

EMPLOYERS AND GENETIC INFORMATION: A NEW FRONTIER FOR DISCRIMINATION

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INTRODUCTION

Rapid advances in genetic technology have resulted in an increasing number of tests becoming available to detect genes associated with disease. However, genetic tests and the information they are able to reveal provide a classic example of 'technology's double edged sword'.¹ An enhanced potential for diagnosing, treating and possibly even preventing many forms of disease has been accompanied by significant potential for abuse. By making it possible to differentiate between individuals on the basis of their genetic makeup, genetic testing has effectively opened up a new frontier for discrimination. There is increasing concern, and even growing evidence to suggest, that individuals who have undergone genetic testing may subsequently be discriminated against on the basis of their genetic makeup by third parties, including insurers, employers and service providers.² Much has been written about the threat of genetic discrimination in the area of insurance.³ This paper will focus instead on the relatively unexplored issue of genetic discrimination in employment. It will be shown that the growing evidence of genetic discrimination by employers, along with the potentially serious consequences of such discrimination can no longer be ignored and that some form of legislative response is now imperative.

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¹ David Suzuki, *Inventing The Future: Reflections On Science, Technology And Nature* (1990) 55-78.

² See generally Kristine Barlow-Stewart and David Keays, 'Genetic Discrimination in Australia' (2001) 8 *Journal of Law and Medicine* 250. This study details instances of alleged genetic discrimination in Australia by insurers, employers and providers of health services and is discussed in detail in this paper.

³ See, eg, Margaret Otlowski, 'Resolving the Conundrum: Should Insurers be Entitled to Access to Genetic Test Information?' (2000) 11(3) *Insurance Law Journal* 193; Lawrence Low, Suzanne King and Tom Wilkie, 'Genetic Discrimination in Insurance: Empirical Evidence from a Cross-Sectional Survey of Genetic Support Groups in the United Kingdom' (1998) 317 *British Medical Journal* 1632.

The nature and quality of the response, however, will be critical. To date, most proposals for reform have opted for an 'acceptable compromise'⁴ between employer and employee interests. In principle, such proposals support the prohibition of genetic discrimination by employers, however they also maintain that there are certain circumstances in which it may be appropriate for employers to discriminate on the basis of genetic information.⁵ This reflects the approach that has already been taken to disability discrimination and embodied in the *Disability Discrimination Act 1992* (Cth)⁶ as well as in relevant State⁷ and territory anti-discrimination legislation.⁸ It will be argued that there are compelling reasons against applying a model of this type to genetic discrimination. The limited predictive value of genetic information, as well as the practical, ethical and privacy considerations that arise from its use call for stronger legislative protections for employees. In essence, this may be an area where an 'acceptable compromise' is simply not possible.

BACKGROUND ISSUES

The Human Genome Project and the Rise of Genetic Testing

The Human Genome Project (HGP) began in 1990 as a concerted international scientific research project to produce detailed maps of the 23 pairs of human chromosomes and to sequence the 3-billion nucleotide bases that make up the human genome.⁹ The enormous social, scientific and philosophical implications of this project have never been in doubt. Sometimes described as 'the Moon Landing of the Nineties',¹⁰ the heavily funded HGP has made rapid progress since that time.

⁴ Margaret Otlowski, 'Genetic Information in the Workplace' (1999) 11(2) *Today's Life Science* 20, 22.

⁵ See, eg, Barlow-Stewart and Keays, above n 2, 259, who argue that genetic discrimination should only be permitted 'where there the genetic trait would give rise to a direct and substantial risk to the public or unless it is for the employee's health and safety'; see also Otlowski, above n 4, 22, who supports specific and limited exceptions so as to allow susceptibility testing in circumstances where this can be demonstrated to be necessary, and genetic screening if it is established that development of a particular condition may jeopardize the safety of others.

⁶ The *Disability Discrimination Act 1992* (Cth) s 15(4) provides that it is not unlawful for an employer to fail to determine that a person with a disability should be offered employment or to dismiss a person with a disability in circumstances where they would be 'unable to carry out the inherent requirements of the particular employment' or would, in order to carry out those requirements 'require special services or facilities that are not required by persons without the disability and the provision of which would impose unjustifiable hardship on the employer'.

⁷ See, eg, *Anti-Discrimination Act 1977* (NSW) s 49D(4); *Anti-Discrimination Act 1991* (Qld) ss 34-35; *Equal Opportunity Act 1984* (SA) s 71; *Equal Opportunity Act 1995* (Vic) s 22; *Anti-Discrimination Act 1998* (Tas) s 45(a); *Equal Opportunity Act 1984* (WA) s 66Q.

⁸ *Anti-Discrimination Act 1992* (NT) s 35(1); *Discrimination Act 1991* (ACT) s 49.

⁹ See Privacy Commissioner, *The Privacy Implications of Genetic Testing*, Information Paper No 5 (1996) 59, who argues that 'genome' is the total genetic complement of an individual, that is, the individual's complete set of genes and chromosomes.

¹⁰ Senator Natasha Stott Despoja, 'The Human Genome Project: How Do We Protect Australians?' (2000) 173 *E Medical Journal of Australia* <http://www.mja.com.au/public/issues/173_11_041200/stottdespoja/stottdespoja.html> [1].

In June 2000, three years ahead of schedule, the HGP and Celera Genomics jointly announced the first near-complete draft of the entire DNA sequence of the human genome.¹¹ This was followed, in February, 2001 by the publication by the Public Sequencing Consortium of the HGP of a series of scientific papers in *Nature* providing a first pass sequence for most of the thirty to forty thousand genes thought to form part of the human genome.¹² The HGP has made a commitment to fill all gaps and resolve all ambiguities in the sequence with ninety nine percent accuracy by 2003.¹³

The HGP has been instrumental in the identification of a large number of genes responsible for various diseases, including glaucoma, colon cancer and cystic fibrosis¹⁴ and has led to the development of a growing number of tests to detect genetically caused diseases.¹⁵

Genetic Testing and Genetic Information

Genetic testing involves examining a person's DNA (deoxyribonucleic acid), RNA (ribonucleic acid) or associated proteins for the purpose of determining the existence of or predisposition to a particular disease.¹⁶ Genetic tests can be conducted on a very small amount of genetic material, such as a drop of blood, a sample of saliva or a scraping of skin.¹⁷ While genetic tests are a means of providing information about a person's genetic makeup ('genetic information'), it is worth noting that genetic information may also be derived non-invasively, by obtaining a detailed medical history from a person.¹⁸ The crucial issue from a legal and ethical standpoint is not so much how genetic information is obtained, but the use to which it is subsequently put.

¹¹ 'International Human Genome Sequencing Consortium Announces "Working Draft" of Human Genome', <http://www.nhgri.nih.gov/NEWS/sequencing_consortium.html>.

¹² See generally Francis Collins, *National Human Genome Research Institute Announces Sequencing and Analysis of the Human Genome* <http://www.nhgri.nih.gov/NEWS/initial_sequencePR.html> at 12 February 2001.

¹³ Francis Collins, Director, National Human Genome Research Institute, National Institutes of Health, *Before the Senate Health, Education, Labor and Pensions Committee* (2000).

¹⁴ According to the Human Genome Database, as at 7 October, 2001, 10,832 genes have been mapped to individual chromosomes. Of these, 1,610 had been identified as being involved in a genetic disorder: see *Hospital of Sick Children (5 October 2001) Reports and Statistics*.

¹⁵ At February 1998, there were in excess of 117 genetic conditions or predispositions that could be diagnosed with genetic testing: (1998) 11(1) *Bulletin of the Human Genetics Society of Australasia*.

¹⁶ For example, mutations in two genes, BRAC 1 and BRAC 2 predispose women to the development of breast and ovarian cancer: See generally Yoshio Miki, Jeff Swensen, Donna Shattuck-Eidens et al, 'A Strong Candidate for the Breast and Ovarian Cancer Susceptibility Gene BRAC1' (1994) 266 *Science* 66.

