

Chapter 6

Wider use of
genetic
information about
mental disorders:

Introduction

- 6.1 Genetic information about mental disorders raises ethical issues which extend beyond those arising from its clinical applications (discussed in Chapter 5). It may affect the ways in which those with mental disorders are viewed by others, and in particular the stigma that they suffer. It might also be invoked to argue for different treatment, or unacceptable forms of discrimination towards those who suffer, or are deemed likely to suffer, mental disorder, particularly in areas such as insurance, employment, education and health care.

Mental disorder and stigma

- 6.2 As noted in Chapter 1, stigma is a notable and pervasive feature of mental disorder. In the words of one person with schizophrenia *"there is nothing more devastating, discrediting, and disabling to an individual recovering from mental illness than stigma, which Webster's (in an older edition) defines as 'the scar or brand left by a hot iron on the face of an evil-doer'. This brand is a mark of disgrace, of shame. It signifies that an individual is different, someone to be avoided."*¹ One US study found that mental illness is one of the most highly rejected conditions, clustering with drug addiction, prostitution and ex-convict status rather than with cancer, diabetes and heart disease.² The degree of stigma differs for different mental disorders. Depression evokes considerable sympathy; schizophrenia frequently leads to social isolation.
- 6.3 Stigma has several different elements. In part, it may be an understandable, if regrettable, response to some of the behaviour of people with mental disorders. People may find such behaviour frightening or disturbing, and deal with their fear by segregating those with mental disorder, by viewing them as alien and by trying to exclude them from society.
- 6.4 In large part, however, stigma results, not from experience of difficult behaviour by the mentally disordered, but from ignorance and misconceptions about mental disorders. According to one recent US study perhaps *"the most pernicious of all myths is that of the dangerousness of psychiatric patients. While less than 3% of mentally ill patients could be categorized as dangerous, 77% of mentally ill people depicted on prime-time television are presented as dangerous."*³ Public fear of random attacks by mentally ill patients, prompted largely by two or three highly publicised cases of so-called 'care in the community killings', has led to research into the matter.⁴ The study of people convicted of homicide found that those with no symptoms of mental illness were more likely to have killed a stranger than those with symptoms (although the risk to relatives of the mentally ill was higher). A recent US study found that over half of respondents in a large survey believed that weakness of character was a likely cause of both depression and schizophrenia, and were inclined to blame those with mental disorders for their condition.⁵ A history or label of mental disorder can even lead to stigma in the absence of any behaviour that differs from the norm.

1 Leete E (1992) The stigmatised patient, Chapter 4 in Fink P and Tasmai A (eds) **Stigma and Mental Illness**, American Psychiatric Press Inc, Washington DC, p18.

2 Albrecht G, Walker V and Levy J (1982) Social distance from the stigmatized: A test of two theories, **Social Science and Medicine** 16:1319-27 cited in Link B, Cullen F, Mirotnik J and Struening E (1992) The consequences of stigma for persons with mental illness: evidence from the social sciences, Chapter 9 in Fink and Tasman (eds), **Stigma and Mental Illness**, p91.

3 Dubin W and Fink P (1992) Effects of stigma on psychiatric treatment, Chapter 1 in Fink and Tasman (eds), **Stigma and Mental Illness**, p3.

4 Appleby L (1997) **Progress Report of the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness**, Department of Health, London.

5 Jorm A, Korten E, Jacomb P, Christensen H, Rodgers B and Pollitt P (1997) Public beliefs about causes and risk factors for depression and schizophrenia, **Social Psychiatry and Psychiatric Epidemiology**, 32:143-8.

