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On the Issue of Discrimination Based on Genetic Status: Legal Approaches in the Judicial Practice of Foreign States

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Abstract: This paper is devoted to the consideration of legal approaches to discrimination based on genetic status, formulated by the judicial practice of a number of foreign countries: Australia, the United States of America and Canada. The author notes that the regulatory framework for combating discriminatory practices based on genetic status has developed at the level of international law with the adoption of key documents in the relevant area. The author makes a conclusion about the ways to apply genetic information, which often acts as a "tool" for the implementation of discriminatory practices. As genetic testing becomes more widespread, the challenge will inevitably arise to determine what role genetic information should play in human and social life.

Keywords: discrimination; genetic information; genetic status; human rights; human genome; insurance; employment; judicial practice; legal regulation; international law; "soft" law

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Contents

I. Introduction

Genetic information can be used for discrimination purposes. The results of genetic testing in an outwardly healthy person can show a high risk of developing a disease that will require expensive medical care. Such information may influence the decision on the employment of a candidate for a job or the conditions for concluding an insurance contract with him.

Today it is difficult to talk about the long-term ethical and legal consequences of the gradual «introduction» of genetic testing in the field of employment, insurance, preventive medicine. Nevertheless, cases of discrimination based on genetic status occur in different parts of the world,[1] for example, the Canadian media report cases of discrimination against applicants by insurance companies, regarding the results of testing in terms of the potential for hereditary diseases.[2] Governments of the United States, Australia and a number of European countries have passed legislation to combat genetic discrimination.

[1] National Center for Biotechnology Information (U.S.), GTR: Genetic Testing Registry. Available at: https://www.ncbi.nlm.nih.gov/ [Accessed 25.01.2021].

[2] Several magazines and websites published a story about a teacher in Germany who was denied a full-time job because her father suffered from Huntington's disease, a genetic disorder, and she was at high risk of developing such a disease. The teacher opposed genetic testing and secured employment. The German court ruled that the employer's refusal was discriminatory and stated that the applicant should have the right to work at this place of work indefinitely.

Canada has legislation on human rights, insurance, and privacy to minimize undue discrimination and prevent inappropriate access to or use of personal information, but there is currently no act that provides specific protection against genetic discrimination.

II. Legal Framework at the International Level

Counteracting discrimination based on genetic status has an international legal component. In the 1990s, the Human Genome Project,[3] through which the complete sequence of the human genome was discovered and studied, highlighted the need to find answers to ethical and legal questions related to genetic testing and genetic manipulation. Subsequently, the "Human Genome" project served as the framework for the adoption of a number of international acts, which dealt with the problem of discrimination based on genetic status.

The United Nations Educational, Scientific and Cultural Organization (UNESCO) advocates that all states provide protection against discrimination based on genetic data or genetic characteristics. In 1997, UNESCO adopted the Universal Declaration on the Human Genome and Human Rights,[4] which, together with the desire to protect the human genome from various kinds of manipulations that threaten the life and personal integrity of future generations, aims at preventing genetic discrimination and any use of genetic information. That would be contrary to the principles of protecting human dignity and human rights. What is also worth mentioning is the UNESCO International Declaration on Human Genetic Data,[5] which establishes ethical principles for the application of human genetic data so that such data is «not used for purposes that discriminate in a way that is intended to infringe, or has

[3] Health Canada, Human Genome Project. Available at: https://www.canada.ca/en/health-canada/services/science-research/emerging-technology/biotechnology/about-biotechnology/human-genome-project.html [Accessed 25.01.2021].

[4] Universal Declaration on the Human Genome and Human Rights (adopted on 11.11.1997 at the 29th Session of the UNESCO General Conference).

[5] International Declaration on Human Genetic Data (adopted by the resolution of the General Conference of UNESCO on the Report of Commission III at the 20th Plenary Meeting on October 16, 2003).

the effect of infringing human rights, fundamental freedoms or human dignity of an individual or for purposes that lead to the stigmatization of an individual, a family, a group or communities» (Article 7 of the Declaration). At the same time, it is important to remember that the abovementioned documents refer to the so-called «soft law acts», which contain recommendatory rules.

