Chapter 6

Employment

Introduction

6.1 The possibility that genetic information could be used in the context of the employment relationship has been recognised for some time. In 1938 J B S Haldane wrote:

> "The majority of potters do not die of bronchitis. It is quite possible that if we really understood the causation of this disease we should find out that only a fraction of potters are of a constitution which renders them liable to it. If so, we could eliminate potters' bronchitis by regulating entrants into the potters' industry who are congenitally exposed to it."[1]

6.2 It has been pointed out that Haldane's reasoning could be extended : if individual genetic variation is a significant contributor to the incidence of workplace disease, and if people could be identified and steered away from workplaces in which they were particularly susceptible to exposures, then the overall burden of occupational disease could be diminished.[2] At the present time there are few work related hazards known to have a genetic origin, though there are some; alpha-1-antitrypsin deficiency in a polluted environment is an example. The position may, however, change in the future as scientific developments help more clearly to identify a larger number of diseases which are affected by a particular workplace environment.

6.3 Employers, in addition to identifying employees who may be exposed to any particular risk arising from a particular employment, may also wish to use genetic screening to exclude people who might be at risk of non-occupational diseases, which are likely to develop regardless of the working environment of the individual in question. Although the onset of the disease may not be caused by or exacerbated by the workplace, the development of the disease may have implications for the manner in which the work is done, and possibly also the safety of the workplace for the individual concerned as well as for fellow employees and other third parties.

Possible reasons for genetic testing in employment

Employers' interests

6.4 Many employers already request a medical examination before granting employment, and there are reasons why an employer might wish to use genetic tests for occupational diseases, or might wish to have access to genetic information about other diseases which may have implications for the employment relationship. Competition drives employers to take advantage of opportunities to reduce costs and improve efficiency. They might thus be concerned to exclude employees or job applicants who could be identified as being at an increased risk of developing a work related illness or an illness which will impair work performance. Healthy workers cost less : they are less often absent through illness, there are lower costs for hiring temporary replacements or for training permanent replacements, and there are fewer precautions which would need to be taken to deal with health and safety risks.

6.5 Market forces and the drive for economic efficiency do not, however, provide an adequate justifation for any behaviour which is ethically unsound. Ethical standards are not determined only by economic considerations, which although clearly relevant, must be balanced against the needs of others as well as of the community as a whole. Businesses are constrained by a wide range of restrictions which may be thought to impede efficiency; those seek to protect employees, consumers and in some cases the environment from the misuse of corporate power.

Employees' interests

6.6 There are good reasons why genetic screening could be in employees' interests. It would enable employees to assess their own susceptibility to occupational disease, permitting them to make free and informed choices concerning the type of employment undertaken, while giving due consideration to personal health and safety. Employees would, in principle, be empowered to avoid occupations which would increase the risk of ill health and which in the long run might be life threatening. In this way they could protect the economic security of themselves and their families. It would also help to provide employers with information necessary for the protection of employees by indicating who needed the protection of special health and safety measures to safeguard against the increased danger of ill health.

6.7 There are also foreseeable circumstances in which genetic screening might prejudice the interests of employees. It could operate to restrict job opportunities to those who, with few employment prospects, or for personal reasons, were prepared to assume the risk of ill health. It could provide a convenient excuse for employers to refuse either to take the reasonable steps necessary to accommodate those at higher risk or to employ certain categories of people able to work normally for an indefinite period. Moreover, there would be no obvious benefit to those employees who might be excluded because of a non-occupational genetic risk. The use of genetic information in these cases would serve only to reduce the opportunities of people with genetic risks which are not occupationally related and for whom the use of genetic information by employers is likely to have few, if any, advantages.

The public interest

6.8 Apart from the private interests of employers in genetic screening or testing, there may also be a public interest in this issue. Screening might in principle lead to a reduction in the incidence of occupational disease. This, if it became feasible, might in turn lead to a reduction in the burden both on the health care system in terms of treatment and also on the social welfare system. On the other hand, if some people were, in the future, entirely excluded from the labour market as a result of genetic screening, the Government would need to review their position, taking into account experience of employment policy and the disabled.