- 6.5 These attitudes are evidence of lack of understanding, lack of sympathy and lack of respect for suffering fellow human beings. Many respondents to the Working Party's consultation highlighted the problems caused by stigma.⁶ Stigma also affects the families of people with certain mental disorders. This may be due partly to fear that contact with the family will result in contact with the affected person; but it runs wider than this. Families are sometimes regarded as tainted with the patient's deviance, and may even be blamed for their relative's mental illness.
- 6.6 Stigmatising mental disorder may injure and harm people in two ways. Firstly, those who stigmatise represent sufferers in ways that demean and debase them, so damaging their reputation and sense of self: stigma **constitutes** an injury to self even if it has no further effects. Secondly, those who stigmatise may **cause** further injury or harm to sufferers, for example, by unfair and even discriminatory action in areas such employment and housing.⁷ In so far as stigma **constitutes** an injury, it resembles practices of defamation on the basis of race, ethnicity or gender, which may injure even when those affected are not, or not fully, aware of the fact, or accept their demeaned status. Such lack of due respect for persons is wrong even when it leads to no further harm. For example, a racist who provides material goods to those whom he regards as despicable, or a child pornographer who looks after the material welfare of his victims, may injure greatly without causing additional harm. More typically, stigmatising others not only **constitutes** injury but also causes further harm. Proper treatment of those with mental disorder must work to eliminate both the injury which stigmatisation **constitutes** and the harm which it **causes**. In general, constitutive injury may be deeper and less easy to rectify.
- 6.7 The serious injury and harms constituted and caused by the stigmatisation of mental illness make mental disorder an object of fear. This fear can in turn have a range of further effects; in particular it may deter people from seeking psychiatric treatment. This avoidance may be partly because they share the negative perceptions of mental illness held by many in the population, but also because they fear the consequences of being labelled as mentally ill and suffering the associated stigma. Taken together, *"Patients' willingness or unwillingness to be treated, the inability to pay for treatment, and the unwillingness of people to have mentally ill persons living near them or working in their companies have combined to form the most powerful anti-therapeutic forces that mentally ill individuals face."*⁸
- 6.8 Some people argue (or hope) that increased knowledge of genetic information relevant to mental disorder might help to reduce the stigma those with these disorders now face. Evidence that mental illness has a physical basis might help to counter traditional notions that mental illness reflects weakness of character, and put mental illness on a par with other, physical illness. The stigma associated with Alzheimer's disease, for example, has decreased, and this may be because understanding of its biological basis has increased. There is also greater familiarity with the disease, both because its incidence has increased and because it is more widely discussed.⁹ But others have noted the possibility that linking mental illness with genetic differences might reinforce the idea that the mentally ill are fundamentally different.

6 Including the National Council of Women of Great Britain and individual respondents to the Working Party's consultation.

7 A recent survey by the mental health charity MIND reported that over two-thirds of all key service providers who responded had encountered opposition to community mental health facilities in the past five years, although none of the residents' fears for children's safety, of violence or of falling house prices, were based on their actual experience or were backed up by research (Repper J, Sayce L, Strong S, Willmot J and Haines M (1997) **Tall Stories from the Back Yard: A Survey of 'Nimby' Opposition to Community Mental Health Facilities Experienced by Key Service Providers in England and Wales**, MIND London).

8 Fink and Tasmai (eds) (1992) Introduction to **Stigma and Mental Illness**, p18.

9 Personal communication, Harry Cayton, Alzheimer's Disease Society. The Tuberous Sclerosis Association, in their response to the Working Party's consultation, also suggested that 'the stigma associated with [tuberous sclerosis] seems to have lessened as there is more research into the condition.'

- 6.9 An increase in the availability of genetic information about mental illness may also affect families who suffer stigma. Genetic research findings can have a salutary influence on the way families view themselves and their role in mental illness.¹⁰ Such information might also shift the blame to families, however, if parents were blamed for their decision to have the child in the first place.
- 6.10 There is evidently no simple way, no single institution and no simple piece of legislation which could eliminate the harm and injury constituted by the stigma of mental disorder. Only long-term changes in public understanding of, and support for, those with mental disorders will improve matters. The Working Party welcomes, therefore, the current Respect campaign by the mental health charity MIND to combat discrimination on mental health grounds and the forthcoming campaign against stigma by the Royal College of Psychiatrists.¹¹ **The Working Party recommends that campaigns to reduce stigma emphasise that it constitutes harm as well as causing it.**

