Disability Discrimination Act Inquiry Productivity Commission Locked Bag 2, Collins St East Melbourne 8003



Re: Review of the Disability Discrimination Act 1992—draft report

Dear Sir/Madam

The Australian Institute of Health and Welfare (AIHW) made a submission to the Inquiry into the *Disability Discrimination Act 1992* in July 2003, and welcomes the opportunity to make a further submission on the draft report *Review of the Disability Discrimination Act 1992*.

In its first submission, the AIHW drew the Commissioners' attention to the World Health Organization's International Classification of Functioning, Disability and Health (ICF) as a basis for reviewing definitional material in the DDA. While the draft report recommends that changes be made to the DDA to clarify definitions, key terms and definitions in the draft report are not consistent with the ICF. The report refers to the WHO's International Classification of Impairments, Disabilities and Handicaps (ICIDH), the predecessor of the ICF and no longer a current or endorsed source of definitions. Reference is also made to the ABS survey-related definitions. While the ABS surveys to 1998 have operationalised the ICIDH definitions, the ABS is understood to be moving, as is its practice, to the current international standard, i.e. the ICF.

The attachment to this letter details ten recommended changes aimed at improving the consistency of the draft report, and ultimately the DDA, with the ICF, and also correcting some errors in the draft report.

I strongly urge the Commissioners to revisit the definitional issues addressed in the draft report with a view to achieving consistency with the ICF as the major, internationally endorsed framework relating to disability. I hope that the attached material will provide some assistance with this, and my staff and I would be happy to provide further advice as needed.

Please do not hesitate to contact me if we can be of any further assistance.

Yours sincerely,

Richard Madden Director, Australian Institute of Health and Welfare 23 December 2003 For health and welfare statistics and information

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# AIHW recommended changes to the draft report 'Review of the *Disability Discrimination Act* 1992'

This attachment first sets out in summary the changes recommended by AIHW. Below, some background information on the ICF is given; then each of the recommended changes is explained in more detail.

# **Changes recommended by AIHW:**

**AIHW Rec. 1.** Several terms and definitions in the glossary of the draft report are outdated and should be revised to be consistent with the ICF; definitions of terms should be consistent throughout the draft report.

**AIHW Rec. 2.** At the start of Ch 3 it should be stated that one of the main objectives of the 1998 ABS Survey of Disability, Ageing and Carers (SDAC) was to measure the prevalence of disability in Australia and consequent need for assistance.

**AIHW Rec. 3.** The discussion of the DDA definition of disability (p.32) should state that the current definition is based on an unstructured mix of impairments, diseases and disorders, and should cite the actual definition.

**AIHW Rec. 4.** The text in Box 3.1 should be revised; currently it is misleading because it implies that only people with limitations related to specific conditions were captured by the SDAC.

**AIHW Rec. 5.** Figure 3.1 should be replaced by Figure 1 (below), which is based on the ICF framework.

**AIHW Rec. 6.** Figure 3.2 should be replaced by Figure 2 (below), which uses disability groups that are consistent with the National Community Services Data Dictionary V3.

**AIHW Rec. 7.** The section on 'incidence of disability' (p.36) should be titled 'prevalence of disability'. Section 3.2 should be titled 'trends in the prevalence of disability'. Related text and table headings should be amended accordingly.

**AIHW Rec. 8.** The HILDA survey should not be used for analysing trends in disability prevalence. SDAC data only should be used.

**AIHW Rec. 9.** It is the AIHW's view that it is possible to develop definitions of disability and discrimination based on and consistent with the ICF that will be practical in the context of the DDA. Draft finding 9.2 should be revised to remove the statement that 'A definition of disability based on the social model is not practical'. The draft report should recognise how the DDA definitions of disability and discrimination, and the DDA objects, fit very well within the ICF framework, which is based on an integration of the medical and social models of disability (or, as WHO puts it, represents a biopsychosocial model of disability).