Within the Council of Europe, most member states have signed, but not ratified, the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (known as the Oviedo Convention at the place of its signature).[6] States signatories[7] have committed themselves to bringing their legislation in line with the principles set out in the Convention. Article 11 of the Convention prohibits any form of discrimination against a person because of his genetic heritage.

In 2008, Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes was adopted. This Protocol expanded the provisions of the Convention in a meaningful way. In particular, the document defined the principles of informing and obtaining patient consent, as well as genetic counseling. Among other things, the document contains provisions regarding the protection of privacy and the right to information obtained as a result of genetic testing. To date, only a few states have signed and ratified this protocol.

III. Legislation and Law Enforcement Practice in the Sphere of Discrimination based on Genetic Status: Experience of Foreign Countries

States that have adopted relevant legal acts aimed at combating discrimination based on genetic status use different approaches. One such approach is to impose restrictions on freedom of contract in the field

[6] Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS N 164).

[7] To date, 35 Council of Europe member states have signed the Convention on Human Rights and Biomedicine, 29 of which have ratified it. The 1997 Convention can be called not only the completion of the codification of bioethical principles, but also the starting point for moving towards much more significant goals. Russia is not involved.

of employment and insurance (Lemmens, 2003), which theoretically could contribute to the emergence of general prohibitions (without a specific field of activity) of discrimination because of genetic status or sectoral legal regulation in this part for insurance companies and employers. In particular, both insurers and employers may be prohibited from requiring an applicant or applicant to undergo genetic testing or provide previous test results. An alternative option is to prohibit the use of test results when making certain decisions that may negatively affect the applicant or applicant (when calculating payments to the insured person or when assigning certain tasks to an employee/applicant).

The second approach is characterized by the adoption of more sophisticated, comprehensive privacy legislation to protect genetic data from unauthorized collection, use and disclosure without the consent of the parties concerned, with a few exceptions. Certain jurisdictions have laws that protect patients' rights and give them broader powers to determine and decide how genetic information may be used and when (Lemmens, 2003).

3.1. Australia

Let us cite as an example the experience of certain foreign jurisdictions. Australian law explicitly prohibits discrimination based on genetic status. In 1992, the Commonwealth of Australia passed the Disability Discrimination Act 1992 containing a similar provision. At the same time, the regulations allow discrimination in relation to the insurance sector where there are sufficient grounds. Insurers have the right to use information on the results of genetic testing, even in the absence of obvious signs of illness, in order to refuse insurance payments or increase insurance premiums in the case of life, income, and travel insurance. However, the legislator emphasizes that the discriminatory attitude must be reasonably justified. The insurers also have a duty to consider all possible measures to reduce the risk of an insured event, including constant medical supervision or surgical intervention. This requirement distinguishes between legitimate (but ethically controversial) discrimination based on genetic status within the scope of applicable law, and unlawful genetic discrimination, which

suggests that the insurer's behavior violates regulations (Rothstein, 2018).

Australian law allows insurers to increase premiums and exclude coverage when a person is at risk of certain diseases, such as cancer, or drop coverage altogether based solely on the results of a genetic test.

As part of genetic testing, human DNA is examined, which contains information about the development and functioning of the human body. DNA modifications can indicate a predisposition to serious diseases such as cystic fibrosis, Huntington's disease, or cancer. Doctors can refer patients for genetic testing if they are likely to inherit certain diseases.

Issues of discriminatory attitudes in the field of insurance have arisen within the Australian legal system, both at the level of case law (*Carter v Boehm (1766) 3 Burr 1905, 1909 (Mansfield LJ*), and at the legislative level (Insurance Contracts Act 1984).[8] In particular, the principle was enshrined according to which the applicant undertakes to disclose to the insurer all known information that is relevant to the insurance contract concluded between them, including genetic information. An important role in this area is also played by industry standards used in relation to the collection of genetic information by insurance companies. It is essential to mention the Investment and Financial Services Association of Australia (IFSA), which is involved in the development of the Genetic Testing Policy.[9]

If we consider the legal framework for regulating nondiscrimination in the field of insurance in a comprehensive manner, it must be noted that it is formed at three levels: federal, state and individual territories. At the federal level, the main acts are identified that affect aspects of discriminatory attitudes in insurance: Sex Discrimination Act 1984, Racial Discrimination Act 1975 and Disability Discrimination Act 1992 cited above. Moreover, the SDA and DDA contain special provisions

[8] Parliament of Australia. Inquiry of the Parliamentary Joint Committee on Corporations and Financial Services. Available at: http://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services/LifeInsurance/Public_Hearings/ [Accessed 25.01.2021].

