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THE GERMAN HUMAN GENOME-PHENOME ARCHIVE

GHGA Webinar

Understanding Genetic Discrimination

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What we'll cover

1. Two Concepts of Discrimination
2. The Asymptomatic Definition of Genetic Discrimination
3. Towards a Broader Understanding
    a. The 'Warrior Gene' Case
    b. The Havasupai Case
4. How to Address Genetic Discrimination?

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1. Two Concepts of Discrimination

Not all differential treatment of people on the basis of genetics constitutes GD.

GD occurs when treating someone differently on the basis of genetic characteristics thereby creating a disadvantage for them.

Non-moralised concept:
Discrimination means treating someone differently thereby creating a disadvantage for them (and this is not necessarily morally wrong).

Moralised concept
Discrimination means treating someone differently thereby creating an unfair (morally unjustifiable) disadvantage for them.

Example: 'positive discrimination' counts as discrimination only if we apply the non-moralised concept; otherwise discrimination cannot be 'positive' or morally acceptable.

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2. The Asymptomatic Definition

The concept of GD was popularised by Billings et al. (1992) to give a name to a new threat of health-related discrimination.

Case 1. Disability

John has a disability and sits in a wheelchair. John is applying for a lecturer position at a University. Behind closed doors, the decision is made to give the job to someone else because working with John would require making additional, laborious arrangements due to his disability.

Case 2. Huntington's

Kate's father has Huntington's disease. Kate is applying for the same job as John. Behind closed doors, the decision is made to give the job to someone else due to fears that Kate will develop the disease too and, if she does, will no longer be able to work.

GD targets asymptomatic individuals (the "asymptomatic ill")—on this understanding, Kate (but not John) has suffered GD.

2. The Asymptomatic Definition

GD has been a reported concern in healthcare, insurance, employment, education, sports, immigration, housing, and forensic profiling; but understanding the harms of GD requires a broader definition not limited to asymptomatic cases (Kaiser et al. 2024, Lemke 2013).

Reasons not to limit the scope of GD to asymptomatic individuals:

(1) The possibility to suffer from discrimination based on genetic characteristics does not seem to disappear once someone becomes symptomatic.
(2) This definition also seems to be based on an unacceptable 'genetic exceptionalism'.

Genetic Exceptionalism
The idea that genetic information "so distinct in concept, practical implications, and moral import that it deserve[s] to be singled out from other types of health-related information"—that it has certain properties that launch it "into some unique universe of moral, legal, and policy concerns" (Murray 2019).

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3. Towards a Broader Understanding

Case 3. Mãori ‘Warrior Gene’

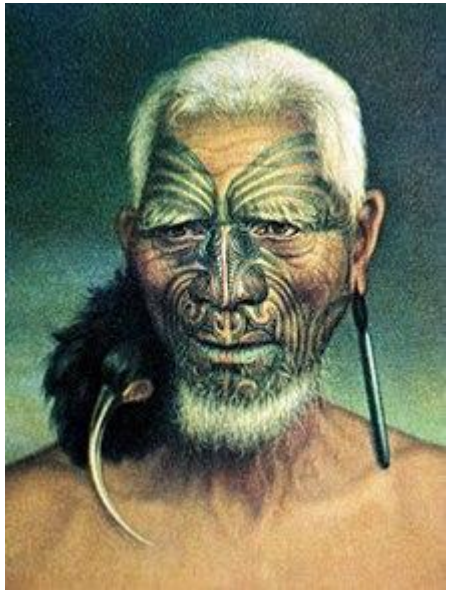

Image source: Wikipedia

MAI Review, 2009, 2, Target Article

“Warrior genes” and the disease of being Māori

G. Raumati Hook

Abstract: The propensity of Māori towards violence and aggression has been assigned to the expression of a unique monoamine oxidase gene (*MAO*) popularly known as the ‘Warrior Gene’. This assignment suggests that the violence supposedly exhibited by Māori is due to the very nature of Māori himself. Although this assignment and assessment by Pākehā falls into the usual pattern of stereotypes offered about Māori over the last 200 years, it is instructive to examine the truth of the matter, since it was based on the results of a scientific investigation. Behavioural problems have been reported in people who have exhibited abnormalities in the expression of unusual forms of *MAO* genes and their conditions have been variously described as diseases. Could those Māori who express the ‘warrior’ gene be diagnosed as having a medical condition similar to those with diseases such as Brunner syndrome or Norrie disease, two diseases involved in the expression of abnormal *MAO* genes? As a consequence is being Māori just another disease?

