Australian Law Reform Commission submission to the Senate Standing Committee on Legal and Constitutional Affairs Inquiry into the Disability Discrimination and Other Human Rights Legislation Amendment Bill 2008

The Australian Law Reform Commission (ALRC) makes the following submission to the Australian Senate Standing Committee on Legal and Constitutional Affairs Inquiry into the Disability Discrimination and Other Human Rights Legislation Amendment Bill 2008 (the Bill).

In making this submission, the ALRC draws on its experience from the joint inquiry (the Inquiry) into the protection of human genetic information by the ALRC and the Australian Health Ethics Committee (AHEC) of the National Health and Medical Research Council (the NHMRC) and the report *Essentially Yours: The Protection of Human Genetic Information in Australia* (ALRC 96, 2003).[1]

Essentially Yours: The Protection of Human Genetic Information in Australia

The terms of reference for the genetic information inquiry directed the ALRC and AHEC to consider, with respect to human genetic information, and the samples from which such information is derived, how best to:

- protect privacy;
- protect against unfair discrimination; and
- ensure the highest ethical standards in research and practice.

The experience of the Inquiry, mirrored overseas, is that the rapid pace of scientific and technological change has produced two powerful, but conflicting, social reactions. On the one hand, there is very strong public support for breakthroughs promising better medical diagnosis and treatments, and for assisting with law enforcement (including identification of missing or deceased persons). On the other hand, there are anxieties about loss of privacy and the potential for genetic discrimination, as well as about the capacity to regulate genetic science in the public interest.

The major challenge for the Inquiry was to find a sensible path that meets twin goals: to foster innovation in genetic research and practice that serve humanitarian ends, and to reassure the community that such innovations will be subject to proper ethical, legal and other controls.

The Inquiry's final report, *Essentially Yours*, covers an extensive range of activities in which genetic information plays—or soon will play—an important role. The two-volume, 1200 page report makes 144 recommendations about how Australia should deal with the ethical, legal and social implications of the New Genetics.

The report has been very well received both in Australia and overseas. For example, Dr Francis Collins, who chaired the international Human Genome Project, described *Essentially Yours* as 'a truly phenomenal job', and 'ahead of what the rest of the world is doing'. Dr Collins noted that this work meant that 'Australia has moved ahead in rather impressive ways'.

The Australian Government provided a formal response to the report in December 2005, accepting the great bulk of the ALRC's 144 detailed recommendations, including key ones such as the establishment of a Human Genetics Commission of Australia (HGCA), and measures to regulate the collection and use of genetic information in such critical areas as employment; insurance; the delivery

1 The report is available at http://www.austlii.edu.au/au/other/alrc/publications/reports/96/.

of clinical services; ethical oversight of medical and scientific research; sports; human genetic registers and databases; immigration and law enforcement.[2]

This submission focuses on the amendment of the definition of 'disability' in the *Disability Discrimination Act 1992* (Cth) to include a genetic predisposition to a disability. The ALRC dealt with this issue in *Essentially Yours*. The submission also addresses Item 60 of the Bill, which amends the *Disability Discrimination Act* to prohibit an employer from requesting or requiring genetic information from a job applicant or employee. The ALRC recommended this reform in *Essentially Yours*.

The ALRC welcomes the Australian Government's introduction of these amendments which will strengthen human rights protections in this country. In *Essentially Yours*, the ALRC and NHMRC expressed serious concern that, unless the matter was addressed adequately by the law, we run the risk of creating a 'genetic underclass' of people who are locked out of, or severely disadvantaged in obtaining, employment. The ALRC warmly supports both Item 5 and Item 60, but would also like to note where these amendments differ from the ALRC's recommendations in *Essentially Yours*.

Disability discrimination

Definition of 'disability' in the Disability Discrimination Act

Item 5 of the Bill proposes to amend s 4(1)(j) of the *Disability Discrimination Act* to clarify that the definition of 'disability' includes a genetic predisposition to a disability that is otherwise covered by the *Disability Discrimination Act*.

The ALRC considers this to be a very important amendment. In Chapter 9 of *Essentially Yours*, the ALRC noted that the existing definition of disability in s 4 of the *Disability Discrimination Act* covers genetic conditions that are manifested by **current symptoms**. The ALRC questioned, however, whether the definitions in the Act and in other anti-discrimination legislation are wide enough to address discrimination on the basis of genetic status where a person may have the genetic markers for a condition but is presently asymptomatic.[3]

The definition of disability in the *Disability Discrimination Act* is divided into two parts—the physical description of what amounts to a disability is set out in para (a)-(g), while some of the circumstances in which disabilities will be recognised for the purposes of the Act are set out in para (h)-(k). These circumstances include present, past, possible future and imputed disabilities. The difficulty with the definition is that para (h)-(k) must relate to a type of physical or mental manifestation in the terms of para (a)-(g) of the definition.

