

# DISABILITY DATA BRIEFING

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The Institute is an independent health and welfare statistics and information agency established under Commonwealth legislation. The Institute is working to improve the collection and analysis of national data in the disability field. These briefings provide data and share information about national data developments with people in the field.

## History of the International Classification of Functioning, Disability and Health (ICF)

This data briefing provides information on some seven years of work by the Institute, as the Australian Collaborating Centre, participating with other World Health Organization (WHO) Collaborating Centres in the preparation of the ICF. It provides an historical complement to Data Briefing No. 20, which outlines the broad features of the ICF.

The AIHW gratefully acknowledges the advice received during these years from its Disability Data Reference and Advisory Group, and the hundreds of people who participated in discussion and tests.

### ICF history—the ICIDH and its redevelopment

The predecessor of the ICF was the ICIDH (International Classification of Impairments, Disabilities and Handicaps) which was originally proposed to describe the effects of chronic conditions such as arthritis and the long-term effects of rehabilitation. In 1980 the ICIDH was published by the WHO, as a 'manual of classification relating to the consequences of disease' (and injuries and other 'disorders') and as a 'conceptual framework for information'.

Since its release, a number of review articles described the potential applications and uses of the ICIDH, including:

- conceptual development in interdisciplinary fields related to disability;
- medical and rehabilitation monitoring systems;
- survey research;
- database development;
- clinical diagnosis and rehabilitation assessment; and
- program evaluation.

By 1994 the ICIDH had been translated into 13 languages. However, some criticism was levelled at the ICIDH, in particular from people with disabilities and many professionals who were critical of the inadequate recognition given to the role of the environment in the creation of disability. Seven years of revision and testing ensued.

A summary of the ICF revision process, focusing on the contribution made by the Australian Collaborating Centre, is outlined in the following table.

**Table 1: ICIDH revision and the Australian role (italicised text refers to relevant reports, which can be accessed from the web version of this Data Briefing)**

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| <p><b>1994</b></p>    | <p>AIHW hosts a workshop on 'measurement of disability' and is subsequently invited to extend its Terms of Reference as a WHO Collaborating Centre to include ICIDH revision.</p> <p>In November, AIHW attends its first ICIDH revision meeting and is asked to take an interest in Participation and Environment.</p>  |
| <p><b>1995</b></p>    | <p>AIHW reports to WHO on work to establish the Disability Data Reference and Advisory Group (DDRAG). A paper is presented on applications in Australia.</p> <p style="text-align: right;"><i>Annual ACC Report to WHO 1995</i></p>   |
| <p><b>1996</b></p>    | <p>AIHW comments on alpha draft and WHO '15 issues', advised by DDRAG.</p> <p style="text-align: right;"><i>AIHW comments on Alpha and WHO '15 issues'</i></p>  |
| <p><b>1997–98</b></p> | <p><b>Beta 1 draft is published.</b></p> <p>AIHW attends meetings and:</p> <ul style="list-style-type: none"> <li>• provides comments to WHO on pre-publication drafts; <p style="text-align: right;"><i>Annual ACC report to WHO 1997</i></p> </li> <li>• publishes discussion paper on definition of disability and the need for consistency, to obtain wide comment on these, in the context of the Beta 1 draft; DDRAG makes significant contribution to this paper and national discussions; <p style="text-align: right;"><i>The definition of disability in Australia</i></p> </li> <li>• negotiates resources from DHFS to support three Beta tests (relating to intellectual and other disability, and disability concepts in Aboriginal communities); <p style="text-align: right;"><i>Testing ICIDH-2 with Indigenous Australians</i><br/><i>Testing ICIDH-2 with people with intellectual disabilities</i><br/><i>Testing the ICIDH-2 Participation domain and Option 15a</i><br/><i>ACC consensus conference on ICIDH 12 basic questions</i></p> </li> <li>• works on Participation qualifiers, as vital to the application of the 'neutral' classification. <p style="text-align: right;"><i>Testing ICIDH-2 Participation qualifiers</i></p> </li> </ul> <p>On the basis of extensive testing and discussion, AIHW reports to WHO several times during the year.</p> <p>AIHW September 1998 report on Beta 1 testing:</p> <p><b>Key findings of March 1998—still applicable to ICIDH revision</b></p> <p>The draft ICIDH-2 is a useful, integrating conceptual framework and represents an improvement on ICIDH-1.</p> <p>The draft ICIDH-2 could provide a framework for the reliable data collections in Australia.</p> <p>'Personal factors', while important, should not be included as contextual factors.</p> <p>The word 'disability' is entrenched in Australian terminology and legislation and is unlikely to be replaced by 'disablement' except as a more theoretical word to denote the process of becoming disabled.</p> <p><b>Key findings of March which have since developed further on the basis of Beta testing</b></p> <p>Editorial effort is needed to:</p> <ul style="list-style-type: none"> <li>• clarify the purpose of the classification, and its location in relation to health and other WHO classifications, and to the UN Standard Rules on the Equalisation of Opportunity;</li> <li>• remove perceived overlap between P and A;</li> <li>• improve the structure of P domains.</li> </ul> |

