Anti Discrimination
Board of New South Wales

24 FEB 2005
Senate Legal & Constitutional Committee

The Chairperson
Senate Legal and Constitutional References Committee
Parliament House
CANBERRA ACT 2600

Dear Chairperson

Inquiry into the *Privacy Act* 1998

Thank you for the opportunity to provide submissions to your inquiry into the *Privacy Act* 1998 (Cth) (the **Act**).

You have requested submissions addressing, in part or in full, the:

> "overall effectiveness and appropriateness of the Privacy Act 1988 as a means by which to protect the privacy of all Australians, with particular reference to …."

There follows a number of matters which were referred to the References Committee and on which it has requested submissions as those matters relate to the Act.

The Anti-Discrimination Board (**ADB**) was established in 1977 to administer the *Anti-Discrimination Act* 1977 (NSW) (**ADA**). The ADB' s functions include:

- investigating and conciliating complaints of discrimination, harassment and vilification made under the ADA;
- informing and educating the people of NSW, employers and service providers about their rights and responsibilities under anti-discrimination law; and
- recommending legislative and policy reform to maximise protection human rights and effectiveness of anti-discrimination law.

The Board has no direct experience of the Act and is therefore unable to comment specifically on the Act as it relates to those matters referred to the Committee. However, insofar as the Board has direct experience in dealing with issues of discrimination, this submission focuses on the issues canvassed in point (a)(ii)(C), that is, the capacity of the current legislative regime to respond to new and emerging technologies which have implications for privacy including *genetic testing and potential disclosure and discriminatory use of such information.*

P.O.Box A2122 Sydney South NSW 1235
Level 17, 201 Elizabeth Street, Sydney NSW 2000
Telephone: 02 9268 5555 Facsimile: 02 9268 5500
TTY: 02 9268 5522 Freecall STD: 1800 670 812
Worldwide Web Address: http://lawlink.nsw.gov.au/adb
Enquiries: 02 9268 5544

Protecting human rights and advancing public health

In November 2001 the ADB published the results of its enquiry into Hepatitis C related discrimination in NSW, the "C Change" report (the **Report**).

Many submissions to the Board's enquiry indicated that once a person's HIV status becomes known, whether by voluntary disclosure, inappropriate requirements for disclosure, or as a result of breaches of confidentiality (by, for example, health care workers) discrimination often follows.

The Report demonstrated the impact that both fear of discrimination and experiencing discrimination has upon individual and public health outcomes. It found:

> "Information about a person's hepatitis C status is highly sensitive. It is common for people with hepatitis C to live with constant fear about their hepatitis C status becoming known. There is little wonder that this is the case given the adverse consequences that so often flow when a person discloses their hepatitis C status or where breaches of confidentiality occur. … fear of stigma and discrimination can lead people who believe they might already have contracted hepatitis C, to be reluctant to seek testing for hepatitis C. Not seeking out testing limits the possibility of either considering appropriate treatment options or taking actions to manage their health effectively. It also means that people with hepatitis C are less likely to be in contact with health and support services and are harder to reach with information about hepatitis C prevention."[1]

Such an analysis has particular resonance in the context of discrimination on the basis of people's genetic make up. There is a very real concern that people will be deterred from undertaking genetic testing unless they are assured that privacy and anti-discrimination laws will be adequate to ensure their confidentiality and human rights, particularly in the context of employment and insurance.

Research reported on in the Issues Paper issued by the Australian Law Reform Commission (ALRC) and the Australian Health Ethics Committee (AHEC) of the National Health and Medical Research Council (NHMRC), as part of its enquiry into the 'New Genetics', indicated that people's fear of genetic discrimination is likely to be well founded.[2] As the Issues Paper identifies, if people fear discrimination they are less likely to be prepared to undergo genetic testing.[3] This has obvious implications for both individual and public health outcomes where people are deterred from undergoing diagnostic testing for conditions for which there are efficacious treatments available.

---

[1] *C-change* - Report of the Enquiry into Hepatitis C Related Discrimination ('*C-change*'), Anti-Discrimination Board, November 2001 at page 128.

[2] Issues Paper, at page 61 - 61, paragraphs 2.30 - 2.34.