¹⁷ Jeremy Colby, 'An Analysis of Genetic Discrimination Legislation Proposed by the 105th Congress' (1998) 24 *American Journal of Law and Medicine* 443, 449.

¹⁸ Paul Steven Miller, 'Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace' (2000) 3(2) *Journal of Health Care Law and Policy* 225, 231.

The Use of Genetic Information

In some instances, genetic information may be used for *diagnostic purposes*, to make or confirm a conclusion about the condition of a person who is already exhibiting symptoms of the condition. For example, a person having a test for haemochromatosis because of liver indices, or a child with a recurrent cough being tested to determine whether they have cystic fibrosis. Where genetic information is used in this way, the legal and ethical implications associated with its use are no different to those associated with other diagnostic procedures such as standard blood tests or X-rays.¹⁹ Genetic information can also be used for *predictive purposes*, to determine the possibility that a person who currently has no symptoms of a particular disorder may develop the disorder at some time in the future. This paper will focus on the predictive use of genetic information, as it is here that most of the difficult legal and ethical questions in an employment context have arisen.²⁰

Characteristics of Genetic Information

In order to fully appreciate the potential impact of genetic information in the workplace, it is important to understand how it differs to other forms of health information. It is generally accepted that genetic information has the following characteristics that tend to make it unique. First, it may have limited predictive value. Genetic information tends to be about possibilities, rather than certainties. Although it may indicate whether or not a particular mutation is or is not present, its value in predicting future health is limited. Many genetic disorders are multifactorial in nature, that is, they are the result of a complex interaction between genes and environmental and lifestyle factors.²¹ In these circumstances, the most that genetic information can reveal is that a person has an increased susceptibility to developing a particular disease. Genetic information is not an absolute indicator that symptoms will develop. For example, while BRAC1 testing may establish that a woman has the particular genetic mutation associated with breast cancer, this does not mean that she will definitely contract that disease. It simply means that the probability of her doing so increases.²² Whether or not she goes on to develop the disease may ultimately depend not only upon her genetic makeup but also upon

¹⁹ Human Genetics Society of Australasia, *Submission to the Senate Legal and Constitutional Legislation Inquiry into the Provisions of the Genetic Privacy and Non-discrimination Bill*, Submission No 6 (1998).

²⁰ Information derived from genetic tests can also be used for prenatal diagnosis and forensic purposes. However, as these forms of testing are not relevant to the workplace, they are not discussed in this paper. For a detailed discussion of these and other forms of genetic testing, see Australian Law Reform Commission, *Protection of Human Genetic Information*, Issues Paper No 26 (2001) [2.1]-[2.158], [13.1]-[13.114], [14.1]-[14.80].

²¹ Examples of multifactorial disorders include cancer and Alzheimer's disease.

²² Only 60-80% of women with the BRCA1 or BRCA2 gene will develop breast cancer during their lifetimes: see Australian Law Reform Commission, above n 20, [2.107]; It has been suggested that the probability of a woman developing breast cancer will depend of whether there is a clear family history of this cancer. If there is no family history, the risk is unknown: See Denise Casey, 'What Can the New Genes Tests Tell us?' (1997) 36 *Judges Journal* 14, 14-15.

factors such as her lifestyle, stress levels, diet, exposure to pollutants and chemicals. In the case of monogenic (single gene) disorders, the predictive value of genetic information is somewhat greater. In these circumstances, the presence of a particular gene associated with a disorder indicates with relative certainty that a person will develop the disorder in the future. However, even in these circumstances, there may be great variation in the timing of onset or the severity of symptoms. A person found to carry a gene for Huntington's disease,²³ for example, will almost certainly develop that disease if they live long enough. However, the age of onset may vary over several decades.²⁴ If a person carries a gene for β -thalassaemia²⁵ they may be completely healthy, mildly affected or severely anemic. In fact, over one hundred and eighty different abnormalities in the gene have been identified, illustrating how complex even apparently simple genetic disorders can be.²⁶

Second, it may be relational in nature. Unlike other forms of health information genetic information extends beyond the individual and its impact cannot therefore be viewed in isolation. Because of its inherited and shared nature, it may disclose significant information about other family members that may have implications for their health. For example, by indicating that an individual is a carrier of a mutation, genetic information also implies that one of that person's parents was also a carrier. Difficult ethical dilemmas may arise as to whether individual test results should also be disclosed to other family members.²⁷ In some cases genetic information may even be pertinent to whole communities. Sickle cell anemia, for example, primarily affects persons of black African descent, while haemochromatosis is very common in persons of northern European descent.²⁸

Third, the information is particularly sensitive. Genetic information may reveal significant insights into a person's future health and life prospects. It may show, for example, that a person is a carrier of a disease, or at a high risk of developing a disease. In some instances, the person may not want others to have access to this information and may even prefer not to know about it him or herself. Fourth, it may

²³ Huntington's disease is a progressive disease of the central nervous system, characterized by involuntary movements, loss of motor control and dementia: see generally Privacy Commissioner, above n. 9, 59.

²⁴ GeneWatch UK, *Genetic Testing, Insurance and Employment: A New Form of Discrimination*, Briefing No 15 (2001) <<http://www.genewatch.org>>. Some studies indicate different progress in identical twins, with one twin developing symptoms of Huntington's Disease much later than the other one: see Anton van Dellen, Colin Blakemore, Robert Deacon et al, 'Environmental Effects of Huntington's Disease in Transgenic Mice' (2000) 404 *Nature* 721, 721-722; see also The Science Show, *Huntington's Disease Study*, Radio National, 9 October 2001, <<http://www.abc.net.au/rn/science/ss/stories/s117687.htm>>.

²⁵ Beta thalassaemia is a single gene disorder that impairs red blood cell production: see David Weatherall, 'Single gene disorders or complex traits: lessons from the thalassaemias and other monogenic diseases' (2000) 321 *British Medical Journal* 1117.

²⁶ Ibid.

²⁷ Loane Skene, 'Patients' Rights or Family Responsibilities? Two Approaches to Genetic Testing' (1998) 6 *Medical Law Review* 1, 5-7.

²⁸ Australian Law Reform Commission, above n 20, [2.117].

be inaccurate and unreliable. Like any other form of laboratory testing, genetic testing inevitably involves errors and uncertainties. It is relatively easy for results to become contaminated by extraneous DNA, either from other samples, or from the operator of the test.²⁹ Given the fact that genetics is a new and developing science, there is perhaps even greater scope for the information that is derived through testing to be incorrect or subject to misinterpretation.

THE USE OF GENETIC INFORMATION IN EMPLOYMENT

Why is Genetic Information of Interest to Employers?

From an employer's perspective, there are clear economic incentives associated with the use of genetic information about employees and potential employees. Such information offers employers an opportunity to exclude from the workforce individuals who have been identified as being at risk of developing a genetic condition that may affect their future capacity for work. Thus, there is potential for an organisation to reduce or avoid the costs associated with absenteeism, sick leave entitlements, and staff turnover. An employer's desire to obtain genetic information may also be motivated by occupational health and safety factors. For example, an employer may wish to use genetic information to determine whether or not an employee has a genetic predisposition that may pose a safety risk to the employee, co-workers or the public or that may render the employee particularly susceptible to workplace hazards. At a more general level, it may be argued that an employer has a legitimate interest in obtaining as much information as possible about a prospective employee in order to maximize its prospects of selecting the best possible person for the job. The use of pre-employment medical, psychological and even drug tests is already widespread in many industries.³⁰ Genetic testing may simply be seen as the next logical step along this continuum.

The Incidence of Genetic Testing in Employment

Despite the above incentives for its use, there is very little evidence to suggest that genetic testing is being carried out in Australian workplaces, or that genetic test results are being accessed or used by employers on a systemic basis.³¹ The Australian Law Reform Commission has recently described the use of genetic information in the employment context as 'still largely only of theoretical concern'.³² This contrasts with the position in the United States, where there is significant evidence of genetic testing being carried out by employers.³³ Recently

²⁹ Ronald Trent, *Molecular Medicine: An Introductory Text* (2nd ed., 1997) 20; Australian Law Reform Commission, above n 20, [2.100].