In *EssentiallyYours*, the ALRC stated:

> Is a genetic mutation that increases a person's risk of heart disease, for example, an 'organism capable of causing disease or illness' (para (d))? Is it a 'malfunction, malformation or disfigurement of a part of the person's body' (para (e))? While it might be possible to argue that a genetic mutation is a malformation of part of a person's body, it seems clear that these provisions were not drafted with this issue in mind and that genetic mutations of this sort do not fit neatly into the existing terminology.

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2 The Australian Government response is available via the ALRC's website at: http://www.alrc.gov.au/inquiries/title/alrc96/response.htm.

3 The ALRC noted that the *Disability Discrimination Act* specifically covers disabilities that 'may exist in the future' or are 'imputed to a person', as well as past or present disabilities. The legislation in New South Wales and Tasmania is similar to the DDA in this respect. However, not all Australian legislation has such wide coverage.

It is more likely that discrimination on the basis of a genetic mutation that increases the risk of a person developing a particular disorder is covered by para (j) of the definition of disability, coupled with para (a), (b) or (e). To take the case of a genetic mutation that increases the risk of heart disease, under the *Disability Discrimination Act* the 'disability' does not arise directly because of the person's present genetic mutation, but because that mutation indicates that a 'partial loss of the person's bodily functions' (para (a)) 'may exist in the future' (para (j)). In short, the disability is not the genetic mutation itself but the possible future expression of that mutation through the malfunctioning of a part of the person's body.

A number of submissions to the Inquiry suggested that there was no need to amend the existing definition in the *Disability Discrimination Act*. The Australian Chamber of Commerce and Industry, for example, expressed the view that any change would be premature. The Law Society of NSW, the acting Disability Discrimination Commissioner and the Anti-Discrimination Board of NSW submitted that the existing definition in the *Disability Discrimination Act* is likely to cover discrimination on the basis of genetic status.

While the Law Society did not support amending the definition, the acting Disability Discrimination Commissioner, the Anti-Discrimination Board of NSW and a significant number of other submissions expressed the view that this should be put beyond doubt. The Anti-Discrimination Board of NSW stated that such clarification would:

- reflect the current state of the law under the *Disability Discrimination Act* and *Anti-Discrimination Act 1977* (NSW);
- have an educative effect;
- serve a symbolic function in clarifying that such discrimination is unlawful conduct under anti-discrimination law; and
- provide certainty regarding people's rights and responsibilities under anti-discrimination law.

The ALRC and NHMRC concluded that there is definitely value in providing greater certainty and raising awareness in relation to the emerging issue of genetic discrimination. The Inquiry was concerned that there is a possibility that the existing definition in the *Disability Discrimination Act* could be construed narrowly by the courts to exclude predictive genetic information. In the Inquiry's view, there was no policy justification for excluding discrimination based on possible future genetic conditions from coverage by the *Disability Discrimination Act*. As well as having an educative effect, an appropriate amendment would put the matter beyond doubt and would ensure that the question did not need to be tested in the courts. The Inquiry recommended, therefore, that the definition of disability in the *Disability Discrimination Act* be amended to specifically include genetic status.[4] The ALRC notes that the amendment outlined in Item 5 is consistent with the recommendation in *Essentially Yours*.

Amendment of Human Rights and Equal Opportunity Commission Regulations and Workplace Relations Act

In *Essentially Yours*, the Inquiry noted that the terms 'impairment' and 'disability' are also used in the regulations made under the *Human Rights and Equal Opportunity Commission Act 1986* (Cth) (HREOC Act) and in the *Workplace Relations Act 1996* (Cth). Both pieces of legislation use general language such as mental, intellectual or psychiatric disability and physical disability without defining these terms. However, the *Human Rights and Equal Opportunity Commission Regulations 1989* (Cth) (HREOC Regulations) do include a definition of impairment and expressly cover past and imputed disabilities. The *Workplace Relations Act* does not. Neither piece of legislation specifically includes possible future disabilities. The ALRC notes that the Bill does not propose to amend the HREOC Regulations or the *Workplace Relations Act*.

4 Recommendation 9–3.

Most of the submissions to the ALRC and NHMRC Inquiry that addressed this issue were supportive of amending the definition of impairment in the regulations so that the HREOC Act applies to discrimination on the ground of a disability that may exist in the future.

