



**Economic and Social
Council**

Distr.
GENERAL

E/CN.4/Sub.2/2004/38
23 July 2004

Original: ENGLISH

COMMISSION ON HUMAN RIGHTS
Sub-Commission on the Promotion
and Protection of Human Rights
Fifty-sixth session
Item 6 of the provisional agenda

SPECIFIC HUMAN RIGHTS ISSUES

Human rights and the human genome

**Preliminary report submitted by the Special Rapporteur,
Iulia-Antoanella Motoc* ****

* This report was submitted late so as to include the most up-to-date information possible.

** The endnotes are reproduced in the original language only.

Summary

Genetic information taken from individuals is a valuable tool of medical research and in fighting crime. However, it also risks opening the door to “genetic discrimination” whereby persons may be denied human rights and fundamental freedoms on the basis of their genetic make-up. For example, job applicants or persons applying for health insurance may be refused on the basis of genetic variations discovered in the course of medical tests, even though such information is not determinant in terms of future risk of disease or disability and the individual may be healthy at the time the application is made.

The report notes genetic discrimination in international and domestic legal instruments, notably the Universal Declaration on the Human Genome and Human Rights and the International Declaration on Human Genetic Data.

The question of the right to privacy also arises. Although everyone stands to benefit from the fruits of medical research, individuals are often reluctant to agree to genetic testing without assurances about the future uses of the information.

Indigenous peoples and the disabled are particularly vulnerable to misuse of their genetic information. In the case of the former, there is a fear that unfair generalizations might be made on the basis of group, rather than individual, genetic variations. The patenting and commercialization of genetic material is also a matter of debate. Concerning the latter, there is the spectre of science being abused to carry out a form of “disability cleansing” on the basis of prenatal genetic tests.

In her conclusion, the Special Rapporteur urges greater protection of privacy, regulation and/or prohibition of secondary uses of personal genetic information, targeted legislation and public education. States have the duty to explain, both to researchers and the public at large, the uses of genetic information and their possible impact on society.

Introduction

1. In its decision 2004/120 of 21 April 2004, the Commission on Human Rights, taking note of Sub-Commission resolution 2003/4 of 13 August 2003, decided to approve the decision of the Sub-Commission to appoint Ms. Iulia-Antoanella Motoc as Special Rapporteur to undertake a study on human rights and the human genome, based on her working paper (E/CN.4/Sub.2/2003/36). The Special Rapporteur was requested to submit her preliminary report to the Sub-Commission at its fifty-sixth session and her final report to the Commission at its sixty-first session. The present report is submitted in accordance with that request.
2. The Special Rapporteur recalls Commission resolution 2003/69, in which the Commission requested the Sub-Commission to consider what contribution it could make to the reflections of the International Bioethics Committee on the follow-up to the Universal Declaration on the Human Genome and Human Rights and to report on this matter to the Commission at its sixty-first session.
3. In her expanded working paper, the Special Rapporteur noted that recent advances in genetics seemed to have given rise to other conflicts between the health law, intellectual propriety and human rights regimes. The working paper tried to address some of these conflicts from a human rights perspective, taking into account four issues: the human genome: common heritage of mankind; human genetic manipulation and human rights; discrimination; and intellectual property and genetics. The specific aim of this preliminary report is to consider the question of discrimination in genetics, which will be fully considered in the rapport to be presented to the Commission at its next session.

I. GENETIC DISCRIMINATION - THE QUEST FOR A DEFINITION

4. Errors in our genes account for an estimated 3,000-4,000 hereditary diseases; they play a role in cancer, heart disease, diabetes and many other common conditions. However, not everyone with defective genes will be noticeably affected. Numerous factors in the environment have a considerable impact on a person's health. These factors, either alone or in conjunction with a certain gene, can augment or reduce an individual's risk of developing a disease. Diagnostics remain approximate and imperfect. According to data from the European Commission, more than 700,000 genetic tests are performed in the European Union (EU) annually. A European study revealed a 30 per cent error rate in molecular diagnostic tests and other genetic tests run by medical laboratories.
5. Diseases caused by defective genes may be treated, cured, or modified via gene therapy. Genetic testing can have important advantages to society. Genetic data banks, furthermore, are multiplying and growing all over the world.¹ In the past few years, countries such as Iceland, Estonia, Latvia, Singapore and the United Kingdom of Great Britain and Northern Ireland have created national genetic databases to capitalize on the knowledge of the human genome.² Such data are also providing answers to certain questions - concerning paternity, for instance, or the identity of law-breakers - posed by judges or police.
6. Genetic data tell us much but, like many other aspects of the genetic revolution that is under way, they are also a source of concern. Do they not risk opening the door to genetic discrimination, and lend themselves to uses contrary to human rights and basic freedoms? There

