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Call for Action: Provinces and Territories Must Protect our Genetic Information

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Call for Action: Provinces and Territories Must Protect our Genetic Information

The Genetic Non-Discrimination Act (GNDA)*, passed by Parliament in 2017, seeks to protect Canadians' genetic information. The* GNDA *establishes certain criminal prohibitions to the use of genetic information and also amends federal employment and human rights legislation to protect against genetic discrimination. However, we argue that the* GNDA *alone is insufficient to protect Canadians given constitutional limitations on the powers of the federal government. Areas of profound importance relating to genetic discrimination are governed by the provinces and territories. We identify three key areas of provincial/territorial jurisdiction relevant to protection against genetic discrimination and outline the applicable legislative environments. We identify problems with the status quo and set out the gaps and limitations of relying solely on the* GNDA*. We conclude that provinces and territories need to amend their human rights, employment, and insurance legislation to ensure comprehensive protection of Canadians' genetic information.*

La Loi sur la non-discrimination génétique (la Loi)*, adoptée par le Parlement en 2017, vise à protéger les informations génétiques des Canadiens.* La Loi *établit certaines règles pénales interdisant l'utilisation des informations génétiques et modifie également d'autres lois fédérales en matière d'emploi et de droits de la personne afin de protéger contre la discrimination génétique. Cependant, nous soutenons que* la Loi *seule est insuffisante pour protéger les Canadiens étant donné les limitations constitutionnelles des pouvoirs du gouvernement fédéral. Des domaines d'une grande importance relatifs à la discrimination génétique sont régis par les provinces et les territoires. Nous identifions trois domaines clés de compétence provinciale/territoriale pertinents pour la protection contre la discrimination génétique et décrivons les environnements législatifs applicables. Nous identifions les problèmes liés au statu quo et exposons les lacunes et les limites du recours à* la *seule* Loi *sur la non-discrimination génétique. Nous concluons que les provinces et les territoires doivent modifier leurs lois relatives aux droits de la personne, à l'emploi et aux assurances afin d'assurer une protection complète des renseignements génétiques des Canadiens.*

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I. *Introduction*

Canadians have long been concerned about protecting our genetic information.[1] Parliament aimed to provide such protection by enacting the *Genetic Non-Discrimination Act* (*GNDA*)[2] in 2017. The *GNDA* establishes certain criminal prohibitions to the use of genetic information and also amends the *Canada Labour Code* and the *Canadian Human Rights Act* (*CHRA*) to protect against genetic discrimination. In July 2020, the Supreme Court of Canada reviewed the constitutionality of the criminal prohibitions in the *GNDA* and found them to be a valid use of the federal

1. Biotechnology Assistant Deputy Minister Coordinating Committee, *Public Opinion Research Into Genetic Privacy Issues,* by Pollara Research and Earnscliffe Research and Communications, (Final Report) (Ottawa: BACC, March 2003) at 9, online: <www.poltext.org/> [perma.cc/C2KJ-L2VZ].
2. *Genetic Non-Discrimination Act*, SC 2017, c 3 [*GNDA*].

criminal law power.[3] The Supreme Court's pronouncement provides a high level of certainty that the protections against genetic discrimination granted by the *GNDA* are secure.[4] However, the *GNDA* alone does not comprehensively protect Canadians' genetic information. Areas of profound importance relating to genetic discrimination are governed by provincial and territorial laws and remain unprotected.

The federal government has taken the lead, but there are gaps and limitations; provinces and territories need to enact legislation to ensure that our genetic information is protected. The *GNDA* prohibits compulsory genetic testing and non-voluntary use of genetic test results, but it does not address genetic information obtained through other means. The amendments to the *Canada Labour Code* and the *CHRA* fill this gap but only apply to the federally regulated sector. Provincial and territorial employment and human rights laws do not include similar protections.

With the vast majority of Canadians' work and personal lives being subject to provincial and territorial laws, this means most Canadians are not comprehensively protected against genetic discrimination, and furthermore do not have access to the redress mechanisms available through those laws. Reliance on statutory interpretation of provincial and territorial laws to argue that genetic information "could" be captured by those existing laws is unacceptable. With the passing of the *GNDA*, Canadians have a clear statement of their rights in regard to genetic discrimination in the federal sphere; we deserve the same clarity regarding rights in the provincial and territorial spheres.

Each of these problems with the *status quo* demands a response: the provinces and territories should amend their human rights, employment and insurance legislation. The amendments to human rights and employment laws should mirror the federal laws. The amendments to insurance legislation should be crafted to ensure clarity and consistency with the prohibitions under the *GNDA*. We argue in this paper that this multi-faceted approach is necessary to ensure that all Canadians receive

3. The Supreme Court of Canada's finding arose out of a reference question brought by the Quebec government, supported by several provinces, questioning the constitutionality of the criminal prohibitions in the *GNDA*. The Quebec Court of Appeal found the legislation was not constitutional, but the Supreme Court of Canada overturned this finding. These decisions are discussed later in the paper *infra* section 1.C. *Renvoi relative 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; *Reference re Genetic Non-Discrimination Act*, 2020 SCC 17 [*Re GNDA*].

4. Reference opinions are not legally binding; however, they have that practical effect. We are not aware of any instances where a court has not followed a reference opinion. See Peter W Hogg, *Constitutional Law in Canada* (Toronto: Thomson Reuters Canada, 2009) at 8.6(d).

the broad protection against genetic discrimination that the *GNDA* and its amendments to federal human rights and employment laws initiated.

In this paper, we review the nature of genetic information and the need for its legal protection. We outline the features of the *GNDA* and the subsequent Supreme Court of Canada decision that found the criminal prohibitions under it to be constitutional. We discuss the three areas of provincial and territorial jurisdiction that are relevant to protecting against genetic discrimination: human rights, employment, and insurance. This lays the foundation for why we think there are problems with the *status quo*, which we alluded to above. We end the paper with recommendations for provincial and territorial legislatures to amend key statutes to ensure comprehensive protection against genetic discrimination for all Canadians.

1. *Overview*

a. *Nature of genetic information*

Genetic information can be conceived in a basic sense as "information about heritable characteristics."[5] Some genetic information is readily discernible, such as hair or eye colour, but much is locked away in our DNA. In recent years, this information can be accessed using genetic testing. There are tens of thousands of genetic tests currently available, rendering science increasingly able to reveal highly significant details about individuals, and to anticipate our medical futures.[6]

Genetic test results can be diagnostic or predictive. In some situations, a genetic test result is clear and highly robust, such as single-gene testing to confirm or rule out a diagnosis when symptoms indicate a specific disease, as is possible in relation to Huntington's disease. However, most tests are merely predictive; the presence of a particular genetic marker will not always result in the disease manifesting.

There has been much debate as to whether genetic information should be treated differently from other forms of information, or whether it is fundamentally health information like any other. Insurers, as well as some academics, have resisted the idea of "genetic exceptionalism."[7] Some

5. *International Declaration on Human Genetic Data*, Records of the General Conference, 32nd Sess, UNESCO, 32 C/Resolutions (2003) 39, art 2(i) at 40 [*Declaration on Genetic Data*].

6. Bill S-201, *An Act to prohibit and prevent genetic discrimination*, 2nd reading, *Senate Debates,* 42-1, vol 150, No 8 (27 January 2016) at the Honourable James S Cowan's comments, online: <sencanada.ca> [perma.cc/7L59-6FCV] [*Bill S-201 Senate Debate*]; National Centre for Biotechnology Information, "GTR: Genetic Testing Registry" (last visited 13 August 2020), online: <www.ncbi.nlm.nih.gov/gtr/> [perma.cc/2HM3-M88E].