The Department of Employment and Workplace Relations noted that the Australian Industrial Relations Commission is required by s 93 of the *Workplace Relations Act* to have regard to the principles embodied in the *Disability Discrimination Act* in the exercise of its functions. The Department did not support inserting a definition into the *Workplace Relations Act* on the basis that it would limit the flexibility of the courts to consider this issue on a case-by-case basis. The Anti-Discrimination Commission of Queensland suggested, however, that the *Workplace Relations Act* should be amended so that the term 'disability' is defined by reference to the *Disability Discrimination Act* to ensure consistency. The acting Disability Discrimination Commissioner was also of this view.

The ALRC and NHMRC concluded that the definition of impairment in the regulations made under the HREOC Act should be amended to make clear that the HREOC Act applies to discrimination on the ground of genetic status. The Inquiry also supported amendments that would make the definitions in the *Disability Discrimination Act* and the HREOC Regulations consistent in a more general sense. The Inquiry recommended that the term 'disability' in the *Workplace Relations Act* should be expressly defined by reference to the definition in the *Disability Discrimination Act*. This would be consistent with the policy underpinning s 93 of the *Workplace Relations Act* and would not, in the Inquiry's view, unduly limit the discretion of the courts.[5]

The ALRC would encourage the Senate Standing Committee to consider whether the Bill should include amendments to the HREOC Regulations and the *Workplace Relations Act* in line with the ALRC and NHMRC recommendation in *Essentially Yours*.

Objects clause

The ALRC welcomes the amendment of the *Disability Discrimination Act*, rather than the enactment of new genetic discrimination legislation, to deal with genetic information. In the ALRC's view, working within the existing legal framework will promote certainty and consistency and build on existing understanding and practice in this field.

The ALRC and NHMRC Inquiry considered whether the name of the *Disability Discrimination Act* should be changed to the Disability and Genetic Discrimination Act 1992. The proposal was put forward on the basis that the change would heighten visibility and public awareness and that it would emphasise that genetic status did not necessarily equate with disability. The Inquiry ultimately concluded that the arguments against changing the name of the *Disability Discrimination Act* are stronger than those in favour of change.

The ALRC and NHMRC were of the view, however, that it would be desirable to make a statement in s 3 of the *Disability Discrimination Act*, which sets out the objects of the Act, indicating that the Act applies to discrimination on the basis of past, present, possible future or imputed disabilities, including discrimination on the ground of genetic status. In the Inquiry's view, a statement of this kind would sit more comfortably with the existing high level statements in s 3 and make clear that discrimination on the basis of genetic status is simply one example of discrimination on the basis of imputed or possible future disability.[6] The ALRC notes that the Bill does not propose to amend the objects clause under s 3 to address discrimination on the ground of genetic status.

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5 Recommendation 9–3.

6 Recommendation 9–2.

Associates

Because of the familial nature of genetic information, it is possible that individuals may be discriminated against on the basis of information about their genetic relatives, rather than their own genetic health information. Employers may seek to rely on the fact that genetic information about a member of a person's family may sometimes provide relevant information about the person. An employer may, for example, refuse to employ an applicant because of a family history of Huntington's disease or breast cancer. In the anti-discrimination context, this act may be characterised either as (a) an act on the basis of the applicant's 'association' with others, which is discussed below, or (b) an act on the basis of an 'imputed' disability.

Anti-discrimination legislation in Australia generally recognises that it is unlawful to discriminate against a person on the basis of his or her association with another person.[7] The Inquiry noted that the HREOC Act and the *Workplace Relations Act* do not expressly address discrimination on the basis of association with another person. The language of the HREOC Act and the *Workplace Relations Act* is potentially wide enough to cover discrimination on the basis of personal association but the issue is unclear.

Most submissions that addressed this issue supported the proposed amendment to the HREOC regulations. The acting Disability Discrimination Commissioner, while supporting the change to the HREOC regulations, raised the following concern in relation to the DDA associate provisions:

> As noted above I would support HREOCA coverage being brought into line with that under the DDA. However, in this context attention is required to how the DDA currently deals with associates.
>
> The difficulty is that while the substantive sections dealing with unlawful discrimination address discrimination against associates as well as against people with a disability, the definitions of direct and indirect discrimination in sections 5 and 6 refer only to a disability of the aggrieved person.
>
> At present (consistent with accepted rules of statutory construction) HREOC seeks to interpret and apply the DDA in a way which gives effect to the substantive provisions regarding associates rather than rendering them meaningless. It would be preferable however for the definitions of discrimination to expressly include associates rather than leaving this to interpretation.

The ALRC and NHMRC concluded that there is merit in amending the regulations made under the HREOC Act to include discrimination on the basis of association.[8] This would bring the HREOC Act into line with the *Disability Discrimination Act* in this regard.

