

The British Institute of
HUMAN RIGHTS

School of Law
King's College London
26–29 Drury Lane
London WC2 5RL

Tel: 020 7848 1818
Fax: 020 7848 1814
Web: www.bihhr.org
Email: admin@bihhr.org

President: The Rt Hon Lord Justice Stephen Sedley
Registered charity no 1101575
Company limited by guarantee, registration no 4978121
Registered office as above

Dr Mark Egan
Commons Clerk of the Joint Committee on Human Rights
Committee Office
House of Commons
Millbank
London SW1P 3JA

22 May 2007

Dear Dr Egan,

The British Institute of Human Rights (BIHR) warmly welcomes the JCHR's inquiry into the human rights of adults with learning disabilities. We see this as another positive example of the Committee's increasing focus on human rights as they relate to the everyday lives of people in the UK and in particular where they are facing discrimination or disadvantage.

BIHR knows from its direct experience of working with organisations in the public sector and the voluntary and community sector that people with learning disabilities, both adults and children, are often denied their human rights. It is essential that learning disabled people, their family members, friends and carers, know their rights and can claim them. We also see the wider potential of human rights ideas and human rights approaches for learning disabled people to claim more power and control over their own lives. In addition to individuals acting to claim their rights, we also see the potential for organisations to behave differently - not only taking steps to avoid the worst human rights breaches but also to fully promote and fulfil the human rights of learning disabled people in a way that enables them to flourish as human beings.

The following are typical examples of poor practice that have become known to us via our capacity building work:

- Failure to provide appropriate support for learning disabled parents expecting a child. In one case we learned about, two learning disabled parents were told their child would be removed because they could not relate to or successfully care for a robotic baby provided by the local authority to 'test' their parenting skills;

- Failure to support families with learning disabled parents to remain together. In one case we learned about, a child was put up for adoption on condition that there would be no contact between the parents and the child until the child reached 18 years of age. Both parents were highly distressed. Advocates involved in the case said that to the best of their knowledge, Article 8 was never considered at any stage of the decision making process;
- A privately run secure unit for people with learning disabilities punishing service users who declined to participate in occupational therapy sessions, including sessions on health and beauty, by disallowing phonecalls to solicitors and social workers;
- Failure to protect learning disabled people from targeting by telemarketing sales teams resulting in their economic exploitation;
- Failure to protect learning disabled residents in care homes from the violent behaviour of other residents; and
- Learning disabled people being tied down for long periods ostensibly to 'protect them' from self-harm.

The Committee has expressed a particular interest in practical means of securing the human rights of people with learning disabilities and positive examples of good practice.

BIHR has direct experience of the positive use of human rights law and wider human rights based approaches (the process of putting human rights principles into practice) to improve the lives of learning disabled people.

In particular, we would like to draw the Committee's attention to our 'Human Rights in Healthcare' framework, developed in collaboration with the Department of Health and five NHS Trusts. Please find enclosed a copy of this framework, published in March 2007 (available at http://www.bihar.org/downloads/Health_framework.pdf). The framework is a groundbreaking attempt to explore how human rights based approaches can be used in the healthcare context.

The Committee has shown an interest in the ability of learning disabled people to make their voices heard. Human rights based approaches are the process of taking human rights principles and standards (like our own Human Rights Act) and making them meaningful in practice. These approaches have been pioneered in the international development context as a way for people in poverty to empower themselves and tackle its root causes but only now are they beginning to be explored in more developed countries. Empowerment and participation are integral to human rights based approaches (see in particular pages 20, 23 and 24 of the framework) and given the experiences of exclusion from decision-making that many learning disabled people report, we believe that human rights based approaches could have much to offer. BIHR, in partnership with other organisations, is developing this work and recently launched Principles to Practice, a programme of work aimed at building the capacity of voluntary and community sector organisations to use human rights based approaches in their work. We will be keen to work with organisations of and for learning disabled people as we develop this programme.

One of the pilot sites for the 'Human Rights in Healthcare' framework was Mersey Care NHS Trust ('Mersey Care'). Mersey Care is somewhat unique amongst NHS organisations in that it has placed 'rights' at the heart of all its operations. As part of the 'Human Rights in Healthcare' project, Mersey Care chose to pilot a 'human rights based approach' to its learning disability inpatient services. It has produced an 'easy read' tool designed to elicit the views of service users about their experience of human rights as inpatients. The learning generated from this tool will be used in the organisation's strategy, policy and decision making (for a discussion of the project see Appendix A in the framework).