Discrimination

- 6.11 The harms which stigma may cause are also important. If and in so far as genetic information about individuals can be used to assess their health, or future health, it might also be used to restrict their access to certain activities or services. Some restrictions may constitute acceptable forms of discrimination; others may not. We have paid particular attention to insurance, employment and education since these are areas in which discrimination on the basis of mental disorder, and potentially on the basis of genetic information about mental disorders, may be significant.

Insurance

- 6.12 There has been considerable debate in the UK, in other European countries and in the US about the use of genetic information for insurance purposes. In the UK, attention has so far been mainly on life insurance, but other types of insurance are now also coming under increasing consideration. In the UK there has been particular interest in the standards of consumer protection and concern that the use of genetic test results to fix levels of premiums or to refuse cover may raise issues of consumer protection that fall outside the competence of the Insurance Ombudsman.
- 6.13 The relation between genetic information and the actuarially significant information which insurers seek, and on which they base premiums and refusal to insure, is often complex. It is simplest in the case of single gene disorders: for example, individuals with the gene mutation for Huntington's disease have a calculable and actuarially significant reduction in life expectancy. However, even in these relatively simple cases, there is considerable and often actuarially significant variability between individuals, for example in age of onset, which may be due to other environmental or genetic factors. By contrast, information about susceptibility genes is often of quite limited actuarial use: it may provide information about slight increases (or decreases) in the risk of suffering from some multifactorial disorder in a population, but shows little, if anything, about any single individual's level of risk. Future research may be able to identify combinations of gene variations which contribute to an actuarially significant greater or lesser risk, or to a greater or lesser likelihood of benefiting from certain sorts of treatment; but at present the genetic information by which insurers could calculate the increased risk to a given individual who has certain susceptibility genes is not available.

¹⁰ Lefley H (1992) The stigmatized family, Chapter 12 in Fink and Tasmai (eds) **Stigma and Mental Illness**.

¹¹ See also Medical Research Council (1997) **Genes and the Mind**, Medical Research Council, London.

- 6.14 The use of genetic information relevant to mental disorders for insurance purposes may therefore be fairly limited and specific. Even where actuarially useful information is available, it may often be useful only for certain types of insurance product. For example, knowing that an individual has the gene mutation for Huntington's disease may be relevant to life insurance; knowing that an individual has susceptibility genes for late onset Alzheimer's disease might (if the actuarial evidence were strong enough) be relevant to long-term care insurance.
- 6.15 In 1997 the Association of British Insurers (ABI) issued a code of practice on the use and handling of genetic test information by insurance companies.¹² The code states that applicants will not be asked to undergo genetic tests, but will be asked to reveal existing genetic test results if they are relevant to a question on the application form. Genetic test information disclosed by applicants will be used only if it shows a clearly increased risk of genetic disease and a low increase in risk will not necessarily justify an increase in the premium. For the time being a moratorium (to be reviewed in 1999) allows that existing genetic test results are not disclosed for applications for life insurance up to £100,000 linked to a mortgage on a primary place of residence.
- 6.16 Simultaneously, a report was published by the Human Genetics Advisory Commission which also concluded that applicants should not be required to take genetic tests for insurance purposes.¹³ This report emphasised the need for insurance companies' policies to be based on sound actuarial assessments of the risks indicated by genetic information. The Commission proposed that a general moratorium on requirements to disclose the results of genetic tests should be lifted **only** as research demonstrates the actuarial relevance of **specific** sorts of genetic test results for **specific** insurance products. In its initial response to the Human Genetics Advisory Commission's report, the Association of British Insurers rejected this call for an approach based on the provision of specific actual information on the grounds that there are already eight specific genetic tests which are known to provide actuarially significant information.¹⁴
- 6.17 A central concern of the Association of British Insurers' code and the Human Genetics Advisory Commission's report is with possible misuse of genetic test results to discriminate unfairly. Both bodies accept that standard insurance practices discriminate between individuals with discriminable actuarial risk, and both hold that insurers should not apply loadings which are not actuarially justified. Neither offers a general reason for modifying standard insurance practice where genetic test results are actuarially significant. However, the Commission's report is more sceptical both about the amount of actuarially significant genetic information now available and about insurers' need for genetic test results. It notes that some insurance companies do not propose to ask for genetic test results at all, and calls on the industry to develop alternative insurance products for those unable to obtain standard ones.
- 6.18 The Human Genetics Advisory Commission report also noted that it is difficult at present for those who feel that they may have been unfairly discriminated against by insurers to obtain hard evidence. A recent MIND survey found that some people had been refused life or other insurance policies because of a psychiatric diagnosis.¹⁵ It is difficult to establish whether this constitutes unfair discrimination, however, since insurers regularly refuse insurance to applicants with a variety of actuarially significant conditions and indicators without providing detailed information about the basis of their decision. The Commission's report therefore also calls for higher standards of consumer protection in the insurance industry, so that individuals can discover whether insurers have unfairly discriminated against them.