[3] *Protection of Human Genetic Information: Issues Paper,* ALRC and AHEC, Issues Paper 26, October 2001
(Issues Paper). For example see page 300, paragraph 10.107 and page 336, paragraph 11.125.

In the Board's experience it is common for people to be asked to provide information or answer questions, in the course of selection and recruitment for employment and access to services in particular, which could be the basis of subsequent discriminatory decisions. Often, however, they are not clear about what information is sought, the reasons it is being sought and their rights in relation to any information subsequently obtained.

Rather than acting as an impediment to the development and application of genetic technology, effective anti-discrimination and privacy legislative regimes are critical to realising the public health benefits of genetic information. Conversely, where there is a failure to provide such protection, discrimination and privacy concerns will act as disincentives to testing and research participation and may have negative consequences for individual and public health outcomes. [4]

People are less likely to be deterred from undertaking genetic testing if they are confident that their human rights will be protected. In order to instil such confidence in the community not only must privacy and anti-discrimination laws provide adequate protection, people must understand their rights. Anti-discrimination and privacy agencies can play an important role in educating those affected about their rights.

The existing legislative framework

It is the Board's view that discrimination on the basis of genetic information is not so fundamentally different from other forms of discrimination that it cannot be adequately addressed under the existing privacy and anti-discrimination legislation framework, state and federal.

Discrimination legislation

Generally, the conceptual framework of anti-discrimination legislation is based on prohibiting discrimination against a person or groups of persons on the basis of *characteristics* such as race, sex, age, homosexuality or disability, where such *characteristics* are applied arbitrarily to determine whether a person is entitled to access particular services, or can perform the inherent requirements of a job. Whether the *characteristic* is a disability such as HIV/AIDS, cancer, a condition diagnosed by genetic testing, or a future and/or imputed disability such as a predisposition to a particular condition, makes little difference.

Under the ADA it is unlawful to discriminate against a person on the grounds of, for example, disability in various defined areas of public life, including the provision of goods and services, employment, accommodation, State education, and registered clubs. The largest number of complaints lodged with the Board concern discrimination in employment.

---

[4] See Miller, P. *Genetic Discrimination in the Workplace,* 1998 Vol. 26 Journal of Law, Medicine and Ethics 189 at page 190 - 191 in relation to the impact of people's fears of discrimination on their willingness to undergo genetic testing.

"Disability" is defined broadly in s.4 of the ADA. It covers past, present, future and presumed disability and has been interpreted to include temporary illnesses.

The Act states that:

> *"**disability**" means:*
>
> *(a)* *total or partial loss of a person's bodily or mental functions or of part of a person's body; or*
>
> *(b)* *the presence in the person's body of organisms causing or capable of causing disease or illness; or*
>
> *(c)* *the malfunction, malformation or disfigurement of a part of a person's body; or*
>
> *(d)* *a disorder or malfunction that results in a person learning differently from a person without the disorder or malfunction; or*
>
> *(e)* *a disorder, illness or disease that affects a person's thought processes, perceptions of reality, emotions or judgement or that results in disturbed behaviour.*

The ***ADA*** covers both direct and indirect discrimination. Direct discrimination means treating someone unfairly or unequally because they belong to a particular group or category of people. Indirect discrimination occurs where there is a requirement (a rule, practice, policy or procedure) that is the same for everyone but has an unequal or disproportionate effect on a particular group. The requirement will be indirectly discriminatory if the requirement is not reasonable in all the circumstances.

Pre-employment medical assessments are a relatively common part of recruitment practice. While the use of pre-employment medicals is not necessarily discriminatory they may be used to discriminate against applicants depending on when the information is sought, the type of information sought and whether the information obtained is relevant to the inherent requirements of a particular position.

Health care professionals are asked on a regular basis to assess people's capacity to do certain jobs, usually by way of taking a medical history and conducting an examination. Where information about a person's health status is disclosed in a medical report and a decision is subsequently made not to employ the person, both the employer and the health care professional may be liable under the ADA either by directly (or indirectly) discriminating against the person, or by aiding and abetting another party to discriminate on an unlawful ground.

It is clear from the findings of the Report (referred to above) that requests for and use of medical information to discriminate in a range of settings already occurs in relation to hepatitis C. Similarly, there is every reason to believe that discrimination on the grounds of genetic information will increase without legislative protection.

