

Unemployable Genes: Genetic Discrimination in the Workplace

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I. INTRODUCTION

Scientific technology is advancing at a staggering pace and providing humanity with a wealth of new knowledge. New genetic technologies promise great advances in areas of human health, providing the means to identify and ultimately understand, prevent, and treat genetically based diseases. However, there is increasing concern that information about an individual's unique genetic make-up could be used as a basis for wrongful discrimination.

This article examines the issues and difficulties surrounding genetic discrimination in employment. These have already been the subject of much discussion in the United States, where the issue is complicated because employers usually provide their employees with healthcare insurance. Consequently, employment is inextricably linked to the provision of private health insurance and access to healthcare. The more employees who are sick, the higher the costs for the employer. As a result, employers routinely test job applicants and employees for a number of health related matters, including workplace susceptibilities and overall health. New Zealand, unlike the United States, has a national health service. However, New Zealand employers are increasingly assisting their employees to obtain additional private healthcare insurance and the fear of increased insurance premiums may be a factor in some employment decisions. A number of other reasons that employers could use to discriminate against individuals on the basis of their genetic heritage will be discussed in this article. It is possible that the limitation of employment prospects on the basis of genetic information could lead to a form of genetic determinism, where an individual's genome would predetermine the opportunities available during his or her lifetime.

Most lawyers know little about genetics. Because a basic understanding is required to grasp some of the issues involved, Part II of this article provides a brief overview of human genetic information. Part III introduces the concept of genetic discrimination in the workplace, and

the concepts of genetic monitoring and screening. Part IV provides three examples of genetic discrimination to illustrate the problems encountered, and Part V examines the legal developments surrounding genetic discrimination. A final conclusion is reached in Part VI.

II. THE HUMAN GENOME AND GENETIC INFORMATION

1. The Human Genome

The term 'human genome' refers to the entire set of human genetic material. While the basic bearer of all genetic information is deoxyribonucleic acid ("DNA"), the fundamental physical and functional units of heredity are genes.¹ Genes are sections of DNA containing information that determines the sequence in which amino acids are joined, and consequently the shape and character of the proteins produced.² This in turn, determines the shape and character of the cells formed, and the subsequent shape and character of the physical body assembled. There are estimated to be around 35,000 genes of varying size in the human genome.³

Launched in 1988, the Human Genome Project (the "HGP") is an international research project that aims to map the entire human genome.⁴ By identifying the genes responsible for disease, and determining how those genes trigger disease, scientists hope to delay and ultimately prevent the onset of disease. In February 2001, two drafts of the human genome were published.⁵

* BSc/LLB (Hons). My thanks to Grant Huscroft from the University of Auckland Faculty of Law for his valuable direction and feedback in the preparation of this article. Special thanks to my wife, for her everlasting love and support.

¹ Griffiths, Miller and Suzuki, *Introduction to Genetic Analysis* (6 ed, 1996) 866.

² U.S. Congress, Office of Technology Assessment, *Mapping our Genes - Genome Projects: How Big, How Fast?* (1988) 3-4.

³ Baltimore, "Our Genome Unveiled" (2001) 409 *Nature* 814, 815.

⁴ *Ibid.*

⁵ International Human Genome Consortium, "Initial Sequencing and Analysis of the Human Genome" (2001) 409 *Nature* 860; and Venter, Adama and Myers, "The Sequence of the Human Genome" (2001) 291 *Science* 1304.

2. Limitations of Genetic Information

The genetic basis of any given disorder is unique and usually complex and the pathology of a genetic disorder is rarely dictated by genetic mutation alone. Predictions are confounded by a multiplicity of genetic, biomedical and environmental factors.⁶ Even with monogenic disorders,⁷ although the predictive power of a genetic test can be high, it is often impossible to predict the time of onset and the degree of penetrance and expression.⁸ Accurate predictions are even more difficult for the majority of genetic disorders, which can be both polygenic⁹ and multifactorial.¹⁰ For the most part, genetic information is “probabilistic and inexact”,¹¹ and it is impossible to reduce all aspects of health, disease or behaviour to the structure and function of the genome.¹²

III. GENETIC DISCRIMINATION AND EMPLOYMENT

All employment decisions are necessarily based on some type of differentiation or ‘discrimination’. Job applicants are frequently discriminated against on the basis of characteristics such as their education level, prior work experience, dress standards and mannerisms. Some employers are beginning to suggest that they should now be able to incorporate genetic information into their decision-making processes.¹³ These employers claim that the use of genetic information can promote cost-effective planning strategies,¹⁴ maximise employee efficiency,¹⁵ reduce workers’ compensation claim costs and medical insurance

⁶ Gostin, “Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers” (1991) 17 Am JL & Med 109, 114.

⁷ Monogenic disorders are determined by a single mutant gene.

⁸ Penetrance and expressivity describe the degree to which a person manifests the trait for which the gene codes.

⁹ Polygenic disorders are determined by the interaction of multiple genes, which may be located on different chromosomes.

¹⁰ Multifactorial disorders have both genetic and environmental influences

¹¹ Lawton, “Regulating Genetic Destiny: A Comparative Study of Legal Constraints in Europe and the United States” (1997) 11 Emory Int’l L Rev 365, 379.

¹² Nussbaum, “Current Research and Future Directions of Genetic Services” in Freeman (ed), *Genetic Services: Developing Guidelines for the Public Health* (1996) 232, 232-233.

¹³ Suzuki and Knudtson, *Genethics: The Clash Between the New Genetics and Human Values* (1989) 161.

¹⁴ *Ibid* 76.

¹⁵ Pulver, “Genetic Screening in the Workplace: A “Fit” for Consumers?” (1992) 5 Loy Consumer L Rep 13, 16.

premiums,¹⁶ and minimise the risks of future liability under tort law.¹⁷ Without legal restrictions, many employers will inevitably seek to exclude individuals from the workplace if they consider them to have poor genetic records.¹⁸

1. Genetic Discrimination

Discrimination is a “nebulous and complex concept”.¹⁹ It involves a process of perceiving, noting, or making a distinction between things.²⁰ The essence of discrimination lies in a difference of treatment in comparable circumstances because of a difference in a particular characteristic that does not justify the difference in treatment. Justification is frequently found in “social policy resting on community values”.²¹ At its widest, ‘genetic discrimination’ would include discrimination based on any ground that is determined or influenced by a person’s genetic make-up. This would include most phenotypic characteristics such as sex, ethnicity, race, and all genetically-based disabilities. In this article, genetic discrimination is limited to “discrimination against an individual or against members of that individual’s family *solely* because of real or perceived differences from the ‘normal’ genome in the genetic constitution of that individual”.²²

Genetic discrimination is not based on the present abilities of the individual, but on future manifestations of genetic conditions or predispositions. Those at risk of genetic discrimination include:²³

1. individuals who, although currently asymptomatic or presymptomatic, possess a genetic hypersensitivity, have a latent genetic disease, or possess a genetic predisposition to future disease;²⁴

¹⁶ Nelkin and Tancredi, *Dangerous Diagnostics: The Social Power of Biological Information* (2 ed, 1994) 96.

¹⁷ Seltzer, “The Cassandra Complex: An Employer’s Dilemma in the Genetic Workplace” (1998) 27 Hofstra L Rev 411, 460-464.

¹⁸ Miller and Huvos, “Genetic Blueprints, Employer Cost-Cutting, and the Americans with Disabilities Act” (1994) 46 Admin L Rev 369, 371.

¹⁹ *Quilter v Attorney-General* [1998] 1 NZLR 523, 530 per Thomas J.

²⁰ Simpson and Weiner (eds), *Oxford English Dictionary* (2nd ed, 1992) vol VI, 758.

²¹ *Quilter*, supra note 19, 527 per Gault J.

²² Natowicz, “Genetic Discrimination and the Law” (1992) 50 Am J Hum Genetics 465, 466 (emphasis added).

²³ Miller and Huvos, supra note 18, 372.

²⁴ Natowicz, supra note 22.

2. individuals who are carriers of a recessive deleterious gene. Such discrimination is based on the mistaken assumption that a carrier heterozygote²⁵ has, or will develop, a disorder, or the chance that their children will develop one; and
3. relatives of individuals who have, or are presumed to have, genetic conditions. This is most likely to occur where the employer provides some form of health insurance for the employee and his or her family.

