in Britain is the fight to keep Human Rights alive and active, moreso than in the world of social care. Because without a solid foundation of care and support disabled people will never be able to express as Albie Sachs poetically put it, "difference through choice in the sphere of culture, lifestyle and personal priorities."

I've decided to stretch the meaning of 'bringing rights home' a little and talk to you about 'bringing rights into the home'. By actively changing the narrative that describes the role of human rights in our society, I hope we can reassert their unique and crucial role in helping all people, whatever their age or disability, to enjoy 'being

valued human beings '. Nowhere does this matter more than in our own communities, homes and private places, famously alluded to by Eleanor Roosevelt, the founding mother of the Universal Declaration of Human Rights, more than half a century ago, as:

'those small places ... so close and so small that they cannot be seen on any maps of the world ... Such are the places where every man, woman and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere.

For thousands of people in Britain, Social Care can and should play a fundamental role in ensuring that in the home, disabled people and their families have dignity, choice and control over their lives. Case law under the Human Rights Act has established that the state has a 'positive obligation' to ensure that the right to a 'private life' enables disabled people to live the lives they would choose if they were not 'disabled' by lack of necessary provisions. Without this support in our private space, some of our essential human rights of freedom, dignity and life are denied us. This is as profound today for disabled and older people and our families, as the slogan 'the personal is political' was for women 40 years ago. When it comes to rights, the home is

often neglected in favour of the public worlds of work, education and civic participation. Rights in our homes, our communities, and on our streets, matter. Without them we are consumed with day to day stresses and cannot lift ourselves up to participate in the wider world.

We need only look at last year's Joint Committee on Human Rights Report 'a life like any other', to know that when there is an absence of a human rights culture backing the private lives of people with learning difficulties, the consequences are very disturbing indeed. None of you will forget Brent Martin, Stephen Hoskin, Fiona Pilkington and her daughter Franky, disabled people who in recent years have been killed after they were targeted, exploited, abused and subjected to acts of extreme hostility and humiliation. For those requiring care and support, the availability and effectiveness of services are very often central factors in determining whether their human rights are upheld and promoted. In the very worst cases this includes the right to life itself - without support, some people die. As the report concludes, the withdrawal of adult social care from Steven Hoskin's life in the name of independent living, did not promote his

choice and control, because the effect was that he lost all control to the people who eventually took his life.

In 1989, someone like me could easily get a care package that got me up in the morning and then supported me throughout the day in work, rest and play. I felt as though my fundamental human rights were supported and protected. Today, 20 years later I believe our commitment to developing care and support public services which align with human rights principles, have got lost along the way. Today, over 70 per cent of local authorities only provide services 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 be dressed, fed, washed and sat in front of day time TV.

So yes, it is definitely time to think again how we might reassert a Human Rights culture and practical framework for delivery in public

support services; in the true sense of the concept of 'independent living'. We do this or succumb to the 'literalists' who suggest, "The declaration is, a work of fiction, as foolish as it is noble!

Well one has to start somewhere and personally I can't find a better set of guiding principles than that of the Human Rights Act and the recently ratified U.N. Convention On The Rights Of Disabled People. Such instruments are essential guides as we embark on reform of public care and support services in the UK. The standards they uphold provide the benchmark by which we can judge whether the Government – any Government - has delivered (as has been promised) "equality for disabled people by 2025".

The CRPD, which is a re-affirmation of disabled people's human rights, includes a specific article requiring States to 'take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, by ensuring that:

- 1) Persons with disabilities have the opportunity to choose their place of residence and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- 2) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- 3) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.'

Sadly it is not exactly enthusiasm for the newly ratified CRPD that is forcing the public to re-evaluate social care in the lives of disabled and older people. Society is waking up to the fact that supporting disabled and older people has to be on today's political agenda, because people live longer, and many more are presenting themselves at the door of public services with challenging health and social care support needs.

Every political party this conference season was queueing up to offer policies and proposals that could demonstrate they were the most “caring” to those most vulnerable! But there you have it that “vulnerable” word again. I ask you, who is more vulnerable: me or City broker who has just lost his job, probably his home and potentially his mental health? Vulnerability is not biological it is almost entirely situational. We need to challenge the politicians and all future policy makers, who hide behind the default position of a quasi medical-victim model solution to the social care crisis.

Until recently, concern about human rights has predominantly focused on people's freedom from abuse, undue interference and discrimination. Whilst these objectives remain important, the European Court of Human Rights, and increasingly our own courts, have demonstrated that a modern approach to human rights – one which is aligned both to disabled people’s expectations and the public interest - should emphasise disabled people's freedom to lead rich, rewarding and fulfilling lives which benefit society as a whole.

