THE LEGAL ASPECTS OF THE GENETIC DISCRIMINATION OF INDIVIDUAL THIRD PARTIES

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Research Question: Why should genetic discrimination be distinguished from general anti-discrimination standards? What rights of individual third parties and what areas are at the greatest danger of genetic discrimination?

Purpose: The purpose of the project is to analyse whether and, if so, to what extent international human rights instruments are sufficient and adapted to protect third parties against genetic discrimination.

Method: The dogmatic analysis, which comprises two elements. The first one is a quantitative and qualitative method involving an analysis of international law. The second is the legal and dogmatic method involving a critical analysis of literature and case-law. The third one involves the comparative law method, the purpose of which is to compare the regulations applicable in the universal and regional human rights systems. The comparison will allow to find possible gaps and determine whether international law offers a model of legal protection against genetic discrimination against third parties.

Results: A number of legal acts contain general anti-discrimination standards. However, examples of genetic discrimination indicate that the current regulations may prove insufficient. It is my hypothesis that the result of the existence of gaps in the relevant definitions is the insufficient protection of individual third parties in comparison with that provided for studied individuals.

Organization: The research seem to indicate that the most sensitive are: the right to information, the right to privacy and the right to ignorance. The analysis of cases, legal acts and case-law initially reveals the image of five such groups: persons who have undergone a genetic test or medical interview; the relatives of that person; the spouse; the population group and future offspring. The analysis seems to indicate that if countries introduce sector-specific protection, this concerns insurance and employment (e.g. GINA – USA). The most vulnerable sectors seem to be insurance, employment, sport, education and adoption.

Society: The results of the project may not only provide a new perspective on the subject matter, but also introduce new paradigms that will speed up normative discourse on discrimination based on genetic characteristics against third parties and on additional topics such as genetic testing, genetic material trafficking and the consequences of disclosing genetic information to entities other than the subject.

Originality: The issue of the genetic discrimination of individual third parties has hitherto not been investigated by scientists in a comprehensive manner. It goes without saying that some publications do refer to the right to privacy, the right to information the right to ignorance (Chadwick 2014), and, what is also a subject-matter in some cases are issues relevant to two areas in the danger of genetic discrimination: insurance, and also employment (Lemke 2016). Nevertheless, none of the relevant dissertations refers to relations between the right to manage freely one's own personal data possessed by a studied individual and the protection of the rights of individual third parties.

Limitations / further research: As progress take place not only in medicine, but also on the social plane, we must not forget the aspect of social media. A 2015 study conducted among over m1000 respondents showed that 7.5% of posts on Facebook are related to health (Padrez, Ungar, Schwartz, Smith 2015). The purpose of the study was to verify whether it is possible to create a medical data repository based on information from social media. It was found that the number of health-related posts and the amount of persons willing to make their data available from Facebook (19%) could be sufficient to create such a database. The results of this study may translate into issues of sharing genetic data.

Keywords: discrimination, genetic data protection, third party rights.

ABOUT THE AUTHOR

Klaudia Kofin-Brończyk is currently a third year PhD candidate in Law at the University of Silesia in Poland. Her thesis title is "Genetic discrimination as a legal problem". Her research is focused on genetic data, human rights and third party rights. Klaudia has presented work at numerous conferences. Klaudia completed a fellowship at the Polish Ombudsman Office in Katowice during which she wrote legal opinions, especially on protecting vulnerable groups' rights.

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