Keywords: gene expression; Māori domestic violence; monoamine oxidases; warrior genes

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3. Towards a Broader Understanding

Here, genetics comes to be involved in racial discrimination —the research gives “a pseudo-scientific gloss to racist beliefs” (Genetic Literacy Project 2023).

Branding indigenous people as savage, violent, and cruel is a colonial project to justify colonial crimes.

(Anti-)social bevahiour depends on many, mostly social factors (poverty, social exclusion, etc).

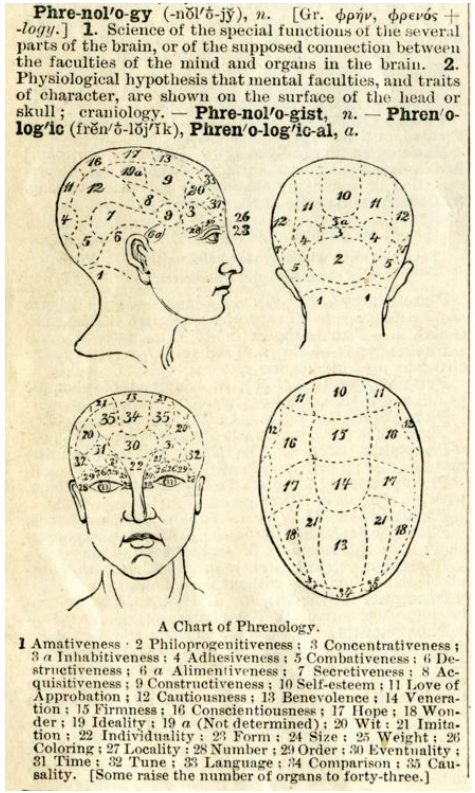

Image source: Wikipedia

3. Towards a Broader Understanding

Case 4. Origins of the Havasupai

Image source: Wikipedia

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Genomic Justice for Native Americans: Impact of the Havasupai Case on Genetic Research

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Abstract

In 2004, the Havasupai Tribe filed a lawsuit against the Arizona Board of Regents and Arizona State University (ASU) researchers upon discovering their DNA samples, initially collected for genetic studies on type 2 diabetes, had been used in several other genetic studies. The lawsuit reached a settlement in April 2010 that included monetary compensation and return of DNA samples to the Havasupai but left no legal precedent for researchers. Through semistructured interviews, institutional review board (IRB) chairs and human genetics researchers at US research institutions revealed their perspectives on the Havasupai lawsuit. For interviewees, the suit drew attention to indigenous concerns over genetic studies and increased their awareness of indigenous views. However, interviewees perceived no direct impact from the Havasupai case on their work; if they did, it was the perceived need to safeguard themselves by obtaining broad consent or shying away from research with indigenous communities altogether, raising important questions of justice for indigenous and minority participants. If researchers and IRBs do not change their practices in light of this case, these populations will likely continue to be excluded from a majority of research studies and left with less access to resources and potential benefit from genetic research participation.

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Taking stock …

1. GD is intersectional—it may overlap with and relate to racial, gender, and other forms of discrimination. *To the extent that genetics allows us to gain deeper insights into people's (biological) life, it also allows discriminatory practices to go deeper.*
2. GD is not a mere personal concern—it picks out someone *as a member of a certain genetically defined group* for disadvantaged treatment (Feinberg 1987: "profound offence").
3. GD can be based on good or bad science—it can be 'rational' or 'irrational'.
4. GD does not have to be intentional, nor direct—for researchers, it is often about becoming *complicit in* pre-existing discriminatory practices.
5. The conceptual and practical relationships between GD and other forms of social injustice (oppression, stereotyping, marginalisation, etc) are complex and require further analysis (see, e.g. Young 1990).