[9] Parliament of Australia. Inquiry of the Parliamentary Joint Committee on Corporations and Financial Services.

on the admissibility of discrimination in the field of insurance in the presence of certain circumstances (Otlowski et al., 2007). The RDA does not contain such a provision. At the same time, it limits the information that insurers are allowed to use in underwriting applications, to ensure that they receive payments in the event of an insurance case. Thus, insurers cannot discriminate between applicants based on race, although life expectancy for Indigenous Australians is known to be markedly lower than for the European population as a whole.

Regarding the legislation at the state and territory level, in each case it is a separate regulation in the field of insurance and non-discrimination. Not surprisingly, states and territories adopted the provisions of the Disability Discrimination Act 1992 under certain conditions. However, such a reception does not exclude the possibility of conflicts of laws adopted at different levels.

In accordance with the *Australian Mutual Provident Society v Goulden* decision[10] of the High Court of Australia, insurance provisions in anti-discrimination law may be challenged on the grounds that they do not comply with federal law which regulates insurance premiums for insurers as per current guidelines and established practice. In the designated case, the High Court held that a provision prohibiting discrimination because of disability in the provision of goods and services under the Anti-Discrimination Act 1977 is invalid to the extent that it does not comply with the Life Insurance Act 1945. As legislation in this area undergoes permanent change in Australia, claims and complaints about genetic discrimination in insurance by default are included in the Disability Discrimination Act 1992.

In 2001, Dr. Christine Barlow-Stewart and David Keyes published a study that identified 48 cases of discrimination in Australia based on genetic information. The research focused on life, health and income insurance. The applicants argued that the insurers' decisions and actions were inappropriate because the insurers did not have up-to-date information and did not have relevant knowledge about the nature of genetic information and genetic disorders.

[10] Australian Mutual Provident Society v Goulden [1986 160 CLR 330].

Researcher David Keyes noted specific cases of discrimination in insurance based on genetic information. In particular, he presented the story of one applicant who was denied income insurance on the grounds that certain members of his family had been diagnosed with myotonic dystrophy. The insurance company said that the decision to provide insurance depends entirely on the results of genetic testing, which he had to undergo. The applicant passed the test and the result was negative, which enabled him to obtain insurance coverage. The Investment and Financial Services Association of Australia (IFSA) commented on the case, noting that «this situation is unlikely to arise at this time as IFSA members cannot require applicants to undergo mandatory genetic testing» (Barlow-Stewart et al., 2009).

The second case concerned an applicant who agreed to undergo genetic testing to identify mutations causing Charcot-Marie-Tutta disease (CMT). The genetic test showed that the applicant had inherited the genetic mutation that causes CMT. Prior to the testing, no such diagnosis was made to the applicant, since its manifestations were minor. He was subsequently denied coverage due to the results of the designated genetic testing. In the opinion of the IFSA, denying insurance coverage in this case does not contradict the statutory exemption and therefore does not constitute illegal discrimination. If it had been about life insurance rather than income, the applicant most likely would not have received a rejection (Lemke, 2005).

These cases have undoubtedly become a valuable source of information about the ways in which genetic information is used by insurance organizations. In the first case, the insurer apparently misinterpreted the concept of «genetic information», so its decision was not fully correlated with the current Australian «anti-discrimination» legislation. In the second case, the insurer's decision to deny coverage appears to be legitimate because the risks to the company were too high.

