

Genetic Discrimination and Canadian Law

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A number of national governments – for example, in the United States, Australia and a number of European countries – have taken legislative action to address genetic discrimination. While Canadian human rights laws, insurance laws and privacy laws do contain provisions that seek to minimize unjustifiable discrimination and prevent improper access to or use of personal information, at present no laws in Canada provide specific protection against genetic discrimination. However, in light of recent events, it appears likely that Canada will in fact join the nations that have enacted legislative action to address genetic discrimination.

Background

Genetic testing, which involves the analysis of a person's chromosomes, genes, or gene products (proteins) to identify the presence of specific traits, can have many benefits. It allows people to learn about their parentage and ancestral origins and is helping scientists to map prehistorical routes of human migration. It can be used to diagnose genetic conditions (diagnostic testing) or to identify a predisposition to a genetic disease (predictive testing). This information can help people initiate appropriate treatment early and adopt lifestyles that will minimize the possible harm of a genetic condition. It can guide the selection of pharmacologic therapies and can identify patients who are candidates for gene therapy, which uses various techniques to replace, correct, suppress, or eliminate a mutated gene.

The possibility of improving outcomes and cost-effectiveness by tailoring therapy to a patient's genetic profile has prompted government funding in the emerging field of "personalized medicine". Although, at present, relatively few tests for genetic conditions are widely recognized as reliable, and while a positive test result does not necessarily predict the onset or severity of an illness, it is expected that genetic testing will continue to open up new areas of medical knowledge and new options for treatment. New tests are being developed at a rapid pace and these will increasingly become available.

At the same time, genetic information can, however, also be used to discriminate against someone. For example, a genetic test could reveal that a person who is otherwise in good health has a higher risk of one day requiring advanced health care or

being unable to work because of an inherited condition. This information could affect how decisions are made in such matters as insurance and employment. If an applicant for insurance has a higher risk for a certain disease, then that applicant presents a higher risk to the insurer of having to make payments for health coverage or life insurance. This may affect the terms of any policy offered to the applicant. Similarly, an employer may be less willing to hire a job applicant who is genetically at high risk of developing an illness or genetic condition.

Although the long-term ethical and legal consequences of genetic testing for employment matters, insurance contracts, and preventive medicine and treatment are not yet fully known, cases of alleged genetic discrimination have been emerging in different parts of the world, prompting calls from concerned citizens for government action.

Proposed Canadian Response

In the lead up to the recent Canadian Federal election, the Government of Canada introduced the "Protection Against Genetic Discrimination Act". However, the Bill died when the House of Commons was dissolved last June.

Earlier this year, a Bill was passed in the Senate of Canada entitled "An Act to prohibit and prevent genetic discrimination" (the "Senate Bill"). Most recently the Senate Bill was introduced in the Canadian House of Commons. Whether the Senate Bill ultimately receives Royal Assent in its current form or in a modified form, it seems quite likely that legislation will be enacted in Canada that prohibits genetic discrimination.

The Senate Bill proposes criminal sanctions for actions such as when one person requires another to undergo a genetic test or disclose the results of one as a condition of (a) providing goods or services to that individual; (b) entering into or continuing a contract or agreement with that individual; or (c) offering or continuing specific terms or conditions in a contract or agreement with that individual. The rationale for the use of the criminal law power is to attempt to bolster this federal effort to extend the protection beyond the ambit of traditional federal authority.

In addition, the Bill proposes amendments to several statutes of the Government of Canada – the *Canadian Human Rights Act*, the *Privacy Act*, the *Personal Information Protection and Electronic Documents Act* and the *Canadian Labour Code*.

The proposed amendment to the *Canadian Human Rights Act* would deem discrimination on the basis of a predisposition to a disability, as inferred from genetic test results, to be discrimination on the ground of disability. This Act applies to the federal government and First Nations governments, as well as to federally regulated businesses and industries, such as banks and telecommunications companies, in matters of employment and the provision of goods, services, facilities and accommodation.

The proposed amendment to the *Privacy Act* and the *Personal Information Protection and Electronic Documents Act* would specify that information resulting from genetic testing is among the types of personal information protected by these Acts. The *Privacy Act* protects personal information collected, used and disclosed by federal government

institutions listed in the Act, as well as any parent Crown corporation and any wholly owned subsidiary within the meaning of the *Financial Administration Act*. The *Personal Information Protection and Electronic Documents Act* protects personal information that is collected, used and disclosed by private sector organizations in the course of commercial activities. It also protects information on employees who work for a federally regulated business.

The proposed amendments to the Canada Labour Code would protect employees from being required to undergo or disclose the results of genetic tests and provide employees with other protections related to genetic testing and test results.

Observations

Various organizations, legal experts and other commentators have argued in favour of the need to pass legislation in Canada to explicitly address genetic discrimination. At the same time, the insurance industry has noted that insurance contracts are generally governed by provincial laws. Although provincial human rights codes may already provide some protection for individuals from genetic discrimination, they also include some exceptions that may allow automobile, life, accident or sickness or disability insurance providers to make distinctions based on an applicant's age, sex, marital status, family status, or physical or mental disability. A discriminatory practice in insurance may be justified on reasonable and bona fide grounds – in other words, if it is based on accepted and sound insurance practices and if no practical non-discriminatory alternative exists.

The current position of the Canadian insurance industry is that, while companies will not require genetic testing of applicants for insurance, they will ask whether the applicant has been genetically tested in the past, and they will require disclosure of those test results where they exist. This position is generally justified on the basis that there exists a good faith obligation under most provincial laws for an insurance applicant to disclose to the insurance company all information that might have a bearing on the company's assessment of risk. The insurance industry has expressed concern that insured persons who learn, after taking a genetic test, that they are at high risk for a genetic disease could knowingly take out policies for large amounts of additional coverage without insurers being aware of any increased risk. Disclosing the results of genetic testing would therefore help ensure that both parties negotiating an insurance contract would have the same knowledge about the health risks of the applicant.

While the position of the insurance sector seems quite reasonable, it is likely that the greater public interest in ensuring Canadians have access to medical advances in genetic testing without the fear of negative consequences or repercussions on them and their families' means that a better defined Canadian legislative framework has merit. This is an issue that will be a subject for further public debate and consideration in the coming months.

By

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