

3 September 2007

Kate Hepher
Discrimination Law Review Team
Women and Equality Unit
Department for Communities and Local Government
Ashdown House
123 Victoria Street
London SW1E 6DE

Dear Ms Hepher,

- 1 Thank you for the opportunity to respond to the Discrimination Law Review – A Framework for Fairness: Proposals for a Single Equality Bill for Great Britain. The Council has carried out work that is relevant to Question 57: ‘Do you agree that there is no current justification for legislating to prohibit genetic predisposition discrimination?’
- 2 The Council has not explicitly recommended that measures to protect against genetic discrimination, for example in insurance and employment contexts, should be enshrined in legislation. However, it has concluded that, although use of genetic information by employers and insurance companies is currently uncommon, it is important that safeguards are in place to protect against potential genetic discrimination in future.

Genetic Screening: A Supplement to the 1993 Report

- 3 In the Council’s publication *Genetic Screening: A Supplement to the 1993 Report* (2006), it notes that there appears to be no evidence that UK employers are carrying out systematic genetic screening (or testing) or using genetic test results in recruitment or occupational health schemes. We endorse the recommendation from a committee established by the Council of Europe that ‘[i]n principle, a pre-employment medical examination should be limited to assessing the ability of the applicant to perform the job at the moment of the examination or in the immediate future’¹ (paragraph 6.2-6.9).

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- 4 With regard to the use of genetic information by insurance companies, the Council endorsed the continuation of the current moratorium on the disclosure of genetic data, which has been extended until 2011. However, it noted that there is some uncertainty whether the issues surrounding genetic tests and insurance will be fully resolved by 2011. For example, the Genetics and Insurance Committee has recognised that there may be people whose uncertainty about their situation after the moratorium is discouraging them from taking medically useful tests before it expires.² (paragraph 6.10-6.17)

Genetics and Human Behaviour: The Ethical Context

- 5 In the Report *Genetics and Human Behaviour: The Ethical Context* (2002), the Council considered the use of genetic information related specifically to behavioural traits within the normal range. It concluded that:
- Employers should not demand that an individual take a genetic test for a behavioural trait as a condition of employment. The proper approach would be to monitor employees for early warning signs of behaviour (such as violence) that would make them incapable of performing the job satisfactorily.
 - Any inquiry into the potential use of genetic testing of behavioural traits in the workplace should include an investigation of the use of other purportedly predictive scientific methods, such as psychometric tests, for similar purposes (paragraph 15.21).
- 6 In the same Report the Council recommended that the use of genetic information about behavioural traits in the normal range should be interpreted as falling under the scope of the five-year moratorium agreed in the UK in 2001, and should therefore not be used by insurance companies in setting premiums. Future discussion of possible legislation should include specific consideration of genetic information regarding behavioural traits. If the use of such information were considered, a thorough examination of the accuracy and reliability of any genetic tests and their likely predictive power would be essential (paragraph 15.37).

Copies of these publications are enclosed and can be downloaded at: www.nuffieldbioethics.org/go/publications/latest_30.html.

Please do not hesitate to contact me if you require clarification on any of the information contained in this letter.

Yours sincerely,

Hugh Whittall
Director

¹ Council of Europe (2000) *Medical Examinations Preceding Employment and/or Private Insurance: A proposal for European guidelines*.

² Genetics and Insurance Committee (2006) *Fourth Report from January 2005 to December 2005* (London: Department of Health).