Appendix 1: Disability Data Reference and Advisory Group

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Caucus of Disability Consumer Organisations</td>
<td>Dianne Temby</td>
</tr>
<tr>
<td></td>
<td>Mark Pattison</td>
</tr>
<tr>
<td>Carers Association of Australia</td>
<td>Rose Ross (to mid 1997)</td>
</tr>
<tr>
<td></td>
<td>David Fisher (mid 1997)</td>
</tr>
<tr>
<td>ACROD</td>
<td>Helen McAuley</td>
</tr>
<tr>
<td>Federation of Ethnic Community Councils of Australia</td>
<td>Kin Win May</td>
</tr>
<tr>
<td>ABS</td>
<td>Jennie Widdowson</td>
</tr>
<tr>
<td>DSS</td>
<td>Trevor Hughes</td>
</tr>
<tr>
<td>DHFS</td>
<td>Angela Hewson</td>
</tr>
<tr>
<td>DEETYA</td>
<td>Monica McMahon</td>
</tr>
<tr>
<td>DSSC</td>
<td>Karl Mortimer (SA)</td>
</tr>
<tr>
<td></td>
<td>Sharyn Campbell (NSW)</td>
</tr>
<tr>
<td>Person expert in Aboriginal and Torres Strait Islander statistics</td>
<td>Tony Barnes</td>
</tr>
<tr>
<td>Independent experts</td>
<td>Maree Dyson</td>
</tr>
<tr>
<td></td>
<td>Bill Jolley (to mid 1997)</td>
</tr>
<tr>
<td></td>
<td>Trevor Parmenter</td>
</tr>
<tr>
<td></td>
<td>John Taplin</td>
</tr>
<tr>
<td></td>
<td>John Walsh</td>
</tr>
<tr>
<td>AIHW</td>
<td>Ching Choi (Chair)</td>
</tr>
<tr>
<td></td>
<td>Ros Madden</td>
</tr>
<tr>
<td></td>
<td>Tracie Hogan</td>
</tr>
</tbody>
</table>
Appendix 2: National Community Services Information Model

The Australian Institute of Health and Welfare is undertaking the development of a National Community Services Information Model in consultation with the National Community Services Data Committee. The Institute has considerable experience in information modelling having published the *National Health Information Model Version 1.0* in January 1996. (This publication extensively describes the concepts, techniques and rules for developing an information model.)

Development of the model has occurred via four workshops held between June and September 1997. Units from the Welfare Division of the Institute (Children and Family Services, Disability, Aged Care, SAAP and Welfare Expenditure) participated in the workshops as well people working on mental health within the Institute’s Health Division. The Institute has not been resourced to undertaken extensive national consultation on this project. National consultation will be facilitated by the Data Committee and the jurisdictions they represent. Representation on the Data Committee includes members from Commonwealth and State Governments as well three representatives from non-government organisations.

The overall objective of the model is to provide a framework for community services information development culminating in the publication of the inaugural National Community Services Data Dictionary. The existence, endorsement and use of a framework will ensure that the Data Dictionary is not driven by individual data collections and their associated data development activities. Other objectives of the model are to:

- identify a commonly agreed information base to enable research and policy development of national community services information;
- assist in minimising duplication of effort in community services information development;
- assist in promoting a common language and the identification of commonality in information requirements across community service sectors;
- inform and facilitate record linkage via improving data comparability; and
- provide a management tool to assist the ongoing development and communication of national community services information, and a coordinating mechanism for this work.

Version 0.5 of the model is shown on the following page. Version 1.0 of the model will be published as part of the Data Dictionary in early 1998. Comment on the current stage of development of the model is welcomed. Feedback can be provided to Joe Christenson (Head, National Information Development Unit, AIHW) by telephone 02 6244 1148 or by mail at GPO Box 570, Canberra, ACT, 2601.