The potential for invidious discrimination based on genetic characteristics is compounded by the fact that genetic diseases are often characteristic of certain racial and ethnic minority groups,²⁶ which are already subject to much discrimination.²⁷ Furthermore, because everyone possesses between five and ten lethal recessive genes, and an undetermined number of genes that predispose him or her to develop certain diseases at some future time, *everyone* is at risk of some form of genetic discrimination.²⁸

(a) *Monitoring and Screening*

There are two distinct techniques of genetic testing, each designed to accomplish quite different goals: genetic monitoring and genetic screening.²⁹

(i) *Genetic Monitoring*

Genetic monitoring focuses on measuring the presence of genetic damage resulting from workplace exposure³⁰ and involves “periodically examining employees to evaluate modifications of their genetic material...that might have evolved in the course of employment. The

²⁵ A heterozygote is an individual who has a copy of the dominant and recessive versions of a gene.

²⁶ For example, sickle cell disease and G6PD deficiency occur more commonly among African Americans, while Tay-Sachs disease and Adult Gaucher disease occur almost exclusively among Ashkenazi Jews. See Duster, *Backdoor to Eugenics* (1990) Appendix C: The Ethnic Distribution of Disease, 160-162.

²⁷ Gostin, *supra* note 6, 111.

²⁸ Capron, “Which Ills to Bear?: Re-evaluating the ‘Threat’ of Modern Genetics” (1990) 39 *Emory LJ* 665, 690.

²⁹ Hubbard and Wald, *Exploding the Gene Myth* (1993) 131-132.

³⁰ Suzuki and Knudtson, *supra* note 13, 162.

putative cause is workplace exposure to hazardous substances.”³¹ Evidence of genetic damage can be used to establish whether current exposure levels pose a health risk to employees,³² and can give employers valuable insight into potential workplace hazards.³³ While not without its difficulties,³⁴ genetic monitoring can enhance employee and workplace health and safety. The focus is on the environment rather than the worker, meaning that genetic monitoring has a minimal discriminatory impact.³⁵

(ii) Genetic Screening

Genetic screening is primarily concerned with identifying and excluding individuals who may place a disproportionate burden on employers. Screening usually involves a one-off test, taken before employment or transfer, to detect pre-existing ‘defects’ in an individual’s genome, and has two broad applications:³⁶

- (i) To determine whether an individual is genetically sensitive or ‘hypersusceptible’ to certain workplace toxins; and
- (ii) To detect more general genetic conditions, such as genetic predisposition to disease, or the presence of undesirable personality traits.

2. Current Practice

There have been no reported cases of genetic discrimination by employers in New Zealand. Even in America, where genetic information has been used in the workforce for some time,³⁷ there have been a number

³¹ U.S. Congress, Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace* (1990) 4.

³² Peirce, “The Regulation of Genetic Testing in the Workplace - A Legislative Proposal” (1985) 46 Ohio St LJ 771, 777.

³³ Weaver, “Genetic Screening and the Right Not to Know” (1997) 13 Issues L & Med 243, 245.

³⁴ U.S. Congress, *supra* note 31, 59.

³⁵ Rowinski, “Genetic Testing in the Workplace” (1988) 4 J Contemp Health L & Pol’y 375, 380-381.

³⁶ Deyelre, “Genetic Testing in the Workplace: Employer Dream, Employee Nightmare – Legislative Regulation in the United States and the Federal Republic of Germany” (1997) 18 Comp Lab L 547, 554.

³⁷ Genetic testing was begun as early as the 1970s by some US chemical companies: Bible, “When Employers Look for Things Other Than Drugs: The Legality of AIDS, Genetic, Intelligence, and Honesty Testing in the Workplace” (1990) 41 LAB LJ 195, 195.

of anecdotal reports of genetic discrimination,³⁸ but no reported cases. However, there have been a number of instances that illustrate the dangers of using genetic information.

For example, in the United States, a sickle cell population screening programme in the 1970s identified African-Americans as carriers of the gene, and many were unnecessarily excluded from a number of occupational settings.³⁹ At the time, it was thought that carriers could suffer decreased blood oxygen levels when exposed to certain chemicals.⁴⁰ Today, heterozygote carriers are still thought to be at risk of losing consciousness at high altitudes, and applicants for aircrew training in both the British and American military are screened for the gene.⁴¹

*Norman-Bloodsaw v Lawrence Berkeley Laboratory*⁴² provides a recent example of an employer's eagerness to use medical tests. In this case, employees provided blood and urine samples for cholesterol testing, but some were then tested for syphilis, pregnancy, and the sickle cell trait, without their knowledge or consent. The Ninth Circuit Court of Appeals held that the constitutional claim for invasion of privacy and the Title VII claim for sex discrimination (pregnancy testing) and race discrimination (sickle cell testing) were valid.⁴³

IV. THE PROBLEMS

1. Genetic Hypersensitivity to Occupational Disease

A genetically hypersensitive or hypersusceptible individual is "inordinately or abnormally susceptible to chemicals, infective agents, or other agents which in the normal individual are entirely innocuous".⁴⁴ Such an individual will react adversely to certain substances at concentrations lower than those normally associated with adverse effects.

³⁸ See Billings, "Discrimination as a Consequence of Genetic Testing" (1992) 50 Am J of Human Genet 476.

³⁹ For a discussion on the controversy surrounding sickle cell screening, see Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (1985) 255-256 and 278.

⁴⁰ Reinhardt, "Chemical Hypersusceptibility" (1978) 20 J Occupational Med 319, 320.

⁴¹ The real risk of sickle cell carrier status at altitude, however, remains uncertain. Uzych, "Genetic Testing and Exclusionary Practices in the Workplace" (1986) 7 J Pub Health Pol'y 37, 49-50.

⁴² 135 F 3d 1260 (9th Cir 1998).

⁴³ Ibid 1272, 1275.

⁴⁴ Reinhardt, *supra* note 40, 319.

*(a) Chronic Beryllium Disease**(i) Hypothetical*

Despite complying strictly with all safety regulations and minimising the exposure to all known toxins, a small number of employees at an anodising plant are suffering from chronic breathing problems. The employer knows that exposure to beryllium can cause lung disease, but beryllium levels have always been well below the recommended safety levels. The employer, hearing that a new genetic test can predict who will develop the lung disease, decides to test all current employees and applicants for this 'sickness' gene and exclude those with that gene from employment. Adam, who is currently healthy, applies for a job but is rejected because he is a carrier of the gene. On further investigation, Adam discovers that the test indicates that he is only seventeen per cent more likely than others to become sick, and claims that he has been unfairly discriminated against.

(ii) Background

Chronic beryllium disease ("CBD") is an inflammation in the lungs that can occur when a person is exposed to respirable beryllium fumes, dusts or powder.⁴⁵ When beryllium particles are breathed into the lungs of susceptible individuals, an allergy-like sensitivity is triggered, resulting in the scarring and damage of lung tissue, causing shortness of breath, wheezing and coughing, and sometimes death.⁴⁶ Only between one and five per cent of the population is acutely sensitive to beryllium and at risk of developing CBD.⁴⁷ Recent studies have identified genetic markers linked to CBD susceptibility,⁴⁸ and it is hoped that a genetic test will soon be developed to detect sensitive individuals.

⁴⁵ Beryllium is used in missiles, springs, electrical contacts, microprocessor connectors, microwave tube parts, solid-state electronic devices and in X-ray lithography in the etching of electronic chips.

⁴⁶ US Department of Health and Human Services, *Toxicological Review of Beryllium and Compounds* (1998).

⁴⁷ Meier B, "The Dark Side of a Magical Metal: Beryllium Disease Reappears, Prompting Suits Against a Producer" *NY Times* (New York, USA) Aug 25 1996, C1.

⁴⁸ Richeldi, Sorrentino, and Saltini, "HLA-DPB1 Glutamate 69: A Genetic Marker of Beryllium Disease" (1993) 262 *Science* 242-244; Stubbs, Argyris, and Lee, "Genetic Markers in Beryllium Hypersensitivity" (1996) 109(3) *Chest* 45S.

(iii) Discussion

There is a tension between two opposing concepts that influence the regulation of the workplace: “paternalism and autonomy”.⁴⁹ Paternalism has been defined as “the imposing of constraints on an individual’s liberty for the purpose of promoting his or her own good”.⁵⁰ Governmental paternalism attempts, to some extent, to compensate for the inequality in bargaining power between employers and employees, and is reflected in current regulatory regimes in laws governing such matters as holiday entitlement, minimum wages, parental leave, and occupational health and safety.⁵¹ Paternalistic policies, even when well intentioned, can be used as a means of rationalising and encouraging discrimination.⁵²

The most striking case upholding employee autonomy in the workplace is the American Title VII sex discrimination case *International Union UAW v Johnson Controls Inc.*⁵³ In that case, the Supreme Court unanimously held that the employer had discriminated on the basis of sex by excluding all fertile women from jobs with exposure to inorganic lead motivated by concerns that a woman could become pregnant and give birth to a child with deformities caused by maternal workplace exposures. The choice of whether or not to work in such hazardous environments while being either pregnant or capable of becoming pregnant “was reserved for each individual woman to make for herself”.⁵⁴

Arguments for exclusion of genetically hypersensitive individuals from the workplace because they may become ill are easy to comprehend. Their exclusion could reduce human suffering and the number of employees who develop workplace-related diseases. If the risk of developing an occupational disease was high and the disease was severe, then most hypersensitive individuals would not want to take up employment in such a hazardous environment.