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|                    | <p>Developmental work is needed to:</p> <ul style="list-style-type: none"> <li>clarify the uses of ICIDH-2, and its relation to assessment tools; the ICIDH-2 provides an integrating framework within which assessment tools can be developed or mapped or evaluated.</li> </ul> <p>While further work has now been done on the development of Participation qualifiers, more work is needed to ensure that:</p> <ul style="list-style-type: none"> <li>the importance of the role of the individual in the classification process is recognised (whatever the outcome of Option 15a testing);</li> <li>in relation to the role of 'choice' in Participation, there is clarification on how to approach the classification when choice itself is limited by social attitudes; and</li> <li>the Participation qualifiers are made more useable in practice.</li> </ul> <p>A final AIHW report to WHO in December 1998 confirms these main issues.</p> <p style="text-align: right;"><i>ACC report to WHO 1998</i></p>  |
| <p><b>1999</b></p> | <p>AIHW participates vigorously in the lead up to finalising a 'Beta 2 draft'.<br/>Recommendations to WHO and revision meeting:</p> <p style="text-align: right;"><i>Annual ACC report to WHO 1999</i></p> <ol style="list-style-type: none"> <li>The final position of the Australian Collaborating Centre on the Beta-2 draft will depend on our satisfaction with our three main areas of concern: the Introduction, the Participation/Activity overlap, and the qualifiers.</li> <li>Activity qualifiers should preserve the key concepts of 'difficulty' and 'assistance'.</li> <li>We recommend adoption of the Australian proposals for Participation qualifiers, namely <ul style="list-style-type: none"> <li>Extent of participation (<i>in relation to the person's goals</i>)—essentially Option 15a; and</li> <li>Extent of participation (<i>external rating or comparisons to statistical averages</i>)—essentially the 1997 Beta draft qualifier.</li> </ul> </li> <li>We support the Environment facilitator/barrier qualifier proposed by the E Task Force.</li> <li>None of the tests currently proposed for Beta-2 testing should be made 'compulsory'.</li> <li>The involvement of people with disabilities in Beta-2 testing is essential.</li> <li>The present 'clinical' emphasis of the proposed tests is inadequate and unsatisfactory.</li> <li>Our suggestions for other tests (above) should be included in the package of possible tests.</li> </ol> <p>Various proposals for resolving the perceived overlap of Activity and Participation are put forward by various Centres.</p> <p>AIHW conducts conference on health and related classifications and a paper on the ICIDH is presented.</p> <p style="text-align: center;"><i>ICIDH paper for AIHW health and related classifications conference</i></p> <p>A paper is presented at the North American Collaborating Centre Meeting on potential users of ICIDH in Australia.</p> <p style="text-align: center;"><i>Potential use of ICIDH-2 in Australia (paper for NACC 1999 meeting)</i></p> <p><b>Beta 2 draft published in mid 1999:</b></p> <p>In terms of its contents, the AIHW probably had most success with the main schematic diagram and the E qualifiers which owe their origin to work we did on the P qualifiers. A number of detailed comments and contributions had an effect, combined with similar comments from other centres.</p> <p>AIHW makes plans for Beta-2 testing using WHO protocols.</p> |