6.9 It is already accepted that people with certain diseases may be debarred from certain occupations. For example, sufferers from epilepsy cannot obtain an HGV licence. Genetic screening may make it possible in the future to identify individuals with a high risk of developing late onset serious conditions. There would be a public interest in such results only if the individual concerned both was in an occupation that put third parties at risk and also was at risk for a condition with a sudden and unpredictable onset.

6.10 But the public interest is not solely concerned with potential benefits. There is the danger that genetic screening could lead to discrimination against those with a genetic disease. Such discrimination could be based on fear, prejudice and misunderstanding or other irrational grounds unrelated to the needs of the employer, leading to the possibility of widespread genetic discrimination, with its attendant social and economic costs. There is in this country no legal protection against genetic discrimination. In some cases, as we shall consider, it may be possible to argue that any such discrimination would be unlawful

under either or both the Sex Discrimination Act 1975 or the Race Relations Act 1976. Discrimination on grounds other than those expressly forbidden by these Acts may well also be against the public interest.

The legal framework

6.11 There would be no specific legal regulation of genetic screening by employers in this country, if it were to be introduced. The position would therefore be governed by the general principles of employment law as they currently exist. Any screening might properly be seen in the general context of the employer's duty to provide a safe place of work, although employers would appear not yet to be required to screen for genetic disease in order to comply with their legal obligations in this field. Employers on the other hand would not be prohibited from undertaking such screening programmes and questions would then arise as to the refusal to employ people as a result of the screening. Questions would also arise if people were dismissed or relocated to other work if screening were introduced after the employment relationship had started.

6.12 There are very few direct legal restrictions on employers' hiring policies in British law. Subject to statutory provisions such as the Sex Discrimination Act 1975 and the Race Relations Act 1976, it would be lawful to require job applicants to agree to genetic screening and to refuse to employ people who refuse. As a general rule it would also be lawful to refuse to employ someone because of the employer's concern about the results of the screening. An employer is not under a duty to give reasons for refusing to employ a job applicant, though under the Access to Medical Reports Act 1988 an employee may have a right of access to a medical report sought in connection with the employment.

6.13 Possible sources of legal protection for job applicants are the Sex Discrimination Act 1975 and the Race Relations Act 1976. In both cases discrimination is defined to include direct discrimination and indirect discrimination. It would be unlawful direct discrimination (on the grounds of less favourable treatment) for an employer to require members of one sex only or one ethnic group only to be screened. It might also be unlawful indirect discrimination (conduct which appears non-discriminatory in principle but which is discriminatory in practice) for an employer to screen for conditions which are confined wholly or mainly to the members of one sex or one racial group. A good example of this might be sickle cell disease, the screening for which may be unlawful

because of its discriminatory impact, unless it can be shown to be justified in the interests of the business.

6.14 The position would be different where the employer introduces genetic screening and applies it to existing employees. One question which would arise is whether the dismissal of an employee following the introduction of screening would be unfair under the terms of the Employment Protection (Consolidation) Act 1978, Part V in the case of those employees who are still protected by the legislation (and many are not). Problems could arise in two quite different situations, one where the employee refuses to participate in the screening programme, and the other where questions have arisen about the results in those cases where the employee has agreed to participate in the programme. There is no clear answer to the question of whether dismissal in either case would be fair or unfair. Much would depend upon the employer's reasons for dismissing the employee and the manner and circumstances of the dismissal. Potentially also relevant would be attempts made by the employer to secure alternative work for the employee. The discrimination legislation discussed in the previous paragraph may be relevant in the context of dismissal as well as in the context of hiring.

The practice of genetic screening in employment

The position in the UK

6.15 Despite extensive enquiries, the Working Party has been unable to identify any employer, with the sole exception of HM Forces, that requires employees or job applicants to undergo genetic testing. From this we could conclude that despite the availability, albeit limited, of genetic screening, employers have so far decided that it is not necessary or in their interests. This is in itself significant. It is perhaps also significant that employers have not been compelled to introduce such testing as a result of pressure from insurance companies who provide liability insurance for employers. Some employers now screen for a variety of other conditions, such as drugs, alcohol and HIV.