7. See e.g. Mark A Rothstein, "Genetic Exceptionalism and Legislative Pragmatism" (2007) 35:2 JL Med & Ethics 59; William Baines, "Genetic Exceptionalism" (2010) 28:3 Nature Biotechnology 212, DOI: <10.1038/nbt0310-212b>.

have argued that a genetic exceptionalism approach—i.e. viewing genetic information as unique and worthy of special protection—is artificial.[8] It has also been argued that insurers are able to, and should, use family medical history to differentiate the "healthy" from the "unhealthy," and that genetic information at its core is medical history.[9] Further, if insurers are unable to utilize genetic information, healthy members of the population end up paying too high a premium to support those with genetic disorders.[10]

On the other hand, there has been much concern that genetic information is highly sensitive, can be used in damaging ways, is not truly capable of anonymization, and should be considered *sui generis* or unique. Individuals may use the results of genetic tests in order to guide medical care and lifestyle choices, but the results may also be used to guide business decisions, most notably in the field of insurance contracts. Further, such information, if not suitably protected, can be used to discriminate against that individual in the course of employment and in the provision of goods or services.[11] A Canadian poll conducted in 2009 found that approximately 51% of those polled were concerned about genetic privacy.[12]

Genetic information about an individual is automatically about their biological family relations as well,[13] so the privacy issues are not confined to the individual who undergoes a genetic test. Furthermore, it is argued that no genetic information can truly be anonymized, as there is always a means to trace back to the individual (and hence their biological relatives).[14] These were some of the concerns driving the development

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8. See e.g. Ine Van Hoyweghen & Klasien Horstman, "European Practices of Genetic Information and Insurance: Lessons for the Genetic Information Nondiscrimination Act" (2008) 300:3 JAMA 326 at 326, DOI: <10.1001/jama.2008.62>; Michael J Green & Jeffrey R Botkin, "'Genetic Exceptionalism' in Medicine': Clarifying the Difference between Genetic and Nongenetic Tests" (2003) 138:7 Annals Internal Medicine at 573.

9. P J Malpas, "Is Genetic Information Relevantly Different From Other Kinds of Non-Genetic Information in the Life Insurance Context?" (2008) 34:7 J Medical Ethics 548 at 549-550, DOI: <10.1136/jme.2007.023101>.

10. Senate, Standing Committee on Human Rights, *Evidence* 41-1, No 2 (17 February 2016) at Jacques Boudrea's comments, online: <sencanada.ca/en/Content/SEN/Committee/421/ridr/02ev-52370-e> [perma.cc/6RJK-YTJB] [*Senate Committee on Human Rights*].

11. *Bill S-201 Senate Debate*, *supra* note 6 at the Honourable James S Cowan's comments.

12. Office of the Privacy Commissioner of Canada, *Canadians and Privacy —Final Report (March 2009)* by Ekos Research Associates Inc, (Report), (Ottawa: Office of the Privacy Commissioner of Canada Communications, 2009) at 22, online (pdf): <www.priv.gc.ca/media/2974/ekos_2009_01_e.pdf> [perma.cc/SG23-8UG9]; A poll conducted in 2003 found 47% were similarly concerned: Biotechnology Assistant Deputy Minister Coordinating Committee, *Public Opinion Research Into Genetic Privacy Issues,* by Pollara Research and Earnscliffe Research and Communications, (Final Report) (Ottawa: BACC, March 2003) at 9, online (pdf): <www.poltext.org> [perma.cc/WU47-W4EH].

13. *Declaration on Genetic Data*, *supra* note 5, art 4(a)(ii) at 40.

14. Henry T Greenly, "The Uneasy Ethical and Legal Underpinnings of Large-Scale Genomic Biobanks" (2007) 8 Annual Rev Genomics & Human Genetics at 352.

of the *GNDA* and are ongoing concerns within provincial and territorial jurisdictions.

b. *History of the* Genetic Non-Discrimination Act (GNDA)

The *GNDA* was designed to resolve multiple problems. First, Canada was a signatory to both the *Universal Declaration on the Human Genome and Human Rights*[15] and the *International Declaration on Human Genetic Data*[16] which prohibit genetic discrimination, but had not yet lived up to its commitments.

Second, Canada was lagging behind most Commonwealth and Western European nations by not having prohibitions against genetic discrimination.[17] For example, the United States has had protection since it passed the *Genetic Information Nondiscrimination Act of 2008*[18]; Australia has had legislation which protects genetic information since 1992[19]; and, since at least as far back as 2005, the United Kingdom has had a voluntary code of practice agreement with the Association of British Insurers on the use of predictive genetic testing information by insurers.[20]

Third, the Canadian Life and Health Insurance Association[21] took the view that life and health insurers should not request that genetic tests be undertaken, but that they could inquire as to whether a person had undergone genetic testing and, if so, could require that the results be divulged.[22] There was substantial concern that permitting insurers to access applicants' genetic information would result in a genetic underclass of individuals who would be uninsurable.[23] Many feared that "Canadians

15. UNESCO, *Universal Declaration on the Human Genome and Human Rights*, 29th Session, 29 C/Resolutions + CORR (1997).
16. *Declaration on Genetic Data*, *supra* note 5.
17. *Senate Committee on Human Rights*, *supra* note 9 at The Honourable James S Cowan's comments; Dale Smith, "Genetic privacy legislation goes to the SCC," *Canadian Bar Association National Magazine* (4 Oct 2019), online: <www.nationalmagazine.ca> [perma.cc/K7K8-LMXF].
18. *Genetic Information Nondiscrimination Act*, Pub L No 110–233, 122 Stat 881 (2008).
19. *Disability Discrimination Act 1992* (Cth), 1992/135.
20. Susan Mayor, "UK insurers postpone using predictive genetic testing until 2011" (2005) 330:7492 BMJ 617; the code was recently replaced by Association of British Insurers, "Code on Genetic Testing and Insurance" (2018), online (pdf): <www.abi.org.uk> [perma.cc/2TV3-T6ZK].
21. The Canadian Life and Health Insurance Association represents approximately 99% of Canadian life and health insurers despite membership being voluntary: "About CLHIA" (last visited 2 September 2020), online: *Canadian Life and Health Insurance Association* <www.clhia.ca> [perma.cc/B2A8-KN8T].
22. Library of Parliament, *Genetic Discrimination and Canadian Law,* by Julian Walker, Parliamentary Reports: Background Paper No 2014-90-E (Ottawa: Library of Parliament, 16 September 2014) at 9.
23. Trudo Lemmens, "Genetics and Insurance Discrimination: Comparative Legislative, Regulatory and Policy Developments and Canadian Options" (2003) 41 Health Law Journal at 53; Ine Van Joyweghen, "Taming the Wild Life of Genes by Law? Genes Reconfiguring Solidarity in Private Insurance" (2010) 29:4 New Genet & Society 431, DOI: <10.1080/14636778.2010.528190>.

who seek this medical treatment [would] become a vulnerable subset of the Canadian population"[24] as genetic testing was becoming both more common and more accurate.

Fourth, many Canadians were becoming reluctant to get genetic testing done for fear of becoming uninsurable. A case study from Quebec illustrates the point. Researchers questioned 36 women, none of whom had ever been diagnosed with breast cancer, on their perception of how insurers used genetic information.[25] 63% of the women responded they would be reluctant to undergo cancer testing if they knew that the results would be accessible to insurers.[26] In the same study, 78% assumed that test results would negatively impact their insurability, and 80% thought insurers would have an interest in genetic information for insurability determination.[27] Overall, the women indicated they would be reluctant to undergo genetic testing for fear of genetic discrimination by insurers. Since testing is generally more effective the earlier it is done, any delay could have serious ramifications for an individual's ongoing health and treatment outcome.

Between 2010 and 2017, multiple attempts were made at both the House of Commons and the Senate to prohibit genetic discrimination in Canada. Prior to the introduction of the Bill which ultimately became the *GNDA*, six private members' bills had been introduced.

