# Productivity Commission Inquiry Into The Disability Discrimination Act

# Submission Of The Anti-Discrimination Board Nsw

## May 2003

**This submission represents the views of the Anti-Discrimination Board and is not a submission on behalf of the New South Wales government.**

## Contents

## Introduction and overview of submission

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 of human rights and effectiveness of anti-discrimination law.

The Board fully supports the need for a federal disability discrimination scheme. The *Disability Discrimination Act 1992* (Cth) (DDA) provides an essential element of any national government's efforts to advance the position of people with disabilities in Australian society.

There have been significant advancements in the protection of the rights of people with disabilities in New South Wales as a result of the operation of both the ADA and the DDA. Many of the achievements of the DDA are outlined in the Human Rights and Equal Opportunity Commission's (HREOC) publication *Ten years of achievements using Australia's Disability Discrimination Act*, March 2003. Further, the provisions of the DDA have influenced legislative amendment of the ADA which now incorporates many similar provisions to the DDA. In turn the Board has witnessed a change in attitudes towards and treatment of people with disabilities which is directly attributable to the operation of disability discrimination legislation at the State and Federal level.

After ten years of the operation of the DDA there is an opportunity to review the Act to further advance the rights of people with disabilities. The Board has some reservations as to whether the Productivity Commission is the most appropriate mechanism for reviewing the operation of the DDA. In the Board's view assessing the effectiveness of human rights legislation within a framework of competition and productivity principles has inherent limitations. Any assessment of the operation of the DDA should occur within a framework where principles aimed at achieving advancements of rights, fairness, equity, participation and equality of opportunity for people with disabilities are paramount. Within that human rights framework it is then, of course, appropriate to ensure that resources are expended in the most efficient and effective manner.

Social and economic costs are incurred when people with disabilities are excluded in a discriminatory manner from participation in education, employment and other aspects of public life. Such exclusion impacts upon the economic position of people with disabilities, their friends, carers, family members and the community as a whole as income support, supported accommodation, health, social services and other assistance is increasingly required as a result of marginalisation.

The Board urges the Productivity Commission to pay particular regard to the social justice objectives of the DDA. The Board provides this submission to assist the inquiry to make recommendations that may further strengthen the DDA. The submission of the Board is primarily focused upon encouraging consideration of legislative reform that in our view may assist in achieving a legislative and policy scheme that is more able to advance the objectives of the DDA into the future.

In the Board's view, it is fundamentally in the public interest to prevent and eliminate unlawful disability discrimination including systemic discrimination. In order to achieve that goal consideration should be given to reframing discrimination legislation to more explicitly impose positive duties upon employers, educational authorities, providers of accommodation, goods, services and facilities to accommodate the requirements of people with disabilities subject to appropriate defences. In addition, consideration should be given to enacting further provisions which go beyond reliance upon individual complaints mechanisms to effect change. The HREOC should be given a set of powers to assist in advancing wide reaching positive change in order to further advance the status of people with disabilities in Australia. Consistent with international trends, such powers should be accompanied by appropriate enforcement mechanisms which do not rely upon the capacity of individuals to pursue compliance.

## Operation of State and Federal laws

A federal DDA is essential in order to ensure that all people with disabilities in Australia have equality of protection from discrimination. As a general principle there is also merit in having consistency between the operation of State and Federal anti-discrimination laws where appropriate. Consistency of laws assists in increasing understanding of rights and responsibilities and may assist in minimising compliance costs. While there are many aspects of the disability provisions of the ADA which are consistent with the DDA, there remain some inconsistencies particularly in relation to the operation of exceptions. The Board has made previous submissions for reform of the ADA where consistency between the ADA and federal anti-discrimination legislation is desirable.

However consistency should not occur at the expense of innovation and best practice. The operation of State anti-discrimination legislation allows for State governments to demonstrate leadership on matters of disability discrimination of particular relevance to their communities. Similarly State governments are not limited by the constitutional parameters which apply to federal legislation. The duel operation of State and Federal law ensures that all people with disabilities in Australia have access to a system for dealing with complaints of disability discrimination.

The Board supports further collaboration between State and Federal anti-discrimination bodies and the examination of the potential for co-operative arrangements regarding complaint handling functions under State and Federal legislation.

## Disability in New South Wales

The Australian Bureau of Statistics defines disability as arising when a person has a limitation, restriction or impairment, which has lasted or is likely to last for six months or more and restricts every day activities.[1] Based on that definition in 1998 almost one in five people in NSW (1.2 million) or 19% of the population had a disability.[2]

Of those people with a disability, around 79% of people had a restriction in one or more fundamental aspects of every day life including self care, mobility and communication.[3] In addition, 44% of people with a disability were not able to participate fully in schooling and/or employment.[4] Statistics show that in 1998, people of working age (15-64 years) with a disability generally had a lower rate of labour force participation (50%) in NSW than those without a disability (80%).[5]

In addition there are large numbers of people in NSW who provide care for people with disabilities. In 1998 it was estimated that 798,300 or around 1 in 8 people in NSW were performing a caring role. Of these, 20% were primary carers.[6]

These statistics show that there are many people in NSW who have a disability and large numbers of carers who provide care or support for some people with disabilities. There may be many more people in NSW who have disabilities which do not fall within the definition used by the ABS. Accordingly there is the potential for large numbers of people in NSW to be assisted, both directly and indirectly, by the operation of disability discrimination legislation.

## Employment of people with disabilities in the NSW public sector

People with disabilities continue to have lower participation rates in employment than people who do not have disabilities. In relation to public sector employment in NSW, state government agencies are required to develop equal employment opportunity (EEO) management plans to eliminate discrimination in employment and to promote equal employment opportunity for “physically handicapped persons”.[7] That requirement is imposed under Part 9A of the ADA which deals with equal employment opportunity in the public sector.

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[1] ABS *Disability New South Wales 2001,* 4443.1, Commonwealth of Australia 2001, p. 7.

[2] *ibid.*

[3] *ibid.*

[4] *ibid.*

[5] *ibid,* p. 79. The level of participation also differed between age groups.

[6] *ibid,* p. 36.

[7] Note that the grounds listed in Part 9A do not accord with the prohibited grounds of discrimination under the ADA generally. The Board has recommended that Part 9A is amended to ensure that the public sector has an appropriate focus on achieving equal employment opportunity for all people with disabilities.

The Office of the Director of Equal Opportunity in Public Employment (ODEOPE) provides information on the profile of NSW government employees and is involved in recruitment strategies to increase the representation of certain groups in the NSW public sector including people with physical disabilities. As well as aiming to achieve an equitable level of representation of EEO groups in the Public Sector workforce, the EEO program seeks to reduce the concentration of EEO groups in lower skilled and lower paid jobs.

An estimated 12% of the working age population in NSW have a disability.[8] An estimated 7% of the NSW working age population have a disability that would require work related adjustments. In 2000, the general representation of people with a disability in the NSW Public Sector was estimated as 6% (a decline from 7% in 1999) and people with a disability requiring work-related adjustments as 1.9% (a decline from 2.2% in 1999).[9] Of the 125 individual Public Sector agencies able to provide data on people with a disability, 18 had met or exceeded the population benchmark of 12%. Of the 125 agencies able to provide data on people with a disability requiring work related adjustment, 2 had met or exceeded the population benchmark of 7%. Representation of people with a disability requiring work related adjustment increased in 27 agencies and decreased in 69.[10]

ODEOPE has developed a Distribution Index which measures the extent to which a particular EEO group is distributed across salary levels compared with other employees. A value of 100 indicates that the distribution of the EEO group in question across salary levels is equivalent to that of other staff. Between 1999 and 2000 the Distribution Index for people with a disability increased from 100 to 101, indicating that people with a disability has the same overall salary level distribution as other staff. In 2000, 30 agencies out of a total of 72 had achieved a Distribution Index of 100 or more for staff with a disability.[11]

Between 1999 and 2000 the Distribution Index for people with a disability requiring work-related adjustment increased from 99 to 101. However ODEOPE state that people with a disability requiring work related adjustment employed in authorities tend to have a poorer salary level distribution than those in other Public Sector agencies. In 2000 20 agencies out of a total of 49 had achieved a Distribution Index for people with a disability requiring work related adjustment of 100 or more. The distribution of people with a disability requiring work related adjustment varied considerably between different agencies.[12]

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[8] The population benchmark for people with a disability is derived from the ABS Survey of Disability, Ageing and Carers (1998) and includes all people aged between 15 and 64 but excludes people who are permanently unable to work because of a disability. See ODEOPE *Advancing Diversity: EEO Statistical Profile of the NSW Public Sector for 1999,* 1999, p. 59 and *People with a disability - Comparative tables 2000 - NSW Public Sector* footnote 1, available at: www.eeo.nsw.gov.au/stats/pwd00.htm

[9] *People with a disability - Comparative tables 2000 - NSW Public Sector* available at: www.eeo.nsw.gov.au/stats/pwd00.htm

[10] *ibid*

[11] *ibid*

[12] *ibid*

While there have been a number of initiatives taken by NSW government agencies, these statistics indicate that additional measures are required in order to increase the participation of people with disabilities in public sector employment.

## Complaints of disability discrimination under the Anti-Discrimination Act NSW

The ADA was amended in 1994 to introduce a more comprehensive definition of disability following the model provided by the DDA. The ADA was also amended to make it unlawful to do any public act that is capable of inciting hatred, serious contempt or severe ridicule of people on the ground that they are, or are presumed to be, living with HIV or AIDS.

In the past decade the Board has dealt with over two and a half thousand complaints of disability discrimination. In addition to formal complaints in writing, the Board also provides an inquiry service to members of the public on discrimination issues. In the last financial year the Board dealt with 2,235 inquiries relating to disability discrimination.

The number of disability complaints lodged under the ADA has increased over time. The table on the following page sets out the numbers of complaints lodged with the Board by area.

The complaint and inquiry statistics show that large numbers of people in NSW raise issues of disability discrimination with the Board. However those statistics may underestimate the incidence of discrimination experienced by people with disabilities. As with allegations of discrimination on other grounds, there are many reasons why people with disabilities may not lodge a formal complaint of disability discrimination. It may be that the nature of the person’s disability itself also impacts upon a person’s ability to access and pursue discrimination remedies. Disability organisations may also be limited in their capacity to make complaints on behalf of people with disabilities as representative bodies due to resource constraints.

Complaints and enquires regarding disability discrimination which do come to the attention of the Board relate to a broad range of issues. Complaints in the area of employment relate to refusing to employ or promote a person with a disability, detrimental treatment during employment and termination of employment. In many cases employers do not appear to have properly considered whether services or facilities could be provided without causing unjustifiable hardship in order to enable an employee who has a disability to perform the inherent requirements of a position. Similar issues arise where people with disabilities are refused accommodation or are unable to access services or facilities as a result of structural barriers.

**Disability discrimination complaints under the ADA received by area**

| **Year/ Area** | **employment** | **goods & services** | **accommodation** | **education** | **registered clubs** | **TOTAL** | **% of total no. of complaints** | **HIV/AIDS vilification** |
|---|---|---|---|---|---|---|---|---|
| 2001/02 | 183 | 100 | 17 | 17 | 9 | **332** | 20 | 5 |
| 2000/01 | 157 | 129 | 16 | 36 | 7 | **349** | 22 | 0 |
| 1999/00 | 175 | 68 | 8 | 19 | 8 | **288** | 21 | 0 |
| 1998/99 | 128 | 55 | 5 | 8 | 7 | **207** | 17 | 3 |
| 1997/98 | 147 | 86 | 5 | 16 | 8 | **274** | 21 | 0 |
| 1996/97 | 152 | 96 | 6 | 24 | 3 | **293** | 18 | 1 |
| 1995/96 | 151 | 63 | 7 | 29 | 5 | **262** | 14 | 2 |
| 1994/95 | 140 | 72 | 6 | 11 | 4 | **239** | 14 | 2 |
| **phys impair & intellectual impairment** | | | | | | | | |
| 1993/94 | 67+4 | 31+6 | 3+0 | 6+14 | 2+3 | **110+28** | 8 | |
| 1992/93 | 93+9 | 40+10 | 9+4 | 2+0 | 1+0 | **146+25** | 12 | |

While it may be that the nature and degree of disability experienced by some people means that participation in all aspects of community life is not possible, none the less the ABS, ODEOPE and complaint statistics appear to indicate that further measures are required that could increase the participation of people with disabilities in employment, education and in access to services, facilities and accommodation generally.

## Limitations of individual complaint focused models

There is no doubt that the current complaint mechanism for resolving complaints has resulted in effective redress for complainants in many circumstances. In addition to providing a remedy directly to a complainant, conciliation may also provide the opportunity for systemic outcomes such as organisational and policy changes, to form part of the settlement of a complaint. Resolution of complaints of indirect discrimination also have the potential to positively impact on people other than an individual complainant. Similarly decisions of the Federal Court or Federal Magistrates Court are able to create binding precedent which can influence the conduct of others.

The Disability Discrimination Unit of the Human Rights and Equal Opportunity Commission has, where the parties consent, taken an innovative approach and conducted public inquiries into discrimination complaints which raise issues of systemic discrimination. An example is that Unit’s inquiry into a complaint of disability discrimination in the provision of services. The complaint was from a person with a hearing impairment who alleged discrimination in the failure to provide captioning at a cinema. Although initially the complaint was lodged against one cinema, the Unit broadened the usual complaint investigation process into a “public investigation” involving a number of cinema chains, film distributors and interested disability bodies. The result was that a number of cinemas across Australia agreed to provide such captioning as part of particular cinema services.[13]

However the current legislative regime in relation to complaints has limitations. The Combined Community Legal Centre’s Group (NSW) has argued that the emphasis on individual complaint mechanisms is problematic for the following reasons:

- those who are most marginalised, and most in need of protection from the law, are the least likely to trust or have contact with complaint bodies;
- individuals who lodge complaints are among the least likely in the community to be able to comply with the procedures necessary to establish their case;

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[13] See Graham Innes, Deputy Disability Discrimination Commissioner Human Rights and Equal Opportunity Commission, *The Role of Public Inquiries and Exemption Powers in Eliminating Disability Discrimination*, Constructing Law and Disability Conference, Australian National University, 4 December 2000.

- the nature of the discriminatory conduct may be such that individuals affected are less likely to complain, due to concerns that publicity regarding the incident will expose them to further discrimination or harassment;
- individuals are more likely to be affected by significant delays in complaints handling,
- there is often a significant imbalance of power between complainants and respondents, particularly in relation to the capacity of the parties to bear the costs involved, often leads to unsatisfactory settlements at conciliation. Complainants are less likely to have the financial resources to proceed to hearing;
- conciliated settlements do not produce binding precedents;
- “burn out” by complainants because of the demands of the process; and
- the inability of a system based on individual complaints to deal with systemic discriminatory practices.[14]

In particular the more vulnerable a community is to discrimination the more difficult it can be for members of that community to bring an individual action to redress that discrimination. This is often because of fears of victimisation or because the very disadvantage suffered makes people less likely to be able to access complainant driven remedies. In some instances these factors also lead to people withdrawing their complaints.

There have also been a number of studies into the effect, utility and accessibility of complaint resolution functions of State and Federal anti-discrimination agencies.[15]

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[14] Combined Community Legal Centre’s Group (NSW) Human Rights and Discrimination Sub-Committee, *Submission on the Human Rights Legislation Amendment Bill 1996* to the Senate Legal and Constitutional Committee Inquiry into the Bill, March 1997, p. 8, cited in Australian National Council on AIDS, Hepatitis C and Related Diseases, *Barriers to access and effective use of anti-discrimination remedies for people living with HIV and HCV,* Occasional Paper No 1, July 2001, prepared for ANCAHRD by Julia Cabassi, member of the ANCAHRD Legal Working Party, p. 6.

[15] See: Annemarie Devereux, “Human Rights by Agreement? A Case Study of the Human Rights and Equal Opportunity Commission’s Use of Conciliation”, *Australian Dispute Resolution Journal,* Vol. 7, 1996, p. 280. This was a study of around 40 conciliation files finalised in the 1989-1990 financial year under the federal anti-discrimination Acts. See also Report of the Steering Committee into Processes under the Western Australian Equal Opportunity Act 1984, *Investigation and Conciliation,* cited in (ed.) David Kinley, *Human Rights in Australian Law,* Sydney, Federation Press, 1998, p. 293, n. 6. The Report is based on data collected from a random telephone survey of 196 complainants and respondents where files were finalised in the 1991/2-1992/3 financial year, an examination of 225 Equal Opportunity Commission complaint files, ministerial submissions and interviews with Commission staff. In relation to NSW see NSW Law Reform Commission, *Discrimination complaints-handling: A study,* Research Report 8, Sydney, 1997, ADB, *Women’s experience of making complaints to the NSW Anti-Discrimination Board or the federal Human Rights and Equal Opportunity Commission,* 1997, Anna Chapman, “Discrimination Complaint-Handling in NSW: The Paradox of Informal Dispute Resolution”, *Sydney Law Review,* Vol. 22, p. 321, Public Interest Advocacy Centre and Wirringa Baiya Aboriginal Women’s Legal Centre, *“Discrimination….have you got all day” – Indigenous women, discrimination and complaints processes in NSW,* Sydney, December 2001. The report is based on quantitative ABS data and data collected by the ADB and the Human Rights and Equal Opportunity Commission (HREOC) and qualitative data drawn from focus group consultations.

Complaint processes of State and Federal anti-discrimination agencies have been criticised for their limitations in redressing discrimination, including systemic discrimination. Criticisms include:

- the need for information, assistance, support, advice, representation, advocacy;
- the lack of investigative powers of some anti-discrimination complaint handling bodies;
- an inability to act on behalf of complainants;
- the onus in establishing a case being on the complainant;
- the adversarial nature of the process;
- the increasing formalism and legalism in the process;
- the reliance upon written correspondence between parties and the complaint handling body;
- the emphasis on procedural fairness and impartiality;
- inequalities of bargaining position between complainants and respondents;
- delays;
- individualised focus; and
- reactive not pro active models.

## Towards a model for the future

While many improvements to the status of people with disabilities have occurred, there remain many outstanding matters. The exclusion of people with disabilities and other detrimental treatment of people with disabilities continue to occur as a result of prejudice, the application of stereotypes and because of a lack of understanding of responsibilities and solutions. In the Board’s experience, some respondents do not view the disability provisions of the ADA or the DDA as imposing a positive obligation to accommodate people with disabilities. In addition, many complaints arise in circumstances where employers do not appear to have given proper consideration to whether a person with a disability may be provided with services or facilities to enable the inherent requirements of a position to be carried out without causing unjustifiable hardship.

In addition there continue to be structural barriers that impact upon equality of opportunity for people with disabilities. Disability discrimination does not only result from the actions of individuals but is a result of structural and systemic inequalities. In the Board’s view is seems inappropriate that the responsibility for preventing and eliminating disability discrimination, a goal which is fundamentally in the public interest, should primarily rest with individuals who are the subject of these inequalities. Rather, a public body such as HREOC should be empowered to take action to assist in achieving the objects of the legislation.

Consideration should be given to ensuring that the DDA is based on a more proactive and preventative model. An objective of any such model should be to prevent and eliminate discrimination against people with disabilities that is embedded in public institutions, buildings, transport systems and the way in which jobs are designed and working time is organised.

## A positive duty

In the Board's view a more proactive DDA would clearly require positive steps to be taken to ensure that people with disabilities are able to participate in employment and education and enjoy access to goods and services, public places and accommodation. For example, a positive duty could more clearly require an employer to take steps to accommodate the needs of people with disabilities at work to enable them to carry out the inherent requirements of the job. An appropriate defence could apply where this cannot be done without causing unjustifiable hardship or the person would be unable to perform the inherent requirements of the job even with the provision of services and facilities. It should be made clear that the provision of "services and facilities" includes changes to working time and the organisation of work.

Such a model is more proactive than the current model which is based on a comparative test and not specifically on a positive compliance requirement. Similar models are already in existence in relation to the positive obligation on employers to provide a safe system of work under Occupational Health and Safety legislation.

In relation to access to premises a new model could provide for application to be made by a person with a disability, a representative or the Commission for an order that premises or services be made accessible. The test could be based on the premise that access should be provided. Where access is found to be precluded or inadequate then the test could take into account the circumstances of the service provider or owner of premises among other factors in determining whether immediate access should be ordered or a plan of action should be implemented over a set period of time.

Such a model should create greater understanding of rights and responsibilities under the DDA by making it clear that positive duties must be complied with unless a defence could be made out. Alternatively, there could be a clear duty to "reasonably accommodate" a person with a disability in order to enable them to carry out the inherent requirements of a position, access services, facilities, premises and accommodation. What amounts to "reasonable accommodation" should require a consideration of all the circumstances including those which are presently considered under the defence of unjustifiable hardship.

## Overseas experience

There are a number of models and propositions for reform in other jurisdictions regarding anti-discrimination laws. An examination of Canada and the UK indicates a trend toward framing anti-discrimination legislation in positive terms. There is also a move away from reliance upon complaint based mechanisms and toward enacting compliance and enforcement powers which do not solely rely upon individuals.

