# 12 FINGERS OR ONE, IT'S HOW YOU PLAY?

## Genetic discrimination in the Australian workforce

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This article examines the issue of genetic discrimination in the Australian workforce, using the movie *Gattaca* as a case study. More so than other pop-culture films, *Gattaca* seems to have struck a chord with academics, politicians and law reform bodies that are debating the best way to legally regulate genetic information. The 2003 Australian Law Reform Commission report entitled 'Essentially Yours: The Protection of Human Genetic Information in Australia'[1] contains references to the movie *Gattaca*, suggesting that this fictional work has (at least to a small degree) informed law reform proposals.

Legal analysis of a popular culture movie therefore has academic merit, especially in an area like human genetics where the law struggles to keep pace with technology, leaving it susceptible to legislative responses driven by public opinion. When commenting on the role that creative arts play in bioethical debates, Tsitas[2] highlights the important contribution that fiction writers make:

> [T]hey step out of the now, the probable, the literal, the factual and explore the unthinkable, the unimaginable. Fiction writers are not constrained by facts, law or current reality, they ask 'what if'? and then take us down that path.[3]

Over the last ten years, the challenge for legislators in respect of genetic discrimination has been to balance the expectations of the public (informed heavily by pop-culture) against the advancing sophistication of genetic testing. The Federal Parliament's decision to outlaw genetic discrimination in the workplace is a measured response, adopted in an environment where the predictive value of genetic information is still developing.

### An Introduction to *Gattaca*

*Gattaca* paints a bleak image of Earth 'in the not too distant future', where employment and social status at the Gattaca Aerospace Corporation are a by-product of genetic make-up, rather than personality, loyalty or perseverance. Vincent Freeman (Ethan Hawke) is a naturally born baby in a society where pre-implantation genetic diagnosis (in essence embryo screening) can ensure that a child receives the best hereditary traits of its parents. As a result of Vincent's 'faith birth', he is born with a 60 per cent chance of suffering from a neurological condition, a 42 per cent probability of suffering manic depression, an 89 per cent chance of suffering attention deficit disorder and a 99 per cent chance of suffering from a heart disorder. His life expectancy is expressed accurate to one decimal point — 30.2 years.

Vincent's childhood dream had been to fly into space, and his early years were dedicated to the acquisition of knowledge and the achievement of physical fitness sufficient to realise this goal. He is initially unsuccessful with job applications, on the basis that pre-employment genetic screening exposes his predisposition towards a number of undesirable genetic conditions. Vincent ultimately gains employment at the Gattaca Aerospace Corporation by borrowing numerous DNA samples (and ultimately assuming the identity of) Jerome Morrow, a genetically superior individual who is wheelchair bound after a failed suicide attempt. These DNA samples are necessary for Vincent to overcome the initial obstacle of gaining employment and are vital in maintaining the charade of genetic perfection required of Gattaca astronauts.

By critiquing the obstacles to employment within the Gattaca Aerospace Corporation, we can draw specific attention to the issue of genetic discrimination and the social implications that may flow from genetic discrimination in the workforce.

### Genetic discrimination

Genetic discrimination can be defined as the differential treatment of an asymptomatic individual on the basis of real or assumed genetic differences or characteristics.[4] Essential to this definition is the genotype/phenotype distinction drawn by Wilhelm Johannsen in 1911.[5] Genetic discrimination is based on a person's genotype (genetic makeup) which means an individual is discriminated against based on their genetic predisposition towards a particular disease, regardless of whether that disease *ever* manifests itself. Professor Margaret Otlowski reasons:

> once a disease has become manifest, discrimination on the grounds of that disease would not constitute genetic discrimination as at that point, the discrimination is based on the person's phenotype (the disease as expressed), and would amount to discrimination on the basis of actual disability rather than genetic status.[6]

Given the wide consensus as to the meaning of genetic discrimination, *Gattaca's* implication that Vincent Freeman had been the subject of genetic discrimination ('genoism') is technically incorrect. Vincent's myopia and heart condition represent physically observable, expressed symptoms and discrimination on these bases would constitute disability discrimination rather than genetic discrimination.