³⁰ Mark Rothstein, 'Genetics and the Work Force of the Next Hundred Years' (2000) 3 *Columbia Business Law Review*, 371, 382.

³¹ See Privacy Commissioner, above n. 9, 43.

³² Australian Law Reform Commission, above n. 20, [10.2].

³³ In 1989, a study conducted by the United States Congress Office of Technology Assessment (OTA) found that 3.6 percent of the 500 largest companies in the United States and 50 of the largest utility companies were carrying out genetic screening. While this figure seems

the American Management Association reported that 53 of its members, who include most of the country's largest employers, conducted genetic testing of applicants or employees.³⁴ Another study found that fifteen percent of the companies surveyed planned to use technology for genetic screening by the year 2000.³⁵

Unlike their counterparts in the United States, Australian employers do not have a responsibility to provide health insurance for their employees. To some extent, this may account for the apparently lower incidence of testing. However, it is likely that the incidence of genetic testing in Australian workplaces will increase, as tests become cheaper and more accessible. In particular, the development of 'DNA chip' technology which is able to screen for numerous mutations at the same time in a single test procedure,³⁶ is likely to greatly accelerate the efficiency of genetic testing. It may well be perceived by employers as an attractive alternative to more expensive and time-consuming medical and psychological tests.

It must also be remembered that genetic science is an area that has developed, and continues to develop, at breakneck speed. Only fifty years separates the first explanation by James Watson and Francis Crick of the double helix structure of DNA from the near completion of the Human Genome Project.³⁷ Should this trend continue, the routine use of test results by Australian employers might soon become reality.

GENETIC DISCRIMINATION IN EMPLOYMENT

What is Genetic Discrimination?

Discrimination involves making distinctions between individuals on the basis of certain characteristics, such as age, race or sex and using those distinctions as the basis for differential treatment. The increasing incidence of genetic testing and the consequent rise in the availability of genetic information have essentially unveiled a new dimension or layer of human difference, that of genetic makeup. This raises the

insignificant, it should be noted that participation in the survey was voluntary, making it less likely that employers who were in fact conducting genetic testing would respond. In addition, the survey was conducted at a time when genetic testing was in its infancy and also very expensive: See United States Congress Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* (1990) 197-208.

³⁴ See Lewis Maltby, 'Genetic Testing: Nightmare in the Making?' *Workplace Rights- American Civil Liberties Union* (2000) <<http://www.aclu.org/issues/worker/gdcolumn.html>>.

³⁵ See Susan Page, 'White House: Ban Gene Bias in Workplace' *USA Today*, 20 January 1998, A1; Shannon Brownlee, 'The Assurances of Genes' (1990) 109(4) *US News and World Report* 57.

³⁶ Ingrid Wickelgreen, 'Gene Readers' (1998) 253(5) *Popular Science* 56.

³⁷ James Watson and Francis Crick, 'A Structure for Deoxy-Ribose Nucleic Acid' (1953) 171 *Nature* 737.

prospect of genetic discrimination – the differential treatment of individuals, or groups of individuals, on the basis of their actual or presumed genetic differences.³⁸

The issue of genetic discrimination has been recognized at an international level for some time. Article 6 of the *Universal Declaration on the Human Genome and Human Rights*, adopted unanimously by the General Conference of UNESCO in November, 1997 states that:

No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.

Legislation has since been passed in a number of overseas jurisdictions specifically prohibiting genetic discrimination in employment.³⁹ At present, however, genetic status is not a specified ground of unlawful discrimination in any Australian jurisdiction, nor has alleged genetic discrimination been the subject of any case before any Australian court or tribunal.

Genetic Discrimination and Disability Discrimination

Unlike genetic discrimination, unlawful disability discrimination is specifically covered in Australian anti-discrimination laws, at the federal level by the *Disability Discrimination Act, 1992* (Cth) (the ‘DDA’) and also by State and territory legislation.⁴⁰ It has been suggested that genetic discrimination may be covered by this legislation.⁴¹ The term ‘disability’ is defined very broadly in section 4(1) of the DDA as including ‘the malfunction, malformation or disfigurement of part of the person’s body’ and extending to disabilities that ‘may exist in the future’ or are ‘imputed to a person’. Thus it may be possible to argue that a person with a genetic trait that causes their body to function abnormally or predisposes them to having a disease or disorder in the future may be regarded as having a disability under the DDA.

³⁸ See, eg, L Geller, et al, ‘Individual, family and societal dimensions of genetic discrimination: A case study analysis’ (1996) 2(1) *Science and Engineering Ethics* 71.

³⁹ In The Netherlands, the *Medical Checks Act 1997* s 3 effectively excludes the use of presymptomatic genetic testing for serious, untreatable conditions. In America, an Executive Order was signed by President Clinton on 8 February, 2000, that prohibits federal departments and agencies from using genetic information in any hiring or promoting action. Legislation has also been passed by 23 states regarding the use of genetic information in employment. A summary of the enacted legislation can be found at <http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/fedlegis.html>.

⁴⁰ *Anti-Discrimination Act 1977* (NSW); *Anti-Discrimination Act 1991* (Qld); *Equal Opportunity Act 1984* (SA); *Equal Opportunity Act 1984* (WA); *Equal Opportunity Act 1995* (Vic) s 22; *Anti-Discrimination Act 1998* (Tas); *Discrimination Act 1991* (ACT); *Anti-Discrimination Act, 1992* (NT).

⁴¹ David Keays, ‘The Legal Implications of Genetic Testing: Insurance, Employment and Privacy’ (1999) 6 *Journal of Law and Medicine* 357.

It is submitted, however, that there are a number of difficulties associated with an attempt to accommodate genetic discrimination within a disability discrimination framework. In general, disability discrimination presupposes an underlying impairment. However, in genetic discrimination, an individual's potential for impairment may never eventuate.⁴² Moreover, disability discrimination is typically based on a person having the symptoms of a genetic disease, whereas genetic discrimination is based simply on the fact that they have a particular genetic makeup that may or may not cause them to show symptoms of a disability in the future.

What Evidence is there of Genetic Discrimination?

There is significant empirical evidence of genetic discrimination in the workplace in the United States. A 1996 survey funded by the HGP surveyed individuals who were members of support groups for rare genetic anomalies, and each person was asked whether he or she or a family member encountered difficulties with employment, health insurance or life insurance. Thirteen percent of the respondents believed that the genetic information had led to job discrimination.⁴³ Another recent survey of genetic counsellors, primary care physicians and patients identified 550 people who had been denied employment or insurance based on their genetic predispositions to an illness.⁴⁴ More recently, disturbing evidence has also begun to emerge of genetic discrimination in Australia. Two separate studies conducted in Australia in 1999 by Dr Kristine Barlow-Stewart and David Keays found reports of genetic discrimination with respect to a wide range of genetic tests including those for haemochromatosis, inherited breast cancer, inherited bowel cancer and Alzheimer's disease. While most allegations of discrimination related to insurance, there were also three reported cases of alleged genetic discrimination in employment, all of which involved healthy, asymptomatic individuals who had tested positive for late-onset neurological conditions. In one case, the individual's employment was terminated, while in the other two cases the employee was demoted after the employer became aware of the genetic test result.⁴⁵

⁴² See Disability Rights Task Force, *Defining Disability and Defining Employment Discrimination*, 16 Recommendation 11 (1999) which recommended that genetic predispositions to impairments should *not* be considered a disability under the *Disability Discrimination Act 1995* (UK). According to the Task Force, it would not be appropriate to deem genetic predispositions to be 'disabilities' as there is no underlying impairment and one may never develop.

⁴³ S Sternberg, 'Genetic Discrimination: A Prejudice is Born' (1996) 150(17) *Science News* 262, 262.

⁴⁴ National Human Genome Research Institute, *Genetic Information and the Workplace*, January 20 1998, <http://www.nhgri.nih.gov/HGP/Reports/genetics_workplace.html>.