The International Labour Organisation has recently released a report which examines discrimination law and policy responses in an international framework.[16] That report notes that:

> A growing number of countries have moved away from a legal approach exclusively based on the imposition of the negative duty not to discriminate to a broader one encompassing a positive duty to prevent discrimination and promote equality. While an anti-discrimination legal model based on prohibiting discriminatory practices has proven successful in eliminating the most blatant forms of discrimination, such as direct pay discrimination, it has encountered less success with the more subtle forms, such as occupational segregation. Moreover, its effectiveness in eliminating discrimination is heavily dependent on litigation and this prevents it from reaching those workers who are the most disadvantaged and vulnerable to discrimination. These workers tend not to make use of the law to have redress because of ignorance or fear of retaliation. [17]

## United Kingdom

The *Race Relations Act 1976* confers a positive duty upon public bodies to promote racial equality and eliminate racial discrimination. Failure to fulfil the duty may be enforced by the Commission for Racial Equality (CRE) taking legal proceedings against the body.

The *Race Relations Act* imposes a general duty on all public bodies to promote racial equality, eliminate racial discrimination in employment and service delivery and to promote good race relations between different racial groups. The Home Secretary (and Scottish Ministers, in Scotland) has the power to make Orders placing specific duties on some or all public bodies which will set out in more detail action that public authorities need to take in order to better comply with the general duty. The CRE has the power to enforce these duties by issuing compliance notices to a public authority which it believes to be failing to fulfil any specific duty laid down and, if necessary, to seek a court order to enforce the notice. The CRE is also empowered to develop Codes of Practice. Codes provide guidance to public authorities on how to fulfil their general and specific duties.[18]

The new legislative framework assists in avoiding race discrimination by placing a positive duty on public authorities to assess the impact on race equality of all aspects of its operations. It is an attempt to address issues of systemic and institutionalised racial discrimination by promoting the public sector as the instrument of change.

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[16] ILO *Time for Equality at Work: Global Report under the Follow-up to the ILO Declaration on Fundamental Principles and Rights at Work,* International Labour Conference 91st Session 2003, International Labour Office, Geneva, Switzerland.

[17] *Ibid* p. 60 para 182.

[18] See *A guide for public authorities, A guide for further and higher education institutions, A guide for Schools, Ethnic monitoring: a guide for public authorities.*

The UK Equal Opportunities Commission and Disability Rights Commission are advocating for comparable provisions in relation to sex and disability discrimination.[19]

In February 2003 a Private Member's Equality Bill was introduced in the House of Lords. The Bill gives effect to the main recommendations in *Equality: A New Framework. Report of the Independent Review of the Enforcement of UK Anti-Discrimination Legislation* ("the Hepple Report").[20] That Report found that there "was general support from our respondents for an inclusive, pro-active non-adversarial approach to achieve employment equity of fair participation".[21]

One of the most innovative features of the Equality Bill is that it would impose a duty on public authorities to promote equality of opportunity with regard to all prohibited grounds including disability.[22] These measures are set out in Part 3. Clauses 25 to 27 require bodies exercising functions of a public nature to have regard to the need to eliminate discrimination and to promote equality of opportunity.

A failure on the part of a public body to observe the duties imposed may be taken into account by the Commission in exercising its functions and may be taken into account in any proceedings before a relevant tribunal or court.

The Bill would also require employers to carry out periodic reviews of the composition of their workforce and their employment policies.[23] These provisions are designed to ensure that if "employment equity groups" are under-represented that there are structured arrangements under which employers and workforce representatives can work together to remedy the problem. The "employment equity groups" are:

- any group of persons identified by reference to a particular disability they have or have had;
- any group of persons identified by reference to their colour, race, nationality or ethnic or national origins; men generally;
- women generally.

Clause 29 of the Bill provides that a workforce review must be conducted at least once every three years by designated employers. The review would evaluate:

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[19] See Disability Rights Commission, *Government consultation document: "Equality and Diversity: Making it Happen" Response from the Disability Rights Commission*, 20 February 2003 at para 2.6.

[20] Bob Hepple QC, Mary Coussey and Tufyal Choudhury, *Equality: A New Framework Report of the Independent Review of the Enforcement of UK Anti-Discrimination Legislation*, Hart Publishing, for The University of Cambridge Centre for Public Law and Judge Institute of Management Studies, Oxford - Portland Oregon, 2000.

[21] *ibid*, p. 59.

[22] Detailed explanatory notes on the Equality Bill are available from www.odysseustrust.org/equality/bg.html

[23] These obligations are set out in clauses 28 to 33.

- the conditions for access to employment by the designated employer, including selection criteria, recruitment conditions, transfer, promotion and other benefit (whatever the branch of activity and at all levels of the professional or occupational hierarchy);
- access provided to all types, and to all levels, of vocational guidance, vocational training, advanced vocational training and retraining, including practical work experience; and
- the employment and working conditions of the workers of the designated employer, including pay, termination and other detriment.

An employer would be required to draw up, adopt and implement an employment equity plan if the workforce review revealed that there was any under-representation in any branch of activity in the workforce, or at any level in the professional or occupational hierarchy, of any of the employment equity groups.[24] The employment plan would set out a program for action for the purposes of:

- identifying barriers to, and in, employment by a designated employer which may adversely affect persons who are members of an employment equity group;
- taking steps to remove such barriers; and
- adopting or maintaining positive policies and practices (including the making of reasonable adjustments to any physical features of premises)to ensure that members of the employment equity groups achieve fair participation in any branch of activity in the workforce of a designated employer or at any level in the professional or occupational hierarchy.

## Northern Ireland

The *Northern Ireland Act 1998* imposes duties on public authorities to promote equality of opportunity. These duties came into force on 1 January 2000. Section 75 requires public authorities, in carrying out functions relating to Northern Ireland, to have due regard to the need to promote equality of opportunity between -

(a) between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation;
(b) between men and women generally;
(c) between persons with a disability and persons without; and
(d) between persons with dependants and persons without.

Schedule 9 of the *Northern Ireland Act 1998* sets out a detailed procedure for the enforcement of these duties.[25] The Equality Commission for Northern Ireland is required to review the effectiveness of the duties imposed by section 75 and to provide

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[24] Clause 30(1),(2).

[25] The Equality Commission for Northern Ireland has prepared a comprehensive *Guide to the implementation of statutory duties on public authorities arising from Section 75 of the Northern Ireland Act 1998.* It can be downloaded from www.equalityni.org.publications/recentpubdetails.cmf?id=5

public authorities and others with advice about these duties. Public authorities are generally required to submit to the Equality Commission an Equality Scheme which states how they propose to fulfil these duties. The scheme must specify what arrangements the authority has made for assessing its compliance with its duties under section 75 and how it intends to consult with those affected by policy decisions or the design of services. In addition, the scheme must set out how the authority will monitor any adverse impacts of policies adopted by the authority on the promotion of equality of opportunity. Before submitting their scheme to the Equality Commission for Northern Ireland, statutory bodies must consult with representatives of people likely to be affected by the scheme. On receipt of a scheme the Equality Commission must either approve it or refer it to the Secretary of State. Where a scheme is referred to the Secretary of State that person must either approve it; request the public authority to make a revised scheme or make a scheme for the public authority.

Of particular interest is that schedule 9 also provides that the Equality Commission may accept complaints about a failure by a public authority to comply with an approved scheme. On receipt of a complaint the Commission must either investigate the complaint or give the complainant reasons for not investigating. It may also conduct an investigation if it believes that a public authority may have failed to comply with an approved scheme. The Commission must send a report on any investigation it conducts to the relevant public authority, the Secretary of State and the complainant (if any). The report may recommend that the public authority should take certain action. If the Equality Commission recommends that certain steps are taken and that these steps have not been taken within a reasonable time, the Commission may refer the matter to the Secretary of State who may give directions to the public authority in respect of any matter referred to him. Public authorities must conduct a review of the Scheme within five years of the submission and must inform the Equality Commission of the results of that review.

## Canadian law reform

In 2000 the Canadian Human Rights Act Review Panel conducted a review of the Canadian *Human Rights Act* and made 165 recommendations for reform.[26] The Panel pointed to a number of barriers to dealing with systemic discrimination and effecting equality in Canada under the current complaint based system.

One reform proposed by the Review Panel focused on repositioning the legislation as imposing positive duties upon employers and service providers. The Review Panel recommended that there should be a duty on the part of employers and service providers to promote equality and eliminate discrimination in much the same way that the *Canadian Labour Code* creates a general duty for employers to ensure the protection of the safety and health of its employees at work. The duty would be detailed by statutory requirements, guidelines and best practice codes. There would also be a duty to provide accommodation to the point of undue hardship. The change

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[26] Report of the Canadian Human Rights Act Review Panel, *Promoting Equality: A New Vision*, Ontario, 2000.

in the language of the Act would not change the meaning of discrimination but rather would signal a change in the approach to attain the purpose of the Act.

The Review Panel also recommended that the Act require employers with more than five employees to have an “internal responsibility system” to deal with human rights matters. The system would have a number of elements including management-labour cooperation, polices and programs promoting equality development, the provision of training, grievance procedures, monitoring, liaison etc. The system would also deal with the provision of service by the employer to the public. Where the employer could show that it had an effective internal responsibility system in place for the resolution of complaints, the Tribunal may dismiss a claim unless the claimant proves that the system failed to deal fully with the human rights issues raised or failed to provide an adequate remedy.

Canada also has a federal *Employment Equity Act.* That Act applies to federally regulated private sector and public sector employers and designated bodies in the public sector which employ more than 100 employees. The Act requires positive steps to be taken by employers to identify barriers and implement measures to increase employment of under-represented groups such as women, members of visible minorities, Aboriginal people and people with disabilities. The federal Canadian Human Rights Commission is responsible for auditing employers to see if they have complied with the Act. The Commission can take legal action if the Act is not complied with. Action does not depend on a complaint being lodged.

The *Employment Equity Act* is a further example of legislation which imposes a positive duty upon employers. While some of the requirements of process which must be complied with before the Commission may take enforcement proceedings against an employer have been criticised, the Review Panel which considered the Act has recommended its retention. The Review Panel stated that:

> The EEA is based on the assumption that the best demonstration that a workplace is free of systemic discrimination is that the representation of disadvantaged groups in the employer’s work force reflects their representation in the pool of available workers. In this way, the EEA shows a way in which discrimination may be approached on a systemic basis. Furthermore, the EEA is based on a proactive approach to the problem. It requires that employers carry out the steps set out in the EEA aimed at eliminating systemic discrimination.[27]

## ***Enforcement mechanisms***

In addition there should be appropriate powers and enforcement mechanisms vested in the HREOC to prevent and eliminate disability discrimination. Reinstatement of the power of the Commission to initiate a complaint could be one such mechanism.

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[27] *ibid.*

The Board also recognises the positive role which may be played by national standards. Provided such standards do not derogate from the provisions of the DDA, they can provide clarity and certainty for respondents and assist in achieving broad ranging change. However at present the DDA relies upon the complaint mechanism to enforce compliance with disability standards. There is merit in examining a mechanism to allow HREOC to enforce compliance with standards as the public body responsible for the administration of the DDA.

## United Kingdom

Discrimination legislation in the UK provides a range of mechanisms for dealing with systemic discrimination which do not solely rely upon individual complaints. Under the *Race Relations Act 1976* the Commission for Racial Equality has power to take legal action against certain acts of unlawful discrimination, including carrying out an investigation if the Commission suspects that an organisation is discriminating on racial grounds. If the Commission is satisfied that unlawful discrimination has taken place, the Commission may issue a “non-discrimination” notice. If not complied with, the Commission can apply to a court for an order to obey the notice. Similar powers exist under the *Sex Discrimination Act* and the *Disability Rights Commission Act.*[28]

The *Race Relations Act 1976* (UK) combines the right of individual access to legal remedies with the strategic functions of the Commission for Racial Equality which has powers to enforce the law in the public interest. The functions of the Commission for Racial Equality in relation to the enforcement of the Act may be summarised as follows

- **Formal Investigations**

  For the purpose of carrying out its duties, the Commission may conduct formal investigations into any matter, and where it discovers conduct which contravenes the Act it is empowered to issue a non-discrimination notice. A discrimination notice can require an organisation not to contravene the Act, take positive action and report on changes made. Where a discrimination notice is not complied with, the CRE may take legal action to enforce compliance;[29]

- **Legal proceedings**

  The Commission is empowered to institute legal proceedings in respect of persistent discrimination.[30] The Commission also has the sole right to institute legal proceedings in respect of discriminatory practices and advertisements, and instruction and pressures to discriminate — such as employers instructing employment agencies not to send them applicants from ethnic minorities, or

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[28] See *Disability Rights Commission Act 1999* especially ss 3-4 and Schedule 3

[29] ss. 48 and 58(a).

[30] s. 62(b).

companies instructing their workers to discriminate in the way they provide goods or services;[31]

- **Acting on behalf of complainants**

The Commission also has certain powers to assist individual complainants in cases before Tribunals and courts where special considerations justify the assistance.[32]

## Other issues raised by the Inquiry's Issues Paper

### *Definitional issues*

#### Definition of disability

The Issues Paper notes at page 12 notes that definitions of disability differ in other federal acts to that which applies under the DDA. In the Board's view the broad definition of disability in the DDA should be retained. The ADA similarly contains a broad definition of disability. It should not be limited by reference to definitions used in other legislation used to determine eligibility for benefits. Legislation such as workers compensation seeks to provide compensation for those people who are injured at work in a manner which impacts on capacity to undertake work. Social security measures for people with disabilities similarly provide economic support in some circumstances where a person with a disability is unable to participate in paid work. However discrimination may impact upon people who have a range of disabilities which do not necessarily impact on their capacity to undertake paid employment. Such discrimination occurs as a result of a range of factors including prejudice, ignorance, because of the application of stereotypes to individual circumstances or because of policies and practices which appear neutral on the surface but which operate to exclude or disadvantage people with disabilities. It is essential that such discrimination remains unlawful regardless of the nature of the disability of the person who is discriminated against or the duration of the person's disability.

The Board has also provided a submission to the Australian Law Reform Commission (ALRC) regarding issues of discrimination which arise in relation to genetic testing.[33] In that submission the Board addressed the concern raised by the ALRC's Issues Paper that genetic discrimination may not be covered by current anti-discrimination legislation. While the Board's view was that the definition of disability in the DDA is sufficiently broad to allow complaints on the ground of a person's genetic makeup, the Board recommended that an amendment to the definition of disability was none the less warranted on the basis of a strong public interest rationale for making such coverage explicit in anti-discrimination legislation. Such clarification would:

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[31] s. 63(c).

[32] s. 66(d).

[33] Anti-Discrimination Board *ALRC and AHEC Inquiry into the Protection of Human Genetic Information : Issues Paper Submission of the Anti-Discrimination Board of NSW April 2002.* Copy attached to this submission.

- reflect the current state of the law under the DDA and ADA;
- 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.

That Board recommended that:

> …the definition of disability in the DDA and all State/Territory anti-discrimination legislation be amended to make clear that 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.[34]

For abundant caution the Board continues to recommend that this amendment is made to ensure that there is clarity regarding coverage of discrimination on the basis of a person’s genetic makeup.

## Indirect discrimination

There are various tests for indirect discrimination in federal and State/Territory anti-discrimination legislation. Under the laws in Victoria and Queensland the complainant must prove that a higher proportion of people without the complainant's particular attribute are able to comply with the requirement or condition (‘the proportionality test’). The federal DDA and New South Wales, South Australia and Western Australia laws go further and require that a ‘substantially higher' differential rate of compliance be shown. On the other hand, the federal RDA and SDA, and the legislation in Tasmania, the ACT and the Northern Territory do not require that any differential compliance rates be shown at all - only that there has been some adverse effect caused by the requirement or condition.

There are a number of complexities associated with the application of the proportionality test. The NSW Law Reform Commission (LRC), in its review of the ADA, also expressed concern about the operation of the proportionality test and recommended reform to address these concerns.[35]

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[34] *ibid*, recommendation 3, p. 11.

[35] Review of the *Anti-Discrimination Act 1977* (NSW), NSW Law Reform Commission, Report 92 (LRC Report), pp. 95 - 103.

The *Sex Discrimination Act 1984* (Cth) (SDA) was amended in 1995 to enact a simpler test of indirect discrimination. Section 5 of the SDA provides:

> **s.5 Sex discrimination**
>
> (2) For the purposes of this Act, a person (the discriminator) discriminates against another person (the aggrieved person) on the ground of the sex of the aggrieved person if the discriminator imposes, or proposes to impose, a condition, requirement or practice that has, or is likely to have, the effect of disadvantaging persons of the same sex as the aggrieved person.

In the Board's view the indirect test in the SDA provides an appropriate model upon which to base a simpler indirect test for the purposes of the DDA. Such a test may more readily assist people with disabilities and potential respondents to understand and implement their rights and responsibilities under the Act.

## *Requests for information*

Section 30 of the DDA provides:

> **30. Requests for information**
> If, because of another provision of this Part (other than section 32), it would be unlawful, in particular circumstances, for a person to discriminate against another person on the ground of the other person's disability, in doing a particular act, it is unlawful for the first-mentioned person to request or require the other person to provide, in connection with or for the purposes of the doing of the act, information (whether by completing a form or otherwise) that persons who do not have a disability would not, in circumstances that are the same or are not materially different, be requested or required to provide.

This provision appears to be limited to circumstances where information is sought from a person who has a disability and such information is not or would not be sought from persons who do not have a disability. It is unclear whether blanket requests, such as for health information in employment from all applicants or employees, which may raise indirect discrimination against people with disabilities, would be covered by the provision.

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. Such requests for information are often in the nature of a blanket requests, for example dental forms which require people to disclose whether they have HIV or hepatitis C or employment application forms or pre-employment medicals that seek information about a person's health which are not relevant to the inherent requirements of the particular position.[36]

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[36] Anti-Discrimination Board *C-change: Report of the inquiry into hepatitis C related discrimination*, November 2001, section 2.4, p. 60.

Blanket requests for information on which discriminatory treatment might be based may not be adequately covered by section 30 of the DDA. In the example where people are required to disclose their hepatitis C status in order to obtain services from a dentist, section 30 only considers circumstances where the information is sought from a person who has a disability and such information is not or would not be sought from persons who do not have a disability. In this case the information is sought from all people, but has a disproportionate impact on people with hepatitis C.

The Board considered the issue of requests for information in its submission to the ALRC regarding issues of discrimination which arise in relation to genetic testing. Recommendation 6 of the Board was that:

> …the DDA and relevant State and Territory anti-discrimination are amended to prohibit a person from requesting or requiring another person to supply information upon which unlawful discrimination might be based, unless the person can prove that the information was reasonably required for a purpose that did not involve discrimination. The provision should be modelled on s.26 of the *Anti-Discrimination Act 1992* (NT).[37]

Section 26 of the *Anti-Discrimination Act 1992* (NT) is a much clearer provision than section 30 of the DDA, because it covers both direct and indirect discrimination. Section 26 also provides a defence where the respondent can prove that the information was reasonably required for a purpose that did not involve discrimination.

> **26. Unnecessary information**
> (1) A person shall not ask another person, whether orally or in writing, to supply information on which unlawful discrimination might be based.
> (2) Subsection (1) does not apply to a request that is necessary to comply with, or is specifically authorised by -
> (a) a law of the Territory or the Commonwealth;
> (b) an order of a court;
> (c) a provision of an order or award of a court or tribunal having power to fix minimum wages and other terms of employment;
> (d) a provision of an industrial agreement; or
> (e) an order of the Commissioner.
> (3) Subsection (1) does not apply if the person proves, on the balance of probabilities, that the information was reasonably required for a purpose that did not involve discrimination.

## Goods and services

The Board has given detailed consideration to issues of disability discrimination which may arise where the insurance industry makes use of genetic information. The Board has also undertaken research into issues which arise for people who have

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[37] Board's submission to the ALRC, p. 19.

hepatitis C in accessing insurance. Those issues are set out in the Board's submission to the ALRC which is attached.

The DDA provides that it is unlawful to discriminate against a person with a disability, in the provisions of goods, services and facilities, including refusing to provide a service and in the terms on which the service is provided.[38] The provision of insurance is considered a service within the meaning of the DDA.[39] The DDA also provides an exception in relation to insurance, in similar terms to the insurance exception provided in the ADA.[40]

In order to properly address the issue of insurance and genetic testing the Board has recommended that the DDA be amended to provide that it will not be unlawful for a person to discriminate against another person, on the ground of the other person's disability, by refusing to offer the other person insurance if:

- the discrimination is based upon actuarial or statistical data on which it is reasonable for the first-mentioned person to rely; or
- in the case of a genetic condition, the discrimination is based upon actuarial or statistical data which has been approved for use in underwriting by the relevant independent body.[41]

## Other matters

### *Disability vilification*

The Board is of the view that a need exists to address the public vilification of people with disabilities. Under the ADA vilification on the ground of HIV/AIDS status is unlawful. The Board has supported the extension of the coverage of vilification under the ADA to people with all disabilities.

Through its complaint handling processes and from consultation with organisations representing people with disabilities the Board understands that disability vilification is a significant issue for people with disabilities and that, in particular, issues of public violence and abuse persist. The legislative prohibition of public conduct which vilifies people with disabilities would be an important step in addressing this.