REFERENCES

1. Australian Law Reform Commission, *Essentially Yours: The Protection of Human Genetic Information in Australia*, Report No 96 (2003).

2. Evelyn Tsitas, 'The Role of the Creative Arts in Bioethical Debates' (2006) 6(2) *Queensland University of Technology Law and Justice Journal* 255.

3. Ibid 260.

4. Lisa Geller et al, 'Individual, family and societal dimensions of genetic discrimination: A case study analysis' (1996) 2(1) *Science and Engineering Ethics* 71.

5. Wilhelm Johannsen, 'The genotype conception of heredity' (1911) 45 *American Naturalist* 129.

## Application of the Australian legal matrix to *Gattaca*

The assertion in *Gattaca* that genetic discrimination is illegal, presupposes that laws exist outlawing the practice of genetic discrimination in the workforce. After acknowledging the genotype/phenotype dichotomy, it is perhaps ironic that in Australia, genetic discrimination in employment is made illegal by the *Disability Discrimination Act 1992* (Cth) section 15.[7] One difficulty faced by Australian workplaces is that until recent legislative clarification, it had been unclear whether a genetic predisposition towards a disability would meet the definition of 'disability' contained in section 4 of the *Disability Discrimination Act*. As a consequence, if a genetic predisposition towards disability was not captured by the definition of 'disability', it was arguable that genetic discrimination in Australia was legal. Appreciating this potential for confusion, the Australian Law Reform Commission ('ALRC') and the Australian Health Ethics Committee ('AHEC') in a 2003 joint report to the Australian Government,[8] recommended that the definition of 'disability' in the *Disability Discrimination Act* be amended to clarify that the legislation applied to discrimination based on genetic status.

The Australian government's response to the recommendations of the ALRC was published on 9 December 2005.[9] The government supported the recommendation that the definition of disability in the *Disability Discrimination Act* include a genetic predisposition towards a disability.[10] However, implementation was slow in coming, and it was not until the commencement of the *Disability Discrimination and Other Human Rights Legislation Amendment Act 2009* (Cth) that discrimination based on genetic status was explicitly made illegal.[11] In the context of Australian law, the assertion in *Gattaca* that genetic discrimination is illegal has proven to be correct. At the time the movie was released (1997) however, it could not be conclusively stated that genetic discrimination was illegal in Australia.

Even if genetic discrimination is established by an employee prima facie, the *Disability Discrimination Act* provides for circumstances where this discrimination is lawful. If an employee, because of their disability, is unable to carry out the inherent requirements of the job, it is lawful for an employer to discriminate on the grounds of that genetic disability.[12] It is also lawful for an employer to genetically discriminate if they would suffer unjustifiable hardship by not being able to do so.[13] This is where *Gattaca's* treatment of genetic discrimination is at best incomplete and at worst, disingenuous.

It is acknowledged that discriminating against an asymptomatic individual on the basis of a genetic predisposition towards a disability is an ethically-challenging notion. After all, the genetic condition may never manifest itself physically, or if it does, it may manifest quite late in life. *Gattaca's* portrayal of its protagonist's (Vincent's) hardships speaks subtly yet powerfully about the undesirability of genetic discrimination. The tagline for the film spruiks that 'there is no gene for the human spirit', and suggests humans are capable of achieving anything regardless of their genetic condition. The movie underscores how genetic discrimination in the workplace reinforces genetic discrimination in society. As a result, *Gattaca* highlights the real danger that a genetic underclass may evolve; a class with a diminished social status and limited employment opportunities.