⁴⁵ See generally Barlow-Stewart and Keays, above n 2. Barlow-Stewart received 703 anonymous responses in survey forms that had been distributed by clinical geneticists and genetic support networks in Australia and New Zealand. She found that these contained 43 cases of alleged discrimination. Keays conducted interviews with 5 other people who had reported instances of alleged genetic discrimination.

In addition, two individuals claimed that they were required to undertake genetic testing as part of the employment selection process. The first case concerned a young woman applying for a position in the public service, who was allegedly informed that her application would only be successful if she achieved a negative test result for familial adenomatous polyposis, a condition known to lead to bowel cancer. The woman in question was undergoing regular colonoscopies for early signs of bowel cancer and the potential employer was aware of this. When she tested positive for the condition, she withdrew her application, believing it to be futile. In the other case, a young man with a family history of Marfan syndrome, which is a connective tissue disorder that can lead to cardiovascular problems, was allegedly required to provide his potential employer, a branch of the armed forces, that he was gene negative for this disorder. When he produced documentation proving that he had not inherited the faulty gene he was accepted into the armed forces.⁴⁶

There is also anecdotal evidence in Australia of perceived genetic conditions being the basis for discriminatory treatment in employment. In one case, described as 'biological determinism at its worst',⁴⁷ an eighteen-year-old male who had matriculated from College with above average results, applied for a position in the public sector and was placed in the top five percent of applicants. The final entry requirement was to pass a medical test. In the course of the test, he divulged that there was a history of Huntington's disease in his family. This meant that there was a fifty percent chance that he had inherited the gene and would only be employed if he took a genetic test and that it subsequently proved to be negative for the genotype that carries Huntington's disease. Having seen his mother suffer with the disease, he preferred not to know whether or not he had it, and refused to take the test. He subsequently began an appeal process through the Department and was eventually offered the job – with reduced superannuation and other benefits for the first ten years of employment that would only revert to normal if he did not contract the disease.⁴⁸

The Consequences of Genetic Discrimination

Genetic discrimination has potentially serious consequences not only for individual employees, but also for society as a whole. First, it raises the specter of a 'genetic underclass' of individuals who are deemed to be unemployable because genetic tests have revealed that they have a susceptibility to a particular disease. This class of people, sometimes referred to as the 'asymptomatic ill',⁴⁹ may be denied employment throughout their lives, yet never actually develop the condition for

⁴⁶ Ibid.

⁴⁷ Sandy Taylor, 'A Case Study of Genetic Discrimination: Social Work and Advocacy Within a New Context' (1998) 51(4) *Australian Social Work* 55.

⁴⁸ Ibid.

⁴⁹ Mathew Stulic, 'Genetic Non-Discrimination, Privacy and Property Rights' (2000) 7(2) *E law – Murdoch University Electronic Journal of Law* <<http://www.murdoch.edu.au/elaw/issues/v7n2/stulic72.htm>>.

which they have a higher than normal risk. The society denied the benefit of the contributions that such individuals could make in their productive years. Further, the social welfare system may, in future years, have to support a new class of individuals who are unable to support themselves financially.

Second, the threat of genetic discrimination by employers may act as a powerful deterrent to people obtaining genetic information that could provide them with potential health benefits. In the United States, there is disturbing evidence that some people who consult health care providers have refused to take health-related genetic tests because they are worried about the impact of the results on insurance and employment. The United States Department of Labor has found that: 'many women are avoiding breast cancer screening because they believe a positive finding would go on their medical records and become available to employers or insurers'.⁵⁰ If individuals avoid taking advantage of available diagnostic tests because of fear that they will be discriminated against, there is a risk that they may suffer more serious health problems in the long term.

A further problem is that genetic discrimination has the capacity to 'spill over' into and support other forms of discrimination, particularly race discrimination. Some conditions are known to be more prevalent in some races and nationalities than others. Thus, genetic explanations of human characteristics can easily be used to bolster discrimination on the ground of race by lending 'scientific' validity to stereotypes. For example, there is evidence that Ashkenazi Jewish women, whose roots go back to Eastern Europe, have a higher incidence of breast cancer than almost any other single groups of females. On the basis of this information, an employer could make a decision, either consciously or unconsciously, not to consider any Jewish women for jobs in their company.⁵¹ Given the above, it is not surprising that there now appears to be significant concern in Australia about the prospect of genetic discrimination, particularly in employment.⁵² In 1994, the Harris Poll found that ninety one percent of employees and human resources managers agreed that it was wrong to screen out job applicants simply on the basis that they might develop an inherited disease in the future.⁵³

THE NEED FOR LEGISLATIVE REFORM

The growing evidence of genetic discrimination in employment and the potentially serious consequences of this type of discrimination, make it imperative that the use

⁵⁰ Anonymous, 'Who's taking our genes – and why?' *The Guardian*, 19 September 2000.

⁵¹ Steve Lebau, 'Genetic Testing: Balancing Benefits and Abuses' (2000) *USA Today (Magazine)* 4, <http://www.findarticles.com/cf_0/m1272/2662_129/63668117/p1/article.jhtml?term=lebau+s>.

⁵² Millward Brown, *Australia, Biotechnology Public Awareness Survey Final Report* Biotechnology Australia, 1 July 2001 <<http://www.biotechnology.gov.au/mbsurveyresults.pdf>>. This survey, which updated a similar study conducted in late 1999 found that 59% of respondents were concerned that screening for genes that may cause incurable diseases could lead to discrimination.

⁵³ See generally Maltby, above n 34.

of genetic information in the workplace be regulated in some way. As noted above, there is no legislation in place in Australia that specifically addresses the issue of genetic discrimination or the regulation of genetic information. Although disability discrimination in the workplace is covered by the DDA, as well as by State and territorial anti-discrimination laws, it is uncertain whether the courts will interpret the notion of 'disability' as encompassing a genetic predisposition to developing a disability. In any event, there are significant variations in disability discrimination laws between different jurisdictions. For example, while the DDA as well as legislation in New South Wales and Tasmania⁵⁴ cover disabilities that 'may' exist in the future the position in other jurisdictions is less clear.⁵⁵

In 1998, the Genetic Privacy and Non-Discrimination Bill was tabled in the Senate by the Australian Democrats. This Bill was based on the *Model Genetic Privacy Act* (which has influenced genetic privacy laws introduced in some American states) and the US *Genetic Confidentiality and Non Discrimination Act 1997* and sought to prohibit discrimination based on genetic information. However, the Senate Legal and Constitutional Affairs Committee, which considered the Bill, recommended that it not be enacted. The Committee reported in 1999 that, as genetic technology is still in an early stage of development, it would be premature to legislate and that further examination of the appropriate regulatory structures was needed.⁵⁶ The issue of protection of genetic information is now the subject of a Joint Inquiry by the Australian Law Reform Commission (ALRC) and the Australian Health Ethics Committee (AHEC).⁵⁷ Under its terms of reference the inquiry is required to report on whether, and to what extent, a regulatory framework is required to provide protection from inappropriate discriminatory use of human genetic samples and information.⁵⁸

A 'LIMITED EXCEPTIONS' MODEL

A potential regulatory framework under consideration by the inquiry is one that attempts to strike a balance between competing employer and employee interests in this area. Proponents of this approach typically acknowledge that employees may require protection from genetic discrimination, but also allege that there are legitimate reasons for an employer to discriminate on the basis of genetic information. For example, Otlowski argues for an option that endorses a general policy against allowing use of genetic test information but specifies limited

⁵⁴ *Disability Discrimination Act 1992* (Cth) s 4(1); *Anti-Discrimination Act 1977* (NSW) s 49A; *Anti-Discrimination Act 1998* (Tas) s 3.

⁵⁵ The *Anti-Discrimination Act 1992* (NT) while not referring expressly to future conditions contains an inclusive definition, so may cover such conditions; the *Equal Opportunity Act, 1984* (WA) refers to impairments imputed to a person; all other legislation contain exclusive definitions which do not refer to, and presumably do not include future conditions.