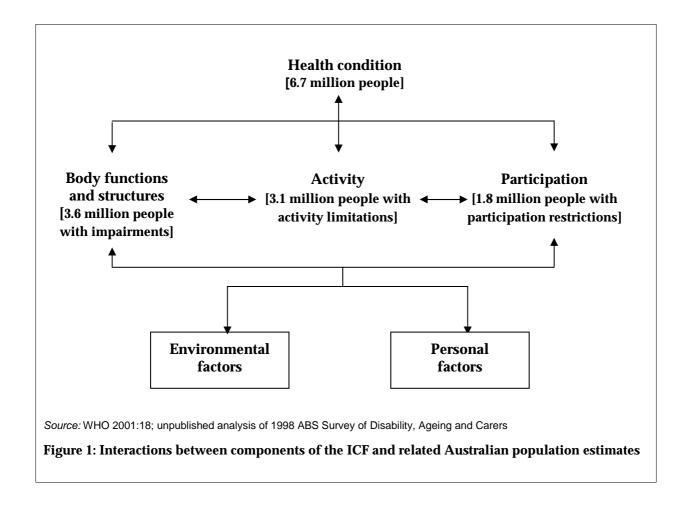
#### **Background information on the ICF**

The International Classification of Functioning, Disability and Health (ICF) defines functioning and disability as multi-dimensional concepts, relating to:

- the body functions and structures of people;
- the activities they do and the life areas in which they participate;
- the factors in their environment which affect these experiences.

Each of these components is defined in the context of a health condition. Disability is the umbrella term for any or all of: an impairment of body structure or function, a limitation in activities, or a restriction in participation.

In the ICF, a person's functioning or disability is conceived as a dynamic interaction between health conditions and environmental and personal factors (WHO 2001:8) (see Figure 1). The AIHW has conducted special analyses to place population estimates against the ICF components.



The following are definitions of the components:

- **Body functions** are the physiological functions of body systems (including psychological functions).
- **Body structures** are anatomical parts of the body such as organs, limbs and their components.
- *Impairments* are problems in body function and structure such as significant deviation or loss.
- Activity is the execution of a task or action by an individual.
- *Participation* is involvement in a life situation.
- Activity limitations are difficulties an individual may have in executing activities.

- **Participation restrictions** are problems an individual may experience in involvement in life situations.
- **Environmental factors** make up the physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning.
- *Disability* is the umbrella term for any or all of: an impairment of body structure or function, a limitation in activities, or a restriction in participation.

Based on analysis of the ABS Survey of Disability, Ageing and Carers, in 1998 (Figure 1):

- 6.7 million Australians had a long term health condition (lasting 6 months or more);
- 3.6 million had an impairment;
- 3.1 million had an activity limitation (in the areas of self-care, mobility, communication, health care, housework, property maintenance, paperwork, meal preparation, transport and guidance);
- 1.8 million had a participation restriction (schooling, employment, social and community participation).

The ICF is an internationally endorsed framework and classification, and its use has been encouraged by the World Health Assembly. It is currently being actively implemented in Australia, in a wide range of applications (see AIHW 2003a, Section 10). In particular, while the 1998 ABS Survey of Disability, Ageing and Carers (SDAC) drew on definitions from the ICIDH (the predecessor of the ICF), the ABS has designed its 2003 Survey to be consistent with the ICF framework. The Survey operationalisation of disability concepts should not be confused with underlying WHO-endorsed definitions and classifications.

The Review of the DDA provides a valuable opportunity to bring key terms and definitions of the DDA into harmony with the ICF, in the interests of promoting a standardised and coherent approach to disability, within Australian and internationally.

