UNNECESSARY AND REDUNDANT? EVALUATING CANADA'S *GENETIC NON-DISCRIMINATION ACT*, 2017

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In 2017, Canada's Genetic Non-Discrimination Act (GNDA) came into force. The GNDA's enactment was prompted by concerns about genetic discrimination given the growing amount of genetic data being collected and stored by medical practitioners, but also by for-profit genetic testing companies. Critics have questioned whether discrimination of this kind even exists, and have suggested that the Act, and the changes that it required to the Canada Labour Code (CLC) and Canada Human Rights Act (CHRA), are redundant. In this paper, I explore the merits of these critiques by evaluating studies, anecdotal evidence, and case law on genetic discrimination. I argue that there is a small but growing body of evidence that genetic discrimination is occurring in Canada. The Act's amendments to the CLC and CHRA may be somewhat redundant. However, given the growing trend of people thinking of diseases and conditions based on their genetic properties, the privacy concerns raised by genetic data, and the deterrent and symbolic potentials of the Act, I argue that it is an important new tool for preventing and prohibiting what could become a growing basis for discrimination. If the Act, which has been challenged for being ultra vires the Parliament of Canada's jurisdiction over criminal law, is invalidated, its enactment, and this assessment of it, nonetheless provide insight into what desirable intra vires legislation might look like at the federal and provincial levels to deal with genetic discrimination.

En 2017, la Loi sur la non-discrimination génétique (LNDG) est entrée en vigueur au Canada. Sa promulgation découle d'inquiétudes au sujet de la discrimination génétique eu égard à la somme croissante de données génétiques recueillies et conservées par les praticiens de la santé, mais aussi par les sociétés de dépistage génétiques du secteur privé. Les détracteurs se sont demandé s'il existe même des discriminations de ce genre et ont suggéré que la LNDG et les modifications qu'elle a imposées au Code canadien du travail (CCT) et à la Loi canadienne sur les droits de la personne (LCDP) sont inutiles. Dans cet article, l'auteure se penche sur les mérites de ces critiques en évaluant les études, la preuve empirique et la jurisprudence en

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matière de discrimination génétique. Elle soutient qu'il existe un ensemble limité, mais croissant, de preuves d'instances de discrimination génétique au Canada. Les modifications du CCT et de la LCDP suscitées par la Loi pourraient être inutiles à certains égards. Cependant, étant donné la tendance croissante à considérer les maladies et troubles en fonction de leurs propriétés génétiques, les préoccupations quant à la protection des renseignements personnels suscitées par la collecte des données génétiques, et les potentiels dissuasif et symbolique de la Loi, elle soutient qu'il s'agit là d'un nouvel outil important pour prévenir et interdire ce qui pourrait devenir un motif croissant de discrimination. Si la Loi, qui a été contestée au motif qu'elle excède la compétence du Parlement du Canada en matière de droit pénal, est invalidée, sa promulgation et l'évaluation qu'en fait l'auteure dans cet article fournissent néanmoins une idée de ce que pourrait être une loi souhaitable, promulguée dans les limites de la compétence fédérale et provinciale, pour traiter de la discrimination génétique.

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1. Introduction

On May 4, 2017 Canada's *Genetic Non-Discrimination Act* ("GNDA" or "the Act")[1] received Royal Assent. The Act came about as a response to concerns about genetic discrimination given the increasing amount of genetic information being collected and stored by medical practitioners, but also by for-profit genetic testing companies like Ancestry.com and the very popular 23andMe. The GNDA follows efforts by other countries to introduce measures (legislative or otherwise) to prohibit and prevent genetic discrimination. Since coming into force, the Act has received a large amount of criticism.[2] The Act has also been challenged by the Quebec government. The Quebec Court of Appeal found the majority of its sections to be *ultra vires* of the Parliament of Canada's jurisdiction over criminal law.[3] The Supreme Court of Canada heard the appeal in the fall of 2019, but has yet to release a decision.[4]

Among the critiques of the Act, the first I will address is the question about whether discrimination of this kind even exists; and secondly, whether the Act, and its amendments to the *Canada Labour Code* ("CLC")[5] and *Canada Human Rights Act* ("CHRA"),[6] are redundant.[7] A small but significant body of research hypothesized about the possible effects of genetic discrimination legislation in Canada before it was created.[8] However, no research has examined the GNDA's effectiveness since coming into place. This is a particularly opportune point to do so

1 SC 2017, c 3 [*GNDA*].

2 See e.g. André Picard, "Anti-genetic-discrimination bill is little more than virtue signaling" (09 March 2017), online: *The Globe and Mail* <www.theglobeandmail.com/news> [André]; Yann Joly, "Do we need legislation to protect Canadians' genetic rights? The No side" (10 May 2018), online: *The Globe and Mail* <www.theglobeandmail.com/news> [Joly].

3 *Dans l'affaire du: Renvoi relatif à la Loi sur la non-discrimination génétique édictée par les articles 1 à 7 de la Loi visant à interdire et à prévenir la discrimination génétique*, 2018 QCCA 2193 [*Quebec Reference*].

4 Leslie MacKinnon, "Genetic non-discrimination bill passed by Parliament, but challenged by government at top court" (10 October 2019), online: *iPolitics* <ipolitics.ca>.

5 RSC 1985, c L-2 [*CLC*].

6 RSC 1985, c H-6 [*CHRA*].

7 André, *supra* note 2; Joly, *supra* note 2.

8 See e.g. Trudo Lemmens, Daryl Pullman & Rebecca Rodal, *Revisiting Genetic Discrimination Issues in 2010: Policy Options for Canada* (Ottawa: Genome Canada, 2010)

because, similar to the amendment that the GNDA required of the CHRA, Ontario has recently considered adding "genetic discrimination" as a protected ground under its provincial human rights legislation.[9]

In this paper I deal with the above two critiques, which boil down to an argument that the Act is both unnecessary and redundant. I explore the merits of these critiques. I argue that there is a small but growing body of evidence that genetic discrimination is occurring in Canada. The Act's amendments to the CLC and CHRA may be somewhat redundant. However, given the growing trend of people thinking of diseases and conditions based on their genetic properties, the privacy concerns raised by genetic data, and the deterrent and symbolic potentials of the Act, I argue that the GNDA is an important new tool for preventing and prohibiting what could become a growing basis for discrimination. Even if the Act is invalidated for being *ultra vires*, its very enactment, and this assessment of it, can still provide valuable insight into what desirable *intra vires* legislation might look like at the federal and provincial levels, to deal with genetic discrimination.

In order to make this argument, I begin by first exploring the context surrounding why the GNDA was introduced. I explain the Act itself and briefly speak to its current challenge by the Quebec government. I then turn to the two critiques of the Act: firstly, that there is insufficient evidence that genetic discrimination is occurring; and secondly, that the Act and its amendments to the CLC and CHRA, are redundant. In assessing these two critiques, I rely on the small body of studies, anecdotal evidence, and case law on genetic discrimination, focusing on the Canadian context. I conclude by making recommendations for *intra vires* legislation at the federal and provincial levels for dealing with genetic discrimination.

2. Context

A) The Human Genome Project

Concerns around the improper use of genetic information began with the advent of the Human Genome Project ("HPG"). The HPG was an international collaborative research program that was formally launched on October 1, 1990 and completed on April 14, 2003.[10] The goal of the project was to map and understand the complete set of genetic instructions

(which explored different possible options for addressing genetic discrimination in Canada) [Lemmens *Revisiting Genetic Discrimination*].

9 Meagan Gillmore, "Genetic discrimination unclear in provincial law" (10 September 2018), online: *Law Times* <www.lawtimesnews.com/>.

10 Francis S Collins, "Medical and Societal Consequences of the Human Genome Project" (1999) 341:1 New Eng J Med 28 [Collins].

of human beings. All humans, and almost all other organisms, have the hereditary material deoxyribonucleic acid ("DNA"), which contains all of our genes. The information in DNA is stored as a code made up of four chemical bases.[11] Genes are made up of stretches of these four different bases. They are arranged in different ways and in different lengths. The order and sequence of this information determines the information for building and maintaining an organism. The project revealed that there are about 20,500 human genes.[12] In addition to revealing these genes, the HPG provided an understanding of the structure and organization of human genes. It did this firstly through providing the different order or sequence of all the bases in DNA. Second, the HPG made maps that illustrate the locations of genes for major sections of our chromosomes. Third, it provided linkage maps (also called genetic maps). These linkage maps allow us to track inherited traits (like genetic diseases) over generations.[13]

B) Genetic Testing by Medical Practitioners and For-Profit Genetic Testing Companies

The information, such as linkage maps, and the technological advances made by the HPG have made it much easier to collect and to understand people's genetic data. For instance, gene-isolation techniques[14] have allowed researchers to confirm whether a disease has a genetic basis and to identify the responsible gene.[15] This means that by looking at someone's genetic information, medical practitioners can diagnose genetic conditions or identify a predisposition to some genetic diseases.[16] This has been used to find the gene responsible for single gene inherited disorders like cystic fibrosis and to identify the genes that play a role in disorders like cancer and heart disease.[17] At this stage, there are still many problems with predicting peoples' predisposition to a disease.[18] This is owing to

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11 "An Overview of the Human Genome Project" (last modified 28 October 2018), online: *National Human Genome Research Institute (NHGRI)* <www.genome.gov> [Human Genome Project] (these four bases are: adenine, guanine, cytosine and thymine).