⁵⁶ Senate Legal and Constitutional Legislation Committee, *Provisions of the Genetic Privacy and Non-Discrimination Bill, 1998* (1999) Parliament of Australia, Canberra, 37.

⁵⁷ See generally Australian Law Reform Commission, above n 20.

⁵⁸ *Ibid* 6.

exceptions that seek to give effect to ‘certain legitimate countervailing interests’.⁵⁹ These interests include the need to protect the employee from exposure to workplace hazards to which they may be particularly susceptible, the need to protect third parties from the consequences of a person’s genetic disability where that may put them at risk; and the need to protect the employer’s commercial interests.⁶⁰

This approach finds expression in a legislative model that prohibits genetic discrimination, either per se, or as a form of disability discrimination, and then seeks to accommodate employer interests in the form of exceptions to this prohibition. This models the legislative approach that has been taken to disability discrimination. While the DDA and related State and territory legislation make it unlawful to discriminate against a person on the ground of disability or impairment, they also allow for exceptions in circumstances where employer interests would be affected adversely. Thus, it is lawful to discriminate against a person with a disability if they cannot perform the inherent requirements of the particular employment. Alternatively, employers can discriminate against those applicants who require special services or facilities, when the provision of those services or facilities would impose unjustifiable hardship on the employer.⁶¹

Difficulties with the Proposed Exceptions to Genetic Discrimination

The ‘limited exceptions model’ is certainly an attractive model. It appears both sound and logical and has the added appeal of striking a balance between competing interests. However, closer analysis reveals that it may be inappropriate in the context of genetic discrimination. As mentioned above, a key feature of a limited exceptions model is the exceptions themselves. Exceptions are part of the framework of anti-discrimination law. They allow employers to discriminate in circumstances where common sense or policy dictates that discrimination is unavoidable. For example, where it is a genuine occupational qualification of a job that the person performing the job is of a certain sex or race, it is allowable to exclude a person not of that sex or race from the job.⁶² Exceptions may be viewed as the ‘margins’ of anti-discrimination law, where litigants test the limits of the law. It is around these exceptions that a great deal of case law tends to develop.

Generally, the circumstances where commentators and legislators have attempted to justify genetic discrimination in employment fall into the following categories:

- (a) Inherent requirements of the job;

⁵⁹ Otlowski, above n 4, 22.

⁶⁰ Ibid 21.

⁶¹ *Disability Discrimination Act 1992* (Cth) section 15(4)(a) and (b).

⁶² For example, the *Sex Discrimination Act 1984* (Cth) s 30(2)(f) and s 30(2)(d) provides an exemption where the duties can only be performed by a man or a woman for privacy or decency reasons, body searches, living on the employer’s premises or where people of the other sex are usually undressed.

- (b) Business necessity;
- (c) Public safety;
- (d) Employee susceptibility to workplace hazards and toxins.

Each of these possible exceptions will be critically evaluated in the context of its applicability to genetic information.

Inherent Requirements of the Job

Existing legislation in Australia dealing with discrimination on the ground of disability or impairment in employment provides for an exception in circumstances where an individual cannot carry out the inherent requirements' of the job because of his or her disability. Thus, the *Disability Discrimination Act 1992* (Cth) provides that discrimination by an employer will not be unlawful in relation to recruitment or dismissal if:

- 15(4) Taking into account the person's past training, qualifications and experience relevant to the particular employment and, if the person is already employed by the employer, the person's performance as an employee, and all other relevant factors that it is reasonable to take into account, the person, because of his or her disability,
 - (a) would be unable to carry out the inherent requirements of the particular employment.⁶³

It is likely that employers will rely upon this exception in order to defend allegations of discrimination based on genetic information about a job applicant or employee, if the existing DDA framework is retained in relation to genetic discrimination. For example, an employer might argue that a teacher who has tested positive to a gene for Alzheimer's Disease, should not be employed, as he or she will not be able to carry out the inherent requirements of their job should they develop the symptoms of the disease. The High Court has interpreted the 'inherent requirements' of a job expansively to mean the characteristics or essential requirements of the employment, including the surrounding context of the employment.⁶⁴ While it is not difficult to see how the 'inherent requirements' exception may apply in the case of existing medical conditions, closer analysis reveals that this exception does not translate comfortably to situations involving genetic information.

First, the exception presupposes some degree of certainty. Given its limited predictive value, genetic information cannot provide this certainty. Most genetic information is only in the form of probabilities about the future events and developments. While it can tell us about the chances that something will occur, it

⁶³ Similar provisions exist in State and territory anti-discrimination legislation. See, eg, *Anti-Discrimination Act 1977* (NSW) s 49D(4).

⁶⁴ *X v The Commonwealth* (1999) 200 CLR 177.

does not tell us that it certainly will. Second, the problem is that in determining whether an employee with a predisposition to a genetic disorder can comply with the 'inherent requirements' of the job, the employer is effectively required to assess their ability to do so over the entire period of employment. This is neither legitimate, nor is it possible. In most situations, it is not possible to predict in advance how long a period of employment is going to be, or when, during this period, the employee will develop symptoms. Third, the exception assumes that an employee will remain with the same employer. However, recent trends in the Australian labour market suggest that this is unlikely. There is growing evidence of a shift towards shorter-term employment.⁶⁵ Many people will change jobs, and even careers, several times in the course of their working lives. This makes it more difficult to justify the exclusion of a person from a job because of a disease they may develop many years in the future. Finally, it assumes that the 'inherent requirements' of the job will remain stable over the period of employment. This is also unlikely to be the case. Advances in technology mean that the way that work is being carried out is constantly changing. A job that requires manual, physical work and may therefore be considered unsuitable for someone with a predisposition to developing a degenerative back disorder may, in the future, be able to be carried out largely with the aid of machinery.

Otlowski argues that there appears to be little room for lawful discrimination against an employer or applicant for employment on the basis of their genetic makeup under the 'inherent requirements' exception. In particular, she argues that it will be virtually impossible for an employer to demonstrate that an asymptomatic individual is presently or in the foreseeable future unable to carry out the inherent requirements of the job.⁶⁶ However, it is not difficult to envisage circumstances where an employer who does not want to employ a particular person because of the possibility that they will develop a particular disease, as evidenced by genetic test results, is able to creatively design the 'inherent requirements of the job' so as to exclude the person from the job, thereby using this exception as a 'safe harbour' for his or her discriminatory behaviour.

Assessment of whether or not someone will be able to carry out the inherent requirements of the job will require a judgment being based at least partially on the present availability of treatment for the disease in question. Given the rapid development of genetic science, it is highly likely that a disease for which there is currently no cure, may be able to be cured, or at least controlled within the next ten years. For example, recent stem cell research suggests those serious diseases such as Parkinson's disease and Alzheimer's disease could one day be cured by replacement tissue grown to order.⁶⁷ Thus someone may be excluded from a job in

⁶⁵ Australian Bureau of Statistics: *Labour Mobility, Australia* 6209.0, released 12.10.2000. 15% of the Australian workforce had been in their current job for less than a year and had worked in a previous job during the year. That is, they had changed jobs during the year.

⁶⁶ See generally Otlowski, above n 4.

⁶⁷ Australian Law Reform Commission, *Protection of Human Genetic Information*, Issues Paper 26 (November, 2001) 34.

the present because of a future disease, that may or may not develop, based on the present availability of treatment for that disease. The 'inherent requirements' exception, therefore, becomes unworkable when an attempt is made to apply it to genetic information. According to one commentator, 'it is simply bad science for an employer to use the presence of a predictive genetic trait or marker to make workplace decisions, because those traits cannot predict how well that person will succeed in the workplace'.⁶⁸ There is no scientific basis for assuming that just because an employee has a predisposition to getting a particular disease, that employee will be unable to carry out the inherent requirements of the job.