Certainly, the cases revealed a number of problems associated with the use of genetic information. On the one hand, allowing the unrestricted use of genetic information in this context is a legitimate concern, as such a permit could trigger the creation of a «genetic underclass» that would be denied access to insurance and other related benefits (Keogh and Otlowski, 2013). In addition, the negative use

of genetic information (expressed in the refusal of the applicant to provide insurance compensation or the refusal to conclude an insurance contract) may not have the best effect on ensuring both individual and public health. On the other hand, a fair position was expressed that it is not necessary to distinguish between genetic and any other medical information in the voluntary insurance market, and a ban on the use of genetic information could negatively affect the viability of the insurance industry.

For more than 15 years, the Australian Government has funded the Genetic Discrimination project, which has reviewed and compiled about 100 claims and complaints from individuals who have suffered discrimination because of genetic status by insurance companies. As a result, a number of recommendations were developed for reforming the insurance system:

1. Human Genetics Commission of Australia, as a matter of priority, should develop procedures to evaluate and recommend whether specific genetic tests are to be used in insurance coverage based on their scientific reliability, relevance and validity.

2. The Investment and Financial Services Association of Australia (IFSA) and the Insurance Council of Australia (ICA) need to develop binding rules for their members to ensure that once the Australian Commission on Human Genetics makes a recommendation for the use of a specific genetic test in underwriting; this test will only be used in accordance with this recommendation. During the transition period, insurers should be allowed to continue to use genetic tests in industry policy until the Australian Commission on Human Genetics makes recommendations for these tests.

3. The Investment and Financial Services Association of Australia (IFSA) must require its members to indicate in their respective insurance applications that not all genetic test results are disclosed and that applicants must be informed.

4. Appropriate amendments should be made to the Insurance Contracts Act 1984 in order to specify in detail the obligation of the insurer to provide written reasons in the event of an unfavorable underwriting decision for the applicant. In cases where such a decision is based on genetic information, including a family history of illness, the

insurer should be required to provide strong and meaningful arguments that support the basis for such a decision.

5. Amendments should also be made to the Disability Discrimination Act 1992 to clarify the nature of the information that the insurer must disclose to the Australian Human Rights Commission and to provide equal opportunities to the parties during the examination of the complaint. Legislation should ensure that the applicant has the right to access to the information disclosed in this way.

6. Expanded powers should be granted to specialized insurance complaint organizations — Financial Industry Complaints Service Ltd (FICS) and Insurance Inquiries and Complaints Ltd (IEC) — to enable these organizations to review underwriting decisions related to the use of genetic information, including family medical history. The inclusion of these provisions should ensure the timely and efficient handling of complaints and applications.

7. With regard to providing confidentiality of genetic information, insurers ought to review their consent forms, including those of the medical authorities, to ensure that they contain sufficient information about the collection, use and disclosure of genetic information to help an individual make an informed decision about applying for and signing the consent form. It should be borne in mind, however, that consent to the collection of genetic information for the purpose of evaluating an insurance claim should not be tied to consent to the use of such information for other purposes.

8. Insurers must protect the public interest under the Privacy Act of 1988 with regard to the practice of collecting genetic information about applicants' genetic relatives for the use in underwriting insurance policies.[11]

World experience and the need to reform the relevant sector pushed Australia to introduce a moratorium on the use of genetic testing results in the consideration of insurance claims from July 2019. By harmonizing the requirements with the legislation of a number of

[11] Parliament of Australia. Inquiry of the Parliamentary Joint Committee on Corporations and Financial Services. [Viewed 25.01.2021]. Available from: http://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services/LifeInsurance/Public_Hearings/.

foreign countries, ordinary Australian citizens were able to receive insurance coverage without the need to disclose adverse test results in the amount of up to 500,000 Australian dollars (life insurance) and 200,000 Australian dollars (health insurance). The coverage limits are quite comparable to those in Switzerland, although significantly lower than those in the UK. The moratorium continues to allow the insured person to disclose favorable genetic test results to prove that genetic diseases and risks of their occurrence in future generations are free. The moratorium will be in effect for 5 years, and an assessment of its effectiveness is planned in 2022.

