Court File No. 38478

IN THE SUPREME COURT OF CANADA

(ON APPEAL FROM THE COURT OF APPEAL OF QUEBEC)

IN THE MATTER OF a Reference by the Government of Quebec to the Court of Appeal of Quebec concerning the constitutionality of the *Genetic Non-Discrimination Act* enacted by sections 1 to 7 of the *Act to prohibit and prevent genetic discrimination* (S.C. 2017, c. 3)

BETWEEN:

CANADIAN COALITION FOR GENETIC FAIRNESS

Appellant
(Intervener)

-and-

ATTORNEY GENERAL OF QUEBEC AND ATTORNEY GENERAL OF CANADA

Respondents
(Applicants/Interveners)

-and-

ATTORNEY GENERAL OF BRITISH COLUMBIA, ATTORNEY GENERAL OF SASKATCHEWAN, PRIVACY COMMISSIONER OF CANADA, CANADIAN HUMAN RIGHTS COMMISSION, CANADIAN COLLEGE OF MEDICAL GENETICISTS, and CANADIAN LIFE AND HEALTH INSURANCE ASSOCIATION

Interveners
(Interveners)

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PART I – OVERVIEW

1. Privacy is an omnipresent concern in the 21st century. Privacy guarantees a sense of personal security, protects democracies,[1] and promotes access to healthcare.[2] Subsection 91(27) of the *Constitution Act, 1867*, the criminal law power, entitles Parliament to prohibit practices that violate individuals' privacy and in turn, their dignity and bodily autonomy.

2. Sections 1 to 7 of the *Genetic Non-Discrimination Act* (*"GNDA")* are an execution of that entitlement. The provisions at issue in this appeal use penal sanctions to ensure individuals control access to, use of, and disclosure of their genetic information. The provisions safeguard against inappropriate practices that interfere with privacy as it relates to individuals' biographical core – a valid criminal law purpose. Prohibiting these serious invasions of personal privacy, and thereby protecting dignity and bodily autonomy, falls squarely within Parliament's domain.

3. The Privacy Commissioner of Canada ("OPC") submits that the *GNDA* involves suppressing an evil (inappropriate access to, use of, and disclosure of genetic information) and safeguarding a threatened interest (genetic privacy). The legislation protects the unique moral interest individuals have in their own genetic material and ensures that individuals have control over the information derived from their own bodies. The *GNDA* equally protects individuals' right to privately learn about their genetic codes *and* the right not to be informed of their "genetic destiny."

4. It is necessary that all levels of government work toward privacy protection. Through the *GNDA*, Parliament took an important, constitutionally valid step.

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[1] *R v. Orlandis-Habsburgo*, 2017 ONCA 649 at para. 42
[2] *R v. Dyment*, [1988] 2 SCR 417 at para. 38

PART II – POSITION ON QUESTIONS ON APPEAL

5. The OPC submits that:

- The pith and substance of ss. 1-7 of the *GNDA* is the protection of privacy in relation to genetic information in order to safeguard individual dignity and bodily autonomy.
- The protection of privacy, dignity, and bodily autonomy constitutes a valid criminal law purpose.
- Privacy protection can, and should be, addressed by all levels of government.

PART III - ARGUMENT

A. The Pith and Substance of the *Act* is the Protection of Individuals' Genetic Privacy

6. In order to determine the pith and substance of a law, the Court asks "what in fact does the law do and why."[3] In this case, the impugned provisions protect an individual's ability to control their own genetic information and in so doing ensure privacy, dignity and bodily autonomy. An examination of both the intrinsic evidence and the extrinsic evidence confirms that the mischief that the *GNDA* seeks to address is the invasion of privacy as it relates to genetic information.