These concerns are equally applicable to the need for such provisions to be included in the DDA at the federal level.

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[38] DDA, ss. 5 and 24.

[39] DDA, s. 4.

[40] DDA, s. 46.

[41] ALRC submission of the ADB, recommendation 19.

## *Industrial Relations*

Under the *Workplace Relations Act* the Australian Industrial Relations Commission has specific obligations to ensure that the terms of industrial instruments do not discriminate on certain grounds including disability. [42] In the performance of its functions, the Commission is also required to take account of the principles embodied in the *Racial Discrimination Act 1975*, *Sex Discrimination Act 1984* and *Disability Discrimination Act 1992* relating to discrimination in relation to employment.[43]

The *Industrial Relations Act 1996* (NSW) has additional provisions which give the President of the ADB the ability to intervene in proceedings involving unlawful discrimination on all grounds.[44] The President may also apply to vary the terms of an industrial instrument to remove any unlawful discrimination arising from it.[45] In addition, the President may appeal against a decision of a single member of the Commission if the President considers that the decision is inconsistent with the principles contained in the ADA.[46]

In the Board's experience the ability to intervene in industrial proceedings regarding discrimination provides anti-discrimination agencies with the ability to prevent and eliminate discrimination at the collective level. In conjunction with effective education of industrial parties, this can also lead to the reduction in complaints arising from the terms of industrial awards and agreements. The Board suggests that consideration could be given to providing the HREOC with intervention rights in the Australian Industrial Relations Commission based upon the NSW model.

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[42] See for example s 143(1C) (f) in relation to awards and s 170LU (5) in relation to certified agreements.

[43] Section 93.

[44] Section 167(2)

[45] Section 169(4)(b)

[46] Section 187(d)

## Conclusion

While there have been many improvements to the position of people with disabilities in Australian society, there is still much to be done to redress past and present disadvantage to enable full equality of opportunity and treatment. In the Board's view there is merit in shifting the focus of the complaint provisions of the DDA towards a more proactive model. There is also the need for enforcement and compliance mechanisms to accompany positive duties. Such provisions would not solely rely upon individuals but would appropriately assist HREOC to ensure the prevention and elimination of disability discrimination, a goal which is fundamentally in the public interest.

The Board recommends that the Inquiry give consideration to:

1. reframing the DDA to clearly require steps to be taken to accommodate the needs of people with disabilities, subject to appropriate defences;

2. the enactment of positive duties on the Federal Public Sector based on the UK model;

3. providing HREOC with enforcement powers to ensure compliance with the DDA in the public interest:

4. amending the definition of disability in section 4 of the DDA to make 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;

5. reforming the definition of indirect discrimination in section 6 of the DDA to enact a simpler definition based on the definition used in the *Sex Discrimination Act 1984* (Cth):

6. amending section 30 of the DDA regarding discriminatory requests for information based on section 26 of the *Anti-Discrimination Act 1992* (NT);

7. amending the exception to discrimination in insurance in section 46 of the DDA to provide that it will not be unlawful for a person to discriminate against another person, on the ground of the other person's disability, by refusing to offer the other person insurance if:

    - the discrimination is based upon actuarial or statistical data on which it is reasonable for the first-mentioned person to rely; or
    - in the case of a genetic condition, the discrimination is based upon actuarial or statistical data which has been approved for use in underwriting by the

relevant independent body.

8. prohibiting disability vilification under the DDA

9. providing the HREOC with intervention rights in the Australian Industrial Relations Commission based upon the NSW model.

# ALRC and AHEC Inquiry into the Protection of Human Genetic Information : Issues Paper

***Submission of the Anti-Discrimination Board of NSW***
***April 2002***

# Contents

# List of recommendations

**Recommendation 1**
That there is uniformity of federal, State and Territory anti-discrimination legislation in relation to providing protection against genetic discrimination.

**Recommendation 2**
That protection against genetic discrimination be retained within the framework of existing anti-discrimination legislation.

**Recommendation 3**
That the definition of disability in the DDA and all State/Territory anti-discrimination legislation be amended to make clear that 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.

**Recommendation 4**
That all State and Territory anti-discrimination legislation provide coverage where a person is discriminated against because their associate has a disability or may develop a disability in future.

**Recommendation 5**
That the DDA and indirect tests within State/Territory anti-discrimination laws which contain the proportionality test, are amended in line with the indirect test in s.5 of the SDA.

**Recommendation 6**
That the DDA and relevant State and Territory anti-discrimination are amended to prohibit a person from requesting or requiring another person to supply information upon which unlawful discrimination might be based, unless the person can prove that the information was reasonably required for a purpose that did not involve discrimination. The provision should be modelled on s.26 of the *Anti-Discrimination Act 1992* (NT).

**Recommendation 7**
That anti-discrimination agencies are adequately funded to enable provision of timely complaints investigation and conciliation and education programs to inform and educate people likely to be affected by genetic discrimination, employers and service providers about their rights and responsibilities under anti-discrimination law and undertake educational activities designed to prevent such discrimination.

**Recommendation 8**
That the DDA and State and Territory anti-discrimination legislation is amended to make clear that an employer is not entitled to assess an individual's ability to comply with the inherent requirements of a particular position in the future.

**Recommendation 9**
That the WRA is amended to make explicit that the term 'disability' in the WRA be interpreted by reference to the DDA.

**Recommendation 10**
That the provision recommended above (recommendation 6) make explicit that such unlawful conduct *includes:*

- requesting or using information relating to a person's genetic make up, hepatitis C or HIV/AIDS status or
- requesting a person to undergo genetic testing or testing to determine a person's hepatitis C or HIV/AIDS status.

That consideration should also be given to what other disabilities should be included in a non-exhaustive list.

**Recommendation 11**
Employers may require genetic testing of employees where:

- the particular positions involve significant safety risks to the public which cannot be eliminated other than by being aware of a person's condition or predisposition; and
- testing is limited to conditions which would effect a person's capacity to carry out the inherent requirements of the particular job.

**Recommendation 12**
Employers may require genetic testing of employees where:

- the particular positions involves risks to the employee or other employees which cannot be eliminated other than by being aware of a person's condition or predisposition; and
- testing is limited to conditions which would effect a person's capacity to carry out the inherent requirements of the particular job.

Employers may undertake genetic monitoring of employees to reduce the risk of employees developing a disorder as a result of environmental cause, only with the informed consent of employees in writing.

**Recommendation 13**
That consideration should be given to whether a statutory authority should be established, or an existing agency should have responsibility for overseeing employment related testing, not limited to genetic testing, including effective implementation of the National Genetic Testing Code of Practice recommended in this submission ( recommendation 14).

**Recommendation 14**
We recommend that a comprehensive national genetic testing code of practice is developed and effectively implemented as outlined in this submission.

**Recommendation 15**
That an independent body be established to evaluate the scientific reliability and actuarial relevance of:

- genetic information proposed for use by the insurance industry before genetic information is used for underwriting; and
- non-genetic information whether used or proposed for use by the insurance industry for underwriting.

**Recommendation 16**
That the independent body (recommendation 15), in conjunction with the insurance industry, also undertake educational activities to ensure that agents, brokers and other significant participants in the insurance industry understand:

- what genetic information has been approved for use in underwriting;
- the different types and implications of genetic information generally; and
- the national genetic testing code of practice (recommendation 14).

**Recommendation 17**
That consumers should have the right to access adequate information about basis for the insurers decision and the actuarial or statistical evidence on which the insurer has relied in making their decisions. This right to access should be reflected in the national genetic testing code of practice and enshrined in legislation. (see recommendation 14)

**Recommendation 18**
That national genetic testing code of practice include guidelines which will enable people to make informed decisions about whether to undergo testing. The guidelines should ensure people are provided with accurate information about their rights under anti-discrimination and privacy legislation and their obligations, if any, regarding disclosure of the information obtained through genetic testing.

**Recommendation 19**
The DDA and State and Territory anti-discrimination be amended such that it will not be unlawful for a person to discriminate against another person, on the ground of the other person's disability, by refusing to offer the other person insurance if:

- the discrimination is based upon actuarial or statistical data on which it is reasonable for the first-mentioned person to rely; or
- in the case of a genetic condition, the discrimination is based upon actuarial or statistical data which has been approved for use in underwriting by the relevant independent body.

**Recommendation 20**
That DDA and State and Territory anti-discrimination laws are amended, where necessary, to provide the President/Commissioner with the power to order a party or non-party to produce documents, including actuarial or statistical data and the information upon which that data is based, in the course of investigation of a complaint.

**Recommendation 21**
That consideration is given to whether the existing review and appeal mechanisms in the *Migration Act 1958* are adequate to enable applicants to challenge decisions which are based on scientifically unreliable data or misinterpretation of genetic and non genetic health information.

**Recommendation 22**
That people's rights and responsibilities in relation to genetic testing and requests for genetic information under the *Migration Act* should be included in the proposed national genetic testing code of practice.

# 1. Introduction

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.

This submission focuses on the discrimination issues canvassed in the Issues Paper. Specifically, we respond to questions in relation to anti-discrimination legislation outlined in Chapters 5, 10, 11 and 12. Where questions posed in chapters 10 (Employment) and 11 (Insurance) are relevant to the operation of anti-discrimination legislation, we address these questions in so far as they relate to anti-discrimination law.

# 2. Context : Protecting human rights and advancing public health

There is no doubt that there is an increasing awareness about the interrelationship between the protection of humans rights and the advancement of personal and public health. While preventing discrimination and thereby protecting people's human rights has obvious merit in its own right, 'there is increasing recognition that public health often provides an added and compelling justification for safe guarding human rights...'[1]

The ADB has recently undertaken an extensive enquiry into hepatitis C related discrimination ('HCV Enquiry'). The findings of the Enquiry clearly demonstrates the impact that both fear of discrimination and experiencing discrimination has upon individual and public health outcomes. The Enquiry found that:

> 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.[2]

Such an analysis has particular resonance in the context of discrimination on the basis of people's genetic make up. Here too, there are real concerns 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.

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[1] *HIV/AIDS and Human Rights International Guidelines*, Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS, United Nations New York and Geneva, January 1998.

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

Central to protecting people's rights in the context of genetic testing is ensuring that people are able to make informed decisions about whether to undergo testing and what obligations, if any, they have to disclose information obtained through genetic testing. This must be a central part of pre and post test discussions.

Recent research indicates that people's fear of genetic discrimination is likely to be well founded.[3] As the Issues Paper identifies, if people fear discrimination they are less likely to be prepared to undergo genetic testing.[4] 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.

Fear of genetic discrimination is also likely to impact upon people's willingness to participate in research. Unlike testing in clinical settings, genetic tests results in the context of genetic research are not usually given to participants in genetic research. Consequently, generally research participants would not be required to make disclosures to employers, insurers and the like. Nonetheless, the general community are unlikely to be aware of this distinction and fear of discrimination in this context is likely to deter people from participating.

Rather than acting as an impediment to the development and application of genetic technology, effective anti-discrimination and privacy legislation are critical to realising the public health benefits of genetic information. Conversely, if we fail to provide such protection, discrimination and privacy concerns will acts as disincentives to testing and research participation and have negative consequences for individual and public health outcomes. [5]

# 3. Coverage of discrimination on the basis of genetic information under anti-discrimination law

Chapter 5 of the Issues Papers considers whether federal anti-discrimination legislation, particularly the *Disability Discrimination Act 1992* (Cth) (DDA), is adequate to address discrimination on the basis of information about a person's genetic make up. The Issues Paper raises a number of concerns regarding the adequacy of existing federal anti-legislation. These concerns are examined in response to Question 5-2 below.

## *3.1 Uniformity of federal, state and territory anti-discrimination laws*

### *Q: 5-1. Should there be uniformity or greater harmonisation of federal, state and territory laws concerning discrimination in relation to human genetic information?*

Uniformity, or at a minimum greater harmonisation, of federal, State and Territory anti-discrimination legislation is crucial to an effective legislative regime to provide protection against genetic discrimination. It would ensure that people are afforded equal protection under the Australian law, regardless of which State or Territory people reside and where the conduct occurs within Australia. Uniformity would reduce the complexity of jurisdictional decisions about whether to proceed under State/Territory or federal legislation for the would-be complainants. It also supports greater certainty about people's

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

[4] *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.

[5] 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.

rights and responsibilities under anti-discrimination law, rather than such understanding being undermining by uncertainty which arises when there are inconsistencies between different federal, State and Territory laws. Uniformity of anti-discrimination legislation would enhance certainty by increasing the likelihood that case law from one jurisdiction is applicable in another and for precedent to be applied.

**Recommendation 1**
That there is uniformity of federal, State and Territory anti-discrimination legislation in relation to providing protection against genetic discrimination.

## *3.2 Is specific genetic discrimination legislation required?*

***Q: 5-2. Do the various federal anti-discrimination laws adequately protect against unfair discrimination on the grounds of genetic status, or is there a need to amend the laws to clarify their application to genetic information? Alternatively, would it be better to enact legislation dealing specifically with genetic discrimination?***

We note the various arguments considered in the Issues Paper about whether genetic information is so unique that it warrants separate legislation. We do not believe that genetic discrimination warrants separate legislation, nor that the nature of such discrimination is so different from other forms of discrimination that it cannot be adequately addressed under existing anti-discrimination legislation. Indeed, it is our view that such discrimination is covered by existing anti-discrimination legislation. Nonetheless, amendments to existing legislation are needed. The bulk of this submission examines the nature of these reforms.

In our view legislation which would prohibit discrimination on the basis of *genetic information* would be at odds with the existing conceptual framework of anti-discrimination in Australia. Existing anti-discrimination legislation, and the framework which underpins such legislation, does provide an appropriate framework for protection against genetic discrimination.

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.

The Senate Legal and Constitutional Legislation Committee, in its consideration of the *Genetic Privacy and Non-Discrimination Bill 1998*, expressed concern about potential for administrative and legal confusion where separate genetic privacy and anti-discrimination legislation implemented and concluded that it was more appropriate to amend existing privacy and anti-discrimination legislation.[6] The ADB shares the Committee's concerns.

There are numerous benefits to retaining genetic discrimination within conceptual framework of existing anti-discrimination legislation. Many of the issues discussed above in relation to uniformity of legislation also apply to this issue including:

- greater clarity about people's rights and responsibilities under anti-discrimination law where there are fewer pieces of legislation

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

- reduces the complexity of jurisdictional decisions for would-be complainants
- increasingly the likelihood that case law from one jurisdiction is applicable in another and for precedent to be applied

We note that what appears to drive some views about the need for separate legislation is that there is something unique about discrimination where it is based on predicative genetic information. That is, that there is qualitative difference between discriminating against a person on the basis of a condition which may or may not arise, or where onset of the condition is uncertain, compared with discriminating against a person on the ground of a disability they currently have. This is a tenuous distinction which does not bear scrutiny. As we outline in detail below, there is no need to distinguish between discrimination on the basis of predictive genetic testing and discrimination which people with disabilities currently face on a daily basis, particularly given the breadth of the definition of 'disability' in the DDA.

Retaining genetic discrimination within conceptual framework of existing anti-discrimination legislation will 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.

**Recommendation 2**
That protection against genetic discrimination be retained within the framework of existing anti-discrimination legislation.

## *3.3 Are existing anti-discrimination laws adequate?*

We turn now to a detailed examination of the federal anti-discrimination legislation, primarily focussing on the extent to which the DDA provides adequate coverage genetic discrimination. In view of the need for uniformity between federal, State and Territory anti-discrimination legislation, where we propose options for reform in relation to the federal regime, such amendments should also be mirrored in State and Territory anti-discrimination legislation where necessary.

### 3.3.1 Definition of disability

The DDA defines disability as follows:

> **"disability"**, in relation to a person, means:
>
> (a) total or partial loss of the person's bodily or mental functions; or
>
> (b) total or partial loss of a part of the body; or
>
> (c) the presence in the body of organisms causing disease or illness; or
>
> (d) the presence in the body of organisms capable of causing disease or illness; or
>
> (e) the malfunction, malformation or disfigurement of a part of the person's body; or
>
> (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
>
> (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;
>
> and includes a disability that:
>
> (h) presently exists; or

(i) previously existed but no longer exists; or

(j) may exist in the future; or

(k) is imputed to a person.

In substance, the definition of disability discrimination in the ADA and the DDA, are the same. The Issues Paper raises concerns about whether the definition of disability in the DDA is adequate to cover discrimination on the basis of genetic information.

The Issues Paper highlights concerns that genetic discrimination may not be covered by anti-discrimination legislation. The Issues Paper states:

> Given the structure of Australian anti-discrimination law, with its emphasis on the characteristics presumed or imputed to apply to people who fit one of the specified grounds or attributes, there is some uncertainty about the applicability of such laws to acts or omissions based on predictive genetic information. While this widens the application of those grounds somewhat, the presumptions or imputations must relate to one of those existing grounds - they do not create new grounds, so that the definitional problems discussed above still persist. [7]

The ADB does not consider that these concerns are warranted. In our view the definition of disability in both the DDA, and the ADA already adequately covers discrimination on the ground of a person's genetic make up. Given the breadth of the definition of disability in the DDA, we cannot conceive of a condition or predisposition to a condition discernible by genetic testing which would not fall within the current definition.

The definition also clearly covers actual, past, future and imputed disability. We note the Inquiry's concern that there may be uncertainty about whether people who have a predisposition to a genetic illness are adequately covered by the DDA. The Inquiry notes that an analogy can be draw with people living with HIV who are asymptomatic and refers to cases where a disability discrimination complaint has been determined both in favour and against the people with living with HIV who are asymptomatic. However, the latter decision, in the case of *X v Commonwealth*, was not the result of lack of coverage under the DDA, but rather the operation of a defence under the DDA. In this case the High Court found that in the particular circumstances of that case, the complainant could not fulfil the inherent requirements of the job.[8] This case, and the interpretation of this case in the Issues Paper, is considered in more detail below in relation to discrimination in employment and the defences which apply in the area of employment.

The ADB is of the view that in relation to genetic testing which is predictive, a person's genetic predisposition to a particular disability, which may or may not arise in the future, would be clearly be covered by the DDA and the ADA. In relation to diagnostic testing, where a disability is diagnosed and the results are the basis of the discrimination, the person is being discriminated against the basis of their actual disability.

Carrier testing is performed on a person to determine whether or not s/he has a mutated allele or chromosome abnormality that will not affected his or her health, but increased his or her chances of having a child with the disorder in question. It is conceivable that a person may be discriminated against on the basis of such abnormalities for a number of reasons. First, carrier test results are open to misinterpretation. It is possible that such

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[7] Issues Paper, page 174 at paragraph 5.57.

[8] X v Commonwealth (1999) 200 CLR 177.

person may be discriminated against because they are perceived to be ‘at risk’ of developing a particular condition in future, although they are not in fact predisposed. Such circumstances would be covered by the current definition as an imputed future disability. Secondly, it is possible that a ‘carrier’ parent maybe discriminated against where their child has the disability. Again, such circumstances would be covered under the DDA. Generally, the DDA and ADA prohibit disability discrimination in a range of areas of public life, both discrimination against a person on the ground of their disability, but also where a person is discriminated against because of the disability of their relative or associate.[9]

In relation to prenatal testing, parents discriminated against as ‘carriers’ would be covered as outlined above, and as would discrimination against the child, on the basis of actual, future or assumed disability.

It is essential that the breadth of the definition of disability in the DDA and ADA is reflected in all State/Territory anti-discrimination laws.

Although The ADB considers the definition of disability in the ADA and DDA covers genetic discrimination, there is a strong public interest rationale for making such coverage explicit in anti-discrimination legislation. Such clarification would:

- reflect the current state of the law under the DDA and ADA;
- 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.

**Recommendation 3**

That the definition of disability in the DDA and all State/Territory anti-discrimination legislation be amended to make clear that 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.

### 3.3.2 Discrimination on the ground of race and sex discrimination

We note the Inquiry’s discussion of the possible application of the *Sex Discrimination Act 1984* (Cth) (SDA) and *Racial Discrimination Act 1975 (Cth* (RDA), in circumstances where women or men or people of a particular racial group may be more predisposed to particular conditions.[10] We agree that it is arguable that there may be circumstances when the SDA and RDA, and relevant sex and race provisions in State/Territory anti-discrimination legislation may be relevant on the basis outlined in the Issues Paper. However, central to discrimination on the basis of a person’s a genetic make up is discrimination on the ground of disability, because discrimination on the basis of a person’s genetic make up is primarily likely to occur because of a health condition which the person has, has had, may have in future or which the discriminator believes the person has, has had or may have in future. As such, it is highly likely that any complaints of sex or race discrimination would be alleged either in the alternative or in addition to actual, future and/or imputed disability discrimination, depending on the circumstances.

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[9] See for example DDA, s.15 and ADA s.49B.

[10] Issues Paper at page 171, paragraphs 5.48 and 5.49.

For example, a company's employment policy contained a requirement or condition of which had the effect of excluding people from employment where they had a predisposition to a particular health condition, and that condition was one which is more prevalent among women than men. It is arguable that this could amount to indirect sex discrimination, subject to the relevant exceptions and defences. Clearly, disability discrimination provisions would also apply.

