

# Chapter 15

Testing and selection  
in employment,  
education  
and insurance





## Testing and selection in employment, education and insurance

- 15.1 As noted in Chapters 13 and 14, the selection of individuals on the basis of a genetic predisposition to behavioural traits may have potential applications in several different settings. These include the streaming of children in schools, aptitude testing for university entrance or employment, and the screening of potential or existing employees on the basis of genetic susceptibility to behavioural traits such as aggression, anxiety, novelty-seeking or sexual orientation. Insurers might also wish to make use of knowledge about genetic predispositions to certain behaviours, such as risk-taking, for some types of personal and life insurance and employer's liability and medical insurance. These possible uses of genetic information are discussed in this chapter, following an account of some relevant general principles.
- 15.2 One series of questions relevant to all these contexts is those relating to privacy, consent and confidentiality. These were investigated in relation to inherited disease and disability in the earlier Report of the Nuffield Council on Bioethics on *Genetic Screening: Ethical Issues* (1993), and in the report of the Human Genetic Commission (HGC), *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (May 2002). Although issues regarding privacy, consent and confidentiality which are specific to behavioural genetics are discussed in this chapter, the reader is referred to those reports for consideration of the broader aspects.<sup>1</sup>
- 15.3 Another general question concerns the accuracy and predictive capacity of genetic tests. Earlier chapters of this Report have indicated that our behaviour is complex, influenced both by genetic and environmental factors, and by our own decisions. At present, accurate and reliable tests of the genetic components of behaviour in the normal range simply do not exist. If a screening device is not accurate and reliable, it cannot be the basis for fair and efficient decisions in relation to education, employment or insurance. In addition, if a behavioural trait is wrongly assumed to be immutable, then many personal achievements, which are the product of learning, individual initiative, determination and hard work, may be neglected. This is not a problem peculiar to genetic testing for behavioural traits. There is considerable use of IQ and aptitude tests for entrance to schools and universities. In the context of employment, interviewing is by far the most commonly used technique for the recruitment for managerial, professional and skilled manual jobs. However, a recent survey by the Chartered Institute for Personnel and Development (CIPD) revealed that questionnaires to evaluate personality traits are increasingly used.<sup>2</sup> These methods profess to assess cognitive ability, personality, propensity for dishonesty or other deviant behaviour and traits such as anger, aggression, anxiety, obsession and low self-esteem. There is much scepticism about the predictive validity of these tests.<sup>3</sup> The major risk is that of wrongly attributing to the individual the characteristics of the group. It is difficult to know how accurately the test will identify those who will act on a particular propensity.

<sup>1</sup> The Reports are available at the websites of the Nuffield Council on Bioethics and the Human Genetics Commission, <http://www.nuffieldbioethics.org/publications/index.asp> and <http://www.hgc.gov.uk/insideinformation/index.htm> respectively (17 June 2002).

<sup>2</sup> CIPD. (2001). *Fifth Annual Report on UK Recruitment Practices*. Personality questionnaires were used by 40.7% of respondents; 54.5% used general ability tests; 60.1% used tests of specific skills and 44.6% literacy/numeracy tests.

<sup>3</sup> See Finkin, M. W. (2000). From anonymity to transparency: screening the workforce in the information age. *Colum. Bus. L. Rev.* 2000, 403–51, at pages 417–26 and 447–51 for a review.

### Box 15.1: Guiding legal principles

The general legal principles relevant to policy and regulation of the use of genetic information can be derived in the main from three instruments:

- The Convention For the Protection of Human Rights and Dignity Of The Human Being with Regard To The Application of Biology and Medicine (Council of Europe, Oviedo, 4 April 1997) ('the Convention')
- The Universal Declaration on the Human Genome and Human Rights (UNESCO, 11 November 1997) ('the Declaration')
- Charter of Fundamental Rights of the European Union (EU, Nice, 7 December 2000) ('the Charter').

The relevant provisions of these instruments may be summarised as follows:

#### *The Convention*

The Convention expressly prohibits any form of discrimination on grounds of genetic heritage. Further, it provides that tests which are predictive of genetic diseases or which serve to identify a person as a carrier of a gene responsible for disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes<sup>1</sup> or for scientific research linked to health purposes and subject to appropriate genetic counselling. Interventions on the human genome are prohibited unless undertaken for preventive, diagnostic or therapeutic purposes and only if the aim is not to introduce any modification to the genome of any descendants. The Convention has not yet been ratified by the UK and has no legal force in this country.

#### *The Declaration*

The Declaration provides that everyone has the right to respect for their dignity and their rights regardless of their genetic characteristics and that such dignity 'makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity' (Article 3). Research, treatment and diagnosis affecting an individual's genome shall only be undertaken after rigorous and prior assessment of the risks and benefits pertaining thereto. Like the Convention, the Declaration includes an express prohibition on discrimination based on genetic characteristics that is intended to or has the effect of infringing human rights. Genetic data must be held in conditions of confidence, and no research or applications of research concerning the human genome (in particular in the fields of biology, genetics and medicine) should prevail over respect of human rights and the dignity of individuals. The Declaration has no legal force and is intended only as a statement of principles which states are asked to promote.