[3] *Reference Re Assisted Human Reproduction Act*, 2010 SCC 61, at para. 22 [*"Reference re AHRA"*]

1. The Structure and Wording of the Statute Confirm that Genetic Privacy is Parliament's Paramount Concern

7. A plain reading of the text of the impugned provisions shows that ss. 1-7 of the *GNDA* are primarily concerned with preventing invasions of personal privacy in the context of contracts, goods, and services.

- Section 3 prohibits forced genetic testing, which protects privacy by preserving individuals' bodily autonomy and their "right not to know"[4] about any genetic diseases that they may carry.

- Section 4 prohibits forced disclosure, which protects privacy by ensuring individuals' ability to decide when and with whom they share their genetic information.

- Section 5 prohibits collection, use, or disclosure without written consent, which protects privacy by ensuring that individuals can understand and decide who has their information, the way it is used, and who can access it.

- Section 7 ensures that privacy is protected by creating sanctions for breaches of ss. 3-5.

8. While the title of the *Act* speaks to preventing genetic discrimination, ss. 1-7 protect the security of individuals' genetic information *before* discrimination can take place. As the Quebec Court of Appeal noted, ss. 1 - 7 do not prohibit genetic discrimination. Rather, the provisions "aim

[4] For a discussion of the "right not to know" see Privacy Commissioner of Canada, *Genetic Testing and Privacy* (Ottawa: Supply and Services, 1995) at pg. 30-31 https://www.priv.gc.ca/media/4144/02_05_11_e.pdf (referred to in AG Canada Record, Vol. VI, pg. 215 (Engelmann), Vol. III, p. 2 (Joly), and Vol. XVI (pg. 199 (footnote 95), Lemmens). There should be no "obligation to learn one's possible genetic destiny."

at prohibiting the access to information obtained through genetic testing." It correctly concluded that the impugned provisions, "on the whole", make access to and use of information more difficult.[5]

2. The "Legal Effect" of the Provisions is Stronger Privacy Guarantees

9. The legal effects of the provisions are to protect privacy in test results and prohibit forced testing.[6] The sections protect confidentiality (ss. 4 and 5) and prohibit forced interference with bodily integrity (s. 3). The common thread amongst ss. 3, 4, and 5, is that they protect privacy, dignity, and bodily autonomy.

10. The provisions do not *only* exist so that Canadians can take advantage of advances in medical science. Section 3[7] is a recognition of the "right not to know". This right confirms that individuals should not be forced to undergo genetic testing, even if the results might inform them of the need for treatment. Professor Joly noted that "imposing genetic testing on individuals goes against fundamental principles of Canadian society, such as respect for human dignity and individual autonomy."[8] While s. 4 and aspects of s. 5 of the *GNDA* may ultimately encourage individuals to employ the extraordinary advances in medical science while armed with the knowledge that their information cannot be shared without consent, s. 3 confirms that individuals have a right to forgo genetic testing entirely, even at the risk of losing health benefits from medical advances.

11. Certain parties take the position that the law aims to regulate contracts of insurance in a manner that promotes health.[9] The OPC submits that the provisions prohibit inappropriate, invasive

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[5] *Reference re Genetic Non-Discrimination Act*, 2018 QCCA 2193 at para. 10
[6] See *R v. Morgentaler,* [1993] 3 SCR 463 at para. 29-30 [*Morgentaler*]
[7] Aspects of s. 5 also affirm the right not to know. In particular, the right not to have genetic test results "collected" without written consent protects individuals' choice to abstain from genetic testing.
[8] See, for example, AG Canada Record, Vol. XII, pg. 38 (Centre of Genomics and Policy Submission)
[9] See AG Canada Respondent Factum, at para. 5, 62

practices across all sectors, public and private – the provisions are of general application.[10] While the debates did address the insurance industry and its use of genetic information, there are references in the Hansard to the use or retention of genetic information by consumer testing organizations like 23andMe,[11] First Nations bands as it relates to eligibility for membership,[12] governments in relation to immigration status,[13] and in adoption denial decisions.[14] Moreover, simply because a criminal prohibition and penalty may impact one industry more obviously and immediately than others, does not mean that the legislation lacks a criminal law purpose.[15]