### 3.3.3 Coverage for associates or relatives

The Issues Paper casts doubt over whether anti-discrimination legislation would provide protection where a is person discriminated against because their associate or relative has a disability or is predisposed to a disability in future, but the person discriminated against does not have the disability. As we have already outlined, the definition of disability in the DDA includes imputed disability.

The Issues Paper provides the following example where the authors suggest that anti-discrimination legislation may be inadequate:

> For example, a male child with no physical disability may be the victim of unlawful discrimination on the basis that his mother suffered an act of discrimination on the basis of her gender or her disability. This can be relevant as genetic information obtained from one person may be indicative of the genetic make up of that person's blood relatives. However, the extension of coverage in this way is nevertheless linked to and dependent on the other grounds for its meaning. Although genetic information has particular potency because of its potential application to other blood relatives, the definitional problems remain significant.

First, it is necessary to clarify how the provisions in relation to discrimination as a result of the disability of a person's associate/relative operate. The DDA provides that it is unlawful to discriminate against a person both on the ground of that person's disability, but also on the ground of the disability of that person's relative or associate.[11] In the area of employment, for example, s.15 of the DDA provides that it is unlawful for an employer to discriminate against a person (the aggrieved person) on the ground of the person's disability *or a disability of any of that person's associates* (emphasis added). It is not necessary that the aggrieved person's associate is be discriminated against, in order for the aggrieved person to be able to loge a complaint under the DDA.

For example, if an employer discriminates against a man by refusing to promote him because they are aware that the man's mother has a genetic condition which predisposes her to breast cancer, the basis of any complaint by him would be that he was being discriminated against on the ground of imputed disability. The fact that the man's mother may be able to lodge a complaint of both sex and disability discrimination, were she to be discriminated against in such circumstances, does not alter his capacity to lodge a complaint were he to be discrimination against on the basis of an future or imputed disability.

Accordingly, we do not agree there are any inadequacies in relation to coverage under the DDA for a person discriminated against where their associate has a disability or is predisposed to a disability in future. However, as noted in the Issues Paper, not all State/Territories anti-discrimination legislation covers circumstances where a person is

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[11] Section 4 of the DDA defines "associates" broadly. The definition includes a spouse of the person, another person who is living with the person on a genuine domestic basis, a relative of the person, a carer of the person and another person who is in a business, sporting or recreational relationship with the person.

discriminated against because their associate or relative has a disability or is predisposed to a disability in future. Precisely because the genetic information obtained from one person may be indicative of the genetic make up of that person’s blood relatives, it is essential that all State/Territories anti-discrimination legislation covers such circumstances.

**Recommendation 4**
That all State and Territory anti-discrimination legislation provide coverage where a person is discriminated against because their associate has a disability or may develop a disability in future.

### 3.3.4 Separate ground for genetic discrimination?

In our view, it is preferable to amend the definition of disability in the DDA and all State and Territory anti-discrimination legislation rather than to create a separate ground of genetic discrimination. It is possible to incorporate a new ground within the framework of State and Territory anti-discrimination laws, which cover multiple grounds of discrimination. However, this is not the case under the federal anti discrimination regime, where separate legislation covers the grounds of racial, sex and disability discrimination. As discussed above, prohibiting discrimination on the basis of *genetic information* in specified areas of public life, rather than prohibiting discrimination on the basis of *characteristics* of a person would be at odds with the existing conceptual framework of anti-discrimination in Australia.

For the reason already canvassed in relation to separate legislation, we do not consider that there are any benefits to including a separate ground of discrimination on the basis of genetic information within State and Territory legislation, given the coverage available under the ground of disability, and where relevant race and sex.

### 3.3.5 Direct discrimination - “material different”

The Issues Paper raises concerns about how the element of “material difference” in the ‘direct discrimination’ test will apply to discrimination on the basis of people’s genetic make up. This issue is raised primarily in the employment chapter of the Issues Paper.[12] We have chosen to considered this issue in this section of our submission, as the test applies in respect of all areas under the DDA. The direct discrimination test is also a feature common to all State/Territory anti-discrimination legislation.

The DDA ‘direct’ discrimination test is set out in s.5 and provides:

> 5. Disability discrimination
> (1) For the purposes of this Act, a person (*discriminator*) discriminates against another person (*aggrieved person*) on the ground of a disability of the aggrieved person if, because of the aggrieved person's disability, the discriminator treats or proposes to treat the aggrieved person less favourably than, in circumstances that are the same or are not materially different, the discriminator treats or would treat a person without the disability.

In our view the Issues Paper does not accurately capture the relevance of circumstances which are “material different”. The Issues Paper states:

> The DDA provides that individuals should be treated alike except where their circumstances are so `materially different' that they justify different treatment. As a result of genetic testing, it is increasingly possible to differentiate between individuals on the basis of their genetic information. The question is whether

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[12] Issues Paper, page 277, paragraph 10.17- 10.19.

> currently asymptomatic individuals who are genetically predisposed to, or who are presymptomatic of, genetic conditions will be regarded as ‘materially different’ to other members of society. If so, they may not share the protection of the DDA in areas such as employment even though they may be currently healthy and, indeed, may never develop the particular genetic condition.[13]

Generally, direct discrimination can be said to arise where a person is treated less favourable on the basis of a characteristic they may possess, such their race, disability or sex, than a person who does not possess that characteristic.

As discussed above, the definition of disability covers future and imputed disability. As such, where a person is genetically predisposed to a particular condition, whether asymptomatic or presymptomatic, will not make the circumstances ‘materially different’. The mere fact that a person has a disability or may have a disability in the future or is thought to have a disability, and the comparator, the person who does not possess that characteristic, does not make the circumstances ‘material different’ for the purpose of determining whether direct discrimination has occurred in given circumstances.

Whether the circumstances are ‘materially different’ turns on whether the circumstances are comparable. For example, if a person with a disability (A) was residing in serviced apartments for a three week period. A person without a disability (B) was residing in the same apartments for a six month period. B received a discount and A did not. If A argued they had been discriminated against by the accommodation provider they would need to show that the denial of the benefit was because the person had a disability. In such circumstances it is arguable that the circumstances would be considered materially different, therefore not capable of comparison.

### 3.3.6 Indirect discrimination - proportionality test

We note the Issues Paper discussion of the various different tests for indirect discrimination in federal and State/Territory anti-discrimination legislation and the problems associated with determining the differential adverse impact.[14] Under the laws in Victoria and Queensland the complainant must prove that a higher proportion of people without the complainant's particular attribute are able to comply with the requirement or condition (‘the proportionality test’). The federal DDA and New South Wales, South Australia and Western Australia laws go further and require that a ‘substantially higher' differential rate of compliance be shown. On the other hand, the federal RDA and SDA, and the legislation in Tasmania, the ACT and the Northern Territory do not require that any differential compliance rates be shown at all - only that there has been some adverse effect caused by the requirement or condition.

The Issues paper identifies the complexities associated with the application of the proportionality test. The NSW Law Reform Commission (LRC), in its review of the ADA, also expressed concern about the operation of the proportionality test and recommended reform to address these concerns.[15]

The *Sex Discrimination Act 1984* (Cth) (SDA) was amended in 1995 to address precisely the sorts of concerns both the ALRC and the LRC have identified.

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[13] Issues Paper, page 275, paragraph 10.17.

[14] Issues Paper, page 168, paragraphs 5.36 - 5.40.

[15] Review of the *Anti-Discrimination Act 1977* (NSW), NSW Law Reform Commission, Report 92 (LRC Report) at pages 95 - 103.

Section 5 of the SDA provides:

> **s.5 Sex discrimination**
> (1) For the purposes of this Act, a person (in this subsection referred to as the discriminator) discriminates against another person (in this subsection referred to as the aggrieved person) on the ground of the sex of the aggrieved person if, by reason of:
>
> (a) the sex of the aggrieved person;
> (b) a characteristic that appertains generally to persons of the sex of the aggrieved person; or
> (c) a characteristic that is generally imputed to persons of the sex of the aggrieved person;
>
> the discriminator treats the aggrieved person less favourably than, in circumstances that are the same or are not materially different, the discriminator treats or would treat a person of the opposite sex.
>
> (2) For the purposes of this Act, a person (the discriminator) discriminates against another person (the aggrieved person) on the ground of the sex of the aggrieved person if the discriminator imposes, or proposes to impose, a condition, requirement or practice that has, or is likely to have, the effect of disadvantaging persons of the same sex as the aggrieved person.
>
> (3) This section has effect subject to sections 7B and 7D.

In considering the SDA indirect test, the LRC suggested that a link between the characteristic and the detriment may be a necessary element in an indirect discrimination test. The Reports states that:

> "..in order for an act to constitute discrimination there must be a link between the person's sex and the detriment...If the only test is detriment or disadvantage, then any act which is detrimental and effects men and women equally (or other groups based on the prohibited grounds) would come within the definition. Thus, although establishing disproportionate impact can be a complex process, it may be necessary to establish the link between the detriment and the ground or characteristic".[16]

In the Board's view, in order to establish discrimination pursuant to s.5 of the SDA, the complainant needs to establish that the condition, requirement or practice in question has, or is likely to have, the effect of disadvantaging persons of the same sex as the complainant. As such, the need to establish disadvantage does incorporate a notion of comparison. However, the test does not require proof of a disproportionate disadvantage vis a vis the opposite sex is in order to make out a case of indirect discrimination, thus avoiding the complexities of the proportionality test.

This is precisely the approach adopted by HREOC in the decision of *Hickie v Hunt and Hunt.*[17]

> Events which occurred after 17 December 1996 come under the current provision on indirect discrimination which provides that a person discriminates against another person on the ground of the sex of the aggrieved person if the discriminator imposes or proposes to impose a condition, requirement or practice

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[16] LRC Report at paragraph 3.100 at page 99.
[17] *Hickie v Hunt & Hunt* (1998) HREOCA 8 (9th March 1998).

> that has, or is likely to have, the effect of disadvantaging persons of the same sex as the aggrieved person, s 5 (2). The conditions, requirements or practices relevant in this case are those that disadvantage or are likely to disadvantage women (as distinct from men). Unfair or unreasonable requirements imposed on employees are not necessarily discriminatory if they apply to men and women in the same terms, but only if they bear more harshly on one sex rather than another.

In the *Hickie* case the complainant argued that she had been indirectly discriminated against in respect of a performance appraisal and refusal to renew her contract, an element of which was that her employer imposed a requirement or condition that she resume full time work after maternity leave in order to maintain her position. The respondent argued that the complainant had not led any evidence to establish that women were likely to be disadvantaged by the requirement or condition, and no statistical evidence to prove that more men than women can work five days a week. Further, the respondent argued that the Commission could not take judicial notice of those matters, consequently there was no basis upon which the Commission could find that the requirement or condition had disadvantaged women.

The Inquiry Commissioner did not accept the respondent's interpretation of what is required to establish indirect discrimination pursuant to the amended indirect test. The Commission's decision demonstrates how disadvantage can be established, without imposing the complexities of the proportionality test. The Inquiry Commission concluded:

> Although no statistical data was produced at the hearing, the records produced by Hunt and Hunt suggest that it is predominantly women who seek the opportunity for part time work and that a substantial number of women in the firm have been working on a part time basis. I also infer from general knowledge that women are far more likely than men to require at least some periods of part time work during their careers, and in particular a period of part time work after maternity leave, in order to meet family responsibilities. In these circumstances I find that the condition or requirement that Ms Hickie work full-time to maintain her position was a condition or requirement likely to disadvantage women.

In the Board's view, an act or imposition of a requirement or condition which has a detrimental affect on men and women equally (or other groups based on the prohibited grounds) would not amount to discrimination as it would not be discriminatory in purpose or effect. Where a condition or requirement equally disadvantages, both men and women, or people of all races for example, it is a neutral condition or requirement and is simply not discriminatory.

We submit that the indirect test in the SDA provides an appropriate model upon which to base a simpler indirect test, which avoids the complexities of the proportionality test.

**Recommendation 5**
That the DDA and indirect tests within State/Territory anti-discrimination laws which contain the proportionality test, are amended in line with the indirect test in s.5 of the SDA.

### 3.3.7 Discriminatory questions and/or requesting information

The ADA does not prohibit requests for information on which discrimination might be based.[18] The DDA provides some protection in relation to requests for information from people with a disabilities. Section 30 provides:

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[18] The Issues Paper also states that Tasmanian, Western Australian, South Australian anti-discrimination laws are also deficient in this regard.

> **30. Requests for information**
> If, because of another provision of this Part (other than section 32), it would be unlawful, in particular circumstances, for a person to discriminate against another person on the ground of the other person's disability, in doing a particular act, it is unlawful for the first-mentioned person to request or require the other person to provide, in connection with or for the purposes of the doing of the act, information (whether by completing a form or otherwise) that persons who do not have a disability would not, in circumstances that are the same or are not materially different, be requested or required to provide.

This provision appears to be limited to circumstances where information is sought from a person who has a disability and such information is not or would not be sought from persons who do not have a disability. It is unclear whether blanket requests, such as for health information in employment from all applicants or employees, which may raise indirect discrimination against people with disabilities, would be covered by the provision.

In our 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. Such requests for information are often in the nature of a blanket requests e.g dental forms which require people to disclose whether they have HIV or hepatitis C or employment application forms or pre-employment medicals that seek information about a person's health which are not relevant to the inherent requirements of the particular position.

For example, evidence to the HCV Enquiry indicated that discriminatory selection and recruitment policies and practices are of significant concern to people with hepatitis C, and impact upon their access to employment. The two major areas of concern were mandatory requirements for prospective employees to have a blood test or disclose their hepatitis C status, and the inappropriate use of pre-employment medical assessments to 'screen out' prospective employees who have hepatitis C. Such workplace policies and practices also dissuade people with hepatitis C from proceeding with their application.[19]

Pre-employment medical assessments are a relatively common part of recruitment practice. The use of pre-employment medicals is not necessarily discriminatory per se, however they may be used to discriminate depending upon 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.

In our experience, it is common for people to be unclear about what information is sought and what tests are conducted as part of pre-employment medical examinations. There are insufficient safeguards in place to ensure that the information sought by employers relates to the inherent requirements of the particular position in issue.

This precise issue has been the subject of litigation in the USA. In the case of *Norman-Bloodsaw v Lawrence Berkeley Laboratory*, the plaintiffs alleged that genetic testing was conducted during routine medical examination without employees' knowledge or consent and that the conditions for which testing was performed were not relevant to the jobs the employees had been hired to perform.[20] On appeal the Court upheld the dismissal of discrimination complaints because no job related action was taken against the plaintiffs as

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[19] *C-change* report, Section 2.4 at page 60.

[20] Miller, P. *Genetic Discrimination in the Workplace*, 1998 Vol. 26 Journal of Law, Medicine and Ethics 189 at page 197. *Norman-Bloodsaw v Lawrence Berkeley Laboratory* 135 F.3d 1260 (9th Cir.1998).

a result of the testing, among other reasons. This case illustrates the inadequacy of anti-discrimination legislation where unlawful conduct is limited to discriminatory use of the information, rather than prohibiting requesting the information itself, unless it can be shown that seeking the information was for a non-discriminatory purpose.

Concerns about access to and use of health information are no different in the relation to people with condition or predisposition to conditions which can be determined by genetic testing than for other people with disabilities, whether actual, future or imputed. As such there is a need to prohibit a person from requesting or requiring another person to supply information upon which unlawful discrimination might be based, unless the person can prove that the information was reasonably required for a purpose that did not involve discrimination.

In order to comply with anti-discrimination legislation, pre-employment medicals *should* only be used to assess a person's capacity to carry out the inherent or essential requirements of a position, once the employer has identified the preferred candidate. Where the preferred candidate has a disability, the employer is required to accommodate the needs of the person to enable the person to carry out the inherent requirements of the job, unless they can demonstrate that this would cause the employer unjustifiable hardship.

It is also worth noting that ADA makes unlawful aiding and abetting discrimination and the DDA makes unlawful assisting and inciting discrimination.[21] 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 a health care worker insists on disclosing a person's health status in a medical report, where such information is not relevant to their capacity to carry out the inherent requirements of the job, these provisions may apply on the basis of having assisted or aided the employer's discrimination.

The HCV Enquiry found that pre-employment medicals are often required of prospective employees prior to culling candidates for interview. For many people with hepatitis C, pre-employment medicals raise the possibility of unfair culling or rejection because they have hepatitis C. Such an approach leaves employers open to allegations of discrimination, where they fail to appoint a person with hepatitis C. Pre-employment medicals also create a deterrent effect for prospective employees who have hepatitis C when testing or disclosure is required.[22]

Such situations also arise in the context of goods and service providers. For example, evidence to the Enquiry indicates that people are often asked to complete forms which specifically ask people to indicate whether they have hepatitis C before they can access a particular service. Such practices appears to be particularly common when people present for dental work or surgery and are often based upon the misapprehension that knowledge of a person's status is the best way to prevent hepatitis C transmission. This is a flawed approach to standard infection control.[23]

There are obvious parallels that can be drawn in relation to discriminatory questions and requests for information in relation hepatitis C and those likely in relation to genetic information. Blanket requests for information on which discriminatory treatment might be based cannot form the basis of a complaint under the ADA per se and may not be adequately covered by s.30 of the DDA.

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[21] DDA s.43, ADA s.52.

[22] *C-change* report, Section 2.4 at page 61.

[23] *C-change* report, Section 2.3 at page 42.

For example, where people are required to disclose their hepatitis C status in order to obtain services from a dentist. Section 30 only considers circumstances where the information is sought from a person who has a disability and such information is not or would not be sought from persons who do not have a disability. In this case the information is sought from all people, but has a disproportionate impact on people with hepatitis C.

Under the ADA, a complainant would need to show that the information obtained was used to discriminate against the person. Where a person refuses to provide the information because they do not believe they are bound to provide the information and/or fear that the information will be used to discriminate against them, they are unlikely to be offered the position or given access to the service. If they provide the information and are refused the service or not offered the position, it is often difficult to prove that the decision was based on the information provided and therefore was discriminatory.

Section 26 of the *Anti-Discrimination Act 1992* (NT) is a much clearer provision than s.30 of the DDA, because it covers both direct and indirect discrimination. Section 26 also provides a defence where the respondent can prove that the information was reasonably required for a purpose that did not involve discrimination.

> **26. Unnecessary information**
> (1) A person shall not ask another person, whether orally or in writing, to supply information on which unlawful discrimination might be based.
> (2) Subsection (1) does not apply to a request that is necessary to comply with, or is specifically authorised by -
> > (a) a law of the Territory or the Commonwealth;
> > (b) an order of a court;
> > (c) a provision of an order or award of a court or tribunal having power to fix minimum wages and other terms of employment;
> > (d) a provision of an industrial agreement; or
> > (e) an order of the Commissioner.
>
> (3) Subsection (1) does not apply if the person proves, on the balance of probabilities, that the information was reasonably required for a purpose that did not involve discrimination.

**Recommendation 6**
That the DDA and relevant State and Territory anti-discrimination are amended to prohibit a person from requesting or requiring another person to supply information upon which unlawful discrimination might be based, unless the person can prove that the information was reasonably required for a purpose that did not involve discrimination. The provision should be modelled on s.26 of the *Anti-Discrimination Act 1992* (NT).

### 3.3.8 Discrimination on the ground of irrelevant medical records

The ADB does not consider that the prohibition in relation to discrimination on the ground of ‘irrelevant medical record’ in Tasmanian and Northern Territory anti-discrimination legislation adds anything additional to that which is already covered by the prohibition of discrimination on the ground of disability, combined with adequate provisions in relation to unlawful questions and requests for information and privacy protection in relation to health information. We refer you to our discussion above in section 3.3.7.

### 3.3.9 Access to anti-discrimination systems

We note the Issues Paper briefly considers the effectiveness of anti-discrimination complaints system in addressing discrimination. [24] Generally, we agree that there are real benefits in the use of alternative dispute resolution proceedings, resulting in some complaints being resolved by conciliation. The investigation and conciliation process can provide redress for some complainants without the stress, delays and cost of court proceedings. Conciliation mechanisms are frequently less daunting to would-be complainants than the prospect of court proceedings.

However, it is important to recognise that the funding for anti-discrimination agencies has not kept pace with expanding grounds of discrimination covered under anti-discrimination laws. This impacts adversely on the extent to which it is possible to provide speedy resolution of complaints. The adverse impact of delays in complaints handling has been well documented in a recent study which examined barriers to access and use of anti-discrimination remedies for people living with HIV and hepatitis C virus. [25] Evidence to the HCV Enquiry found that delays in the handling of complaints are a disincentive to people lodging complaints in the first instance, and as a significant factor in complaints being withdrawn prior to resolution.[26]

It is also important to recognise that in order to utilise complaint mechanisms, people must be able to name their experience as one of discrimination, understand their rights under anti-discrimination law and have sufficient information and support to utilise anti-discrimination complaint mechanisms as a means of addressing the discrimination they experience. Given this, anti-discrimination agencies also have a critical educational role to play to ensure that people affected by genetic discrimination are aware of their rights. As the use of genetic testing becomes increasingly common, it is likely that there will be increasing demands on anti-discrimination agencies in relation to both complaints handling and education functions.

