

# Information annexes

The following Information annexes have been included to help inform users about particular data concepts or items (or groups of items) and to assist them in using the dictionary. These annexes provide additional background information that explains why particular definitions or domains have been included in the dictionary.

## 4.1 Cultural and Language Indicators

### Australian Bureau of Statistics (ABS)

The following is an excerpt from *Suitable Indicators for a Culturally and Linguistically Diverse Society, Results from the Cultural and Language Indicators Study*, prepared for the National Council of Ministers of Immigration and Multicultural Affairs by the Australian Bureau of Statistics (ABS):

The public policy context within which governments and community service providers operate requires timely and appropriate data collection in order to reach better equity outcomes. Collecting the appropriate data is integral to good planning and effective distribution of resources. It is also a prerequisite to good evaluation: if agencies do not know the characteristics of their community, then it is not possible to determine if programs or services are meeting their needs.

The term non-English speaking background and its acronym NESB are no longer considered to be an appropriate measure of disadvantage for a variety of reasons. The term has many conflicting definitions; it groups people who are relatively disadvantaged with those who are not disadvantaged; it is unable to separately identify the many cultural and linguistic groups in Australian society; and it has become a negative term.

Consequently, all levels of government have increasingly sought to develop an effective and consistent measure of cultural and language diversity in order to improve strategic planning and evaluation. To progress the need for the development and implementation of standardised cultural and language indicator data, the ABS was engaged to develop and pilot a data collection instrument.

Of the cultural and language indicator variables piloted, the following provide the most effective measures of the cultural and language background of the community and of potential disadvantage in terms of access to services.

- Birthplace of person
- Main language other than English spoken at home
- Proficiency in spoken English

Therefore the ABS recommends that the above three data items be considered the minimum core set for the purposes of collecting information relevant to cultural diversity in respect of people who have migrated to Australia, and their descendants.

In addition the ABS recommends that the following variables be considered as standard cultural indicators in respect of people who have migrated to Australia, and their descendants. These indicators can be added, either individually or in combination, to the minimum core set to meet particular information requirements.

- Birthplace of mother
- Birthplace of father
- Year of arrival in Australia (Period of residence in Australia)
- First language spoken
- Religious affiliation

### **Implications for the NCSDD**

To comply with ABS standard the following data items related to cultural identity are included in the NCSDD Version 2:

- Country of birth (Birthplace of person)
- Main language other than English spoken at home
- Proficiency in spoken English
- Year of arrival in Australia
- First language spoken
- Religious affiliation

Birthplace of mother and father may be collected using the same data domain as for Country of birth.

### **Department of Immigration and Multicultural Affairs (DIMA)**

DIMA have produced a classification of countries into English proficiency groups, based on the English proficiency of new arrivals into Australia between 1991 and 1996 (DIMA 1999). Data from the 1996 census are used to obtain a classification of countries, from which Australia has received recent immigrants, into 4 broad groups based on the English proficiency of the recently arrived. The four groups are:

- Main English-speaking countries
- Non-English-speaking countries (English proficiency group 2)
- Non-English-speaking countries (English proficiency group 3)
- Non-English-speaking countries (English proficiency group 4)

It should be noted that this categorisation is based on recent immigrants only and is therefore a useful classification for that group of people. However, it will not give accurate information about the English proficiency of individuals, particularly those that have been in Australia for a number of years. It should also be borne in mind that immigrants to Australia may have greater proficiency in English than the general population in their country (and have been successful in immigrating partly because of that English proficiency).

## 4.2 Labour force

Measurement of labour force details is quite complex, involving several data items and a number of standard questions. The following provides a very brief summary of ABS information that details the inter-relationships and complexities. Full details can be found in the *Information Paper: Questionnaires used in the Labour Force Survey, Australia, ABS, 6232.0* (available in *A Directory of Concepts and Standards for Social, Labour and Demographic Statistics*).

The ABS measures and describes the labour force characteristics of the population through a group of variables referred to as the Labour Force Variables. 'The Core Labour Force Variables' identified by ABS are:

1. Labour Force Status
2. Employment Status
3. Hours Worked
4. Full-time/Part-time Status
5. Duration of Unemployment

Three of these are defined in the data dictionary as individual data items. Hours worked and Duration of unemployment are not included as individual data items.

The five Labour Force Variables are interlinked in the following way:

- (a) 'Status in Employment' and 'Hours Worked' apply only if 'Labour Force Status' = employed.
- (b) 'Full-time/Part-time Status' applies only if 'Labour Force Status' = employed, unemployed (if actively seeking full-time/part-time work).
- (c) 'Duration of Unemployment' applies only if 'Labour Force Status' = unemployed.

They form a coherent set of variables, which collectively provide a detailed description and understanding of the Labour Force.

**Labour force status** is the variable which, establishes whether persons aged 15 years or over are currently economically active. (i.e. It identifies whether a person is employed, unemployed or not in the labour force). It is derived from a series of questions about a person's activities in relation to work in a reference week, using a set of priority rules. The criteria are based on whether a person had a job or was actively looking for work and available to start work.

The most important aspect of establishing Labour force status is that it is a measure of the 'currently economically active' segment of the population. This is why details of work activity in a specified reference week are obtained. For the currently economically active population, the reference period must be short to provide a measure of the labour supply (a stock) at a particular point in time, without problems arising from either population change or status change, while minimising recall and other memory dependent errors. Where full-time employment is the norm, a reference period of a week is suitable. This provides stable estimates with a similar average but lower variance than estimates relating to shorter reference periods.

**Employment status** is a classification of jobs held by persons at a point in time. Employed persons may be distinguished as employees, employers, own account workers or contributing family workers according to the type of job held. The standard proposed for this variable may be applied to the main job of an employed person or to 'last job', 'last full-time job' and 'second job' etc.