Senator James Cowan introduced the two most significant bills, both numbered S-201. Bill S-201 (2013) was stand-alone legislation which prohibited contracts from requiring genetic testing or results as terms of the agreement. It included criminal sanctions, but it also contained a significant compromise with the insurance industry. High-value insurance contracts (over $1,000,000 value or $75,000 per annum) would have been exempt from the criminal sanctions.[28] It was these two elements—the criminal sanctions and the concession to the insurance industry—that

24. *Reference re Genetic Non-Discrimination Act*, 2020 SCC 17 (Factum of an Intervener: Canadian College of Medical Geneticists at para 4), online (pdf): <www.scc-csc.ca> [perma.cc/QVG7-B3ZZ]..
25. Gratien Dalpé et al, "Breast Cancer Risk Estimation and Personal Insurance: A Qualitative Study Presenting Perspectives from Canadian Patients and Decision Makers" (2017) 8 Frontiers in Genetics 128, DOI: <10.3389/fgene.2017.00128> (we acknowledge that the sample size is small).
26. *Ibid* at Table 2.
27. *Ibid* at Tables 3, 4.
28. *Bill S-201 An Act to prohibit and prevent genetic discrimination*, 2nd Session, 41st Parliament, 2013, section 6, online: <https://parl.ca/Content/Bills/412/Private/S-201/S-201_1/S-201_1.pdf>.

would be the source of particular debate at the Standing Senate Committee on Human Rights.[29] Ultimately, this bill died on the order paper.[30]

Senator Cowan introduced a new stand-alone Bill in 2015, this time with success in both the Senate and House of Commons. Bill S-201(2015) removed the exceptions for insurers but retained the criminal sanctions. Praised by many as being long-overdue[31], the *Genetic Non-Discrimination Act* protects Canadians against genetic discrimination in contracts, including in insurance and employment.

2. *Elements of the* GNDA

The *GNDA* has three elements: (1) criminal prohibitions to the use of genetic information in contracts; (2) amendments to the *Canada Labour Code*; and (3) amendments to the *Canadian Human Rights Act.*

a. *Criminal law prohibitions*

Sections 3-7 of the *GNDA* make it a criminal offence to require that a person undergo a genetic test, or to disclose the results of a previously-conducted genetic test, in order to obtain goods or services or to enter into or continue a contract.[32] There are exceptions permitted which make these requirements acceptable, including the written consent of the individual, the provision of health care services, and participation in research.[33] There is no definition of genetic information within the *GNDA.* However, a genetic test is defined in section 2 as "a test that analyzes DNA, RNA or chromosomes for purposes such as the prediction of disease or vertical transmission risks, or monitoring, diagnosis or prognosis".[34] This definition includes both predictive and diagnostic genetic testing but does not offer protection for other forms of genetic information including family history, medical test results such as biopsy or metabolic testing, genetic counselling, and genetic education.

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29. Senate, Proceedings of the Standing Senate Committee on Human Rights, *Evidence*, Issue 15 (19 February 2015), online: <sencanada.ca/en/Content/SEN/Committee/412/ridr/15ev-51922-e> [perma.cc/LET3-DMEZ].
30. Following examination by the Standing Senate Committee on Human Rights, Bill S-201(2013) was referred back to the Senate. However, the 41st Parliament dissolved before the Bill went to third reading. Library of Parliament, *Legislative Summary: Bill S-201: An Act to prohibit and prevent genetic discrimination,* by Julian Walker, Parliamentary Reports: No. 42-1-S201-E (Ottawa: Library of Parliament, 2016) at 3.
31. Nicole Ireland, "Genetic discrimination law urgently needed, experts say," *CBC News* (30 January 2016), online: <www.cbc.ca/news> [perma.cc/M8V6-M53R]; Yvonne Bombard, Bev Heim-Myers, "The Genetic Non-Discrimination Act: critical for promoting health and science in Canada" (2018) 190:19 CMAJ E579.
32. *GNDA*, *supra* note 2, ss 3-7.
33. *Ibid*, ss 5, 6.
34. *Ibid*, s 2.

The sanctions for violation are extensive, including a fine of up to $1,000,000 and/or up to five years' imprisonment.[35] Given that a violation constitutes a criminal offence, the Crown and not the individual complainant decides whether or not to bring charges and how the case is to proceed (i.e. by way of indictment or summary conviction, etc.).

b. *Amendments to the* Canada Labour Code

The *GNDA* supplemented federal employment law by amending the *Canada Labour Code*.[36] The *Canada Labour Code* sets out the rights and responsibilities of employees and employers in federally-regulated workplaces (i.e. employment standards) and it sets out the rights and responsibilities that govern relations between unions and federally-regulated employers (i.e. labour relations). The amendments to the *GNDA* fall under the employment standards portion of the Code. They prohibit federally-regulated employers from taking disciplinary action against an employee for refusing to submit to genetic testing or disclosing previous test results, and prevents employers from taking action based on an employee's refusal to test or to provide previously undertaken test results.[37] These amendments also prohibit third party disclosure of test results or an employer receiving test results without the employee's permission.[38]

c. *Amendments to the* Canadian Human Rights Act

The *GNDA* also amended the *CHRA* to prohibit genetic discrimination from occurring in federal departments, agencies, Crown corporations, and federally-regulated businesses. The amendments specify that "genetic characteristics" constitute a prohibited ground of discrimination,[39] and add section 3(3), which states: "Where the ground of discrimination is refusal of a request to undergo a genetic test or to disclose, or authorize the disclosure of, the results of a genetic test, the discrimination shall be deemed to be on the ground of genetic characteristics."

3. *Constitutionality of the* GNDA *criminal prohibitions*

The *GNDA* received Royal Assent in May 2017 but was almost immediately challenged in court. The following section summarizes the basics of the judicial history of this challenge. What is important for purposes of our

35. *Ibid*, s 7.
36. *GNDA*, *supra* note 2, s 9; *Canada Labour Code*, RSC, 1985, c L-2.
37. *Canada Labour Code*, *supra* note 35, ss 247.98(2-4); *Bill S-201 Senate Debate*, *supra* note 6 at The Honourable James S Cowan's comments.
38. *Canada Labour Code*, *supra* note 36, ss 247.98(5-6).
39. *Canadian Human Rights Act*, RSC 1985, c H-6, ss 2, 3(1) [*CHRA*]. The *Canadian Human Rights Benefit Regulations* permit discriminatory practices in relation to certain pension, benefit and insurance plans based on particular grounds, but genetics is not one of the grounds.

analysis is that the entirety of the *GNDA* has survived the challenge and been found by the Supreme Court of Canada to constitute valid federal legislation.[40] The federal legislative context is now stable and so any gaps that currently exist in the protections against genetic discrimination in Canada will remain unless the provincial and territorial legislative landscape changes.

a. Reference to Quebec Court of Appeal

Following rigorous debate, the *GNDA* received Royal Assent in May 2017; one month later, the Quebec government filed a reference asking the Quebec Court of Appeal whether or not sections 1 to 7 of the *GNDA* fell within the criminal law power of Parliament.[41] In December 2018, the Quebec Court of Appeal, in a unanimous five-member decision, found these sections to be *ultra vires* of the federal government.[42] The Court ruled that the purpose of sections 1 to 7 of the *GNDA* was primarily "to protect and to promote health by fostering the access by Canadians to genetic tests for medical purposes," which did not constitute in pith and substance a criminal law matter.[43] The *GNDA* modifications to the *CHRA* and the *Canada Labour Code* to include genetic discrimination were not challenged.[44]

The Canadian Coalition for Genetic Fairness, an intervener at the Quebec Court of Appeal reference, appealed the decision and was granted leave to appeal at the Supreme Court of Canada as an *amicus curiae.* The Attorney General of Canada, for possibly the first time in Canadian history,[45] joined with several provinces in arguing that sections 1 to 7 of the *GNDA* should be found to be ultra vires in attempting to rely on the federal criminal law power.[46] Therefore, the Canadian Coalition for Genetic Fairness was the sole appellant defending the legislation at the

40. For further analysis of the constitutional challenge and its aftermath, see Shannon Hale & Dwight Newman, "Constitutionalism and the Genetic Non-Discrimination Act Reference" (2020) 29:3 Const Forum Const 31.

41. *GNDA*, *supra* note 2, ss 1-7.

42. *Renvoi relative 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 at paras 24-25 [*Quebec Re GNDA*].

43. *Ibid* at paras 9-12, 21.

44. These amendments protect against genetic discrimination only in the federal sector and prevent only federally regulated employees from being required to undergo or reveal genetic testing to their employer: *GNDA*, *supra* note 2, ss 8-10 ; *CHRA*, *supra* note 39; *Canada Labour Code*, *supra* note 36.