Further information on the ICF can be accessed via the following links:

<u>http://www3.who.int/icf/icftemplate.cfm</u> (ICF information on the WHO website) <u>http://www.aihw.gov.au/disability/icf/index.html</u> (ICF Australian User Guide)

#### Recommended changes explained in detail

### Glossary of the draft report

**AIHW Rec. 1**. Several of the terms and definitions in the glossary (page XXI) and Box 2.1 (page 12) are based on the old WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH), which was replaced in 2001 by the ICF. In particular, the term 'handicap' is generally no longer used in the disability field in Australia and is viewed as unacceptable by many in the field, due to its pejorative connotations. The  $\underline{\text{AIHW}}$  recommends that:

- the ICF definitions of disability and impairment given above should be used in preference to those currently in the glossary and Box 2.1;
- the term 'activity restriction' should be replaced by 'activity limitation' (as defined above);
- the term 'handicap' should be replaced by 'participation restriction' (as defined above).

The definition of disability in the glossary differs from that given in Box 2.1. Definitions of terms should be consistent throughout the report.

## Chapter 3. Disability in Australia

**AIHW Rec. 2.** It should be stated that the one of the main objectives of the 1998 SDAC was to measure the prevalence of disability in Australia and consequent need for assistance (paragraph 1 or 3 on p.31 would be an appropriate place to state this).

**AIHW Rec. 3**. The description of the DDA definition of disability is misleading (bottom para, p.32). The definition does not explicitly cover the four broad types of disability referred to (i.e. physical, disease related, intellectual and mental); rather, it includes an unstructured mix of impairments, diseases and disorders. The discussion of the DDA definition of disability should state this, and should cite the actual definition:

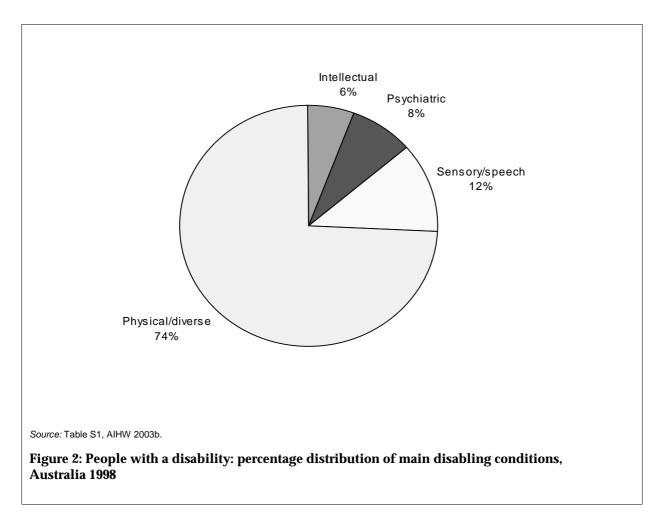
"disability", in relation to a person, means:

- (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.

**AIHW Rec. 4**. The text in Box 3.1 is misleading. It implies that only people with limitations related to specific conditions were captured by the SDAC. In fact, some of the screening questions for the 1998 SDAC were quite broad, for example, 'any other long-term condition that restricts everyday activities'. (It is true that the SDAC definition of disability is narrower than the current DDA definition in that it only includes current disabilities that have lasted, or are likely to last for six months or more.)

**AIHW Rec. 5**. Figure 3.1 should be replaced by Figure 1, above, which presents prevalence estimates of health conditions, impairments, activity limitations and participation restrictions based on the 1998 SDAC and in the framework of the ICF dynamic model of disability.

**AIHW Rec. 6**. The disability groups used in Figure 3.2 (page 34) are not consistent with the National Community Services Data Dictionary (NCSDD) V3 data item 'disability grouping' (AIHW 2004). Figure 2, below, is suggested to replace Figure 3.2 in the draft report. It shows the percentage distribution of main disabling conditions among people with a disability for the disability groups intellectual, psychiatric, sensory/speech, and physical/diverse; this grouping is consistent with the NCSDD V3. The percentages are based on AIHW's analysis of the 1998 SDAC, based on reported 'main disabling condition' (see AIHW 2003b for further information).