**Full-time/Part-time Status** distinguishes persons in employment as Full-time/Part-time workers and unemployed persons as looking for Full-time/Part-time work. For employed persons Full-time/Part-time status is measured by counting the total number of hours actually worked in all jobs in the reference week and/or usually worked per week in all jobs. For unemployed persons, Full-time/Part-time Status is determined by whether the person is looking for full-time or part-time work. Full-time refers to 35 hours or more per week

## Standard questions regarding Labour force

There are two versions of the standard questions for the 'Labour Force' Module for use in collections conducted by interview. The extended version (maximum set) is used in the Labour Force Survey and Monthly Population Survey and a shorter module (minimum set) is used in all other collections, which use personal interviews. A third module is required for use in self-enumerated collections such as the Census.

### Maximum Set:

The full Labour Force questionnaire module is too long to reproduce here but is that used in the current Labour Force Survey. Full details can be found in the Information Paper: *Questionnaires used in the Labour Force Survey*, Australia, ABS, 6232.0 (available in *A Directory of Concepts and Standards for Social, Labour and Demographic Statistics*).

### Minimum Set:

The Minimum Set recommended for household-based surveys comprises thirteen questions. They are available in *Standards for Social, Labour and Demographic Statistics*, ABS.

The recommended module for self enumerated collections

The following questions should be asked in self-enumerated data collections. The sequencing is important due to the inter-relationships between the labour force data items. (i.e. First it must be established if the person was working, then the type of work and then whether Full-time or part time etc). This should be borne in mind when collecting data on labour force.

#### Q.1

Last week, did the person have a full-time or part-time job of any kind

Mark one box only

A job means any type of work, including casual or temporary work or part time work if it was for one hour or more.

Yes, worked for payment or profit

Yes, but absent on holidays, on paid leave, on strike or temporarily stood down.

Yes, unpaid work in a family business

Yes, other unpaid work.

**Now go to 10.**

No, did not have job.

**Now go to 10.**

#### Q.2

In the main job held *last week*, was the person:

Mark one box only.

If the person had more than one job last week then 'main job' refers to the job in which the person usually works the most hours.

A wage or salary earner?

A helper not receiving wages?

**Conducting own business in a limited liability company**

With employees?

Without employees?

**Conducting own business which is not a limited liability company**

With employees?

Without employees?

Q.3, 4, 5, 6, 7, *Occupation and industry questions.*

Q.8

Last week how many hours did the person work in all jobs?

Subtract any time off, add any overtime or extra time worked.

None

1-15 hours

16-24 hours

25-34 hours

35-39 hours

40 hours

41-48 hours

49 hours or more

Q.9 *Journey to work question.*

Q.10

Did the person actively look for work at any time during the *last 4 weeks*?

Examples of actively looking for work include being registered with a job placement agency, checking or registering with any other employment agency, writing, telephoning or applying in person to an employer for work, or advertising for work.

No, did not look for work.

**No more questions for this person.**

Yes, looked for full-time work

Yes, looked for part-time work

Q.11

If the person had found a job, could the person have started work last week?

Yes, could have started work last week.

No, already had a job to go to.

No, temporarily ill or injured.

No, other reason.

## 4.3 Geographic indicators

### **Related data elements – Geographic identifier, Postcode, State/Territory identifier, Geographic location, Address, Suburb/town/locality name**

A geographic indicator is a classification scheme for the collection and dissemination of geographic information. Areas within a particular classification are mutually exclusive. Some of the commonly used geographic indicators are detailed below.

Whatever measure is used it is important to be clear that the information on location is actually the location of the person of entity that is sought. For example, the postal address of an organisation (and therefore the postcode and SLA) may not be the same as the location from which the service is actually provided.

It is also important to note that most of the classification schemes are revised either regularly or as required. The latest version of the scheme should be used where possible.

### **Postcode**

Postcode is a relatively easily collected data item, as it is one of the components of address. It can be mapped to ASGC classifications (such as SLA) using an ABS Postal Area to ASGC Concordance. However, as postcodes do not amalgamate to SLA's or vice versa, some inaccuracies can occur during the mapping process.

Postcodes cover the whole of Australia and are mutually exclusive.

For comparison purposes, information from the Census of Population and Housing is available by Postal Area of CD of Enumeration and Postal Area of Usual Residence. A Postal Area of CD of Enumeration is formed, by aggregating whole CDs that fall within the physical boundaries of a Postcode area on a 'best fit' basis. The ABS Census package 'Socio Economic Indexes for Areas (SEIFA)' is also available on a Postcode basis. It contains five indexes of socio-economic conditions within an area.

Postcodes vary over time and are updated. This needs to be taken into account when comparing data over time.

### **Australian Standard Geographical Classification (ASGC)**

*For full details regarding this classification refer to the ABS Australian Standard Geographical Classification 1998,1216.0.*

The ASGC is an ABS geographical classification for collecting and disseminating geographically classified statistics. It is an essential reference for users to understand and interpret the geographic context of ABS statistics. ABS data is collected and published using this classification. The ABS Census package 'Socio-Economic Indexes for Areas (SEIFA)' is also available for ASGC classifications.

Since 1994 the ASGC has been updated annually.

The ASGC is a hierarchical classification system consisting of 6 inter-related classification structures:

- Main structure
- Local Government Area Structure
- Statistical District Structure
- Statistical Region Structure
- Urban Centre/Locality Structure; and
- Section of State Structure

The Main Structure, The Statistical Region Structure and the Section of State Structure cover the whole of Australia without gaps or overlaps. The other structures only cover part of Australia.

The structures are hierarchical with spatial units at the higher level being aggregations of the spatial units at the previous lower level.

During Population Census years the smallest spacial unit is the Census Collection District (CD). It is the basic building block of the 6 classification structures. Between censuses, the smallest spacial unit is the Statistical Local Area (SLA) which is the level above CD in the hierarchical structure. SLAs are defined on administrative areas of local governments.

### **Main Structure:**

The Main Structure of the ASGC is used to collect and disseminate a broad range of ABS social, demographic and economic statistics. It is the most widely used Structure and has broad application.