is a danger of reducing human life and social relationships to their genetic dimension, which can lead to social discrimination. In the words of the French expert Axel Kahn of the Institut Cochin, "If we are not careful, we will be preparing a society where the rights of genes replace human rights." Discoveries in genetics have opened the door to new notions of discrimination. As a result, people who are afraid of potential genetic discrimination may be discouraged from obtaining genetic information that could bring health benefits to them and their families.

7. Genetic discrimination describes the differential treatment of individuals or their families based on their actual or presumed genetic differences (social discrimination) as distinguished from discrimination based on having symptoms of a genetic-based disease (medical discrimination).³

8. Genetic discrimination can be distinguished from traditional disability-based discrimination in that the former includes only discrimination against those who are obviously asymptomatic at the time of the discriminatory act. Thus, genetic discrimination encompasses unfavourable employment decisions against an asymptomatic worker or applicant that are based on the individual's possession of a particular genetic condition that has yet to manifest itself.⁴ Thus, genetic discrimination is not based on the present abilities of the individual; the employer relies on the results of genetic screening to calculate the risk of future dysfunction and financial burden.⁵ Many individuals believe that they were not hired or were fired because they were at risk for genetic conditions. Other individuals are reluctant to change jobs because they fear losing health insurance coverage.

9. One of the most common forms of discrimination is rejection of health insurance based on a person's genes. Insurance companies assemble and use medical information to predict a person's risk of illness and death. They use this "risk" information to determine which individuals and groups they will insure and at what price. That information plays a decisive role for people in determining access to health care.

10. As in other comparable areas, discrimination particularly affects vulnerable groups such as women, children and indigenous people. Discrimination has also occurred when medical professionals counsel individuals about prenatal diagnostic testing, or tell them they should not have children. Adoption agencies have refused to agree to adoptions by persons on the basis of their genetic profile.⁶

II. GENETIC DISCRIMINATION IN INTERNATIONAL AND DOMESTIC INSTRUMENTS

11. In 1997, the General Conference of the United Nations Educational, Scientific and Cultural Organization (UNESCO) adopted the Universal Declaration on the Human Genome and Human Rights. The Declaration contains several provisions aimed at preventing genetic discrimination - for example, the right of everyone to respect for his/her dignity and human rights regardless of genetic characteristics. Furthermore, "[t]hat dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity" (art. 2 (b)). The Declaration also prohibits discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity. It also proposes strict rules for genetic research.

12. Attempts to protect genetic privacy have also been made at the international level, such as through the 1997 European Convention on Human Rights and Biomedicine. The Convention bans all forms of discrimination based on a person's genetic make-up and allows predictive genetic tests only for medical purposes. The Convention also sets out rules for medical research and recognizes a patient's right to know, but also not to know if he/she so wishes.

13. In resolution 2001/39 on genetic privacy and non-discrimination, the Economic and Social Commission urged States to ensure that no one shall be subjected to discrimination based on genetic characteristics and to take measures to prevent the use of genetic information and testing leading to discrimination or exclusion against individuals, particularly in social, medical or employment-related areas, whether in the public or the private sector.

14. In October 2003 UNESCO published its International Declaration on Human Genetic Data, which is a normative instrument that establishes the ethical principles that should govern the collection, processing, storage and use of human genetic data. Article 7 refers to non-discrimination and non-stigmatization as follows:

“(a) Every effort should be made to ensure that human genetic data and human proteomic data are not used for purposes that discriminate in a way that is intended to infringe, or has 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.

“(b) In this regard, appropriate attention should be paid to the findings of population-based genetic studies and behavioural genetic studies and their interpretations.”

As is the case when other “grounds of discrimination” are mentioned in human rights documents, further interpretation is needed. The aim of anti-discrimination provisions is to prohibit discrimination that impacts on human rights, fundamental freedoms and human dignity.