6.16 In the one genetic screening programme currently in use by a UK employer, those who apply to join occupational categories of HM Forces which involve exposure to atypical atmospheric conditions undergo sickle cell screening. An example is aviation. Candidates who are carriers of the sickle cell gene are considered to be unfit for duty in such occupational categories. They may,

however, be accepted for other duties. This is primarily because of the risk of sickling on exposure to reduced atmospheric pressure or hypoxia. (Sickling is a change in the shape of the red blood cells which can lead to blockage of blood vessels.) Candidates with sickle cell disease are considered to be unfit for any form of service. This screening process is not part of a NATO-wide programme although other NATO Forces undertake sickle cell screening and may have different policies on acceptability.

The position in the USA

6.17 In the United States, where health insurance is usually provided by the employer, genetic screening of employees has more serious implications. Employers who provide health insurance may seek to avoid hiring people who may be sources of higher medical bills. The health of both the employee and the employee's family may be at issue. There is also the danger that employees with health coverage may find it impossible to change employment without losing insurance cover in whole or in part. A family's life may be restricted by the necessity for a parent of a child with a genetic disorder to maintain employment in the same state and at the same job in order to have health insurance.

6.18 In 1982 the US Congressional Office of Technology Assessment (OTA) conducted a survey to determine the extent of genetic screening in the workplace.[3] Confidential questionnaires were sent to the 500 largest US industrial companies, the 50 largest private utility companies, and 11 major unions that represent the largest numbers of employees in those companies. Of the 366 organisations responding, 6 were currently conducting genetic testing, 17 used some of the tests in the past 12 years, 4 expected to use the tests in the next 5 years, and 55 stated that they would possibly use the tests in the next 5 years. These results were widely construed to suggest that genetic screening by employers was likely to increase dramatically.

6.19 The OTA conducted a further survey in 1989[4] which demonstrated that no such increase had in fact occurred. Using a similar base of large industrial companies, private utilities and unions, the survey found 12 companies currently using genetic screening tests and 8 that had used them in the past 19 years. Companies were also asked if they expected to conduct such tests in the next 5 years : biochemical genetic tests and direct DNA tests were asked about separately. Four companies answered yes about biochemical genetic screening, 25 were unsure, and 218 said no. No company expected to use direct DNA testing, 23 were unsure, and 224 said no. The available evidence suggests

that at the present time there is no major demand for the genetic testing of employees, though the possibility of more widespread use in the future should not be ruled out.

Ethical issues

6.20 In our view people should be excluded from employment opportunities only where this is shown to be absolutely necessary. We see no reason why people should be required by employers to undergo genetic screening unless the illness or condition will present a serious danger to third parties. Where the concern is limited to the health of the employee, it should be a matter for the individual employee to decide whether or not to participate in the screening programme. Where an individual does participate in a screening programme, we accept that a responsible employer may not wish to employ someone disclosed to be at risk of a condition, particularly if its onset is unpredictable, that might imperil the employee or third parties. But even here steps would have to be taken to ensure that individuals were not unfairly treated and that there were in place, through agencies such as the Employment Services' Placing Assessment and Counselling Teams (PACTs), procedures to assist the individual and to facilitate his or her employment in other areas.

6.21 So far as existing genetic information is concerned, this should not normally be used to exclude people from employment unless the condition had developed so as to impair efficient performance in the job. It would be particularly inappropriate to rely on this information where the risk of disease was misunderstood by the employer or where the risk did not lead to the onset of the disease. In relation to screening for late onset genetic disorders (for example, Huntington's disease) it is important for all involved to recognise that the genetic defect is detectable from birth, but that the individual is only likely to develop the actual disease from a relatively late age, being healthy for most of his or her life. We do not overlook the likelihood for some people that a disabling disease may develop in the future. But it would be possible at that stage for an employer to transfer the employee to other work. There is a legal requirement for employers to ensure that 3% of the workforce are registered disabled.[5] It should only rarely be necessary to dismiss such an employee. We have no information at present about any employment discrimination against people in this category, but we are concerned that discrimination could occur if genetic information had to be disclosed on job application forms, or could properly be made available to employers who seek medical reports about potential employees.