12 The first draft of the human genome was published in "Nature" in February 2001. See International Human Genome Sequencing Consortium, "Initial sequencing and analysis of the human genome" (2001) 409:6822 Nature 860.

13 Human Genome Project, *supra* note 11.

14 Also known as positional cloning.

15 Collins, *supra* note 10.

16 Yvonne Bombard, Ronald Cohn & Stephen Scherer, "Why we need a law to prevent genetic discrimination" (19 September 2016), online: *The Globe and Mail* <www.theglobeandmail.com/opinion> [Bombard, Cohn & Scherer] (note that 6000 genetic diseases have been discovered as of yet).

17 Claudia Gonzaga-Jauregui, James R Lupski & Richard A Gibbs, "Human Genome Sequencing in Health and Disease" (2012) 63 Annual Rev Medicine 35.

18 Steven J Schrodi, "Genetic-based prediction of disease traits: Prediction is very difficult, especially about the future" (2014) 5 Frontiers in Genetics 162.

for instance, the interplay between genetic and environmental factors, and how the relationship between multiple genes affects susceptibility to a disease. However, using genetic findings to inform medical practice, through for instance personal genome sequencing, is a sought after goal of human genetics, and we are well on our way to redefining the way that we look at disease. Before genetic testing, genetic diseases were characterized by clinical signs and symptoms, which are the manifestations of gene abnormalities. Now, genetic diseases are being characterized by their underlying genotypes, meaning by people's genes themselves.[19] Even where a gene's role in a disease is not yet fully understood, diagnosis can be used to guide reproductive planning, treatment, or encourage people to adopt lifestyles to prevent or minimize the development of potential health consequences. It can also help to identify patients who would be well-suited to gene therapy, which can involve correcting, replacing or eliminating a mutated gene.[20] New genetic tests are being developed rapidly and are becoming increasingly available in health care settings. This means that the amount of genetic information being collected and stored in publicly-funded biobanks is growing exponentially.

In addition to the collection of genetic information by healthcare practitioners, genetic testing is also being conducted by commercial interests. Genetic testing companies are now aggressively marketing to consumers. What is called the "direct-to-consumer" ("DTC") genetic health test industry began in 1996.[21] The idea was that consumers could explore their own human genome without a medical practitioner to help them. This industry has since boomed with companies like 23andMe and Ancestry.com being prominent examples. These companies collect DNA information through saliva samples and give patients a genotype readout. Other companies offer to reanalyze this data. Recent DTC industry estimates are that over 26 million people are now using these tests globally.[22] The majority of these people are in the United States.[23]

C) Genetic Discrimination

This growing knowledge about human genetics, and the greater use and proliferation of genetic tests, has many possible benefits, but also many

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19 Joseph S Alper et al, "Genetic Discrimination and Screening for Hemochromatosis" (1994) 15:3 J Public Health Policy 345 at 345 [Alper et al].

20 Bombard, Cohn & Scherer, *supra* note 16; Collins, *supra* note 10.

21 Scott Bowen & Muin J Khoury, "Consumer Genetic Testing Is Booming: But What are the Benefits and Harms to Individuals and Populations?" (12 June 2018), online (blog): *Office of Genomics and Precision Public Health* <blogs.cdc.gov>.

22 Antonio Regaldo, "More than 26 million people have taken an at-home ancestry test" (11 February 2019), online: *MIT Technology Review* <www.technologyreview.com>.

23 *Ibid.*

potential hazards.[24] One such hazard is the inappropriate collection, storage and use of this genetic information, and the potential for genetic discrimination. Genetic discrimination is defined as "the denial of rights, privileges, opportunities, or other adverse treatment based solely on genetic information, including family history or genetic test results."[25] This form of discrimination results from actual or presumed genetic differences.[26] As disease and impairment begin to be defined by their underlying genetic cause, individuals are more likely to face discrimination on the basis of their genotype, possibly even irrespective of whether they have resulting symptoms.[27]

Genetic testing, and this focus on identifying "problems" in people's genetic information stems from a medical model of disability. The medical model of disability is shaped by conceptions of normality and abnormality. Society demands conformity to idealized physiological norms.[28] The medical model views disability as a medical problem or "abnormality" that exists in a person's body and that does not conform to these bodily norms.[29] Genetic testing supports this way of thinking by identifying "abnormalities," "mutations" or "pathologies" in people's bodies. These impairments are thought to cause disadvantages, or disabilities, for the person.[30]

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24 Lisa N Geller et al, "Individual, family, and societal dimensions of genetic discrimination: A case study analysis" (1996) 2:1 Science Engineering Ethics 71 [Geller et al].

25 Cheryl Erwin et al, "Perception, experience, and response to genetic discrimination in Huntington disease: The international RESPOND-HD study" (2010) 153B:5 American J Medical Genetics Part B: Neuropsychiatric Genetics 1081 at 1082 [Erwin et al]; See also Lawrence O Gostin, "Genetic discrimination: the use of genetically based diagnostic and prognostic tests by employers and insurers" (1991) 17:1–2 Am J L & Med 109 [Gostin]. See "What is Discrimination?" online: *Canada Human Rights Commission* <www.chrc-ccdp.gc.ca/eng/content/what-discrimination> (note the Canada Human Rights Commission definition of discrimination which defines it as "an action or decision that treats a person or a group badly for reasons such as their race, age, or disability").

26 Geller et al, *supra* note 24.

27 Alper et al, *supra* note 19 at 345.

28 Simon Brisenden, "Independent Living and the Medical Model of Disability" in Tom Shakespeare, ed, *The Disability Studies Reader: Social Science Perspectives* (New York: Cassell, 1998) 20 at 23 [Brisenden].

29 Sara Goering, "Rethinking disability: The social model of disability and chronic disease" (2015) 8:2 Current Rev in Musculoskelet Medicine 134 at 134 [Goering]; Natasha Saltes, "'Abnormal' Bodies on the Borders of Inclusion: Biopolitics and the Paradox of Disability Surveillance" (2013) 11:1/2 Surveillance & Society 55 at 57 [Saltes].

30 Liz Crow, "Including All of Our Lives: Renewing the Social Model of Disability" in Jenny Morris, ed, *Encounters with Strangers: Feminism and Disability* (London, UK: Women's Press, 1996) 206 [Crow].

The medical model elicits a medical response to disability, as though it needs to be treated or cured.[31] One of the narratives in support of genetic testing is that it allows medical professionals to intervene in order to help avoid the suffering associated with an impairment.[32] In so doing, however, the medical model reduces and invalidates impaired bodies by regarding them as "abnormal, deviant, inferior and even sub-human."[33]

Many disability scholars and activists have responded to the problems that exist with the medical model. Simon Brisenden, for instance, argues that the only difference between people with impairments and those without impairments are that society looks at people with impairments through a lens that only focuses on their limitations.[34] To replace the medical model, disability scholars have adopted the social model of disability. This model relies on a distinction between impairment and disability. With a medical model, a person's impairment is thought to be the cause of the disadvantages experienced.[35] However, in a social model of disability, "impairment" or "disease" are just descriptions of the body. The impairment may or may not be evaluated as negative by the person possessing it.[36] Disability is reframed as a social construct.[37] Disability is the "disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities."[38] Thus, disability emerges from social practices that do not take into account the needs of people with impairments. The social model, in using this lens, centres the experience of the person with the impairment, respecting their agency to assess and take action about any impact if they wish, instead of a medical practitioner telling a person how an impairment affects their experiences.

The medical model continues to persist and has underscored a long history of discriminatory laws and practices that have been directed

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31 Michael Oliver, *Understanding Disability: From Theory to Practice* (New York: St Martin's Press, 1996) at 58 [Oliver].

32 Tom Shakespeare, "'Losing the plot'? Medical and activist discourses of contemporary genetics and disability" (1999) 21:5 Sociology Health & Illness 669 at 669 [Shakespeare].

33 Fiona Kumari Campbell, *Contours of Ableism: The Production of Disability and Abledness* (London, UK: Palgrave Macmillan, 2009) cited in Ema Loja et al, "Disability, embodiment and ableism: stories of resistance" (2013) 28:2 Disability & Society 190 at 191.

34 Brisenden, *supra* note 28 at 23

35 Crow, *supra* note 30.

36 Goering, *supra* note 29 at 135.

37 Oliver, *supra* note 31.

38 *Ibid* at 22.

towards people with disabilities.[39] For instance, in Canada, the *Living Archives* project reveals the history of eugenics in Canada, particularly in Western Canada.[40] It reveals how laws were used to authorize the institutionalization and sterilization, without consent, of individuals diagnosed as "mentally defective."[41] This project explores the relationship between this history and current practices, such as in biomedicine. The sterilization of people with disabilities also has a long history in the United States, where a recent whistleblower report alleges that women in a Bureau of Immigration and Customs ("ICE") detention center have received coerced hysterectomies. These allegations are just further evidence of the fact that the long-time practice of forcefully sterilizing specific groups is alive and well.[42] Apprehensions about eugenic intents behind genetic testing technologies have raised concern about whether genetics are "a totalitarian conspiracy to rid the world of disabled people."[43]

Research has also investigated the ways in which the medical model of disability leads people with disabilities to being undervalued, feeling excluded, and being denied equal opportunities.[44] The lives of peoples with disabilities are over-regulated and their privacy often invaded. Every facet of the lives of people with disabilities have been regulated including sexual relations, marriage, procreation, and child-rearing.[45] Privacy law scholar Roger JR Levesque, for instance, describes the ways that the private relations of people with disabilities have been regulated in the United States in ways that disenable them.[46] Disability scholar Natasha Saltes explains how people with disabilities are subject to additional surveillance.[47] Saltes employs the concept "disability surveillance" to encapsulate the data collection, documenting and monitoring of impairment, which Saltes argues is used as a form of social sorting.[48] Disability surveillance is often carried out in a way that excludes people with disabilities for the purpose

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39 See e.g. David Pfeiffer, "Eugenics and Disability Discrimination" (1994) 9:4 Disability & Society 481.