However, there are many dangers of allowing employers to exclude hypersensitive individuals from the workplace. First, employers stand to benefit economically from the exclusion of hypersensitive individuals. Second, genetic hypersensitivity could be used to oversimplify the cause

⁴⁹ Rothstein M, “Genetics and the Workforce of the Next Hundred Years” (2000) *Colum Bus L Rev* 371, 392.

⁵⁰ Thompson D, “Paternalism in Medicine, Law, and Public Policy” in Callahan and Bok (eds), *Ethics Teaching in Higher Education* (1980) 246.

⁵¹ Rothstein, supra note 49, 392-393.

⁵² Cyr, “The Americans with Disabilities Act: Implications for Job Reassignment and the Treatment of Hypersusceptible Employees” (1992) 57 *Brooklyn L Rev* 1237,1275.

⁵³ (1991) 499 US 187.

⁵⁴ *Ibid* 206.

of workplace-related diseases.⁵⁵ Employers could find it more economic to exclude susceptible workers from the worksite than to reduce the environmental hazards. Furthermore, the exclusion of hypersensitive individuals cannot of itself solve all health and safety problems. Just because certain genetic susceptibilities have been discovered does not mean that there are no other dangerous substances in the workplace, and the fact that individuals with certain genetic mutations face high risks when exposed to toxins does not mean that those without the mutations face no risks. Excluding the former will do nothing to help the latter, who still need to work in safety.⁵⁶ Unfortunately, reducing exposures to levels where even the most sensitive individual could work safely is neither technologically nor economically feasible. This is because of the wide variability among individuals and because the difficulty and cost of reducing exposure increases exponentially as exposure levels are reduced.

A number of organisations have put forward recommendations regarding the use of genetic information to exclude hypersensitive individuals from the workplace.⁵⁷ The following prerequisites could promote a morally defensible exclusionary policy:

- (i) There must be strong evidence of a clear connection between the working environment and the development of the condition for which genetic testing can be conducted;⁵⁸ and
- (ii) The condition in question must be 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 others; and
- (iii) The condition must be 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.

⁵⁵ Matthewman, "Title VII and Genetic Testing: Can your Genes Screen you out of a Job?" (1984) 27 Howard LJ 1185-1220.

⁵⁶ Draper, *Risky Business: Genetic Testing and Exclusionary Practices in the Hazardous Workplace* (1991) 174.

⁵⁷ For example, the Nuffield Council on Bioethics: Nuffield Council on Bioethics, *Genetic Screening: Ethical Issues* (1995) para 10.13, available at: <<http://www.nuffield.org/bioethics/publication/geneticscreening/rep0000000062.html>> (last accessed 15 November 2000).

⁵⁸ Canter, "Employment Discrimination Implications of Genetic Screening in the Workplace under Title VII and the Rehabilitation Act" (1984) 10 Am JL & Med 323, 324.

Ideally, the number of those actually excluded should be very small and there should be relatively few jobs involved to avoid severely limiting workers' employment choices. Genetic tests should not be disproportionately administered to groups that have traditionally experienced discrimination.⁵⁹

Even if such guidelines are followed, the result will continue to be the exclusion of a presently healthy and qualified individual on the paternalistic ground that that person must be protected. Should employment decisions be based on paternalistic views about what is best for a person with a genetic susceptibility? This is essentially a policy decision that needs to be clarified.

2. Genetic Factors Unrelated to the Workplace

Discriminating against individuals on the basis of non-workplace-related latent genetic disorders and predispositions differs significantly from screening for genetic hypersensitivity. The disease or predisposition is not related to the workplace and working will not place affected individuals at increased risk. Excluded individuals receive no reduction in risk, and there is no public health benefit.

(a) Huntington's Disease

*(i) Case Example*⁶⁰

During an in-house training session on caring for patients with Huntington's disease, a twenty-four-year-old social worker revealed to her employer that she had a family history of Huntington's disease. Shortly after the session, she was given a negative performance review and was dismissed, although her employers could not give any examples of her poor performance. Prior to her dismissal, the social worker had been promoted three times and been given outstanding performance reviews. A co-worker later informed her that the employer had expressed concern about her risk of developing Huntington's disease.

⁵⁹ Richter, "Taking the Worker as You Find Him: The Quandary of Protecting the Rights as well as the Worker with a Genetic Susceptibility to Occupational Disease" (1997) 8 Md J Contemp L Issues 189, 215-216.

⁶⁰ This is a real case, described in Billings, "Individual, Family and Societal Dimensions of Genetic Discrimination: Case Study Analysis" (1996) 2 Sci & Engineering Ethics 71, 77.

(ii) Background

An individual with Huntington's disease remains completely free of symptoms until midlife,⁶¹ when an extended period of dementia and loss of body control will begin.⁶² An individual with the Huntington gene is characterised as having a pre-symptomatic genetic condition.⁶³ Eventually, the patient becomes incapacitated and invariably dies, usually from a complication such as heart disease, pneumonia, or choking.⁶⁴ Current estimates suggest that up to one in 15,000 people in New Zealand have the disorder.⁶⁵

The disease is caused by a single dominant gene defect. It is transmitted in typical Mendelian fashion: a child with one parent who has Huntington's disease and one who does not has a fifty per cent chance of inheriting the disease.⁶⁶ A simple genetic test can now determine whether an individual has the gene, and can indicate the likely age of onset.

(iii) Discussion

There are a number of arguments surrounding the use of genetic information by employers to determine the future capacity of an employee for work. Employers put forward two main reasons to justify the exclusion of pre-symptomatic individuals from the workforce. The first is that a pre-symptomatic individual will leave or retire early, and the employer will not get an adequate return from its training and other input. The second is that the pre-symptomatic individual will, in the future, take more sick leave and be less productive because of the genetic disorder, and may also cost the employer more if the employer subsidises or provides health insurance.

These justifications may be disposed of easily. Firstly, it is not necessary or reasonable to use genetic information for the prediction of future health, because many employees only stay in a given job for a relatively short period of time. Secondly, the possibility that an individual might present increased costs in the future is a poor reason for

⁶¹ Epstein, "The Legal Regulation of Genetic Discrimination: Old Responses to New Technology" (1994) 74 BUL Rev 1, 8.

⁶² Terrenoire, "Huntington's Disease and the Ethics of Genetic Prediction" (1992) 18 J Med Ethics 79, 79.

⁶³ Gin B, "Genetic Discrimination: Huntington's Disease and the Americans with Disabilities Act" (1997) 97 Columbia L R 1407, n 50.

⁶⁴ *Ibid.*

⁶⁵ New Zealand Health Consumer Information, "Huntington's Disease". Available at: <http://www.everybody.co.nz/docsd_h/hunting.htm> (last accessed 30 Nov 2000).

⁶⁶ Gelehrter, Collins and Ginsburg, *Principles of Medical Genetics* (2 ed, 1998) 217.

discrimination against that individual. Employment decisions are usually based on the attributes that an individual possesses at that time, not on speculation about the future. For example, in most jurisdictions the law prohibits age discrimination. This prevents an employer from discriminating against elderly applicants because they may only have a short time to work before they retire or are likely to cost more at some time in the future.

Other dangers weigh against the use of genetic information to predict and discriminate against the pre-symptomatic. Once a precedent is set, persons other than those predisposed to disease could become stigmatised as bad risks for employment.⁶⁷ Employers could test for genetic indicators of any characteristic, such as intelligence or aggression, and individuals would risk being judged on the basis of their genome rather than their actual abilities. If unchecked, this could create a genetic underclass of undesirable employees.

(b) Alcoholism

(i) Hypothetical

Allan owns a small taxicab business and has decided not to employ Robert, mostly because he knew that Robert's father and brother were both alcoholics. Allan is aware of a current campaign to clean up the taxicab industry and is anxious not to lose his operator's license. Although Allan does not believe that Robert has a drinking problem now, he knows that alcoholism runs in families and he is not prepared to take the risk that Robert could turn to the bottle. In addition, Allan has heard from a friend that he could be held liable if Robert crashes while on the job and injures someone while under the influence of alcohol.

