

The Ultimate Weapon against Genetic Discrimination: Comprehensive Genetic Anti Discrimination Legal Package

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Abstract

Biotechnology is speedily developing in the twenty-first century. Unfortunately, the law is notorious for its inability to remain at par with technological developments. In this paper, I address the issue of genetic discrimination as a result of the advancements of genetic technologies. I demonstrate how genetic discrimination occurs and stress the importance of preventative laws. Canadian law has lagged behind the legal systems of other countries in adapting to the advancement of technologies. Thus, I offer a comprehensive package which can be utilized to prevent genetic discrimination in Canada.

Introduction

Each organism has a genome. A genome is a complete set of genetic information which reveals what is necessary to build and maintain that organism (National Center for Biotechnology Information, 2004). In 2000, scientists discovered the Human Genome which led to the genetic revolution. Genomics, the study and mapping of genomes, encompasses a very broad field. This paper focuses on the Human Genome. Its discovery, though celebrated, has rightly caused great concern. Race, religion, age, gender– they help define each individual. Unfortunately, these are also used as weapons of discrimination. The Human Genome – the latest identifier of humanity – is now the newest weapon of discrimination. Though other countries have passed laws and several cases have demonstrated that genetic profiles can be abused by employers, insurers and others, Canada has yet to pass a comprehensive federal genetic anti-discrimination act regulating the use of genetic information (Caulfield, 2003). This paper aims to explain that legislation geared towards genetic anti-discrimination must be improved in Canada. It is divided into two parts. Part one identifies forms of genetic discrimination in Canada and other countries, indicating the need for improvement in the Canadian genetic anti-discrimination legislation; part two offers recommendations for the development of federal and provincial laws aimed at tackling genetic discrimination.

Types of Genetic Discrimination

Genetic discrimination occurs when an individual's genetic profile is used against him by an insurer and/or employer. It is discrimination based on a future or perceived disability. A healthy asymptomatic individual may be in possession of a gene which predisposes him to an inherited disease. When this information is used against the individual, genetic discrimination has occurred (Genetics Home References, 2012). This is of concern to the public, as the predictability of genetic tests is very low. No individual has perfect genes. Yet, a human's genetic profile is being used to determine their human dignity and their rights. This is discrimination. Thus, the law

must remain at par with technological advances and prohibit such discrimination in order to preserve human dignity and human rights.

“Résumé and Genetic Profile, Please”

When employers use prospective and current employees’ genetic information against them, they practice genetic discrimination. Though not the most common form, there are cases whereby employers refuse to hire, dismiss, or demote qualified persons on the mere basis of their genetic profile. Employers may also sanction employees who refuse to take a genetic test. According to a 2006 survey on Canadians at risk for Huntington’s disease, approximately 7% experienced genetic discrimination in the workplace (Watton, 2009: 21). Though not as prevalent as that by insurers, it still exists and, thus, must be addressed in legislation.

That genetic information is even requested is a bizarre idea for many people, since DNA not only reveals highly personal information about the donor but about family as well. This includes predisposition to disease, mental status, behavioural traits, sexual orientation, family relationships and ethnicity (Bauman, 2000). Some call it a “future diary” (Bauman, 2000) as it can reveal a possible future disability. Because DNA not only reveals information about the donor, the disclosure of such information can affect many. Thus, legislation is needed to regulate the use of this information.

Insuring Discrimination

One of the most pervasive forms of genetic discrimination is committed by insurers. This sort of discrimination would not seem to be an issue in Canada, where health care is universal. Unfortunately, it still exists – genetic information may prevent people from attaining life insurance, critical care and disability insurance, and even the mandatory health insurance. One example is Kate Lingard, a woman from Toronto who tried to obtain long term disability insurance for her chiropractic practice. She filled out an insurance form, informing the insurance company that her father had Huntington’s disease. The insurance company responded by asking her to take a genetic test to determine whether or not she had the gene. Lingard explained, “As Canadians, it is instilled in us that people not be discriminated against based on a disability, yet insurance companies discriminate freely based on a perceived and potential future disability” (Watton, 2009: 22). Lemmens writes that family diseases are indeed considered by insurance companies in determining insurance premiums; he also informs readers that participants of research which reveals that they are carriers of a genetic mutation can also have that information used against them by insurers (Lemmens, 2010). According to the same 2006 survey mentioned above, 39.9% experienced genetic discrimination; 29.2% responded that they were either denied coverage, their premiums were increased, or they were told to take a predictive test before attaining coverage (Watton, 2009: 21). People with the gene for hereditary hemochromatosis, porphyria, and phenylketonuria are also denied insurance (Barash, 2008: 82). This is the type of discrimination which legislation would prohibit. When these tests reveal genetic susceptibilities to costly diseases, insurers are able to use that information to deny mandatory health insurance to those gene carriers. or offer insurance at higher rates.