12. In this case, the Court should be reluctant to place undue weight on the "hoped for" or "predicted practical effect" of the law in determining its pith and substance.[16] The precise impact of the *GNDA* on the insurance[17] and other industries or on health is currently unknown. The use of genetic testing in different fields is rapidly growing and changing. In the early 2000s, there were 100 genetic tests, in 2013, 2000, and by 2014, there were 13,800 tests for 4,000 conditions and 2,600 genes.[18] While it is impossible to know the different ways in which individuals and organizations might employ genetic information, the importance of protecting privacy and bodily autonomy in relation to this information will remain central and unchanged. The Court should resist

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[10] See AG Canada Record, Vol. X, pg. 73 (Oliphant); See also AG Canada Record, Vol. XI, pg. 24 (Hogg)
[11] AG Canada Record, Vol. VI, pg. 202-203, 210 (Hibbs)
[12] AG Canada Record, Vol. VI, pg. 232 (Langtry); Determining eligibility for band membership constitutes a "service" (see *Beattie v. Aboriginal Affairs and Northern Development Canada*, 2014 CHRT 1, at paras. 95-106; cited with approval in *Canada (Canadian Human Rights Commission) v. Canada (Attorney General)*, [2018] 2 SCR 230 at para. 57).
[13] AG Canada Record, Vol. VII, pg. 56 (Eaton and Cowan)
[14] AG Canada Record, Vol. V, pg. 170 (Bombard)
[15] See for instance, *Reference re AHRA*, *supra* at para. 288-291 (the *AHRA* had a greater impact on health/human reproduction more obviously than any other industry, but certain provisions nonetheless had a valid criminal law purpose.)
[16] See discussion in *Morgentaler*, *supra* at para. 29, 31, 33-34
[17] See AG Canada Record, Vol. XII, pf. 150-151 (*Genetic Information, the Life and Health Insurance Industry and the Protection of Personal Information: Framing the Debate)*; see also AG Canada Record, Vol. VIII, pg. 218-219 (Commissioner Therrien)
[18] AG Canada Record, Vol. V, pg. 62 (Cowan); AG Canada Record, Vol. VI, pg. 189 (Ataullahjan); Heim- Myers estimated that the number, in 2014, was closer to 23,000 genetic tests (pg. 189)

determining the constitutionality of the *Act* on unknowable future impacts and instead should focus on the obvious ways in which the *Act* protects privacy.[19]

3. Hansard Demonstrates that Parliament's Concern is with Genetic Privacy

13. The Hansard also supports the conclusion that the *Act* is, in pith and substance, about privacy. Throughout the debates, parliamentarians and speakers noted the centrality of privacy protection to the legislation. In particular, numerous participants noted that genetic information is more personal and elemental to identity than other health information.[20] The debates also demonstrate that privacy protection is an important step to combatting genetic discrimination.[21] Finally, the debates suggest that there can be no access to the advances in health care without strong privacy protections.[22] Privacy concerns weave the debates together.

14. In any event, and even though the Hansard supports the OPC's position, this Court cautions that the debates are limited in their reliability and weight.[23] In this case, the best indication of legislative intent is the text of the statute enacted which clearly speaks to the preservation of an individual's privacy, dignity, and bodily autonomy. The words of the impugned provisions are an affirmation that individuals have a fundamental, enforceable right to genetic privacy and that Parliament will protect individuals from unwanted invasions of the same.