(ii) Background

Alcoholism has long been recognised as a disease.⁶⁸ It is chronic, progressive, and potentially fatal.⁶⁹ Alcoholism is produced by a shifting confluence of genetic, environmental, and socio-cultural factors.⁷⁰ Individuals with a family history of alcohol abuse or dependence are at

⁶⁷ Gostin, "Genetic Privacy" (1995) 23 *JL Med & Ethics* 320.

⁶⁸ Since 1953, alcoholism has been included in every edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*.

⁶⁹ Seixas, "Definition of Alcoholism" (1976) 85 *Annals of Internal Med* 764, 764.

⁷⁰ See generally Zimberg, *The Clinical Management of Alcoholism* (1982).

increased risk of developing the disease,⁷¹ but alcoholism does not follow the simple rules of Mendelian inheritance. It is a genetically complex disorder, influenced by multiple genes that interact in a poorly understood fashion with each other and with environmental factors. However, progress is being made to track down its genetic basis.⁷²

(iii) Discussion

Alcohol-related losses due to absenteeism and reduced productivity amongst the working population of New Zealand have been conservatively estimated at \$57 million per year.⁷³ Absenteeism, secondary illness and poor performance can result in both “direct costs to the employer and negative effects on other employees”.⁷⁴

Inattention due to the effects of a hangover and fatigue mean that alcoholics are more accident prone, and some alcoholics may be drunk at work. An individual with a genetic predisposition to alcoholism presents an increased risk to themselves and others, but is this risk – the chance that they will become an alcoholic, and then the chance that that alcoholism will result in harm to themselves or others – enough to warrant excluding him or her from the workplace?

(c) Can Discrimination be Justified?

One example that is often given in support of the case for discrimination against the predisposed is the case of the pilot who has a genetic predisposition to heart attacks. The argument goes that if such a predisposition is known of, or able to be identified, then it would be in the interest of all employees and the public for that information to be used to disqualify an individual from a position. Proponents of the use of genetic testing to reduce the risk of harm in the workplace claim that because such a genetic predisposition or condition will put the health and lives of so many other people at such a major risk, discrimination is justified. But employees could put themselves and others at risk because of a genetic predisposition in almost any job. Should people predisposed to alcoholism

⁷¹ Winokur, “Alcoholism: III. Diagnosis and Familial Psychiatric Illness in 259 Alcoholic Proband” (1970) 23 Archives Gen Psychiatry 104.

⁷² See Reich, Edenberg, and Goate, “Genome-wide Search for Genes Affecting the Risk for Alcohol Dependence” (1998) 81(3) Am J Med Genet 207.

⁷³ Jones, Casswell and Zhang, “The Economic Costs of Alcohol-related Absenteeism and Reduced Productivity Amongst the Working Population of New Zealand” (1995) 90 Addiction 1455, 1459.

⁷⁴ Voss, “Employing the Alcoholic under the Americans with Disabilities Act of 1990” (1992) 33 Wm and Mary L Rev 895, 920.

be disqualified from any job involving the use of cars, trucks or buses? Should individuals with a genetic predisposition to epileptic seizures be disqualified from using heavy machinery? Once the gates are open, it could be very hard to stop genetic discrimination from becoming rampant in the workplace, and any attempt to make a distinction between occupation and degree of risk to others could result in arbitrary and unfair discrimination. To justify the exclusion of an individual from the workplace, the potential danger to others would need to be great, and the likelihood of that danger occurring would need to be high.

A good employer could offer the 'predisposed' additional healthcare monitoring to assess their health status or place them in a lower-risk position. However, it is more likely that an affected applicant would not be employed, and existing employees dismissed, particularly since an employer who fails to make use of genetic information could face potential liability. In some jurisdictions, if employers do not discriminate on the basis of genetic conditions, then they may face liability in tort for injuries caused by the manifestation of those genetic conditions.

Under the tort theories of negligent hiring, retention, and entrustment, employers may be held directly liable for injuries to third parties caused by the acts of their employees, whether within or outside the scope of their employment.⁷⁵ There are currently no decisions attributing tort liability to an employer for the harmful manifestations of an employee's genetic condition, but cases that involve hidden and potentially destructive conditions such as an employee's propensities for violence, alcohol or drugs may be instructive.⁷⁶

(i) *Negligent Hiring*⁷⁷

The doctrine of negligent hiring states that an employer may be liable for the negligent or tortious conduct of its employees if the employer breaches its duty to use due care in selecting and retaining only competent and safe employees.⁷⁸ The doctrine, which is almost exclusively confined to the United States,⁷⁹ directs scrutiny to whether or not the employer exercised due care when hiring an employee and creates a cause of action

⁷⁵ Seltzer, *supra* note 17, 460.

⁷⁶ *Ibid.*

⁷⁷ See generally Camacho, "How to Avoid Negligent Hiring Litigation" (1993) 14 Whittier L Rev 787.

⁷⁸ Restatement (Second) of Agency Section (1958) 213.

⁷⁹ Limited discussion of negligent hiring as a cause of action has occurred in Canada. See *JP v Sinclair et al* (1997) 148 DLR (4th) 472, 478-479; Tuytel, Clark and Wilson, "Sexual Misconduct Claims: A Primer for Insurers on Liability and Coverage Issues Involving Sexual Assault, Abuse and Harassment" (1998) 16(5) Can J Ins L 81, 116-121.

from the negligent conduct of the employer in exposing third parties to a potentially dangerous employee.⁸⁰ In situations where there is a risk of substantial harm to third parties, “the employer has the duty to use reasonable care to investigate [an applicant’s] competency and reliability prior to employment”.⁸¹ In a negligent hiring case, the characteristics of the employee relating to competency and skill are at issue and may be proven by incidents and reputation.⁸²

For example in *Ponticas v KMS Investments*,⁸³ prior to hiring the resident manager of an apartment complex a realty company failed to make reasonable inquiry into the employee’s background,⁸⁴ and was unaware of the employee’s convictions for armed robbery, burglary, and receiving stolen property.⁸⁵ The manager then raped a tenant at knife-point. The Court determined that the employer was negligent, stating that:⁸⁶

Liability is predicated on the negligence of an employer in placing a person with known propensities, or propensities which should have been discovered by reasonable investigation, in an employment position in which... it should have been foreseeable that the hired individual posed a threat of injury to others.

This places employers in a difficult position. They must sufficiently investigate a job applicant’s background to protect themselves from potential tort liability, but must be careful not to invade the applicant’s privacy or unlawfully discriminate against the applicant. It is not difficult to foresee the liability of an employer who knew or could have discovered that a job applicant was predisposed to a potentially dangerous condition, such as mental illness, seizures, or alcoholism, and could therefore have foreseen the possibility of harm. If the predisposition becomes a reality, third parties could argue that the employer’s failure to exclude that employee from the workplace was negligent and that the employer should be held liable for damage caused by the employee.

(ii) *Negligent Retention*

The theory of negligent retention is based on the idea that an

⁸⁰ 27 Am Jur 2d Employment Relationship 472 (1996).

⁸¹ *Ponticas v KMS Invs Inc* 331 NW 2d 907, 913 (Minn 1983).

⁸² *Woodward v Mettelle* 400 NE 2d 934, 946-947 (Ill App Ct 1980).

⁸³ 331 NW 2d 907 (Minn 1983).

⁸⁴ *Ibid* 909-910.

⁸⁵ *Ibid* 909.

⁸⁶ *Ibid* 911.

employer has a continuing duty to retain only those employees who are fit and competent, and the employer will be directly liable for the foreseeable acts of incompetent, dangerous, or otherwise unsuitable employees. Liability depends upon whether the employer becomes aware or should have become aware of an employee's condition or propensity, yet fails to take further action.⁸⁷

For example, in *Cox v Brazo*,⁸⁸ the theory of negligent retention was extended to recognise a cause of action against an employer with constructive knowledge of an employee's reputation for sexual harassment. Because the defendant employer could reasonably have foreseen the employee's future sexual harassment of a fellow employee, liability attached to the employer when the foreseeable events in fact occurred. Therefore, it seems possible that an employer who becomes aware of an employee's genetic predisposition and could reasonably foresee the possibility of harm that could arise if the condition were to manifest itself, could be liable for any such harm caused.