It has 5 hierarchical levels at Population Census time, comprising in ascending order:

- Census Collectors Districts (CDs)
- Statistical Local Areas (SLAs)
- Statistical Sub-Divisions (SSDs)
- Statistical Divisions (SDs)
- States and Territories (S/Ts)

CDs aggregate to SLAs, SLAs to SSDs and so on. Each spatial unit collectively (e.g., SLAs) covers all of Australia without gaps or overlaps

### **Other Structures**

For details regarding the other Structures refer to the *ABS Australian Standard Geographical Classification 1998,1216.0*.

### **Coding to ASGC**

Street addresses can be mapped to ASGC codes using the ABS National Localities Index (NLI). Refer to ABS Catalogue No. 1252.0 for full details of the NLI. The NLI is updated regularly and maintained in accordance with each edition of the ASGC.

To ABS has also developed a number of concordance files (for example, 1996 SLAs to 1998 SLAs, Postal Area to ASGC 1996, and customised concordances tailored to meet individual requirements) to enhance comparability of data. These are available from the ABS.

## **Rural, Remote and Metropolitan Area Classification (RRMA)**

The Rural, Remote Area and Metropolitan Area classification was developed jointly by the then Commonwealth Department of Human Services and Health and the then Commonwealth Department of Primary Industries and Energy in 1994 (DPIE & DSHS 1994). The seven categories according to which SLA's are classified are as follows: 'capital cities'; 'other metropolitan centres'; 'large rural centres'; 'small rural centres'; 'other rural areas'; 'remote centres'; and 'other remote areas'.

Prior to 1994 the Rural and Remote Area Classification (RRRA) was developed by the then Commonwealth Department of Human Services and Health (DHS 1994). Each SLA was classified according to one of seven categories: 'capital city'; 'other major urban'; 'rural major'; 'rural other'; 'remote major'; 'remote other'; and 'other offshore areas'.

## **Accessibility/Remoteness Index of Australia (ARIA)**

Accessibility/Remoteness Index of Australia (ARIA) classification was developed by the National Key Centre for Social Applications of Geographical Information Systems (GISCA) on behalf of the Department of Health and Aged Care (under a Steering Committee) and released early in 1999. In brief GISCA used a geographic information system (GIS) methodology to produce a remoteness index and classification, and a database of road, locality and service information. ARIA interprets remoteness as accessibility to 201 service centres. Remoteness values for 11,338 populated localities are derived from the road distance to service centres in 4 categories. Values for populated localities are interpolated to a 1 kilometre grid, and averages calculated for larger areas. These values are grouped into five categories:

1. Highly accessible
2. Accessible
3. Moderately accessible
4. Remote
5. Very remote

While no attempt was made to 'force' the classification of individual areas to correspond to that under the RRMA, it was considered desirable that one or more of the categories correspond in size to the 'Remote Zones' ('Remote Centres plus Other Remote Areas') of the RRMA. These two categories correspond most closely to the 'Remote' plus 'Very Remote' categories in the ARIA classification shown above.

Remoteness values are produced at Census Collection District (CD), Postcode and SLA levels. Data collected by Address can be mapped to ARIA through the ABS National Localities Index, which maps address to the ASGC codes.

## Country

The ABS has developed the *Standard Australian Classification of Countries (SACC) 1998*, ABS Catalogue No. 1269.0, for use in the collection, storage and dissemination of data classified by country. It replaces the Australian Standard Classification of Countries for Social Statistics (ASCCSS). The classification is intended for classifying data relating to personal characteristics such as birthplace, country of origin, country of residence. It is not intended for classifying correlative variables such as the language spoken by individuals or the ethnicity of individuals.

A mapping of codes from the ASCCSS to SACC is available in the *Standard Australian Classification of Countries (SACC) 1998*, ABS Catalogue No. 1269.0.

### Major groups and minor groups of SACC

(See *Standard Australian Classification of Countries (SACC) 1998*, ABS Catalogue No. 1269.0 for Country codes which provide the other digits)

1. Oceania and Antarctica
  - 11 Australia
  - 12 New Zealand
  - 13 Melanesia
  - 14 Micronesia
  - 15 Polynesia
  - 16 Antarctica
2. North-west Europe
  - 21 United Kingdom
  - 22 Ireland
  - 23 Western Europe
  - 24 Northern Europe
3. Southern and Eastern Europe
  - 31 Southern Europe
  - 32 South Eastern Europe
  - 33 Eastern Europe
4. North Africa and the Middle East
  - 41 North Africa
  - 42 Middle East
5. South-East Asia
  - 51 Mainland South-East Asia
  - 52 Maritime South-East Asia



6. North-East Asia
  - 61 Chinese Asia (includes Mongolia)
  - 62 Japan and the Koreas
7. Southern and Central Asia
  - 71 Southern Asia
  - 72 Central Asia
8. Americas
  - 81 Northern America
  - 82 South America
  - 83 Central America
  - 84 Caribbean
9. Sub-Saharan Africa
  - 91 Central and West Africa
  - 92 Southern and East Africa

## 4.4 Disability

### Introduction

Many different definitions of disability are used in Australia, both in administrative data collections and in Acts of Parliament. The consistent identification of disability in national data collections has been recommended in a number of reports, so as to enable:

- the monitoring of access to generic services by people with a disability;
- the collection of more consistent data on disability support and related services, including data on service use by different groups; and
- population data and service data to be related, thereby improving the nation's analytical capacity in relation to the need for and supply of services.

Disability definitions in use in Australia were examined (Madden & Hogan, 1997) and an attempt made to relate the definitions to the concepts and definitions of the International Classification of Impairments, Disability and Handicaps (ICIDH-2 Beta-1 draft, 1997). Four main categories of definitions were considered:

- broad inclusive definitions for population research and anti-discrimination measures (such as Commonwealth Disability Discrimination Act (1992));
- definitions for generic or 'mainstream' services (such as Commonwealth Higher Education Programs, AUSTUDY);
- definitions for income support, insurance and social security (such as Social Security Act (1991), Disability Support Pension, Carer Allowance (Child), Carer Payment); and
- definitions for disability support services (such as Disability Services Acts for Commonwealth, States and Territories).