Privacy legislation

The *Privacy Act* creates a framework for national regulation of health information in the private sector, as well as protecting privacy in the Commonwealth public sector. However, there is no comprehensive framework for consistent national regulation of health information across public and private sectors, state and federal. Health information is subject to different protection depending on whether it is held by a Commonwealth agency, state or territory agency or private sector organisation.

A complicating factor is that many different organisations may be responsible for delivery of health services to any one individual meaning that different legal regimes and privacy protection, with different privacy standards, may apply to different parts of the health information relating to a single individual. Practical difficulties can also arise when organisations are required to comply with a number of related but conflicting laws.

Particular complexity arises where States and Territories have health privacy legislation purporting to cover the private sector, as is the case in New South Wales, Victoria and the ACT.[5] Various aspects of this state and territory legislation may be inconsistent with the Act which can, in turn, create confusion and uncertainty for those organisations and individuals needing to comply with both sets of regulations.

There are also differences in the way the Act treats personal information, health information and other sensitive information. Health and other sensitive information are provided higher levels of protection than ordinary personal information.[6] Generally, genetic information will receive the special protection afforded to sensitive information under the *Privacy Act* if it can be defined as health information or some other element of sensitive information, for example, if it constitutes information or an opinion about an individual's racial or ethnic origin, their sexual preferences or their criminal record.

There are circumstances in which genetic information may not be health information, as defined in the Act. This may occur either because the information is not about health, disability or the provision of a health service (as in the case of parentage or forensic

---

[5] *Health Records and Information Privacy Act 2002* (NSW); *Health Records Act 2001* (Vic); *Health Records (Privacy and Access) Act 1997* (ACT).

[6] Subject to some limited exceptions, NPP 10 requires consent for the collection of sensitive information: compare Ibid, NPP 1, which requires only that individuals be informed about various matters such as their access rights, the purposes of collection and to whom the organisation usually discloses information of that kind. The use and disclosure of sensitive information other than for the primary purpose of collection is more constrained than is the case with ordinary personal information—the secondary purpose must be directly related to the primary purpose: *Privacy Act 1988* (Cth), NPP 2.1(a).

testing) or because it is not about the health or disability of an existing individual (as may sometimes be the case with genetic carrier traits).

The future

The Board notes that the Senate Legal and Constitutional Legislation Committee, in its consideration of the *Genetic Privacy and Non-Discrimination Bill 1998* expressed concern about the potential for administrative and legal confusion to be created where separate genetic privacy and anti-discrimination legislation was implemented. The committee's report concluded that it was more appropriate to amend existing privacy and anti-discrimination legislation.[7] The ADB shares the Committee's concerns.

There are numerous benefits to retaining genetic discrimination within the conceptual framework of existing anti-discrimination legislation including:

- greater clarity about people's rights and responsibilities under anti-discrimination law where there are fewer pieces of legislation;
- a reduction in the complexity of jurisdictional decisions for would-be complainants; and
- increasing the likelihood that case law from one jurisdiction is applicable in another and for precedent to be applied

Retaining genetic discrimination within the conceptual framework of existing anti-discrimination legislation will also ensure that we do not afford different levels of protection to people with disabilities diagnosed by genetic testing, or future or imputed disabilities based on predictive genetic testing compared with other people with disabilities.

Although in the Board's view the current definitions of disability in both the ADA and the *Disability Discrimination Act* 1992 (Cth) (**DDA**) cover genetic discrimination, there is a strong public interest rationale for making such coverage explicit in all state/territory anti discrimination legislation. Such amendment would make it clear that disability includes genetic mutations or chromosome abnormalities:

- causing or capable of causing disease, illness, malfunction, malformation or disfigurement of a part of the person's body, or
- resulting in the person learning differently from a person without the disorder or malfunction, or
- affecting a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour.

---

[7] Senate Legal and Constitutional Legislation Committee, Consideration of the *Genetic Privacy and Non-Discrimination Bill 1998,* March 1999, paragraphs 5.24 - 5.33.