40 Colette Leung, "Profile: The Living Archives Project: Canadian Disability and Eugenics" (2012) 1:1 Can J Disability Studies 143.

41 See Jana Grekul, Arvey Krahn & Dave Odynak, "Sterilizing the 'Feeble-minded': Eugenics in Alberta, Canada, 1929–1972" (2004) 17:4 J Historical Sociology 358 (e.g. in Alberta people were sterilized under the authority of the *Sexual Sterilization Act*).

42 Jerry Flores, "ICE detainees' alleged hysterectomies recall a long history of forced sterilizations" (28 September 2020), online: *The Conversation* <theconversation.com>.

43 Shakespeare, *supra* note 32 at 669.

44 Saltes, *supra* note 29 at 55; Gostin, *supra* note 25 at 112.

45 See e.g. Roger J R Levesque, "Regulating the Private Relations of Adults with Mental Disabilities: Old Laws, New Policies, Hollow Hopes" (1996) 14:1 Behav Sci & L 83.

46 *Ibid.*

47 Saltes, *supra* note 29.

48 *Ibid* at 70.

of limiting their access to resources and/or citizenship.[49] When disability surveillance is carried out in this way, it is because disability is being defined in terms of a functional limitation and people with disabilities are seen as those with non-normative, or 'abnormal' bodies. 'Abnormal' is associated with posing a "danger, threat and risk to the health of the population and to economic stability and progress."[50]

The proliferation of genetic testing and the collection of genetic information exacerbates concerns for people with disabilities because of its potential for privacy infringement, use for surveillance, and the potential for discrimination on the basis of genetics. In particular, a number of scholars have raised concerns about the the potential for discrimination on the basis of genetic information in employment and insurance contexts.[51] Since health care in Canada is publicly-funded, it is anticipated that this discrimination will occur in regards to disability and life insurance.[52] There are also concerns for genetic discrimination in the education, adoption, and immigration contexts.[53]

D) Genetic Anti-Discrimination Laws Around the World

In response to concerns about genetic discrimination, a number of countries, including Australia, France and the United States, have passed laws to address these potentialities. Many of these laws rely on the social model of disability. The United Nations also passed resolutions controlling the use of human genetics such as the *Universal Declaration on the Human Genome and Human Rights*, 1997.[54]

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49 *Ibid* at 56.

50 *Ibid* at 64.

51 Gostin, *supra* note 25; Mark A Rothstein, "GINA, the ADA, and Genetic Discrimination in Employment" (2008) 36:4 JL Med & Ethics 837; Marvin R Natowicz, Joseph K Alper & Joseph S Alper, "Genetic discrimination and the law" (1992) 50:3 American J Human Genetics 465; Jill Gaulding, "Race, Sex, and Genetic Discrimination in Insurance: What's Fair?" (1995) 80:6 Cornell L Rev 1646; Kathy L Hudson et al, "Genetic Discrimination and Health Insurance: An Urgent Need for Reform" (1995) 270:5235 Science 391.

52 Yann Joly & Bartha Maria Knoppers, "Physicians, genetics and life insurance" (2004) 170:9 CMAJ 1421 [Joly & Knoppers]; Trudo Lemmens, "Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?" (2000) 45:2 McGill LJ 347 [Lemmens *Selective Justice*].

53 Lemmens *Selective Justice*, *supra* note 52; Lemmens *Revisiting Genetic Discrimination*, *supra* note 8.

54 *Universal Declaration on the Human Genome and Human Rights* (Geneva: United Nations Educational, Scientific and Cultural Organization, 1997).

Most countries have taken one of two approaches to dealing with concerns around genetic discrimination. The first approach involves adding prohibitions against genetic discrimination to human rights legislation and/or creating specific legal rules for insurance providers and employers.[55] For instance, the United Sates adopted the *Genetic Information Non-Discrimination Act of 2008* ("GINA").[56] GINA deals with genetic testing in the context of health insurance and employment.[57] Through amending other pieces of federal legislation it prohibits a group health plan from denying coverage or adjusting a person's premiums on the basis of genetic predisposition. It allows individuals to make complaints against employers when they experience discrimination that adversely affects their status or deprives them of employment opportunities.

The second approach that countries have taken is to adopt privacy legislation that specifically deals with the collection and use of genetic data.[58] The United Kingdom's approach, although non-legislative, falls within this second category of approaches. In the UK, employers and insurance providers have to abide by the *Data Protection Act 1998*[59] in the way that they deal with genetic information. Much like Canada's privacy laws, this Act has rules surrounding the use of personal information. In 2001, the insurance industry in the UK voluntarily implemented a restrictive agreement: the *Code on Genetic Testing and Insurance*.[60] Insurers agreed that customers would not be asked to undergo a predictive genetic test to obtain insurance or to disclose their own genetic test results or those of another person, like a close relative.[61]

E) *Canada's Genetic Non-Discrimination Act, 2017*

Canada's GNDA began as Bill S-201, which was a Senate Public Bill introduced by Senator James S. Cowan in December 2015. The Act falls most closely into that first category of approaches taken by countries to deal

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55 Julian Walker, "Genetic Discrimination and Canadian Law" (2014) 90:E Library Parliament Background Papers, online (pdf): <lop.parl.ca> [Walker].

56 Pub L No 110-233, 122 Stat 881 (2008) [*GINA*].

57 GINA does not cover life insurance, disability insurance, or long-term care insurance.

58 See e.g. Germany's *Human Genetic Examination Act, Gesetz über genetische Untersuchungen bei Menschen Gendiagnostikgesetz,* GenDG 379/09. For an explanation of how the Act functions see Sirpa Soini, "Genetic testing legislation in Western Europe—a fluctuating regulatory target" (2012) 3:2 J Community Genetics 143.

59 *Data Protection Act 1998* (UK), c 29.

60 UK, HM Government, *Code on Genetic Testing and Insurance* (October 2018) online (pdf): <www.abi.org.uk/globalassets/files/publications/public/genetics/code-on-genetic-testing-and-insurance_embargoed.pdf>.

61 There are some exceptions such as for life insurance policies over £500,000.

with genetic discrimination. Its stated objective is to prohibit and prevent genetic discrimination. It includes a number of offences.[62] Section 3(1) of the Act makes it a criminal offence for anyone to require an individual to undergo a genetic test in order to provide them goods and services, enter into or continue a contract with someone, or offer or continue specific terms or conditions in a contract.[63] Per section 3(2), a person also cannot refuse to engage in service provisions or contractual agreements because an individual has refused to undergo genetic testing. Service providers or contractual parties described in section 3(1) cannot require that someone disclose the results of a genetic test already taken, or refuse to engage in these activities until the test results are shared. There is also a requirement to have a person's written consent to collect, use, or disclose their genetic results. Penalties for contravention on an indictable offence could be a fine not exceeding $1 million, or imprisonment for up to five years, or both. If there is a conviction on a summary offence, penalties could be a fine not exceeding $300,000, or imprisonment for up to 12 months, or both.[64] It is important to note that there is an exemption in the Act: section 6 makes it clear that the offences do not apply when people are providing medical or pharmaceutical care, or conducting medical or scientific research.[65]

Bill S-201 also amended the CLC and CHRA. The CLC applies largely to employment issues among industries within federal jurisdiction. Bill S-201 added two new sections (247.98 and 247.99) which form their own subdivision in the CLC. Section 247.98 protects employees from having to undergo a genetic test or disclose the results of a test they have already taken.[66] Employers cannot take actions like dismiss or refuse to pay an employee because of the results of an employee's test, or because an employee refuses to take a genetic test.[67] No other person is allowed to disclose to an employer that an employee has taken a genetic test, or the results of that test.[68] Section 247.99 sets out provisions for enforcement of these protections. If someone makes a complaint, it is sent to an inspector designated by the Minister of Labour. The inspector tries to help parties settle the dispute, and if this fails then the Minister may appoint an adjudicator who can take steps such as to reinstate the employee or vary the result.[69]

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62 These are included in the Act, rather than being introduced as amendments to an existing law, like the *Criminal Code,* RSC 1985, c C-46.

63 *GNDA*, *supra* note 1.

64 *Ibid*, s 7.

65 *Ibid*, s 6.

66 *CLC*, *supra* note 5 at ss 247.98(2), (3).

67 *Ibid*, s 247.98(4).

68 *Ibid*, ss 247.98(5), (6).

69 *Ibid*, ss 247.99(4), (5).