45. According to Joseph Arvay, counsel for the Coalition of Genetic Fairness, this may be the first time in history the Attorney General contested the constitutionality of a piece of federal legislation. Dale Smith, "Genetic privacy legislation goes to the SCC," *CBA National Magazine* (4 Oct 2019), online: <www.nationalmagazine.ca/en-ca> [perma.cc/R6AX-7L5K].

46. British Columbia and Saskatchewan joined Quebec in making the constitutional challenge.

Supreme Court of Canada.[47] The Court completed hearings on October 10, 2019 and handed down its decision on July 10, 2020.[48]

b. *Decision at the Supreme Court of Canada*

The Court ruled in a five to four split decision[49] that sections 1 to 7 of the *GNDA* constituted a valid exercise of the criminal law power[50] and, therefore, Parliament had the authority to enact such legislation.[51] Justice Karakatsanis indicated that the rules were focussed on combatting genetic discrimination and protecting health, which aims were a valid exercise of the criminal law power (Justices Abella and Martin agreed).[52] In a concurring judgment, Justice Moldaver stated that Parliament was entitled to make these rules under the criminal law power because they were aimed at ensuring that individuals have control over their genetic information and thereby protecting health (Justice Côté agreed).[53]

Justice Kasirer in dissent found that the impugned sections of the *GNDA* fell within provincial jurisdiction (Chief Justice Wagner and Justices Brown and Rowe agreed).[54] Justice Kasirer stated that the aim of sections 1 to 7 is to promote health by regulating contracts along with the provision of goods and services, and that this is in pith and substance not a threat that should attract criminal sanctions.[55]

II. *Relevant provincial/territorial legislation*

Three areas of provincial and territorial jurisdiction are relevant to protecting against genetic discrimination: human rights, employment and insurance. The federal and provincial/territorial governments share jurisdiction over human rights and employment standards. The *CHRA* and the *Canada Labour Code* apply only to federally regulated activities and undertakings as set out in the *Constitution Act 1867*.[56] Federally regulated undertakings, such as banking, telecommunications, inter-provincial transportation, air transportation and the federal public service, account for approximately 6% of services, agencies and organizations subject to

47. *Re GNDA*, *supra* note 3.
48. *Ibid*.
49. Justice Karakatsanis' judgment was supported by Justices Abella and Martin, and Justice Moldaver delivered concurring reasons supported by Justice Côté. Justice Kasirer authored the dissent supported by Chief Justice Wagner and Justices Brown and Rowe. *Ibid*.
50. *Ibid* at paras 80-81 (Karakatsanis), 137 (Moldaver).
51. *Ibid* at paras 4 (Karakatsanis), 110-112 (Moldaver).
52. *Ibid* at paras 38-39.
53. *Ibid* at para 111.
54. *Ibid* at para 272.
55. *Ibid* at para 154.
56. *Constitution Act*, *1867* (UK), 30 & 31 Vict, c 3, s 91 reprinted in RSC 1985, Appendix II, No 5.

regulation.[57] This means a substantial majority of Canadians must rely on provincial and territorial employment and human rights legislation.[58] In addition, the provinces and territories have exclusive jurisdiction over the regulation of insurance.[59]

The Supreme Court of Canada has held that human rights codes have a quasi-constitutional character.[60] Therefore, when a human rights law conflicts with other legislation, the human rights law prevails unless specifically indicated in the relevant legislation. Most jurisdictions have codified this principle by including a statutory clause that explicitly states that their human rights legislation takes precedence over other provincial legislation.[61]

In this part of the paper, we outline provincial and territorial legislation related to human rights, employment, and insurance, none of which contains explicit protection against genetic discrimination. This discussion lays the foundation for the next part of the paper in which we outline problems with the *status quo*.

1. *Human rights*

Human rights legislation is broadly aimed at preventing and remedying discrimination; it is not aimed at punishing wrong-doers.[62] Each province

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57. Government of Canada, Canadian Centre for Occupational Health and Safety, "OH&S Legislation in Canada—Introduction," online: <www.ccohs.ca/oshanswers/legisl/intro.html> [perma.cc/QSL2-SY6Z].

58. The *Constitution Act*, *1867* assigns the provinces broad authority over property and civil rights and all matters of a purely local and private nature. These authorities grant jurisdiction over goods, services and employment, *supra* note 56.

59. Insurance regulation is not specified in the *Constitution Act*, *1867*, but since *Citizens' Insurance Co v Parsons* (1881), regulation of insurance contracts and companies has been considered to fall within section 92(13) of the *Constitution Act* as Property and Civil Rights under provincial power. 4 SCR 215, [1881] 7 AC 96 [*Parsons*].

60. See *British Columbia Human Rights Tribunal v Schrenk*, 2017 SCC 62 at para 85; *Ontario Human Rights Commission v Simpsons-Sears Ltd*, [1985] 2 SCR 536 at para 12, 52 OR (2d) 799; *McCormick v Fasken Martineau DuMoulin LLP,* 2014 SCC 39 at para 17; *Insurance Corp of British Columbia v Heerspink*, [1982] 2 SCR 145 at para 32, 137 DLR (3d) 219 [*Heerspink*]; *Zurich Insurance Co v Ontario (Human Rights Commission)*, [1992] 2 SCR 321 at para 18, 9 OR (3d) 224 [*Zurich*].

61. See *Human Rights Act*, 2010, SNL 2010, c. H-13.1, s 5 [*NLHRA*]; *Human Rights Code*, RSBC 1996, c 210, s 4 [*BCHRC*]. In Alberta, Ontario, Saskatchewan, Nunavut and Yukon, the human rights legislation states that it supersedes all other legislation unless the relevant legislation contains a clause explicitly exempting it: *Alberta Human Rights Act,* RSA 2000, cA-25.5, s 1(1) [*AHRA*]; *Human Rights Code*, RSO 1990, c H.19, s 47(2) [*OHRC*]; *Saskatchewan Human Rights Code*, 2018, SS 2018, c S-24.2, s 44 [*SHRC*]; *Human Rights Act,* SNu 2003, c 12, s 5 [*NuHRA*]; *Human Rights Act,* RSY 2002, c 116, s 39 [*YHRA*]. The quasi-constitutional nature of human rights legislation applies even in jurisdictions that do not explicitly so state (*Human Rights Act,* RSNS 1989, c 214 [*NSHRA*]; *Human Rights Act,* RSNB 2011, c 171; *Human Rights Act*, SNWT 2002, c 18 [*NWTHRA*]): see *Zurich* citing *Heerspink*, *supra* note 60 at para 58; ***Heerspink, supra note 60*** at 157-158.

62. *Canadian National Railway Co v Canada (Canada Human Rights Commission),* [1987] 1 SCR 1114 at para 27, 40 DLR (4th) 193.

and territory's human rights legislation is unique, but they all aim to protect citizens from certain types of discriminatory conduct and to promote respect for human rights. For the most part, the Acts address common grounds of discrimination and areas of application. The list of prohibited grounds commonly includes race, national or ethnic origin, colour, religion, age, sex, sexual orientation, gender identity or expression, marital status, family status, and disability.[63] As discussed earlier, the *CHRA* was amended by the *GNDA* to add the prohibited ground of genetic characteristics, and also to add a deeming provision for refusal to undergo genetic testing or disclose test results[64] however, it only applies to federally regulated employees. The ground of genetic characteristics does not exist in any current provincial or territorial human rights law.[65]

Human rights legislation also circumscribes the areas of activity protected by the law. In other words, the legislation does not apply in all aspects of one's life, but only in certain designated areas. Generally, the Acts apply to the broad areas of employment, accommodation, and goods and services offered to the public. Insurance generally falls within the areas of goods and services or employment, depending on the context.[66]

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63. Variations within the Acts may be more apparent than real because "the interpretation given to grounds listed in one Act may be broad enough to include the items in the more detailed lists contained in other Acts." For example, some jurisdictions list addiction as a ground, which has been interpreted to be included within the ground of "handicap." See Jennifer J Llewellyn & Gillian MacNeil, "A Primer on Human Rights Law" in Michael Hadskis, Leah Hutt & Mary McNally, eds, *Dental Law in Canada*, 3rd ed (Toronto: LexisNexis Canada Inc, 2019) at 106.

