GENETIC DISCRIMINATION AND THE NEED FOR APPROPRIATE LEGISLATION

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ABSTRACT

This article aims to discuss genetic discrimination and its implications in the Indian legal context. It explores the concept of genetic discrimination particularly in relation to the domains of health insurance and employment. Shortcomings of the current legal precedents about said discrimination are discussed, highlighting the need for all-encompassing legislation that addresses the gaps in the current setup.

Genetics is the study of heredity. Various genetic material—deoxy-ribonucleic acid (DNA), ribonucleic acid (RNA), etc.—allow us to predict how the genes of an individual will manifest themselves, both in terms of traits (e.g., colour of the iris, height, blood type) and in terms of harmful mutations and disorders. Genetic discrimination, then, would mean discrimination on the basis of the possible manifestations (phenotype) of the genes. Genetic testing involves examining genetic material, its patterns and its implications. Genetic testing in, say, sports leads to *positive* genetic discrimination, e.g., persons identified with higher athleticism or endurance are preferred over others. On the other hand, the same genetic tests may have negative consequences, such as discrimination with respect to employment opportunities and health insurance, which this essay aims to discuss, focusing on the need for proper regulation and legislation in these areas.

The accessibility of laboratories and hence, genetic testing has seen an increase in the recent years. For a reasonable sum[1], one can have their genetic material analysed for any possible disorders or diseases that may develop in the course of their life. The simplification of and lack of monitoring in this transactional process is a cause for concern. The labs are not bound by any specific legislation. Though most labs have a privacy policy, they may store the genetic data of an individual even after the test results have been communicated. This data is not secure, and agencies (such as law enforcement) may be given access to it.[2] There are no all-encompassing or specific laws on genetic information security or regulation of privatisation of testing. Although the Personal Data Protection Bill, 2019, classifies biometric data as 'sensitive personal data'[3] and attempts to regulate that data (along with its collection, retention, disclosure, and transfer)[4], it was tabled. Additionally, the definition of biometric data as given by the Ministry of Communications and Information Technology includes only DNA when it comes to personal data of genetic nature.[5] It does not mention RNA or mRNA, despite these being utilized widely as material for testing.

The lack of security with respect to genetic data welcomes the threat of misuse, especially by sectors seeking commercial gain on this basis. Health insurance companies sustain their

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[1] Raghu Krishnan, *Genetic testing gets affordable with customised offerings from start-ups*, Business Standard, 2016, https://www.business-standard.com/article/companies/genetic-testing-gets-affordable-with-customised-offerings-from-start-ups-116050900027_1.html (last visited Oct 14, 2020).

[2] DNA Genetic Testing & Analysis - 23andMe AU, DE, FR & EU, 23andme.com (2020), https://www.23andme.com/en-int/about/privacy/ (last visited Oct 14, 2020).

[3] Personal Data Protection Bill, 2019, Bill No. 373 of 2019, § 15, 2019.

[4] Personal Data Protection Bill 2019, Bill No. 373 of 2019, § 6, 9, 20(1), 34, 2019.

[5] Ministry of Communications and Information Technology, G.S.R. 313(E) (Notified on 11 April 2011).

business by targeting a relatively healthy population as potential policy-buyers. They do so through discrimination based on various factors, such as lifestyle, income level, profession, and of course, genetics. Healthier clients mean fewer instances of claims that need payment, and hence less liability. A person applying for a policy must disclose any relevant information regarding their health, including family history of disease. Thus, whether it is direct (based on test results as testing becomes mainstream) or indirect (based on deductions made from family histories), insurance companies perpetuate the concept of genetic discrimination. Only recently—following a landmark Delhi High Court case in 2018—was this notion open to discourse. In *United India Insurance Company Limited v Jai Parkash Tayal*[6], the judgement by Justice Pratibha M Singh stated –

> Discrimination in health insurance against individuals based on their genetic disposition or genetic heritage, in the absence of appropriate genetic testing and laying down of intelligible differentia, is unconstitutional.[7]

The court's judgement, along with the subsequent Insurance Regulatory and Development Authority (IRDA) guidelines[8], bars insurance companies from featuring any clause which excludes genetic disorders from their claim policy, i.e., claims based on genetic disorders cannot be denied.