15. The majority of the provisions of domestic legislation affecting genetic privacy and discrimination are found in laws of more general application. They appear in constitutional law, laws governing professional confidentiality, an emerging set of provincial laws dealing with health information, data protection and human rights laws and the criminal law. Many of these general laws were drafted without genetics in mind. Still, they provide a substantial, if incomplete, legal framework for handling personal genetic information. However, the list of laws and proposed laws applying specifically to genetics is growing in developed countries, mainly in three areas - insurance, employment and criminal forensics.⁷

16. Some countries seem reluctant to introduce specific protection against genetic discrimination in human rights legislation. One reason may be that they see no need for such a genetic-specific approach, or they are concerned about the consequences of adding another ground of discrimination to existing legal, often constitutional documents. Others have

expressed concern that distinguishing genetic information from other grounds of disability in human rights legislation could reinforce genetic determinism: the belief that carrying a specific genetic mutation has a much more determinant and inevitable impact on people's health, well-being, and potentially even behaviour, than other health factors. This could contribute to stigmatization and discrimination, and thus have the contrary effect.⁸

III. THE RIGHT TO PRIVACY

17. Given the demands of privacy advocates for close to total individual control over medical information, the problem is how to maintain the objectives of medical progress and the improvement of public health through research that cannot be accomplished without ready, albeit controlled, access to medical information. The stored clinical proceedings and archived tissues of generations of patients have proven to be a unique source of new knowledge about diseases and their treatment.

18. The current doubt relating to the confidentiality of genetic data is an obstacle to progress in genetic testing. Health policy is not the only issue raised by storage of individual genetic data in databases. Respect for individual autonomy can be used as the basis to argue that individuals should not be forced to acquire genetic information about themselves.

19. One might even state that individual patients, every one of whom stands to benefit directly from the fruits of research conducted with medical information, have an ethical responsibility to add to the ongoing research by contributing the record of their experiences to this vast population database.

20. Individual consent is significantly easier to secure than group consent. Consent to genotyping can be included in the set of standardized consent and release of liability forms supplied to blood donors, hospital admissions, and patients scheduled for tests or surgical procedures. Questions may however be raised as to whether comprehensive consent to genotyping given by a possibly distressed patient at the time of first admission can be regarded as authentically informed or voluntary, especially with respect to research projects that have not yet even been designed. Indeed, consent to a specific existing research project does not imply consent to the use of genetic information for future research. Preserving the anonymity of specimens to protect individual donors also has the effect of depriving donors of any knowledge of how their specimens will be used later.

21. In accordance with the International Declaration on Human Genetic Data, "prior, free, informed and express consent, without inducement by financial or other personal gain, should be obtained for the collection of human genetic data, human proteomic data or biological samples, whether through invasive or non-invasive procedures, and for their subsequent processing, use and storage, whether carried out by public or private institutions. Limitations on this principle of consent should only be prescribed for compelling reasons by domestic law consistent with the international law of human rights" (art. 8 (a)).

22. Moreover, it is not enough to merely get consent from a potential study participant; the person must be informed of what their participation will entail in order for their consent to be considered valid. While there is some debate about just how much information a potential subject must be given in order for consent to be considered informed consent, it is generally

agreed that the participant must be fairly well informed in order for their consent to be valid. Otherwise, the potential subjects are not aware of which they are consenting to. For instance, in Iceland the rules on how to obtain consent for the processing of personal data issued in 2001 stipulate that the patient has to be informed in writing about the purpose of the project, the ways that the project will be conducted, security data, when personal data will be destroyed, and how and where the information will be used.

23. As a category of health-care information, genetic information is sensitive because genetic screening and monitoring reveal more personal information than other types of medical surveillance; a genetic disorder affects a person throughout his/her life. States have to maintain direct means of protecting patients from unauthorized disclosure of genetic information, including medical information. Among other necessary measures needed to prevent genetic discrimination is legislation and policies to protect the confidentiality of medical information.⁹

IV. EMPLOYMENT AND INSURANCE

24. Thus, the public's reticence in the face of use of genetic tests by insurers is based on the understanding that discrimination by insurers is just the sharp end of a much larger eugenic tendency that may be returning, along with the new ascendancy of genetics. Surveys in developed countries show that a large percentage of people with genetic disorders in their families have been discriminated against by insurers.