**Recommendation 7**

That anti-discrimination agencies are adequately funded to enable provision of timely investigation and conciliation of complaints and provide education programs to inform and educate people likely to be affected by genetic discrimination, employers and service providers about their rights and responsibilities under anti-discrimination law and undertake educational activities designed to prevent such discrimination.

# 4. Employment

***Q: 10-1 Do federal anti-discrimination and workplace relations laws adequately protect a person with a predisposition to a genetic illness, but no symptoms, from unfair discrimination in the employment context?***

## *4.1 Future and imputed disability discrimination*

As previously outlined, the definition of disability in the DDA and ADA covers future and imputed disabilities. Generally, where a person is discriminated against on the basis of a predisposition to a genetic illness, where they *will* develop symptoms in future, such as conditions which have uncertain onset, such a situation may be characterised as discrimination on the basis of a future disability. Where a person is discriminated against on the basis of a predisposition to a genetic illness, where they *may* develop symptoms in

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[24] Issues Paper at page 184, paragraph 5.103.

[25] Cabassi, J. *Barriers to access and effective use of anti-discrimination remedies for people living with HIV and HCV*, ANCAHRD Occasional Paper No. 1, May 2001. <http://www.ancahrd.org/pubs/pdfs/occasional.pdf>

[26] *C-change* report, Section 4.1 at page 120.

the future, such a situation may be characterised as discrimination on the basis of a future and/or imputed disability, as the disability may never actually arise in future. Given the breadth of the definition we cannot conceive of a condition or predisposition to a condition discernible by genetic testing which would not fall within the current definition.

## *4.2 Defence of inherent requirements*

The Issues paper raises concerns about the scope of the defence of inherent requirements, particularly whether this defence would allow an employer to assess an individual's ability to comply with the inherent requirements of a particular position in the future.

### 4.2.1 When the defence may apply

Generally, under both the ADA and the DDA an employer may have a defence to a complaint of disability discrimination in relation to recruitment and termination of employment where the person with a disability:

- is unable to perform the inherent requirements of the job even with the provision of services or facilities, or
- where the provision of services or facilities to enable the employee to carry out the inherent requirements of the job would cause the employer unjustifiable hardship.[27]

In substance, the 'inherent requirements' defence as set out in s.15(4) of the DDA and s.49D(4) of the ADA, are the same. The defence incorporates a requirement that employer accommodate a person's disability in order that they can perform the inherent requirement of the job, unless it would be unjustifiable harsh to require the employer to do so.

The defence applies only in relation to recruitment and termination of employment and is not generally available in relation to existing employees unless the employee is being dismissed. However, a recent decision the Administrative Decisions Tribunal *Rabadi v Commissioner of Corrective Services* [28] has held that the defence may be available in relation to existing employees applying for promotion. The Tribunal held that in such a case the relevant section was s 49D(1)(b) and therefore the defence could be relied upon.

The onus is on the respondent to make out the defence. The defences do not apply:

- in relation to the arrangements for carrying out the selection processes, or
- in relation to the terms and conditions and benefits on which employment is offered.

### 4.2.2 Inherent requirements and future disability discrimination

As a matter of policy, the context in which this issue arises is important. There has been a considerable increase in job mobility in recent decades, therefore it is an increasingly unrealistic expectation that people will remain with the same employer for any extended periods of time. Accordingly, it is unfair for employers to be able to discriminate on the basis of a person's capacity to do the job which may not arise for many years, and indeed which may not arise at all. However, it is possible that an employer may argue that a person's capacity to do the job in future forms part of the inherent requirements of a particular position.

The relevant provisions of the ADA and DDA, on their face, do not provide clarity about whether the defence would allow an employer to do so. There has been no judicial consideration of application of the defence in such circumstances. However, the normal

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[27] See DDA, s.15 and ADA s.49D.

[28] *Rabadi v Commissioner of Corrective Services*[2002] NSWADT 23

principles of statutory construction apply. The meaning of the relevant provisions in the DDA and ADA need to be examined in light of the purpose of the legislation and read in the context of the legislation as whole. In taking such an approach, we are of the view that the correct interpretation of the defence should be that a person's capacity to fulfil the inherent requirements of the job is to be assessed at the point when the employer is making the decision about recruitment or termination. This is so for a number of reasons.

First, the DDA and ADA specifically prohibits discrimination on the basis of a future disability in specific areas of public life, including employment. A reading of these provisions which would allow an employer to assess an individual's ability to comply with the inherent requirements of a particular position in the future, would be incongruous with this prohibition. Secondly, the onus is on the respondent to show the defence applies at the date of the discrimination. If the incapacity will not arise until a future date, s/he will be unable to do so. The only way the employer may be able to prove the defence at this point in time is to argue that it is an inherent requirement of the position that the person be able to do the job for a specified period/ reasonable period. Such an approach would be inconsistent with case law on what constitutes the 'inherent requirement' of a particular position.

The decision of the (then) NSW Equal Opportunity Tribunal in *Gallagher v Commissioner of Police, NSW Police Service* [29] illustrates the importance of the respondent being able to demonstrate that the factors in their decision not to rehire Mr Gallagher related to the inherent requirements of the position, rather than on assumptions about what he may be able to do in future.

Mr Gallagher, a member of the Police Service, resigned from his position in October 1993. In October 1994 he applied to rejoin the Police Service. However, his application was not approved on the basis of his previous sick leave record - 311 days in 22 years.

The Tribunal found that the Police Service indirectly discriminated against Mr Gallagher on the ground of presumed future disability in the arrangements it made for the purpose of determining who should be offered employment – s.49D(1)(a).

The Tribunal looked at the meaning of future disability under the ADA. The EOT considered how the previous sick leave record of an employee can lead an employer to make assumptions about whether or not a potential employee will be able to do a job. The EOT held that the Police Service had made assumptions about future quality of work, absenteeism and managerial issues as well as about future disability on the strength of sick leave record. None of the issues on which the Police Service based its decision not to re-hire the complainant related to a consideration of what the job involved and whether the complainant could actually do it.

The EOT stated that the imposition of the requirement "was arbitrary in this regard. It did not relate to any analysis of the implications for the Police Service or its operations in employing people with a disability, nor to any assessment or measure of any consequent cost to the Police Service". The case highlights the importance of an employer being clear about the inherent requirements of a particular job. When these requirements are clear only then can an employer determine whether or not potential employees can do the job.

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[29] *Gallagher v Commissioner of Police, NSW Police Service* NSW , Equal Opportunity Tribunal, 24 April 1998, unreported.

The High Court has considered the concept of the inherent requirements of the particular *position* in the case of *Qantas Airways Ltd v Christie.*[30] In this case, Gaudron J's consideration of the phase is instructive:

> "And certainly, an employer cannot create an inherent requirement for the purposes of s170DF(2) by stipulating for something that is not essential or, even, by stipulating for qualifications or skills which are disproportionately high when related to the work to be done… there is nothing to suggest that the expression "inherent requirements" in s 170DF(2) is used other than in its natural and ordinary meaning. And that meaning directs attention to the essential features or defining characteristics of the position in question…. A practical method of determining whether or not a requirement is an inherent requirement, in the ordinary sense of that expression, is to ask whether the position would be essentially the same if that requirement were dispensed with."

Applying this test to the above proposition, if the requirement to do the job for a specified period/ reasonable period was removed, it is arguable the position itself, and the skills needed to carry out that position, would essentially be the same.[31]

Our conclusion regarding the correct reading of the defence is consistent with the purpose of prohibiting future disability discrimination, that is that an employer should not be entitled to terminate a person's employment or elect not to employ a person unless and until a person is *actually* unable to fulfil the inherent requirements of the job. To do otherwise, is to allow an employer to arbitrarily determine whether a person will be able to do the job, without any knowledge about what the impact of symptoms will be, how debilitating such symptoms will be and so forth. This issue is one that not only affects people who have a genetic predisposition to a particular condition which will arise in the future. This also the case for many people with HIV/AIDS and hepatitis C and who are asymptomatic, equally people who have been diagnosed with a degenerative disease, where onset and gravity of symptoms is uncertain.

The interpretation we favour is consistent with the principles of statutory construction. Nonetheless, the relevant provisions of the DDA and ADA are, on their face, unclear about whether an employer to entitled to assess an individual's ability to comply with the inherent requirements of a particular position in the future.

**Recommendation 8**

That the DDA and State and Territory anti-discrimination legislation is amended to make clear that an employer is not entitled to assess an individual's ability to comply with the inherent requirements of a particular position in the future.

***Q: 10-2 How should a genetic predisposition be considered in relation to an individual's ability to fulfil the 'inherent requirements' of a particular position?***

We refer you to our discussion of this issue above in section 4.2.2.

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[30] *Qantas Airways Ltd v Christie* (1998) (HC) 193 CLR 280. In this case the High Court considered phrase "the inherent requirements of the particular *position"* in s.170 DF(2) of the then *Industrial Relations Act* 1988 (Cth). The phrase was similar but not identical to the phrase "the inherent requirements of the particular *employment*" in s.49D(4)(a) of the ADA or s.15(4)(a) of the DDA.

[31] See also the application of the Gaudron J's test in *Laz v Downer Group Ltd* [2000] FCA 1390, 11 October 2000.

## 4.3 Workplace Relations Act 1996 (Cth)

Generally, the *Workplace Relations Act 1996* (Cth) (WRA) provides that employee may seek relief in respect of termination of employment in certain circumstances, including where the termination was harsh, unjust or unreasonable or where the termination was by reason of a person's race, colour, sex, sexual preference, age, physical or mental disability, marital status, family responsibilities, pregnancy, religion, political opinion, national extraction or social origin.[32] The WRA also provides a defence where the termination was based on the inherent requirements of the particular position concerned.

Section 170CK (1) states:

> In addition to the principal object of this Division set out in section 170CA, the additional object of this section is to make provisions that are intended to assist in giving effect to:
>
> > (a) the Convention concerning Discrimination in respect of Employment and Occupation, a copy of the English text of which is set out in Schedule 1 to the *Human Rights and Equal Opportunity Commission Act 1986*; and
> >
> > (b) the Family Responsibilities Convention.

The WRA does not define the term disability, nor any of the other characteristics outlined above which may be the reason for termination of employment. Neither of the above conventions refer explicit to the prohibition against discrimination on the ground of disability. The Convention concerning Discrimination in respect of Employment and Occupation does define discrimination to include race and sex among other characteristics. While it is arguable that the interpretation of term disability in the WRA would enable reference to the definition in the DDA, this is not clear on the face of the legislation.

**Recommendation 9**
That the WRA is amended to make explicit that the term 'disability' in the WRA be interpreted by reference to the DDA.

If this recommendation and recommendation 3 above are accepted, there will be sufficient clarity in the definition of 'disability' in the DDA to ensure that the provisions of the WRA will apply where people are unlawfully terminated on the basis of actual, future or imputed disability.

We also refer you to our discussion of the operation of the inherent requirements defence in relation to future disabilities, Section 4.2 above.

## 4.4 Obtaining and using genetic information in employment

### 4.4.1 General principal - prohibit obtaining and using information upon which unlawful discrimination might be based

There are sound public policy reasons for clear statement of principle that employers be prohibited from requesting genetic information or requiring genetic testing. Given the significance of genetic testing, people should retain the right 'not to know', particularly given the uncertainty of much of the information discernible by genetic testing. As discussed in section 2 above, people may be deterred from undergoing genetic testing, even where such testing may diagnose a condition for which treatment is available, if they consider that they are likely to be required to disclose that information to future employers.

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[32] *Workplace Relations Act 1996* (Cth) (WRA), s.170CE.

Exclusion from employment should be the exception, not the rule. It is a fundamental tenet discrimination law, that a person's actual, assumed or future disability should not be used as a basis upon which to arbitrarily determine whether a person can perform the requirements of a job. We must keep uppermost in our mind the fact that 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, other may be able to be treated in future, should the person develop the condition. Given this, we must guard against genetic difference becoming an unchallenged rationale for excluding person from employment who can be productive members of society.[33]

It is also important that concerns about risks to the safety of employees and the public, and the related liability of employers, are not exaggerated in the context of genetic conditions. In the far majority of employment contexts the focus should not be, nor does it need to be, knowing about the health conditions or susceptibility of employees. The primary focus needs to remain anticipating and eliminating workplace hazards to employees and risks to public safety. Nevertheless, we also need to bear in mind that there are limited circumstances where certain conditions in certain jobs, may give rise to exceptions to the general rule. We consider this in more detail below (see 4.4.2 and 4.4.3).

In our view the Clinton Executive Order on Genetic Information strikes a good balance between a clear prohibition as a matter of general principle, subject to limited exceptions in relation to a person's capacity to undertake the inherent requirements of the job and occupational health and safety of employees.[34] We consider this below in more detail. As outlined above, however, we do not consider that separate legislation in relation to genetic discrimination is warranted.

We favour 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 one of the exceptions discussed below applies. We refer you to our previous discussion in section 3.3.7 and recommendations 6 above.

It is clear from our discussion above of the findings of the HCV Enquiry that requests for and use of medical information to discriminate in a range of settings already occurs in relation to hepatitis C. In our experience there are also many other health conditions to which this issue applies, notably HIV/AIDS among others. Therefore prohibiting the request for, receipt and use of genetic information specifically would afford better anti-discrimination protection to those affected by genetic conditions, than are available to other people with disabilities. The above approach would avoid this by enabling other health conditions, not just conditions or predispositions that can be detected by genetic testing, to be covered.

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

[34] *Executive Order to Prohibit Discrimination in Federal Employment based on Genetic Information*, 8th February 2000.

The obvious disadvantage with this approach is that it is not explicit that it is unlawful to request and use information relating to a person's genetic make up or require a person to undergo genetic testing. However, nor is it explicit in relation to a request for information about a person's hepatitis C or HIV/AIDS status and require a person to undergo hepatitis C or HIV testing, or any other medical condition.

**Recommendation 10**

That the provision recommended above (recommendation 6) make explicit that such unlawful conduct *includes:*

- requesting or using information relating to a person's genetic make up, hepatitis C or HIV/AIDS status or
- requesting a person to undergo genetic testing or testing to determine a person's hepatitis C or HIV/AIDS status.

That consideration should also be given to what other disabilities should be included in a non-exhaustive list.

### 4.4.2 Public health and safety

***Q: 10- 4 Should employees in positions involving significant safety risks to the public and/or other employees (eg airline pilots and professional drivers) be required to undertake genetic testing? If so, how should this testing be regulated?***

Employers should take all steps necessary to reduce the risks to public safety, without requiring testing of employees. However, we recognise that there may be limited circumstances where genetic testing of employees may be appropriate where particular positions involve significant safety risks to the public or the safety of the employee concerned or other employees. We consider safety risks to the employees in the context of occupational health and safety below (section 4.4.3).

However, genetic testing of employees or applicants in order to reduce significant safety risks to the public should only occur where testing is limited to:

- positions where the risk to public safety could not be eliminated other than by being aware of a person's condition or predisposition; and
- conditions which would effect a person's capacity to carry out the inherent requirements of the particular job.

Whether a risk to public safety cannot be eliminated other than by being aware of a person's condition or predisposition will vary considerably, even in contexts which appear to present significant safety risks to the public. For example, as Michael Yeasley notes:

> A sudden incapacity might have substantial consequences for an airline pilot, but insignificant consequences in the case of a train engineer with a 'dead man's switch'.[35]

If the DDA is amended to prohibit a person from requesting or requiring another person to supply information upon which unlawful discrimination might be based (see recommendations 6 and 10 above) then no specific exception is required. The onus is on the employer to show that the testing they undertook or sought to undertake was reasonably required for a purpose that did not involve discrimination, but ensuring public safety.

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[35] Yesley, M. *Genetic Difference in the Workplace*, 1999 American Bar Association, Fall 1999, 40 Jurimetrics 129 at page 138.

The need to ensure that people are able to fulfil the inherent requirements of the job such that public safety is not compromised, is again, not unique to condition which can be diagnosed or preconditions determined by genetic testing. We refer to our discussion above regarding pre-employment medicals at 3.3.7. Likewise, it is likely that in cases where public safety is in issue, and there are no ways of eliminating such risks without knowledge of a person's health, that monitoring of people's health occurs in employment to ensure that people are able to undertake the inherent requirements of the job.

Currently, employee records are not covered by privacy legislation. If the approach proposed here is adopted, it will become even more critical that existing inadequacies in relation to privacy in the employment context are addressed.

**Recommendation 11**

Employers may require genetic testing of employees where:

- the particular positions involve significant safety risks to the public which cannot be eliminated other than by being aware of a person's condition or predisposition; and
- testing is limited to conditions which would effect a person's capacity to carry out the inherent requirements of the particular job.

### 4.4.3 Occupational health and safety

***Q: 10- 5 Should an employer have access to an employee or job applicant's genetic information for occupational health and safety reasons (such as to determine which employees have a genetic susceptibility to a disease that may triggered by specific environmental factors or substances present in the workplace)? If so, how should access to, and use of, such information be regulated?***

Generally, the principles which should apply in relation to obtaining information or requiring employees to undertake testing for occupational health and safety purposes are the same of we have outlined in relation to public safety concerns above at 4.4.2.

Where a person has a genetic predisposition or a current health condition which may expose themselves of other employees to occupational health and safety risks the employers should take all steps necessary to reduce the occupational health and safety risks, without requiring testing of employees. Genetic testing of employees or applicants in order to reduce occupational health and safety risks should only occur where testing is limited to:

- positions where the risk to public safety could not be eliminated other than by being aware of a person's condition or predisposition; and
- conditions which would effect a person's capacity to carry out the inherent requirements of the particular job.

This is the approach that should be adopted in relation to hepatitis C and HIV/AIDS, yet there evidence that standard infection control procedures are all too often flouted, especially in health care settings. The HCV Enquiry found that "despite a clear NSW Health infection control policy, one of the most common problems people with hepatitis C experience is disclosure of their status in the name of infection control".[36] So rather than eliminate the risk of infection by applying standard infection control procedures, where knowledge of a person's status is irrelevant, disclosure is often required on the justification that it is necessary for the elimination of risk to the public and employees.

The concern is that such flawed logic can as easily be applied to genetic information, where employers may consider that they are in a better position to protect against liability

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[36] *C-change* report, Section 2.3 at page 46.

in relation to public and occupational health and safety if they know about a person's health condition. The reality is this is often a flawed assumption. In the context of hepatitis C for example, approximately 40% of people in NSW who have been exposed to hepatitis C are unaware of their status, this includes both employees and patients. Infection control measures based on assumptions or knowledge about a person's hepatitis C status are ineffective in reducing the risk of transmission. Infection control practices that rely on knowledge of a person's hepatitis C status expose both health care workers and patients to the risk of infection. This in turn exposes Area Health Services in terms of their legal obligation in relation to the health and safety of their employees, and their duty of care to their patients.[37]

As discussed above in relation to public safety concerns, no specific exception is needed in order to adopt this approach if the DDA is amended to prohibit a person from requesting or requiring another person to supply information upon which unlawful discrimination might be based (see recommendations 6 and 10 above). The onus is then on the employer to show that the testing they required their employees to undertake was reasonably required for a purpose that did not involve discrimination, namely that the person can fulfil the inherent requirements of the job by being able to perform the job without risking the safety of him/herself or other employees.

Different issues arise in relation to employee testing and employer's liability where genetic mutations may make an employee susceptible to risk of developing a disorder as a result of environmental cause. Consistent with the above discussion, employers should make every effort to reduce the risks, without the need for testing employers.[38] Where a workplace may expose susceptible employees to higher risk than those without the genetic mutation, employees should have choice as to whether to undertake testing in such circumstances. Generally, we support the approach take in the Clinton Executive Order, that genetic monitoring of the effects of hazardous substances in the workplace should be permitted subject to a range of factors, the most important of which is that the employee must give their informed consent to testing in writing.

Employers will need to ensure that employees, whether or not they are susceptible to the particular hazard, have sufficient information to enable them to make an informed decision about whether to undergo genetic testing. This approach addresses concerns about the extent of employer's duty of care in relation to employees safety. Where an employee has been given adequate information about the risks and elects not to be tested and to continue to work in the environment in question, significantly reduces the likelihood that the employer would be liable in such circumstances.

As discussed above, it is critical that existing inadequacies in relation to privacy in the employment context are addressed. Legislation alone is a limited tool in term of educating employers and employees about the rights and responsibilities in relation to testing in the workplace. We recommend that a national genetic testing code of practice is developed. This is discussed in more detail below in section 4.4.5.

**Recommendation 12**

Employers may require genetic testing of employees where:

- the particular positions involves risks to the employee or other employees which cannot be eliminated other than by being aware of a person's condition or predisposition;

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[37] *C-change* report, Section 2.4 at page 62 - 63. See also discussion on balancing the rights of hepatitis C positive health care workers and occupation and public health safety.

[38] See for example Issues Paper discussion of the NOHSC's *Guidelines for Health Surveillance*, which provides that employers have an obligation to assess health risks involving exposure to hazardous substances and employers obligation regarding preventing or minimising the health risks to employees, at page 283.