64. *CHRA*, *supra* note 38, ss 2, 3(1), 3(3).

65. Over the years, three Canadian jurisdictions (Ontario, Manitoba and the Northwest Territories) have proposed amendments to add genetic characteristics as a prohibited ground in their human rights legislation. To date none have passed. In 2018, Ontario introduced Bill 40, which passed second reading on October 18th, 2018 but has not progressed: Bill 40, *Human Rights Code Amendment Act (Genetic Characteristics)*, 1st Sess, 42nd Leg, Ontario, 2018, (Ordered referred to Standing Committee on 18 October 2018), online: <www.ola.org> [perma.cc/9VC6-AVNF]**.** In 2018, a private members' bill was introduced in Manitoba but died on the order paper: Bill 225, *Human Rights Code Amendment Act (Genetic Characteristics),* 3rd Sess, 41st Leg, Manitoba, 2018 (did not progress past first reading), online: <web2.gov.mb.ca/bills/41-3/b225e.php> [perma.cc/HM3W-VWAR]. A second Act by the same name, Bill 222, was introduced the following year but did not progress past first reading: Bill 222, *Human Rights Code Amendment Act (Genetic Characteristics),* 4th Sess, 41st Leg, Manitoba, 2019, online: <web2.gov.mb.ca/bills/41-4/b222e.php> [perma.cc/N5UW-HN9A]. The Northwest Territories introduced proposed amendments to its *Human Rights Act* which included genetic discrimination on October 31st, 2018. The Act was passed by the Legislative Assembly; however, the addition of "genetic characteristics" as a prohibited ground of discrimination was defeated following the Committee report and has not been reintroduced: Bill 30, *An Act to Amend the Human Rights Act,* 3rd Sess, 18th Leg, Northwest Territories, 2018, (passed 6 June 2019), online: <www.ntassembly.ca> [perma.cc/QQ89-TVM9].

66. Ontario Human Rights Commission, "Discussion Paper: Human Rights Issues in Insurance" (Toronto: Ministry of the Attorney General, 1999), online: <www.ohrc.on.ca/en/discussion-paper-human-rights-issues-insurance> [perma.cc/59GX-MK7P].

The human rights statutes tend not to define discrimination, but rather outline what is required for a finding of discrimination. In general terms, a discriminatory practice is deemed to exist wherein a benefit is withheld or a burden imposed based on personal characteristics that are set out as prohibited grounds in the legislation.[67] Discrimination will be found where the discriminatory practice cannot be justified.

The statutes specify that conduct that would otherwise be discriminatory may be defended if there is a *bona fide* justification for the practice, and if accommodating the needs of the person or class of persons would impose an undue hardship on the respondent. The Supreme Court of Canada has provided further guidance for satisfying the *bona fide* justification. The respondent must show three things: the standard was adopted for a purpose rationally connected to the function; the standard was adopted in an honest and good faith belief that it is necessary to achieve the purpose; and the standard is reasonably necessary to accomplish the purpose in that the respondent cannot accommodate the person without experiencing undue hardship.[68]

Several jurisdictions explicitly exempt certain types of insurance from the general right of an individual to contract/service without discrimination on certain grounds—usually age, sex and disability—if there is a *bona fide* and/or reasonable justification.[69] The Supreme Court of Canada has indicated that exceptions to human rights protections for insurance must be both explicit and interpreted narrowly.[70] Furthermore, for a plan to meet the *bona fide* and reasonable requirement, it needs to be a legitimate plan

67. See *Law Society of British Columbia v Andrews,* [1989] 1 SCR 143 at paras 37-38, 56 DLR (4th) 1.

68. *British Columbia (Public Service Employee Relations Commission) v BCGSEU,* [1999] 3 SCR 3 at para 54, 176 DLR (4th) 1 (*sub nom Re Meiorin*); *British Columbia (Superintendent of Motor Vehicles) v British Columbia (Council of Human Rights*), [1999] 3 SCR 868 at para 20, 181 DLR (4th) 385 (*sub nom Re Grismer Estate*).

69. Some jurisdictions require a "reasonable and *bona fide*" justification in their human rights legislation; others require one or the other. Ontario, British Columbia, Manitoba, and Saskatchewan, for example, all require discriminatory practices in insurance to be based on reasonable and *bona fide* grounds. *OHRC*, *supra* note 61, s 22; *BCHRC*, *supra* note 61, s 8(2); *SHRC*, *supra* note 61, s 15(3). Other jurisdictions, e.g. Nova Scotia and the Northwest Territories, allow insurers to differentiate where there is only a *bona fides* reason to do so. *NSHRA*, *supra* note 61, ss 6(g), 9; *NWTHRA*, *supra* note 61, s 7(2). Some jurisdictions require a reasonable justification for differentiation within insurance contracts, although legislation differs slightly in how they qualify "reasonable": Nunavut (reasonable in the circumstances and good faith); Alberta (reasonable and justifiable in the circumstances) and Yukon (reasonable cause). *NuHRA*, *supra* note 61, ss 12(3)(a-c); *AHRA*, *supra* note 61, s 11; *YHRA*, *supra* note 61, s 10(d). Newfoundland requires only a "good faith ground" for discriminatory practice. *NLHRA*, *supra* note 61, s 21(3). In Quebec, the practice must be "warranted" and "based on actuarial data". *Charter of Human Rights and Freedoms*, CQLR c C-12, s 20.1.

70. *Zurich*, *supra* note 60 at para 18.

adopted in good faith, and not aimed at defeating protected rights under human rights legislation.[71]

As discussed earlier, the purpose of human rights legislation is to prevent and remedy discrimination. Generally, human rights legislation grants broad and flexible remedial powers to help further that purpose. Monetary remedies may be ordered where there is a financial loss such as lost wages, expenses resulting from the discrimination, or lost opportunity.[72] Although human rights legislation is not meant to be punitive, it does sometimes allow for awards of money for pain and suffering when the discrimination was done wilfully or recklessly.[73] Non-monetary remedies can be tailored to meet the situation and to achieve the goal of providing redress for discrimination or preventing such action going forward; they can include an apology, reinstatement of a lost benefit/employment, a plan to address discriminatory practices, and the institution of a program to address systemic discrimination.[74]

Each jurisdiction has its own complaints process; however, there are a number of common features. A commission is created and mandated by the relevant government to educate the public with the goal of preventing discrimination, receiving and assessing complaints, and investigating complaints. If the commission believes the complaint has merit, it may refer the matter to mediation or conciliation. Some jurisdictions mandate settlement efforts.[75] A commission may decide that a human rights tribunal should consider the complaint and render a decision. A tribunal is a quasi-judicial administrative body and not a court, and therefore the proceedings

71. *Ibid* at para 24; *New Brunswick (Human Rights Commission) v Potash Corporation of Saskatchewan Inc*, 2008 SCC 45 at para 41.

72. *CHRA*, *supra* note 39 See e.g. Mark A Rothstein, "Genetic Exceptionalism and Legislative Pragmatism" (2007) 35:2 JL Med & Ethics 59; William Baines, "Genetic Exceptionalism" (2010) 28:3 Nature Biotechnology 212, s 53(2), DOI: <10.1038/nbt0310-212b>. Provincial Human Rights Acts also authorize tribunals and courts to award compensation. In Nova Scotia, for example, the *Human Rights Act* authorizes the board of inquiry order compensation to "rectify any injury caused to any person." *NSHRA*, *supra* note 61, s 34(8).

73. *CHRA*, *supra* note 39, ss 53(2)–(3). Provincial human rights codes also address the mental effects of discrimination. The Ontario *Human Rights Code* authorizes compensation for "compensation for injury to dignity, feelings and self-respect." Unlike the federal Act, it does not require wilful or reckless discrimination: *OHRC*, *supra* note 61, ss 45.2(1), 46.1 (1).