The relevant Australian practice is formed not only from the legislative regulation of various levels, but also the requirements and standards used in the insurance industry and developed by the professional community on their own. The standards and requirements that are being developed by the professional community are designed to balance the interests of both consumers of insurance services and the insurers themselves. At the same time, professional associations and market participants are obliged to take into account the social consequences of decision-making in the field of ensuring non-discrimination based on genetic status in the field of insurance. Australian model is aimed not only at averting the concerns of applicants, whose insurance could be entirely dependent on favorable or unfavorable results of genetic testing, the development of medical knowledge and genetic research, but also at fulfilling the financial obligations of insurers.

3.2. The United States of America

Notable is the American jurisprudence in the field of combating discrimination based on genetic status. The US Equal Employment Opportunity Commission[12] contributed to the resolution of a dispute related to the filing of a claim against an employer who violated the

[12] The United States Equal Employment Opportunity Commission (EEOC) is the Federal agency that governs and enforces civil rights laws against discrimination in the workplace. The EEOC investigates complaints of discrimination based on race, national origin, religion, gender, age, disability, sexual orientation, gender identity, genetic information, and participation and/or opposition to discriminatory practices.

Genetic Information Nondiscrimination Act 2008. The employer requested a family medical history from its employees and applicants (*EEOC v. BNV Home Care Agency, Inc.*).[13] BNV allegedly demanded that employees and applicants pass the so-called «health assessment» (testing), which included a checklist of 29 diseases such as diabetes, various heart diseases and cancer. In the proposed questionnaire, people were asked to answer «yes» or «no» to the question, whether the employee or someone from his or her family was sick with one or another disease. As stated in the case file, applicants were required to complete such a questionnaire after receiving a conditional job offer, and employees were required to submit an updated questionnaire annually.

The Commission filed a lawsuit on its own behalf and an undefined group of persons, because, in its opinion, the activities of the defendant company grossly violated the requirements of the Genetic Information Nondiscrimination Act. The parties settled the dispute in October 2016. The defendant agreed with the injunction for further violations of the Act. The company mentioned it destroyed all confidential disease information forms received since 2014 and agreed to change the form of the questionnaire in order to comply with the requirements of the US law. The defendant also paid USD 125,000 in damages (this amount was divided equally among the employees).

Another notorious case was the *Lowe v. Atlas Logistics Group,*[14] which confirmed the breadth of application of the Genetic Information Nondiscrimination Act 2008. The circumstances of the case were as follows: the respondent Atlas Logistics provided services for the delivery and storage of products. In 2012, one of the company's employees began to periodically defecate at one of the warehouses where food was stored, thereby harming both the products in the warehouse and the health

[13] EEOC v. BNV Home Care Agency, Inc., No 1:14-cv-05441 (E.D.N.Y., Sep. 17, 2014). Available at: https://www.newyorkemploymentattorneyblog.com/files/2014/09/EEOC_v_BNV_HOME_CARE_AGENCY_14-CV-5441.pdf [Accessed 25.01.2021].

[14] Lowe v. Atlas Logistics Group, No 1:13-CV-2425-AT. (N.D.G., May 5, 2015). Available at: https://www.leagle.com/decision/inadvfdco160219000191 [Accessed 25.01.2021].

of people who could be potential buyers of such products. In order to identify the employee, the company decided to obtain genetic samples from two warehouse workers who were suspected of being involved in this "prank".

The company asked two workers to agree to take cheek swabs, and then hired a forensic laboratory to check if the DNA samples matched the excrement found in the warehouse. Despite the fact that the results of laboratory tests did not confirm the participation of these employees in the "giveaway", rumors of testing spread throughout the company. No wonder that employees filed a lawsuit in federal district court in Georgia, alleging that DNA testing initiated by Atlas violated the Genetic Information Nondiscrimination Act 2008, which prohibits employers from requesting "genetic information" from their employees. Judge Amy Totenberg ruled in favor of the warehouse workers, leaving the issue of damages to a jury. It is curious to note that the jury's verdict in this case was positive for the employees: the jury awarded two workers a whopping $ 2.2 million: $ 475,000 in damages and $ 1.75 million in penalties.