If ever genetic discrimination could be justified (and it is suggested in this article that it can), then surely an organisation like the Gattaca Aerospace Corporation should have that prerogative. Contra to the strong moral stance taken against genetic discrimination in *Gattaca,* it is suggested that the *Disability Discrimination Act* would allow the Gattaca Aerospace Corporation to genetically discriminate when hiring and firing employees. Section 21A of the *Disability Discrimination Act 1992* (Cth) states:

(1) This Division does not render it unlawful for a person (the discriminator) to discriminate against another person (the aggrieved) on the ground of a disability of the aggrieved person if:

(a) the discrimination relates to particular work (including promotion or transfer to particular work); and

(b) because of the disability, the aggrieved person would be unable to carry out the inherent requirements of the particular work, even if the relevant employer, principal or partnership made reasonable adjustments for the aggrieved person.

Assume for a moment that Vincent Freeman was genetically predisposed to a neurological condition (Huntington's disease), myopia and a heart condition, but is currently asymptomatic. This article suggests that it would be lawful for the Gattaca Aerospace Corporation to refuse to employ Vincent on the basis of his genetic condition, given that he would be unable to carry out the inherent requirements of the job. When assessing the inherent requirements of a job, McHugh J in *X v The Commonwealth*[14] stated:

> Employment is not a mere physical activity in which the employee participates as an automaton. It takes place in a social, legal and economic context. Unstated, but legitimate employment requirements may stem from this context. It is therefore always permissible to have regard to this context when determining the inherent requirements of a particular employment.[15]

These broader considerations need to be read alongside the joint judgment of Gummow and Hayne JJ, who concluded that the inherent requirements of a job must entail the circumstances in which the particular employment will be carried on.[16]

> Those circumstances will often include the place or places at which the employment is to be performed and may also encompass other considerations. For example, it may be necessary to consider whether the employee is to work with others in some particular way. It may also be necessary to consider the dangers to which the employee may be exposed and the dangers to which the employee may expose others.[17]

The physical rigours of working as an astronaut are intense. The Gattaca Aerospace Corporation

6. Margaret Otlowski, 'Exploring the Concept of Genetic Discrimination' (2005) 2(3) *Journal of Bioethical Inquiry* 165, 166.7.

7. *Disability Discrimination Act 1992* (Cth) s 15(1).

8. Australian Law Reform Commission, above n 1.

9. *Government Response to Recommendations from Essentially Yours: The Protection of Human Genetic Information in Australia*, Report No 96, <alrc.gov.au/inquiries/title/alrc96/agd.htm> at 4 April 2010.

10. Australian Law Reform Commission, above n 1, Recommendation 9–3.

11. The definition of disability in section 4 the *Disability Discrimination Act 1992* (Cth) was amended to include a disability that: '(j) may exist in the future (including because of a genetic predisposition to that disability)'.

12. *Disability Discrimination Act 1992* (Cth), s 21A.

13. *Disability Discrimination Act 1992* (Cth), s 21B.

14. *X v The Commonwealth* (1999) 200 CLR 177.

15. Ibid, [33].

16. Ibid, [103].

17. Ibid.

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could assert that the physical training and intensity of space travel would pose a real danger to Vincent given his genetic predispositions. If such working conditions increased the possibility of a heart condition suddenly manifesting (heart attack), then the Gattaca Aerospace Corporation should have the lawful right to refuse Vincent employment on the basis that such employment would be detrimental to his own health. This right assumes great importance in light of workplace health and safety laws and an employer's duty of care in respect to its employees.[18]

Vincent's genetic predispositions also could expose fellow employees to dangerous situations. Space travel with Vincent could have fatal consequences for his co-workers if his predisposition towards Huntington's disease were to suddenly manifest. One of the early symptoms of Huntington's disease is irrational behaviour.[19] Given the specific (and often complicated) tasks that must be completed by astronauts in space, it is not difficult to envisage a scenario where the onset of sudden, irrational psychiatric behaviour could put the safety and welfare of other employees at risk.

Finally, the Gattaca Aerospace Corporation and the general public might suffer significant financial harm if the company could not lawfully discriminate against Vincent due to his genetic condition. Space travel is an expensive endeavour (requiring billions of dollars of public and private funds) and the economic consequences of failed missions can be catastrophic. To minimise the chance of failure, the Gattaca Aerospace Corporation should legally possess the right to refuse Vincent employment as an astronaut on the basis that his genetic predispositions could jeopardise billions of dollars of private (and public) money.