Though in Canada insurance companies cannot legally oblige interested customers to get a genetic test, they can request that the client provide information from a genetic test taken in the past.

In 1990, the Quebec case *Audet v Industrielle-Alliance* foreshadowed genetic discrimination as a widow's claim for her husband's life insurance was denied. Her husband who had myotonic dystrophy, but no symptoms of the disease, told his insurers that he had no medical conditions. Even though he died as a result of a car accident and not his disease, the Quebec Superior Court ruled in favour of the insurance company. Genetic anti-discrimination legislation would protect against such occurrences.

What is greatly troublesome about this is that it discourages healthy people from attaining genetic tests in order to detect the presence of a mutated disease-causing gene as a precaution. Detecting a genetic predisposition towards a disease can save someone's life. As Winnipeg North MP Judy Wasylycia-Leis said in an interview in May 2010, regarding her proposal to amend the Human Rights Act to include "genetic characteristics", 'Unless genetic test results are protected, there's a real danger that Canadians will just refuse to be tested, putting their health at risk' (Roberts, 2010). Genetic anti-discrimination legislation would encourage people to take these tests without fear of the results being used against them.

Comprehensive regulation of genetic information: Assembling the Units

That genetic discrimination exists cannot be denied. The question is how Canada can prevent it. How should it be punished? Legislation is crucial in preventing such discrimination, yet Canada lacks federal legislation concerned with the prevention and punishment of genetic discrimination. Instead, provinces have expanded provincial statutes to include cases for genetic discrimination. However, these are inconsistent and fragmented. There is insufficient regulation of how private genetic and health information is protected, secured and verified (Florencio and Ramanathan, 2001).

Provinces have expanded statutes (mainly those on privacy and disability) to include genetic characteristics. On May 28, 2011 Mike Colle (MPP for the riding of Eglinton-Lawrence) introduced a Private Member's Bill—Bill 199—entitled the Human Rights Code Amendment Act (Genetic Characteristics), 2011. As a result of this bill, discrimination on the basis of "Genetic characteristics" would be prohibited according to Ontario's Human Rights Code (Office of MPP Mike Colle, 2011). This bill is still in review.

A bigger announcement was made by Winnipeg North MP Judy Wasylycia-Leis who said that she would announce a proposal in the House of Commons to include "genetic characteristics" in the Human Rights Act.

How should Canada proceed in regulating the use of genetic information? I present theories offered by scholars, and assemble these units together to create a comprehensive package which regulates genetic information in order to prevent its misuse.

The Constitutional Approach

One theory has been to use the constitutional approach, whereby the human rights legislation is applied to the new advances in genetic technology. The decisions of high-ranking courts can be used to set precedents and express public interests by using interest groups as interveners (Knoppers, 2000). The problem with this is that the decisions made are ad hoc decisions which act after the discrimination has occurred – not in the prevention of discrimination. Though the Canadian Charter of Rights and Freedoms is considered a "living tree" which can evolve and adapt to new developments, it is not sufficient on its own to address

this issue. Judges may not possess the necessary expertise in making decisions that have far-reaching effects on the legal perceptions of genetic discrimination.

A better option would be to amend Canada's human rights legislation – a suggestion already offered by Winnipeg North MP Judy Wasylycia-Leis. This would ensure a legal foundation for all cases of genetic discrimination.

Redefining “Disability”

Redefining “disability” in the Disability Act has been seen as the most favourable recommendation by scholars who question the fairness in isolating genes. This theory suggests that singling out genes in law is in itself unfair, as other health information can also lead to discriminatory practices (Lemmens, 2010).