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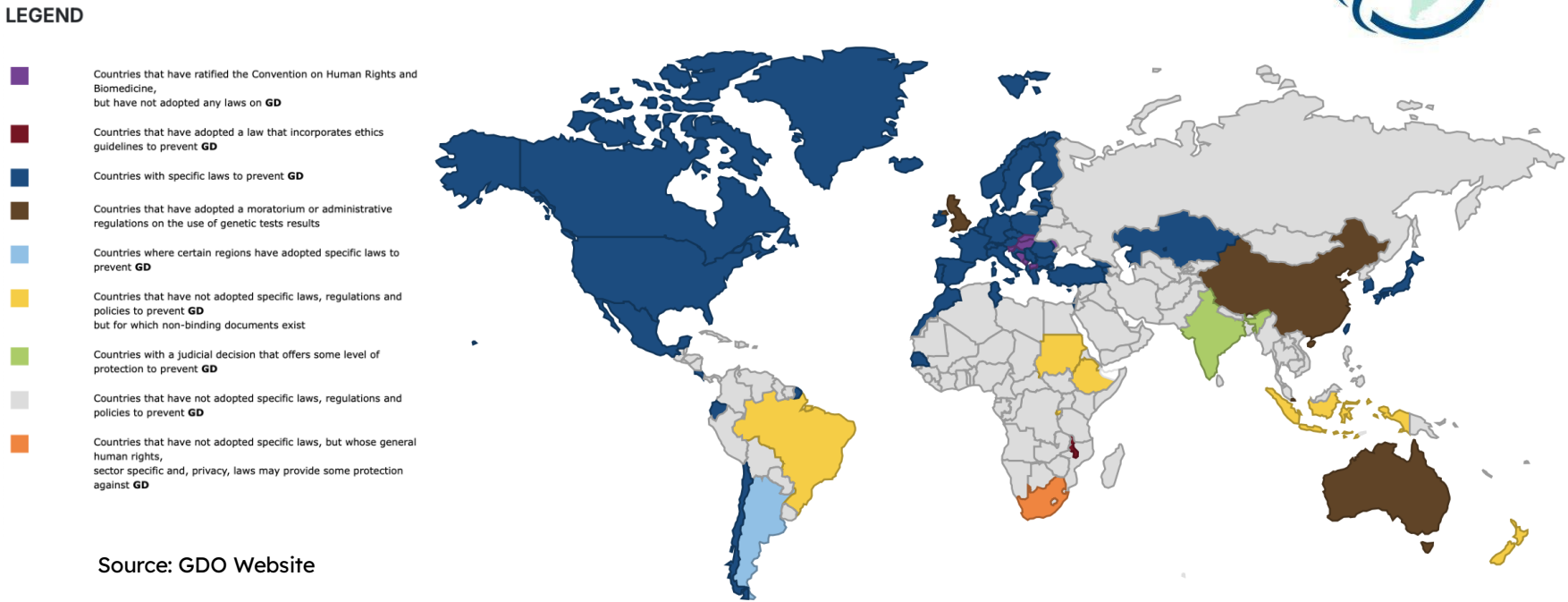
4. How to Address Genetic Discrimination?



Source: GDO Website

4. How to Address Genetic Discrimination?

(Some of the) challenges:

1. Laws need to be specific enough to be actionable but this makes it hard to capture the many facets of GD.
2. The 'soft law' approach doesn't come with the same actionability.

> "The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. [...] No one shall be subjected to discrimination based on genetic characteristics..." (Universial Declaration on the Human Genome and Human Rights, 1997)

3. It's often poorly understood how new technologies relate to the risks of GD. E.g.:

    a. Epigenetics

    b. Polygenic Risks Scores (PRS)

    c. DNA-methylation

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