Of the approximately 1,600 genetic linked conditions, by far the majority are conditions which *may* develop in the future; of these the absolute risk associated with a particular mutation varies widely. Even if a person develops a particular condition, the severity of symptoms varies, some conditions can be treated, others may be able to be treated in future, should the person develop the condition. In light of this, there is a need to guard against genetic difference becoming an unchallenged rationale for excluding from employment persons who are, otherwise, productive members of society.[8]

The Board favours an approach which prohibits employers, service providers and the like from obtaining and using genetic information, in employment and other areas covered by anti-discrimination law. This can be best be achieved by ensuring:

- that the DDA and state and territory anti-discrimination legislation prohibits requests or requirements for people to supply information upon which unlawful discrimination might be based. (Such a provision should provide a defence, where the information was reasonably required for a purpose that did not involve discrimination, and /or subject to limited exceptions, for example, a person's capacity to undertake the inherent requirements of the job and occupational health and safety/public safety issues.); and
- by amending the Privacy Act to prevent the inappropriate or inadvertent disclosure of information on which discriminatory decisions about employment or the provision of services could be based.

Ensuring that anti-discrimination legislation provides a clear prohibition in relation to requesting or requiring another person to supply information on which unlawful discriminatory decisions may be based, can play an important educative role. Nonetheless, relying on individual complaint mechanisms will be inadequate to ensure that employers only request genetic testing within certain confined circumstances and that when they have the information, that they will understand it before making a decision.

For this reason in its submission to the ALRC and AHEC Inquiry into the Protection of Human Genetic Information in April 2002 the Board proposed the establishment of a national genetic testing code of practice which would include clear guidelines in relation to genetic testing and the potential for discrimination as a result of inappropriate or inadvertent disclosure. The guidelines should enable people to make informed decisions about whether to undergo testing and also ensure they are provided with accurate information about their rights under anti-discrimination and privacy legislation. Ideally, such a code should be enforceable and sanctions apply for breaches of the code.

In regard to privacy, it is critical that existing inadequacies are addressed, for example, employee records are not currently covered by privacy legislation.

---

[8] Yesley, M. *Genetic Difference in the Workplace*, 1999 American Bar Association, Fall 1999, 40 Jurimetrics 129 at page 130.

The exemption does not cover future employment relationships so that personal information collected from prospective employees who are subsequently not employed by an organisation, such as unsuccessful job applicants, will not be covered by the employee records exemption (and the information will be covered by the privacy principles).

However, once an employment relationship is formed with an individual, the records the employer holds relating to that individual's pre-employment checks become exempt.

Employee records include health information about an employee and personal information relating to the engagement, training, disciplining, resignation or termination of employment of an employee.

To the extent that such information may be used by a current employer, for example, to determine suitability for on-going employment, advancement, training opportunities, or other terms and conditions of employment, the exemption may operate to disadvantage a person in the course of their employment. It is also not clear to what extent information obtained in the process of engaging employees may be caught by the employee records exemption; this is an issue which has significant implications on a determination of suitability for employment.

This, in the Board's view requires further consideration and possible amendment of the Act to prevent potential discrimination.

As a matter of priority the Commonwealth, States and Territories should pursue the harmonisation of information and health privacy legislation as it relates to human genetic information.

The Board endorses the recommendation of the ALRC Inquiry that the definition of health information in the *Privacy Act* be amended to make clear that it includes genetic information predictive of health, whether or not the information is collected in relation to the health of, or the provision of a health service to, the individual or a genetic relative.[9]

Summary

Anti-discrimination and privacy agencies have a critical role to play in working with employers, insurance companies and other service providers to prevent the possible disclosure and discriminatory use of genetic information.

Given the implications of genetic testing, at the outset people need to have adequate information to be able to make informed decisions about whether to undergo testing, including information about their rights under anti-discrimination and privacy legislation. A national genetic testing code of practice should provide clear guidance on what information is needed in pre and post test discussion, in addition to clarity about

---

[9] And bodily samples from individuals whose identity is apparent or reasonably can be ascertained from the sample: See Ch 8.

employers' and service providers' responsibilities under anti-discrimination and privacy laws and other relevant legislation.

In the Board's view, it is fundamentally in the public interest that discrimination and privacy laws, Federal and state, be harmonised to enhance the capacity of the current legislative regime to respond to the new and emerging technologies associated with genetic testing.

Should you wish to discuss any of the matters raised in this submission please contact Fiona Kerr, Legal Officer, on 9268 5572.

Yours faithfully

Elizabeth Wing
Acting President

18 February 2005