Please note the NCS Information Model (and Data Dictionary) are undergoing development, and changes will be made continually. If using the Model (or Dictionary) for development or presentation in another context, please be advised of their developmental status. If you have any comments or queries on the latest versions of the Model or Dictionary please contact Joe Christenson.
Appendix 3: One- and two-digit codes of the draft ICIDH-2

Classification of impairment

Classification of impairments of function
Chapter 1 Mental functions
Chapter 2 Voice, speech, hearing and vestibular functions
Chapter 3 Seeing functions
Chapter 4 Other sensory functions
Chapter 5 Cardiovascular and respiratory functions
Chapter 6 Digestive, nutritional and metabolic functions
Chapter 7 Immunological and endocrinological functions
Chapter 8 Genitourinary functions
Chapter 9 Neuromusculoskeletal and movement related functions
Chapter 10 Functions of the skin and related organs

Classification of impairments of structure
Chapter 1 Brain, spinal cord and related structures
Chapter 2 Structures involved in voice and speech
Chapter 3 Structures of the ear and vestibular system
Chapter 4 The eye and related structures
Chapter 5 Structures of the circulatory and respiratory systems
Chapter 6 Structures related to the digestive system and metabolism
Chapter 7 Structures related to the immunological endocrinological systems
Chapter 8 Structures related to the urogenital system, continence and reproduction
Chapter 9 Structures related to movement
Chapter 10 Skin and related structures
Classification of activities

Chapter 1 Seeing, hearing and recognising
seeing
hearing
recognising by sensory input
recognising relationships in space and time

Chapter 2 Learning, applying knowledge, and performing tasks
remembering
acquiring and applying knowledge
problem solving
learning a task
performing tasks
managing different kinds of tasks
sustaining performance
managing general psychological demands
other activities relating to knowledge acquisition and use

Chapter 3 Communication activities
understanding messages in speech and formal sign language
understanding non-verbal messages (other than sign language)
understanding written language
producing messages in speech or formal sign language
communicating messages
producing non-verbal messages other than formal sign language
producing written language
using communication devices/techniques

Chapter 4 Movement activities
maintaining a body position
shifting the weight of the body
changing a body position
walking and related activities
transferring oneself while sitting or lying
activities involving fine hand use
activities aimed at making objects move

Chapter 5 Moving around
moving around in the general environment
climbing
moving around in specified environments
moving around in traffic situations as a pedestrian
using transportation
moving around in traffic situations as a driver
Chapter 6   Daily life activities
washing oneself
care of body parts, teeth, nails, hair
activities related to excretion
dressing
eating and drinking
caring for own wellbeing
dealing with everyday objects and appliances

Chapter 7   Care of necessities and domestic activities
procuring and taking care of daily necessities
procuring and taking care of shelter
taking care of meals
laundry and caring for clothes and footwear
taking care of dwelling
taking care of other household or family members
looking after possessions, plants and animals

Chapter 8   Interpersonal behaviours
general interactive skills
other interpersonal skills
managing own personal behaviour
maintaining close personal relationships
maintaining relationships with friends and peers

Chapter 9   Responding to and dealing with particular situations
managing in a specific climate or temperature
managing in other environmental circumstances
managing in a dangerous environment
work- and school-related behaviours
work acquisition and retentions skills
personal social activities
economic skills

Chapter 10   Use of assistive devices, technical aids and other related activities
using aids for therapy and training
using orthoses and prosthesis
using aids for personal care and protection
using aids for personal mobility
using aids for housekeeping
using furnishings and adaptations to homes and other premises
using aids for communication, information and signalling
using aids for handling products and goods
using aids and equipment for environmental improvement, tools and machines
using aids for recreation
Classification of participation

Chapter 1 Participation in personal maintenance
- participation in personal care
- participation in health maintenance
- participation in nourishment
- participation in housing and shelter

Chapter 2 Participation in mobility
- participation in home environment mobility
- participation in mobility outside the home
- participation in transportation

Chapter 3 Participation in exchange of information
- participation in spoken and non-spoken exchange of information
- participation in written exchange of information
- participation in exchange of information by symbols and signs
- participation in exchange of information by public symbols
- participation in exchange of information by means of telecommunication

Chapter 4 Participation in social relationships
- participation in family relationships
- participation in intimate relationships
- participation in relationships with friends and acquaintances
- participation in relationships with peers
- participation in relationships with strangers
- participation in other social relationships

