

GENETIC TESTING AND DISCRIMINATION

FORUM ON GENETICS, INSURANCE AND EMPLOYMENT, CENTRE FOR
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I accepted this invitation to speak today for a personal reason, not just because I am presently Acting Commissioner for Equal Opportunity for Western Australia.

Forty-two years ago my father took me aside and said he had something very important to tell me. With the utmost grief he told his 11-year-old daughter that he had just learned that our family carried the gene for a Huntington's chorea. He explained the symptoms -why Aunt Ruby had been 'as she was', and my cousins had died, and the effect it had on both physical and psychiatric well being. He said I needed to know this before I made a decision about marrying and having children.

The effect of this was, of course, profound. My father carried the burden of that knowledge for decades, seeing in every nervous tic or attack of depression of his own, or his children, and his siblings (his parents had both died early before the diagnosis was made) the first signs of the dreaded illness. When my cousin was diagnosed -wrongly, it is now apparent, because no genetic test was performed before the idiot psychiatrist imparted the news to a deeply depressed and histrionic patient- my father slipped into a deep and lasting sadness. Yet it is now obvious - my father having achieved the ripe age of 82

- that he did not carry that gene; he did not have the disease; he need not nor need I have feared the onset of the illness or its passage to my own children; and my cousin need not have convinced herself over her youth that she, too, 'must have' the disease, whose symptoms she convincingly displayed until her father's genetic testing results shocked them into stillness.

We did not suffer *from* discrimination because of a disability or an impairment. We suffered an impaired life, as a family, because we could not be sure that we did not have the disease, so we started at its shadows, unnecessarily. So you will understand that in my view, genetic testing is a Good Thing -though it may be used *for* Bad Purposes.

Insurance contracts are *uberrimae fides*, or reliant on complete good faith and disclosure between the parties. That is why I have made my own disclosure.

As Commissioner *for* Equal Opportunity I am delighted to speak to you about the fundamental right to equitable access to insurance. It is a key aspect of equal participation by people with actual or imputed disabilities in our society's economic and social life.

'Equal opportunity' is just one aspect of equality before the law, on which our State anti-discrimination law -the 1984 Equal Opportunity Act -and the Federal Disability Discrimination Act 1992 is based. It is a fundamental human right, and protected as *few* human rights are, in Australia. Insurance is as important to people with disabilities as anyone, because we all have to live with risk of injury, loss of income or property.

The Disability Discrimination Act has been in *force* for nearly ten years now, making discrimination unlawful in insurance and in many other areas of life.

I Discrimination on the ground of 'impairment' (the preferred term under State anti -discrimination Acts) has been prohibited in Western Australia since 1988, including in superannuation or provident funds.

The insurance industry has obligations not to discriminate in its business, as do all businesses. But there is not any definitive statement on what is and is not unlawful in this area.

Insurance requires 'discrimination' or differentiations based on risk, except in the case of health insurance, which permits exclusions for pre-existing conditions.

Anti discrimination laws do allow 'lawful' discrimination based on disability or impairment where this is 'reasonable.' Both the W A (e.g. Section 66 ZQ, added in 1992) and the Federal Acts permit discrimination in insurance or superannuation that is justified by actuarial or statistical data on which it is reasonable to rely, or if there is no data, on whatever else makes it 'reasonable'. It goes without saying that proof of reasonableness lies on the person making that claim, that is, upon the insurer.

I will give the organisers of this forum a copy of my paper, to which I have appended the Guidelines to the insurance industry issued by the federal Disability Discrimination Commissioner in 1998, rather than seeking to go into them in detail. They apply specifically to life insurance, but the principles are as applicable to any insurance -including, may I point out, mortgage insurance, worker's compensation and superannuation.

Suffice it to say that the law presumes that people who have or are likely to develop disabilities and impairments because of genetic conditions or states are nonetheless entitled to participate fully in the ordinary activities of public life.

If 'risk' is something the community is not willing to assume without the comfort of an indemnifier, then access to insurance against risk must be available, as a matter of a fundamental human right, to everyone.

If insurers cannot determine precisely who will prove to be affected by a genetic condition or family trait, then it is not fair to consign family members as a whole as an at risk group or someone to be shunned. If insurers do not wish to cover those persons, as was the case for a very

long time in the case of HIV infection, then they may expect to be challenged and required to demonstrate that it is reasonable not to do so.

Discrimination by insurers on the basis of genetic information is a matter of very considerable currency, given the recent collapses of insurance companies and the explosion of concern about our 'litigious society' (there is no objective evidence that class actions or 'no win no fee' litigation has resulted in greater litigation in fact).

The Australian Law Reform Commission and the National Health and Medical Research Council are jointly conducting an inquiry into what sort of regulation may be needed, in relation to human genetic samples and information, to:

- Protect privacy;
- Provide protection from unfair discrimination; and
- Ensure high ethical standards of conduct.

It will not report until March 2003. In the meantime, we have a very real conundrum. Genetic information is the same as any other information to which, logically, insurers should have access for risk assessment purposes. Yet if that information is used to treat symptom-free, functioning human beings less favourably than others whose future accidents, ailments, injuries or lightning strikes cannot be predicted, it may be discriminatory -in the moral sense -and unlawful as well.

We have no guidelines on what is or is not 'reasonable'. By definition, it is not a 'test' but a process. It will depend on statistical and actuarial data (underwriting manuals, local research studies, international research, claims histories in general); on medical opinions (but only on medical matters not suitability for jobs or insurance or risk), actuarial advice and information from the person themselves (crucially) including their own attitudes and beliefs and behaviours.

The industry itself has tried to deal with some of these matters, but frankly not very well. The Investment and Financial Services Association code, for instance, provides that insurers

- Should not initiate any genetic tests on applicants for insurance;
- May request that existing test results be made available to the insurer for the purposes of classifying the risk;
- Will ensure that the results of existing genetic tests are only obtained with the written consent of the individual concerned;
- Will ensure that strict standards of confidentiality apply in the handling and storage of the results of genetic tests;
- Will only use the results of genetic tests in the assessment of the insurance application of the individual on whom the test was conducted -the results will not be used in the assessment of insurance applications of relatives of the tested individual;
- Will not make the results of genetic tests available to third parties other than reinsurance companies that may be directly involved in assessing the risk.

These are all important points, but they do not deal with discrimination, rather privacy, which is by and large a concern of the 'worried well'. It says nothing at all about what should happen about carrying out genetic tests on children who may carry a gene of a late-onset condition -and as you can see, I would have benefited both from testing and ongoing counselling

We should, as those 'worried well', be much more aware of the lived experience of people with existing disabilities who are already treated less favourably by employers, their insurers, and superannuation funds. What is 'reasonable' for "them" now, if we do not fancy it being applied to "us" in the future? This is an opportunity to take our own concerns, and ensure that the experience of discrimination is minimised for everyone who has a disability or loves and cares for someone else who does.

I have for a long time said that 'discrimination' is not the preserve of women, or ethnic minorities, or Aboriginal people, or victims of religious persecution. It is more than pique or a personal concern: discrimination is a breach of the fundamental human right to real equality, before the law and in substance. I comment-that thought to you, today.