Appendix 1: Disability Data Reference and Advisory Group

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

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.

**National Community Services Information Model
Version 0.5**
Prepared by the National Information Development Unit
Australian Institute of Health and Welfare
GPO Box 570, Canberra ACT Australia 2601

Phone: (06) 244 1000   Fax: (06) 244 1255

PARTY

PERSON

AGENCY

PARTY GROUP

FAMILY

HOUSEHOLD

TARGET GROUP

OTHER PARTY GROUP

LOCATION

ADDRESS

SETTING

SERVICE DELIVERY SETTING

OTHER SETTING

Party characteristics

PERSON CHARACTERISTIC

DEMOGRAPHIC CHARACTERISTIC

SOCIO-CULTURAL CHARACTERISTIC

EDUCATIONAL CHARACTERISTIC

LABOUR CHARACTERISTIC

ACCOMMODATION / LIVING CHARACTERISTIC

INCOME CHARACTERISTIC

LEGAL CHARACTERISTIC

IMPAIRMENT CHARACTERISTIC

DISABILITY CHARACTERISTIC

FUNCTIONAL CHARACTERISTIC

OTHER PERSON CHARACTERISTIC

PARTY GROUP CHARACTERISTIC

FAMILY CHARACTERISTIC

FAMILY INCOME CHARACTERISTIC

OTHER FAMILY CHARACTERISTIC

HOUSEHOLD CHARACTERISTIC

HOUSEHOLD INCOME CHARACTERISTIC

OTHER HOUSEHOLD CHARACTERISTIC

AGENCY CHARACTERISTIC

STATE OF WELLBEING

PERSON VIEW

NEED

PERSON PARTICIPATION / INDEPENDENCE

ENVIRONMENT

TOOLS AND EQUIPMENT

PERSONAL SUPPORT

SOCIAL AND CULTURAL ENVIRONMENT

ECONOMIC AND POLITICAL ENVIRONMENT

HUMAN-MADE PHYSICAL ENVIRONMENT

NATURAL ENVIRONMENT

EVENT

PERSON EVENT

BIRTH EVENT

LIFE EVENT

DEATH EVENT

ENVIRONMENTAL EVENT

ENVIRONMENTAL MODIFICATION EVENT

ECONOMIC TRANSACTION EVENT

EXPENDITURE

TRANSFER/SUBSIDY

REVENUE/RECEIPT

COMMUNITY / FAMILY EVENT

INFORMAL CARER ASSISTANCE EVENT

INFORMAL CARE EVENT

HEALTH AND WELFARE SERVICE EVENT

REFERRAL EVENT

ASSESSMENT OF ELIGIBILITY FOR SERVICE EVENT

ENTRY INTO SERVICE EVENT

ASSESSMENT EVENT

SERVICE PROVISION EVENT

CASE MANAGEMENT EVENT

LEAVE FROM SERVICE EVENT

EXIT / DISCHARGE FROM SERVICE EVENT

DETERMINATION OF LEGAL STATUS EVENT

OTHER HEALTH AND WELFARE SERVICE EVENT

OTHER EVENT

Enabling factors

RESOURCE

KNOWLEDGE FACTOR

AVAILABILITY FACTOR

ACCESSIBILITY FACTOR

PARTY ROLE

PERSON ROLE

CITIZEN ROLE

FAMILY RELATIONSHIP ROLE

CARER ROLE

RECIPIENT ROLE

SERVICE PROVIDER ROLE (Person)

AGENCY ROLE

SERVICE PROVIDER ROLE (Agency)

SERVICE FUNDER ROLE

SERVICE PURCHASER ROLE

OTHER ROLE

OUTCOME

HEALTH AND WELFARE PROGRAM

SERVICE

FEE STRUCTURE

ACTIVITY

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

Suggested code	Suggested interpretation
0	No response needed in usual environment to participate to desired level.
1	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)
2	Needs equipment and/or financial assistance only—and then experiences at most only minor or occasional difficulty to participate at desired level.
3	Needs no assistance (other than perhaps aids and/or financial assistance), but is experiencing moderate to significant difficulty, or experiencing some curtailment in participation.
4	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
5	Needs occasional or infrequent help to participate to desired level, even with equipment or financial assistance. Includes use of signing translator for deaf people Includes when social interaction is difficult beyond friends, colleagues and family?
6	Needs regular support with particular tasks eg 1-4 times per week, but manages many tasks independently on a daily basis. Includes when person does not participate in relationships beyond spouse or immediate family, or can obtain employment only under special circumstances. Includes curtailed participation without support.
7	Needs regular support most days with particular tasks, to participate to desired level. Includes: • total dependence on external economic supports; or • difficulty with sustaining employment, education or leisure activities under most favourable circumstances.
8	Needs significant daily support by a carer but can be left alone safely for at least an hour.
9	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.

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

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

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'.