12 Association of British Insurers (1997) **Genetic Testing: ABI Code of Practice**, Association of British Insurers, London.

13 Human Genetics Advisory Commission (1997) **The Implications of Genetic Testing for Insurance**, Human Genetics Advisory Commission, London.

14 Association of British Insurers (1997) **Genetics Code of Practice Published by Insurers**, Press Release, 17 December 1997.

15 Read J and Baker S (1996) **Not Just Sticks and Stones: A Survey of the Stigma, Taboos and Discrimination Experienced by People with Mental Health Problems**, MIND UK.

- 6.19 It is important that insurers do not exaggerate the actuarial implications of genetic test results, and doubly important that they do not do so in the case of genetic test results relevant to mental disorders, where the risk of stigma and of its effects is high. Any exaggeration of the actuarial implications of genetic test results amounts to unfair discrimination. It is important to have systems in place that can monitor whether insurers are discriminating unfairly on the basis of genetic test results. **The Working Party recommends that the Government, in consultation with the insurance industry, makes arrangements for monitoring insurers' use of genetic tests for mental disorders, and for reporting on any tendency to load premiums excessively, any actuarially unwarranted refusal of insurance and any other forms of unfair discrimination.**

Employment

- 6.20 Employment is an area in which the stigma attached to mental disorders plays a large part. A survey of people with a psychiatric diagnosis, by MIND, found that *"the largest problem in people's lives was that of employment, either trying to return to work, staying in their current jobs, or even getting into work in the first place."* Over half of respondents had had to conceal their psychiatric history for fear of losing their jobs.¹⁶ The stress of secrecy, the fear of being found out and exclusion from work can all be very damaging, the more so since being in work is known to play an important role in maintaining mental health. Yet employers may have evident reasons for concern when employees, or prospective employees, have poor health records of any type.
- 6.21 Until now, the use of genetic information for employment purposes has attracted much less attention than its use for insurance. Employers' and prospective employers' use of psychometric tests has been of far greater concern than their use of genetic tests hitherto. However, in view of the employment difficulties and discrimination faced by those with mental health problems, and by those who have had such problems, it is important to consider how the use of genetic information, including genetic test results, could improve or worsen matters.
- 6.22 The introduction of specific genetic screening programmes for employees or potential employees was considered in the Nuffield Council's first report, **Genetic Screening: Ethical Issues**. This report, which focused on occupational risk linked to genetic make-up, did not specifically consider the issues raised by genetic tests related to mental disorders. It recommended 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."*¹⁷
- 6.23 That report also added that 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 co-ordinating body recommended"*. Such bodies

16 Ibid.

17 Employment, Chapter 6 in Nuffield Council on Bioethics (1993) **Genetic Screening: Ethical Issues**. Nuffield Council on Bioethics, London, p64.