The CHRA applies to federally-regulated activities such as federal government departments and agencies, Crown corporations, and federally-regulated businesses, such as banks or telecomunnication companies. Canadian provinces and territories have human rights legislation dealing with matters within their own jurisdiction.[70] Section 3(1) of the CHRA sets out prohibited grounds of discrimination that include race, national or ethnic origin, religion, age, sex, sexual orientation, and disability, among others. The Act sets out, in sections 5 through 14.1, different discriminatory practices like denying access to goods and services,[71] or refusing to employ or continue to employ someone[72] on the basis of prohibited grounds. Bill S-201 amended the CHRA to include "genetic characteristics" in the purpose section of the Act[73] and as a listed prohibited ground.[74] When it was introduced, the Bill included a definition of discrimination on the ground of genetic characteristics.[75] This definition was not ultimately included, so the Canadian Courts and Canada Human Rights Tribunal will have to interpret it.[76]

F) The Quebec Government's Challenge of the GNDA

The Quebec government has challenged whether the GNDA is *ultra vires* of the Parliament of Canada's jurisdiction over criminal law. The Government of Quebec referred the question to the Quebec Court of Appeal, where a five-judge panel found that the purpose of sections 1 through 7 of the Act is not to prohibit genetic discrimination. Rather, the Act's purpose is to encourage access to genetic tests for medical purposes by helping to alleviate people's fear that this information could lead to discrimination against them, particularly in employment and insurance contexts.[77] This is not a criminal law objective, which would fall under federal jurisdiction, as there is no real evil here. Fostering and promoting health cannot constitute a primary criminal law object.[78] These have to do with the regulation of contracts and the provision of goods and services—

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70 These laws have been considered to have quasi-constitutional status, and so the rights they contain have greater protection. See e.g. *Zurich Insurance Co v Ontario (Human Rights Commission)*, [1992] 2 SCR 321, 93 DLR (4th) 346.

71 *CHRA*, *supra* note 6 at s 5.

72 *Ibid*, s 8.

73 *Ibid*, s 2.

74 *Ibid*, s 3(3).

75 Bill S-201, *An Act to prohibit and prevent genetic discrimination*, 1st Sess, 42nd Parl, 2015 (as passed by the Senate 08 December 2015) [Bill S-201] (the definition set out that this was discrimination based on the results of a genetic test, refusing to take a genetic test, or refusal to disclose or authorize disclosure of the results).

76 Walker, *supra* note 55.

77 *Quebec Reference*, *supra* note 3 at para 11.

78 *Ibid* at para 21.

an area of provincial jurisdiction.[79] There was no issue taken with sections 8 through 10 of the Act which amended the CHRA and CLC. The Court of Appeal found that the prohibition of discrimination based on genetic characteristics only actually appears in sections 9 and 10 which amend the CHRA.[80] An intervener, the Canadian Coalition for Genetic Fairness, filed an appeal to the Supreme Court of Canada, which was heard in the fall of 2019.[81] If the Supreme Court of Canada comes to a similar decision to the Quebec Court of Appeal, then the Act will be invalidated.[82]

3. Criticisms of the Act

In the years leading up to the passing of the GNDA, there was much debate about what steps should be taken, if any, to prevent genetic discrimination in Canada.[83] Possible policy options were explored by a large number of research groups, governmental departments and agencies, advisory bodies and task forces.[84] During the time that policy options were being debated, there were questions around whether genetic discrimination was just a rhetorical concern, or whether there was any evidence of its occurrence. Another question had to do with whether the human rights laws and policy that existed at the time were already equipped to deal with genetic discrimination In other words, did we even need legislation specifically dedicated to genetic discrimination, or were people already protected under existing legislation? For instance, genetic information could be associated with a number of existing prohibited grounds of discrimination in provincial human rights legislation and the CHRA. As outlined above, the CHRA already set out (in sections 5–14.1) different discriminatory practices barred on the basis of enumerated grounds, like

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79 *Constitution Act, 1867* (UK), 30 & 31 Vict, c 3, ss 92(13), (16), reprinted in RSC 1985 Appendix II, No 5.

80 *Quebec Reference*, *supra* note 3 at para 20.

81 Mathieu Gagné et al, "Québec Court of Appeal Strikes Down Federal Genetic Non-Discrimination Act" (24 January 2019), online: *Fasken* <www.fasken.com>; Julia Kalinina, "QCCA Says Prohibitions on Genetic Discrimination Are Not Valid Use of Federal Criminal Law Power" (21 January 2019), online: *theCourt.ca* <www.thecourt.ca>.

82 Yann Joly, Gratien Dalpé & Miriam Pinkesz, "Is Genetic Discrimination Back on the Radar? A Commentary on the Recent Court of Appeal Reference Decision on the Genetic Non- Discrimination Act (GNDA)" (2019) 2:2 Can J Bioethics 94 at 95.

83 See e.g. Lemmens, *Revisiting Genetic Discrimination*, *supra* note 8 who explored three possible options for addressing genetic discrimination. These include: (1) strengthening existing human rights and privacy regimes, (2) a new regulatory framework for genetic-testing, and (3) sector-specific solutions for insurance.

84 These include: the Canadian Genome Analysis and Technology Program, a federal inter-departmental initiative on genetic information and privacy by the Department of Justice in 2001–2002, and a Provincial Advisory Committee on New Predictive Genetic Technologies. See Lemmens, *Revisiting Genetic Discrimination*, *supra* note 8 at 2 for a comprehensive list.

denying access to goods or services, or refusing to employ or continue to employ someone. The CLC also protects employees from unfair treatment like unjust dismissal,[85] so refusing to take a genetic test, to disclose results from a test, or having test results that show a genetic disease would all be prohibited reasons to dismiss an employee. These questions have persisted since the GNDA came into force. The validity of these arguments are the focus of this next section.

A) The GNDA, as well as Changes to the CLC and CHRA are Not Unnecessary

In this section I argue that genetic discrimination is occurring. I highlight examples from existing research, anecdotal reports on genetic discrimination, as well as a number of lawsuits being brought on the basis of genetic discrimination.

i) Studies and Anecdotal Experiences of Genetic Discrimination

Most of the research on genetic discrimination has taken place in the United States, although a small number of studies have extended to Canada and Australia.[86] Data for these studies was collected through a questionnaire, or through a questionnaire with a follow-up phone interview. The research indicates a few key findings. Firstly, there is clear support of systemic genetic discrimination among people at risk for Huntington's Disease ("HD"), hemochromatosis, phenylketonuria ("PKU"), and mucopolysaccharidoses ("MPS"), and those with the gene mutation for these diseases.[87] This discrimination happened irrespective of whether people had symptoms or not.

Second, people at risk of these diseases alleged discrimination largely by health and life insurance companies.[88] Erwin et al., who looked at Americans, Canadians and Australians, found that individuals at risk for

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85 *CLC*, *supra* note 5 at s 240.

86 See e.g. Erwin et al, *supra* note 25 (collected data from individuals in the United States, Canada and Australia who were at risk for Huntington's Disease).

87 Geller et al, *supra* note 24; Alper et al, *supra* note 19. Hemochromatosis is a disease where too much iron builds up in the body, which can eventually cause organ failure. Phenylketonuria is a metabolism error that can lead to issues including seizures, behavioural problems, mental disorders, etc. Mucopolysaccharidoses are a group of metabolic diseases that can result in a wide range of symptoms including skeletal irregularities, enlarged organs, hernias, etc: see *Merriam-Webster Medical Dictionary*, sub verbo "hemochromatosis", "phenylketonuria", "mucopolysaccharidoses", online: <www.merriam-webster.com/medical> [Merriam-Webster].

88 Geller et al, *supra* note 24; Alper et al, *supra* note 19.

HD reported discrimination with insurance to be the most significant. Significance here was not based on statistical significance, but rather on how meaningful the event was to the person within the context of their life.[89] Alper et al. found that individuals with hemochromatosis reported having faced problems with life insurance companies refusing to insure them, and with being rejected from individual health insurance.[90]

Third, there were also reports of discrimination among people at risk for HD, hemochromatosis, PKU, and MPS that involved employers,[91] adoption services,[92] and blood banks.[93] For the most part, reports of discrimination in employment were relatively low. Geller et al. and Erin et al. found that in the employment context, people were not hired or fired, denied a promotion, covertly watched, or badly treated by coworkers (without repercussions to the coworkers) because they were at-risk for genetic conditions.[94] Individuals with the HD mutation and those who were at risk but had not been tested, experienced discrimination in family and social settings,[95] and a small number experienced discrimination in health care, with housing, and in the legal system.[96] Looking specifically at people at risk for HD, Yvonne Bombard et al. found that more people were discriminated against in these various contexts because of family history of HD than because of genetic testing.[97]

Fourth, a number of studies found that people at risk of a genetic disease spend a lot of time worrying about discrimination. Notably, Erwin and colleagues found that people at risk for HD worry more about the possibility of discrimination than it actually happens.[98] For instance, they found that 70% of participants worried about discrimination in insurance, whereas only 25.9% of participants actually reported having experienced discrimination by insurance. Forty-four percent of participants had worried about employment discrimination, but only 6.5% had experienced it.[99] Geller et al. found that people at risk to develop a genetic condition

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89 Erwin et al, *supra* note 25 at 1087.