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[19] *Morgentaler*, *supra* at paras. 31-36
[20] See for example, AG Canada Record, Vol. V, pg. 116 (Cowan); AG Canada Record, Vol. VI, pg. 216, 228 (Engelmann, Canadian Association of Labour Lawyers); AG Canada Record, Vol. VIII, pg. 167 (Heim-Myers); AG Canada Record Vol. IX, pg. 192 (Frum); AG Canada Record, Vol. X, pg. 86 (Oliphant); AG Canada Record, Vol. X, p. 110 (Schiefke)
[21] See for example, AG Canada Record, Vol. VI, p. 215-217 (Englemann); AG Canada Record, Vol. VIII, pg. 165, 168 (Heim-Myers); See also, AG Canada Record, Vol. IV, p. 141 (Bombard)
[22] AG Canada Record, Vol. X, pg. 95 (Malcolmson); AG Canada Record, Vol. X, pg. 91-92 (Davies)
[23] *Morgentaler*, *supra* at para. 31; See *R. v. Banks*, 2007 ONCA 19, at para. 49

B. The Protection of Privacy, Dignity and Bodily Autonomy is a Valid Criminal Law Purpose

15. Parliament uses its criminal law power to protect privacy, dignity and bodily autonomy. Privacy, like peace, order, security, and a sense of morality is necessary to the preservation of a free and democratic society. While medical and scientific research moves forward using genetic information, countries need to ensure that privacy practices keep pace.

1. Parliament Often Uses the Criminal Law Power to Protect Privacy

16. Parliament has created many criminal offences to protect privacy, dignity and bodily autonomy. For instance, in *Jarvis*, this Court confirmed that the offence of voyeurism exists to protect the dignity, autonomy, and integrity of individuals. The Court wrote "safeguarding information about oneself, which is also closely tied to the dignity and integrity of the individual, is of paramount importance to society."[24] Similarly, distribution of intimate images without consent is criminalized because the conduct infringes on an individual's ability to control and access visual representations of their own bodies.[25] The wilful interception of private communication is a crime,[26] as is prowling at night.[27] The criminalization of these acts that interfere with privacy, like the prohibited behaviors in the *GNDA*, is a recognition that privacy is crucial to a healthy democracy and individual freedom.

17. The importance of privacy takes on added significance in the context of genetic materials. There is a qualitative difference between other personal information and genetic makeup – DNA is the ultimate identifier.[28] Not only does it have the capacity to provide information about

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[24] *R v. Jarvis*, 2019 SCC 10, at para. 66
[25] See, for example, *R v, A.C.*, 2017 ONCJ 317 at para. 20
[26] *Criminal Code*, s. 184
[27] *Criminal Code* s. 177
[28] AG Canada Record, Vol. V, pg. 26 (Cowan), pg. 64 (Cowan)

individuals to others, it engages the privacy interests of those individuals' parents, children, siblings, and other close relatives.[29] The number of inferences that the genetic information is capable of providing is unknowable. As a result, an intrusion into individuals' biographical core, the center of which is DNA, qualifies as an extreme interference with dignity and bodily autonomy.[30]

18. Further, the privacy rights at issue in these provisions encompass both the right not to have others know and the right not to know about an individual's own genetics. Individuals require mechanisms of control to decide if and when to share their own genetic make-up with the government, private individuals, and organizations. Individuals also have a right to protect themselves from the information "that their own bodies can yield."[31] Forced testing removes individual choice and can be the "genesis of a life-long psychological prison – the prison of one's perceived genetic 'programming'."[32] Parliament can use the criminal law power to prohibit forced disclosure and forced testing, thereby protecting bodily autonomy.

19. In protecting genetic privacy, Parliament is suppressing inherently reprehensible behavior.[33] There can be no question that forcing genetic testing, forcing disclosure of genetic test results, or collecting, using or disclosing genetic test results without consent are actions worthy of punishment. The aim of the legislation – to protect genetic privacy, autonomy and dignity – is entirely different from a nuanced regulation about matters unrelated to bodily integrity. Unwarranted and unwanted invasions of genetic privacy raise serious moral and ethical concerns that are properly the domain of the criminal law.