- testing is limited to conditions which would effect a person’s capacity to carry out the inherent requirements of the particular job; and

Employers may arrange for genetic monitoring of employees to reduce the risk of employees developing a disorder as a result of environmental cause, only with the informed consent of employees in writing.

### 4.4.4 Interpretation of genetic information by employers

***Q: 10-3 Where employers are permitted to conduct genetic testing, what measures should be put in place to establish the reliability, accuracy and proper interpretation of any genetic testing before making decisions based on that information?***

In the limited circumstances where employers are permitted to request employees or applicants undertake genetic testing, it is vital that employers understand the information the tests provide, including the reliability of the tests in determining a predisposition, the certainty or otherwise onset of the condition, likely symptoms, whether the condition can be treated, and the differences between diagnostic, predictive and carrier testing.

Ensuring that anti-discrimination legislation provides clear prohibition in relation to requesting or requiring another person to supply information upon which unlawful discrimination can play an important educative role. Nonetheless, relying on individual complaint mechanisms will be inadequate to ensure that employers only request genetic testing within the confined circumstances articulated in this submission, and when they have the information, that they will understand it before making decision. Some form of regulation is needed.

While occupational health and safety legislation does allow for development of approved industry codes of practice, the issue of regulating testing and understanding the meaning of such tests in the employment context is wider than OH&S concerns. We suggest that consideration should be given to whether a statutory authority should be established, or an existing agency should have responsibility for overseeing employment related testing, not limited to genetic testing.

We envisage that such an agency would:

- assess whether testing is necessary - i.e determine whether public safety or OH&S risks can be eliminated without testing/ medical examination and whether the testing/examination sought relates to the inherent requirement of the job
- where appropriate, arrange or provide pre and post test counselling to employees
- in light of the information obtained determine whether the person can fulfil the inherent requirements of the job, including what services or accommodations may be necessary to enable the person to do so
- certify whether the person can fulfil the inherent requirements of the job.

Such an approach would ensure there was a proactive mechanism for determining whether testing is necessary, support uniformity in testing, confidentiality and privacy practice and protocols. It would also ensure appropriate expertise in determining whether the tests relate to the inherent requirements of the job and where tests are undertaken, in assessing what the test result mean for the person’s capacity to undertake the inherent requirements of the job, including the consider the impact of a person’s condition on public safety and OH&S.

**Recommendation 13**
That consideration should be given to whether a statutory authority should be established, or an existing agency should have responsibility for overseeing employment related testing, not limited to genetic testing, including effective implementation of the National genetic testing Code of Practice recommended in this submission ( recommendation 14).

### 4.4.5 National genetic testing code of practice

There is a need for clear guidelines in relation to genetic testing in employment and insurance, as the use of testing has significant consequences for individuals and rights and obligation derive from a range of legislation including anti-discrimination, occupational health and safety and privacy legislation. Ideally, such a code should be enforceable and sanctions apply for breaches of the code. However, this presents particular difficulties if the code is to be comprehensive, because binding codes usually need to be approved pursuant to a specific piece of legislation. In the case of genetic testing, the issues are relevant to both State and Federal legislation, a range of pieces of legislation and relate to procedures and practice which may not have a direct legislative basis.

Given this, we do not propose a definitive view on the form of the code. However, we consider that there is merit in a national code that covers the full range of issues because of its potential educative effect and the capacity of such a code to ensure that there is clarity about people's rights and responsibilities.[39] The Australian National Council on AIDS Hepatitis C and Related Diseases (ANCAHRD) HIV Testing Policy provide a good example of such a code.[40]

We propose that a comprehensive genetic testing code should include guidelines on:
- legal requirements regarding informed consent to testing;
- what information is to be contained in pre and post test counselling;
- rights and obligations under anti discrimination, privacy ,occupational health and safety and any other relevant legislation;
- testing in employment including general prohibition on request information and testing and specific public safety and occupational safety exceptions;
- testing by insurers including the prohibition against testing and use genetic information by insurers, subject to approval for use in risk assessments;
- testing, requests for information and rights of review and appeal under the *Migration Act 1958;*
- right of access by consumers to research which forms the basis of the actuarial or statistical evidence and the actuarial or statistical data upon insurers may seek to reply.

If such a code were developed then specific sections of the code could then be incorporated into codes under specify pieces of legislation. For example industry codes of practice under *Occupational Health and Safety Act 2000 NSW* (OH&S Act) can be approved by the Minister for Industrial Relations.[41] The approval of such codes is then published in the NSW *Government Gazette*. Once gazetted, an approved code of practice is designed to be used in conjunction with OH&S legislation. A person or company cannot be prosecuted for failure to comply with an approved industry code of practice. However, in proceedings under the OH&S Act or Regulations, failure to observe the code can be used as evidence that a person or company has failed to comply with the OH&S Act or Regulations.

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[39] Australian National Council on AIDS Hepatitis C and Related Diseases (ANCAHRD) , HIV Testing Policy.
[40] http://www.health.gov.au/pubhlth/ancard/pdf/hivtest.pdf
[41] *Occupational Health and Safety Act 2000 NSW,* Part 4, section 43.

**Recommendation 14**
We recommend that a comprehensive national genetic testing code of practice is developed and effectively implemented as outlined in this submission.

# 5. Insurance

## 5.1 Overview

Chapter 11 considers a wide range of issues in relation to the use of genetic information by the insurance industry. We have identified and provide responses to the questions in this chapter which are relevant to issues of discrimination.

We recognise that the provision of insurance is a commercial activity and fundamental to the process of insuring a person against future illness, injury or death, is the need to *assess the particular risk factors* for injury, illness or early death. Such an assessment of risk may lead to differential treatment based on the degree of risk associated with providing insurance to one person compared with another.

The Deputy Disability Discrimination Commissioner of the Human Rights and Equal Opportunity Commission (HREOC), Mr Graeme Innes, explains the obligations of insurers in respect of disability discrimination under the DDA, which also reflects insurers' obligations under the ADA, as follows:

> The legislation recognises that the nature of insurance is one of making differentiations based on risk — at least, that is the case outside of the health insurance area where the community rating principle applies. Even there, exclusions on payment for pre-existing conditions recognise that insurers are in the business of insuring against risks, not already known certainties. Of course, insurers are no more entitled than any other industry to act on basis of prejudices, misconceptions or inaccurate or outdated information about people with disabilities. But the *Disability Discrimination Act* does permit distinctions and exclusions based on disability if and where this is reasonable.[42]

## 5.2 Coverage under DDA and ADA

Generally, under both NSW and Commonwealth anti-discrimination legislation, insurance providers cannot discriminate on the ground of disability by refusing to provide insurance or by offering unfavourable terms or conditions.

The ADA provides that it is unlawful to discriminate against a person with a disability, in the provisions of goods and services, both by refusing to provide the service or in the terms on which the service is provided.[43] The provision of insurance is considered a service within the meaning of the ADA.[44] However, the ADA does not apply to life insurance, which also includes insurance for continuing disability. For constitutional reasons, because the Commonwealth has specifically legislated in relation to life insurance, the ADA does not apply, but complaints in relation to discrimination in the provision of insurance can be made under the Commonwealth DDA.[45]

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[42] Innes, G. *Disability Discrimination and Insurance*, Speech by the Deputy Disability Discrimination Commissioner, HREOC, at the Australian Life Underwriters Association and Claims Association Conference, 5 November 2000, <http://www.hreoc.gov.au/disabilityrights/speeches/underwrite.htm>.

[43] ADA, sections 49B and 49M.

[44] ADA, section 4.

[45] *Life Insurance Act 1995* (Cth).

Other types of insurance are covered by the ADA, although there is an exception in relation to insurance. In order to rely upon this exception, the insurer needs to be able to demonstrate that it is reasonable to discriminate against the person given the available actuarial or statistical data, or where such evidence cannot reasonably be obtained, that the terms and conditions are reasonable having regard to any other relevant factors.[46]

The DDA provides that it is unlawful to discriminate against a person with a disability, in the provisions of goods, services and facilities, including refusing to provide a service and in the terms on which the service is provided.[47] The provision of insurance is considered a service within the meaning of the DDA.[48] The DDA also provides an exception in relation to insurance, in similar terms to the insurance exception provided in the ADA.[49]

## *5.3 Scientific and actuarial relevance of genetic information*

***Q: 11-1 Is the information that agents and brokers currently receive from insurers adequate for them to advise insurance applicants effectively about the implications of genetic information? If not, what improvements could be made to the provision of such information?***

Clearly, agents, brokers and other significant participants in the insurance industry need to understand the different types and implications of genetic information. This can best be achieved by the development of a national genetic testing code of practice. This is considered in detail below at section 5.5.

***Q: 11-7 How should insurers and government address the need to ensure the scientific reliability and actuarial relevance of genetic information used for underwriting purposes?***

Assessing the degree of risk on the basis of genetic information is be no means clear cut. The Issues Paper highlights that the scientific reliability or actuarial relevance of genetic information is, in the far majority of cases, unproven. The nature of the information varies significantly depending upon factors such as whether the information indicates a predisposition to a disorder that is dominant or recessive and the fact that the degree of symptom expression and time of onset will vary between individuals. These factors will influence the relevance of predictive genetic information when applied to risk rating for insurance purposes.

Given this, it is vital that adequate mechanisms are in place to ensure that scientific reliability and actuarial relevance is established *before* genetic information is used for underwriting. In our view, concerns about the scientific reliability and actuarial relevance of genetic information are only one part of the equation. This issue is no different in the relation to people with condition or predisposition to a condition which can be determined by genetic testing than for other people with disabilities, whether actual, future or imputed.

For example, concerns regarding the relevance of actuarial data and its interpretation in the underwriting process were raised in the ADB’s enquiry into hepatitis C related discrimination, including that the data relied upon was out of date or based on data which is not relevant to the Australian context. Current research about the natural history of the hepatitis C virus and clinical evidence about hepatitis C disease progression does not justify routine refusal of insurance or exclusion of people with hepatitis C from applying for

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[46] ADA, section 49Q.
[47] DDA, sections 5 and 24.
[48] DDA, section 4.
[49] DDA, section 46.

insurance as a matter of standard policy.[50] Nonetheless, the evidence to the Enquiry indicated that people with hepatitis C have been refused insurance or dissuaded from applying for insurance. The only way in which this issue can be addressed is through individual complaint mechanisms. For the reasons we have outlined below in section 5.4, this is an inadequate means of addressing systemic discrimination.

There is a need to establish an independent body to evaluate the scientific reliability and actuarial relevance of genetic information before it is used for underwriting. The UK Genetics and Insurance Committee (GAIC) provides a useful model. In light of the above discussion, we consider that such a body should not be limited to evaluating genetic information only and should also have a role in examining the scientific reliability and actuarial relevance of health research information generally. We propose that this body should have the power to assess whether the research upon which actuarial data is based, whether currently in use or proposed for use in the future, is sufficiently current and appropriate to be relied upon in the Australian context for the purposes of determining risk.

Without an adequate independent mechanisms for evaluating the scientific reliability and actuarial relevance of genetic information, an onerous burden will fall to individuals to lodge complaints under anti-discrimination legislation in order to test the actuarial relevance of the genetic information upon which the insurers seek to rely and the accuracy of the interpretation of that information in the underwriting process. To allow the scientific reliability and actuarial relevance of predictive genetic test information to be determining on a case by case basis is totally inadequate to address the complexities of determining the use of genetic information when applied to risk rating for insurance purposes.

The exception in relation to insurance in the DDA and State and Territory anti-discrimination legislation will need to be amended to reflect this approach. This is discussed in more detail in section 5.6 below.

**Recommendation 15**
That an independent body be established to evaluate the scientific reliability and actuarial relevance of:

- genetic information proposed for use by the insurance industry before genetic information is used for underwriting; and
- non-genetic information whether used or proposed for use by the insurance industry for underwriting.

**Recommendation 16**
That the independent body (recommendation 15), in conjunction with the insurance industry, also undertake educational activities to ensure that agents, brokers and other significant participants in the insurance industry understand:

- what genetic information has been approved for use in underwriting;
- the different types and implications of genetic information generally; and
- the national genetic testing code of practice (recommendation 14).

## *5.4 Access to actuarial data*

### *Q: 11-2 How and to what extent should insurers be required to provide applicants with information and data that supports unfavourable underwriting judgments based on genetic information?*

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[50] *C-Change*, see section 2.6 at page 79 -81.

It is essential that insurers are required to provide applicants with information and data that demonstrates the basis upon which unfavourable underwriting decisions have been made, whether or not the actuarial or statistical evidence is based on genetic information.

We strongly disagree with the view expressed by IFSA that the current methods of risk assessment using genetic information are sufficiently transparent and accountable to the public because the DDA provides consumers with the capacity to lodge a complaint and this in turn would mean that the insurer may be required to provide evidence in support of their underwriting decision.[51] We do not consider that it is acceptable for insurance companies to require individuals to lodge a complaint before such information is provided to consumers.

In our view, consumers should have the right to access adequate information about basis for the insurers decision and the actuarial or statistical evidence on which the insurer has relied in making that decision. It is only with such information that consumers can determine whether to challenge the decision under anti-discrimination legislation. In any event, merely lodging a complaint under anti-discrimination legislation will not necessarily result in insurance companies being required to provide the actuarial or statistical data during the investigation or conciliation process. This is considered in more detail below in section 5.6 below.

IFSA's approach also fails to acknowledge the power inequities which exist between individuals and insurance companies. Where an application for insurance is refused, the onus is on the individual to lodge a complaint under anti-discrimination law. This means people have to understand their experience as discrimination, and have sufficient information and resources to use the complaints mechanisms available.

Even if consumers can do so, there is a significant imbalance of power between consumers and the insurance industry, particularly in relation to their respective capacities to bear the costs involved in pursuing a matter to hearing. This can lead to unsatisfactory settlements at conciliation, while in turn conciliated settlements do not produce binding precedents. It is clear that from the HCV Enquiry that there are very real limitations with individual complaint mechanisms in bringing about systemic change.[52] Given this context, it is unacceptable to require that consumers lodge a complaint under anti-discrimination legislation in order to obtain access to the information upon which the insurance companies seeks to rely.

As we have discussed above in section 5.3, concerns about the actuarial relevance of information on which insurance companies may rely in determining risk are not unique to genetic information. Accordingly, people with disabilities should have the right to access adequate information about basis for the insurers decision and the actuarial or statistical evidence on which the insurer has relied in making their decisions. See also our discussion of the need for a national genetic testing code of practice at 4.4.5.

**Recommendation 17**

That consumers should have the right to access adequate information about basis for the insurers decision and the actuarial or statistical evidence on which the insurer has relied in making their decisions. This right to access should be reflected in the national genetic testing code of practice and enshrined in legislation. (see recommendation 14)

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[51] Issues Paper paragraph 11.84 at page 325.

[52] *C-Change*, Chapter 4, pages 119 - 121.

## *5.5 Use of genetic information by insurers*

### 5.5.1 What genetic information should insurers be entitled to access?

***Q: 11-5 To what extent would it be appropriate for insurers to request for underwriting purposes:***

- ***information about family medical history?***
- ***the results of any existing genetic tests or analysis in relation to the applicant?***
- ***that the applicant undergo genetic testing?***
- ***the results of any existing genetic tests or analysis from members of the applicant's family?***

We note the discussion in the Issues Paper regarding equity of access to insurance. Debates about the degree to which public policy should intervene in the insurance market will no doubt continue. For the purpose of our submission, particularly in this section, we take as the starting point that insurance is at present a commercial endeavour, an integral part of which is assessing risk and differential treatment based on those risks.

So we return again to Deputy Disability Commissioner, Graeme Inne's comments:

> …insurers are in the business of insuring against risks, not already known certainties. Of course, insurers are no more entitled than any other industry to act on basis of prejudices, misconceptions or inaccurate or outdated information about people with disabilities. But the *Disability Discrimination Act* does permit distinctions and exclusions based on disability if and where this is reasonable.[53]

The key issue is whether we should permit distinctions based on genetic tests when at this stage they have little probative value in determining risk. If, as we propose above (recommendation 14), an independent body is established to determine the scientific reliability and actuarial relevance of genetic information then the question about whether genetic information is of any probative value and therefore necessary for underwriting will be far clearer. That is say, if it is determined by an independent body that the information is not scientifically reliable and relevant and actuarially relevant, then insurers should not be entitled to use such information in the underwriting process, as there would be no basis for arguing that adverse selection would result from the prohibition. The converse is also true. Where the genetic information is scientifically reliable and relevant and actuarially relevant, then insurers should be entitled to use such information in determining risk.

We have proposed that an independent body be established to evaluate the scientific reliability and actuarial relevant of genetic information before it is used in the underwriting process (recommendation 15). We have also recommended a general prohibition against requesting or requiring information (recommendations 6 and 10).

Consistent with this approach, insurers should not be permitted to request :

- existing genetic tests or analysis in relation to the applicant;
- that applicants undergo genetic testing; and
- the results of any existing genetic tests or analysis from members of the applicant's family,

until the independent body has approved the information for use in underwriting because of it's scientific reliability and actuarially relevance.

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[53] Innes, G. *Disability Discrimination and Insurance*, Speech by the Deputy Disability Discrimination Commissioner, HREOC, at the Australian Life Underwriters Association and Claims Association Conference, 5 November 2000, <http://www.hreoc.gov.au/disabilityrights/speeches/underwrite.htm>.

In practical terms, this will mean that in the short to medium term genetic information cannot be used in underwriting. This is entirely consistent with the current state of the use of genetic information in insurance in other jurisdictions. [54] As the Issues Paper documents, the UK House of Commons Science and Technology Committee noted:

> [A]t present the very small number of cases involving genetic tests results could allow insurers to ignore all genetic test results with relative impunity, allowing time to establish firmly their scientific and actuarial relevance.[55]

However, in future, should the scientific and actuarial data prove relevant in determining risk, once approved, insurers would be entitled to use such information in the underwriting process.

The DDA and State and Territory anti-discrimination legislation, if amended in the manner recommended in this submission, will be sufficient flexible to accommodate changes in the probative value of genetic information for determining risk overtime. First, we propose that the DDA and State and Territory anti discrimination laws are amended to prohibit a person from requesting or requiring another person to supply information upon which unlawful discrimination might be based, unless the person can prove that the information was reasonably required for a purpose that did not involve discrimination (see recommendations 6 and 10). Secondly, we propose that consumers should have the right to access adequate information about basis for the actuarial or statistical evidence and the actuarial or statistical data on which the insurer has relied in making their decision to refuse insurance or determine the premium (recommendation 16). Thirdly, we propose that an independent body be established to evaluate the scientific reliability and actuarial relevance of genetic information before it is used in the underwriting process.

Given this, unless and until scientific and actuarial data prove relevant in determining risk, insurers will be prohibited from requiring genetic testing or requesting genetic information from tests already undertaken, unless such information that is reasonably required for a purpose that did not involve discrimination. Such information would not involve discrimination if the exception in relation to insurance applied, that is that the insurer can demonstrate that it is reasonable to discriminate against the person given the available actuarial or statistical data. The insurance exception will need to be amended to reflect the approval process discussed above. However, the exception in an amended form would allow for the insurer to discriminate where it was reasonable to do so based on actuarial or statistical data or, in the case of genetic information, where the actuarial or statistical data has been approved for use in the underwriting process.

As the Issues Paper identifies, family medical history is already used in assessing risk. As the Human Genetics Commission has found:

> The issue of family history information presents particular difficulties. The Commission is concerned that the insurance industry's principle of open disclosure and utmost good faith by the parties seems to fall most heavily on the consumer. Few people are provided with information as to how their premiums are loaded. HGC understands that family history information can amount to genetic information and is not always interpreted appropriately in underwriting. During the moratorium period HGC will address the issue as to how family history information is used by insurers.

In our view use of family medical history, whether or not such information can amount to genetic information, should be subject to greater scrutiny to determine whether or not the information used in the underwriting process is scientifically reliable and actuarially

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[54] Issues Paper, for example, the ABI Code section (e), paragraph 11.164 at page 349.

[55] Issues Paper, paragraph 11.133 at page 340.

relevant. The independent body we propose above should play a role in evaluating the scientific reliability and actuarial relevance of both genetic and non-genetic information.

The national genetic testing code of practice, which we have considered in section 4.4.5, would also be a valuable tool in making explicit the rights and obligations of the insurers and applicants for insurance in relation disclosure of information and requests for genetic testing and genetic information.[56]

***Q: 11-9 Does existing family medical history information requested from applicants in the majority of personal insurance proposals provide a sufficient level of information for risk rating, such that genetic test information might be excluded altogether from insurance underwriting?***

As discussed above, generally genetic test information at this point in time is of limited value in determining risk for the purposes of insurance underwriting. Nonetheless, in the future this may not necessarily be the case. The approach we propose above is sufficiently flexible to accommodate changes in the probative value of genetic information in assessing risk overtime.