#### *The Charter*

In common with the Convention and the Declaration, the Charter contains an express and free-standing provision which prohibits any discrimination based on genetic features. As part of the right to respect for physical and mental integrity, Article 2 provides that, in the fields of medicine and biology, particular respect must be given to prohibition of eugenic practices,<sup>1</sup> in particular those aimed at the selection of persons. The UK, as a Member of the European

Union, is a party to the Charter. The Charter is a non-binding instrument which is likely to have only indirect legal force through resort to it by the European Court of Justice as a source of legal principle.

\* The Explanatory Report to the Convention (paragraphs 84 to 86) makes clear that genetic testing for employment or insurance purposes or other commercial purposes falls outside the legitimate testing for health care purposes, and is a disproportionate interference with the rights of the individual to privacy. Paragraph 86 provides: 'An insurance company will not be entitled to the holding of a predictive genetic test. Nor will it be able to refuse the conclusion of modification of such a policy on the ground that the applicant has not submitted to a test as the conclusion of a policy cannot reasonably be made conditional on the performance of an illegal act'. The Convention does, however, provide (in Article 26) that the restriction on predictive genetic tests may be overridden where prescribed by law and necessary in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others.

† It is to be noted that the European Group on Ethics in Science and New Technologies, when reporting on the draft Charter insisted (by a majority) that a specific additional provision dealing with eugenic practices be included. The minority considered that there was a difficulty in defining eugenics and the group as a whole recognised that certain current practices might be properly termed as eugenics. The majority, however, insisted on inclusion of a specific prohibition because otherwise 'the Charter would be missing the point if it did not refer to one of the main challenges of human genetics.' See European Group on Ethics in Science and New Technologies. Citizens Rights and New Technologies: A European Challenge (Brussels, 23 May, 2000). [http://www.europarl.eu.int/charter/civil/pdf/con233\\_en.pdf](http://www.europarl.eu.int/charter/civil/pdf/con233_en.pdf) (18 Jul 2002).

## Employment

### *The current legal framework*

- 15.4 In this section we set out how the law currently deals with the use of genetic information in the context of employment. It is important to note that, to date, most discussion in this area has focused on clinical disorders. The potential use of genetic information that concerns behavioural traits in the normal range of variation has not been widely considered.
- 15.5 At present there is no legislation in the UK that directly regulates genetic testing or the use of genetic information in employment. At common law, an employer may lawfully require an applicant to undertake genetic testing in order to be appointed to a particular job. Whether an existing employee can be required to submit to a genetic test depends on the express or implied terms of the individual's contract of employment. Employers have no general power to require employees to submit to medical examination (this would include a genetic test). However, it may be implied that the employee could be required to do so if the employer had reasonable grounds for believing that the employee might be suffering from a mental or physical disability likely to cause harm to the employee or to other people. This is an aspect of the so-called duty of mutual trust and confidence between employer and employee, which is an obligation of uncertain scope that depends upon judicial interpretation.<sup>4</sup> Similarly, at common law the right to use genetic information about an employee depends upon the express or implied terms of the employment contract. In some circumstances, discrimination law, the law on unfair dismissal and the developing law of privacy and confidentiality for employees might give rise to rights for jobseekers and employees (see paragraphs 15.11 – 15.15).

<sup>4</sup> See, for example, *Bliss v South East Thames Regional Health Authority*. (1985). Industrial Relations Law Reports 308. The Court of Appeal found that a medical examination had been imposed without reasonable cause because what the employer did (according to Lord Justice Dillon) was 'by any objective standard outrageous'.

- 15.6 By contrast, about half the states in the US have enacted laws prohibiting genetic discrimination in employment. President Clinton signed a similar Executive Order applicable to federal employees, excluding the Armed Forces, on 8 February 2000. The main reasons for this legislation in the US are, first, that employers responsible for the medical costs of employees and their dependants have a strong incentive to exclude those genetically predisposed to certain illnesses and, secondly, that individuals who are at a genetic risk of illness may be discouraged from taking genetic tests if they believe that their employers will have access to this information. Both of these reasons are significant in the US because of the employer's role in financing health care. The existence of the National Health Service (NHS) means that these motivations are of less significance in the UK.