It is intended that all four categories of definitions (above) may be related to the data elements in the NCSDD. The data elements serve as building blocks with which data items and systems can be constructed for specific services and purposes. The resulting data items, systems, and the data produced will then be able to be related to other systems and data relevant to disability.

These data elements are of major importance in the disability services field. But it is also important that the data items be useful in a wider range of community services. This is because of the importance of other community services to people with a disability, and the need to identify access by people with a disability to other community services and to 'mainstream services'.

### The revision of the ICIDH

The first international classification relating to disability was the International Classification of Impairments, Disabilities and Handicaps (ICIDH). The ICIDH was published in 1980 as 'a manual of classification relating to the consequences of disease' and 'intended to offer a conceptual framework for information' (WHO, 1980). As such, the framework of the ICIDH may also be used for investigating public health risk factors and outcomes, in areas such as rehabilitation and mental health, and where a person has contact with both health and community services sectors (Madden & Sykes, 1999).

The ICIDH is now in the process of revision, to embrace developments in the field since 1980. The revised classification (ICIDH-2) is being developed by the World Health Organisation in cooperation with a range of countries, including Australia, as well as specialist task forces and organisations representing people with a disability. A first public draft was released in 1997 for world-wide testing and evaluation.

The latest (and final) public draft classification (WHO, 1999) is now renamed the International Classification of Functioning and Disability. The abbreviated reference is still ICIDH-2, pending its formal finalisation and adoption by WHO.

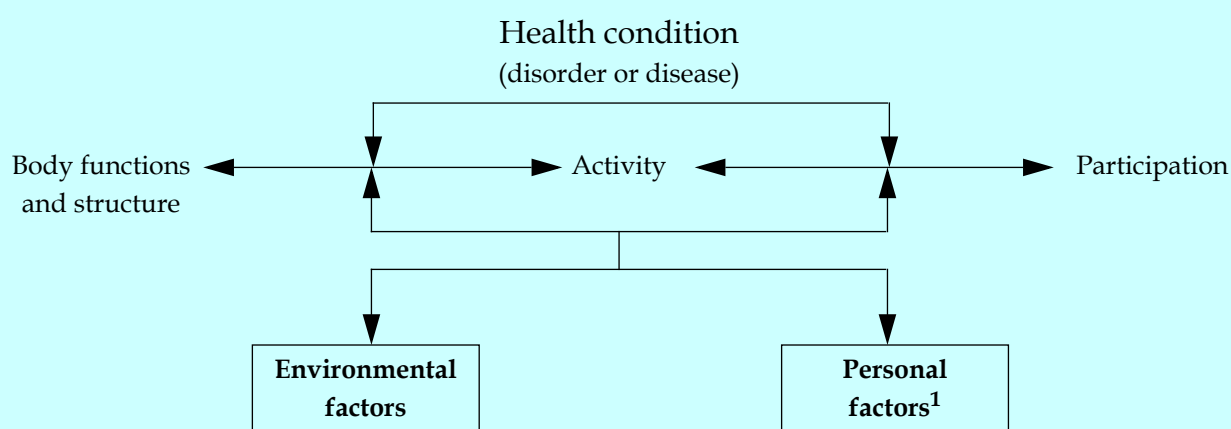
The ICIDH-2, Beta-2, 1999 can be found on the WHO website: <http://www.who.ch/icidh>.

## The conceptualisation of disability and the draft International Classification of Functioning and Disability (ICIDH-2)

Disability is conceptualised as being a multi-dimensional experience for the person involved. There may be effects on organs or body parts, for example impairment of the structure and/or function of the ear. There may be effects on certain activities such as understanding and producing messages. There may be effects on a person's participation in areas of human life such as education and work or leisure; participation may be facilitated in various ways, for instance by the provision of assistive technology or sign language interpretation.

Correspondingly, three dimensions of disability are recognised in the draft International Classification of Functioning and Disability – body structure and function (and impairment thereof); activity (and activity limitations); participation (and participation restriction) (WHO 1999). The classification also explicitly recognises the role of physical and social environmental factors in affecting disability outcomes (see Figure 1).

**Figure 1: Current understanding of interactions between the dimensions of ICIDH-2**



1 Data elements for some personal factors are in the National Community Services Data Dictionary, for example, indigenous status, marital status, sex.

Disability arises when any or all of the negative outcomes occur – impairment, activity limitation and/or participation restriction – when they are associated with a related 'health condition'. While restrictions in participation may occur for reasons other than a health-related condition, these restrictions are not considered to be included in the scope of 'disability'.

The dimensions of the ICIDH-2, Beta-2, 1999 are defined in relation to a health condition. 'A health condition is an alteration or attribute of the health state of an individual that may lead to distress, interference with daily activities, or contact with health services. It may be a disease (acute or chronic), disorder, injury or trauma, or reflect other health-related states such as pregnancy, ageing, stress, congenital anomaly or genetic predisposition' (WHO, 1999). In the WHO's international classifications,

health conditions are classified mainly in the International Classification of Diseases, Tenth Revision (ICD-10). Definitions from the draft ICIDH-2 are set out in Box 1.

### Box 1: Definitions of Dimensions ICIDH-2 (1999)

*IN THE CONTEXT of a HEALTH CONDITION:*

***Body functions** are the physiological or psychological functions of body systems.*

***Body structures** are anatomical parts of the body such as organs, limbs and their components.*

***Impairments** are problems in body function or structure such as a significant deviation or loss.*

***Activity** is the performance of a task or action by an individual.*

***Activity limitations** are difficulties an individual may have in the performance of activities.*

***Participation** is an individual's involvement in life situations in relation to Health Conditions, Body Functions and Structure, Activities, and Environmental and Personal factors.*

***Participation restrictions** are problems an individual may have in the manner or extent of involvement in life situations.*

***Environmental factors** make up the physical, social and attitudinal environment, in which people live and conduct their lives.*

Source: WHO 1999

The ICIDH-2 classification 'is to provide a language and framework for the description of human functioning and disability' (WHO 1999:5). It provides information on 'functioning at body, individual and society levels'. The three dimensions of ICIDH-2 'contain various domains of body functions and structure, performance of activities, and involvement in life situations' (WHO 1999:9). A fourth component of the classification relates to Environmental factors. 'The dimensions are distinct but parallel classifications (which) can be used alone or in an interrelated manner'.