Their solution, then, is to redefine disability. Presently, the Disability Act is used to resolve cases of genetic discrimination. It, however, does not prevent discrimination from occurring. Rather, it is only useful after the discrimination occurs. Still, it is necessary to amend this act as well as others in the creation of a comprehensive package geared towards genetic anti-discrimination. The term “disability” in the Human Rights Code should be amended to include perceived disability or the belief of future disability. This would directly relate to genetic information that has a probability of causing a disease in the future. It is important to note that the results of genetic tests are very uncertain and that genes express themselves in great variation (Mendes, 2010). This is why asymptomatic individuals who possess a gene predisposing them to a disease should not have the information used against them.

The disability act would prohibit insurers from discriminating against an individual with a gene but no symptoms of that gene. One major concern is raised by insurers. Insurers provide insurance by classifying persons into certain risk-pools. Given that 5% of clients cover more than 50% of costs (Florencio and Ramanathan, 2001), it is reasonable that insurers try to eliminate high-risk clients. Consequently, when a person has symptoms of the disease, the law can no longer protect them from discrimination as it is necessary for insurance companies to assess prospective clients and provide them with reasonable premiums. Thus, as soon as a person becomes symptomatic of the disease, insurers are able to use that information in their assessment.

Re-enforcing Privacy Legislation

Florencio and Ramanathan (2001) suggest the creation of “comprehensive privacy legislation that adequately addresses each of the three pillars of the modern conception of privacy rights: choice, secrecy and confidentiality.” According to the writers, the law should explicitly protect an individual's choice whether to submit to genetic testing. This would prohibit employers and insurers from asking for genetic tests. The second pillar, secrecy, must also be explicitly protected as the right to complete decision-making. Individuals which decide to submit to genetic tests have the right to ask for that information to remain private. The third pillar, confidentiality, is used to ensure that those who do access the information (administrators of the test, for instance) are prohibited from disclosing the information to insurers or employers. This right is necessary as common law only recognizes confidentiality between a doctor and a patient; a doctor may not be the only person privy to the information. Anyone else with access to one's information would be obliged to keep it private.

Assembling the Units: Federal Legislation + Disability Acts + Privacy Acts

Because Canada has lagged behind other countries such as America and European countries, legislators are able to learn from these countries. I argue that Canada should follow America in its creation of federal legislation which amends many laws; it should create a comprehensive package to include genetic information as prohibited grounds of discrimination. It should follow America in the creation of GINA (Genetic Information Nondiscrimination Act) – a far reaching act which touches on disability acts, privacy acts, and insurance law.

Redefining disability, amending the privacy legislation and creating federal legislation would all work together to prevent genetic discrimination. Choosing only one of these approaches would result in flaws and inconsistencies.

Employers should be explicitly forbidden to ask for genetic information except in cases whereby employees would be exposed to toxins or chemicals that can interact with one's genes. The argument that employers need information to create a safe workplace would be effective only in this circumstance. Furthermore, the public can be reassured by the high costs it would take an employer to investigate each prospective employee (Gordard, et al., 2003).

Insurance companies do not need to access genetic information to be able to fairly assess a prospective client. Genetic information, as noted earlier, does not have high predictive validity. It is quite uncertain. Thus, insurers should not be allowed to request genetic information either.

Federal legislation is the final step in consolidating this genetic anti-discrimination package; Judy Wasylycia-Leis has begun this lengthy process. Her movement, M-444, reads

the government should develop and implement anti-discrimination protections with respect to genetic information including, but not limited to, information gathered through genetic testing and family history

It also includes effective enforcement mechanisms and a public campaign to raise awareness of the issue, as well as a body of experts to document and evaluate cases and provide information to the government.

Conclusion

Assembling the units will create a comprehensive package geared at tackling genetic discrimination. Canada, a country of tolerance and diversity, must no longer lag behind other countries. Like other legal issues, this will be a lengthy and likely costly process. Still, the development of technology must be accompanied by the development of the law. Genetic research has great benefits. Law will ensure that it remains beneficial. Insurers, employers and other parties cannot be allowed to use one's genetic profile to determine their value. Canadians must fight to preserve human dignity and equal rights as no one has perfect genes. Amending the privacy laws, the disability act and implementing federal legislation is the comprehensive package that Canada needs. Soon, other countries will be emulating Canada.

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