### **Discrimination laws**

- 15.7 In both the US and the EU, genetic screening and the practice of using genetic information may run foul of employment discrimination laws, if the test or practice has a disproportionately adverse impact on a protected class such as women or ethnic minorities which cannot be objectively justified for reasons other than the gender, race and so on of the affected group. In the landmark case of *Griggs v Duke Power Co.*,<sup>5</sup> the US Supreme Court held that under Title VII of the Civil Rights Act, facially neutral standardised tests and high school graduation requirements had a disparate impact on black applicants and employees, and accordingly, the employer had to prove that the qualification requirements were job-related and consistent with business necessity.<sup>6</sup> Genetic testing would offend Title VII only if the effect of the test were to discriminate on the basis of race, colour, religion, sex or national origin. So far as is known, Title VII has not yet been invoked in respect of genetic testing. This may be due to the availability of the Americans with Disabilities Act 1990 (ADA) which can be used to challenge mandatory medical examinations that are not related to employment. However, even this is of limited significance because a genetic test that revealed the susceptibility of an employee to stress or other traits in certain working environments would be job-related and hence lawful.<sup>7</sup>
- 15.8 In the EU, a similar approach is taken to that in the US, under Article 141 (ex 119) of the European Community (EC) Treaty and the Equal Treatment Directive 76/207/EEC, in respect of what is termed 'indirect' sex discrimination. UK law has recently been amended, in line with the Burden of Proof Directive 97/80/EC, to define indirect sex discrimination as existing where 'an apparently neutral provision, criterion or practice disadvantages a substantially higher proportion of the members of one sex unless that provision criterion or practice is appropriate and necessary and can be justified by objective factors unrelated to sex.' For example, a factor which favours spatial ability may tend to be biased against women and the use of this criterion will have to be objectively justified. The Race Relations Act 1976, in section 1(1)(b), contains a slightly differently worded definition but the effect is also to make unlawful a requirement or condition which has an unjustifiable adverse impact on a particular racial group. On 29 June 2000, the EC adopted a directive on discrimination on grounds of race or ethnic origin, which must be implemented by the

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<sup>5</sup> *Griggs v Duke Power Co.* (1971). 401 US 424 .

<sup>6</sup> A test is facially neutral if it does not appear to be discriminatory. As illustrated, facially neutral practices may be found in violation of law if they result in significant differences in the distribution of benefits or services to persons based on race, national origin, sex or disability without a substantial legitimate justification, or, if there are equally or comparably effective alternative practices available that meet the same goals with less disparate impact.

<sup>7</sup> Rothstein, M. A. (2000). Genetics and the work force of the next hundred years. *Colum. Bus. L. Rev.* **2000**, 371–401. See p. 388.

UK by 19 July 2003. This defines 'indirect discrimination' as occurring where a provision, criterion or practice 'puts persons of a racial or ethnic origin at a particular disadvantage' without objective justification. On 28 November 2000, the EC adopted Directive 2000/78/EC for combating direct and indirect discrimination in employment on the grounds of religion or belief, disability, age or sexual orientation.<sup>8</sup> This contains a definition of indirect discrimination similar to that in the UK Race Relations Act. The provisions in the EC Directive on sexual orientation must be implemented by the UK by 2 December 2003. They will effectively prevent the use of genetic information relating to sexual orientation in the field of employment. Those relating to disability must be implemented by 2 December 2006, but are unlikely to involve any significant change in existing UK law.

- 15.9 Although these prohibitions in indirect discrimination do provide a potential barrier to the use of genetic testing and information, their limitations are obvious. The employer can justify its actions on the grounds that the specific test is accurate and reliable and that the use of the information is 'appropriate and necessary' to the requirements of the job. Effectively, discrimination law leaves the control of genetic testing in the employer's hands and is not primarily concerned with its effect on the dignity or autonomy of the employee.
- 15.10 The Disability Discrimination Act 1995 (DDA) in the UK aims to protect disabled persons from discrimination. A disability is defined as 'a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day to day activities.' 'Impairment' is not defined but Regulations provide that addiction to alcohol, nicotine or any other substance is to be treated as not amounting to an impairment for purposes of the Act.<sup>9</sup> Similarly, the following conditions do not amount to impairments: a tendency to set fires, a tendency to steal, a tendency to physical or sexual abuse of other persons, exhibitionism and voyeurism. Although mental illness is covered by the Act, the illness must be 'clinically well-recognised'.<sup>10</sup> Moreover, a person is disabled only if their 'ability to carry out normal day-to-day activities is impaired' and the impairment must have a 'substantial and long-term adverse effect' on the ability to carry out those activities.<sup>11</sup> While some 'progressive conditions' are covered, this does not include those who merely have a genetic or other predisposition to (or risk of) a progressive condition in the future. In the US, on the other hand, the Equal Employment Opportunity Commission has issued an interpretation of the ADA that an employer who discriminates against an individual on the basis of the results of a predictive genetic test would be 'regarding' the individual as having a disability and so violating the ADA. The view of at least one leading legal expert is that this interpretation will not withstand judicial scrutiny.<sup>12</sup> In any event, the UK legislation does not at present include those who are simply 'regarded' as having a disability. The DDA, therefore, at present has little relevance to genetic predisposition to behavioural traits in the normal range.