'The Activities dimensions covers the complete range of activities performed by an individual. The chapters are organised from simple to complex activities. The Participation domain classifies areas of life in which the individual is involved, has access to, and has societal opportunities or barriers. The domains are organised from simple to complex areas' (WHO 1999:10).

An overview of the components of ICIDH-2 is presented in Table 1.

**Table 1: Overview of components of ICIDH-2 (1999)**

|                                      | <b>Body Functions &amp; Structures</b>        | <b>Activities</b>                          | <b>Participation</b>                                    | <b>Contextual Factors<sup>1</sup></b>                                                                                                          |
|--------------------------------------|-----------------------------------------------|--------------------------------------------|---------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------|
| Level of Functioning                 | Body<br>( <i>body parts</i> )                 | Individual<br>( <i>person as a whole</i> ) | Society<br>( <i>life situations</i> )                   | Environmental Factors<br>( <i>external influence on functioning</i> )<br>+<br>Personal Factors<br>( <i>internal influence on functioning</i> ) |
| <i>Characteristics</i>               | Body Function<br>Body Structure               | Performance of individual's activities     | Involvement in life situations                          | Features of the physical, social, and attitudinal world<br>+<br>Attributes of the person                                                       |
| <i>Positive aspect (Functioning)</i> | Functional and Structural Integrity           | Activity                                   | Participation                                           | Facilitators                                                                                                                                   |
| <i>Negative Aspect (Disability)</i>  | Impairment                                    | Activity limitation                        | Participation Restriction                               | Barriers/hindrances                                                                                                                            |
| <i>Qualifiers:</i>                   | <i>Uniform Qualifier: Extent or Magnitude</i> |                                            |                                                         |                                                                                                                                                |
| <i>First</i>                         | Localization                                  | Assistance                                 | Subjective Satisfaction<br>( <i>under development</i> ) | ( <i>under development</i> )                                                                                                                   |
| <i>Second</i>                        |                                               |                                            |                                                         |                                                                                                                                                |

1 Contextual Factors are an essential component of the classification and interact with all three dimensions.

Source: World Health Organization 1999 International Classification of Functioning and Disability. World Health Organization, Geneva.

The Dictionary bases its data elements on this international framework. However, the ICIDH-2 is still a draft classification, subject to further testing, and is not yet finalised and endorsed. Use of excessive detail (of what is currently a draft) has been avoided. This should ensure that a balance is struck between remaining consistent with international developments, and moving forward in the best possible way to respond to the very significant, urgent need for a more consistent approach to disability data in Australia. Future editions of the Dictionary will allow further evolution, as is the case with all data elements.

## Disability: the concept and related data elements

*The ICIDH-2 is a framework in which to map functioning and disability. Each of the three dimensions of the ICIDH-2, together with the relevant qualifiers, provides a spectrum, somewhere on which all people will be able to find themselves. The terms 'functioning' and 'disability' are the overarching concepts of the classification – the more a person considers their activities to be limited or their participation to be restricted, the more they may describe themselves as having a disability. Likewise a service may describe its eligibility criteria in terms of the activities with which people need assistance, the equipment they require to perform an activity without difficulty, or the participation they wish to increase. A different service may 'set the bar' to entry at a different point in the framework provided by the data elements.*

*There can thus be no single definition of disability. Each person and each service may identify the presence of disability differently. In the Institute's previous work, reviewing Australian definitions in use, we concluded that the goal of disability data development was not to arrive at a single definition of disability; indeed, in the current Australian context and service system, this would be impossible (Madden & Hogan, 1997). The goal was to define terms, which could be used to **relate** definitions and data. As noted in (1) above, the ICIDH appears the best available framework in which to pursue this goal.*

*The NCSDD thus contains:*

- *a definition of disability as a concept*
- together with
- *a suite of related data elements, which enable different definitions to be related to each other **via a common framework**.*

*These related data elements are:*

- *Body structures; Body functions; Impairment extent*
- *Activity areas; Activity – level of difficulty; Assistance with activity*
- *Participation areas; Participation extent; Participation – satisfaction level*
- *Environmental factors; Environmental factors – extent of influence*
- *Disability grouping – Australian national*
- *Disability grouping – International*

The 'Disability concept' guides the user to, and relies on, this set of defining data elements which are intended to be the building blocks for Australian data collections (collections relating to disability specifically and generic collections where it is necessary to identify disability). When the individual user is selecting the data elements in the combination suitable for the desired use or service to be described statistically, an operational definition of disability is built up, as a derived data element for that use or service. Consistency is enhanced in that all the definitions will relate to the overarching framework of the ICIDH-2.

The concept of 'Duration' is sometimes used in administrative data collections in Australia. The time scales used vary. For example eligibility for the Disability Support Pension is based on a medical impairment that attracts at least 20 points under the DSP impairment tables and a continuing inability to work 30 hours or more per week at award wages, or to be retrained within two years. A minimum duration of six months is used in the ABS Survey of Ageing, Disability and Carers. The terms: 'presently exists', 'previously existed but no longer exists' and 'is imputed to a person' are used in the Disability Discrimination Act (1992).

Because of this inevitable variability, depending on the purpose of the definition and data collection, it has been decided not to include a data element 'duration' in this version of the NCSDD. Specific collections may use a specific duration of disability as part of their specific definition.

## Qualifiers and relationships between the data elements and some existing assessment tools

### Qualifiers

Since the dimensions of the ICIDH-2 and the related disability data elements are framed in neutral terms they cannot be used to indicate outcomes or needs without the addition of some descriptor or qualifier, useable in each domain (Madden & Sykes, 1999).

