

1st April 2010

Equality and Human Rights Commission
Arndale House
The Arndale Centre
Manchester
M4 3AQ

Dear Sir/Madam

Comments on Equality Bill Draft Statutory Code of Practice on Services, public functions and associations

I am writing in response to your consultation on the Equality Bill Draft Statutory Code of Practice on 'Services, public functions and associations'.

Drawing on the recently published report of the Nuffield Council on Bioethics, *Dementia: ethical issues*, I would like to make a number of points in relation to how the Code of Practice relates to the discrimination of people with dementia. Paragraph numbers in brackets refer to the Council's report.

Reference to dementia in the Code of Practice

The Bill specifies that a person has a disability if they have a physical or mental impairment which has a long-term and substantial adverse effect on their ability to carry out normal day-to-day activities. This clearly includes dementia – a term that we take to describe a collection of signs and symptoms such as memory and communication problems, changes in mood and behaviour, and the gradual loss of control of physical function caused by a variety of different diseases, of which Alzheimer's disease is the most common – but it is not currently mentioned at all in the Code of Practice. It would be helpful if the Code could make clear that dementia does constitute a disability.

The Bill specifies that a form of discrimination against a disabled person occurs where a service provider fails to comply with a duty to make reasonable adjustments imposed on them in relation to that disabled person. The Code of Practice includes a range of examples of how discrimination of this kind can be avoided, for example, against people with hearing or sight impairments. Again,

Chair
Professor Albert Weale FBA

Deputy Chairman
Professor Hugh Perry FMedSci

Members
Professor Steve Brown FMedSci
Professor Roger Brownsword
Dr Amanda Burls
Professor Robin Gill
Professor Sian Harding FAHA FESC
Professor Ray Hill FMedSci
Professor Søren Holm
Professor Christopher Hood FBA
Dr Rhona Knight FRCGP
Professor Graeme Laurie FRSE
Dr Tim Lewens
Professor Ottoline Leyser CBE FRS
Professor Anneke Lucassen
Professor Alison Murdoch FRCOG
Dr Bronwyn Parry
Professor Nikolas Rose
Professor Dame Marilyn Strathern DBE FBA
Professor Joyce Tait
Geoff Watts
Professor Jonathan Wolff

Director
Hugh Whittall

Assistant Directors
Dr Alena Buyx
Katharine Wright

the Code does not refer to dementia, despite the fact that 800,000 people currently have dementia in the UK and this is set to rise. **We therefore urge the ECHR to revise the Code to include examples of good practice with regard to how service providers can make 'reasonable adjustments' for people with dementia [paragraph 4.31].**

Inclusion in 'everyday' society

The Council found that a diagnosis of dementia may be seen as placing people immediately in an 'other' category, where it is assumed that the person will not be able to participate in ordinary activities. However, we should not make the generalisation that people with dementia cannot or should not participate in ordinary activities where they wish to do so. The emphasis in our ethical framework on the value and equality of people with dementia, and the importance of solidarity in responding to the challenges that dementia poses, put the onus on society as a whole to make itself as inclusive as possible towards people with dementia [paragraph 4.19].

'Dementia-friendly' environments

Good practice guidance on building 'dementia-friendly' environments is becoming available with organisations such as the Dementia Services Development Centre in Stirling, and the Oxford Centre for Sustainable Development, publishing checklists on both interior and exterior design for people with dementia. Indeed, the development of 'dementia-friendly' premises within the NHS is highlighted in the Scottish dementia priority paper, and there is growing interest in the importance of environmental design in specialist dementia care environments. However, practical guidance on what reasonable adjustments ordinary service providers such as shops, leisure services and restaurants could be expected to make for people with dementia is not readily available. Yet relatively minor environmental adjustments, such as clearer signage, strong lighting and non-slip, non-reflective flooring, as well as an increase in staff awareness and understanding of dementia, could do much to make services more accessible to people with dementia, particularly in the relatively early stages [paragraph 4.21].

Role of EHRC in publicising legal duties of service providers


The EHRC has a remit, not only to enforce equality law, but also to promote good practice with respect to equality and human rights in the public, private and voluntary sector; and to undertake high-profile media campaigns to highlight particular equality issues. It is therefore well-placed to provide the practical guidance required to ensure that people with dementia are able to access services in the same way as anyone else, with or without disabilities.

We recommend that the EHRC takes appropriate action to publicise both the legal duties to which all “service providers” are subject under the Equality Bill to ensure equal access to their services by people with dementia, and appropriate ways in which this could be achieved [paragraph 4.31].

The Council’s report *Dementia: ethical issues* is available to download at www.nuffieldbioethics.org/dementia. A copy will also be posted to you, along with a hard copy of this response.

Please do not hesitate to contact me if you would like further information or assistance.

Yours sincerely

A handwritten signature in black ink that reads "Hugh Whittall". The signature is written in a cursive style with a large initial 'H' and a long, sweeping tail on the 'l'.

Hugh Whittall
Director