25. Competitive use of genetics by insurers would be likely to lead, for example, to destruction of the existing system of pooling good and bad risks. Insurers are already awarding lower premiums to those judged healthy; taken to an extreme this could lead to a "genetic underclass" of people unable to access insurance and the social goods that are dependent upon it, such as mortgages.

26. Cases of discrimination by employers have also been reported. Workers, employers and third parties might seek to obtain genetic information collected by health-care providers during screening or monitoring in the workplace. Workers need the information in order to make employment or health-care decisions. Employers use the information in considering a worker's aptitude to complete a given job. Other parties, such as unions, would like such information in order to insure overall workplace safety.¹⁰

27. It should be unlawful for employers, employment agencies, labour organizations and training programmes to hire or fire anyone because of genetic information. They cannot provide different compensation, terms, conditions or privileges of employment to employees because of genetic information. Furthermore, they cannot use genetic information to limit, segregate or classify employees in any way that would deprive them of opportunities.

28. Even when the employer provides the genetic services, only the employee and his or her health-care professional should be given access to individually identifiable information obtained from these genetic services. Health-care professionals should provide genetic information to an employer only in aggregate terms that do not disclose the identity of specific employees.

29. If an employer, employment agency, labour organization or joint labour-management committee possesses genetic information, it must treat this information as part of a confidential medical record and keep it in separate medical files. Additionally, it cannot disclose genetic information unless so requested by the employee or a court order.

V. VULNERABLE GROUPS

Indigenous people

30. “Scientists say it’s just DNA. For an Indian, it is not just DNA, it’s part of a person, it is sacred, with deep religious significance. It is part of the essence of a person. To us, any part of ourselves is sacred.”¹¹ The genes of some indigenous peoples are of special interest to researchers because their relative homogeneity facilitates the search for correlations between specific genes and phenotypic traits. During the 1990s the Human Genome Diversity Project undertook to collect DNA samples from hundreds of indigenous groups for this purpose. The project has since disbanded, but indigenous peoples are still the subjects of genetic research. They are concerned about the patenting and commercialization of the information derived from these samples, the lack of fully informed consent by many of those from whom samples were taken, the potential for genetic discrimination based on the identification of group differences, and the disproportionate allocation of public funds to genetic research rather than to direct health-care and prevention programmes.

31. The problem here is the usurpation of group identity in favour of an individualistic one that may not be reflected in other cultures. Many cultures hold a different notion of the role of the individual in a society. By overriding the wishes of the group and conferring only with an individual, researchers diminish the authority of the group to make compulsory decisions concerning its members. This violates the draft United Nations declaration on the rights of indigenous peoples by compromising the right to self-determination and cultural independence. It is necessary to incorporate all levels of consent in a way that conform to the cultural norms of a particular group.¹²

32. Despite the increased measures of protection, the HapMap¹³ is still vulnerable to misuse. The public nature of the project has cast aside questions of individual ownership and commercialization, yet unrestricted access to the database creates an opportunity for abuse. HapMap cannot guarantee that the public will not mischaracterize results of the study and associate negative results with certain groups. Unless there are regulatory measures to enforce sanctions, such groups and individuals within those groups will be unprotected against discrimination and social marginalization.

33. Very little genetic-diversity research has focused on the health of indigenous peoples. Across populations, different genes may be implicated in what appears to be the same syndrome, for example as non-insulin-dependent diabetes mellitus. This means that diversity research can play a very important role in ensuring that therapeutic methods are effective in diverse populations. Another real danger is that research will neglect the genetic bases of disease among relatively isolated, traditional communities.

34. A brief glance at the future plans of major pharmacogenomic companies shows that some of their work is relevant to the specific health concerns of indigenous peoples, such as diabetes and osteoporosis. Most recent pharmacogenomic research has been directed at cancer, asthma and allergies, cardiovascular disease and neurodegenerative conditions such as Parkinson's and Alzheimer's diseases. Indigenous peoples' main concern for the future should be assuring the responsiveness of pharmacogenomic research to the needs of genetically distinct but marginalized societies, so that they fully benefit from new medical technologies rather than remaining - insofar as genetic research is concerned - an academic sideshow.¹⁴

35. With regard to the sharing of benefits, the International Declaration provides that "benefits resulting from the use of human genetic data, human proteomic data or biological samples collected for medical and scientific research should be shared with the society as a whole and the international community". Benefit is defined broadly and includes, among other things:

- “(i) Special assistance to the persons and groups that have taken part in the research;
- “(ii) Access to medical care;
- “(iii) Provision of new diagnostics, facilities for new treatments or drugs stemming from the research;
- “(iv) Support for health services;
- “(v) Capacity-building facilities for research purposes;
- “(vi) Development and strengthening of the capacity of developing countries to collect and process human genetic data, taking into consideration their specific problems; and
- “(vii) Any other form consistent with the principles set out in this Declaration.”