Despite *Gattaca's* negative view of genetic discrimination in the workforce, there may be one small concession that genetic discrimination could be warranted in certain circumstances. In a scene from the movie, Vincent and his love interest Irene attend a musical concert performed by a 12-fingered pianist. After the concert is completed, Irene asks Vincent whether he knew that the piano player had 12 fingers. Vincent shrugs in reply and states, '12 fingers or one, it's how you play'. Irene then informs Vincent that the piece played by the pianist could only be performed with 12 fingers.

It is suggested that this interplay between Vincent and Irene is analogous to the broader issue of genetic discrimination, and whether it is ever justifiable. There is no doubt that genetic discrimination in the workforce is an unfortunate outcome *whenever* it occurs. If an employee is able to carry out the inherent requirements of a job, they should never be refused employment on account of their asymptomatic genetic condition ('12 fingers or one, it's how you play'). Some jobs, however, necessitate that an employee has (or does not have) a particular genetic profile. Due to the inherent requirements of such roles, an employer is legally entitled (and perhaps morally obliged) to discriminate against an individual who possesses certain genetic predispositions. The danger posed to the employee themselves, the danger to which the employee may expose co-workers and the danger posed to broader society, all militate towards the appropriateness of genetic discrimination in certain contexts. Some piano pieces can only be performed with 12 fingers.

## Current legal framework vs genetic exceptionalism

Leaving aside the specific case study of *Gattaca,* it is suggested in this article that the *Disability Discrimination Act 1992* (Cth) is the appropriate legal vehicle for addressing issues of genetic discrimination in the workforce. Any law that purports to deal with genetic discrimination must balance the concerns of competing stakeholders — the employee, fellow employees, the employer and the public at large. It would be undesirable to vindicate or give primacy to individual rights (ie the right not to be discriminated against) without considering the context in which competing positions or rights may arise. The example given above demonstrates that in some circumstances, the right not to be genetically discriminated against should be trumped by concerns for the health of the employee, the safety of other employees and the wellbeing of the public. The *Disability Discrimination Act 1992* (Cth) achieves this balance by prima facie interdicting the practice of genetic discrimination,[20] yet winding back this prohibition if the discriminatory conduct falls under a particular exception.[21]

The alternative to dealing with genetic discrimination under the *Disability Discrimination Act 1992* (Cth) is to enact genetic-specific legislation in Australia. This course of action is not without precedent. The United States of America Senate passed the *Genetic Information Non-discrimination Act* (GINA) in May 2008,[22] ten years after Senator Natasha Stott Despoja introduced — without success — the Genetic Privacy and Non-discrimination Bill to the Federal Parliament of Australia. This article suggests that genetic-specific legislation is no better

18. Under the *Occupation Health and Safety Act 1991* (Cth) s 16, a duty is placed on an employer to take all reasonably practicable steps to protect the health, safety and welfare of all employees at work.

19. Margaret Otlowski, 'Employers' Use of Genetic Test Information: Is there a need for Regulation?' (2002) 15 *Australian Journal of Labour Law* 1, 17.

20. *Disability Discrimination Act 1992* (Cth), s 15.

21. *Disability Discrimination Act 1992* (Cth), s 21A.

22. Part 1 of the *Genetic Information Non-discrimination Act* deals with genetic discrimination in health insurance and Part 2 of the Act covers genetic discrimination in the workforce.

suited to the task of preventing genetic discrimination than more general anti-discrimination legislation. There are strong arguments to suggest that genetic-specific legislation may prove counterproductive.