90 Alper et al, *supra* note 19.

91 Geller et al, *supra* note 24; Alper et al, *supra* note 19.

92 Geller et al, *supra* note 24.

93 *Ibid*.

94 Geller et al, *supra* note 24; Erwin et al, *supra* note 25.

95 Erwin et al, *supra* note 25; Yvonne Bombard et al, "Perceptions of genetic discrimination among people at risk for Huntington's disease: a cross sectional survey" (2009) 338:b2175 Brit Med J, online (pdf): <www.bmj.com/content/bmj/338/bmj.b2175.full.pdf> [Bombard et al].

96 Erwin et al, *supra* note 25.

97 Bombard et al, *supra* note 95.

98 Erwin et al, *supra* note 25.

99 *Ibid* at 1088–89.

were scared to change their job out of fear that they would not be able to get health insurance in their new position.[100] Another study looked at genetic testing and discrimination among women who had the BRCA1/2 mutation.[101] These women rated fear of life insurance discrimination as a moderately or very important factor in their decision to undergo genetic testing. For those who were nervous about it, it made them less likely to undergo genetic testing.[102] Fatima Syed reports on an anecdotal story shared by a doctor of a patient at the University of Montreal's Research Centre. That patient wanted to have her breasts and ovaries removed to prevent any chance of cancer but refused to be genetically tested for cancer because she thought it could harm her children in future.[103] Her doctor had seen insurance companies deny protection to patients based on their own genetic results, or the genetic results of their family members.

It is important to keep in mind when assessing this research that most confirmed cases of genetic discrimination have been on a small group of disorders—in particular HD, hemochromatosis, PKU, and MPS. There is a growing body of studies on people with the BRCA1/2 genes that confirm discrimination. The reason that there may not be more confirmation of genetic discrimination in other populations could be because, whereas the genetic basis for HD has been known for a while, researchers have only begun to develop knowledge about the genetic basis of many other diseases in the last decade. Many of these studies are based in the United States, so the findings about health care insurance, especially, are less applicable given that the Canadian provinces provide healthcare. People are also self-reporting what they perceived to be instances of discrimination, so it is possible that some of these examples were not in fact discrimination based on genetics. However, many of these studies are also very large (reports from hundreds of people) so even if there is less discrimination occurring than reported, it is still a large amount, and at a systemic level.

ii) Case Law on Genetic Discrimination

Another indicator of the occurrence of genetic discrimination is the amount of case law on the issue. A United States news article, for instance, that made its way across the Internet a few years ago, described a Connecticut woman (Pamela Fink) who alleged that her employer

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100 Geller et al, *supra* note 24 at 77.

101 Katrina Armstrong et al, "Life insurance and breast cancer risk assessment: adverse selection, genetic testing decisions, and discrimination" (2003) 120A:3 American J Medical Genetics Part A 359 [Armstrong] (the BRCA mutations increase the chances of ovarian and breast cancer). See Merriam-Webster, *supra* note 87.

102 Armstrong, *supra* note 101.

103 Fatima Syed, "Should Insurers Have Access To Your Genetic Test Results?" (01 November 2016), online: *The Walrus* <thewalrus.ca> [Syed].

wrongfully fired her after learning that she carried the BRCA2 genetic mutation.[104] If a settlement was not negotiated, Fink planned to pursue the claim in court.[105]

To find out whether genetic discrimination is appearing in the case law in Canada, I conducted an in-depth search for all court and tribunal cases in Canada through QuickLaw, CanLII and through the websites of individual tribunals (like the Canada Human Rights Tribunal website). I firstly looked at whether any cases had been brought under the GNDA, by using the search term "genetic non-discrimination act." The only cases that cited the Act were the Quebec Reference, and a criminal case: *D'Amico c R.*[106] A sample of D'Amico's DNA was taken in the course of an investigation into the sexual assault and murder of a sex worker. Although the DNA evidence showed that D'Amico was not a suspect for this crime, the DNA sample raised the police's suspicions that he was involved with a number of unresolved sexual assault cases. The police then followed D'Amico with the goal of retrieving "abandoned" DNA and succeeded.[107] The case looked at whether the state can trick their criminal suspects into giving up DNA, keep the samples and use them at their leisure. The Court referenced the GNDA in the context of discussing the complex "scientific, moral, ethical and legal issues" surrounding the handling of another person's DNA.[108] This case highlights reasons why the protection of genetic data is important.

The second search phrase that I used was "genetic discrimination." Lilith Finkler, Roxanne Mykitiuk, Jennifer Nisker and Mark Pioro conducted a similar search of Canadian legal databases in 2010.[109] For this reason, I focused largely on cases after 2010. In their search for legal cases in 2010, their original search term was also genetic discrimination. It yielded them no results which prompted them to change the focus of their research. Of the approximately 220 cases that I found with these search terms, I focused on instances of people bringing discrimination claims and the discrimination being linked (although sometimes very loosely) to a genetic predisposition. Among the cases that came up with these search words were tort and worker's compensation cases. In these cases, genetics came up in the context of employers arguing that a plaintiff's

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104 MacKenna Roberts, "US woman accuses employer of genetic discrimination after breast cancer test" (04 May 2010), online: *BioNews* <www.bionews.org.uk>.

105 *Ibid.*

106 *D'Amico c R*, 2019 QCCA 77 [*D'Amico*].

107 *Ibid.*

108 *Ibid* at para 356.

109 Lilith Finkler et al, "Understanding the use of 'Genetic Predisposition' in Canadian Legal Decisions" (2014) 10:09 Osgoode Legal Studies Research Paper Series Working Paper No 37, online: <digitalcommons.osgoode.yorku.ca> [Finkler et al].

work-related injuries were caused by pre-existing genetic conditions, rather than work conditions. People having their workers' compensation reduced because of a genetic characteristic could certainly be considered discrimination. However, I chose not to examine this here because the way that genetic disease is being looked at in the context of causation for workers' compensation and torts law is explored in-depth by Lilith Finkler and colleagues.[110] I was left with five cases on employment, to which I add one pre-2010 case ("*Boisbriand*") that was discovered by Finkler and colleagues through academic references.[111] I found two cases on alleged discrimination by a school board,[112] and one on alleged discrimination by a hospital.[113] All of these cases, except one arbitration case,[114] had been decided prior the GNDA coming into force.

This small number of cases might indicate that people are not bringing their cases of genetic discrimination through legal avenues. It could also be an indicator that there is not a lot of genetic discrimination occurring in Canada. In terms of the GNDA, the fact that only *D'Amico* and the Quebec reference relied on the Act, might have to do with the fact that the Act has only been in force for two years now. Given how long it can take for a case to come to trial, and for a judgment to be rendered, it could be that judgments have not had the time to be released. This is less applicable to arbitration cases which I explored as well. The lack of cases relying on the Act could also point to its possible redundancy—perhaps people do not realize that this is a form of discrimination, are calling genetic discrimination by another name, or are using other tools to deal with instances of genetic discrimination. That is what I turn to next.

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110 *Ibid* at 32–53.

111 *Toronto District School Board v Ontario Secondary School Teachers' Federation, District 12*, 2011 CarswellOnt 10662 (WL Can), [2011] OLAA No 461 [*Toronto District School Board* cited to WL Can]; *Dotchin v Simply Computing and another (No 2)*, 2013 BCHRT 189 [*Simply Computing*]; *Northern Interior Woodworkers' Assn obo Souter v Pacific Island Resources*, 2011 BCHRT 294 [*Northern Interior Woodworker's*]; *Farlow v Hospital for Sick Children*, 2009 HRTO 739 [*Farlow*]; *Quebec (Commission des droits de la personne et des droits de la jeunesse) v Montréal (City of), Quebec (Commission des droits de la personne et des droits de la jeunesse) v Boisbriand (City of)*, 2000 SCC 27 [*Boisbriand*]; *Canada Bread Co v Bakery, Confectionery, Tobacco Workers, and Grain Millers International Union, Local 468*, 2011 CarswellBC 3831(WL Can), [2011] BCCAAA No 154 [*Canada Bread Company* cited to WL Can]; *Waterloo (Regional Municipality of) (Sunnyside Home) v Ontario Nurses' Assn (D.S. Grievance)*, 2019 CarswellOnt 443 (WL Can), [2019] OLAA No 16 [*Ontario Nurses' Association* cited to WL Can].

112 *Saskatchewan Human Rights Commission v Prince Albert Roman Catholic School Division No 6*, 2008 SKQB 227 [*Prince Albert Roman Catholic School*]; *MR v Halton District School Board*, 2012 HRTO 1290 [*Halton*].

113 *Farlow*, *supra* note 111.

114 *Ontario Nurses' Association*, *supra* note 111.

B) The GNDA and Changes to the CLC and CHRA are Somewhat Redundant

The second critique of the GNDA is that the GNDA and the changes to the CHRA and CLC are redundant. In reviewing the relevant nine cases, four findings emerged. The first two findings suggest that the GNDA and the changes to the CHRA and CLC might be redundant. However, the second two findings reveal the growing importance of the GNDA and the amendments to the CHRA and CLC. The findings are as follows: firstly, complainants are successfully bringing claims of discrimination that could be based on genetics under the already protected ground of disability. Secondly, in human rights legislation the definition of disability and handicap includes "perceived disabilities." This strengthens the potential of bringing claims of genetic discrimination under the ground of disability. Thirdly, complainants are emphasizing the genetic basis of diseases and disabilities using existing avenues. However, as people begin to think more about disease and disability, in terms of their underlying genetic causes, it might become more important that genetic discrimination be a protected ground. Fourthly, one case indicated that concerns over the sharing of private genetic information might be warranted. The GNDA explicitly deals with the sharing of people's private genetic information without their consent.