(iii) Negligent Entrustment

The United States doctrine of negligent entrustment has been traced back to the English case of *Dixon v Bell*,⁸⁹ and is recognised elsewhere.⁹⁰ Negligent entrustment occurs where the employer supplies an employee with a chattel knowing the employee to be likely "to use it in a manner involving unreasonable risk of physical harm to himself and others".⁹¹ This theory of liability is often used in cases where the employer has allowed an incompetent employee to use a motor vehicle, causing subsequent injury to third parties.⁹²

In addition to liability to third parties for injuries caused by an entrustee, an employer may also be held liable for injuries caused to the entrustee himself. In *Casebolt v Cowan*,⁹³ an employer who allowed an employee to drive a company car while intoxicated was held liable for

⁸⁷ See *Yunker v Honeywell Inc* 496 NW 2d 419. (Minn Ct App 1993) where an employer was held liable for the murder of an employee by a co-worker where an employer had knowledge of the co-worker's criminal propensity but retained him in his position.

⁸⁸ 303 SE 2d 71 (Ga. App. 1983), aff'd 307 SE 2d 474 (Ga 1983).

⁸⁹ (1816) 105 ER 1023.

⁹⁰ The doctrine has been discussed in the New South Wales' case of *Rogers v Valosi Pty Ltd* (1996) 25 MVR 213, and in the Canadian cases of *Schulz v Leaside Developments Ltd* (1979) 90 DLR (3rd) 98, 105; *Cella (Litigation Guardian of) v McLean* (1997) 148 DLR (4th) 514, 517.

⁹¹ Restatement (Second) of Torts § 390.

⁹² For example, in *Carolina Cable Contractors Inc v Hattaway* 487 SE.2d 53 (Ga Ct App 1997) a trucking company was sued for injuries caused by an intoxicated truck driver. However, under Georgian law, "all knowledge" of incompetency is required, which was not satisfied in this case.

⁹³ 829 P.2d 352 (Colo 1992).

injuries sustained by the employee.⁹⁴ The risk presented by the entrustment of a vehicle to a person likely to drive it while inebriated was held to be an unreasonable one.⁹⁵ Therefore, if an employer knows or has the ability to discover genetic information revealing a condition that might impact upon an employee's driving abilities, then it could be found negligent for failing to act upon or discover that information.

3. Conclusion

There are a number of legitimate justifications for genetic discrimination in certain circumstances. However, there are compelling reasons to prohibit genetic discrimination. Individuals who are denied employment in one kind of job or industry because of a given genetic condition cannot always turn elsewhere for work, and genetic discrimination will not be felt equally by all applicants or in all jobs.⁹⁶ For example, a highly skilled or highly qualified person applying for a specialised position is less likely to be excluded than an applicant for a more routine job, for which many others could be hired. Therefore, the least powerful segments of society are likely to be exposed to the most discrimination.⁹⁷

Left to their own devices, most employers would understandably welcome information that would prevent the hiring of employees who could be a burden.⁹⁸ Even now, employment decisions are often influenced by the medical histories of applicants and their families.⁹⁹ However, employers are in a difficult position. They could face a charge of unlawful genetic discrimination if they discriminate, but could also face liability if they do not discriminate. The law needs to give employers clear guidance on how they should act.

V. ANTI-DISCRIMINATION LAW AND GENETICS

Two main strategies have dominated the debate about how best to

⁹⁴ Ibid 360.

⁹⁵ Ibid 362.

⁹⁶ Hubbard and Wald, *supra* note 29, 134.

⁹⁷ Ibid.

⁹⁸ Miller and Huvos, *supra* note 18, 371.

⁹⁹ Ibid 371-372.

protect people from genetic discrimination.¹⁰⁰ The ‘privacy approach’ urges more sophisticated privacy legislation to protect genetic data from being distributed without the consent of those involved. This approach gives individuals more power over the control of their own genetic information, but does not necessarily restrict its use if that information becomes known. Often employees and job applicants do not have a strong bargaining position and cannot refuse to undergo genetic testing or refuse to disclose genetic information.¹⁰¹ Furthermore, there may often be cases of unauthorised, inadvertent, or unwise disclosure. The anti-discrimination approach, often used in combination with increased privacy controls, centres on the use of non-discrimination laws to prohibit discrimination based on genetic characteristics if that information becomes known. It is this approach that will be examined more closely.

1. International Developments

There has been increasing international recognition of the need for legal regulation of the use of genetic information by employers. The two most important recent international texts are examined here. These are the Universal Declaration on the Human Genome and Human Rights and the European Convention on Human Rights and Biomedicine.

(a) Universal Declaration on the Human Genome and Human Rights

On 11 November 1997, the General Conference of the United Nations Educational, Scientific and Cultural Organisation unanimously adopted the Universal Declaration on the Human Genome and Human Rights (“UNESCO Declaration”).¹⁰² Although the Declaration is a non-binding document, it is hoped that it will be followed by the development of a binding convention. The UNESCO Declaration’s main aim is to protect the human rights and freedoms of the person, while providing for the freedom of research and the progress of knowledge.¹⁰³ It emphasises that research should fully respect human dignity, freedom, and human

¹⁰⁰ Lemmens, “Selective Justice, Genetic Discrimination, and Insurance: Should we Single Out Genes in our Laws?” (2000) 45 McGill LJ 347, 354.

¹⁰¹ Yesley, “Protecting Genetic Difference” (1999) 13(2) Berkeley Tech LJ 653, 658.

¹⁰² UNESCO, 29th Sess, 29 C/Resolution 19, at 41 (1997).

¹⁰³ UNESCO, “The Main Principles behind the Declaration”. Available at: <<http://www.unesco.org/opi/29gencon/eprince.htm>> (last accessed Nov 15 2000).

rights,¹⁰⁴ stating that “everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics”¹⁰⁵ and that “that dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity.”¹⁰⁶

The UNESCO Declaration does not prevent employers from inquiring about the results of prior genetic tests, or prohibit genetic testing by employers, provided that “the prior, free and informed consent”¹⁰⁷ of the employee is obtained, and his right to “decide whether to be informed or not on the results of genetic examination and the resulting consequences”¹⁰⁸ is respected.

Article 6, intended to “prohibit discrimination against an individual or against groups, especially ethnic minorities with certain specific genetic characteristics, in the exercise of their rights, for example in access to employment”, states:¹⁰⁹

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.

Unfortunately, the Article is poorly drafted. It attempts to define the extent of a human right by reference to conduct that “infringes human rights, fundamental freedoms and human dignity”.

UNESCO recognised the possibility of “positive discrimination”,¹¹⁰ and has said that the presence of certain genetic characteristics could “justify differences of treatment provided that these differences of treatment correspond to a purpose of general interest and are in keeping with the principle of proportionality”.¹¹¹ Discrimination that is based on the best interests of the individual and does not infringe on their human rights is therefore acceptable. An example of such discrimination, given in the Explanatory Report, is that of a hypersensitive individual.¹¹²

¹⁰⁴ Preamble.

¹⁰⁵ Article 2(a).

¹⁰⁶ Article 2(b).

¹⁰⁷ Article 5(b).

¹⁰⁸ Article 5(c).

¹⁰⁹ UNESCO, *Birth of the Universal Declaration on the Human Genome and Human Rights* (1999)

4.

¹¹⁰ *Ibid.*

¹¹¹ *Ibid.*

¹¹² *Ibid.* 64.

(b) Convention on Human Rights and Biomedicine

The member states of the Council of Europe (“the Council”) have come under a much stronger obligation to deal with genetic discrimination by prohibitory legislative measures. On 19 November 1996, the Council adopted the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (“Convention on Human Rights and Biomedicine”).¹¹³ The Convention is the first legally binding international text designed to preserve human dignity, rights and freedoms through a series of principles and prohibitions against the misuse of biological and medical advances. Additional protocols are foreseen to clarify, strengthen and supplement the overall Convention.¹¹⁴ To date, twenty-nine states have signed the Convention.¹¹⁵

Article 11 of the Convention provides that:¹¹⁶

Any form of discrimination against a person on grounds of his or her genetic inheritance is prohibited.

This anti-discrimination provision appears to allow no exceptions. The Explanatory Report states that the term “discrimination” means “unfair discrimination”, but does not elaborate on or provide examples of what is meant by the term “unfair”.¹¹⁷ As an example of “fair” discrimination, the Report states that the Convention does not “prohibit positive measures which may be implemented with the aim of re-establishing a certain balance in favour of those at a disadvantage because of their genetic inheritance”.¹¹⁸ Article 12 of the Convention states that genetic testing may only be performed for healthcare purposes or for scientific research. Accordingly, it may be permissible to discriminate against hypersensitive individuals solely in order to protect their health. However, the case for genetic discrimination under the Convention on any other grounds is

¹¹³ Council of Europe, *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*, ETS No 164 (1997). For updated information, see the Website of the Council of Europe, <<http://www.coe.fr/eng/legaltxt/164t.htm>> (last accessed 27 April 2000).