<sup>8</sup> The Sex Discrimination Act and the EC Equal Treatment Directive do not apply to discrimination on grounds of sexual orientation: *Secretary of State for Defence v MacDonald*. (2001). *Industrial Relations Law Reports* 431.

<sup>9</sup> Disability Discrimination (Meaning of Disability) Regulations. (1996). SI 1996 No.1455.

<sup>10</sup> Disability Discrimination Act. (1995). Schedule 1, paragraph 1(1).

<sup>11</sup> Disability Discrimination Act. (1995). Schedule 1, paragraph 1(1).

<sup>12</sup> Rothstein, M. A. (2000). Genetics and the work force of the next hundred years. *Colum. Bus. L. Rev.* **2000**, 371–401. See p. 388.

### *Unfair dismissal*

15.11 An employee who is already working for an employer may have a remedy under the Employment Rights Act 1996 (ERA).<sup>13</sup> The weakness of this protection, from the employee's viewpoint, is that in determining this question, the tribunals give employers a broad margin of discretion (the so-called 'band of reasonable responses') in deciding whether or not to dismiss the employee. An employer would, however, be bound to follow a fair procedure, including a reasonable investigation and an opportunity for the employee to contest the facts or show why he or she should not be dismissed.

### *Privacy and confidentiality*

15.12 Article 8 of the European Convention on Human Rights and Fundamental Freedoms (ECHR) provides that everyone has the right to respect for their 'private or family life'. The ECHR was incorporated into domestic law by the Human Rights Act 1998 (HRA), giving individuals the right to claim compensation against public authorities (including public employers) who violate this right. Courts and tribunals are bound to give effect to the ECHR, so that when interpreting the duty of mutual trust and confidence or the law on unfair dismissal (paragraph 15.11) they must have regard to Article 8.

15.13 It seems likely that aspects of biometric and genetic testing and the use of genetic information about an individual fall under the concept of 'private and family life'. This can be deduced from the case law of the European Court on Human Rights which has afforded a high degree of protection under Article 8 to personal health and bodily integrity. The right is not, however, absolute. The infringement may be justified if it is shown to be 'necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of crime or disorder, for the protection of health or morals, or for the protection of the rights and freedoms of others.'<sup>14</sup> In the employment field, it is likely that courts and tribunals will require the employer to show both that the use of genetic information was necessary in relation to a specific job, and that its use was proportionate to a legitimate aim such as protecting the health and safety of others. It seems that a contractual restriction on the right to privacy will also have to pass this strict test of justifiability.

15.14 Another possible form of protection for genetic information is the common law on breach of confidence. An obligation of confidence arises in an employment relationship, but it is by no means clear what kinds of personal information would be protected since nearly all the decided cases involve breach of commercial confidences. Accordingly, the Data Protection Act 1998 (DPA) is much more significant than the common law. Under the DPA 'sensitive personal data' is given special protection. This includes personal data of a person's 'physical or mental health or condition'. Most genetic information would appear to fall under this protection, as would genetic information about a person's 'sexual life'.

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<sup>13</sup> For example, an employee who is dismissed for refusing to submit to a genetic test or for not allowing the use of genetic information, where this is not provided for in the contract of employment and amounts to a breach of the duty of mutual trust and confidence may complain that the dismissal is unfair. Even short of actual dismissal, there may be a 'constructive' dismissal entitling the employee to resign and claim compensation. The employer will have to show that it genuinely believed that the dismissal related to the employee's 'capability' or 'conduct' or 'some other substantial reason' justifying dismissal. The employment tribunal will then assess whether the dismissal is fair or unfair 'having regard to equity and the substantial merits of the case'.

<sup>14</sup> European Convention on Human Rights and Fundamental Freedoms. Article 8(2).



15.15 The handling of genetic test results is required to meet the DPA's principles of fairness and lawfulness. In particular, the explicit consent of the individual is required (unless there is a legal obligation to process the data). The EC Data Protection Directive 95/46/EC, on which the DPA is based, specifies that consent must be 'freely given, specific and informed'. The UK Information Commissioner has given guidance interpreting this as meaning that there must be some active communication between the parties.<sup>15</sup> An individual or organisation who uses data cannot infer consent simply from non-response to a communication. The Information Commissioner has issued a draft code of practice on the use of personal data within employer/employee relationships, under section 53 of the DPA. This contains a section dealing with the use of genetic testing in employment which is based on the recommendations of the 1999 report of the Human Genetics Advisory Commission's (HGAC) on *Implications of Genetic Testing for Employment*.<sup>16</sup> The final version of the Code relating to medical and genetic testing is due to be published by the end of 2002.

### Earlier reform proposals

15.16 The potential uses of personal genetic information in employment have been the subject of several earlier reports. However, all of these focus on information that is predictive of inherited disease or information about particular genetic variations that might indicate that a person is susceptible to a specific occupational disease or workplace chemical. None of these reports has considered the use of personal genetic information relevant to particular traits within the normal range of behaviour. Our focus is on whether the conclusions in those earlier reports relating to inherited disease and occupational hazards are also applicable to normal behavioural traits.