It is important to point out that none of the nine cases are federal. The GNDA itself is a criminal piece of legislation and so applies in all circumstances. As described previously in this paper, the CHRA applies to federally-regulated activities and the CLC applies to employment issues among industries within federal jurisdiction. Therefore, even if the amendments to the CHRA and CLC had been in place at the time that these cases were decided, these pieces of legislation would not have been applicable. However, looking at these cases as examples of the ways that genetic discrimination might arise is still helpful for thinking about how useful the changes to the CLC and CHRA could be in the context of federal claims. This is particularly so because the amendments to the CLC and CHRA (through sections 8 and 9 of the GNDA) were not among those sections of the GNDA that were contested for being *ultra vires.* Given that provincial legislatures, like Ontario, might make similar changes to their respective human rights and labour laws, it is also helpful to look at the tools that people are using in provincial genetic discrimination claims to think about how and whether changes similar to those by the GNDA would be useful.

i) Genetic Discrimination is Dealt with as Discrimination on the Basis of Disability

In all of the cases and tribunal decisions that referenced genetics and discrimination, the plaintiffs had brought their claims as discrimination on the basis of disability. Some of these plaintiffs saw their disease or condition as just that: a disability that also happened to have a genetic basis. The genetic component of the disease or condition was secondary. Since the alleged perpetrators were not basing their discrimination on knowledge about the claimant's genetics (which is how genetic discrimination is defined), but on their symptoms, this category was appropriate. In *Toronto District School Board v Ontario Secondary School Teachers' Federation District 12*,[115] a case of arbitration in Ontario, Ms. P, a secondary school teacher, argued that the Toronto School Board had failed to adequately accommodate her. Ms. P had been diagnosed in 2001 with Multiple Chemical Sensitivity ("MCS") which causes a person to experience symptoms when they encounter certain smells like perfumes. Ms. P and the school board had developed a plan to accommodate the diagnosis. The plan dealt with the products that would be used to clean the school, and procedures that would be put in place to ensure that staff and students did not wear fragrances, etc.[116] The plan, however, ended up being more difficult to put in place than was expected and the accommodations were not effective. In the evidence provided, Ms. P's expert, Dr. Bested, stressed that recent research had suggested that six genes influence people's susceptibility to MCS,[117] thus, MCS could actually be based on genetic characteristics.

In a case heard by the British Columbia Human Rights Tribunal, *Northern Interior Woodworkers' Association v Pacific Island Resources,*[118] the Northern Interior Woodworkers' Association brought a claim on behalf of Mr. Souter—a mill worker. They alleged that Pacific Island Resources had discriminated against Mr. Souter on the basis of physical and mental disability, contrary to section 13 of the BC *Human Rights Code.*[119] Section 13 protects individuals from discrimination based on enumerated characteristics in hiring, firing and terms of employment.[120] Mr. Souter had taken time off from work because he could not stand for long periods of time because he had osteoarthritis in one knee and was obese; he also suffered from depression. Eventually, after not working for two years,

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115 *Toronto District School Board*, *supra* note 111.

116 *Ibid* at para 5.

117 *Ibid* at para 160.

118 *Northern Interior Woodworkers*, *supra* note 111.

119 *Human Rights Code Regulation*, BC Reg 373/96.

120 *Ibid*, s 13.

Pacific Island Resources told Mr. Souter that it seemed like he would not be able to return to work and so they were terminating his employment. Mr. Souter based his claim on disability. However, a medical doctor, Mr. Zetner, testified to the fact that there is a genetic predisposition to obesity. Again, if the employer had known Mr. Souter's genetic information, then this could have been genetic discrimination. Since the discrimination was based on his symptoms, it was brought on the grounds of disability.

Other plaintiffs knew they had special genetic characteristics that had or would lead to a condition or disease, and the alleged perpetrator knew this as well. For these plaintiffs, a "genetic characteristics" ground of discrimination, like that added to the CHRA, might have been more appropriate. These plaintiffs, however, were still able to bring their claim on the ground of disability. In another BC case, *Dotchin v Simply Computing and another*,[121] Timothy Dotchin brought a complaint under section 13 of the BC *Human Rights Code* against Simply Computing, his former place of employment, and against his former supervisor Kyle Bennett. Mr. Dotchin had a genetic disease, for which common side effects included depression and anxiety.[122] Eventually Mr. Dotchin's health began to deteriorate and he had trouble meeting his sales targets. He told his supervisor, Kyle Bennett, in confidence that he had a genetic disease.[123] Despite promising that he would keep this information confidential, Mr. Bennett reported it to Simply Computing's CEO.[124] Simply Computing's CEO then became involved in Mr. Dotchin's employment issues.[125] The CEO arranged for Mr. Dotchin to work as a sub-contractor, so that he could keep his own hours.[126] Eventually he was terminated.[127] The BC Human Rights Tribunal found that it would have been undue hardship for Simply Computing to continue to pay Dotchin for work he could not complete. This is a case where the plaintiff, Dotchin, knew that he had genetic characteristics that could lead to certain symptoms, and perceived the discrimination as being based on those characteristics. However, he was able to bring the claim under the existing recognized ground of disability.

In *Saskatchewan Human Rights Commission v Prince Albert Roman Catholic School,* the Saskatchewan Human Rights Commission brought an application on behalf of Travis Mahussier who has Williams Syndrome—a

121 *Simply Computing*, *supra* note 111.
122 *Ibid* at para 4.
123 *Ibid* at para 9.
124 *Ibid* at para 10.
125 *Ibid.*
126 *Ibid* at para 13.
127 *Ibid* at para 17.

genetic disorder that affects cognitive development.[128] Travis had been suspended from school for using profane language. The school knew that he had Williams Syndrome. His parents argued that the suspension was discriminatory as it was for behaviour related to his syndrome.[129] Although the Court did not find that there was discrimination, this was another example of a complainant bringing a claim for discrimination on the ground of disability. The discrimination, however, might have been based on genetics.[130] Barbara Farlow is another example of a parent bringing a claim that their child had been discriminated against. Barbara Farlow brought a claim to the Ontario Human Rights Tribunal that her daughter, who had been born with the genetic condition Trisomy 13,[131] had been denied life-saving treatments by the hospital because of the genetic condition, and that this had lead to her daughter's death.[132] Farlow alleged discrimination, on the basis of disability, because of the hospital's failure to provide services to her daughter.[133]

These cases illustrate that plaintiffs who know that their disability is based on genetic characteristics and who perceive the discrimination as being based on genetic characteristics first and foremost, are still able to ground the discrimination claim in disability. This perhaps suggests that "genetic characteristics" did not need to be added to the CHRA.

ii) Genetic Discrimination Could Be Argued as "Perceived Discrimination"

This argument that a claim on the basis of genetic discrimination can be brought under the ground of disability is further backed up by the fact that a very broad interpretation is given to disability and handicap in human rights legislation in Canada. This broad interpretation includes perceived disability, meaning that it includes situations where a plaintiff is discriminated against because the defendant believes the plaintiff has a disability, even though the plaintiff may not actually have a functional limitation.[134] Finkler and colleagues point out the case of *Boisbriand*: a Supreme Court of Canada case that looked at three different appeals together.[135] Two of these involved employers (City of Montréal and

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128 *Prince Albert Roman Catholic School*, *supra* note 112.

129 *Ibid* at para 7.

130 *Saskatchewan Human Rights Code*, SS 1979, c S-24.1, as repealed by *Saskatchewan Human Rights Code, 2018*, SS 2018, c S-24.2, s 59.

131 See Merriam-Webster, *supra* note 87 (trisomy 13 is a chromosome disorder that can cause severe intellectual disability, and many physical abnormalities).

132 *Farlow*, *supra* note 111.

133 *Ibid* at para 3.

134 *Boisbriand*, *supra* note 111 at para 49.

135 *Ibid*.

Communauté urbaine de Montréal) refusing to hire people (Mercier as a gardener-horticulturalist and Jean-Marc Hamon as a police officer) because both had anomalies on their spinal columns.[136] In the third case, Palmerino Troilo was dismissed from his position as a police officer for the municipality of Boisbriand because he had Crohn's disease.[137] All three people filed complaints with the Commission des droits de la personne et des droits de la jeunesse alleging discrimination on the basis of their handicaps.

The Supreme Court case does not discuss genetic discrimination specifically, however, the case is relevant to a discussion on genetic discrimination because two of the complainants (Mercier and Hamon) had no symptoms, and the third (Troilo) was capable of performing the work.[138] The City of Montréal did not want to hire Mercier because they were worried about how her spinal column anomaly might affect her work in the future. Communauté urbaine de Montréal was worried that Hamon might develop incapacitating back pain in the future. With Troilo, even though the medical reports said that Troilo would be able to perform the police work, the municipality of Broisband was concerned about future absences from work and so Troilo was dismissed. These three cases had to do with assumptions being made about these people's medical situations and mere possibilities about what this could mean in future. In the cases discussed in the last section, the complainants had already begun to experience symptoms (except Dotchin who had not at the time he was hired). Here, however, each of these people were currently asymptomatic. The discovery of the spinal anomalies, in particular, is much like finding out someone's genetic test results and being concerned about what this will mean in future. Discrimination on the basis of knowing someone's genetic information, and on the possible implications of those results, is the type of scenario that was envisioned when the GNDA was developed.