Business Necessity

Business necessity has also been mooted as a possible justification for genetic discrimination. Section 18(b) of the Genetic Non-Discrimination and Privacy Bill provides that an employer may request or require or use the genetic information of an employee for the purposes of determining a genotype that is 'otherwise directly related to work and is consistent with business necessity'. Similar language was used in the United States Genetic Confidentiality and Non-Discrimination Bill 1997 upon which the Genetic Non-Discrimination and Privacy Bill was based.

However, the boundaries of the term 'business necessity' are very unclear. The notion of business necessity is a subjective one, and will vary enormously from employer to employer and business to business. It may also vary over time such that while today, 'business necessity' may require that an employee who has to stand for long periods of time in a factory does not have a predisposition to develop deep vein thrombosis. However, in twelve months time, work procedures and machinery may have changed in the factory, so that it may be now possible for employees to carry out most of their work while seated. It is also unclear who is to decide whether a particular genetic type is consistent with business necessity. Courts may well take the view that the employer, being most familiar with the requirements of their business, is best equipped to make this decision. On this basis, it would be relatively easy for employers to define 'business necessity' creatively, in a way that excludes a person with a genetic predisposition perceived to be undesirable. It is also difficult to know where to draw the line. Would truck drivers be able to be screened to determine whether they are predisposed to developing alcoholism? Would psychiatrists be screened to determine whether they are predisposed to developing mental illnesses such as depression? Given the potential breadth of its application, a 'business necessity' exception may well lead to an initial prohibition on genetic discrimination becoming almost meaningless.⁶⁹

⁶⁸ See generally Miller, above n 18.

⁶⁹ See, eg, the criticisms of the 'inherent requirements' exception in relation to age discrimination by Jocelyne Scutt, 'These Days Equal Opportunity Stops at the Border', *Sydney Morning Herald*, <<http://www.smh.com.au>> at 30 January 2002.

Public Safety

A number of commentators have argued strongly in favour of an exception to genetic discrimination where issues of public safety arise such that an employee with a particular genetic predisposition may pose a threat to himself or to others.⁷⁰ A frequently used example to bolster this argument is that of an airline pilot who may be predisposed to a condition that results in blackouts at high altitude, thus causing death or injury to large numbers of the public as well as other employees.⁷¹

There is strong support for this approach in the United Kingdom. The Nuffield Council on Bioethics recommended that screening should only be contemplated where the condition in question is one that seriously endangers the health of the employee or is one which is likely to present a serious danger to third parties.⁷² The House of Commons Science and Technology Committee recommended that legislation should forbid employers testing for genetic traits other than those that might put the public at direct and substantial risk.⁷³ The Human Genetics Advisory Commission has even gone so far as to recommend: '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 genetic test'.⁷⁴

At first glance, this argument appears to be eminently sensible. Courts have already been willing to accept mandatory drug testing in workplaces involving dangerous work activities. In *Kay v Cargill Foods Australia*⁷⁵ the court held that an employer was justified in imposing drug and alcohol tests on its employees who worked as meat boners on the basis that they could pose a risk to their own and others' safety if they were 'under the influence' of drugs or alcohol at work. In *Denbo v Transadelaide*⁷⁶ an employer's policy of drug testing its train driver employees was considered justified in the light of the employer's duty to ensure public safety.

However, there is a major difference between drug and alcohol testing and genetic testing. While drug testing provides information about an employee's current medical or physical conditions, genetic testing can really only provide information about what *may* happen to the employee in the future. Even in the case of single gene disorders, where the predictive capacity of genetic testing is comparatively high, it is unlikely that such disorders will be sudden in onset and thus lead to an incident such as an aircraft accident that threatens safety. Most sudden-onset disorders are multifactorial in nature that means that it will be impossible for

⁷⁰ Keays, above, n.41, 371, for example, argues that genetic tests should be allowed if a worker's genetic trait causes a direct and serious risk to the public.

⁷¹ 'Rare Gene May Cause Fatal Clots on Flights' *The Sydney Morning Herald*, 10 July, 2001.

⁷² Nuffield Council of Bioethics, *Genetic Screening: Ethical Issues* (1993), [6.23].

⁷³ House of Commons Science and Technology Committee (Shaw Committee) *Human Genetics: the Science and its Consequences* (1995) Vol 1, [232].

⁷⁴ Human Genetics Advisory Commission, *The Implications of Genetic Testing for Employment*, 3.19 <http://www.doh.gov.uk/hgac/papers/papers_g/g_03.htm>.

⁷⁵ *Kay v Cargill Foods Australia* [1996] IRCt (NSW) 432/96, (Unreported 6 September 1996)

⁷⁶ Unreported, Australian Industrial Relations Commission, 7 September, 1999.

genetic tests to predict with any accuracy whether or when they will occur. Thus, it is possible that individuals may be excluded from employment as potential safety risks, despite the fact that they do not have any symptoms of the disease in question and may never in fact go on to develop that disease.

To a large extent the people who might be screened out of employment on safety grounds may be dependent on the current state of play with genetic technology. Each person is susceptible to certain ailments and has certain predispositions. Researchers estimate that each human being carries at least 20 'defective' genes that may indicate predisposition to disease, however, such genes have yet to be 'mapped'.⁷⁷ The science of genetics is constantly evolving, and new tests are being developed all the time. According to Stulic, 'it is a tenuous position to attach conditions to some individuals and not to others in employment, merely because the technology and knowledge exists to detect some genetic diseases, but others cannot have their own risks similarly assessed'.⁷⁸

Employee Susceptibility to Workplace Hazards and Toxins

According to this suggested exception, it is appropriate for employers to be able to carry out genetic testing in order to detect individuals with increased susceptibility to certain workplace hazards. Therefore, it would not be discriminatory for an employer to avoid placing a more than usually susceptible employee in an environment that might activate a disease or illness. In the United Kingdom, the Human Genetics Advisory Commission advocated, and the UK Government subsequently agreed, that it would be appropriate to use genetic tests to assess the susceptibility of employees to conditions existing in their particular workplace.⁷⁹ The Genetic Non-Discrimination and Privacy Bill also uses this exception, providing in section 18 that an employer may request or require or use the genetic information of an employee for the purposes of 'permitting a genetically susceptible employee to avoid exposures to substances with a mutagenic or teratogenic effect'.

The AMA, in its response to the Genetic Non-Discrimination and Privacy Bill was particularly critical of this exception, claiming that it allows employers to require genetic information under the pretence of protecting an employee from hazards to which he or she may be particularly susceptible.⁸⁰ Overall, the AMA viewed the proposed legislation as not going far enough to balancing the protection of individuals from potential genetic discrimination. The main problem with this exception is that it sanctions a shifting in responsibility for management of workplace risks. This approach makes it all too easy to remove the worker, rather

⁷⁷ C Saucer, 'Do the Right Thing – Laws Designed to End Prejudices in Insurance' (1997) 98 *Best's Review – Property Casualty Insurance* Edition 7, November 1997, 108(3).

⁷⁸ Stulic, above n 49, [7].

⁷⁹ Lord Sainsbury and Yvette Cooper, 'Genetic testing and employment- letter to Baroness Helena Kennedy, Chair, Human Genetics Commission', <<http://www.doh.gov.uk/genetics/hgacgovresp.htm>> at 24 July 2000.

⁸⁰ R Leeb-du-Toit, 'Genetic Databanks for the People' (1998) 3-4 *Law and Technology* 4.

than the risk from the equation, therefore undermining workplace safety generally. In most cases, it would be more cost-effective for an employer to simply deny a susceptible person employment, than it would be to modify working conditions. There is also the potential for the genetic information obtained to be used to limit or defeat workers compensation claims. A recent case in the United States concerned a rail company that demanded genetic testing of its employees for carpal tunnel syndrome following a number of claims by employees for work-related injuries.⁸¹

Interestingly, recent evidence suggests that the genetic screening is not always a cost-effective option for an employer. One study carried out by researchers at the University of California found that screening for susceptibility to a rare, benzene-induced cancer showed a reduction in long-term incidences of the diseases from 4 out of every 1,000 workers to approximately 3 per 1,000. The researchers concluded that the slight reduction in disease incidence and health care costs would probably not even cover the cost of the screening program.⁸²

In conclusion, while they purport to protect legitimate employer interests, the suggested exceptions to genetic discrimination are, for the most part, problematic. Very little thought appears to have been given to how these exceptions will operate in practice. Proponents suggest that genetic discrimination is justifiable in circumstances where there 'is conclusive evidence that it is valid and necessary'.⁸³ However, who will decide what is valid and necessary and how will such a decision be made? It is difficult to see how a national regulatory body could operate across such a diverse area as employment, and in the absence of such a body, it would appear to be the employer who will ultimately make this decision. This may lead to the 'creative interpretation' problems mentioned above.