74. Systemic discrimination "results from the cumulative operations of systems and not from a single rule or regulation and can affect an entire class of individuals." Llewellyn & MacNeil, *supra* note 63 at 98-99. Systemic discrimination is addressed in the *CHRA* at ss 53(2)(a)(i–ii), *supra* note 38. Systemic discrimination is likewise addressed in provincial human rights codes. For example, Manitoba*'s Human Rights Code* addresses systemic discrimination in section 9(3), CCSM c H175.

75. See e.g. *AHRA*, *supra* note 61, s 21(1); New Brunswick's *Human Rights Act,* RSNB 2011, c 171, s 19(1); Prince Edward Island's *Human Rights Act*, RSPEI 1988, c. H-12, s 22(3).

are less formal. At the hearing before the tribunal, the commission usually represents the complainant and assumes carriage of the case.[76]

2. *Employment*

The *GNDA* includes amendments to the employment standards part of the *Canada Labour Code* for the protection of federally regulated employees against genetic discrimination.[77] Each province and territory also has employment standards legislation setting out the basic obligations of employers in relation to hours of work, termination, minimum wage, etc.[78] Further, provincial legislation prohibits certain terms from being included in applications for employment or as a condition of the employment itself.[79]

As with human rights, each jurisdiction has its own complaints process related to employment; however, there are a number of common features. Employment complaints are generally made to the governmental department responsible for employment.[80] An employment standards officer will attempt to help the parties resolve the complaint. If unsuccessful, the process may proceed to an investigation, mediation or hearing. Decisions may be appealed to an independent tribunal.[81] The nature of the orders are responsive to the infringement. For example, in Ontario, an employer may be ordered to pay wages owed, pay compensation or reinstate an employee or bring their practices into compliance with the legislation.[82]

Also similar to human rights, the government responsible for administering the relevant legislation may be tasked with providing compliance support to help employers and employees understand their rights and obligations, including offering general and targeted outreach.[83] The legislation also authorizes employment standards officers to conduct proactive inspections of certain records (e.g. payroll) and employment practices.[84]

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76. See e.g. *CHRA*, *supra* note 39, s 50.1 and *OHRC*, *supra* note 61, s 31(1).
77. *GNDA*, *supra* note 2, s 8.
78. See e.g. *Employment Standards Act,* 2000, SO 2000, c 41 [*OESA*]; *Labour Standards Code*, RSNS 1989, c 246.
79. For example, in Ontario, employers are prohibited from requesting that a person take a lie detector test. *OESA*, *supra* note 78, ss 68-71.
80. For example, in British Columbia, complaints are made to the Employment Standards Branch of the Department of Labour, and in Nova Scotia to the Labour Standards Division of the Department of Labour and Advanced Education.
81. For example, *Employment Standards Act,* RSBC 1996, c 113, s 112.
82. *OESA*, *supra* note 78, ss 103, 104, 108 (respectively).
83. See for example Ontario Ministry of Labour, Training and Skills Development, "Your guide to the *Employment Standards Act:* Role of the ministry" (last modified 15 June 2021), online: <www.ontario.ca/document/your-guide-employment-standards-act-0> [perma.cc/K29Q-XZR7].
84. *OESA*, *supra* note 78, s 91.

3. *Insurance*

The responsibility for regulating insurance lies with the provinces and territories.[85] Each province and territory has legislation aiming to provide oversight and regulation of the insurance industry. The primary aim of this legislation is to protect consumers.[86] The legislation is intended to ensure the financial stability of insurers, promote the honesty and competence of insurance intermediaries such as agents, and place limits on the freedom of contract enjoyed by insurers.[87]

Insurance legislation sets out a regulatory scheme that establishes a superintendent of insurance or similar authority who is responsible for regulating and licensing insurers and intermediaries.[88] The superintendent has the authority to take disciplinary action, such as suspending or revoking a license, where there is misconduct or where the Act is violated.[89]

Legislation also places obligations on consumers when they apply for insurance. In order to evaluate the nature and extent of the risks involved in contracting with an applicant, insurers require information.[90] Insurance laws, therefore, require applicants to fully disclose facts material to the insurance. If applicants fail to do so, the contract could be rendered voidable.[91]

III. *Problems with the status quo*

1. *Lack of parity*

The *GNDA* prohibits compulsory genetic testing and non-voluntary use of genetic test results.[92] The prohibitions do not address genetic information obtained through other means. The amendments to the *CHRA* fill this gap for federally regulated employees by the addition of "genetic characteristics" as a prohibited ground and by including provisions deeming discrimination based on a refusal to undergo a genetic test or to disclose genetic test results.[93] The amendments to the *Canada Labour Code* further fill this gap through its prohibitions around genetic tests. The lack of such provisions in provincial and territorial human rights and

85. *Parsons*, *supra* note 59 (see commentary within the footnote for clarification).
86. This is done through a range of mechanisms, including ensuring insurers remain financially solvent, that sellers of insurance are licensed, and by setting rules for market conduct.
87. Denis Boivin, *Insurance Law*, 2nd ed (Toronto: Irwin Law, 2015) at 61.
88. For example see Nova Scotia's *Insurance Act,* RSNS, 1989, c 231, ss 6, 36 [*NSIA*]; Northwest Territories *Insurance Act,* RSNWT 1988, c 4, ss 3, 254.
89. See e.g. *NSIA*, *supra* note 88, ss 6, 45.
90. Boivin, *supra* note 87 at 130.
91. *NSIA*, *supra* note 88, s 82.
92. *GNDA*, *supra* note 2, ss 3-4.
93. *CHRA*, *supra* note 39, ss 3(1)–(3).

employment legislation means that individuals in their spheres of authority do not have the comprehensive protections for their genetic information which their counterparts in the federal sphere enjoy.

Furthermore, human rights legislation aims at preventing, remedying and ameliorating discriminatory conduct at the individual and systemic levels.[94] This legislation contains broad remedial powers to enable the realization of these aims. Employment legislation is aimed at ensuring minimum standards are established, that proactive steps are taken to support compliance, and that remedies address non-compliance, including changing workplace practices broadly. Individuals in the federal sphere have access to these comprehensive protections and broad remedies for discrimination based on genetic characteristics. Currently, individuals outside the scope of federal human rights and employment legislation do not have the same comprehensive protections for genetic information nor access to a broad range of remedies.[95]

2. *Lack of clarity*

a. *Human rights*

It is unclear whether genetic characteristics would fall within the meaning of existing prohibited grounds in human rights laws. The most likely ground would be disability/handicap, discrimination against which is prohibited in all Canadian human rights legislation.[96] Many jurisdictions include "perceived" disability in their definitions,[97] where there is not an explicit reference to "perception," courts have read it in to the definition so as to be consistent with the interpretation of equality rights in the Canadian *Charter of Rights and Freedoms*.[98] While the Supreme Court of Canada has referenced genetics in the context of disability/handicap,[99]

94. See e.g. *OHRC*, *supra* note 61, preamble; *NSHRA*, *supra* note 61, s 2; *NWTHRA*, *supra* note 61, preamble.

95. Bill S-201, *An Act to prohibit and prevent genetic discrimination*, 2nd reading, *Eleventh Report of Human Rights Committee-Debate Continued,* 42-1, vol 149, No 137 (5 May 2015) at the Honourable James S Cowan's comments. online: <sencanada.ca/> [perma.cc/TTN8-NZGX].

96. *CHRA*, *supra* note 39, s 2. See e.g. *OHRC*, *supra* note 61, s 1.

97. See e.g. *OHRC*, *supra* note 61, s 10(3); *NSHRA*, *supra* note 61, s 3(l). The inclusion of perceived disability has relevance in relation to the predictive aspects of genetic information.

98. See *Québec* (*Commission des droits de la personne et des droits de la jeunesse*) *v Montréal (City)*; *Québec* (*Commission des droits de la personne et des droits de la jeunesse*) *v Boisbriand* (*City*), 2000 SCC 27 at para 39, [2000] 1 SCR 665 [*Boisbriand*].