36. The Permanent Forum designated on Indigenous Issues has “indigenous knowledge” as the theme of its 2005 session to bring attention to the need for protection of indigenous peoples' rights to free prior and informed consent regarding the use of their indigenous knowledge, innovations and practices, both traditional and contemporary and including cultural expressions, art forms, and related to the utilization of genetic resources.

The disabled

37. With every year, the advance of genomic science brings new paradoxes that have to be resolved. Disabled parents are now seeking the right to choose not to have disabled children, on the basis of new genetic screening tests that are becoming more widely available. Parents have expressed the view that they should be allowed to “choose” children more like themselves. The issue has divided opinions amongst obstetricians and gynaecologists; some who have considered the matter regard the notion of deliberately choosing an embryo manifesting genes for deafness or dwarfism as pandering to the desires of parents rather than reflecting the best interests of a child.

38. The social model of disability shifts responsibility away from the disabled person's biological, psychic or cognitive equipment and towards the social, institutional and physical world designed with the characteristics and needs of the non-disabled in mind. The social model has yet to gain wide currency in many societies. The public understanding of disabilities, namely as "illnesses" or "deformities" to be eradicated, is difficult to maintain when the eradication of difference through genetic manipulation is within reach.¹⁵

39. This can be seen as an attempt to manipulate science to carry out a form of "disability cleansing". It reflects a stereotyped conception of the perfect child, which itself can be manipulated by the media and public opinion. We must listen to what patients' associations have to say on the subject of genetics. Patients and their families have concrete expertise of their own which must be taken into account.

VI. CONCLUSION

40. The possible use of personal genetic information against individuals may justifiably stifle acceptance of further genetic inquiry. Failure to protect privacy and prevent discrimination therefore threatens greatly to diminish the potential for genetics to improve health care.

41. The key to benefiting from genetic information while avoiding its negative aspects lies in determining how information will be used beyond the health-care needs of the individual to whom the information pertains. Regulation and, in some cases, prohibition on secondary uses of personal information are indispensable once personal genetic information has been collected. DNA collected and analysed for health-care purposes should not automatically be available for further uses, including research, if the DNA can be linked to an identifiable individual.

42. General laws governing personal health information can frequently protect genetic information, even if these laws are sometimes inadequate. The fact of genetic information imparts new intensity to the need to protect personal health information. Legislation to address specific issues relating to genetic testing may be required to complement existing legislation. Legislation related to the taking of DNA from criminal suspects and the establishment of DNA databanks relating to convicted offenders must be carefully monitored to prevent an unwarranted enlargement of its scope.

43. Public education is necessary to protect genetic privacy and prevent discrimination. Governments in particular have a duty to explain the uses of genetic information and their possible impact on society and to educate the public and researchers about what the results of genetic studies mean and do not mean. Research should focus on individual variations within populations, not among populations. Researchers need to shape their studies and present their results cautiously. They should define the population being studied precisely. They should also explain to what extent the threat of disease can be ascribed to genetic variants and how such variants interrelate with environmental factors. Where these matters are not well understood, doubts should be acknowledged.

44. Even though new treatments still belong to the future and the emphasis is currently on developing genetics for diagnostic purposes, we are at a turning point when it has become crucial to think judiciously about the failures of these technologies before we generalize their use.

45. Genetic tests are expensive, especially when they are monopolized by private companies. We must consider the implications of genetic tests from a public health perspective. In the words of the 1997 Jakarta Declaration on Health Promotion “decision makers must be firmly committed to social responsibility. Both the public and private sectors should promote health by pursuing policies and practices that: avoid harming the health of other individuals; protect the environment and ensure sustainable use of resources; discourage unhealthy marketing practices; safeguard both the citizen in the marketplace and the individual in the workplace; and include equity-focused health impact assessments as an integral part of policy development.”