¹¹⁴ Already there is a protocol forbidding the cloning of human beings.

¹¹⁵ Council of Europe, “Chart of Signatures and Ratifications of a Treaty”. Available at: <<http://conventions.coe.int/treaty/EN/searchsig.asp?NT=164&CM=2&DF=07/10/00>> (last accessed 15 Nov 2000).

¹¹⁶ Article 11.

¹¹⁷ Convention on Human Rights and Biomedicine Explanatory Report, ETS no. 164, available at: <<http://conventions.coe.int/treaty/EN/cadreprincipal.htm>> para 77.

¹¹⁸ *Ibid.*

poor.

2. The United States of America

In January 1998, Vice President Al Gore called for federal legislation to prevent discrimination by employers on the basis of genetic information. This proposed legislation was designed to prohibit employers from requesting or requiring genetic information from applicants for the purpose of hiring, to prohibit discrimination against employees in the workplace, and prevent the disclosure of genetic information without the express authorization of the individual.¹¹⁹ President Clinton signed a similar Executive Order applicable to federal employees on February 8, 2000,¹²⁰ and bills along the same lines are pending in Congress.¹²¹

As of October 2000, approximately half of the US states have enacted laws prohibiting genetic discrimination in employment.¹²² However, most of the discussion about genetic discrimination has occurred under the definition of “disability” under the Americans with Disabilities Act 1990 (“ADA”).¹²³

(a) *Americans with Disabilities Act 1990*

The ADA seeks to end discrimination in the workplace, while balancing the legitimate interests of individuals with disabilities and their employers. Regarding the potential use of genetic tests by employers, the ADA creates a three-phase system:¹²⁴

- (i) Pre-employment. The ADA prohibits pre-employment “medical examination[s]”.¹²⁵ The ADA does not mention genetic tests, but because genetic tests are intrusive, and are conducted by medical personnel for determining biological conditions, they fall within the definition of “medical examination” and are prohibited.¹²⁶

¹¹⁹ See HR 2198, 105th Cong (1997) 2.

¹²⁰ Exec Order No 13,145, 65 reprinted as amended in Fed Reg 6, 877 (2000).

¹²¹ For example, S 1322, 106th Cong (1999); HR 2457, 106th Cong (1999).

¹²² See Rothstein, *supra* note 49, n 78.

¹²³ Pub L No 101-336, 104 Stat 376 (codified in scattered sections of 42 USC §§ 12101-12213).

¹²⁴ 42 USC §§ 12101-12213.

¹²⁵ 42 USC § 12112(d)(2).

¹²⁶ Lawton, “Regulating Genetic Destiny: A Comparative Study of Legal Constraints in Europe and the United States” (1997) 11 *Emory Int’l L Rev* 365, 400.

- (ii) Post-offer, pre-employment. The employer may conduct any medical examination in the post-offer pre-employment stage provided that the employer does not single out certain employees for genetic testing,¹²⁷ and the employer keeps all results of genetic tests in “separate medical files” and treats the results “as a confidential medical record.”¹²⁸
- (iii) Employment. Once an individual commences employment, all medical examinations and inquiries must be either voluntary or job-related,¹²⁹ and the results must be kept in separate, confidential files.¹³⁰

Regardless of how the genetic information has been obtained, Title I of the ADA prohibits¹³¹ discrimination against a qualified individual¹³² with a disability in hiring, promotion, discharge, compensation, and other terms and conditions of employment.¹³³ Employment decisions made on the actual attributes of a disability are not discriminatory if they can be shown to be “job-related and consistent with business necessity”¹³⁴ and the disability cannot be reasonably accommodated.¹³⁵

In order to establish a discrimination claim under the ADA, an applicant or employee must show that they:

- (i) Have a disability;
- (ii) Were otherwise qualified for the employment or benefit in question; and
- (iii) Were excluded from the employment or benefit because of the disability.¹³⁶

¹²⁷ 42 USC § 12112(d)(3)(A).

¹²⁸ There are some exceptions: Ibid § 12112(d)(3)(B)(i)-(iii).

¹²⁹ 42 USC § 12112(d)(2)(A).

¹³⁰ Ibid § 12112(d)(4)(C).

¹³¹ By employers with fifteen or more employees: 42 USC § 12111(5)(A); 29 CFR § 1630.2(e)(1).

¹³² A qualified individual is “an individual with a disability who, with or without reasonable accommodation, can perform the essential functions of the employment position that such individual holds or desires”: 42 USC § 12112(a), 12111(8).

¹³³ Ibid § 12112(a), 12111-12117. The Equal Employment Opportunity Commission (“EEOC”) is the agency authorized to enforce and issue regulations implementing Title I of the ADA.

¹³⁴ Ibid § 12112(d)(3)(C), (d)(4)(A).

¹³⁵ 29 CFR § 1630.15(b)(1).

¹³⁶ 42 USC § 12112(a).

Whether an individual has a “disability” is the most controversial issue in a genetic discrimination claim. The ADA defines an individual with a disability as:

- (i) A person with one or more physical or mental impairments that substantially limits him or her in performing a major life activity;
- (ii) A person with a record of such impairment; or
- (iii) A person who is regarded as having such impairment.¹³⁷

The third, ‘perception’ definition of disability reflects the view that a disability may result from a physical or mental condition, or from societal misconceptions, prejudices, or stereotypes.¹³⁸ Pre-symptomatic individuals and individuals predisposed to genetic disorders, who have no actual disabilities, may fall within the scope of the ADA as a result of being perceived as disabled. On 15 March 1995, the EEOC stated:¹³⁹

This [“perception” definition of disability] applies to individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease, or other disorders. Covered entities that discriminate against individuals on the basis of such genetic information are regarding the individuals as having impairments that substantially limit a major life activity. Those individuals, therefore, are covered by the third part of the definition of “disability”.

This view, contained in EEOC’s interpretive guidance manual, does not have the force of law, and has yet to be tested in the courts. It seems likely that the genetically hypersensitive, the genetically predisposed, and those with pre-symptomatic genetic conditions are protected from discrimination under the ADA, provided that the condition is perceived to be an impairment that substantially limits a major life activity.¹⁴⁰

(i) The Direct Threat Defence

Under the ADA, an employer may legally exclude an otherwise qualified individual if that individual poses a direct threat or “significant

¹³⁷ Ibid § 12102(2).

¹³⁸ Gostin, *supra* note 6, 124.

¹³⁹ EEOC, *Compliance Manual* (1995) Vol 2, [sections] 902.

¹⁴⁰ Alper, “Does the ADA Provide Protection Against Discrimination on the Basis of Genotype?” (1995) 23 *JL Med & Ethics* 167, 168; Gin, *supra* note 63, 1422.

risk to the health or safety of others that cannot be eliminated by reasonable accommodation".¹⁴¹ In drafting regulations to implement this "direct threat" defence, the EEOC expanded the defence to allow disqualification of an individual if he poses a direct threat to the health or safety of *himself* or others.¹⁴² This interpretation seems aimed at correcting what may have been an oversight in the drafting of the ADA.¹⁴³ However, it is questionable whether the EEOC can adopt an interpretation that departs so significantly from the language of the ADA.¹⁴⁴ Including "risk to self" in the direct threat defence introduces an element of paternalism into the employment decision, and increases the risk that "determinations [will be] based on negative stereotypes and paternalistic views about what is best for individuals with disabilities".¹⁴⁵

When applied to pre-symptomatic genetic conditions, the EEOC interpretation of the ADA's direct threat defence is problematic. According to the EEOC, the determination of whether or not an individual with a disability is qualified should always be based on the capabilities of the individual at the time of the employment decision, not on future speculation.¹⁴⁶ A decision based on a pre-symptomatic individual's genetic predisposition is speculative and discriminatory, and should therefore be prohibited. However, the EEOC interpretation of the direct threat provision allows an employer to take into account whether individuals might pose a risk to themselves at some time in the future. If the employer determines that an individual's predisposition poses a substantial enough risk to that individual, then that individual may be legitimately disqualified.¹⁴⁷ This 'loophole' allows employers to exclude those who are at risk of future injury or disease – provided that the decision is not made on the basis of speculation. The point at which an employer's knowledge about an individual's genetic predisposition ceases to be speculation and becomes a valid reason for disqualification is unknown. The EEOC's interpretation of the direct threat defence may therefore give employers the legal justification for screening out pre-

¹⁴¹ 42 USC § 12111(3) (emphasis added).