The judgement is criticised for its contradictory elements, as it discusses the violation of Articles 14 (right to equality) and 21 (right to life including right to health) of the Indian constitution by the clause, but then proceeds to permit insurers to discriminate on the bases of pure genetic disorders e.g. Huntington's and Down Syndrome.[9] Although it is noted that the allowance given to pure genetic disorders was done so from a practical and functional perspective, the judgement displays incoherence according to some, and sets a questionable precedent. Moreover, the judgement merely allows claims based on genetic disorders to be successfully paid. Insurers are still free to refuse to sell policies to sufferers or prospective sufferers of genetic disorders. They are also free to provide policies but charge higher premiums for the same. This ambiguity and lack of uniformity highlights the need for dedicated and rational legislation on these topics.

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[6] 2018 SCC Online Del 7415.

[7] *United India Insurance Company Limited v Jai Parkash Tayal (2018)* SCC Online Del 7415 [87].

[8] Insurance Regulatory and Development Authority, IRDAI/HLT/REG/CIR/046/03/2018 (Issued on 19 March 2018).

[9] *United India Insurance Company Limited v Jai Parkash Tayal (2018)* SCC Online Del 7415 [78].

Another domain in which misuse of genetic data is internationally prevalent is employment. Certain jobs—that of pilots, drivers, plant operators, etc.—require genetic discrimination as the norm. Members of the armed forces are recruited based on such criteria—even for administrative roles, persons with genetic abnormalities or hereditary conditions are rejected.[10] These examples are generally not seen in a negative light. But when employers have access to employees' genetic information, a new evaluation factor gets incorporated, and starts influencing promotions, demotions, salaries, and opportunities to grow. For two employees with similar performance records and contributions in the workplace, this factor, under relevant circumstances, becomes an inherently discriminatory one. Additionally, in the employment context, any decisions based on the genetic constitution of an individual can be seen as unsubstantiated, because without actual onset symptoms of the disorders, the genetic tests become prognostic—indicating the likely course of a disease—rather than diagnostic. India has not yet witnessed these discriminations at a large scale and thus it is imperative that appropriate legislation be introduced at this key juncture.

The United States protects individuals from genetic information discrimination in health insurance and employment through Genetic Information Non-discrimination Act (GINA).[11] The European Convention on Human Rights & Biomedicine (ECHRB) does the same across Europe, and any form of discrimination on the basis of genetic heritage is prohibited; testing is permitted for health and scientific research only.[12] Inspired by these Acts, India must recognize its unclear and inadequate guidelines and absence of proper laws on genetic information discrimination. The emergence of a dialogue surrounding these concerns is quite recent when compared to the long history of genetic testing labs in India. A legislative effort of this nature would require extensive consultation with experts in the field.

The ethical arguments against current Bills (such as the Personal Data Protection Bill, 2019) are those of India becoming an 'Orwellian state'[13]—collection and maintaining banks of genetic data have been discussed, but there is a lack of detailing when it comes to access and confidentiality. A lack of control and surety with respect to personal data implies a loss of bodily autonomy for a citizen of India. Under the current circumstances, the principles of

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[10] Director General Medical Services (Army), 76060 Rule 4(p) (dated 1 August 2019).

[11] Genetic Information Non-discrimination Act, titles I, II, 2008.

[12] European Convention on Human Rights and Biomedicine, ETS 164, art. 11, 12.

[13] Megha Mandavia, *Personal Data Protection Bill Can Turn India Into 'Orwellian State'*, The Economic Times, 2019, https://economictimes.indiatimes.com/news/economy/policy/personal-data-protection-bill-can-turn-india-into-orwellian-state-justice-bn-srikrishna/articleshow/72483355.cms (last visited Oct 15, 2020).

confidentiality are under risk to be breached—either deliberately or carelessly. Right to privacy was deemed a fundamental right by the Supreme Court (*Justice K.S. Puttaswamy* (*Retd) & Anr v Union of India & Ors*[14]*)*, and to avoid the compromise of that privacy and hence the dignity of a citizen, drafting of new laws with effective implementation strategies is paramount.

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[14] 2017 SCC Online SC 996.