now exist. Since the publication of the report Government has established both the Advisory Committee on Genetic Testing and the Human Genetics Advisory Commission which has wider responsibilities and is charged with looking at the economic and employment implications of human genetics. Indeed, the Commission has identified the issues around genetics and employment as a priority.¹⁸ **The Working Party recommends that the Human Genetics Advisory Commission, in its consideration of genetics and employment, determines which is the appropriate body to monitor any introduction of genetic screening programmes for increased occupational risks.**

- 6.24 So far as we have been able to establish there is at present only one programme for the genetic screening of employees. The Ministry of Defence tests applicants for the forces for sickle cell trait if they would be exposed to atypical atmospheric pressures; carriers as well as known sufferers are considered to be at risk of sickling on exposure to reduced atmospheric pressures or hypoxia. There are, however, other genetic tests which can identify individuals who are more sensitive than others to certain occupational hazards. For example, individuals exposed to organic solvents are at increased risk of developing Goodpasture's disease if they have a particular genotype.¹⁹ The Royal Society, in their response to the Working Party's consultation, pointed out that the relevant genetic test has been available for many years, but has not apparently been used significantly for employment or insurance purposes. They raised the possibility that an employee who becomes ill as a result of exposure to this foreseeable risk might regard the employer as negligent for not having offered genetic testing.
- 6.25 We have not learnt of any genetic sensitivities to chemical or biological agents which are associated with increased risk of mental disorder. However, other features of some working environments, for example, stress, isolation or danger, might represent greater risk factors for mental disorder for individuals with susceptibility genes for mental disorders than for others. Employers are legitimately concerned to identify whether some current or prospective employees may be more vulnerable than others to such factors. Hence, it is not entirely unrealistic to think that genetic tests might be used in the future to screen for employment, and that some employers might be interested in genetic tests for susceptibility to mental disorders.
- 6.26 Any use of genetic tests relevant to mental disorders for employment purposes other than those of controlling exposure to occupational hazards, so protecting both employees and employers, raises a number of ethical questions. While employers should act within the context of an Equal Opportunities policy, tests could be used to exclude some people from employment, to restrict the sorts of employment which they could obtain, or the sorts of promotion or benefit for which they were eligible. Employers might use this information to ensure a healthier work force with lower sickness rates; pension funds might use it to reduce the costs of early retirements. Policies of these sorts could have serious adverse implications for people whose genetic test results indicated a susceptibility to mental health difficulties.
- 6.27 In the UK the Disability Discrimination Act 1995 makes it unlawful for employers of twenty or more people, and for providers of goods and services, land, property and accommodation, to treat a person with a disability less favourably than other people unless they can justify their behaviour. For the purposes of the Act, disability includes physical or mental impairment which has a substantial and long-term adverse effect on abilities to carry out normal day-to-day activities. There has been concern that many people who suffer discrimination as a result of

18 Human Genetics Advisory Commission (1998) **Implications of Genetic Testing and Employment is Commission's Next Priority**, Press Release, 9 February 1998.

19 Goodpasture's disease involves inflammation of the small blood vessels of the kidneys and lungs. The genotype concerned is HLA (human leucocyte antigen) type DR2.

mental health problems will not fit into this narrow definition of disability. Moreover, while the Act covers those who have, or have had, a disability, it would not cover cases where genetic tests suggest that an individual will, or may, develop a disability in the future. Amendments to ensure that the Act would cover this category were discussed in both Houses but not incorporated into the final Act. The House of Commons Select Committee went further in its report on Human Genetics, concluding that a "*law making unauthorised release or use of genetic information an offence should give greater protection against discrimination than simply defining genetic susceptibility to a disease as a disability under the terms of the Disability Discrimination Bill.*"²⁰ It suggested that a Privacy Bill should make misuse of genetic information both a criminal and a civil offence. However, in its response to the report the Government indicated a reluctance to legislate on personal privacy either in general or in the area of genetics.