6.22 There is clearly a need to strike a balance which takes into account the competing interests in this area. We are concerned to ensure that nothing should be done to undermine the employer's ultimate responsibility to provide a safe working environment. Genetic screening should not be an excuse for cutting costs on health and safety standards, nor should it become a justification for excluding people from the labour market. Indeed in view of the sensitive issues raised, it is open to question whether the decision to introduce a screening programme ought properly to be that of the employer alone. It may be appropriate that such a programme should be implemented only in consultation with workplace representatives, with the coordinating body proposed in paragraph 9.7 and possibly also only with the approval of the Health and Safety Commission.[6]

6.23 Subject to this prior consultation and authorisation, genetic screening of a workforce for increased occupational risks ought to be contemplated in our view only where:-

(i) there is strong evidence of a clear connection between the working environment and the development of the condition for which the screening is conducted;

(ii) the condition in question is one which seriously endangers the health of the employee or is one in which an affected employee is likely to present a serious danger to third parties;

(iii) the condition is one for which the dangers cannot be eliminated or significantly reduced by reasonable measures taken by the employer to modify or respond to the environmental risks.

But although it may be appropriate to introduce a screening programme on these limited grounds, it should only be done if accompanied by safeguards for the employee, as indicated in paragraph 6.20.

A need for further legal provision?

6.24 Under the law as it presently stands, employers may introduce genetic screening, and may require potential employees to be screened as a condition of employment. There are no pre-conditions to be satisfied before a screening programme is introduced, and there are no safeguards against misuse or abuse where such a programme is introduced. The absence of specific

legal regulation does not appear to be peculiar to this country, though there are a number of jurisdictions where there is more direct legal intervention.

Legal regulation elsewhere

6.25 In Europe draft legislation has been introduced in Denmark which would prohibit an employer from demanding or making use of a genetic test at the time of appointment or at a subsequent stage.[7] This would be subject to a proviso to permit the Minister of Labour to authorise genetic tests for "any disorders which might jeopardise other people in the relevant function or job." Rather different forms of regulation in a number of jurisdictions in the United States prohibit discrimination in employment on the basis of one or more genetic traits. Florida, Louisiana, and North Carolina prohibit discrimination based on sickle cell trait, the prohibition in the last case extending also to haemoglobin C. New Jersey goes further in prohibiting discrimination on the additional grounds of carrier states for thalassaemia, Tay-Sachs disease and cystic fibrosis.[8]

Legal Intervention in Britain?

6.26 In the light of our comments about the circumstances in which genetic screening ought properly to be conducted in this country, and in the light also of the lack of any regulation of the practice, the question arises as to whether it would be appropriate to introduce legislation such as that now in draft in Denmark or provided in some of the states of the USA. We are reluctant to recommend any initiative at this stage because of the lack of evidence which we have been able to uncover about the systematic use of genetic screening programmes by employers in this country. Still less is there evidence of any systematic abuse by employers.

Conclusions and recommendations

6.27 At present, the use of genetic screening by employers in the UK does not appear to be a cause for concern. We have found evidence of only one existing screening programme : that programme can be justified quite readily on the grounds of safety, not only of those being screened but also of third parties. Nevertheless we recognise that the matter needs to be kept under review. **We recommend that the Department of Employment keeps under review the potential use of genetic screening by employers.**

6.28 Subject to prior consultation with workplace representatives, and with, as necessary, the Health and Safety Commission, **we recommend that genetic screening of employees for increased occupational risks ought only to be contemplated where:-**

(i) there is strong evidence of a clear connection between the working environment and the development of the condition for which genetic screening can be conducted;

(ii) the condition in question is one which seriously endangers the health of the employee or is one in which an affected employee is likely to present a serious danger to third parties;

(iii) the condition is one for which the dangers cannot be eliminated or significantly reduced by reasonable measures taken by the employer to modify or respond to the environmental risks.

Although it may be appropriate to introduce a genetic screening programme on these limited grounds, it should only be done if accompanied by safeguards for the employee, and after consultation with the coordinating body recommended in paragraph 9.7.