

Jane Campbell Introduction to the day

“All are equal before the law and are entitled to equal protection of the law”.¹
There cannot be a soul in this room who would disagree with this basic human rights principle, enshrined in 1948 by the United Nations in the Universal Declaration of Human Rights.

When the government introduced the Human Rights Act in the UK in 1998, its intention was to do more than require public authorities to comply with the European Convention. The then Home Secretary, Jack Straw said: “Over time, the Human Rights Act will bring about the creation of a human rights culture in Britain”.

We have much to gain from a philosophy that provides a basis to craft a powerful tool to combat inequality and exclusion and build society where everyone’s dignity and basic citizenship is protected and enhanced. However the Right to Liberty, the right to life, the right to respect for private and family life, the right to freedom of movement: are just a few rights that often fall short of this HRA commitment.

I will offer here one example which had a huge impact on me last year. I was asked by the DRC to intervene as an expert witness in the High Court case of Regina versus the General Medical Council. Regina in this case acted for Mr. Oliver Leslie Burke, a 43-year-old man with cerebella ataxia. Mr Burke challenged aspects of guidance as being unlawful, and incompatible with his human rights, in particular Articles 2, 3, 6, 8 and 14 of the European Convention for the protection of Human Rights and Fundamental Freedoms. In essence Mr Burke wanted to make an advance directive that when his condition became worse such that he would require ANH to continue living, he should receive ANH and this should not be withdrawn. The guidance as it currently stands, gives that authority to the doctor to decide what is “in the best interests of the patient including, ANH.” The High Court found for Mr Burke and, although the Court of Appeal later modified the judgment significantly, the original objective of introducing human rights principles into the debate had been met.

The right to life in my opinion is one of the most emotionally loaded and complex rights to be debated. For disabled people like me who are constantly up against society's belief that our lives are of less quality, the right to life

¹ Universal Declaration of Human Rights, 1948

article is literally “a matter of life and death”. To participate in its development is of vital importance.

I see the High Court’s verdict as marking a significant event in the history of service user rights within UK healthcare provision. It aims to balance the power relationship between Doctor and patient which for too long has been weighted against us. Both have a breadth of knowledge and experience not available to the other. Even on appeal, the Court of Appeal considered the knowledge base of both a competent patient and doctor to be of equal merit on ‘quality of life issues’ and that in respect of the withdrawal of nutrition or treatment the competent patient’s wish to live must prevail.

Today’s conference is again about bringing together a range of opinions on the development of a human rights framework for public service delivery. Human rights must be developed by a range of stakeholders. It must not be the sole domain of lawyers or academics. At SCIE we talk a lot about inclusive knowledge and practice development, where we synthesise the knowledge and experience of individual service users along with those who provide and manage services. Today will be another exercise in that form of inclusive debate. When I think of human rights in this context I think of a quote by Eleanor Roosevelt in 1958;

“Where after all, do universal human rights begin? In small places, close to home, so close and so small that they can’t be seen on any map of the world. Yet they are the world of the individual person.”

We have set out some ambitious aims for today’s conference:

- to promote and defend the values enshrined in the Human Rights Act and show people how HRA can benefit them in their everyday lives , thus enhancing public services,
- to demonstrate how HRA can be used to challenge human rights violations and, help people understand the framework it provides for resolving conflicts
- to explore how Human rights and equality are inextricably linked. For example the HRA asserts the dignity and worth of every individual. Equality without a HR framework could lead to people being denied dignity equally. And of course the HRA itself is also a potentially powerful tool to tackle inequalities.

In short, we want to do no less than analyse the different mechanisms by which human rights have and will affect the provision of public services in the future. Not all cases will be as dramatic as Mr Burke’s or so literally a matter of life and death: whilst a DRC Commissioner I have also been involved in a widely reported human rights case against East Sussex County Council that ensured that two young disabled women were able to continue living at home rather than go into residential care, despite the local authority’s original plan to insist that health and safety reasons made this impossible. I know too that the British Institute of Human Rights has helped local authorities, such as

Southwark Council, to understand the value of human rights principles in frontline service delivery and decision-making. The results can be impressive and of an 'everyday' sort: I am thinking, for example, of a social worker who used a human rights approach to get a free travel pass for someone who had difficulty staying on a bus for more than ten minutes as a result of post-traumatic stress and so was running up unnecessarily high travel costs. Eleanor Roosevelt was certainly right: 'small places' and 'close to home'.

To help us achieve our aims today, we have brought together a group of experts from health, social care, education and the law. Mr Justice Munby, who ruled in favour of Leslie Burke's challenge to the General Medical Council, a ruling which resonated throughout the disability world. Judy Heumann who brings us an international perspective from her position as Adviser on Disability and Development with the World Bank, Professor Gerard Quinn, Murray Hunt and Francesca Klug who am sure will provide us with a formidable knowledge base on human rights law and policy research. These and other notable speakers will give us much food for thought. Our hope, and that of all those who depend upon public services to live and flourish, is that, at the end of the day we will find ourselves that much closer to the aims we are setting out to achieve.