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Review of the *Disability Discrimination Act* 1992

Comment on the Draft Report

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Presentation of statistical detail in the Draft Report

The level of analytic detail in the draft report:

Table 3.1, p.35 describes the types of disability by restriction. 76% of people with a mental disability are restricted by core disabilities. The lower representation in the non-core category is no doubt due to the age of onset of many severe mental disabilities where the greater onset occurs in late adolescence and early adulthood; that is following the school years. It may be useful therefore to depict this table in two parts; that is, one as already depicted and a second by age. This would enable a better understanding of the differentiation in disability categories.

The table demonstrates the significance of mental illness as one of the highest contributors to disability in this country. Despite mental illness being one of the most disabling conditions, services provided through disability funds at state level often exclude people with a mental illness. Further, mental health funds remain biased toward the provision of services considered part of a medical model; that is, acute services provided in hospitals. Services provided to enhance the social model of service delivery, that is, community-based services, employment and accommodation options remain grossly under-funded within most disability types and particularly by people with a mental illness. Considering the high representation of people with a mental disability among the unemployed and homeless and the contemporary service orientation toward services in the least restrictive environment; this deficit results in inequities in service provision. While it is acknowledged that some service rationing occurs this should not disadvantage any one particular disability group over any other.

Discrimination in service provision:

The major reforms in disability services in the past two decades have not included mental disability and whole services have developed which excluded people with a mental illness. For example HACC services while focusing on 'the frail aged, younger disabled and their carers' actively excluded [and in some jurisdictions continues to exclude] people with a mental illness. The supposed rationale for the exclusion is that mental illness is a [medical] diagnostic grouping excluded under HACC policy. I believe this policy interpretation is discriminatory. Mental illness has multiple sub-categories that do fall under the classification as a diagnostic group according to the International Classification of Diseases Version 10 or the DSM 1V. However 'mental illness' is a classification of people categorized according to the location of the affect within the body - such as 'spinal injuries' describes a class of people according to the location of the affect within the body.

We concur with the comments by Robert and Pauline Atkins on p. 35 that services to and programs for different forms of disability require different solutions. Contemporary research into severe mental illness recommends a recovery/rehabilitation model of service orientation. Such a service model may not be suitable for people with physical or sensory disabilities. Alternately services focusing on sensory training, for example, are not suitable for other forms of disabilities.

Increasing legislative protections:

Protection from vilification:

A further requirement that relates to people with a mental illness and other disability groups is legislative protection from stigma. Mental illness has long been the butt of jokes, poor media presentation and marginalisation by society. I note that p. 57 of the report gives examples of harassment which is defined in the Racial Discrimination Act 1975 and the Racial Hatred Act 1995 as vilification and is unlawful according to those Acts. It is timely during this review of the Disability Discrimination Act that serious consideration be given to legislative protections against vilification being offered to people with psychiatric and other disabilities. While I note that several submissions have suggested a public awareness campaign [p.235] I maintain that this approach falls short for a number of reasons. The Mental Health Branch developed guidelines for media reporting of matters relating to people with a mental illness some time ago. These guidelines have gone some way to improving media reporting – however not all media complies with the guidelines. Further stigmatisation extends beyond representation within the media, advertising agencies continue to present negative images of people with a mental illness which perpetuate stigma and the myths surrounding mental illness. A legislative imperative to present accurate and non-stigmatising information and images about psychiatric disability would give some redress to vilification of people with disabilities. While the current Act contains 9 areas of specific activity where it is unlawful to discriminate, there is also a need to include vilification as an unlawful activity in relation to people with disabilities.

Protection from the use of genetic information to discriminate:

Genetic research into disabilities is a growing field as technologies improve and the potential for improved approaches to diminish the effects of disability become apparent. While wanting to protect the benefits arising from such research it is vital to protect the privacy and confidentiality of genetic information about individuals and families. The NHMRC published an Information Paper on the Ethical Aspects of Genetic Testing. In that paper they comment that:

Concern about the possibility of stigmatisation or discrimination could discourage a person from taking advantage of the medical benefits of obtaining genetic information, with consequent adverse effects on his/her health. This could have effects for current and future family members as well as for the individual. The chance that this outcome will occur **can be minimised if there is legislation to prevent unfair discrimination** based on the results of genetic testing, and if the community is educated about the potential benefits of genetic testing and has factual information about the circumstances in which it is necessary for test results to be revealed.¹

[emphasis added].

¹ NHMRC [2000] Ethical Aspects of Human Genetic Testing: an Information Paper

Legislation covering genetic information should address: the multiple facets involved in genetic testing including the collection, storage, use and release of such information. Further comment made by the Federal Privacy Commissioner in a submission to the Joint Inquiry into the Protection of Human Genetic Information stated :

...In the interests of consistent and coherent regulation of information privacy, the abuses or misuses of that information need to be regulated, rather than the sources of that information...²

One of the potential areas for abuse is in the employment sector. The Commonwealth Government specifically supports privacy legislation for employee records. There is a gap in the legislation however in regard to the coverage of health information in the form of small business exemption under section 6C of the *Privacy Act 1988*. Genetic information is considered a sub-set of health information. Sensitive information, which may include health information, held by small businesses would fall outside the protection of the private sector provisions.³ This is an area of great concern particularly with a group that is already so disadvantaged in employment options.

A further area for potential abuse is in the insurance sector. Financial institutions are not infrequently making it a mandatory condition that access to their services includes an individual's information. If such conditions expand in future to require genetic information as well then this information has the potential to determine the degree of risk to the insurer which would result in further discriminatory practices in insurance coverage for people with disabilities.

Yet again implications for the development of pharmacogenetics, that is, the refinement of the design of pharmaceutical drugs so that they will be effective in populations defined by identifiable genetic conditions, raises the risk of abuse of such information. Since the development of such pharmaceuticals will involve the use of private sector finance rather than government finance many of the current impediments to abuse will be removed. For example the current NHMRC *National Statement of the Ethical Conduct in Research involving Humans* does not mandate compliance from the private sector.

The above examples of the risk of abuse of genetic information will be driven by the commercial interests of the market place which has a history of failing to apply sufficient self-regulatory frameworks to address the protection of human rights, privacy and confidentiality matters in society. The counter to abuse is a legislative framework that ensures the protection of the individual.

² submission from the Federal Privacy Commissioner to the Australian Law Reform Commission/Australian Health Ethics Committee's *Joint Inquiry into the Protection of Human Genetic Information*. P.21

³ *ibid.* p. 21-22.