Chapter 5 Participation in the areas of work, education, leisure and spirituality
- participation in education
- participation in work
- participation in play, recreation and leisure
- participation in spirituality

Chapter 6 Participation in economic life
- participation in economic transactions
- participation in economic security

Chapter 7 Participation in civic and community life
- participation in citizenship
- participation in community
List of contextual factors

Chapter 1 Products, tools and consumables
products or substances for personal consumption
money and other assets
assistive technology
products for personal use in daily living
products for commercial, industrial or employment use
educational products and equipment
cultural or religious objects

Chapter 2 Personal support and assistance
family members
friends
acquaintances, peers and colleagues
personal assistants and other care providers
health service providers
animals

Chapter 3 Social, economic and political institutions
social security system
social assistance and health system
education and training system
associations and organisations
economic institutions
political institutions
other public infrastructure

Chapter 4 Sociocultural structures, norms and rules
sociocultural structures
informal social attitudes
formal social rules
population composition, variation and movement

Chapter 5 Human-made physical environment
architecture
land use

Chapter 6 Natural environment
geography
flora and fauna
weather and air quality
time-related changes
sound
light
Appendix 4: Australian proposals about participation qualifiers (December 1996)—excerpt and adaptation

‘Enabling response’ is the response, from supports or factors external to the person, needed by the person to enable their desired level of participation in a particular domain. Because participation reflects an interaction between the person with an impairment and/or activity limitation and the environment, the enabling response may be provided in the form of assistance to the person or modification of the environment.

Enabling responses may be, broadly:

- person-focused enabling response—assistance to the person (employment support, equipment, carer etc.); and/or
- environmental-focused enabling response—systemic or environmental modification (ramps, toilets, parking spaces, large print or plain English publications, legislative reforms, attitudinal change, etc.)

‘Enabling response’ identifies what the person needs in order to achieve the desired level of participation. They may or may not be receiving this response. Information gathered on this variable gauges the ongoing need for various responses (e.g. equipment, personal assistance in various areas). Further questions, for instance, in population surveys or service-related interviews, would elicit what the current level of unmet need is, either on a personal or population basis.

The information or rating should be provided, as far as possible, by the person concerned.

The proposed ‘qualifier’ is related to the rest of the draft classification in the following way:

- it complements the other originally proposed qualifier of the third dimension (level of satisfaction); whereas that indicates the level of individual satisfaction with participation in various areas, this qualifier indicates the individual’s analysis of what external ‘response’ will enhance their level of participation;
- whereas the ‘environmental factors’ as presently classified, provide a framework in which an environment can be evaluated, the ‘enabling response’ indicator shows the specific factors which, for a particular individual in a particular area of participation, need to change or respond in order to enhance participation in a given domain by that individual.
### Table A4.1: Person-focused enabling response

<table>
<thead>
<tr>
<th>Suggested code</th>
<th>Suggested interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No response needed in usual environment to participate to desired level.</td>
</tr>
<tr>
<td>1</td>
<td>No response generally needed if person is in a suitable community environment (of a standard it is reasonable to expect)—or may experience minor difficulty in a suitable environment. (May imply need for environmental response — eg workplace modification.— but no person-focussed response)</td>
</tr>
<tr>
<td>2</td>
<td>Needs equipment and/or financial assistance only—and then experiences at most only minor or occasional difficulty to participate at desired level.</td>
</tr>
<tr>
<td>3</td>
<td>Needs no assistance (other than perhaps aids and/or financial assistance), but is experiencing moderate to significant difficulty, or experiencing some curtailment in participation.</td>
</tr>
<tr>
<td>4</td>
<td>Is not participating to desired level, is experiencing significant financial hardship (as a result of their disability?), and chiefly requires financial assistance rather than personal assistance with particular activities</td>
</tr>
<tr>
<td>5</td>
<td>Needs occasional or infrequent help to participate to desired level, even with equipment or financial assistance. Includes use of signing translator for deaf people.</td>
</tr>
<tr>
<td></td>
<td>Includes when social interaction is difficult beyond friends, colleagues and family?</td>
</tr>
<tr>
<td>6</td>
<td>Needs regular support with particular tasks eg 1-4 times per week, but manages many tasks independently on a daily basis.</td>
</tr>
<tr>
<td></td>
<td>Includes when person does not participate in relationships beyond spouse or immediate family, or can obtain employment only under special circumstances.</td>
</tr>
<tr>
<td></td>
<td>Includes curtailed participation without support.</td>
</tr>
<tr>
<td>7</td>
<td>Needs regular support most days with particular tasks, to participate to desired level. Includes:</td>
</tr>
<tr>
<td></td>
<td>• total dependence on external economic supports; or</td>
</tr>
<tr>
<td></td>
<td>• difficulty with sustaining employment, education or leisure activities under most favourable circumstances.</td>
</tr>
<tr>
<td>8</td>
<td>Needs significant daily support by a carer but can be left alone safely for at least an hour.</td>
</tr>
<tr>
<td>9</td>
<td>Needs substantial support by a carer on a daily basis and cannot be left alone safely. Includes someone who is totally economically reliant on others, including government assistance. Generally signifies extremely low levels of participation in the domain.</td>
</tr>
</tbody>
</table>