15.17 The report of the HGC concluded that at present there is no evidence in this country of any systematic use of predictive personal genetic information in employment.<sup>17</sup> This confirms the findings of the earlier reports of the Nuffield Council and the HGAC.<sup>18,19</sup> Indeed, since the latter reports were published, the only employer that had been known to use such tests (the Ministry of Defence, to screen aircrew recruits for sickle cell disease) has ceased the practice. The HGAC concluded that 'it will take major developments both in our understanding of common diseases and in genetic testing itself before genetic testing becomes a serious issue for employment practice' and this conclusion applies equally strongly to behavioural traits and non-clinical characteristics.

15.18 The report of the HGAC proposed a common set of principles for policy, aimed at providing appropriate protection to the public if and when genetic testing for diseases in employment becomes a real possibility. We consider that these principles form a useful basis for policy-making and apply equally to behavioural traits as to diseases. They are:

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<sup>15</sup> The Information Commissioner enforces and oversees the Data Protection Act 1998 and the Freedom of Information Act 2000. The Commissioner is an independent supervisory authority reporting directly to the UK Parliament.

<sup>16</sup> Human Genetics Advisory Commission. (July 1999). *Implications of Genetic Testing for Employment*.

<sup>17</sup> Human Genetics Commission. (2002). *Inside Information: Balancing Interests in the Use of Genetic Data*. paragraph 8.9.

<sup>18</sup> Nuffield Council on Bioethics. (1993). *Genetic Screening: Ethical Issues*. Chapter 6.

<sup>19</sup> Human Genetics Advisory Commission. (1999). *The Implications of Genetic Testing for Employment*, para.3.5; Trade Union Congress. (1998). *Genetic Testing by Employers*. 2nd ed., reported that 'genetic testing by employers is still rare in this country'. The Health and Safety Commission. (1996). *Report of the Working Group on Genetic Screening and Monitoring*, p.7, made a similar finding.

- (i) An individual should not be required to take a genetic test for employment purposes – an individual's 'right not to know' their genetic constitution ought to be upheld.
- (ii) An individual should not be required to disclose the results of a previous genetic test unless there is clear evidence that the information it provides is needed to assess either current ability to perform a job safely or susceptibility to harm from doing a certain job.
- (iii) Employers should offer a genetic test (where available) if it is known that a specific working environment or practice, while meeting health and safety requirements, might pose specific risks to individuals with particular genetic variations. For certain jobs where issues of public safety arise, an employer should be able to refuse to employ a person who refuses to take a relevant genetic test.
- (iv) Any genetic test used for employment purposes must be subject to assured levels of accuracy and reliability, reflecting best practice in accordance with the principles established by the Advisory Committee on Genetic Testing: '[A]ny use of genetic testing should be evidence-based and consensual. Results of any test undertaken should always be communicated to the person tested and professional advice should be available. Information about and resulting from the taking of any test should be treated in accordance with Data Protection principles ... Furthermore, test results should be carefully interpreted, taking account of how they might be affected by working conditions.'
- (v) If multiple genetic tests were to be performed simultaneously, then each test should meet the standards set out in (ii), (iii) and (iv).

15.19 The Report of the HGC concluded that genetic testing is unlikely to provide any information that cannot be gathered by means of existing medical and screening procedures. Given the current uncertainties about interpreting genetic information, the HGC considered that it would be more appropriate to monitor the health of a person by other more direct means.<sup>20</sup> It recommended a voluntary undertaking by employers to inform the HGC of any proposals to use genetic testing for health and safety purposes.<sup>21</sup> The HGC also recommended that genetic tests should not be a condition of employment.<sup>22</sup>

### **Testing for behavioural traits**

15.20 As already noted, the recommendations in earlier reports are concerned with the occupational health and safety of employees and jobseekers. They apply a model of the autonomy of the individual patient in the medical sphere to the employment relationship. In the case of behavioural traits within the normal range, which are the subject of this Report, we are not concerned with patients. Moreover, the employment relationship is less receptive to the application of the medical model. The inherent inequality of bargaining position and power between the employer and the individual employee means that the employer is likely to initiate the tests and to decide how they are to be administered and used. A 'right to refuse' to take a test to disclose genetic information or a 'right to know'

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<sup>20</sup> Human Genetics Commission. (2002). *Inside Information: Balancing Interests in the Use of Genetic Data*. paragraph 8.18.

<sup>21</sup> *Ibid.* paragraph 8.19.

<sup>22</sup> *Ibid.* paragraph 8.15.

the outcome, is likely to be of little practical value where the employee has to choose between exercising the right or waiving it in order to secure a livelihood. The public interest or paternalistic justifications for overriding the individual's wishes where there is a serious danger to the health or safety of the employee or third parties do not exist in the case of non-clinical behavioural traits.