Notes

¹ In 2002 an international research consortium of several countries including Nigeria, Japan, China and the United States launched a project called the International HapMap. The HapMap hopes to accelerate the discovery of genetic relationships linked to common yet complex diseases such as heart disease, cancer, asthma and diabetes. It involves compiling genetic samples to map the human genome according to haplotypes, blocks of DNA that contain genetic variation. Combining resources from both public and private agencies, the HapMap will be based on 200-400 genetic samples from each of four different populations: the Yorubas in Nigeria, the Japanese, the Han Chinese and individuals in the United States with Northern or Western European ancestry.

² In December 1998, Iceland’s Parliament passed legislation creating a national centralized database of health information and DNA samples of the country’s citizens. In December 2000, Estonia passed the Human Genes Research Act, setting a legal and ethical framework for the operation of a population genetic database of at least three quarters of the country. In December 2002, Singapore announced the official opening of the Singapore Tissue Network, a national, non-profit tissue and DNA bank that will contribute to a better understanding of human diseases. In September 2003, the United Kingdom Biobank published its first draft of the Ethical and Governance Framework, a protocol for the collection of the DNA samples and medical records of 500,000 volunteers.

³ L. Geller et al., “Individual, Family and Societal Dimensions of Genetic Discrimination: A case study analysis”, *Science and Engineering Ethics*, vol. 2-1, 1996, pp. 71-88.

⁴ A. Hsieh, A Nation’s Genes for a Cure to Cancer: Evolving Ethical, Social and Legal Issues Regarding Population Genetic Databases, *Columbia Journal of Law and Social Problems*, vol. 137, Spring 2004, p. 359.

⁵ [No text provided.]

⁶ Geller, op. cit.

⁷ Trudo Lemmens, Yann Joly and Bartha M. Knoppers, “Genetics and Life Insurance: A Comparative Analysis”, *GenEdit*, vol. II, No. 2, 2004, B.M. Knoppers (ed.), *Populations and Genetics: Legal and Socio-Ethical Perspectives*, Martinus Nijhoff Publishers, Leiden, 2003.

⁸ Ibid.

⁹ L.B. Andrews and A. Jaeger, “The Human Genome Initiative and the impact of genetic testing and screening technologies”, *American Journal of Law and Medicine*, vol. 17, 2002; J. Kulynych, D. Korn, *The Genetics Revolution: Conflicts, Challenges and Conundra*, and “Use and Disclosure of Health Information in Genetic Research: Weighing the Impact of the New Federal Medical Privacy Rule”. *American Journal of Law and Medicine*, vol. 28, 2002.

¹⁰ For instance, there is a large amount of research aimed at discovering genetic differences in people’s susceptibility to environmental chemicals, including chemicals found in the workplace, and it is likely that employers will want to use genetic tests to exclude those who are susceptible, rather than clean up their workplace.

¹¹ Debra Harry and Frank Dukepoo, *Genes and Genetics: What Indians Should Know About the New Biotechnology*, 1998.

¹² Z.Q. Khan, *Colonialism Revisited: Insights into the Human Genome Diversity Project*, *Journal of Law and Social Challenges*, Spring 1999.

¹³ Unlike the Human Genome Development Project, the HapMap’s goal is biomedical: to create a resource that can be used in many future studies of health and disease. In addition, unlike the Project, which would have studied primarily small, isolated populations, the International HapMap Project will study only large, less vulnerable populations. Another problem with the interpretation of genetic variation is assuming that “genetic” means “unchangeable”, and that because someone has a particular genetic variant they are “doomed” to get a disease. These incorrect assumptions are called genetic determinism. Genetic determinism overlooks the strong contributions that environmental factors make to diseases and that there may be ways to reduce the risk of getting those diseases. So, even though people may have genetic variants that heighten their risk, many of them will never fall ill. Genetic discrimination and genetic determinism are both potential problems that can arise from any study in which researchers relate genetic variation to disease risk.

¹⁴ R.L. Barsh, “Pharmacogenomics and Indigenous Peoples: Real Issues and Actors”, Yeshiva University, *Cardozo Journal of International and Comparative Law*, 2003.

¹⁵ H. Koh, “Different but Equal: The Human Rights of Persons with Intellectual Disabilities”, *Maryland Law Review*, vol. 63, 2004.