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[29] AG Canada Record, Vol. VI, pg. 181 (Gordon)
[30] See *R. v. Stillman*, [1997] 1 SCR 607 at para. 39 [*Stillman*]
[31] See AG Canada Record, Vol. IV, pg. 112, Y. Bombard et al:
[32] See, *supra* at note 4, OPC, *Genetic Testing and Privacy* (1995) at pg. 30
[33] See discussion in *Reference re AHRA*, *supra* at paras. 23-25

20. Much like voyeurism and the unauthorized distribution of intimate images, the impugned provisions may have the ultimate, hoped-for, and predicted effect of improving health and well-being. However, the pith and substance of the criminal provisions is the protection of privacy, dignity and bodily integrity – important purposes in their own right.

2. Reference re Assisted Human Reproduction Act Confirms the Provisions at Issue Have a Valid Criminal Law Purpose

21. The *Reference re AHRA* supports the conclusion that the protection of genetic privacy qualifies as a criminal law purpose. A 5-4 majority of this Court in the *Reference re AHRA* confirmed that Parliament, under its criminal law power, can protect individuals' control over their own genetic material.[34] In particular, both Cromwell J. and McLachlin C.J. (as she then was) found that s. 8 of the *AHRA*, which prohibited the use of reproductive material without consent, had a valid criminal law purpose. The Chief Justice (as she then was) determined that the requirement for consent relates to the *unique moral interest* in control over an individual's own genetic materials.[35] Similarly, Cromwell J. concluded that legislation protecting control over the "products" of individuals' own bodies falls within "the traditional boundaries of criminal law."[36]

22. The *GNDA* protects the same "unique moral interests". Sections 3 to 5 are aimed at protecting an individual's control over information relating to his or her own body. Practices which result in forced access to, use of, or disclosure of an individual's own DNA infringe on bodily autonomy and integrity which "may constitute the ultimate affront to human dignity."[37]

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[34] Both McLachlin, C.J. (as she then was) (writing for Binnie, Fish and Charron JJ.) and Cromwell J. upheld the constitutional validity of s. 8 of the *AHRA*. It is worth noting that protecting against invasions of privacy, dignity, and bodily autonomy, would also meet the test for a criminal law purpose set out by LeBel and Deschamps JJ. In the *Reference re AHRA* at para. 233 (namely, the provisions suppress the evil of invasions into genetic privacy, with residual impacts on dignity and bodily autonomy.)
[35] *Reference re AHRA*, *supra*, at para. 90 (per McLachlin C.J. (as she then was)).
[36] *Reference re AHRA*, *supra* at paras. 289-291 (per Cromwell J.)
[37] *Stillman*, *supra* at para. 39

The provisions of the *GNDA* are simply a recognition of the importance of that dignity, and a protection of bodily autonomy.

C. Privacy Protection Can be Addressed by Valid Federal or Provincial Legislation

23. Privacy does not fit into a watertight jurisdictional compartment. The protection of privacy can, and should be, addressed by both levels of government. The *GNDA* fits into the wider privacy mosaic that is a national norm. Co-operation is critical to ensuring privacy protection in an era of technological and informational advancements.

PART IV – SUBMISSIONS ON COSTS

24. The Privacy Commissioner seeks no costs and asks that no costs be awarded against him.

PART V- ORDER REQUESTED

25. The Privacy Commissioner does not request any orders.

ALL OF WHICH IS RESPECTFULLY SUBMITTED, this 3rd day of July, 2019.

per

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PART VI – TABLE OF AUTHORITIES AND STATUTES

CASES		PARA(S). CITED
Beattie v. Aboriginal Affairs and Northern Development Canada, 2014 CHRT 1		11
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Criminal Code, R.S.C., 1985, c. C-46	177, 184	16
Genetic Non-Discrimination Act, S.C. 2017, c. 3	1-7	2, 5, 7, 8-10, 22
REFERENCES	**PROVISION**	**PARA(S). CITED**
Privacy Commissioner of Canada, *Genetic Testing and Privacy* (1995)		7, 18