Perhaps more fundamentally, the problem with the suggested exceptions to genetic discrimination stems from the fact that they are modeled on exceptions that applies in relation to disability discrimination. There are compelling reasons suggesting that it may be inappropriate to simply import disability related exceptions into a framework that purports to deal with genetic discrimination. While the exceptions may be sustainable in situations where an employee or potential employee has a known disability or underlying impairment, they do translate easily to situations where all that an employee has is a genetic predisposition to developing a disability. Furthermore, the very notion of disability underlying the exceptions may itself be

⁸¹ *EEOC v Burlington Northern and Santa Fe Railroad Co.*, No. C01-4013-MWB (N.D. Iowa Apr. 18, 2001). The employer was successfully challenged in the Equal Employment Opportunity Commission.

⁸² Mark Nicas and Geoffrey Lomax, 'A Cost Benefit Analysis of Genetic Screening for Susceptibility to Occupational Toxicants' (1999) 41(7) *Journal of Occupational and Environmental Medicine* 535. Note that the same study found, using a different model, that in the case of a beryllium-related lung illness screening could reduce the incidence of illness from 50 cases per 1,000 to 16 cases per 1,000. However, the researchers concluded that while in specific instances screening can be cost-beneficial on average, but can yield an unfavourable outcome with high probability.

⁸³ Otowski, above n 4, 22.

fundamentally flawed. The exceptions are premised upon a model of disability that focuses on the functional impairments and vocational limitations of people with disabilities. In recent years, however, disability discrimination related literature has questioned this construction of disability and there has been a growing acceptance of the idea that the functional limitations of people with disabilities are the result of other people's attitudes, rather than their own capacities.⁸⁴ It makes little sense to simply import disability discrimination exceptions into a genetic discrimination framework, when the fundamental rationale for such exceptions is being actively questioned in current legal discourse.

Privacy Concerns

The effective application of a 'limited exceptions' model requires that there also be strong supports in place to protect the privacy of employee genetic information. However, under current privacy laws, these supports are limited. Despite the recent enactment of the *Privacy Amendment (Private Sector) Act 2000* (Cth) which extends privacy protection to most of the private sector, effective privacy protection for employee genetic information appears to be sadly lacking. The new privacy provisions have a broad exemption in section 7B(3) for employee records. This means that the National Privacy Principles (NPPs) that will regulate the use, storage and disclosure of personal information will not apply to the records relating to current or former employees. Therefore, if a person undergoes genetic testing by the employer and the information obtained relates to the employment relationship, there is nothing to prevent the employer disclosing this information to other people, including other employers.⁸⁵ Genetic information collected at a pre-employment medical assessment would be covered by the legislation. However, if the applicant is ultimately recruited, any information collected by the employer during the pre-employment stage and held in the new employee's record is also likely to be subject to the exemption.

Is Consent a Panacea?

A 'limited exceptions' model tends to utilise the concept of 'informed consent' and 'authorization' to justify employers being able to access employee genetic information. For example, the Genetic Privacy and Non-discrimination Bill 1998 proscribes disclosure of genetic information and the collection of DNA samples from an individual for genetic analysis except with the authorization of the individual, or in other limited circumstances. A 'limited exceptions' model assumes that so long as the employee gives informed consent to being genetically tested or to the employer accessing the results of genetic tests, the use of his or her genetic information in a potentially discriminatory manner is somehow made legitimate.

⁸⁴ Harlan Hahn, 'Accommodations and the ADA: Unreasonable Bias or Biased Reasoning?' (2000) 21(1) *Berkeley Journal of Employment and Labor Law* 166-209.

⁸⁵ House of Representatives Standing Committee on Legal and Constitutional Affairs, Parliament of Australia, Canberra, 29 November 2000, 34 (Kate Lundy) <<http://saerch.aph.gov.au/search/ParlInfo.ASP?action=view&item=0&resultsID=17T2dW>>.

Mathew Stulic argues that the concept of 'informed consent' in the context of genetic privacy may not be appropriate, as the fundamental unit of the 'individual', upon which informed consent is based, ignores the fact that genetic composition is an issue that extends beyond the concept of the 'individual'.⁸⁶ The traditional unit of the 'individual' is a redundant concept in the context of 'shared' information. As shown earlier, genetic information extends beyond the bounds of the category of the 'individual'. It is unique in the sense that it carries 'shared' information about an individual, his or her relatives and indeed human kind. In any event, a real question arises as to whether an employee would be sufficiently empowered within the context of the employment relationship to refuse to undergo genetic testing or to provide the results of previous genetic tests. Typically an employee in these circumstances will also be under considerable pressure to obtain or to hold onto employment. It is therefore very doubtful that any consent that they provide could ever really be perceived as 'voluntary'.

Ethical Considerations

A limited exceptions model fails to take into account important ethical considerations that arise from the nature of genetic information. Obtaining information about one's genetic makeup is not the same as obtaining information about a known disability. Genetic information is particularly sensitive in that it may also affect other people and have a serious psychological and emotional impact on the person who is tested. That is, genetic information raises the issue of a right 'not to know'. Many people may prefer not to know whether or not they have a potentially fatal illness, such as cancer. However, under limited exceptions models, they may have no choice in the matter. For example, a person who is required to undergo genetic testing to determine whether they are a risk to safety is effectively denied the right 'not to know'. As a result, in addition to being denied employment, they may find themselves living in the shadow of a potentially fatal disease.

It may of course be argued that it will be in an individual's best interests to 'know', as they will be able to benefit by accessing preventative treatment. But will this always be the case? Genetic testing and screening for inherited disorders is happening at a pace that far outstrips the availability of gene therapy or other treatments.⁸⁷ There are a number of conditions for which there is no known cure and in these cases; the right 'not to know' becomes even more important. The psychological and emotional effects of this knowledge are likely to be severe, not only for the individual who is affected, but also for their families.⁸⁸

⁸⁶ Stulic, above n 49, [2].

⁸⁷ Justice Michael Kirby, 'Human Freedom and the Human Genome: the Ten Rules of Valencia', *International Workshop of Freedom and Risk Situations* Valencia, Spain, 25 January, 1999 <http://www.lawfoundation.net.au/resources/kirby/papers/19990125_val.html> at 10 July 1999.

⁸⁸ Theresa Marteau and Robert Croyle, 'Psychological Responses to Genetic Testing' (1998) 316 *British Medical Journal* 693-696.

As discussed earlier, genetic information is relational in nature. When a person learns that they have a gene that places them at increased risk of certain diseases, they face the dilemma of whether or not to tell other family members about their potential susceptibility to disease. This information is directly relevant to their biological relatives, for other family members being at risk of genetic discrimination, since genetic information about an individual is also information about that individual's family.

The Limitations of Anti-Discrimination Analysis and Legislation

As has been discussed, the limited exceptions model stems from an anti-discrimination framework. However, a real question arises as to whether this type of framework is an appropriate one in the context of genetic information. According to Susan Wolf, the real danger associated with use of genetic information lies not simply in genetic discrimination, but rather in 'geneticism' – the tendency to see individuals as their genes, and the promotion of the idea that genetic differences are real, biological and neutral grounds for different treatment. She argues that anti-discrimination analysis merely serves to entrench genetic bias and, by ensuring uniform treatment within the existing system, fails to question the system itself, thus thwarting structural change. Just as anti-discrimination analysis has failed to make any significant inroads against pervasive racism and sexism, so too it must fail against geneticism.⁸⁹ Therefore, it may be that anti-discrimination analysis provides a flawed foundation for dealing with potential abuse of genetic information and that some other approach is required.