The idea of genetic-specific legislation plays like a sweet melody to those who sing the tune of genetic exceptionalism. The phrase 'genetic exceptionalism' was initially coined by Thomas Murray[23] and encapsulates a view of genetic information as so unique and powerful (vis-a-vis other forms of personal and medical information) that its use must be regulated by special policies and/or legislation.[24] Proponents of genetic exceptionalism highlight:

1. Genetic information can identify an individual's pre-disposition towards a condition or disability. As a result, such information can 'affect and undermine an individual's view of his/her life's possibilities.'[25]
2. Genetic information is relational in nature, which means that such information extends beyond the individual and provides information about that individual's parents, siblings and children.[26]
3. Genetic information is highly sensitive in nature and many individuals would prefer that others were not privy to their genetic test results. Given that therapies for genetic disorders have not progressed concurrently with our ability to identify genetic disorders, an individual may not wish to know about their own genetic makeup.[27]

These characteristics of genetic information drive exceptionalists to the conclusion that a phenomenon like genetic discrimination is best met with genetic-specific legislation.

The difficulty with genetic-specific legislation is the subtle social undertone that it carries. Even though genetic information is unique to an individual, it does not follow that it should be the subject of unique stand-alone legislation. Thomas Murray argues that:

> we do not have to pretend that genes are unimportant to avoid [genetic] determinism or reductionism. We should give genes their due, but no more than that... [T]here is a vicious circularity in insisting that genetic information is different and must be given special treatment. The more we repeat that genetic information is fundamentally unlike other kinds of medical information, the more support we implicitly provide for genetic determinism, for the notion that genetics exerts special influence over our lives.[28]

In the context of genetic discrimination in the workforce, it is imperative that employers do not overestimate the importance and predictive power of genes. Ekberg contends that such overestimation is synonymous with concepts of genetic determinism, genetic reductionism, genetic essentialism and genetic fatalism.[29] Her argument is that 'such concepts are misleading because they ignore the role the social and physical environment play in the aetiology of all disease and the expression of all human traits.'[30] Putting aside for one second the multifactorial nature of so many genetic disorders (and the contribution that physical environment plays), we cannot ignore the *social* drivers that promulgate genetic discrimination. If employers believe that the genetic profile of an employee constitutes a 'coded probabilistic future diary',[31] they will find a way not to employ an individual who is genetically predisposed to a disability, regardless of what a piece of legislation mandates.

Perhaps the key is changing the *social* mindset of the actors involved in genetic workplace discrimination. When discussing 'How not to think about Genetic Information',[32] Manson argues that:

> we risk thinking of certain kinds of information as possessing an intrinsic ethical significance — such that any use of it is ethically problematic — rather than recognising that what matters, ethically speaking, is always types of action, and that the actions that use medical information form a heterogeneous class.[33]

As a pop culture example of this phenomenon, *Gattaca* provides a perfect example of a society that has 'bought in' to the idea of genetic exceptionalism. This society's focus on the intrinsic value and significance of genetic information has bred a culture where genetic pre-disposition towards a disability has become a real, biological and neutral ground for differential treatment.[34] No ethical significance is placed on the decision of an employer to discriminate based on genome — it is simply a logical course of action that follows the discovery of a genetic abnormality.

## Conclusion

James Watson, director of the Human Genome Initiative, claims that our fate is in our genes.[35] *Gattaca* claims that there is no gene for fate. Which view is correct? It is suggested in this article that the pop culture view should prevail. Personhood and what it means to be human is being challenged by advances in genetic technology. We must not forget that we are in a prime position to determine the social significance of genetic information. There is a human element to genetic information that is separate and must remain divorced from the science. Legislative responses to issues like genetic discrimination play a role in preserving the social side of genetics. If the message that genetic-specific legislation exudes is that genetic information is uniquely powerful, and uniquely personal,[36] then employers who are governed by that legislation will treat genetic test results of employees (or potential employees) as being uniquely important. The irony of this result is that genetic-specific legislation designed to combat discrimination may, to an extent, end up promoting it. By dealing with genetic discrimination under the current *Disability Discrimination Act* framework, we acknowledge that a genetic disability (or genetic pre-disposition towards a disability) is no more special than other forms of medical disability. We give genes their due, but no more than that.

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35. Leon Jaroff, *Science: The Gene Hunt (1989)* Time magazine <time.com/time/magazine/article/0,9171,957263,00.html> at 5 August 2010.

36. Annas, Glantz and Roche, above n 25, 365.