In addition, the approach we propose does not rely on treating genetic test information any differently from other health information, except to the extent that it recognises that the scientific reliability and actuarial relevance of genetic testing is that such an early stage of its developments that the probative value is particularly limited. Given this, the approach we recommend emphasises that the scientific reliability and actuarial relevance needs to be evaluated *before* it is acceptable to use the information in the underwriting process. In respect of other health information, which is currently used by insurers, there is a need for greater scrutiny of the scientific reliability and actuarial relevance of the information, including the currency of the information and application of such information to the Australian context (see section 5.3).

### 5.5.2 Should access to genetic and non genetic information be treated differently?

***Q: 11-11 Would the equitable treatment of all applicants for insurance be affected by distinguishing among, or restricting the use of, particular types of health information, such as:***

- ***genetic test information;***
- ***other genetic information, such as family medical history; and***
- ***non-genetically linked health risks?***

As we have outlined above, the approach we propose does not rely on treating genetic information any differently from other health information, except to the extent that we recognise that the scientific reliability and actuarial relevance of genetic testing is at such an early stage in its developments that the probative value is particularly limited.

We agree with the views outlined in the Issues Paper which emphasis the anomalies which are likely to arise if genetic information is excluded from assessing risk while non-genetic health information is not excluded.[57]

### 5.5.3 Impact of use of genetic information on health and research

***Q: 11-8 Is there any evidence that the potential use of genetic information by insurance companies is deterring individuals from taking genetic tests for clinical***

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[56] Issue Paper, see for example the UK Genetic Testing Code of Practice at page 349.

[57] Issues Paper see paragraph 11.149 at page 344.

***diagnosis or volunteering for genetic research? If so, how should these issues be addressed?***

As we discussed in section 2 above, 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. We refer you to section 3.3.9 above where we emphasise the important role anti-discrimination agencies can play in educating those affected about their rights. As we have discussed, if complaint handling mechanisms are fraught with delays, people are unlikely to feel confident that anti-discrimination legislation will provide effective redress. Community confidence is also likely to be supported where people are assured that they can access information upon which insurance companies base their decision (see section 5.4).

So too, anti-discrimination agencies have a critical role to play in working with employers, insurance companies and other service providers to prevent discrimination. General practitioners and other primary health care providers need to be supported to enable them to provide accurate information about the implications of genetic testing.

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 and their obligations, if any, regarding disclosure of the information obtained through genetic testing. The national genetic testing code of practice we have proposed should provide clear guidance on what information is needed in pre and post test discussion, in addition to clarity about employers and insurers responsibilities under anti-discrimination and privacy laws and other relevant legislation.

**Recommendation 18**
That national genetic testing code of practice include guidelines which will enable people to make informed decisions about whether to undergo testing. The guidelines should ensure people are provided with accurate information about their rights under anti-discrimination and privacy legislation and their obligations, if any, regarding disclosure of the information obtained through genetic testing.

## *5.6 Adequacy of anti-discrimination legislation*

***Q: 11-6 In the specific context of insurance, do existing anti-discrimination laws provide an adequate framework for protection against discrimination based on genetic information?***

### 5.6.1 Coverage under anti-discrimination law

We refer to section 3.3 above regarding the coverage of genetic discrimination within the definition of disability, including coverage of future disability discrimination and our discussion of coverage under the ADA and DDA in relation to insurance (see section 5.2).

We recognise that the provision of insurance is a commercial activity and fundamental to the process of insuring a person against future illness, injury or death, is the need to *assess the particular risk factors* for injury, illness or early death. Such an assessment of risk may lead to differential treatment based on the degree of risk associated with providing insurance to one person compared with another.

Given this, we consider that the exception in relation to insurance is appropriate if:

- there is an independent mechanism for evaluating the scientific reliability and actuarial relevance of genetic information before insurers may rely on the data (see section 5.3);

- the exception is amended to reflect the approval process; and
- people have ready access to the information upon which the insurers seek to rely (see sections 5.4 and 5.6.2).

**Recommendation 19**

The DDA and State and Territory anti-discrimination be amended such that it will not be unlawful for a person to discriminate against another person, on the ground of the other person's disability, by refusing to offer the other person insurance if:

- the discrimination is based upon actuarial or statistical data on which it is reasonable for the first-mentioned person to rely; or
- in the case of a genetic condition, the discrimination is based upon actuarial or statistical data which has been approved for use in underwriting by the relevant independent body.

### 5.6.2 Power to obtain actuarial and statistical evidence

As we have recommended above (see 5.4), consumers should have the right to access adequate information about basis for the insurers decision and the actuarial or statistical evidence on which the insurer has relied in making that decision, without being required to initiate proceedings. Nonetheless, it is also important to ensure that disclosure provisions the context of anti-discrimination proceedings are also adequate.

The DDA does enable the President or the Commission to issue a notice in writing requiring disclosure to the President or to the Commission the source of the actuarial or statistical data. It is an offence to fail to comply and a penalty of $1,000 applies.[58]

There are some inadequacies with this provision. First, the provision appears to limit disclosure to the *source* of the data, rather than the data itself. Secondly, the provision only refers to "disclosure to the President or to the Commission". As far as we are aware, the terms of the provision have not been used to prevent disclosure of the information to the complainant. However, in the interests of clarity, it should be made clear that complainants are entitled to access the information disclosed to the President or the Commission.

The ADA does not enable the President to compel the parties to a complaint to produce documents which may be relevant to the investigation of the complaint. As such, where the respondent seeks to rely upon actuarial and statistic evidence for their decision, the insurer cannot be compelled to provide the information until that matter is before the Administrative Decision Tribunal. It is only then, that the complainant could subpoena the relevant material. As a result individuals are often unable to assess the merits of their case until the matters has been referred to the relevant court or tribunal for hearing. We do not consider this appropriate for the reasons outlined in section 5.3 above.

**Recommendation 20**

That DDA and State and Territory anti-discrimination laws are amended, where necessary, to provide the President/Commissioner with the power to order a party or non-party to produce documents, including actuarial or statistical data and the information upon which that data is based, in the course of investigation of a complaint.

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[58] DDA, section 107.

# 6. Other services and contexts for genetic discrimination

***Q: 12-1 Do existing anti-discrimination laws provide adequate protection against unfair or improper use of genetic information in the context of:***

***a) the provision of government services, including access to education and health services?***
***b) immigration processes?***
***c) determining Aboriginal or other communal identity?***
***d) participation in sport?***
***e) or any other activities, services or entitlements?***

***To the extent any deficiencies may be identified, how should these be remedied?***

Generally, the areas of public life covered by DDA and State and Territory anti-discrimination laws are adequate to address disability, race and sex discrimination in the provision of government services, including access to education and health services and participation in sport. However, there are exceptions in anti-discrimination legislation, many of which apply to disability discrimination which we do not consider are appropriate and which need to addressed.

Under the ADA businesses with five or less employees are exempt from provision relating to disability discrimination in employment. As small businesses are one of the largest employers in NSW, it is essential in order to afford protection to all workers that this exception be repealed. Private educational authorities are also exempt in relation to disability discrimination in education under the ADA. The DDA does not provide exemptions for small businesses and private eduction authorities, state and territory anti-discrimination legislation needs to be consistent with coverage under the DDA.

The *Migration Act 1958* and processes under that Act are specifically exempt under the DDA.[59] While we have concerns about the extent to which it is necessary to exempt the entire Act from the DDA, we recognise that people's health status is a relevant factor in determining applications under the Migration Act, given that consideration needs to be given to the future burden on the Australian health system.

Nonetheless, as we have already discussed in detail in relation to insurance, the scientific reliability of genetic information in determining the extent to which people are likely to develop health conditions in future, is far from clear. It is certainly conceivable that people's immigration applications may be refused on the basis of their genetic make up, even where the possibility of developing the condition is remote or where their are health is unaffected and therefore there is no likelihood that they present a future burden on the health system. These same arguments apply to the misinterpretation of any health information provided to the Department of Immigration. There is a need to ensure that immigration department decision makers understand the different types and implications of genetic information. The department and individuals rights and responsibilities in relation to genetic testing and requests for genetic information under the *Migration Act* should also be included in the proposed national genetic testing code of practice (see 4.4.5).

The Federal Government, in administering the *Migration Act,* should be subject to similar limitations on the use of genetic information as we have proposed for insurers. The review

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[59] DDA, s.52.

and appeal mechanisms available under the *Migration Act 1958*, need to be adequate to ensure that people challenge decisions which based on scientifically unreliable data or misinterpretation of genetic and non genetic health information.

**Recommendation 21**
That consideration is given to whether the existing review and appeal mechanisms in the *Migration Act 1958* are adequate to enable applicants to challenge decisions which are based on scientifically unreliable data or misinterpretation of genetic and non genetic health information.

**Recommendation 22**
That people's rights and responsibilities in relation to genetic testing and requests for genetic information under the *Migration Act* should be included in the proposed national genetic testing code of practice.

The concerns which are raised by genetic testing to determine Aboriginal or other communal identity are mainly outside of the framework of anti-discrimination legislation. As the Issues Paper identifies this issue which is one which is relevant to people being entitled to accessing Indigenous specific service, programs and benefits and participate in Indigenous organisations.

For example, where a person is denied the right to access an aboriginal medical service on the basis that they are not 'genetically' indigenous, the special measures provision in the RDA would apply. [60] So, where programs and services are established for the benefit of certain a particular racial groups or individuals, in order to redress disadvantage, and a person is refused access because they are not part of that racial group, they are unlikely to be able to argue they have been discriminated against on the basis of race.

Special measure provisions or capacity to exempt particular services and programs from anti-discrimination legislation, in order that programs, services and other benefits can be provided to specific groups of people to redress disadvantage are vital to the purpose and effectiveness of anti-discrimination legislation.

The central issue is not about the role of anti-discrimination legislation. It is whether it is appropriate to use genetic information to determine community, racial and ethnic affiliation. This is a question better answered by Indigenous communities themselves. We are concerned that should a purely genetic approach to community, racial and ethnic affiliation be adopted, it is conceivable that people who identify as indigenous and are accepted within Indigenous communities as Indigenous may be refused access to Indigenous services programs and benefits, which were specifically designed to address disadvantage of Indigenous people.

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[60] RDA, s.8(1), see Article 1, paragraph 4 of the International Convention on the Elimination of All Forms of Racial Discrimination.

# ALRC and AHEC Inquiry into the Protection of Human Genetic Information

## *Discussion Paper 66*

## *Anti-Discrimination Board of NSW comments*

***November 2002***

# Overview

The ADB's submission in response to the *Issues Paper* focused on the discrimination matters. This document outlines the ADB's position in response to the proposals and questions outlined in the *Discussion Paper* which are relevant to the matters raised in our submission. We also include reference to relevant recommendations made in our submission relating to the proposal and questions in the Discussion Paper. We have annexed the list of our recommendations for ease of reference.

This submission outlines the views of the NSW Anti-Discrimination Board. It is not a submission on behalf of the NSW Government.

# Chapter 3 : Standing advisory body on human genetics

### *Establishment of a Human Genetics Commission of Australia*

**Proposal 3–1** A Human Genetics Commission of Australia (HGCA) should be established under federal legislation as an independent, stand-alone, statutory authority with sufficient resources to fulfil its mission.

**Proposal 3–2** As a general matter, the role of the HGCA should be to provide:

- on-going, high-level technical advice to Australian governments about existing and emerging issues in human genetics;
- similar high-level advice on the ethical, legal and social implications arising from these developments;
- national leadership in managing the process of change, including engagement of the public on these issues;
- direct expertise and a consultative mechanism for the development of policy statements and national guidelines in this area, where appropriate in association with other governmental agencies or the relevant industries and organisations;
- assistance with the development of community, school, university and professional education about human genetics; and
- a focus for the coordination and integration of various national — and perhaps regional and international — programs and initiatives.

**Proposal 3–3** The HGCA also should have specific responsibility for:

- identifying genetic tests that have particular concerns or sensitivities attached to them, and thus may require special treatment — such as through restricted clinical request pathways or through the assignment of a higher risk classification by the Therapeutic Goods Administration;
- approving specific genetic tests for use by the insurance industry for risk-rating purposes, or by employers for compelling occupational health and safety reasons; and
- performing any similar function or providing expert advice on any other matters relating to human genetics, upon the request of the responsible minister or ministers.

**Proposal 3–4** The HGCA structure should involve at least two principal committees: (a) a Technical Committee, and (b) an Ethical, Legal and Social Implications Committee.

**Proposal 3–5** Appointments to the HGCA should ensure a balanced and broad-based range of expertise, experiences and perspectives relevant to the use and protection of human genetic information. The appointments process should involve consultation with appropriate communities and stakeholders.

**Proposal 3–6** As a general rule, meetings of the HGCA and its committees should be open to the public.

**Proposal 3–7** The HGCA should liaise closely with other relevant governmental departments, authorities and entities (such as the NMHRC and its committees, state and territory departments of health, the TGA, the OGTR, and AHMAC) to promote a national approach to the protection of human genetic information.

**ADB's position**
Generally, these proposals are supported. In our view the HGCA's role in relation to policy statements and national guidelines must include development of a national testing policy in broader terms than outlined in proposal 3-3. Such a policy should include employment related testing (see Recommendation 13 and 14), pre and post test discussions to enable informed consent to testing (see recommendation 18) and issues in relation to insurance companies access to or use of genetic tests (see recommendations 15 - 17 and 19).

In addition to testing issues in insurance and employment, we strongly agree that the HGCA should have a policy development role in critical areas such as insurance and employment generally.

# Chapter 8: Anti-Discrimination Law

## *Legislative framework covering genetics discrimination*

**Proposal 8–1** Discrimination on the ground of genetic status should continue to be dealt with under the framework of existing federal, state and territory anti-discrimination laws, subject to the specific proposals for legislative amendments identified in this Discussion Paper.

**ADB's position**
The ADB supports proposal 8-1 (see recommendations 1 and 2).

## *Amending the DDA title and objects*

**Question 8–1.** (a) Should the name of the *Disability Discrimination Act 1992* (Cth) (DDA) be amended to the *Disability and Genetic Discrimination Act 1992* (Cth)? (b) Should the objects of the DDA be amended to clarify that discrimination on the basis of genetic status falls within the Act?
(a) *Disability and Genetic Discrimination Act 1992*

**ADB's position**
We do not support the *Disability Discrimination Act 1992* (Cth) (DDA) being amended to the *Disability and Genetic Discrimination Act 1992* (Cth).

In our view this would suggest that a distinction should or does exists where people are discriminated against on the basis of future or imputed condition detectable by genetic testing, as compared with people who are discriminated against on the basis of future or imputed condition which are not detected by genetic testing. Concerns about access to and use of health information are no different in the relation to people with conditions or predisposition to conditions which can be determined by genetic testing than for other people with disabilities, whether actual, future or imputed.

It is vital that we 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 discriminated against on the basis of future, imputed or currently living with disabilities.

*(b) Amending objects of the DDA*

We recognise and support the need to give discrimination on the ground of genetic status a heightened emphasis or increased visibility. However, given the generality of the objects clause, it does not seem an appropriate place to highlight discrimination on the basis of genetic status. In our view, clarity in the definition of the disability is preferred. See our comments in relation to proposal 8-2.

### *Defining 'disability'*

**Proposal 8–2** Federal anti-discrimination legislation should be amended to:

- define 'disability' in the DDA and define 'impairment' in the regulations made under the *Human Rights and Equal Opportunity Commission Act 1986* (Cth) (HREOC Act) to clarify the application of the legislation to discrimination based on genetic status;
- define 'impairment' in the regulations made under the HREOC Act to clarify the application of the legislation to a disability that may exist in the future;
- insert a definition of 'disability' in the *Workplace Relations Act 1996* (Cth) to conform with federal anti-discrimination legislation, as amended by these proposals.

**Proposal 8–3** The States and Territories also should consider amending their anti-discrimination legislation to accord with the policies reflected in Proposal 8–2.

**Question 8–2** What form of words should be used in federal anti-discrimination laws to ensure that they apply to discrimination based on genetic status?

**ADB's position**
We support proposals 8-2 and 8-3. In relation to Question 8 -2 we refer you to recommendation 3.

### *Inclusion of ground of 'irrelevant medical records'*

**Question 8–3** Should discrimination on the ground of a medical record be added to the DDA and other relevant legislation as a prohibited basis of discrimination?

**ADB’s position**
We do not consider that the prohibition in relation to discrimination on the ground of ‘irrelevant medical record’ in Tasmanian and Northern Territory anti-discrimination legislation adds anything additional to that which is already covered by the prohibition of discrimination on the ground of disability, combined with adequate provisions in relation to unlawful questions and requests for information and privacy protection in relation to health information. We refer you to sections 3.3.7 and 3.3.8 of our submission.

### *Coverage of ‘associates’*

**Proposal 8–4.** The regulations made under the HREOC Act should be amended expressly to include discrimination on the basis of association with a person who has an impairment or disability.

**ADB’s position**
We do not agree that the regulations should be amended. In the main, the regulations specify grounds of discrimination which can be investigated under the HREOCA, but which cannot be the subject of proceedings in the Federal Court or the Federal Magistrates Court and therefore cannot be the subject of a binding decision. The inclusion of the narrower term ‘impairment’ is merely a consequence of inclusion of grounds from international conventions upon which the federal Government derives it’s authority to legislate in this area.

It would therefore create confusion to include discrimination on the basis of a person’s genetic make up within regulation 4, when such discrimination is covered by the DDA and can be the subject of court proceedings in this category in the regulations.

In our view it is preferable to amend the DDA definitions of ‘associate’ and ‘relative’ where necessary.

We note that Inquiry’s view that families members who are not genetically related to some other members of that family, such as adopted children, step-children, or children born through artificial reproductive technology using donor sperm may not be adequately protected given the definition of associates in the DDA.

Section 3 of the DDA provides:

> **"associate"**, in relation to a person, includes:
>
> (a) a spouse of the person; and
>
> (b) another person who is living with the person on a genuine domestic basis; and
>
> (c) a relative of the person; and
>
> (d) a carer of the person; and
>
> (e) another person who is in a business, sporting or recreational relationship with the person.
>
> **"relative"**, in relation to a person, means a person who is related to the first-mentioned person by blood, marriage, affinity or adoption.

Adopted children, step-children, or children born through artificial reproductive technology using donor sperm will be covered where they fall within (b) above. Adopted children clearly would be covered in relation to their adoptive parents regardless of where they reside. Children born through artificial reproductive technology using donor sperm are likely to be covered given legislation such as the *Status of Children Act* 1996 (NSW).

Children of same sex partners may not be adequately covered in relation to both their parents. Consideration will need to be given to equivalent legislation in other State and Territory jurisdictions. Given this, amendment of these definitions is likely to be necessary to order to cover all family members who are not genetically related to some other members of that family and do not reside together.

In addition to amending the DDA, we stress the importance of uniformity across federal and State and Territory anti-discrimination legislation. We refer you to recommendations 1 and 4. Consideration will need to be given to how best to supports State and Territory legislative reform, in line with any amendments to the DDA.

# Chapter 24: Genetics discrimination in Insurance

### *HGCA's role in monitoring insurance industry use of genetic information*

**Proposal 24–1** Although there is no demonstrated justification for departing from the fundamental principle underlying the market in voluntary, mutually rated personal insurance (namely, equality of information between the applicant and the insurer), where the underwriting of such insurance involves the use of human genetic information, the process of underwriting should be subject to the qualifications identified in Proposals 24–3 to 24–9 below.

**Proposal 24–2** The proposed HGCA should monitor the experience of the insurance industry in using genetic information in underwriting, both in Australia and overseas, with a view to reviewing Australian insurance practices at a later time.
Proposal 24-2 is generally supported (see recommendation 15 and16).

**Question 24–1** Should there be a fundamental change to the way in which genetic information is used to underwrite personal insurance, such as the introduction of a two-tier system; a prohibition on the use of genetic information; or a public subsidy for poorer risks?

**ADB's position**
See our response in section 5.3 and 5.4 of our submission and related recommendations 15 - 17.

### *Disclosure of the result of a genetic test undertaken while that person was a child*

**Question 24–2.** Should an adult applicant for insurance be obliged to disclose the result of a genetic test undertaken while that person was a child?

**ADB's position**
We do not consider creating specific exceptions in relation to people who have been tested as children would be useful. The ADB understands that insurance is a commercial endeavour, an integral part of which is assessing risk and differential treatment based on those risks. The issue must remain whether the information is relevant to risk, not how the

person became aware of the information. In our view, the principles we have outlined in our submission remain the same in these circumstances.

The following principles outlined in our submission are relevant and should apply in all circumstances:
- that people, including parents making decisions about whether their children should undergo genetic testing, have sufficient information to be able to make informed decisions about whether to undergo testing and what obligations, if any, they have to disclose information obtained through genetic testing;
- that an independent body evaluates the scientific reliability and actuarial relevance of genetic information before it is used for underwriting and determines what genetic information, if any, can be used in the underwriting process;
- that insurers are then only entitled to use genetic information which is scientifically reliable and relevant and actuarially relevant in determining risk;
- ensuring agents, brokers and other significant participants in the insurance industry understand the different types and implications of genetic information; and
- that consumers should have the right to access adequate information about basis for the insurers decision and the actuarial or statistical evidence on which the insurer has relied in making that decision.