¹⁴² 29 CFR § 1630.15(b)(2). The direct threat determination is to be made on the basis of reasonable medical judgement, and must take account of: the duration of the risk, the nature and severity of the potential harm, the likelihood that harm will occur, and the imminence of the potential harm.

¹⁴³ Rothstein, *supra* note 49, n 106.

¹⁴⁴ *Ibid.*

¹⁴⁵ Wong, "Distinguishing Speculative and Substantial Risk in the Presymptomatic Job Applicant: Interpreting the Interpretation of the Americans with Disabilities Act Direct Threat Defense" (2000) 47 UCLA L Rev 1135, 1144.

¹⁴⁶ 29 CFR § 1630.2(m).

¹⁴⁷ Wong, *supra* note 145, 1139.

symptomatic individuals who pose a direct threat to themselves.

The EEOC's interpretation has received mixed reviews in the courts. The Eleventh Circuit agreed that the direct threat defence applies where only the employee is endangered,¹⁴⁸ but the Ninth Circuit, which discussed the issues involved in detail, disagreed. In *Echazabal v Chevron USA Inc*,¹⁴⁹ an applicant was denied a job as an oil refinery worker because he had been diagnosed with asymptomatic, chronic active hepatitis C, and the employer believed that exposure to refinery chemicals would damage his liver. The Court, rejecting the idea that the ADA contained a drafting error, relied on the express language of the ADA and legislative history, and concluded that the direct threat defence was not available to the employer because only the plaintiff was at risk from exposure.¹⁵⁰ The Court further reasoned that Congress' decision not to include threats to one's own safety in the ADA direct threat defence was consistent with the ADA's prohibition against discrimination based on paternalism¹⁵¹ and with the Supreme Court's Title VII cases prohibiting paternalistic employment policies.¹⁵²

The scope of the direct threat defence needs further clarification, but what is clear is that the defence should apply only when the risk is immediate and severe, and that the defence is a difficult one to prove.

3. New Zealand

There are currently concerns in New Zealand over the legality of drug testing in the workplace¹⁵³ and similar concerns are raised by the spectre of genetic testing. The major source of legal constraints on genetic testing in the workplace is the Privacy Act 1993. A detailed discussion of privacy aspects is beyond the scope of this article, but where there are significant gains to be made for employee health and safety there appears to be a strong case for genetic testing. Information Privacy Principle One provides that an employer may not collect personal information such as genetic information unless:

¹⁴⁸ See *Moses v American Nonwovens Inc* 97 F.3d 446. (11th Cir 1996).

¹⁴⁹ 213 F.3d 1098 (9th Cir 2000), reprinted as amended at 226 F.3d 1063 (9th Cir 2000) and amended by 2000 Cal Daily Op Service 7915 (9th Cir 2000).

¹⁵⁰ 213 F 3d at 1102.

¹⁵¹ *Ibid* 1103-1104.

¹⁵² *Ibid* 1104 (citing *International Union UAW v Johnson Controls Inc* 499 US 187 (1991) and *Dothard v Rawlinson* 433 US 321 (1977)).

¹⁵³ See, for example: Edwards, "Workplace Drug Testing" (1995) 1 Human Rights L & P 43; Webb, "Workplace Drug Testing: Another Perspective" (1995) 1 Human Rights L & P 131; Hodge, "Workplace Drug Testing: Recent Developments" (1998) 4 Human Rights L & P 192.

- (i) The information is collected for a lawful purpose connected with the function or activity of the employer; and
- (ii) The collection of the information is necessary for that purpose.¹⁵⁴

The collection of genetic information for the purpose of ensuring the safety of the worker or others is arguably a lawful purpose, and in certain circumstances may be necessary for that purpose.

Under the Health and Safety in Employment Act 1992 (“HSEA”), employers have a legal duty to take all practicable steps to ensure the safety of their employees and others.¹⁵⁵ In the absence of a specific provision, however, the general provisions of the HSEA are not likely to provide employers with a mandate for genetic testing. Nevertheless, the legislative requirements under the HSEA provide strong encouragement for employers to reduce injury and accident levels by whatever means possible, including genetic discrimination.

(a) *Anti-discrimination Legislation*

The ‘right’ to freedom from discrimination is spelt out in section 19(1) of the New Zealand Bill of Rights Act 1990, which states that “[e]veryone has the right to freedom from discrimination on the grounds of discrimination in the Human Rights Act 1993 (“HRA”)”.¹⁵⁶ The HRA prohibits discrimination on any of the prohibited grounds in all aspects of the employment process, including hiring, training, compensation, and benefits. The prohibited grounds are sex, marital status, religious belief, ethical belief, colour, race, ethnic or national origin, disability, age, political opinion, employment status, family status, and sexual orientation.¹⁵⁷ Genetic characteristics are not included as a prohibited ground for discrimination.

In some cases an employer’s decision that is based on genetic information could indirectly discriminate against persons of a certain sex, colour, race, or ethnic or national origin. Indirect discrimination occurs where apparently neutral practices, requirements, or conditions *have the*

¹⁵⁴ Privacy Act 1993, s 6.

¹⁵⁵ Sections 6 and 15.

¹⁵⁶ Subsection (2) provides that measures taken in good faith for the purpose of assisting or advancing persons or groups of persons disadvantaged because of discrimination which is unlawful is not to constitute discrimination.

¹⁵⁷ Human Rights Act 1993, s 21(1).

effect of treating a person or group of persons differently on one of the prohibited grounds of discrimination in a situation where that treatment is unlawful, unless the person responsible is able to establish a good reason for it.¹⁵⁸ For example, an employer who discriminated on the basis of a disorder such as diabetes, a form of which is genetically determined and disproportionately impacts individuals of Polynesian descent, could be guilty of indirect discrimination. Situations such as this one are likely to be rare.

(i) *Genetic Discrimination and Disability*

The HRA defines disability as:¹⁵⁹

- (i) Physical disability or impairment;
- (ii) Physical illness;
- (iii) Psychiatric illness;
- (iv) Intellectual or psychological disability or impairment;
- (v) Any other loss or abnormality of psychological, physiological, or anatomical structure or function;
- (vi) Reliance on a guide dog, wheelchair, or other remedial means; or
- (vii) The presence in the body of organisms capable of causing illness.

The orthodox position would be that latent genetic disorders that are not yet manifest are not disabilities under the HRA. However, in interpreting human rights legislation the New Zealand courts have often resisted any attempt to limit their impact, noting that:¹⁶⁰

The proper construction ...requires an appropriate regard for the substantial body of authority, both in New Zealand and abroad, as to the special character of human rights legislation and the need to accord it a fair, large and liberal interpretation.

¹⁵⁸ Section 65.

¹⁵⁹ Section 21(1)(h).

¹⁶⁰ *Coburn v Human Rights Commission* [1994] 3 NZLR 323, 333 per Thorp J.

Given this, an attempt will be made to discover if a “liberal and enabling interpretation”¹⁶¹ could include pre-symptomatic genetic disorders and predispositions under the definition of disability.

For the purpose of analysis here, genetic disorders can be sorted into three main categories: genetic hypersensitivity, purely genetic disease, and genetic predisposition to disease.

(ii) *Genetic Hypersensitivity*

Until a genetically hypersensitive individual has developed a disease, it seems difficult to say that they are a person with a disability. However, an analogy may be made with individuals who are highly allergic to foods such as peanuts and experience immediate and dramatic reactions to trace quantities of peanut. Upon exposure to a usually harmless substance, they experience abnormal and potentially life-threatening physiological and physical responses that would come under the definition of disability. The only real difference between these individuals and genetically hypersensitive individuals is that the former suffer an immediate allergic reaction, and the latter suffer a gradual allergic reaction. Hypersensitive individuals, such as those hypersensitive to beryllium, can be characterised – as suffering from genetically detectable, abnormal physiological¹⁶² processes that result in the development of disease on exposure to certain stimuli. Consequently, they should be protected as individuals with disabilities under the HRA.

An employer is required to accommodate a person with a disability if it is reasonable to do so.¹⁶³ Where it is not reasonable for the employer to provide special services or facilities in order for a person to satisfactorily perform the duties of the position, then he may discriminate against that person.¹⁶⁴ This means that if an employer had to eliminate a normally harmless chemical in the workplace in order for a genetically hypersensitive individual to work there, and it was technically impossible or economically unfeasible to do so, then he need not employ that person.

Section 29(1)(b) provides that if the workplace environment or the nature of the position is such that a person would present an unreasonable risk of harm to himself or to others, and the employer is unable to reduce the risk to a normal level without unreasonable disruption, then the

¹⁶¹ *New Zealand Van Lines Ltd v Proceedings Commissioner* [1995] 1 NZLR 100, 103 per Smellie

J.