99. See *ibid* at para 76. The Court stated that "the ground 'handicap' must not be confined within a narrow definition that leaves no room for flexibility. Instead of creating an exhaustive definition of this concept, it seems more appropriate to propose a series of guidelines that will facilitate interpretation and, at the same time, allow courts to develop the notion of handicap consistently with various biomedical, social or technological factors. Given both the rapid advances in biomedical technology, and more specifically in genetics, as well as the fact that what is a handicap today may or may not be

we have not identified any decisions that squarely indicate whether genetic characteristics are encompassed within the meaning of "disability/handicap."[100]

This leaves an open question as to whether individuals can rely on the present ground of disability in human rights legislation to protect genetic characteristics. The lack of clarity is problematic in a number of respects: it presents a risk of confusion; subverts the ability to understand one's obligations and build protections to prevent discrimination[101]; creates an onus on the individual for a complaint to be brought; and relies on tribunals and courts to make consistent decisions.

Layered on top of this already uncertain situation is a complication: the *CHRA* both names genetic characteristics as a distinct prohibited ground, and also deems refusals to undergo genetic testing or disclose genetic test results to be discrimination on this ground. A tribunal or court may well view a province/territory's choice not to include similar provisions in their human rights acts as a rejection of genetic characteristic as a prohibited ground.

At a practical level, without an explicit ground, a human rights commission may only consider a complaint of genetic discrimination if the offending action can be linked to another prohibited ground.[102] At proceedings leading up to the passage of the *GNDA*, the Canadian Human Rights Commission advocated for inclusion of a separate ground of "genetic characteristics" to allow people to file complaints without having to link it to another ground. Doing so, they argued, would make it clear that people have a right to be treated equally regardless of their *genetic characteristics.*[103] Such clarity helps to improve access to justice, especially for people in vulnerable circumstances.[104]

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one tomorrow, an overly narrow definition would not necessarily serve the purpose of the Charter in this regard."

100. See *ibid*; see also *Toronto District School Board v OSSTF, District 12* in which the arbitrator, citing *Boisbriand*, indicated that "disability" was broadly interpreted and did not require scientific certainty about the condition or cause when discussing a disability potentially resulting from a genetic characteristic. *Toronto District School Board v OSSTF, District 12*, [2011] OLAA No 461 at paras 217-218, 108 CLAS 92.

101. Senate, Proceedings of the Standing Senate Committee on Human Rights, *Evidence*, Issue 2 (24 February 2016) at Marcella Daye's comments, online: <sencanada.ca> [perma.cc/DV58-BGG2] [*Senate Committee Comments Feb 24/2016*].

102. House of Commons, Justice Committee, *Evidence,* No 34 (15 November 2016) at Marie-Claude Landry's comments, online: <openparliament.ca/committees/justice/42-1/34/marie-claude-landry-1/> [perma.cc/R5M7-8H8Q].

103. *Ibid*.

104. *Senate Committee Comments Feb 24/2016*, *supra* note 101 at Marcella Daye's comments.

The situation may be analogous to one of the points that was argued to justify the addition of "gender identity or expression" as a prohibited ground in human rights legislation.[105] Minister of Justice (as she then was) Jody Wilson-Raybould stated as follows when introducing the amendments to the *CHRA* in 2017:

> Tribunals and courts in several jurisdictions in Canada have found that discrimination against trans persons is a kind of discrimination based on sex, which is already a prohibited ground of discrimination. However, it is not enough to leave the law as it is. Canadians should have a clear and explicit statement of their rights and obligations. Equal rights for trans persons should not be hidden but be plain for all to see.[106]

Canadians have a clear statement of their rights in regard to genetic discrimination in the federal sphere; they do not have such a statement of their rights in the provincial and territorial sphere.

b. *Employment*

The *Canada Labour Code* makes it explicit that employers may not require employees to undergo or to disclose genetic tests. It also makes clear that employers may not take disciplinary action against an employee on the basis of the results of a genetic test, or for refusing to undergo or disclose the results of a genetic test.

It is possible that the *GNDA*'s criminal prohibition against requiring genetic tests to enter or continue a contract[107] may be broad enough to encompass the employment context. However, solely relying on this element for an employment related matter in the provinces could prove problematic. First, as will be discussed in the next section, accessing the criminal justice process has its challenges. Second, the federal government chose to explicitly address genetic discrimination in federal employment legislation. A court may interpret that to mean the intention of the *GNDA* was not to address employment issues. This poses a threat in the provincial/

105. See "Sexual Orientation, Gender Identity and Gender Expression" (last visited 5 August 2020), online: *Canadian Bar Association,* <www.cba.org> [perma.cc/JV36-ND5L]; see e.g. *Transgendered Persons Protection Act*, RSNS 1989, c 214, s 2 (amending the *NSHRA* to include gender identity and expression); *An Act to amend the Human Rights Code with respect to gender identity and gender expression*, SO 2012, c 7; see generally Marie-Claude Landry, "Statement – Trans rights are finally human rights in Canadian Law" (15 June 2016), online: *Canadian Human Rights Commission*, <www.chrc-ccdp.gc.ca> [perma.cc/2DLC-M6CG].

106. "Bill C-16, An Act to amend the Canadian Human Rights Act and the Criminal Code," *House of Commons Debates*, 42nd Leg, 1st Sess, Vol 148, No 92 (18 October 2016) at the Honourable Jody Wilson-Raybould's comments, online: <www.ourcommons.ca> [perma.cc/RZA8-NYQG] [*House Debates on Bill C-16*].

107. *GNDA*, *supra* note 2, s 3(1)(b).

territorial realm that employer requests for genetic testing or test results may be viewed differently than those in the federal realm.

Also, reliance on human rights legislation to address requests for genetic testing in the employment context is inadequate. Human rights legislation includes protection against discrimination in the employment context and thus there is certainly a role for human rights laws. In addition, labour arbitrators apply human rights legislation when adjudicating grievances under collective agreements that involve human rights matters.[108] However, as discussed earlier, human rights legislation affords an opportunity in the employment context to justify certain types of discrimination where there is a *bona fide* requirement. In the federal realm, the *Canada Labour Code* makes clear that employers simply cannot ask for genetic testing, regardless of their reasons for wanting it. Without a similar amendment in the provincial/territorial sphere, federally regulated employers will be held to a stricter standard with respect to what information they can request.

c. *Insurance*

Current insurance legislation requires applicants to fully disclose facts material to the insurance being sought, or risk the contract being voidable. The *GNDA* makes it clear that an individual cannot be forced to get genetic testing or disclose genetic test results. Justice Karakatsanis highlighted the tension between these laws and noted the likely impact on the operation of the insurance legislation. She said of the *GNDA:*

> These prohibitions and penalties will likely affect the operation of provincial and territorial legislation that requires the disclosure of genetic test results. The *Genetic Non-Discrimination Act* provisions would be paramount over provincial provisions to the extent of any conflict in operation … For instance, *provincial legislation that requires an individual seeking health or life insurance to disclose all material health information could not operate so as to require the individual to*

108. *Parry Sound Social Services Administration Board v OPSEU, Local 324,* 2003 SCC 42. Further, some jurisdictions have explicitly vested labour arbitrators with authority to interpret and apply human rights legislation when adjudicating grievances; see for example *Ontario Labour Relations Act*, 1995, SO 1995, c 1, SchA, s 48 (12). The question of whether labour arbitrators have exclusive jurisdiction to address human rights issues for employees governed by collective agreements is currently before the Supreme Court of Canada. On April 15, 2021, the Court reserved judgment on this question in *Northern Regional Health Authority v Linda Horrocks, et al,* SCC File 37878; appealing 2017 MBCA 98. In general, allegations of discrimination are not dealt with under employment standards laws (as distinct from labour laws); Ontario Human Rights Commission, "Appendix B – Human rights in the workplace: which laws?" in *Human Rights at Work 2008*, 3rd ed (Toronto: Carswell, 2008), online: <www.ohrc.on.ca> [perma.cc/FUY2-6PF4]. There are some limited exceptions such as wage discrimination (*Saskatchewan Employment Act*, SS 2013, c S-15.1, s 2-21(5)) and protection against recrimination for refusal to work on Sunday if authorized (*Employment Standards Act*, SNB 1982, c E-7.3, 17.1(1)–(5)).

disclose genetic test results…[109]

Existing insurance legislation is inconsistent with the prohibitions under the *GNDA*. As such, there is a lack of clarity about the rules for disclosing material facts as they relate to genetic information. Indeed, some lawyers have said this is an issue requiring further judicial determination.[110] We disagree. This is an issue requiring provincial and territorial governments to act. There is always a responsibility on legislatures to ensure the rules are clear; however, it is all the more necessary when the legislation at issue is aimed at consumer protection. The Minister of Justice (as she then was) Jody Wilson-Raybould's comments discussed earlier regarding human rights are equally relevant in the insurance realm: "Canadians should have a clear and explicit statement of their rights and obligations."[111] Those rights and obligations need to be clearly set out in insurance legislation and reflect the prohibitions established under the *GNDA.*

3. *Redress limitations*

The *GNDA* offers redress under the criminal law for offences related to compulsory genetic testing and non-voluntary use of genetic test results.[112] These are important protections, but they are insufficient. The criminal law does not provide an accessible path to prevent or redress harms for individuals or harms of a systemic nature. It is focused on punishment of the perpetrator and not on remediation for the victim,[113] although there may be an element of general deterrence that comes with the threat of criminal sanction.