### *Insurers use of genetic information*

**Proposal 24–3** No predictive genetic test should be used by insurers in underwriting mutually rated insurance unless the test has been approved for that purpose by the proposed HGCA.

**ADB's position**
See our response in section 5.3 and 5.4 of our submission and related recommendations. Generally, this proposal is supported. However, it is not clear to the ADB why this proposal is limited to predictive genetic tests only. It appears to the ADB that there may be circumstances where there may be concerns about the scientific reliability and actuarial relevance of diagnostic genetic tests. If this is so, then the proposal should include both predictive and diagnostic genetic tests.

We also wish to highlight our concern that a regime that will determine what, if any, genetic information can be used in the underwriting process, will lead to better protection for people where their disability or future/imputed disability is determined by genetic testing, than for people whose condition is not determined by genetic testing. This is also a relevant consideration in relation to proposals in this section (proposals 24- 4 on 24-9).

As the Discussion paper notes, we have proposed a broader role for the HGCA ( see recommendation 15). If this broader role is not accepted, than alternative strategies to address this differential protection will need to be considered. In raising this matter, we acknowledge the limitations of the Inquiry's terms of reference. Nonetheless, it is important that the final report make express reference to the anomalies that will arise from some of the recommendations of the Inquiry. We urge you to make clear reference to the need for such anomalies to be addressed when consideration is given to implementing the report's recommendations.

### *Implementing proposal 24-3*

**Question 24–3** Would Proposal 24–3 be implemented most effectively through an industry code or legislation? If the latter, should this be through amendment to: (a) the insurance exemption in anti-discrimination legislation; (b) the duty of disclosure in the *Insurance Contracts Act 1984* (Cth); or (c) both?

**ADB's position**
It may that these strategies need not be mutually exclusive. As a minimum the limitations on the use of predictive genetic information set out in proposal 24-3 should be enshrined in legislation. Legislative requirements should then be incorporated into industry codes.

We note that the Discussion Paper appears to suggest that anti-discrimination legislation may be amended to make it lawful for an insurer to discriminate on the basis of information obtained from a genetic test approved by the HGCA and cites our submission (recommendation 19) in support of this proposal. However, we have some concerns that the proposal as outlined will create a broader exception than we had intended.

The HGCA's role in approving the use of genetic tests by insurers is not related to the individual circumstances of the persons seeking insurance. The HGCA's role is to determine whether it is reasonable for the insurance industry to rely upon the genetic information given the scientific reliability and the actuarial relevance of that information. But the HGCA will not consider if the discrimination is reasonable in the circumstances of a given case.

Currently, s.46 of the DDA ( and the comparable provision in the ADA) require both these elements before the exception will apply. See s.46(1) (f) ( i) **and** (ii).

> **46. Superannuation and insurance**
> (1) This Part does not render it unlawful for a person to discriminate against another person, on the ground of the other person's disability, by refusing to offer the other person:
>
> (a) an annuity; or
>
> (b) a life insurance policy; or
>
> (c) a policy of insurance against accident or any other policy of insurance; or
>
> (d) membership of a superannuation or provident fund; or
>
> (e) membership of a superannuation or provident scheme;
>
> if:
>
> (f) the discrimination:
>
> (i) is based upon actuarial or statistical data on which it is reasonable for the first-mentioned person to rely; and
>
> (ii) is reasonable having regard to the matter of the data and other relevant factors; or
>
> (g) in a case where no such actuarial or statistical data is available and cannot reasonably be obtained---the discrimination is reasonable having regard to any other relevant factors.
>
> (2) This Part does not render it unlawful for a person to discriminate against another person

If both these elements are not contained in any exception, it would be lawful for an insurer to discriminate against a person on the basis of genetic tests approved by the HGCA by refusing them insurance, when in all the circumstances of that case, the person should have been offered cover but at a higher premium. The mere approval of the test for use by the insurer in assessing risk generally, should not make refusal reasonable in isolation of the circumstances in a given case.

We agree with the Inquiry's view that amending the *Insurance Contracts Act 1984* (Cth) so that an applicant's duty of disclosure in relation to predictive genetic tests is limited to results of tests approved for use by the HGCA would be complementary.

**Proposal 24–4** The insurance industry, through its peak bodies and in consultation with the proposed HGCA, should develop and publish policies on the use of family medical history for underwriting mutually rated insurance.

**ADB's position**
Generally, this proposal is supported. We note however, that it is not clear what role the HGCA will play in this process. Our concern remains the need to independently assess the scientific reliability and actuarial relevance of family medical history information.

We refer you to our recommendations regarding a general prohibition against requesting or requiring information (recommendations 6 and 10). The purpose is to ensure consistency in determining whether information used, from whatever source is relevant to determining risk.

### *Written reasons under the ICA*

**Proposal 24–5** The *Insurance Contracts Act 1984* (Cth) should be amended to clarify the nature of the obligation of an insurer to provide written reasons for an unfavourable underwriting decision. Where such a decision is based on genetic information, the insurer should give reasons that are clear and meaningful and that explain the actuarial or statistical basis for the decision.

**ADB's position**
We refer you to our comment above regarding the improved protection which will be afforded to those whose disability is predicted or diagnosed by genetic testing compared with people whose condition is not determined by genetic testing. We submit that the amendment proposed should not be limited to genetic information.

We refer you to our discussion of hepatitis C related discrimination in section 5.3, which demonstrates that the actuarial relevance of information on which insurance companies may rely in determining risk are not unique to genetic information. Accordingly, people with disabilities should have the right to access adequate information about basis for the insurers decision and the actuarial or statistical evidence on which the insurer has relied in making their decisions.

### *Disclosure under the DDA*

**Proposal 24–6.** The *Disability Discrimination Act 1992* (Cth) and related legislation should be amended to clarify the nature of the information required to be disclosed by an insurer and to ensure that the complainant is entitled to access to the information so disclosed.

**ADB's position**
This proposal is supported.

**Proposal 24–7** The insurance industry, through its peak bodies, should develop a policy regarding the provision of reasons by an insurer to an applicant in response to an unfavourable underwriting decision based on family medical history. The policy should ensure that the reasons given are clear and meaningful and that they explain the actuarial or statistical basis for the decision.

### *Disclosure under industry policy*

**ADB's position**
This proposal is supported.

### *Mechanisms for review of underwriting decisions*

**Proposal 24–8** The insurance industry, through its peak bodies, should develop appropriate mechanisms for reviewing underwriting decisions involving the use of genetic information. Such reviews should be:

- conducted in a timely and efficient manner;
- undertaken by a panel of individuals, each of whom is independent of the insurer that made the decision;
- carried out by suitably qualified individuals with a demonstrated understanding of insurance law and anti-discrimination law, underwriting practice, and clinical genetics; and
- binding on the insurer but not on the complainant.

**ADB's position**
This proposal is supported.

### *Public and insurance industry education*

**Proposal 24–9** The insurance industry, through its peak bodies, should review its policies and practices in relation to the training and education of industry members and their authorised representatives in relation to the nature, collection and use of genetic information in insurance.

**ADB's position**
This proposal is supported. We also note and support the role envisaged for the HGCA in relation to education and training outline in chapter 3.

We refer you to our recommendation in relation to anti-discrimination agencies function. We note that the ADA, as with all State and Territory anti-discrimination legislation have been amended to include additional grounds of discrimination, often without adequate additional resources (see recommendation 7). We would welcome the Inquiry's stated support for the unique role anti-discrimination agencies can play in ensuring consumers are aware of their rights and insurers are aware of their responsibilities under anti-discrimination legislation.

## Chapter 27: Genetics discrimination in employment

### *Employers use of genetic information*

**Proposal 27–1** Employers should be able to collect and use genetic information in relation to their employees only where this is reasonable and relevant within the terms of anti-discrimination and occupational health and safety legislation, and subject to the limitations set out in the proposals in Chapters 28–30.

**ADB's position**
This proposal is supported, subject to comments below.

## Chapter 28: Inherent requirements of the job & related issues

### *Current ability to perform inherent requirements*

**Proposal 28–1** In assessing whether an applicant or employee is able to perform the inherent requirements of a job, only current ability to perform the inherent requirements should be relevant. The term 'inherent requirements' in the DDA, the HREOC Act and the *Workplace Relations Act 1996* (Cth) should be clarified accordingly. The States and Territories also should consider amending their legislation to similar effect.

**ADB's position**
This proposal is supported (see recommendation 8).

### *Job descriptions*

**Proposal 28–2** Peak employer associations should encourage members to produce clearly defined job descriptions that set out the inherent requirements of every position in the workplace.

**ADB's position**
This proposal is supported.

### *Prohibition on employers from requesting or requiring genetic information from a job applicant*

**Proposal 28–3** The DDA should be amended to prohibit an employer from requesting or requiring genetic information from a job applicant or employee unless the employer can demonstrate that the information is necessary for a purpose that does not involve unlawful discrimination, such as ensuring that a person is able to perform the inherent requirements of the job. The States and Territories should consider adopting a similar provision in their anti-discrimination legislation, where one does not already exist.

**ADB's position**
This proposal is generally supported, but is too narrow in scope, in that it is limited to information requested or required in the employment context. Currently, s.30 of the DDA applies to the whole of Part 1 and therefore to all areas, including employment, good and services, accommodation, education among others. Section 26 of the *Anti-Discrimination Act 1992* (NT), upon which this recommendation is based, also applies across all areas covered by that Act.

In our view, the proposed amendment must apply on all areas under the DDA and State and Territory anti-discrimination legislation (see section 3.3.7 of our submission). The amendment as proposed would mean that service providers and educational institutions (as providers, not employers) could request or require genetic information from a person in determining whether to provide a service or enrol a student.

As we outlined in our submission, if this proposal is implemented, this will lead to better protection for people where their disability or future/imputed disability is determined by genetic testing, than for people whose condition is not determined by genetic testing.
It is essential that the Inquiry draw the Government's attention to the anomalies that will arise as a result (see section 3.3.7 of our submission and 4.4.1).

### *Disability Standards on collection and use of genetic information in employment*

**Proposal 28–4** HREOC should, in consultation with the proposed HGCA and other relevant stakeholders, develop Disability Standards dealing with the collection and use of genetic information in employment. As an interim measure, HREOC should issue guidelines in this area.

**ADB's position**
We agree with the Inquiry's view that:

- requests for genetic tests or genetic information should be confined to situations in which this information is required for a non-discriminatory purpose
- some level of independent oversight of the use of genetic tests and information by employers is justified to ensure that test results are interpreted accurately and that genetic information is not used inappropriately.

However, we have some concerns about whether Disability Standards in relation to the collection and use of genetic information are the appropriate strategy to ensure that people are not excluded from employment on the basis of irrelevant tests or on the basis of misinterpretation of test results.

Section 31 of the DDA provides for the making of Standards to supplement the federal Act. Standards are intended to offer greater guidance as to what constitutes discrimination in certain circumstances. A breach of a Standard is unlawful (s.32), whereas acts in compliance with the Standard cannot be unlawful disability discrimination under the DDA (s.33). In providing greater clarity, the Standards may act to prevent a person who might otherwise have had a claim under the DDA from lodging a complaint.

In our view, the collection and use of genetic information by employers will be very context specific. Whether it is lawful to collect and use genetic information will be entirely dependent upon the nature of the work undertaken, the relationship of the work environment to particular conditions;

In the far majority of circumstances, employers do not need to know about the health conditions or susceptibilities of employees. The primary focus needs to remain anticipating and eliminating workplace hazards to employees and risks to public safety.

As the purpose of Standards is to provide greater guidance about what constitutes discrimination in certain circumstances, then Standards would need to be very specific, including identifying specific types of work environments and conditions, or prepositions to particular conditions, which cannot be eliminated by any other means. Anything short of this degree of specificity would be unacceptable, given that compliance with a Standard may prevent a person who might otherwise have had a claim under the DDA from lodging a complaint. In our view it will be extremely difficult to develop Standards with sufficient precision to warrant usurping people's right to lodge a complaint under the DDA, given that the rapid pace at which the science of genetics is evolving.

However, we do support the proposal that HREOC issue guidelines in this area. Guidelines do not effect people's right to lodge a complaint in the way that Standards do. Guidelines provide a more flexible approach to providing guidance and are more amenable to regular updating as knowledge in this area is likely to change rapidly overtime.

# Chapter 29: Occupational health and safety

## *Genetic screening of applicants or employees for susceptibility to work-related conditions*

**Proposal 29–1** Genetic screening of applicants or employees for susceptibility to work-related conditions should be conducted only where:
- there is strong evidence of a clear connection between the working environment and the development of the condition;
- the condition may seriously endanger the health or safety of the applicant or employee; and
- the danger cannot be eliminated or significantly reduced by reasonable measures taken by the employer to reduce the environmental risks.

**Proposal 29–2** The National Occupational Health and Safety Commission (NOHSC), in consultation with the proposed HGCA, should develop model regulations regarding genetic screening for susceptibility to work-related conditions. The model regulations should:
- specify the genetic tests that have been approved for use;
- provide guidelines for interpreting test results;
- indicate the circumstances in which family medical history may be collected and used;
- make provision for genetic counselling for those undergoing screening;
- provide for the confidentiality of test results; and
- indicate appropriate responses by employers where genetic screening reveals relevant susceptibilities.

**ADB's position**
Generally, this proposal is supported, subject to following issues. We note the Inquiry states that screening should only be conducted on a voluntary basis. In our view, it is important that Proposal 29-1 specifically state that employers may only conduct tests with the informed consent of applicants or employees.

Secondly, there is a need to distinguish between the situation of applicant, compared with existing employees. In order to ensure that tests are only carried out where absolutely necessary, we consider that the proposal should reflect the fact that employers should only seek to determine any susceptibility of the applicant once the employer has selected their preferred candidate. This will ensure that employers will not test all applicants or some applicants and reject any applicants where there may be any prospect of susceptibility.

If the latter approach is taken, then it is often more difficult to establish that the test result was the reason that a particular applicant was not selected and hence the employers discriminatory use of the information is harder to prove.

We refer you to the analogous examples which emerged form the ADB's Enquiry into hepatitis C related discrimination in our submission (see section 3.3.7). For example, two major areas of concern were raised in the Enquiry were mandatory requirements for applicants to have a blood test or disclose their hepatitis C status, and the inappropriate use of pre-employment medical assessments to ‘screen out’ prospective employees who have hepatitis C.

Finally, we want to emphasise the need for effective education for employers in the industries that are more likely to seek to undertake such testing. It is vital that employers understand the information the tests provide, including the reliability of the tests in determining a predisposition, the certainty or otherwise of the onset of the condition, likely symptoms, whether the condition can be treated, and the differences between diagnostic, predictive and carrier testing.

### *Genetic monitoring for workplace induced diseases*

**Proposal 29–3** Genetic monitoring of employees should be conducted only where:

- there is strong evidence of a clear connection between the working environment and the development of the condition;
- the condition may seriously endanger the health or safety of the employee; and
- the danger cannot be eliminated or significantly reduced by reasonable measures taken by the employer to reduce the environmental risks.

**Proposal 29–4** NOHSC, in consultation with the proposed HGCA, should develop model regulations for the conduct of genetic monitoring of employees exposed to hazardous substances in the workplace.

**ADB’s position**
Generally, this proposal is supported, subject to the issues we raise above relating to informed consent and employer education (see our position in relation to proposal 29-1 above.)

### *Genetic screening for protection of third party safety*

**Proposal 29–5** Genetic information should be collected from an applicant or employee and used for the protection of third party safety only where:

- the applicant or employee’s condition poses a real risk of serious danger to the health or safety of third parties; and
- the danger cannot be eliminated or significantly reduced by other reasonable measures taken by the employer to eliminate or reduce the risks.

**Proposal 29–6** NOHSC, in consultation with the proposed HGCA, should develop model regulations with respect to the collection and use of genetic information from applicants and employees for the protection of third party safety. (See also Proposal 29–2).

**ADB’s position**
Generally, this proposal is supported, subject to the issues we raise above in relating proposal 29-1.

# Annexure - ADB recommendations

**Recommendation 1**
That there is uniformity of federal, State and Territory anti-discrimination legislation in relation to providing protection against genetic discrimination.

**Recommendation 2**
That protection against genetic discrimination be retained within the framework of existing anti-discrimination legislation.

**Recommendation 3**
That the definition of disability in the DDA and all State/Territory anti-discrimination legislation be amended to make clear that 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.

**Recommendation 4**
That all State and Territory anti-discrimination legislation provide coverage where a person is discriminated against because their associate has a disability or may develop a disability in future.

**Recommendation 5**
That the DDA and indirect tests within State/Territory anti-discrimination laws which contain the proportionality test, are amended in line with the indirect test in s.5 of the SDA.

**Recommendation 6**
That the DDA and relevant State and Territory anti-discrimination are amended to prohibit a person from requesting or requiring another person to supply information upon which unlawful discrimination might be based, unless the person can prove that the information was reasonably required for a purpose that did not involve discrimination. The provision should be modelled on s.26 of the *Anti-Discrimination Act 1992* (NT).

**Recommendation 7**
That anti-discrimination agencies are adequately funded to enable provision of timely complaints investigation and conciliation and education programs to inform and educate people likely to be affected by genetic discrimination, employers and service providers about their rights and responsibilities under anti-discrimination law and undertake educational activities designed to prevent such discrimination.

**Recommendation 8**
That the DDA and State and Territory anti-discrimination legislation is amended to make clear that an employer is not entitled to assess an individual's ability to comply with the inherent requirements of a particular position in the future.

**Recommendation 9**
That the WRA is amended to make explicit that the term 'disability' in the WRA be interpreted by reference to the DDA.

**Recommendation 10**
That the provision recommended above (recommendation 6) make explicit that such unlawful conduct *includes:*

- requesting or using information relating to a person's genetic make up, hepatitis C or HIV/AIDS status or
- requesting a person to undergo genetic testing or testing to determine a person's hepatitis C or HIV/AIDS status.

That consideration should also be given to what other disabilities should be included in a non-exhaustive list.

**Recommendation 11**
Employers may require genetic testing of employees where:

- the particular positions involve significant safety risks to the public which cannot be eliminated other than by being aware of a person's condition or predisposition; and
- testing is limited to conditions which would effect a person's capacity to carry out the inherent requirements of the particular job.

**Recommendation 12**
Employers may require genetic testing of employees where:

- the particular positions involve risks to the employee or other employees which cannot be eliminated other than by being aware of a person's condition or predisposition; and
- testing is limited to conditions which would effect a person's capacity to carry out the inherent requirements of the particular job.

Employers may undertake genetic monitoring of employees to reduce the risk of employees developing a disorder as a result of environmental cause, only with the informed consent of employees in writing.

**Recommendation 13**
That consideration should be given to whether a statutory authority should be established, or an existing agency should have responsibility for overseeing employment related testing, not limited to genetic testing, including effective implementation of the National Genetic Testing Code of Practice recommended in this submission ( recommendation 14).

**Recommendation 14**
We recommend that a comprehensive national genetic testing code of practice is developed and effectively implemented as outlined in this submission.

**Recommendation 15**
That an independent body be established to evaluate the scientific reliability and actuarial relevance of:

- genetic information proposed for use by the insurance industry before genetic information is used for underwriting; and
- non-genetic information whether used or proposed for use by the insurance industry for underwriting.

**Recommendation 16**
That the independent body (recommendation 15), in conjunction with the insurance industry, also undertake educational activities to ensure that agents, brokers and other significant participants in the insurance industry understand:

- what genetic information has been approved for use in underwriting;
- the different types and implications of genetic information generally; and

- the national genetic testing code of practice (recommendation 14).

**Recommendation 17**
That consumers should have the right to access adequate information about basis for the insurers decision and the actuarial or statistical evidence on which the insurer has relied in making their decisions. This right to access should be reflected in the national genetic testing code of practice and enshrined in legislation. (see recommendation 14)

**Recommendation 18**
That national genetic testing code of practice include guidelines which will enable people to make informed decisions about whether to undergo testing. The guidelines should ensure people are provided with accurate information about their rights under anti-discrimination and privacy legislation and their obligations, if any, regarding disclosure of the information obtained through genetic testing.

**Recommendation 19**
The DDA and State and Territory anti-discrimination be amended such that it will not be unlawful for a person to discriminate against another person, on the ground of the other person's disability, by refusing to offer the other person insurance if:

- the discrimination is based upon actuarial or statistical data on which it is reasonable for the first-mentioned person to rely; or
- in the case of a genetic condition, the discrimination is based upon actuarial or statistical data which has been approved for use in underwriting by the relevant independent body.

**Recommendation 20**
That DDA and State and Territory anti-discrimination laws are amended, where necessary, to provide the President/Commissioner with the power to order a party or non-party to produce documents, including actuarial or statistical data and the information upon which that data is based, in the course of investigation of a complaint.

**Recommendation 21**
That consideration is given to whether the existing review and appeal mechanisms in the *Migration Act 1958* are adequate to enable applicants to challenge decisions which are based on scientifically unreliable data or misinterpretation of genetic and non genetic health information.

**Recommendation 22**
That people's rights and responsibilities in relation to genetic testing and requests for genetic information under the *Migration Act* should be included in the proposed national genetic testing code of practice.