Submission from Margaret Otlowski, Professor,

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to the Productivity Commission,

Review of the *Disability Discrimination Act* 1992

This is intended to be only a very brief submission which addresses one specific matter raised in the Productivity Commission's Draft Report on the *Disability Discrimination Act* 1992 (Cth) concerning the insurance exemption under that legislation.

Draft finding 10.5 of the Productivity Commission's Draft Report provides that 'A partial exemption for insurance and superannuation in the *Disability Discrimination Act* 1992 (s 46) is appropriate, but its current scope is uncertain.'

Draft Recommendation 10.3 of the Report recommends that the Act should be amended to clarify what are 'other relevant factors' for the purpose of the insurance and superannuation exemption (s 46), and that these should not include stereotypical assumptions about disability that are not supported by reasonable evidence or unfounded assumptions about risks related to disability.

I wish to write in support of this recommendation. My particular interest in this area stems from research I have been involved in exploring the use by insurers of genetic test information and

concerns about the potential for genetic discrimination.[1] I am currently leading an interdisciplinary team funded by the Australian Research Council which is investigating the nature and extent of genetic discrimination in Australia: this encompasses a study of the insurance sector (the website for this project is www.gdproject.org).[2]

In the course of this work, it has been necessary to give close consideration to the terms of the insurance exemption under Australian anti-discrimination legislation, including the *Disability Discrimination Act* 1992 (Cth). This exemption acknowledges that insurance inherently involves differentiating between individuals, but seeks to prevent discrimination which is not based on relevant grounds; for example, where there is no evidence to substantiate the conclusion that the disability in question increases that individual's risk. I have been particularly interested to consider the applicability of the insurance exemption in the context of genetic information and to examine the adequacy of current data relied on by the insurance industry to justify decision-making which would otherwise (ie in the absence of the insurance exemption) amount to disability discrimination It is generally accepted that discrimination on the basis of genetic status (*genotype* as opposed to *phenotype*) would come within the framework of the federal disability discrimination legislation (even though it is presently not specifically referred to) on the basis that it amounts to a form of discrimination on the grounds of future or imputed disability.[3]

Significantly, the recent report of the Australian Law Reform Commission and the Australian Health Ethics Committee, *Essentially Yours*[4] which culminated a two year inquiry into the protection of human genetic information, has recommended that more specific attention be given to genetic discrimination within the legislation, to raise awareness that it is indeed covered under this legislation. To this end, the ALRC/AHEC recommended that the objects clause of the *Disability Discrimination Act* 1992 (Cth) be amended to clarify that it applies to discrimination in relation to past, present, possible future or imputed disability, including discrimination on the ground of genetic status.[5]

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[1] See for example, M Otlowski, *Implications of Genetic Testing for Australian Insurance Law and Practice*, Centre for Law and Genetics, Occasional Paper No. 1 (2001) (pp 74); M Otlowski, *Implications of Genetic Testing for Australian Employment Law and Practice*, Centre for Law and Genetics, Occasional Paper No. 2 (2001) (pp 96); M Otlowski, 'Resolving the Conundrum: Should Insurers be Entitled to Access Genetic Test Information?' (2000) 11 *Insurance Law Journal* 193-215; M Otlowski, 'Employers' Use of Genetic Test Information: Is there a Need for Regulation?' (2002) 15 *Australian Journal of Labour Law* 1-39.

[2] For an outline of the aims and methodology of this study, see M Otlowski, S Taylor and K Barlow-Stewart, 'Major Study Commencing into Genetic Discrimination in Australia' (2002) 10 *Journal of Law and Medicine* 41-48.

[3] See the ALRC/AHEC Report, *Essentially Yours* (2003) Chapter 9.

[4] ALRC 96, 2003. The Report can be accessed via the ALRC's website www.alrc.gov.au

[5] *Ibid* 304.

Further, whilst proposing no change to the terms of the insurance exemption, the ALRC/AHEC recommended that a new standing advisory body on human genetics be established, to be called the Human Genetics Commission of Australia (HGCA). The role of the HGCA would be to provide high-level advice to government, industry and the community about current and emerging issues in human genetics.[6] Such advice would cover technical and strategic matters as well as advice on the ethical, legal and social implications arising from these developments. Amongst other things, this would include the role of determining which genetic tests should be used in underwriting mutually rated insurance, having regard to their scientific reliability, actuarial relevance and reasonableness.[7] If this recommendation were implemented, it would go some way to ensuring the scientific and actuarial reliability of the genetic test information used for the purposes of insurance underwriting. The insurance exemption in the *Disability Discrimination Act* 1992 (Cth) would still apply in these circumstances, requiring insurers to be accountable in the use that they make of the genetic test information that they are authorised to use. The ALRC/AHEC Report made complementary recommendations addressed to the insurance peak bodies Investment and Financial Services Association (IFSA) and Insurance Council of Australia (ICA) that they should develop mandatory policies for their members to make sure that genetic tests are used in conformity with HGCA recommendations.[8] Other recommendations sought to clarify and strengthen the applicant's right to written reasons for an unfavourable underwriting decision based on genetic information in terms that are clear and meaningful and that explain the actuarial, statistical or other basis for the decision.[9] There was also a perceived need to expand appeal options for aggrieved individuals. It was accordingly recommended that IFSA and the ICA should extend the jurisdiction of the existing insurance complaints bodies in the life and general insurance sectors (Financial Industry Complaints Service Ltd (FICS) and Insurance Enquiries and Complaints (IEC) respectively) to allow those organisations to review underwriting decisions involving the use of genetic information.[10]