15.21 This leads us to the following conclusions and recommendations in the context of the use by employers of genetic testing for behavioural traits:

- **The primary duty of employers is to provide a safe environment for their employees and others. The aim should be to remove hazards from the workplace, not to remove employees on the basis of inherited characteristics or susceptibility to particular forms of behaviour within the normal range.**
- **Employees should be selected and promoted on the basis of their ability to meet the requirements of the job, and they should be monitored to ensure that their performance meets those requirements.**
- **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.**

15.22 There is a question whether the Disability Discrimination Act (DDA) should be extended to cover (i) genetic predispositions in general, and (ii) non-clinical behavioural traits in particular. On the first question, the Disability Rights Commission (DRC) has recommended that the DDA should be extended to people who have a genetic predisposition and that legislation should prohibit employers from viewing the results of genetic tests save in very limited circumstances.<sup>23</sup> The DRC has not dealt specifically with the second question. In our view, there is a danger that singling out genetic predispositions to behavioural traits within the normal range for special treatment or labelling them as 'disabilities' will aggravate the stigma attached to certain behavioural traits. This danger might be overcome by including discrimination on grounds of 'genetic features' in a single general statute covering all forms of unlawful discrimination.<sup>24</sup> Such legislation should specifically cover asymptomatic employees.

## Education

15.23 Some of the traits that are studied in behavioural genetics are of particular relevance to education. The most obvious link is with intelligence, but research into traits such as antisocial behaviour may also have implications for the education system. Educationalists have already developed a range of tests with which children can be assessed, such as

<sup>23</sup> Disability Rights Commission (2002). *First Review of the Disability Discrimination Act*.

<sup>24</sup> This would be in accordance with Article 25 of the EU Charter of Fundamental Rights.

reading ability, verbal ability, IQ scores and so on. The classification of children based on such skills and the provision of particular types of educational programme accordingly is also an established part of our educational system. It is not clear how findings in behavioural genetics and the potential development of genetic tests might or should impinge upon current practices. Some researchers in behavioural genetics have highlighted the potential importance of the research in informing practices in education but as yet the issue has not received substantial attention.<sup>25</sup>

15.24 The development of tests that provide information about genetic influences on traits such as intelligence and antisocial behaviour would raise a number of questions:

- Should genetic tests be used to identify children who may be susceptible to traits that could affect their own educational achievement, such as lower than average IQ?
- Should genetic information be used to determine which type of educational programme a particular child, or group of children, receives?
- Should genetic tests be used to identify children who may be susceptible to traits that could affect the educational achievement and wellbeing of other children, for example antisocial behaviour?

15.25 The use of such tests in the educational context may lead to stigmatisation or a tendency towards 'genetic self-fulfilling prophecies' that constrain a child's self-image. We noted in paragraphs 14.41 – 14.43 that carrying out a genetic test on a child unable to consent to the procedure would have to be in the best interests of the child. It may be argued that in relation to education, the predictive use of genetic information could be justified, if the aim of such an approach was to provide better and more appropriate schooling for children. Whether genetic information could be used in this way to positive effect is currently unclear. It may be that, when used in conjunction with other information about children, including evidence from previous educational performance, such information could play a useful role. However, wider arguments about the advantages and disadvantages of tailoring educational programmes to groups of children, in whatever way such groups are defined, will also be relevant.

15.26 We note, with some concern, that the implications for education of research in behavioural genetics have not yet received significant critical attention. **In the light of the issues that may arise if genetic information about behavioural traits is applied in the context of education, we recommend that further investigation of the ways in which such research might be applied, and the resulting ethical and social issues, be undertaken. We recommend that dialogue between those involved in education and researchers in behavioural genetics be promoted. We recommend, further, that until such dialogue and research is undertaken, genetic information about behavioural traits in the normal range should not be used in the context of the provision of education.**

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<sup>25</sup> For example, see suggestions made regarding the constructive use of genetic information in education by Professor Robert Plomin in the following article: *Genius of genes*. 8 August 2000. <http://news.bbc.co.uk/1/hi/sci/tech/850358.stm> (20 August 2002).