- 6.28 It is conceivable that employers might consider offering certain genetic tests to employees as a health benefit, although the financial cost would make this unlikely. In any case, the relevant ethical considerations would be those set out in Chapter 5. However, it would be particularly important to determine who would have access to test results, responsibility for undertaking any intervention indicated by those results (such as the removal of some occupational risk factor), and liability in the event of failure to so intervene.
- 6.29 Any wider use of genetic tests in employment may raise far-reaching issues about discrimination; but so far there is little legal or other framework for addressing these issues in the UK. We believe that this lack reflects the newness of the issues and not their lack of importance. Elsewhere there has already been legislation to address the use of genetic information by employers. Danish legislation on the use of personal health information in employment decisions established a Health Information Council and set out stringent regulation on the use of genetic information by employers; however, the enforcement of these measures is relatively weak.²¹ In the US, a number of states have prohibited the acquisition and/or use of information about current or prospective employees' genetic characteristics by employers.²²
- 6.30 When employment is in the UK public sector, the provisions of the European Convention on Human Rights will become relevant. In particular, any requirement for genetic testing as a condition of employment could compromise the right to respect for private and family life guaranteed by Article 8. With the imminent enactment of the European Convention into UK statute law, other aspects of the Convention may well apply.
- 6.31 The Working Party welcomes the forthcoming consideration of genetics and employment by the Human Genetics Advisory Commission and **recommends that, in view of the special significance of stigma in mental disorder, the Commission pays particular attention to the implications of testing for genetic factors relevant to mental disorders for employment purposes.**

20 Shaw G (Chairman) (1995) **Human Genetics: The Science and Its Consequences**, House of Commons Science and Technology Committee Third Report, Session 1994-95, Volume I Report and Minutes of proceedings, 41-I, HMSO, London, paragraph 226.

21 Presentation by Soren Holm, member of the Danish Health Information Council, at the conference **Genetic information: acquisition, access and control** held at the University of Central Lancashire, Preston, 5-6 December 1997.

22 Yesley M (1997) Genetic privacy, discrimination, and social policy: Challenges and dilemmas, **Microbial and Comparative Genomics** 2:19-35.

Education

- 6.32 Education is another area in which the use of genetic information might become a controversial issue. On one hand, genetic test results might be relied on, for example, to establish a case for special educational provision. On the other hand, current methods of educational assessment might prove entirely adequate for this purpose. Such dilemmas may arise both for certain single gene disorders (for example, fragile X syndrome) and for conditions such as dyslexia where little is yet known about the involvement of genetics.
- 6.33 Reliance on genetic tests should not, we believe, become automatic in educational assessment even for single gene disorders, since testing itself may have other, possibly adverse, implications. For example, the debate about fragile X syndrome screening and the benefits and disadvantages of testing school age children for the syndrome is by no means settled. Some argue that a specific diagnosis is helpful in tailoring an educational programme and that a diagnosis itself can be therapeutically helpful and can help parents and children get the resources they need. Others consider that there is little, if any, evidence that a genetic test for fragile X syndrome would suggest any drug treatment or educational programme that would not be recommended on the basis of conventional assessment of the child's needs, although test results might be of use to a family making further reproductive decisions.
- 6.34 The reasons for or against using other genetic tests of children for educational purposes may vary. In some cases a genetic test might be useful in identifying the specific educational approach of most use; in others it might be of doubtful value. In the latter case there would be *prima facie* grounds for relying on conventional tests. Even in the former case, reliance on genetic tests should not, we believe, become automatic in educational assessment since testing itself may have other, possibly adverse, implications.
- 6.35 In the US there have been moves to demand that education systems take more systematic account of cognitive ability, and it is conceivable that pressure will develop for genetic screening for cognitive ability. We have not found evidence to support wider use of genetic tests, and suggest only that their use for children with special needs be systematised with due regard for the child's and family's needs.