



## **COMMISSION ON A BILL OF RIGHTS**

### **Response to Consultation on Human Rights Act**

**8th November 2011**

We are a user-led organisation committed to raising aspirations and confidence amongst Disabled people. We are working towards increasing choice and control to promote and support independent living.

We are writing this response to the consultation on the Human Rights Act because this Act is vital to protecting the rights of disabled people in this country to lead an independent life with dignity, free from abuse or neglect.

**Article 19 (living independently and being included in the community)** *provides that disabled people have an equal right to live in and take part in the community with the right to the same choice and control as non-disabled people. Governments should do everything they can to ensure disabled people enjoy these rights, in particular they should ensure that disabled people have the right to choose where, and with whom, they live; have access to a wide range of support services (at home and in the community) including personal assistance to prevent isolation and support inclusion, and can access the same community services as everyone else.*

Despite the above article, many disabled people are still not given the correct amount of support to help them make their own choices, often leaving them isolated within their own communities. Many needs are not being met by some local authorities to ensure disabled people have an equal part in the community.

Disabled people have been under constant attack lately. Whether it's the vast and wide-ranging benefit cuts; Birmingham city council refusing care to people with substantial needs, which has since been ruled unlawful; cuts in Access to Work, ironically when we are being told we should all be getting jobs; or the impending closure of the Independent Living Fund, the hits feel like they are coming from every direction.

A known case is of Elaine McDonald who lost a Supreme Court fight for her local council to allow her to continue to have overnight care. Funding was withdrawn by the Royal Borough of Kensington and Chelsea for the overnight care that is needed to assist her with going to the toilet during the night, and the council instead gave her some incontinence pads, stating that this was cheaper. However she is not incontinent! And she, quite rightly, objects to being asked to lie in bed for 12 hours at a time (since her care has been cut), in her own waste.

Without the Human Rights Act Disabled people will have no safety net to protect us, particularly in this current economic climate when so many of us are finding essential support and care is being reduced and/or withdrawn but often it is Disabled and older people who have the least energy and resources to fight the decisions made about their lives making them most vulnerable to Human Rights abuses.

## Personal Stories

- 1 *"I have recently moved from living with family to living independently and the struggles and fights that I am having pursue to be able to do this with the right amount of support. At the moment my Local Authority and Continuing Health Care Fund are arguing who is going to pay for this, in the meantime I am expected to go on struggling. I have a long term congenital condition and require help and support for all my needs and yet the local authority told me that i could manage without support at night even though i am unable to move or use the toilet unaided. My social worker also suggested I be strapped into my wheelchair. This is a clear breach of my human rights, as well as dangerous I need to quickly sit forward to prevent choking and couldn't release myself if needed."*
- 2 *"I have severe Arthritis meaning I have limited range of moment and strength in all my joints. I have been on Direct Payments/Personal Budgets for 12 years and have had considerable problems in getting the local authority and ILF to understand they are not giving flexibility and choice of use of the monies. I am using the Human Rights Act with other such acts to challenge the local authority. Quite simply, without such legislation we are back in the 1960 s and institutionalisation, meaning that all the ideas and resources of personalisation choice and control are wasted money!"*
- 3 *"Having lost my husband and having to pay for my own care, due to his pension. I find that I've got no-one for advice and checking that I'm ok. I'm disabled, living alone and just left to carry on as if nothing has happened. All the council will say is you've got the money so you pay, or you get assessed by us, pay the full amount for our service as we'll as pay your carers wages then we can help. You take away my human rights too and you will find that I and many others like me are just left to rot. People will take advantage of the situation and I and others will not have a leg to stand on. We won't be independent we will be some-one that society forgot about like they did in the olden days. Are we moving forward or just finding away to stop caring for the elderly and vulnerable"*
- 4 *"30 years ago I suffered a spinal cord injury due to a work related accident resulting in lower limb paralysis. On discharge from hospital I received personal care from Social Services but over the years the amount of care given was slowly decreased to a point where I had hardly any quality of life & other health related conditions started happening. 18 months ago I took up a Direct Payment/Personal Budget & now employ two PA/Carers on a rota system. Back in the 80's care was fairly freely available through local Social Services, but over the years the availability & meeting the assessment criteria has changed very much for the worse. Should the Human Rights law be changed or partly withdrawn the Disabled person will have no recourse to law to fight for reasonable care. Active Independence feel that people who are in need of social care will be returning back to the 1950's when there was hardly any provision."*

We urge the commission to do all in its power to protect the Human Rights Act to make sure that Disabled people have at least their **basic** human rights protected so that in a civilised society they can aspire to live independently with dignity and respect

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