Source: Australian Collaborating Centre comments on Alpha draft ICIDH, December 1996.

The Australian proposal represents a change of focus from ‘degree of difficulty’ in the 1980 ‘handicap’ and in the June 1996 US proposals on ‘level of satisfaction’, to the idea of ‘response needed’. The gain is a shift from a static view or assessment of difficulty to an emphasis on enabling the person to achieve their desired level of participation.

Similarly there is a shift from the consideration of norms to the consideration of the person’s own goals. ‘Restricted occupation’ (p. 196 of 1980 ICIDH) is measured against some norm. The Australian proposal relates to the person’s own goals, i.e. what is needed to help them achieve their potential—thus focusing on avoidable disadvantage rather than some objective ‘extent of disadvantage’ against social norms.

This qualifier indicated the individual’s analysis of what external response will enhance their participation. The ‘severity of handicap’ scale of the 1980 ‘handicap’ classification can be mapped fairly well onto the ‘person-focused enabling response’—thus affording some continuity of the old and new versions of the ICIDH.

The environment-focused response (box A4.2) explicitly incorporates the impact of the environment into the third level by describing the particular factors of the
environment that need to change or respond in order to enhance participation in the area by that individual.

Table A4.2: Environment-focused enabling response

<table>
<thead>
<tr>
<th>Suggested code</th>
<th>Suggested interpretation: Environmental factor needed to respond</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No environmental response needed to enhance participation</td>
</tr>
<tr>
<td>1</td>
<td>Physical factors</td>
</tr>
<tr>
<td>2</td>
<td>Technological change, equipment (Comment: not just support needed—see above—but change in the mix of services etc)</td>
</tr>
<tr>
<td>3</td>
<td>Social, psychological climate, culture</td>
</tr>
<tr>
<td></td>
<td>Includes informal support, from family, friends, community Organizations</td>
</tr>
<tr>
<td></td>
<td>(Comment: not just support needed—see above—but change in the mix of services etc)</td>
</tr>
<tr>
<td>4</td>
<td>Legal factors and other administrative policy, practice ('politico economic' factors)</td>
</tr>
<tr>
<td>5</td>
<td>Economic system including labour market</td>
</tr>
<tr>
<td>6</td>
<td>Health and social services</td>
</tr>
<tr>
<td></td>
<td>(Comment: not just support needed—see above—but change in the mix of services, eligibility etc)</td>
</tr>
<tr>
<td>7</td>
<td>Education and training system response</td>
</tr>
<tr>
<td>8</td>
<td>Public infrastructure including public transport</td>
</tr>
<tr>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>

Source: Australian Collaborating Centre comments on Alpha draft ICIDH 1996.

The specific types of response would probably have to be culture-specific and modified by individual countries. In Australia such responses could include: formal disability support services, informal assistance, environmental modification, other improved access to mainstream services, assistive equipment, ongoing medication, or ‘self-help’.