## Insurance

- 15.27 The implications of the use of genetic information by insurers have been considered in detail by various bodies in recent years.<sup>26</sup> Many concerns have been raised, including the risk of basing decisions on unreliable tests and the possibility of excluding vulnerable groups from obtaining insurance. The Nuffield Council on Bioethics recommended a moratorium on the use of genetic information by insurers in most situations in 1993, and many other groups subsequently endorsed this suggestion, most recently the HGC.<sup>27</sup>
- 15.28 In the late 1990s, most British insurance industry, acting through the Association of British Insurers (ABI)<sup>28</sup> agreed on a self-regulatory Code of Practice<sup>29</sup> on use of genetic tests in insurance.<sup>30</sup> In April 1999, the UK Government established the Genetics and Insurance Committee (GAIC) to evaluate genetic tests, to recommend to insurers and the Government whether particular tests are appropriate for use by insurers and to oversee the use of genetic tests by insurers. In 2001, a moratorium, which exceeds in length and financial limits that recommended by the HGC, was announced by the insurance industry on the use of DNA test results in insurance. This remains a voluntary agreement and the Government has not yet considered it necessary to make any legislative interventions in this area.
- 15.29 The existing debate has not addressed the regulatory issues which arise from the possibility of using genetic information about behaviour. Indeed, the ABI Code of Practice itself defines a 'Genetic Test' in a manner which is limited to tests which indicate the risk of a disease developing in the future.<sup>31</sup> This is principally because, as the ABI has stated, 'behavioural genetics is unlikely to be of relevance to insurers, because [the ABI] cannot see that it would be possible to robustly demonstrate a clear link between genetic information regarding susceptibilities to particular behavioural traits and a change in the risk of an individual claiming on an insurance policy'.<sup>32</sup>
- 15.30 If research in behavioural genetics were to provide such evidence, there are clearly important social and regulatory issues which arise. The ABI has asserted that the suggestion that genetic information indicating susceptibility to particular types of behaviour (such as aggression or novelty-seeking) would be used displays a misunderstanding of the manner

<sup>26</sup> Nuffield Council on Bioethics. (1993). *Genetic screening: ethical issues*; Human Genetics Advisory Commission. (December 1997). *The Implications of Genetic Testing for Insurance*; House of Commons Select Committee on Science and Technology. (April 2001). *Genetics and Insurance*, Fifth Report; Human Genetics Commission. (May 2001). *The Use of Genetic Information in Insurance: Interim Recommendations of the Human Genetics Commission*. The HGC convened various meetings to discuss insurance and genetics and the relevant minutes are collected at <http://www.hgc.gov.uk/topics.htm#ins> (19 July 2002).

<sup>27</sup> Human Genetics Commission. (May 2001). *The Use of Genetic Information in Insurance: Interim Recommendations of the Human Genetics Commission*.

<sup>28</sup> The ABI comprises over 400 insurance companies which between them account for over 96% of the business of insurance companies in Britain.

<sup>29</sup> Association of British Insurers. (December 1997 and revised August 1999). *Genetic Testing: ABI Code of Practice*. The principal feature of this code is that applicants for insurance may not be asked to undertake a genetic test to obtain insurance and only tests approved by, or currently under consideration by, the GAIC may be taken into account. People with negative test results may benefit where the test result counteracts a family history of a condition.

<sup>30</sup> Both the House of Commons Select Committee and the HGAC have been critical of the system of self-regulation, and particularly the lack of uniformity of application of the Code of Practice amongst insurance companies. The House of Commons Select Committee noted in particular as one of its conclusions (paragraph 23) that 'There must be doubts whether the ABI, a trade organisation funded by insurers to represent their own interests, is the right body to regulate the use of genetic test results'.

<sup>31</sup> A Genetic Test is defined as 'an examination of the chromosome, DNA or RNA to find out if there is an otherwise undetectable disease related genotype, which may indicate an increased chance of developing a specific disease in the future'.

<sup>32</sup> Association of British Insurers. (August 2001). *ABI Response to Public Consultation*, paragraph 2.2.

in which the risk profile of an individual is established.<sup>33</sup> However, in its response to the Working Party's consultation with the public, the Genetics Group of the Faculty and Institute of Actuaries observed that while 'at this stage, no-one knows whether information on behavioural traits which is useful for predicting abnormal levels of insurance risk will ever be obtained from Genetic Tests ... it cannot be ruled out. Further, the distinction between behavioural and medical conditions could well be blurred.' When one considers the manner in which information as to past behaviour is currently required by insurers in proposals for policies and then used as an actuarial predictor of future risks, the view of the ABI seems less convincing than that of the Faculty and Institute of Actuaries. This matter is considered further in paragraph 15.33.

15.31 There are various types of relevant insurance in this context: life insurance, critical illness insurance, income protection and medical insurance. As noted by the Consumers' Association, with the contraction of the welfare state and prominence being given by both major political parties to private sector provision, insurance-based and insurance-related products and services are likely to play an increasing role in the lives of citizens.<sup>34</sup> Society is moving towards a position where access to insurance can no longer be seen as a mere commercial decision by an individual to purchase an extra benefit which he or she will enjoy in addition to a guaranteed safety-net of state provision. This change in the role of insurance strongly suggests that access to insurance should more properly be viewed in terms of an essential social right rather than an option for the few with appropriate financial resources. This change requires one to ensure that unreasonable discrimination on the basis of genetic information as to behaviour is prevented by strict regulation. Without such regulation, there is a real risk that scientific developments in the future will lead to the creation of a group of individuals whose genetic characteristics make them either uninsurable in the commercial judgement of the insurance industry, or insurable only at a level of prohibitively high premiums. The HGC has emphasised the wider moral and social consequences of allowing use of genetic information (albeit in the context of disease prediction) in decision-making in insurance.<sup>35</sup> We concur with the HGC that where insurance is linked to important public goods such as house ownership or life insurance and persons are restricted from obtaining these goods because of personal genetic qualities, it is not unreasonable to balance the costs to these individuals and to society against the costs to the insurance industry.