The 'Body functions' and 'Body structures' data elements are qualified by 'Impairment extent'. 'Activity areas' are qualified by 'Activity – level of difficulty' and 'Assistance with activity'. 'Participation areas' is qualified by 'Participation extent' and 'Participation – satisfaction level'.

### The WHO 'uniform' qualifier

The ICIDH-2, Beta-2 draft (WHO, 1999) has a uniform qualifier with a five point negative scale to indicate the extent or magnitude of the 'problem' in the dimension. There are verbal descriptors and percentage figures related to each level of the scale. The National Community Services Data Dictionary (NCSDD) disability data elements are based on the ICIDH qualifiers. The ICIDH uniform qualifier is shown in Box 2. The WHO uniform qualifier relates to the 'Impairment extent', 'Activity – level of difficulty' and the 'Participation extent' qualifiers in the NCSDD.

#### Box 2: The ICIDH uniform qualifier for use with all three dimensions of the ICIDH-2

|   |                                                                                                                                 |                          |         |
|---|---------------------------------------------------------------------------------------------------------------------------------|--------------------------|---------|
| 0 | No impairment of body structure or function, <b>or</b> no difficulty with activities, <b>or</b> no restriction in participation | none, absent, negligible | 0–4%    |
| 1 | Mild                                                                                                                            | slight, low              | 5–24%   |
| 2 | Moderate                                                                                                                        | medium, fair             | 25–49%  |
| 3 | Severe                                                                                                                          | high, extreme            | 50–95%  |
| 4 | Complete                                                                                                                        | total                    | 96–100% |
| 8 | Not specified                                                                                                                   | –                        | –       |
| 9 | Not applicable                                                                                                                  | –                        | –       |

The ability to select a particular level in a reliable and consistent way is necessary for data to be meaningful. The next section looks at some commonly used tools to suggest how they might relate to the WHO percentages. Each of the ICIDH-2 dimensions is addressed in turn and examples of how the scores may relate are given.

### Impairments

Centrelink uses Schedule 1B Tables for the assessment of work-related impairment for Disability Support Pension (FaCS, 1999). Various clinical tests are used to determine the level of function of body systems. For example, the rating for loss of respiratory function is determined by forced expiratory volume in one second (FEV1) and forced vital capacity (FVC) and rated as a percentage of predicted capacities based on nomograms. The ratings are scaled, see Table 2 over page.

**Table 2: The Schedule 1B ratings according to percentage loss of respiratory function**

| Schedule 1B Scale | Percentage loss |
|-------------------|-----------------|
| Nil               | 80+             |
| Ten               | 75-79           |
| Fifteen           | 70-74           |
| Twenty            | 65-69           |
| Twenty-five       | 60-64           |
| Thirty            | 50-59           |
| Forty             | 49 or less      |

Theoretically the WHO percentages could be used to relate the percentage loss to the 'no', 'mild', 'moderate' 'severe' and 'complete' categories. Alternatively the percentage loss could be mapped to the NCSDD data element scale by grouping the Schedule 1B levels (Table 3). Testing would establish which is more useful. The issue is transparency in the allocation to a particular rating.

**Table 3: Relating the NCSDD Scale to the percentage loss of respiratory function in Schedule 1B**

|   | NCSDD scale         | Percentage loss according to WHO categories | Percentage loss by grouping Schedule 1B levels |
|---|---------------------|---------------------------------------------|------------------------------------------------|
| 0 | NO impairment       | 96+                                         | 80+                                            |
| 1 | MILD impairment     | 50-95                                       | 70-79                                          |
| 2 | MODERATE impairment | 25-49                                       | 60-69                                          |
| 3 | SEVERE impairment   | 5-24                                        | 50-59                                          |
| 4 | COMPLETE impairment | 4 or less                                   | 49 or less                                     |
| 8 | not specified       |                                             |                                                |
| 9 | not applicable      |                                             |                                                |

In Schedule 1B the criteria for psychiatric impairment are grouped into five categories, mild, moderate, serious, serious affecting several life areas and major. These categories relate well to the categories in the ICIDH and the proposed NCSDD data elements.

The Weschler Adult Intelligence Scale, the Adaptive behaviour score and the Capacity for Independent Living scores are used to rate level of intellectual impairment in Schedule 1B. These are then converted to a six-point work-related impairment rating. The six-point scale does not relate directly to the NCSDD scale, however percentages of the scores of the tests could be related using the WHO suggested levels.

Other body functions are assessed in similar fashion and many use numerical scores or percentage losses in function, which can be related to the NCSDD data element.

The Department of Veterans' Affairs uses the *Guide to the Assessment of Rates of Veterans' Pensions* (DVA, 1998) to determine level of disability. The majority of the scales look at the level of impairment in individual body systems. There are also tables that look at "lifestyle effects" or level of participation (e.g. personal relationships, mobility, recreational and community activities and domestic and employment activities).

The five-point scales use precise questions with precise answers usually determined by clinical tests. The five point scales can be directly related to the five point NCSDD scale. Testing would need to be undertaken to determine whether the results are sensible.



### Activity qualifiers

The uniform qualifier is 'Activity – level of difficulty', which is measured as the performance without assistance unless it is specified that it is with assistance. Assessment is against a generally accepted population standard, relative to cultural and social expectations. The Standard Rules for the Equalisation of Opportunities for Persons with Disabilities (UN, 1994) is the reference.