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| <p><b>2000</b></p> | <p>Beta-2 testing starts.</p> <p>AIHW reports to WHO interim meeting in June on ICIDH Beta testing conducted so far and suggested changes to the classification. (This is essentially the final Australian report, with a subsequent final report on Study 3 testing submitted separately.)</p> <p style="text-align: right;"><i>Annual ACC report to WHO 2000</i></p> <p>In May 2000 WHO circulates a paper on 'ICIDH-2 development options', outlining new issues to be addressed in final draft, e.g. health and health status measurement, leading to new concepts and qualifiers. Debate among Collaborating Centres ensues.</p> <p style="text-align: right;"><i>Comments on 2000 ICIDH development options</i></p> <p><b>In October WHO releases a new 'pre-final' draft</b></p> <p>After Australian intervention at a meeting on health status measurement in Ottawa in October, Collaborating Centres and WHO begin to work on a compromise to preserve the best of the Beta 2 and the WHO proposal.</p> <p style="text-align: right;"><i>Collaborating Centres response to ICIDH-2 pre-final draft</i></p> <p>Final revision meeting held in November in Madrid. Several centres (Netherlands, US, Canada, UK and Australia) propose a 'compromise' which is further developed in out-of-session meetings.</p> <p style="text-align: right;"><i>ACC presentation at final ICIDH revision meeting</i></p>  |
| <p><b>2001</b></p> | <p><b>The World Health Assembly officially endorses the International Classification of Functioning, Disability and Health and the acronym ICF in May 2001:</b></p> <p>The Fifty-fourth World Health Assembly,</p> <ul style="list-style-type: none"> <li>(1) ENDORSES the second edition of the 'International Classification of Functioning, Disability and Health' (ICF).</li> <li>(2) URGES Member States to utilize the ICF in their research, surveillance and reporting as appropriate, taking into account specific situations in Member States, and, in particular, in view of potential future revisions;</li> <li>(3) REQUESTS the Director General to assist Member States, on request, to make use of ICF.</li> </ul> <p>A UN seminar on measurement of disability is held in New York in June. An Australian paper is given on ICF implementation issues.</p> <p style="text-align: right;"><i>UN conference on measurement of disability: Australian paper</i></p> <p>The first meeting of the Collaborating Centres for WHO Family of International Classifications is hosted by the North American Collaborating Centre in Bethesda.</p> <p style="text-align: right;"><i>www.who.int/whosis/bethesda</i></p> <p>Australian papers presented at Bethesda are:</p> <ol style="list-style-type: none"> <li>1. <i>Bethesda.09.doc: Annual report of the Australian Collaborating Centre</i></li> <li>2. <i>Bethesda.55.doc: Implications for ICD of the ICF</i></li> <li>3. <i>Bethesda.58.doc: Possible application of International Classification of Functioning, Disability and Health in Rehabilitation</i></li> <li>4. <i>Bethesda.60.doc: ICF Australian User Guide—An outline for discussion</i></li> <li>5. <i>Bethesda.61.doc: National information agreements, data dictionaries and quality health and welfare data</i></li> </ol> <p><b>The Australian launch of the ICF is held in Canberra in December 2001.</b></p> <p style="text-align: right;"><i>www.aihw.gov.au/conferences/icf2001/index.html</i></p> |

An on-line version of this Data Briefing, and links to relevant papers, can be found at: <http://www.aihw.gov.au/disability/icf/ddb21/index.html>