The Effect of Genetic Determinism and Exceptionalism on Law and Policy

Michael Sharp

“We used to think our fate was in the stars. Now we know [it] is in our genes.”

– James Watson, 1989

Genetic determinism and genetic reductionism are important concepts that, in the latter half of the twentieth century, have caused the geneticization of medical and social issues. In turn, the idea of genetic exceptionalism became prevalent in legislative and policy development. Exceptionalism, which has arisen with issues relating to HIV, is associated with the idea that certain material and information is distinct from standard material or information and requires special governance for its acquisition, possession, and use. As a result of genetic exceptionalism, laws and policies around the world in the areas of informed consent, privacy, patenting and discrimination, have been influenced in different ways and at varying levels. The purpose of this study is to examine this influence as there is little discourse on the impact of genetic determinism and exceptionalism on policy development.

There are several theories that have developed about the role of genetics in human existence. The most commonly used terms are determinism, reductionism, essentialism, and exceptionalism. Determinist theory provides that all events are inevitable consequences of antecedent causes; denying the possibility of free will. For example, the statement ‘It’s in my blood/genes, I can’t avoid it’ is deterministic. In a reductionist framework, the belief is held that uncovering the base-pair sequence of the human genome will lead to an understanding of what it is to be human because the whole can be understood as a sum of its component parts. Genetic essentialism also attributes human nature to our genetic make-up because our DNA is essential (although not necessarily sufficient) to making a person the way they are. Finally, exceptionalism asserts that genetic material and information is unique from other biological material and medical information and requires special laws and policies to govern its use.

As genetic theory has moved beyond the one gene – one trait paradigm into a complex networking theory of gene expression and environmental interaction, the ELSI (ethical, legal, and social issues) academic community has since followed with the abandonment of deterministic ideas. It is hypothesized that policy instruments have also begun to follow this trend and that legislation, being the least flexible, will react even more slowly. It is difficult to predict how deterministic and exceptionalist attitudes in public perception have been altering as public attitude is informed by science and media, but also influenced by the creation and implementation of policy and legislation.

The ethical and pragmatic issues of this project can be generalized to the examination of how policy and law is influenced by theory, media hype and public attitudes. What is the responsibility of law and policy-makers to ensure that their document drafting is properly informed and if policy is incorrectly informed, how would one go about and fix it? In the past, public representations of genetics have featured
An ongoing compilation and analysis of pertinent legislative and policy documents is being performed to investigate these issues. In large part, documents were compiled through the HumGen International database, explicit statements for or against deterministic or exceptionalist attitudes are being noted, and the presence of longitudinal trends in attitude are being examined. Although results are preliminary, it appears that the idea of genetic determinism is being rejected by contemporary policy-makers; however, exceptionalism is still prevalent as genetic issues have been afforded special treatment in many laws and policies around the world.

Policy statements exist that demonstrate a determinist or exceptionalist influence; however, there are also statements that are explicitly against this. Occasionally a mixture of statements can appear within the same document as a paradox. For example, a 2003 UNESCO declaration contains an anti-reductionist statement followed immediately by a pro-exceptionalist statement. A second juxtaposition of explicit statements of theory occurs in a Nuffield Council report where one of the most articulated statements of genetic exceptionalist justifications is cited, followed by an anti-exceptionalist conclusion that these reasons apply to other medical information and that all medical data should be kept with special care:

The HGC [Human Genetics Commission] considers that genetic information:

1. is uniquely identifying and provides information about family relationships;
2. can be obtained from a small sample, possibly taken without consent;
3. can be used to predict future events;
4. may be used for purposes other than those for which it was collected;
5. is of interest to third parties such as employers and insures, families, friends, potential spouses;
6. may be important for determining susceptibility and effectiveness of treatment;
7. can be recovered from stored specimens even after many years.

1.9 However, against these arguments in favour of genetic exceptionalism, we observe that the majority of the seven features listed above have parallels in other areas of medical practice, for example testing for human immunodeficiency virus (HIV), and cholesterol testing…

1.10 Given the similarities between genetic and other forms of personal information, it would be a mistake to assume that genetic information is qualitatively different in some way. In our view, the information provided by a medical test is the key to considering its implications, not whether the test involves genetic data.

This statement can be seen as an example of the movement away from the strong genetic exceptionalist message in the policy making of the 1990s.

Whether or not an explicit statement exists, the exceptionalist attitude is implicitly demonstrated by the volume of legal and policy instruments addressed specifically to genetic issues. These laws, for the most part, remain untested in the courts and their impact is unclear. The courts could take into account the current understanding of genetics when applying these laws and can treat genetic material or information the same as other biological material or medical information. A more detailed analysis of specific laws and policy statements can also lead to policy reform recommendations that would reflect the more complete, current genetic theory.

Michael Sharp is a third year law student, Faculty of Law, University of Alberta, Edmonton, Alberta.

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11. Supra note 8.