The *Boisbriand* case was dealt with under section 10 of the Quebec *Charter of Human Rights and Freedoms*[139] and section 15 of the *Canadian Charter of Rights and Freedoms.*[140] Justice Brossard of the Human Rights

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136 *Québec (Commission des droits de la personne) et Hamon v Montréal (Communauté urbaine)*, [1996] JTDPQ No 1, 1996 CanLII 11 (QC TDP); *Québec (Commission des droits de la personne) et Mercier v Montréal (Ville de)*, [1995] JTDPQ No 4, 1995 CanLII 13 (QC TDP).

137 *Québec (Commission des droits de la personne) et Troilo v Boisbriand (Ville de)*, [1995] JTDPQ No 5, CHRR D/412.

138 Finkler et al, *supra* note 109 at 10.

139 *Charter of human rights and freedoms*, CQLR c C-12 (the relevant sections were ss 10, 16, 20, 20.1, 49, 57, 71, 74, 78, 80, 84).

140 *Canadian Charter of Rights and Freedoms*, s 15, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c 11.

Tribunal had presided over the *Mercier* and *Troilo* cases and found that both Mercier and Troilo had been denied employment because of a subjective perception of their handicaps. Although a subjective handicap is included in the human rights legislation in other provinces, like Ontario and Nova Scotia, this concept is not included in Quebec legislation.[141] Mercier and Troilo had no remedy under section 10 of the Quebec *Charter*.[142] Madame Justice Rivet had presided over the *Hamon* case and had found that the assessment of a handicap could be subjective and so Hamon had been discriminated against on the basis of a handicap. Justice L'Heureux-Dubé, on behalf of the Supreme Court of Canada, said that given the quasi-constitutional nature of human rights legislation "handicap" needed to be interpreted in light of its context and objectives.[143] When you apply a liberal and purposive method of interpretation, along with a contextual approach, and consider the way that "handicap" has been interpreted elsewhere in Canada, this all supports a broad definition of the word handicap.[144] It recognizes the subjective component of discrimination on this ground and does not require the presence of functional limitations.[145] Further, the Quebec *Charter* also prohibits "discrimination based on the actual or perceived possibility that an individual may develop a handicap in the future."[146] This case has since been cited to emphasize that in human rights legislation, disability includes "perceived disability."[147] So, as Finkler et al. point out, this might mean that if someone refused to hire or insure someone based on a genetic predisposition (even if there were no symptoms), the person would be able to argue discrimination on the basis of perceived disability.[148] There has not yet been any case law to verify this, however, it points towards a finding that the GNDA and the changes to the CHRA and CLC might be somewhat redundant.

iii) Greater Emphasis is Being Placed on the Genetic Component of Disease and Disability

The third and fourth findings from reviewing the nine cases suggest that the GNDA, and the inclusion of "genetic characteristics" in the CHRA and CLC are not completely redundant, and are important. One of the reasons that the GNDA is important has to do with the emphasis that is now being placed on the genetic components of disease. As I noted, our understanding of disease is currently being re-conceptualized as we begin

141 *Boisbriand*, *supra* note 111 at para 12.
142 *Ibid* at para 13.
143 *Ibid* at paras 27, 71.
144 *Ibid* at para 71.
145 *Ibid*.
146 *Ibid* at para 81.
147 See e.g. *Toronto District School Board*, *supra* note 111.
148 Finkler et al, *supra* note 109 at 10.

to learn more about the genetic basis of diseases and conditions.[149] As a result, people are beginning to highlight the genetic characteristics that are connected with their various diseases and conditions. For example, experts were brought in to point out the genetic components of MCS on behalf of Ms. P in *Toronto District School Board*, and of obesity for Mr. Souter in *Northern Interior Woodworkers' Association.* Mr. Dotchin, in *Simply Computing*, also explicitly framed his depression and anxiety as a result of his genetic characteristics.

In *Canada Bread Company v Bakery*,[150] an arbitration case that took place in British Columbia, the grievor[151] had a full-time sanitation position at one of the Bread Company's locations. The grievor was dismissed after putting a note on the vehicle of a co-worker that contained a threat of physical violence against the co-worker. There had been other incidents in the past. The Union, representing the grievor, argued that the grievor had been discriminated against on the basis of disability. The grievor suffered from a number of mental health issues, such as depression and anxiety. As in *Simply Computing*, the grievor framed these mental health issues in terms of their genetic components.

In *Ontario Nurses' Association,*[152] an arbitration case, the Ontario Nurses' Association Union represented D.S.[153] D.S. had been terminated by her employer for misappropriating narcotics for her own use. She now wanted to return to work for the employer but the employer would not re-hire her.[154] The Union argued that this was discrimination on the basis of disability under section 5 of the *Ontario Human Rights Code* which says that "every person has a right to equal treatment with respect to employment without discrimination."[155] The Union argued that it was discrimination because D.S. had an addiction. In coming to the decision that discrimination had been established, the arbitrator, Larry Steinberg, cited the fact that addiction has a genetic component. Steinberg used this in order to support his finding that addiction is not just a bad habit as D.S.'s employer suggested, and that D.S. was entitled to human rights protection.[156]

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149 Alper et al, *supra* note 19.

150 *Canada Bread Company*, *supra* note 111.

151 He is not identified by name because of personal privacy reasons.

152 *Ontario Nurses' Association*, *supra* note 111.

153 Again, D.S.'s full name was not given for personal privacy reasons.

154 *Ontario Nurses' Association*, *supra* note 111 at para 4.

155 *Human Rights Code*, RSO 1990, c H.19, s 5 [*ON Human Rights Code*]. The case also referenced ss 11, 17. See *Ontario Nurses' Association*, *supra* note 111 at para 99.

156 *Ontario Nurses' Association*, *supra* note 111 at paras 129, 135, 137–38; *ON Human Rights Code*, *supra* note 155.

In another Ontario case, M.R., by his next friend C.R.,[157] brought an application to the Human Rights Tribunal of Ontario alleging discrimination in the provision of goods and services on the basis of disability.[158] M.R.'s school had identified him as having a developmental disability and had put him in a special education class. Because of this, he argued that he was denied the appropriate placement at his local high school. M.R. argued that there needs to be an MRI diagnosis or genetic testing to determine that a student actually has a learning disability.[159] The adjudicator did not deal with this argument from M.R. on the basis that it had already been dealt with by the Special Education Tribunal to which this application had been originally deferred. However, this is yet another example of someone defining a condition, in this case a learning disability, based on its underlying genetic factors.

People highlighting the genetic component of their conditions, and even using the fact that a condition has a genetic basis to try to legitimize their claim that they experienced discrimination, illustrates a shift whereby people are beginning to place more emphasis on genetic characteristics. As we begin to learn more about the genetic components of diseases and conditions, what people might have once perceived of as discrimination based on disability might start to be considered discrimination based on genetic characteristics. Additionally, people whose conditions appear to flow from individual choice (like D.S. in *Ontario Nurses' Association*) have often, problematically, been treated as less deserving of human rights protection, even when the condition is protected under human rights law.[160] This is often the case with addiction, even though addiction is a recognized disability.[161] These individuals might receive better protection by virtue of being able to illustrate the genetic component to their condition. On the flip side, where no genetic component to a condition is uncovered, it could exacerbate the belief that these are entirely individual choices and impair the court from being able to objectively assess the discrimination claim.

The more that we know about the role of genetics in certain diseases and conditions, the more possibility there will be for people to discriminate against others based solely on this information, if they have access it. For instance, people may be more likely to discriminate against someone on

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157 A "next friend" represents someone who has a disability and who also does not have a legal guardian.

158 *ON Human Rights Code*, *supra* note 155 at s 34; *Halton*, *supra* note 112.

159 *Halton*, *supra* note 112 at para 20.

160 See e.g. *Stewart v Elk Valley Coal Corp*, 2017 SCC 30 at para 58.

161 *Ibid*. In his dissent, Justice Gascon observes that even though addiction is a recognized disability, stigmas around drug dependence impair the court's ability to assess the merits of a discrimination claim.

the basis of being able to see from their genetic information that they have a greater propensity for substance use. This supports the importance of the GNDA and its amendments to the CHRA and CLC.

iv) There is a Risk of Inappropriate Sharing of Private Genetic Information

Finally, a concern that motivated the enactment of the GNDA was over the inappropriate sharing of people's genetic test results. Section 5 of the GNDA sets out that it is prohibited for anyone providing goods or services to an individual, entering into or continuing a contract with an individual, or offering or continuing specific terms in a contract with an individual, to collect, use or disclose the results of an individual's genetic test without that individual's written consent.[162] In the employment context, the new section 247.98(5) and (6) of the CLC say that no other person is allowed to disclose to an employer that an employee has taken a genetic test, or disclose the results of that test.[163]

As recounted earlier, in *Simply Computing,* Mr. Bennett had shared Mr. Dotchin's private information about having a genetic disease with the CEO of Simply Computing.[164] Mr. Bennett sharing this confidential information is not dealt with directly by the BC Human Rights Tribunal. In this case, the CEO, having obtained this information, tried to better accommodate Mr. Dotchin in the workplace, and Justice Catherine McCreary of the Human Rights Tribunal found that there was no discrimination. However, this situation could have gone in the opposite direction. Section 5 of the GNDA makes it clear that even collecting a person's genetic information is prohibited. If this had been a federally-regulated business, the new amendments to the CLC would have given Mr. Dotchin a specific route under which he could have filed a complaint.