Real concerns have been raised about the availability and accuracy of data to justify insurance underwriting founded on genetic test information, particularly in respect of multi-factorial disorders. It is noteworthy that in some jurisdictions, including the UK, this has led to a moratorium on the use of genetic test information except in the case of large policies in which

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[6] *Ibid*.
[7] *Ibid* 711, Recommendation 27-1.
[8] *Ibid*, Recommendation 27-2.
[9] *Ibid* 723, Recommendations 27-5–27-7.

instance only tests approved by the Genetics and Insurance Committee (GAIC) are permitted to be used. To date, this Committee has only approved a couple of tests for the purposes of such underwriting. The experience in relation to the assessment of risk associated with the BRCA1 test for breast cancer illustrates that the situation is presently very fluid and unreliable. Estimates of risk linked with this mutation were originally thought to be in the range of 60-80%, however this was reduced to 40-60% once population-based studies were undertaken. It can be convincingly argued that there is presently insufficient reliable evidence regarding the extent to which genetic test results can be used to predict life expectancy or onset of ill health, and it is therefore impossible for insurers to be in a position to use this information accurately. Actuarial models need to be developed relevant to the Australian experience before insurers can reliably draw on genetic test information, although this is acknowledged to be incredibly difficult.[11]

The broad and open-ended scope of the current terms of the insurance exemption under the *Disability Discrimination Act* 1992 (Cth) has compounded the difficulties in this area, in particular inclusion of the reference to 'other relevant factors.' For this reason, I strongly support the Productivity's Commissions' draft recommendation that this provision be amended to clarify what 'other relevant factors' are for the purposes of the insurance (and superannuation) exemption and that it be made clear that stereotypical assumptions about disability that are not backed by reasonable evidence, or unfounded assumptions about risks related to disability, do not qualify as 'other relevant factors' to justify adverse decision-making (which *prima facie* would amount to disability discrimination.)

This is particularly important in the context of potential discrimination on the basis of genetic status because of the reality that genetic information is commonly perceived as powerful and accurate. There is inadequate appreciation of the limitations of predictive genetic test information which usually merely indicates predisposition to or heightened risk of developing a particular disorder. Because of deterministic suppositions that are frequently made, there is a real danger that genetic test information may be ascribed greater significance than it justifies. Whilst it is accepted that the insurance exemption in s 46 of the *Disability Discrimination Act* 1992 (Cth) represents a necessary concession to insurers it is important that it scope is contained and that its terms are well understood so that its operation is no broader than is necessary. For the foregoing reasons, it is essential that insurers are kept fully accountable in the use they make of genetic test

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[10] *Ibid* 733, Recommendation 27-9.
[11] Ferris S. and Doble A., *Genetics in Society 2001,* Institute of Actuaries, Chapter 8.

and other information, and that the grounds that they can rely on to secure exemption from disability discrimination are clearly elucidated.

Also significant is the fact that for those who believe that they have encountered discrimination on this basis (and there have been quite a number of alleged instances of genetic discrimination),[12] there is little incentive to bring proceedings when the scope of the exemption is so wide and uncertain. Uncertainty about the scope and operation of the provision operates to the disadvantage of parties who may wish to exercise their rights, and potentially has a disempowering effect. In these circumstances, it is hardly surprising that few if any proceedings claiming unfair genetic discrimination by insurers, outside the terms of the exemption, have been brought. This is notwithstanding that the researchers who gathered the data about alleged instances of genetic discrimination took the view that at least some of the allegations reported are likely to have involved unlawful discrimination.[13]

I appreciate this opportunity to make a submission and to have some input into the Productivity Commission's decision making process. I would be happy to be involved further if I can be of any assistance.

Your faithfully,

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[12] Barlow-Stewart, K. & Keays, D. 'Genetic Discrimination in Australia' (2001) 8 *Journal of Law and Medicine* 250-262. This study documented 48 cases of alleged genetic discrimination although it should be noted that these were anonymous and unverified cases.
[13] *Ibid.*