This case was another important testament to the inadmissibility of violating the Genetic Information Nondiscrimination Act 2008, demonstrating the dire consequences of employers' reluctance to act according to its provisions. Regardless of the employer's motive (for example, to identify employee health and safety misconduct), and even if the employer does not act on this information, it is illegal to request or require genetic testing of an employee for genetic information.

3.3. Canada

Canada has come a long way towards its own specialized legislation to prohibit discrimination based on genetic status. Only in 2017 the Genetic Non-Discrimination Act was adopted at the federal level.[15] In 2019, in one of the Canadian courts, the question arose about its unconstitutionality. An important case here is *Canadian Coalition for*

[15] Genetic Non-Discrimination Act (S.C. 2017, c. 3). Available at: https://laws-lois.justice.gc.ca/eng/acts/G-2.5/page-1.html#h-1 [Accessed 25.01.2021].

Genetic Fairness v. Attorney General of Quebec, et al.,[16] in which the provincial Government of Quebec made a prejudicial request to the Quebec Court of Appeal. The question was Is the Genetic Status Non-Discrimination Act (its specific provisions) contrary to the jurisdiction of the Parliament of Canada in criminal law under paragraph 91 (27) of the Constitution Act, 1867? The court unanimously replied "yes", finding that the subject of legislative regulation, which provides for access to genetic testing for medical purposes by preventing unauthorized use of the results by third parties, does not really fit into the framework of criminal law.

During these proceedings, the Canadian court considered critical issues that are likely to shape Canadian jurisprudence in future genetic discrimination cases. The Canadian Coalition for Genetic Fairness (the applicant) argued that the Non-Discrimination Act promotes public health by not preventing people from undergoing genetic testing. Thus, the Act, in her opinion, is the current criminal law, which is under the jurisdiction of the federal government. The Coalition proceeded from the premise that if patients fear that the results of a genetic test will put them at a disadvantage when applying for insurance, they will not take such tests and will not know anything about the possibility of certain diseases. The Attorney General, however, argued that the Non-Discrimination Act relates to the obligation of applicants for insurance to properly inform insurers, which in turn is subject to provincial law. According to the Attorney General, the question of the use of genetic testing by the insurance industry is open to provincial regulators, however, the subject of litigation lies in the area of property and civil rights, which is also part of the provincial jurisdiction.

Canada's legislation on anti-discrimination based on genetic status remains the subject of controversy. However, the Privacy Commissioner of Canada supports the Genetic Non-Discrimination Act, arguing that its purpose is to protect people's privacy with respect to genetic information. In addition, the Act is supported by the Canadian

[16] Canadian Coalition for Genetic Fairness v. Attorney General of Quebec, et al. (38478). Available at: https://www.scc-csc.ca/case-dossier/info/dock-regi-eng.aspx?cas=38478 [Accessed 25.01.2021].

Human Rights Commission, which believes that the document pursues a completely legitimate purpose, prohibiting mandatory genetic testing, unauthorized use and disclosure of its results. I hope that after overcoming the differences, Canada will be able to form its own law enforcement practice in this sphere.

IV. Conclusion

The study of foreign experience in the legal regulation of countering discrimination based on genetic status may be useful in the context of ongoing discussions in the Russian media space on the introduction of genomic certification. A genetic passport is a document based on the analysis of a DNA sample, which contains information about a person's genetic uniqueness. In addition to ensuring the health of future generations, preventing hereditary diseases, the task of ensuring the protection of this information as personal data, preventing its use by state authorities and commercial structures for discriminatory purposes becomes urgent. The legal approaches formulated in foreign law enforcement practice will allow the Russian legislator to ensure a balance of private and public interests when resolving the issue of using information on genetic status in spheres other than healthcare.

Genetic information and the methods of its applicability are already changing the world, the view of human history and the approach to health. It is expected that as genetics is applied to more aspects of our lives, further changes will occur that are not yet imagined. One of the important changes will be the emergence of personalized medicine. If it can help people get treatment specifically tailored to their genetic profiles, this could lead to significant savings in the health care system. As genetic testing becomes more widespread, the challenge will inevitably arise to determine what role genetic information should play in human and social life.

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