The Inquiry noted the concern of the acting Disability Discrimination Commissioner in relation to the operation of the existing associate provisions in the *Disability Discrimination Act*. In light of these concerns, the Inquiry supported a more comprehensive review of these provisions by the Commonwealth. However, given the Inquiry's Terms of Reference, the recommendation was limited to addressing the gap in coverage under the HREOC Act.

Again, the ALRC notes that the Bill does not include an Item to amend the HREOC Act to include discrimination on the basis of association. The ALRC would encourage the Committee to consider whether the Bill should include such an amendment. It is very important that the *Disability Discrimination Act* covers real or perceived genetic status. The Inquiry heard stories—especially from people from 'Huntington's families'—that they had been discriminated against in relation to

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7 For example, *Disability Discrimination Act 1992* (Cth) s 15.

8 Recommendation 9–4.

employment and training. For example, the ALRC heard of people being told that an employer would not risk hiring them and spending time and money to train them, unless they got a genetic test to show they were negative to Huntington's Disease.

Requesting genetic information from a job applicant or employee

Item 60 of the Bill implements Recommendation 31–3 of *Essentially Yours*, that the *Disability Discrimination Act* should be amended to prohibit an employer from requesting or requiring information, including genetic information, from a job applicant or employee, except where the information is reasonably required for purposes that do not involve unlawful discrimination. The new section will apply to all requests for information to all areas of discrimination covered by the *Disability Discrimination Act*.

The ALRC considers this to be an important amendment. Requests for, or requirements to produce, genetic information lie at the heart of concerns about genetic discrimination in employment. Such requests could include a request for information about family medical history, the results of a past genetic test or a request to undertake a new genetic test. Several submissions to the Inquiry expressed the view that the circumstances in which employers are able to request or require such information should be very limited. Irrelevant questions about genetic status are unlikely to contribute to fair recruitment and employment processes. This is particularly so in relation to genetic information because of its sometimes predictive nature and the possibility that the information may be misinterpreted or misapplied.

The proposed amendment is consistent with the ALRC and NHMRC recommendation in *Essentially Yours*. In *Essentially Yours*, the ALRC and NHMRC expressed the view that in relation to genetic information (whether genetic test results or family medical history), the *Disability Discrimination Act* should prohibit an employer from requesting or requiring such information unless the information is reasonably required for a purpose that does not involve unlawful discrimination.[9]

The ALRC and NHMRC noted that s 30 of the *Disability Discrimination Act* does not make a clear statement of this kind and should be amended. Although the Inquiry was particularly concerned about requests by employers for genetic information, it recognised that there may be sound reasons for a general amendment that would have a wider application, such as an amendment relating to requests for all information in the areas covered by the *Disability Discrimination Act*.[10] The ALRC strongly supports Item 60 as it provides for such a general amendment.

Genetic Information Non-discrimination Act (GINA)

The ALRC notes that the United States *Genetic Information Non-discrimination Act* (GINA) provides an alternative model for dealing with some of these issues. The Act was passed by the United States Senate in May 2008. Title I of GINA prohibits genetic discrimination in the area of health insurance, while Title II ensures non-discrimination in employment. The employment provisions become effective on 21 November 2009.

Prior to the passing of GINA, the only federal United States law that directly addressed the issue of genetic discrimination was the 1996 *Health Insurance Portability and Accountability Act* (HIPAA). HIPAA prohibits group health plans from using any health status-related factor, including genetic information, as a basis for denying or limiting eligibility for coverage or for charging an individual more for coverage. A number of states have addressed the issue of genetic discrimination in employment through state legislation. However, these state laws vary widely.

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9 Recommendation 31–3.

10 However, consistently with the Inquiry's Terms of Reference, the ALRC's recommendation was limited to questions in relation to genetic information in the employment context.

Under GINA, 'genetic information with respect to the employee' becomes a new protected classification upon which employers, employment agencies, and labour organisations may not discriminate. 'Genetic information' is defined as:

with respect to any individual, information about—

(i) such individual's genetic tests,

(ii) the genetic tests of family members of such individual, and

(iii) the manifestation of a disease or disorder in family members of such individual.

Genetic information also includes 'any request for, or receipt of, genetic services, or participation in clinical research which includes genetic services', but does not include information about the sex or age of any individual.

The term 'family member' is then defined to include a 'dependent', and first through fourth degree relatives of such dependents. 'Genetic services' are broadly defined to include tests, counseling (including obtaining, interpreting, or assessing genetic information) and education, while 'genetic test' means 'an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes'.

In addition to prohibiting discrimination based on genetic information, GINA makes it an unlawful employment practice for a covered entity 'to request, require, or purchase genetic information with respect to an employee or a family member of the employee' except in limited circumstances. Where covered entities possess genetic information, they must maintain it on separate forms, keep it in separate files and treat it as confidential medical information.