15.32 Against this one must, however, balance another aspect of the public interest, namely the need to ensure that the cost of obtaining insurance is not rendered prohibitive to society as a whole because premiums are calculated without access to important predictive genetic information which would allow those without genetic predispositions to certain behaviour to benefit from lower premiums. An argument can be made that the greater transparency provided by accurate genetic information in assessing individual risk will be of benefit in setting appropriate premiums for particular individuals. In addition, the insurance industry contends that the problem of so-called 'adverse selection' might arise if there were a prohibition on use of genetic tests. 'Adverse selection' can occur if applicants for insurance need not disclose relevant risk factors and consequently individuals at high-risk apply more

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<sup>33</sup> Association of British Insurers. (August 2001). *ABI Response to Public Consultation*, paragraph 2.3.

<sup>34</sup> Consumers' Association, Consumer Briefing, *Genetics and Insurance: Unravelling the Code for Consumers*.

<sup>35</sup> Human Genetics Commission. The use of genetic information in insurance: Interim recommendations of the Human Genetics Commission. 1 May 2002. [http://www.hgc.gov.uk/business\\_publications\\_statement\\_01may.htm](http://www.hgc.gov.uk/business_publications_statement_01may.htm) (20 August 2002).

for insurance, or persons at low-risk apply less, thereby skewing the pool of individuals requesting insurance.

- 15.33 Although science has not yet developed to a stage where genetic information can be used to indicate susceptibility to specific behavioural patterns, it is not difficult to foresee how insurers could use such information in the future to decide which individuals will be offered insurance, and on which terms. This is because the decision to underwrite and the terms of insurance are based essentially on personal information concerning a proposed person. In the example of driving insurance, this will include data such as age, sex, occupation, past driving record and so on. Such information determines premiums. If one were able to classify a person as being more likely than others to be aggressive or exhibit novelty-seeking behaviour using genetic tests, this is just a further layer of information which an insurance company could use to inform its decisions. Just as an individual's past record of driving is an indicator of the likelihood of future accidents, it could be said that an aggressive personality equally bears on the future risks of an accident. Conversely, an insurer may consider that a person with a passive personality is a much better risk to insure.
- 15.34 The essential issue for regulation and policy is whether, if such information can in future be obtained, an insurance company should be able to demand an appropriate test and use the results, and to refuse to offer insurance to those who refuse to take the test or offer higher premiums. This is a difficult question and the answer depends on the social and ethical perspective from which it is approached.
- 15.35 From a purely commercial perspective, one could view such information as being merely another fact which an insurer should be permitted to act upon in making a commercial decision as to whether he will contract with a person and the terms upon which he will contract. As observed above, there is a cogent case to be made for permitting the use of such information in the public interest. However, when one considers the fact that a genetic predisposition to certain patterns of behaviour is not a matter within one's control, and that use of such information could lead to denial of access to an essential social benefit (the ability to contract for insurance), the right of the insurer to demand and use a test is much less clear. It could be said against this that using such information regarding susceptibility to certain future behaviour patterns is no different from the current use of family history of illness by insurers in determining access to, for example, life insurance and critical illness policies and in the setting of premiums.<sup>36</sup> This presupposes that the use of family history, an equally unchangeable fact about an individual, is a legitimate factor in decisions about the provision of insurance. It can be argued that if one views access to insurance as being a social right, family history should not be permitted to weigh against an applicant for insurance.
- 15.36 Given that even in the case of predicting genetic diseases, scientific developments have not yet caused the UK Government to intervene with a system of regulation for the insurance industry, it is premature to arrive at any conclusions on the use of genetic information

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<sup>36</sup> In the context of genetic tests which predict disease, this very argument appears to have already been deployed by the insurers: see Minutes of Plenary Meeting of HGC, 2 March 2001, paragraph 5.5 where the consultation responses to *Whose Hands on Your Genes?* were considered ([www.hgc.gov.uk/business\\_meetings\\_02march.htm](http://www.hgc.gov.uk/business_meetings_02march.htm)). The HGC has expressed particular concern that the existing use of family history, especially where this clearly has a large genetic (inherited) component, should be given further consideration (Human Genetics Commission. (May 2001). *The Use of Genetic Information in Insurance: Interim Recommendations of the Human Genetics Commission.*)

about behavioural traits in the normal range. It is clear, however, that one cannot continue to view insurance provision and the terms of such provision as purely commercial decisions. The commercial imperative of insurers is clearly to set premiums and offer insurance based on the best possible information as to risk. Genetic information may be valuable in this regard and safeguards as to its use must be developed to ensure that an uninsurable group of individuals is not created.

- 15.37 We recommend 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.**