C) A Final Assessment: Even if not the GNDA, Laws with Provisions Dedicated to Preventing Genetic Discrimination Are Important

What an examination of these cases illustrates is that part of the reason that it might have been so difficult to find cases on genetic discrimination in Canada is that there is a lot of overlap between discrimination on the grounds of disability and genetic discrimination. People are bringing claims of discrimination on the basis of disability where there might also have been genetic discrimination. However, if they or the person who

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162 *GNDA*, *supra* note 1 at s 5.

163 *CLC*, *supra* note 5 at ss 247.98(5), (6).

164 *Simply Computing*, *supra* note 111 at para 10.

discriminated against them did not know about the genetic basis for the condition, *and* are discriminating based on the condition or its symptoms, then this makes disability an appropriate category under which to bring these claims. The GNDA seems to have been developed with the intention of prohibiting and preventing genetic discrimination where the discrimination is based on knowing a person's genetic information, even when the person has no symptoms. The fact that disability is interpreted to include "perceived" disability, means that disability remains an appropriate ground under which to bring these claims even where there are no symptoms and the discrimination is made only based on knowledge of genetic information.

If you apply this train of thought to the federal context, this may imply that the GNDA and amendments to the CLC and CHRA are redundant. However, the case law also reveals that as we find out more about genetics people may be re-conceptualizing diseases and conditions on the basis of their genetics. As more is discovered about the connection between diseases and genetics, it seems that genetic characteristics might become a more fitting category under which to bring a claim of discrimination. For example, it might once have made sense to bring a claim of discrimination on the basis of obesity under the category of disability. As we find out more about the genetic characteristics of obesity, someone might feel that in actuality they are being discriminated against on the basis of genetic characteristics that contribute to making them pre-disposed to obesity. This would require that the person who is being discriminatory is aware that the individual they are discriminating against has these genetic characteristics. It also oversimplifies the relationship of correlation and causation of genetic underpinnings to diseases and conditions. It is often multiple genes and lifestyle and environmental factors that contribute to a disease or condition. Although there are some exceptions, like HD, a disease or condition cannot usually be pinned on one genetic characteristic.[165] This might be why there is more evidence of genetic discrimination for those at risk of HD.[166] However, this does not mean that this type of thinking about genetics and discrimination will not occur.

Another example that the case law illustrated was that of Dotchin's co-worker sharing Dotchin's personal genetic information. Having laws that ensure the privacy of people's genetic information is all the more important given the fact that people with disabilities have historically faced systemic discrimination where they have had their privacy invaded and been subjected to additional, often state, surveillance.[167] Privacy laws

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165 Syed, *supra* note 103; Joly, *supra* note 2.

166 Joly & Knoppers, *supra* note 52.

167 Saltes, *supra* note 29 at 70.

in Canada, such as the *Personal Information Protection and Electronic Documents Act* ("PIPEDA")[168] prevent the collection, use and disclosure of certain types of personal information, including health information, by businesses in the private sector and federally-regulated businesses (like banks, airlines). The *Privacy Act*[169] deals with the personal information of federal employees. A number of provinces have also passed legislation considered substantially similar to PIPEDA.[170] Some provinces have passed health-related privacy laws—like the Personal Health Information Protection Act ("PHIPA") in Ontario—that are considered substantially similar to PIPEDA when it comes to health information.[171] However, if this had happened in a federal employment context, the changes to the CLC would have given Dotchin an explicit basis under which to file a complaint.

There is also a symbolic nature to the GNDA and the amendments to the CLC and CHRA. The fact that genetic discrimination is now explicitly set out in the CLC and CHRA, and the GNDA is a piece of criminal legislation that explicitly sets out what is prohibited sends a strong message that this kind of behavior is unacceptable. The GNDA also recognizes that disability is the disadvantage that is caused when social organizations mistreat people because of an impairment. In so doing, it emphasizes the importance of the social model of disability and may also make room for the voices of the people discriminated against.

Additionally, the research on genetic discrimination illustrates that a large number of people fear genetic discrimination.[172] Bombard et al. found that before the GNDA came into force, Canadians were declining genetic testing even when the results would guide their best-practice treatment because their genetic information was not protected by legislation.[173] Some of the research illustrated that people at-risk for

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168 SC 2000, c 5 [*PIPEDA*].

169 RSC 1985, c P-21.

170 Alberta's *Personal Information Protection Act*, SA 2003, c P-6.5; BC's *Personal Information Protection Act Regulations,* BC Reg 473/2003; Québec's *Act respecting the protection of personal information in the private sector,* CQLR c P-39.1. The Alberta Human Rights Commission, for instance, says that an employer can only request informationthat is relevant to the employee's job duties. See "Obtaining and responding to medical information in the workplace" (December 2013), online: *Alberta Human Rights Commission* <www.albertahumanrights.ab.ca/publications/bulletins_sheets_booklets/bulletins/Pages/obtaining_med_info_in_workplace.aspx>.

171 See e.g. Ontario's *Personal Health Information Protection Act*, SO 2004, c 3, Schedule A; New Brunswick's *Personal Health Information Privacy and Access Act*, SNB 2009, c P-705.

172 Erwin et al, *supra* note 25; Syed, *supra* note 103; Armstrong, *supra* note 101.

173 Bombard, Cohn & Scherer, *supra* note 16.

genetic conditions worry more about the possibility of discrimination than it actually happens.[174] Thus, if the existence of the Act helps suppress people's concerns, then this makes the Act important.

Finally, a problem with discrimination is that it is often dealt with after the discrimination has occurred, and there are not enough efforts to prevent it from happening. These symbolic factors of the GNDA and its significant penalties for breach, along with the more concrete amendments to the CLC and CHRA, might act to prevent and deter genetic discrimination, at least on the federal level.

4. Conclusion and Recommendations

Whether or not the GNDA is declared *ultra vires* by the Supreme Court of Canada, an assessment of the GNDA is useful in its revelation that laws with provisions dedicated to preventing genetic discrimination are important. There is evidence with HD, PKU, MDS, hemochromatosis, and the BRCA1/2 gene to suggest that genetic discrimination is a real concern, particularly with regard to employment and insurance. An assessment of the GNDA provides valuable insight into what *intra vires* and desirable legislation to deter genetic discrimination might look like. It also provides an indication of what steps the provinces and territories might want to take to prevent genetic discrimination.

In terms of federal legislation, the most important step would be to ensure that the changes to the CHRA and CLC remain in place. Since sections 8 and 9 of the GNDA—the sections of the Act that amend the CHRA and CLC—are not among the sections being challenged for their constitutional validity, this should not be a problem.[175]

The inclusion of "genetics characteristics" in the purpose section of the CHRA, and as an enumerated ground in human rights legislation is also important. Advances in genetic testing technologies have been rapid, and the law often does not keep pace with these scientific advancements. As we learn more about genetics, there may be a continuance of the shift whereby society begins to think of conditions more often in terms of their genetic components. These types of changes in the ways that people think about disability and genetics, paired with the possibility that peoples' genetic information might continue to become more easily available, could mean that people think of these forms of discrimination as being based on genetic characteristics, rather than disability. This legislation can provide some more specific protections in that eventuality. Inclusion of genetics in

174 See e.g. Erwin et al, *supra* note 25.

175 *Quebec Reference*, supra note 3 at para 1.

the CHRA is also important because it helps to serve a symbolic purpose by specifically highlighting the unacceptability of discrimination on the basis of a person's genetic information.

Additionally, the changes to the CLC help protect an employee's privacy when it comes to their genetic information. It protects them from having to undergo a test or disclose the results of a test they have taken.[176] It also prevents any other person from disclosing to an employer than an employee has taken a genetic test, or the results of that test.[177] The CLC also gives individuals a route by which they can make a complaint if they are dismissed, suspended, laid off, or demoted because they refused to undergo a genetic test, disclose the results of a genetic test, or because of the results of their genetic test.[178]

Since the CHRA applies to federally-regulated activities, and the CLC applies to employment issues among industries within federal jurisdiction, provincial and territorial governments might consider making similar changes to their human rights and labour laws. This would be valuable because it would shift legal intervention in the provinces to the social model of disability. By design, this gives focus to people with disabilities to explain how, or if, an impairment exists, and it gives a more robust picture of disability, which ultimately enriches the adversarial system.

In sum, even if the GNDA is declared *ultra vires* so soon after coming into force, it has highlighted the need for law to get ahead of fast-paced scientific research and medical developments in the realm of genetic testing, and the quickly growing accessibility of genetic testing and genetic information. It serves as a lesson on how to make it known that genetic discrimination is intolerable, and on how to provide those who experience this form of discrimination with different remedies.

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176 *CLC*, *supra* note 5 at ss 247.98(2), (3).

177 *Ibid*, ss 247.98(5), (6).

178 *Ibid*, s 247.99(1).