The criminal law can be a blunt and unwieldy mechanism. It requires an apparent offence to have already been committed and police to decide whether to lay a charge under the *GNDA*. The prosecution service—not the alleged victim—decides whether to carry the case forward on behalf of the public.[114] This means that the likelihood of an adequate response from the criminal justice system to a circumstance in which a person believes their genetic information has been used inappropriately is minimal. Further, the

109. *Re GNDA*, *supra* note 3 at para 53 [emphasis added].
110. Bernice Karn & Gordon Goodman, *Genetic Non-Discrimination Act Upheld By The Supreme Court: Implications for Insurers* (25 August 2020), online: Cassels <cassels.com> [perma.cc/N3Z3-5XMV].
111. *House Debates on Bill C-16*, *supra* note 106 at the Honourable Jody Wilson-Raybould's comments.
112. *GNDA*, *supra* note 2, s 7. The *GNDA* also included amendment to the *Canadian Human Rights Act* so, in the federal realm, the criminal route is not the only option available.
113. *Ibid*, s 7 (a)–(b).
114. See e.g. *The Criminal Case: Step-by-Step* (last visited 28 August 2020), online: Manitoba Justice <www.gov.mb.ca/justice/crown/prosecutions/stepbystep.html> [perma.cc/9UMJ-YWSU].

only penalty available under the *GNDA* is a criminal prosecution, which might ultimately punish the wrongdoer, but only after a victim of the wrongful use of genetic information has been harmed.[115]

Criminal law also requires that offences be established beyond a reasonable doubt; this is an onerous standard to meet. In contrast, complaints under human rights, employment and insurance legislation need only be established on a balance of probabilities, which requires a lower burden of proof for the complainant.

In addition, human rights legislation offers an administrative complaint process that is accessible and offers flexibility in resolving grievances and preventing discrimination.[116] The process often includes mediation or conciliation.[117] It also offers support for an aggrieved person through the commission's involvement and, if needed, carriage of the matter at a tribunal hearing.[118] The mandate of the commission and the flexibility in the processes established in the statutes affords the opportunity not only to address individual grievances but also to address discrimination of a systemic nature.[119]

Employment legislation also offers an administrative complaint process that builds in flexibility aimed at resolving complaints where possible. Employment standards officers are often mandated to try to resolve issues, sometimes before an investigation occurs[120]; mediation is also a commonly mandated consideration for resolving complaints before proceeding to an administrative tribunal. Unlike in human rights, however, the process does not involve an administrative body directly supporting the complainant.

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115. *GNDA*, *supra* note 2, s 7 (a)–(b).

116. Peter Barnacle, Michael Lynk & Roderick Wood, *Employment Law in Canada*, vol 1, 4th ed (Toronto: LexisNexis, 2005) (loose-leaf updated February 2020), ch 5 at 5.3, 5.188, 5.204.

117. "About the Process" (visited 24 August 2020), online: *Canadian Human Rights Commission* <www.chrc-ccdp.gc.ca/en/complaints/about-the-process> [perma.cc/VMN7-2UF3] [*CHRC Process*]; Barnacle, Lynk & Wood, *supra* note 116, ch 5 at 5.188.

118. *CHRC Process*, *supra* note 118; Barnacle, Lynk & Wood, *supra* note 117, ch 5 at 5.201 (the Commission can also initiate complaints where it has reasonable grounds to suspect a breach of statute at ch 5 5.177 (a)).

119. Thomson Reuters, *Fundamentals of Human Rights Law in Canada*, 4th ed (Toronto: Thomson Reuters, 2017) at 108-110. The human rights system offers "specialised statutory procedures" tailored to human rights issues and for this reason, individuals with human rights complaints are encouraged to use this forum rather than the civil courts. The system is not perfect; for example, complainants in civil courts have greater control over their suit, as the Commission often has the power to dismiss complaints. Barnacle, Lynk & Wood, *supra* note 117, ch 20 at 20.13. However, the civil courts are subject to even more serious critique, particularly in relation to access: see e.g. Jacques Gallant, "Ontario Lawyers warn civil court delays a 'worsening disaster'" *The Star* (2017), online: <www.thestar.com> [perma.cc/E8KG-SB3H].

120. See for example *Labour Standards Code,* RSNS 1989, c 246, s 21.

In the insurance context, the superintendent plays an important role in curbing misconduct. The authority to suspend or revoke a license is a powerful tool which may in practice be more effective in ensuring compliance with the substance of the prohibitions in the *GNDA* than the risk of and high-threshold for criminal prosecution. It would also ensure that all players involved in the sale of insurance are held accountable. Insurance legislation that incorporates a prohibition on the requirement that a person undergo a genetic test or disclose the results of a previously-conducted genetic test ensures that the superintendent of insurance has the authority to sanction an insurer or intermediary based on a violation of the Act. Explicit prohibition in insurance legislation provides a straight line to the sanction of suspending or revoking a license and is a powerful deterrent against insurer/intermediary misconduct.

IV. *Recommendations*

We have argued that provinces and territories need to amend their human rights, employment and insurance legislation. We recommend that the amendments mirror the federal legislation as closely as possible.

Human rights statutes are the primary vehicles for protecting human rights and establishing anti-discrimination laws. Each provincial and territorial statute needs to be amended to ensure comprehensive protection against genetic discrimination. The amendments to human rights legislation should mirror the provisions in the *CHRA* to ensure consistency of application and interpretation. The amendments should include the following additions:

- Identify "genetic characteristics" as a prohibited ground of discrimination; and
- Deem the refusal of a request to undergo a genetic test or to disclose, or authorize the disclosure of, the results of a genetic test, to be discrimination on the ground of genetic characteristics.

Employment legislation needs to be amended to mirror the provisions in the *Canada Labour Code* similarly in order to ensure consistency of application and interpretation. The amendments should include the following additions:

- Prohibit employers from requiring employees to undergo or disclose genetic tests; and
- Prohibit employers from taking disciplinary action against an employee on the basis of the results of a genetic test, or for refusing to undergo or disclose the results of a genetic test.

In the context of insurance, Canadians' concerns about the impact of genetic testing were a key driver behind the enactment of the *GNDA.*

Each provincial and territorial insurance statute needs to be amended to ensure clarity and consistency with the prohibitions under the *GNDA*. The amendments should include the following:

- Prohibit insurers and intermediaries from requesting or requiring that a person undergo or disclose genetic tests;
- Exempt the disclosure of genetic test results from the requirement to disclose all material information; and
- Confirm that an insurance contract may not be rendered voidable for failure to disclose genetic test results.

A multi-faceted approach in the provinces and territories is necessary.[121] The Supreme Court of Canada indicated that it is appropriate to "take a coordinated approach to tackling genetic discrimination based on test results, using different tools."[122] These proposed amendments are necessary in order to realize the coordinated approach initiated by the federal government and thereby ensure that all Canadians receive broad protection against genetic discrimination.

121. *Re GNDA*, *supra* note 3 at para 4, 38, 39.
122. *Ibid* at para 47.