In any event, it must be acknowledged that anti-discrimination legislation has serious practical limitations. There is evidence that many employees are unaware that they can bring discrimination claims. According to Barlow-Stewart and Keays, not one of the individuals who reported genetic discrimination in their study appeared to have exhausted available appeal mechanisms after the alleged discriminatory conduct took place. Only one individual sought redress internally, but was unsuccessful and no further action was taken.⁹⁰ Even if they are aware of their rights, many employees may be discouraged from pursuing them through equal opportunity tribunals, given the significant legal costs likely to be involved and uncertainty of outcome. In most jurisdictions, the complainant will bear the onus of proving that he or she was discriminated against on the basis of their genetic status. This will be a very difficult onus to discharge especially in the recruitment context, where it is relatively easy for most employers to give other reasons to justify a decision not to hire someone. These limitations mean that even though in theory employees who have been subjected to genetic discrimination may be able to take legal action to protect their rights, in practice they are unlikely to do so. It may be argued that these limitations impact upon all forms of discrimination.

⁸⁹ Susan Wolf, 'Beyond Genetic Discrimination: Towards the Broader Harm of Geneticism' (1995) 23(4) *Journal of Law, Medicine and Ethics* 345-53.

⁹⁰ Barlow-Stewart and Keays, above n 2, 254.

However, the consequences of genetic discrimination may be particularly severe and whereas with other forms of disability, the differential treatment is based on a characteristic that is known (for example, sex, race or disability) whereas with genetic discrimination, it is based on information that is uncertain and possibly inaccurate. It is submitted that this tips the balance in favour of stronger protection for employees in this area.

AN ALTERNATIVE APPROACH

Analysis of the limited exceptions model therefore reveals serious weaknesses with its foundations and practical application. This model may effectively sanction discrimination against employees on the basis of uncertain and possibly inaccurate information, potentially undermining fundamental employee rights and freedoms. In short, the uncertain predictive nature of genetic information makes it very difficult to imagine any circumstances in which genetic discrimination may be justified in employment. A regulatory framework that prohibits genetic discrimination while attempting to provide for exceptions to it, may be fundamentally flawed.

An alternative regulatory framework is one that seeks to prohibit the practice of genetic testing by employers. Indeed, employers should not be allowed to use any genetic information in their recruitment decisions. This broader, rights-based approach overcomes some of the difficulties associated with the traditional anti-discrimination analysis discussed above. Under this type of framework, scenarios such as those reported by Barlow-Stewart and Keays would not have arisen. Employers would not be able to require individuals to undergo genetic testing.

Prohibition of genetic testing has some public support in Australia and is not without legislative precedent.⁹¹ In Austria, employers are prohibited from requesting or collecting genetic information in employment.⁹² Governments in Norway and France have also legislated to ban genetic testing by employers.⁹³ The *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine* was adopted by the Council of Europe in 1997.⁹⁴ It prevents testing for diseases unless for health or scientific purposes.⁹⁵ Although Australia is not a signatory, the *Convention* provides some

⁹¹ In June, 2001 a Sydney Morning Herald internet poll found that 93.5% of respondents thought that the government should ban the use of genetic testing in insurance, employment and borrowing until a detailed policy was worked out: *Sydney Morning Herald – Online Poll*, <<http://www.smh.com.au>> at 1 June 2001.

⁹² GeneWatch UK, 'Genetic Testing in Insurance and Employment: A New Form of Discrimination' Briefing Number 15 June 2001.

⁹³ Human Genetics Commission, *Who's Hands on Your Genes?* (2000) 40.

⁹⁴ (1997) 36 ILM 817.

⁹⁵ Council of Europe, 'Explanatory Report to the Convention for the Protection of Human Rights and the Dignity of the Human Being with Regard to the Application of Biology and Medicine' (1997) 36 ILM 817, 834.

justification for an approach precluding genetic tests being carried out for employment-related purposes.

Interestingly, in the area of insurance, there has been strong international support for an outright prohibition of genetic testing. A number of countries, including Austria, Denmark, Norway, Sweden and the USA have legislation in place to the effect that insurers should not be able to require applicants for insurance to undergo genetic testing.⁹⁶ Most commentators cite the limited predictive value of genetic tests as a reason for banning their use by insurers. According to Stulic, one argument for justifying an outright prohibition on the use of genetic information by insurers is that: 'prediction of loss when genotype is not determinative of phenotype, at present, is a lottery'.⁹⁷

It is submitted that similar considerations should be taken into account when dealing with genetic testing by employers. Because of the complexity and the limited predictive value of genetic testing, it should not be used to make employment decisions. Moreover, the inherently unequal nature of the employer and employee relationship justifies a strong stance being taken. An employer who treats an employee adversely because of his or her genetic makeup usually has access to a large pool of labour and can simply employ someone else. However, the employee who has been discriminated against has been excluded from employment and may have been given inaccurate information about their future health.

There are sound policy reasons for not allowing employers to carry out genetic testing or to use the results of genetic tests in making decisions about employment. Genetic science is a complex and constantly evolving area and it is not unfair to assume that the majority of employers will not have a good understanding of it for quite some time (if at all). This may lead them to misinterpret genetic test results and to make employment decisions based on incorrect assessments of an individual's state of health. A likely scenario, for example, may be that an employer may misinterpret the results of a test for a multifactorial condition as determining that an individual has, or will develop the disease, whereas tests for these conditions can only ever predict the probability of a disease. It is of interest that the Barlow-Stewart and Keays study outlined above suggested that in many of the reported cases, the discriminatory decision or action of the employer or insurer was inappropriate, based on misinformation or a lack of understanding of genetic information and the nature of genetic disorders.⁹⁸

History has shown that employers may also misunderstand the difference between a person who is a carrier of a particular disease and a person who has that disease. In the 1970s, United States armed forces and airline industries for a number of years tested pilots and other airline crew for the sickle cell trait. People with sickle cell have sickle shaped red blood cells that have trouble squeezing through small blood

⁹⁶ Gene Watch UK, above n 92.

⁹⁷ Stulic, above n 49.

⁹⁸ Barlow-Stewart and Keays, above n 2, 255.

vessels. This can lead to blockages and oxygen shortage, resulting in severe pain, organ damage and, in some extreme cases, death. However, many of the individuals who were screened out were only carriers of the condition and therefore were not capable of developing the disease themselves.⁹⁹ Although public education campaigns have been suggested to increase awareness amongst employers and others, the utility of these is doubtful, given the enormous complexity of the subject. A regulatory framework that prohibits both the practice of genetic testing by employers as well as limiting their access to, and use of, employee genetic test results also have the advantage of overcoming deficiencies in privacy legislation.

Legislation is urgently needed in Australia to deal with the threat of genetic discrimination in employment. A 'limited exceptions' model is likely to result in perfectly healthy people being discriminated against on the basis of uncertain and possibly inaccurate information. Such a model fails to fully address the distinct nature of genetic information and is therefore both illogical and unworkable. It may also undermine important employee rights and freedoms, as well as the very safety standards it is seeking to protect. Given the complex, constantly evolving nature of genetic technology and the limited predictive value of genetic information, adverse treatment of employees on the basis of their genetic makeup cannot be justified under any circumstances. Genetic information should be used for the benefit of the individual who is undertaking genetic testing, rather than for the benefit of a third party, whose primary motivation may be financial gain.¹⁰⁰ Genetic testing and genetic information have no place in the workplace.

⁹⁹ Dave King, 'Testing Times: Dave King Examines the Potential Downsides of Genetic Testing' (2001) <<http://www.oneworld.org/ni/issue293/testing.html>>.

¹⁰⁰ Transcript, 7.30 Report, 'Genetic Discrimination Starts in Australia' <<http://www.abc.net.au/7.30/s154671.htm>> at 21 July 2000.