¹⁶² Physiology, the study of biological functions, is defined as the “the study of normal functions of living organisms” in Koenigsberg (ed), *Churchill’s Medical Dictionary* (1989) 1444.

¹⁶³ There is a limited exception in relation to work involving national security – s 25.

¹⁶⁴ Section 29(1)(a).

employer may exclude that person from the workplace. This section does not suffer from the problems of the ADA's direct threat defence because its language clearly allows consideration that such a person may present a risk to themselves. It may be legitimately criticised on the ground that it is paternalistic and takes employment decisions away from individuals with disabilities. In the case of a genetically hypersensitive individual, if the employer is unable to reduce the risk for the sensitive individual to a normal level, then the employer could lawfully exclude that individual from the workplace.

Therefore, even if individuals with genetic hypersensitivities could be classified as disabled and protected from discrimination, the "reasonable accommodation" and "risk of harm" exceptions may still allow an employer to discriminate against them.

(iii) Purely Genetic Disorder

Disorders that are purely genetic, with little or no environmental influences, fall into two categories: those that are manifest at birth or are early onset, such as Down's syndrome or Phenylketonuria; and those that are latent until mid to late life, such as Huntington's disease. The former are easily classified as individuals with disabilities, while the latter defy simple classification.

An individual with the Huntington's gene who has not developed any symptoms has a pre-symptomatic genetic disease, but does not appear to have a disability under the HRA. However, there is a persuasive argument that such an individual should be protected from discrimination in a way similar to that in which an HIV-positive individual is protected (because of the presence of "organisms capable of causing disease").¹⁶⁵ A person with HIV is pre-symptomatic until the development of AIDS. At the time of diagnosis, victims of both conditions have no symptoms and may remain healthy for many years. In each case, an earlier-than-normal death is likely, although the exact time of onset of each condition is not clear. HIV and Huntington's disease can be characterised as current, rather than future impairments:¹⁶⁶ the person who is HIV positive has a current infection manifesting a clear disease process because the HIV virus "creates a physiological disorder of the haemic (blood) and lymphatic systems";¹⁶⁷ and the person with the Huntington's gene has a current

¹⁶⁵ Gin, *supra* note 63, 1422-1429.

¹⁶⁶ *Ibid* 1425.

¹⁶⁷ *Cain v Hyatt* 734 F Supp 671, 679 (ED Pa 1990), citing *Doe v Dolton Elem. School Dist. No. 148*, 694 F. Supp. 440, 444 (ND. Ill. 1988).

“defect in a specific chromosome [that] can be identified as the beginning of a genetic disease process in the same way as infection is identified as the beginning of a contagious disease process”.¹⁶⁸ The Huntington gene codes for an abnormal protein called Huntington,¹⁶⁹ which gradually accumulates in aggregate chunks.¹⁷⁰ These lumps of protein cause the death of certain cells in the brain as the disease progresses. This process could be characterised as an abnormal physiological process, and therefore the pre-symptomatic individual may have a disability under the HRA.

If pre-symptomatic individuals can be classified as disabled, they will be afforded protection from discrimination by the HRA. There seem to be no significant exceptions to the protection from discrimination, because no accommodation usually needs to be made for such individuals to perform the duties of the position, and the environment or nature of the job presents no increased risk.

(iv) *Genetic Predispositions*

An individual who has a genetic predisposition to disorders such as alcoholism, high cholesterol, or heart attacks is not clearly covered under the definition of disability under the HRA. However, following similar lines of reasoning to those used above, if the physiological process of the predisposition is known, then an argument can be mounted that the individual is suffering from an abnormality of physiological process or function. As a person with a disability, that individual should be protected from discrimination in employment unless she cannot be reasonably accommodated or she presents an unreasonable risk of harm.

If all the complex physiological processes and interactions between variant and mutant genes and their expression products could be identified, then there is a good basis on which to consider predisposition to any disease as a disability due to an abnormal physiological function.

4. Recommendations

An enabling and purposive approach to the interpretation of disability under the HRA could conceivably result in the classification of latent genetic disorders and predispositions as disabilities. However, the

¹⁶⁸ Gostin, *supra* note 6, 126.

¹⁶⁹ Ridley, *Genome: The Autobiography of a Species in Twenty-three Chapters* (1999) 58-59.

¹⁷⁰ *Ibid* 59.

analysis offered here may be legitimately criticised for being strained, and outside Parliament's original intention. If Parliament had intended to include genetic conditions within the definition of disability, then it could easily have used clear language to do so. In order to clarify the situation, promote certainty in the law, and provide more complete protection from genetic discrimination, legislative action is required. There are three main possibilities:

- (i) The amendment of the definition of disability under the HRA to include genetic disorders:

... (h) Disability, which means–

... (viii) *Having a genetic disease that is currently asymptomatic, a genetic predisposition to a disease, or a genetic hypersensitivity to an environmental stimulus.*

- (ii) The amendment of the HRA to include a person's genetic heritage as an additional prohibited ground of discrimination:

21. Prohibited grounds of discrimination – (1) For the purposes of this Act, the prohibited grounds of discrimination are–

... (n) *Genetic heritage, which means a person's genome and includes any genetic disorder, genetic disease, genetic hypersensitivity, and genetic predisposition to any disease or disability.*

- (iii) The enactment of a comprehensive new legislation dealing specifically with genetic discrimination. Such a law would probably consider genetic discrimination in the context of

both employment and insurance, and would provide clear guidelines regarding the use of genetic tests, the access and control of genetic information, and discrimination on the basis of genetic characteristics.

As a first step, option (i) or (ii) should be taken immediately. They would both have a similar effect, but possibility option (ii) would protect an individual from discrimination on the basis of genetic characteristics other than “diseases”, such as genetic indicators of low intelligence or laziness. Eventually, option (iii) would be required to provide comprehensive protection for employees and guidance for employers. Because of the complexity of the issues, such an Act would need to be well thought out and drafted.

(v) *Difficulties*

It is recognised that there are two main difficulties in enacting legislation to prevent genetic discrimination.¹⁷¹ The first is that it is extremely difficult to develop working legal definitions of genetic information and genetic discrimination. For example, some laws have defined genetic discrimination as discrimination based only on genetic information received from a DNA-based test,¹⁷² while other laws have extended the definition to include discrimination based on information gained from family history.¹⁷³ In a scientific world that is increasingly recognising that virtually all disease and personality states have an underlying genetic component, genetic discrimination could include anything.

The second difficulty with singling out genetic discrimination is that legislation prohibiting discrimination based on predictive genetic information but not discrimination based on non-genetic predictive medical information is unfair. Imagine someone who is genetically predisposed to a mental illness like schizophrenia, but is not presently affected. Under a genetic anti-discrimination law, such an individual would be protected from discrimination. Now consider a second person who has been in a car accident and received a blow to the head that

¹⁷¹ Recently, commentators have questioned the effectiveness of genetic antidiscrimination legislation: see Beckwith Alper, “Reconsidering Genetic Antidiscrimination Legislation” (1998) 26 *JL Med & Ethics* 205; Rothstein, *supra* note 40.

¹⁷² See Tex Rev Civ Stat Ann art 21.73 (West Supp 1999); Tex Lab Code Ann 21.402 (West Supp 1999).

¹⁷³ Preston, “Trenton Votes to Put Strict Limits on Use of Gene Tests by Insurers”, *New York Times*, New York, United States, 18 June 1996, A1, B6.

increases the risk of developing schizophrenia. Both individuals could be at equal risk for developing schizophrenia, but the second person would not be protected by anti-discrimination legislation that focuses entirely on genetics. This problem can be solved easily by including in anti-discrimination legislation a prohibition against discrimination based on any predictive medical information, genetic or non-genetic.

VI. CONCLUSION

Alarmist predictions heralding the danger of genetic discrimination and the creation of a new genetic underclass of unemployable genetically defective citizens have so far failed to eventuate. Genetic discrimination is presently a minimal problem, but the risk of genetic discrimination may be exacerbated by the constant developments in genetic research. It is important for the law to provide clear guidance and ensure that science is not used to perpetuate discrimination and support social inequality. This requires lawyers, judges, policymakers, and politicians to have a sound understanding of genetics and ensure that all decisions are based on good science, which recognises that undue emphasis and reliance must not be placed on a person's genetic identity because genetic information is probabilistic and inexact.

In New Zealand, the extent of protection from genetic discrimination under the HRA is presently unclear. A simple amendment to the HRA would clear up some uncertainty, but new legislation will eventually be required to regulate the collection and use of genetic information by employers.

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