**AIHW Rec. 7**. The section on 'incidence of disability' (p.36) should be titled 'prevalence of disability'. 'Incidence' is the number of new cases of a condition diagnosed or reported during a specified time period (usually one year). 'Prevalence' is the total number of cases of a condition within a population at a given point in time. The data presented in this section are prevalence data. Similarly, Section 3.2 should be titled 'trends in the prevalence of disability' and table headings should be amended accordingly.

**AIHW Rec. 8**. The HILDA survey should not be used for analysing trends in disability prevalence.

Projections of disability rates between 1998 and 2001 (Table 3.5) should be based only on data from the ABS disability surveys, which are specifically designed to collect comprehensive

information about disability in the Australian population. Data on disability collected in the ABS disability surveys tend to be more comprehensive, and thus result in higher prevalence estimates, than those collected in other ABS surveys. The HILDA survey is not comparable with the ABS disability surveys in terms of survey coverage and definitions of disability. The exclusion of children aged under 15 years and people living in institutions in the HILDA survey could result in an underestimation of disability prevalence. Therefore it should not be used to generate disability prevalence estimates to compare with those of the ABS disability surveys.

### **Chapter 9. Defining discrimination**

**AIHW Rec. 9**. The AIHW does not agree with the statement that a definition of disability based on the 'social model' is not practical and it is therefore appropriate that the DDA definition of disability is a medically-based definition (Draft finding 9.2).

The ICF is based on an integration of the medical and social models, to provide a coherent view of functioning and disability from a biological, individual and social perspective. The usefulness of the ICF as a foundation for the development of anti-discrimination legislation is strongly argued by Bickenbach et al. (forthcoming). Because the ICF recognises the central role of environmental factors in creating disability, rather than viewing disability as intrinsic to the individual, it 'justifies anti-discrimination law and policy by identifying society as responsible for the disadvantage associated with impairments'.

It is the AIHW's view that it is possible to develop definitions of disability and discrimination based on and consistent with the ICF that will be practical in the context of the DDA.

One approach would be to retain the content of the current definitions, but to explicitly present the definitions in the context of the ICF framework. In this way, the DDA could retain its current impairment-based definition of disability, but could adopt ICF language as follows:

"disability", in relation to a person, means problems in body function or structure such as significant deviation or loss, and includes: ...(points (a) to (g) in current definition)

The current DDA definition of discrimination relates to how the 'discriminator' treats a person with a disability. In the context of the ICF framework, discrimination so defined fits within the 'environmental factors' component—that is, discrimination is viewed as an environmental barrier which may affect a person's activities and participation.

The objects of the DDA talk about elimination of discrimination on the grounds of disability in a range of areas that, in the context of the ICF framework, relate to areas of activity and participation.

Even if the ICF is not explicitly mentioned in the DDA itself, it will be important that the report of the review process states that the general approach of the Act and, in particular, its definitions, are in harmony with the ICF framework. This may guide future interpretation of the Act. In the recent High Court decision in Purvis v NSW, Justices McHugh and Kirby noted that, when the Act was drafted, the most widely accepted disability classification scheme was the ICIDH, and that the DDA definition of disability incorporates the key terminology of the ICIDH. They thus looked to the conceptual framework of the ICIDH in interpreting the Act.

Thus, the AIHW recommends that the draft report should recognise that the DDA definitions of disability and discrimination, and indeed the DDA objects, fit within the ICF framework, which is based on an integration of the medical and social models of disability.

#### References

AIHW 2003a. Australian ICF user guide version 1.0. AIHW Cat. No. DIS 33. Canberra: AIHW.

AIHW 2003b. Disability prevalence and trends. AIHW Cat. No. DIS 34. Canberra: AIHW.

AIHW 2004. National community services data dictionary. Version 3. Canberra: AIHW.

Bickenbach J, Gray D, Madden R, Walsh J & Bricknell S (forthcoming). ICF and disability policy outside the domain of health. Social Science and Medicine.

WHO (World Health Organisation) 2001. International classification of functioning, disability and health. Geneva: WHO.