We understand that other submissions to the Committee refer to the excellent work of Mersey Care in this area. For our part, we would like to stress to the Committee that the staff who attended our 'human rights based approaches' induction day were extremely enthusiastic about the potential of human rights to improve their services in a wide range of areas including service user involvement, religious and spiritual care, delayed discharges, equality and diversity, impact assessment processes, and policy making. This reflects our experience of human rights capacity building generally which demonstrates that once equipped with knowledge about human rights ideas and laws and how these might work in practice, service providers quickly see their value as a tool for improving the quality of services and for engaging and involving people who use services more closely in decision-making.

Please also find enclosed a copy of our recent report 'The Human Rights Act – Changing Lives' (available at http://www.bihhr.org/downloads/Health_framework.pdf). This report, launched in April 2007, tackles the fallacy that the Human Rights Act is only useful for lawyers, or for 'chancers' seeking to frustrate our justice system. It reveals instead a range of ways in which the Act has been used by groups and individuals to make a difference to everyday life in the UK. Three of the fifteen case studies involve people with learning disabilities and they show how BIHR's capacity building activities with service providers and voluntary and community organisations has led to real change. Case studies 2, 13 and 14 are reproduced below:

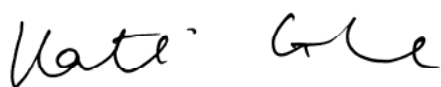
- Case study 2 - A learning disabled man in a care home became very anxious about bathing after slipping in the bath and injuring himself. Afterwards, in order to reassure him and to build his confidence once again, a carer, usually female, would sit in the room with him as he bathed. His female carers felt uncomfortable with the arrangement. One carer commented during a BIHR training session: 'I knew in my heart he was being treated without dignity, and now I recognise that his human rights are perhaps being violated.' A discussion of the human rights principle of dignity had served as a 'trigger' for her and together with co-workers she was able to develop solutions that would both protect the man's dignity, whilst also providing him with the support he needed. She indicated that she would use the language of human rights, specifically the right not to be treated in an inhuman and degrading way and the right to respect for private life, to seek a new care assessment for the man who, in her view, required manual lifting. In the meantime she resolved to erect a screen in the bathroom for herself and other carers to sit behind while the man bathed;
- Case study 13 - A local authority had a policy of providing school transport for children with special educational needs living more than 3 miles from their school. A

young learning disabled girl lived 2.8 miles from the special school she attended. Despite being unable to travel independently, she was advised by the authority that she should instead take two buses to and from school each day. An independent parental supporter who had attended a BIHR training session supported the girl's mother to challenge the decision using human rights language. The mother approached the head teacher of the school and explained that the decision was a disproportionate interference with her daughter's right to respect for private life, given the failure to consider her specific circumstances. The head teacher took the issue to the local authority, and the decision was reversed. Thereafter the young girl was provided with transport to and from school; and

- Case study 14 - A learning disabled man in a privately run residential care home had a history of starting fires. Although this had not occurred for over two years, care home staff were instructed by his psychiatrist to routinely search him each time he returned from being out unsupervised to ensure he did not have matches or a lighter. This practice was challenged by a health commissioner for the NHS Primary Care Trust (PCT) which had contracted the care home to provide the man with residential care. The health commissioner invoked the man's right to respect for private life to argue successfully that the blanket policy should be replaced with a proper decision-making process. The new decision-making process was based on ongoing risk assessment and was communicated to the man to ensure he understood why, when, how and by who he would be searched and when the practice would be reviewed. It was agreed that routine searching would cease after six months if no matches or lighter were found on the man and if he was not involved in any fire related incidents.

Finally, we have also enclosed a copy of 'Your Human Rights – A guide for disabled people' (available at http://www.bihar.org/downloads/guide/bihar_disabled_guide.pdf). This plain English guide touches on the relevance of Articles 3, 8, 2 and 14 to disabled people and we hope it will be useful for the Committee as it considers the range of human rights that apply to people with learning disabilities in particular.

Yours sincerely,



Katie Ghose
Director

Enclosures:

1. BIHR and the Department of Health, 'Human Rights in Healthcare – A Framework for Local Action'
2. BIHR, 'The Human Rights Act – Changing Lives'
3. BIHR, 'Your Human Rights – A guide for disabled people'