The Inventory for client and agency planning (ICAP) and the Scales of independent behaviour – revised (SIB-R) are tools that address 'difficulty with activities'. The assessment is made without help or supervision. In Tasmania the scores are related to a five-point scale indicating level of support needs.

|       |       |             |                                                 |
|-------|-------|-------------|-------------------------------------------------|
| Score | 1-29  | High        | Total personal care and intensive support       |
|       | 30-49 | High/medium | Extensive personal care and constant support    |
|       | 50-69 | Medium      | Regular personal care and close support         |
|       | 70-90 | Low/medium  | Limited personal care and periodic support      |
|       | 90+   | Low         | Infrequent personal care and no regular support |

The **Work Ability Tables (WATs)** used by the Commonwealth are made up of nine tables each of which measures a different dimension of work ability on a scale of 0-90, indicating the degree of impact on work ability. A final combined score is calculated using an algorithm. The scores on the WATs have been divided into three categories (DSS, 1998):

- Work Ability scores > 70 are assumed to indicate a very low level of work ability
- Work Ability scores < 30 are assumed to indicate a reasonable level of work ability
- Work Ability scores 30-70 are assumed to indicate a borderline level of work ability requiring a closer examination.

These levels may equate with the mild, moderate and severe difficulty categories in the NCSDD data elements. Alternatively the WHO percentages could be related to the scores from the WATs if tests indicate that the results are sensible.

### Participation qualifiers

Extent of participation is assessed in relation to The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (United Nations, 1994) In the absence of norms for participation in Australia collecting extent of participation in a consistent and reliable way may be problematic. It may be more appropriate to make statistical comparisons of the extent of participation among groups with differing levels of impairment or activity restriction.

### Second qualifiers

The Activities and Participation dimensions of the ICIDH-2 have second qualifiers under development. The Activity qualifier is Assistance with activity. Some of the rehabilitation assessment tools map to this qualifier. The second qualifier for participation is 'Participation – satisfaction level' and this relates strongly to the concept of quality of life.

### Assistance with activity

The **Functional Independence Measure (FIM)** measures 18 items, over 6 different domains. The individual performance is scored on an ordered scale of 7 down to 1 on each item. A score of 7 is recorded if the performance is fully independent and 1 indicates that the individual is fully dependent on another to complete the task. The FIM measures whether the individual can carry out a specific activity independently, or if help is needed, and how much help is required. A study to investigate whether his/her score on the FIM can predict the amount of attendant care needed by an individual with cerebral palsy found that it was possible to equate attendant care needs with a FIM score in broad terms (Balandin & Alexander). The lower

the score the more attendant time is required. The finding that one point on the FIM score equates to three minutes of attendant care was in keeping with studies conducted in the USA.

The FIM uses a seven-point scale only one level of which is for 'modified independence' i.e. non-personal assistance and five levels for personal assistance ranging from supervision to total assistance. The concepts of personal and non-personal assistance are present in the FIM and can be related to the NCSDD data element.

The **Client Information, Assessment and Referral Record (CIARR)** uses a three-point scale to rate activities of daily living; independent, with assistance and dependent. The first and last of these may equate to the 'No' and 'Complete' categories of the WHO qualifier. 'With assistance' in the CIARR relates to three levels of assistance in the data element for the NCSDD. The data element would provide greater sensitivity.

The **Support Need Assessment** was developed by Vermont Consulting and used in NSW, SA and Victoria. The scope of support need is limited to the intensity of personal assistance, and does not include equipment needs.

The levels are:

None

Minimal (monitoring, prompting required light physical guidance)

Some (provided regularly, clearly beneficial, but not absolutely essential)

Substantial (always required, essential)

Total (continuous, undivided attention of one staff member required to perform task)

Intensive (continuous, undivided attention of two staff members required to perform task)

All levels of the Support needs Assessment relate to the 'Personal assistance' category of the Assistance with activity data element. The Support Needs Assessment is performed by a service provider and based on other assessment tools. It may be useful to relate the original tools to the data elements, rather than this derived scale.

### **Satisfaction with participation**

A number of jurisdictions determine a person's goals as part of data collection. Recording participation against the person's own goals using the NCSDD 'Participation – satisfaction level' data element may be feasible.

The 'Participation – satisfaction level' qualifier was developed as part of the revision of the ICIDH. Extensive consultation with people with disabilities, their carers and service providers as well as disability administrators as part of the testing of the first draft (WHO, 1997) suggested that the key concepts of choice and satisfaction were of paramount importance to people with disabilities. These concepts are present in the quality of life literature. The four major themes in the quality of life literature are well represented in the ICIDH framework and are reflected in the NCSDD data elements particularly to the Participation dimension and its qualifiers. (Madden & Sykes, 1999). 'Participation – satisfaction level' is an alternative rather than a complement to the more objective 'Participation extent' qualifier.

- **Universal and holistic life domains**

A principal idea is that quality of life measures for people with disabilities should relate to the same areas of life as those relevant to all people, and that these areas should be holistic in scope. This principle explicitly underpins the Participation dimension of the draft ICIDH-2, with its holistic life domains. The 'Participation areas' data element is based on the ICIDH-2 dimension.

- **Autonomy and choice**

One of the main guiding principles set out for the consideration of quality of life is that "although basic components of quality of life are the same for all people, the meaning attached to quality of life will differ to varying degrees from one person to another. This is because individuals attach differing relative

importance to the basic components of quality of life and have differing opportunities and constraints within their lives" (Brown et al. 1996). Cummins' ComQol scale (Cummins 1993) reflects similar key ideas.

In the NCSDD data elements, autonomy and choice are reflected more strongly in the 'Participation – satisfaction level' qualifier where the primary role of the person in 'driving' the coding of their satisfaction with participation is stressed.

- **Objective measures**

Many people in the disability field have been highly receptive to the Participation – satisfaction level which rates in relation to the person's own goals. It is recognised that this is in line with the philosophy on rights and equality of opportunity. Nevertheless there has also been frequent discussion about the need to recognise that some people have not had the life experience, which enables them to make full and free choices. For these people, advocates or 'experts' of some kind may have a role in gauging the extent of participation against perhaps higher expectations than the people may hold for themselves. Cummins (1993) also emphasises the balancing of individual choice and weighting with 'objective measures' thus, gauging 'Participation extent' in terms of social averages may also be useful.

- **Person-environment interaction**

The fourth key factor in the quality of life literature relating to disability is the interaction between people and their environments (Madden & Sykes, 1999). The recognition of environmental factors in either facilitating Participation or creating barriers to Participation is an important new aspect of the ICIDH-2 and is included in the NCSDD as the 'Environmental factors' data element.

