

Bill S-201: An Act to prohibit and prevent genetic discrimination

I am writing in support of Bill S-201. As a genetic counsellor with 20 years' experience it is clear that Canadians need protection from genetic discrimination. I participated in the development of a position statement on genetic discrimination for the Canadian Association of Genetic Counsellors (CAGC). The statement, issued in 2012, expressed the organization's belief that the public should be protected from genetic discrimination and that legislation was necessary. The full position statement is included at the end of this brief.

Advancements in technology are changing the scope of genetic testing and this has increased the possibility for genetic test results to be used unfairly. Within the past couple of years, genetic testing has evolved from testing targeting single genes to panels containing large numbers of genes and even testing person's entire genome. With these broad testing approaches, there is the possibility that while searching for an answer to one medical problem a completely unexpected genetic discovery could be made. For example, while testing a pregnancy for a genetic change that would cause significant mental handicaps, a predisposition to adult cancers or a risk for early onset Alzheimer disease could be found. This discovery could make that unborn child and possibly one of the parents uninsurable. It is challenging for health care providers to prepare patients for the medical implications of choosing to do or not do genetic testing without having to talk about the uncertainty of how this information may be used against the patient in the future.

Bill S-201's proposed amendment to the Canadian Human Rights Act to include genetic characteristics seems particularly appropriate. Genetic characteristics deserve a place next to race, national or ethnic origin, colour, religion, age, sex, sexual orientation, marital status, family status, disability or conviction for an offence for which a pardon has been granted or in respect of which a record suspension has been ordered seems absolutely appropriate when it comes to protecting people from being treated unfairly. To many people, the concept of discrimination may seem less tangible than some of the other forms of discrimination because they have had limited experience with genetic testing and are unaware of.

Some people claim that genetic discrimination is not a reality because of the lack of documented cases. Just because there are very few people coming forward to report genetic discrimination does not mean it is not happening and does not mean that it will not happen in the future. Legislation like Bill S-201 will give the people who have been discriminated against the confidence to come forward.

Genetic counsellors and geneticists see patients' fear about the potential unfair use of their genetic test results influencing their decisions on whether to have genetic testing. These tests are being offered because it will help with the patient's medical care but the health care providers cannot guarantee that these results will not be used in a discriminatory way at some point in the future. This bill will provide reassurance to patients that they have protection so the fear of genetic discrimination will not factor into their decisions around proceeding with genetic testing.

I hope that the Senate Committee will see that Bill S-201 will provide protection for Canadians against genetic discrimination. This is an area that needs to be addressed urgently given the trends in genetic testing that increase the likelihood of discovering unexpected results that may affect that person's health.

CAGC Genetic Discrimination Position Statement

The CAGC is opposed to genetic discrimination. Genetic discrimination is defined as the unfair use of genetic test results or genetic risk determined by family history.

Individuals should not be deterred from seeking genetic services, undergoing genetic testing or participating in genetics research out of concern for genetic discrimination. Individuals should not be coerced to undergo genetic testing by third parties. The decision to have genetic testing is a personal one and should be at the discretion of the individual.

Individuals should be protected from genetic discrimination by employers, insurers and society. The CAGC supports and encourages the immediate development and implementation of legislation to protect the Canadian public from unfair use of genetic test results or family history.