The opportunity now presents itself for us to subject and subordinate all social care support policy initiatives to the pursuit of disabled people's human rights. This offers us a springboard, rather than a safety net. This approach would bring an end to tired welfarist models which have little regard for people's civil and political rights to choice, control and participation. The new UN Convention challenges us to further reconcile civil and political rights with social, economic and cultural rights. Instead of wallowing in the mire of the economic downturn and giving way to a knee-jerk safety net service, we have the opportunity to reframe care and support services by getting behind recent initiatives such as the Government's Independent Living Strategy and the Right to Control.

In March 2008 the Government published its Independent Living Strategy. The strategy details policy commitments that seek to realise the Government's vision of equality for disabled people by 2025.

There are various sticks and carrots to help make this happen such as Public Service Agreements and National Indicator targets, but most exciting of all is the legislative Right to Control.

The Right to Control is a further stage in the implementation of the policy set out in the White Paper, Improving Life Chances (2005).

This paper committed government to delivering choice and control for disabled people. The Right to Control proposals contained in the Welfare Reform Bill, which is at Joint Committee Stage, give new rights to enable disabled people to exercise choice and control over the support resources they receive. When passed, hopefully, in a few months:

Disabled people will be told how much money is available to meet their needs, from the significant number of public support services funding streams set out in legislation,. We will then be able to work with the relevant public authority to plan how the money should be spent.

Disabled people will also be able to choose to have services commissioned for them by that public body, or take the money available as a cash payment to purchase services or support themselves; or a combination of the two. Having control over

services beyond social care, and combining them in ways that take disabled people out of a traditional caring environment - and into social and economic activity - is the social model liberation we have long fought for.

For instance, at present no less than 80% of people with mental health problems are out of work. Research shows that with flexible employment support and choice of jobs this rate of worklessness could be halved. The Right to Control could also mean, for people with fluctuating mental health conditions, being able to draw down support when it is needed – which makes the difference between losing your job – or keeping it; between taking the risk of trying work – or giving up on yourself for good.

The disability movement has increasingly engaged in - and is indeed winning - the battle of ideas when it comes to developing social care legislation, policy and practice. By integrating the support that we receive from social care services with that from employment, education - and hopefully in the future health services, -disabled

people should be freed to pursue their life chances with similar opportunities to everyone else. Such an approach will help us to access our human rights across all aspects of our lives – rather than our needs being fragmented across different public services. We will no longer be 'done unto', instead, we will be enabled to exercise autonomy and self-determination.

Most importantly, the Right to Control legislation is the result of government working in genuine partnership with disabled people and their organisations. Its success will depend on this continued co-production. I believe the Right to Control framework will assist with the translation of the human rights rhetoric of dignity, respect and personal autonomy, into practical realities; mostly because disabled people's views have been given dignity and respect in the actual formation of this law; Not only is it based on the case that disabled people have been making for choice and control for over 20 years, but, as the legislation passes through its final stages in the House of Lords, it is coproduction with disabled people that improves and strengthens it.

For example, before the summer I laid down 2 amendments developed with disabled people's organisations, to the Right To Control section of the Welfare Reform Bill. These amendments extend the control and reach that disabled people will have in the future over their state funded support. There is no greater lever than personal autonomy. For me this is summed up in a quotation that I come back to time and time again by philosopher SAUL ALINSKY in his book Rules for Radicals...

We learn, when we respect the dignity of the people, that they cannot be denied the elementary right to participate fully in the solutions to their own problems. Self respect arises only out of people who play an active role in solving their own crises and who are not helpless, passive, puppet-like recipients of private or public services. To give people help, while denying them a significant part in the action, contributes nothing to the development of the individual. In the deepest sense, it is not giving but taking – taking their dignity.

A collaborative approach is absolutely necessary when we attempt to apply a human rights framework to social care and support. It must not be the sole domain of medics, academics and lawyers. Disabled people talk a lot about inclusive knowledge and policy coproduction. I guess it's an extension of 'nothing about us without us', where we synthesise the ideas, expertise and experience of all stakeholders equally.

So in conclusion, I challenge all in this room to re-examine notions of care and support, in light of what disabled people, whatever their age or diversity, need to be equal, active, and human. Are you ready to discard the traditional view that your disabled clients are vulnerable adults? Can you see yourself leaving this conference determined to use your legal skills to fight for rights to give us freedom to exercise our human rights, rather than constantly repairing the safety net, which may at best, give us freedom from abuse and neglect.

Disabled people have changed the social agenda, which in theory,

accepts - that with choice and control over our lives, we will be healthier, happier and safer. All those involved in taking forward the human rights agenda need to recognise and build on the progress that disabled people have made in bringing human rights both home to disabled people and into the home.

Thank you