The *Healthy Communities Survey* in Tasmania (HWOU, 1999) collects data on quality of life in relation to a number of life areas. Two concepts are used, the importance of the life area and satisfaction with the life area. A statistically constructed measure combines importance and satisfaction. In the NCSDD the Participation qualifier asks the person with a disability to do this combination. The priority system in the dictionary asks that the first life situation in which participation or participation restriction is recorded is that which has the greatest impact on the individual and his/her current goals. Second and subsequent life situations are also of relevance to the individual. The 'Not applicable' category may be coded when the person has no interest in participating in a particular area in order to fulfil their current life goals. For example a person may have no interest in participating in sport. Rural and remote respondents may have substantially different priorities to urban respondents.

The areas of importance to the person are likely to change over time. A person who is successful at improving participation in mobility may develop new goals in different life situations. Data collectors will need to consider the frequency of their collection to reflect the person's changing goals as a result of interventions or changed life circumstances.

### **Collecting satisfaction data**

There are several issues to consider when collecting 'Satisfaction' data. Reporting of satisfaction is affected by various biases, such as social desirability, acquiescent response, fear of reprisal, gratitude, low expectations and issues of loyalty (Cooper & Jenkins, 1998). As a result data may be distorted. The subjective nature of the service experience has prompted some researchers to argue that individuals are not in a position to provide reliable data. Genuine information may be improved where the data collector is aware of the biases and uses collection methods, which minimise the likelihood, that distortions will occur (See also Cummins 1993).

Differences may occur when collecting data from people of non-English speaking background, and Indigenous groups because of both language and cultural barriers. Some people with disabilities may need methods of data collection that provide alternative means of communication, such as signing or communication boards.

The use of proxy or surrogate respondents represents a potential source of bias in the collection of information. Llewellyn, McConnell and Bye (1998) investigated the perceived service needs of parents with intellectual disabilities. They found that there were substantial differences in the perception of need

according to who was making the appraisal. Advocates completing the 'Participation – satisfaction level' on behalf of people with disabilities should be aware of the need for the individual to 'drive' the coding choice.

## Putting the data elements into operation

The disability data elements can be used to:

- build specific purpose data collections and develop data items consistent with national standards;
- relate two or more data sets, by mapping existing data items to the NCSDD data elements.
- guide data collection methods;

The following examples of each of these purposes illustrate the potential benefits of these types of use.

### Building specific purpose data collections

The first steps in building a data collection are to determine its main purpose, the main information needed from it and the main users.

Suppose, for example, that it was desired to record the number of employees in a particular industry sector, in order to monitor EEO performance, and also to plan adaptations to the work environment to make it more suited to the employment of people with disabilities. A personnel data system could then include data items developed from:

- Activity areas; Activity – level of difficulty; Assistance with activity
- Participation (possibly limited to 'Participation in work and employment'); Participation extent, Participation – satisfaction level;
- Environmental factors; Environmental factors – extent of influence

The resulting data from the collection could be related to data from the ABS Survey of Disability Ageing and Carers, thereby monitoring the achievements of EEO employment goals in relation to numbers of people in the population with similar activity limitations. They could also indicate the environmental modifications, which should be considered in order to make the workplace more suitable for people with disabilities.

### Relating two or more data sets

This example illustrates the benefits to policy analysis from being able to relate two or more data sets, via their relationship to the NCSDD data elements.

The Australian Bureau of Statistics (ABS) built its 1981 national disability survey on the then new ICIDH-1 concepts. The 1998 Australian Survey of Disability Ageing and Carers continued the previous basic survey concepts, but now aligns itself towards the new ICIDH. An adapted use of the draft ICIDH-2 concepts was made, in introducing the concept of 'activity restriction'. There are five 'specific restrictions' which are actually equivalent to areas of 'handicap' in the 1993 survey: restrictions in the three 'core' activities of daily living (self-care, mobility and communication), and restrictions in schooling and employment (see Box 3).

The Commonwealth/State Disability Agreement (CSDA) defines its target group in terms of specific impairments, reduced capacity for communication, self care/management or mobility, and the need for ongoing support services – all concepts which can be mapped to the ICIDH, and now to the NCSDD.

Because the ABS survey and the CSDA itself used similar concepts, based on or related to a major international classification and framework, data from the survey could be used for policy analysis for the CSDA. The ABS concept of a 'severe or profound core activity restriction' was thus able to be used as an indicator of need for disability support services funded under the CSDA, when the Institute was commissioned by national administrators to carry out a study of unmet demand (AIHW 1997). The ICIDH concepts have thus been demonstrably useful in ensuring the reliability of large national data sets – in this case relating population data on need to service definitions and data on supply.

### Box 3: ABS 1998 Survey of Disability, Ageing and Carers: restrictions and their severity

Specific restrictions are:

- Core activity restrictions; and/or
- Schooling or employment restrictions.

Core activities are:

- Self care – bathing or showering, dressing, eating, using the toilet, and managing incontinence;
- Mobility – moving around at home and away from home, getting into or out of a bed or chair, and using public transport; and
- Communication – understanding and being understood by others: strangers, family and friends.

A core activity restriction may be:

- Profound – unable to perform a core activity or always needing assistance;
- Severe – sometimes needing assistance to perform a core activity;
- Moderate – not needing assistance, but having difficulty performing a core activity: or
- Mild – having no difficulty performing a core activity but using aids or equipment because of disability.

Source: ABS 1999

#### Guiding data collection methods – an example from rehabilitation

A selection from the Activities dimension of the ICIDH-2 may be useful to provide information on treatment outcomes in the rehabilitation of a person following a multiple lower limb fractures. Table 4 gives an example of the sorts of items that may be selected and the way in which difficulty experienced and assistance needed may be recorded. A subsequent recording would give an indication of changes as an outcome of the healing and rehabilitation processes.

**Table 4: Areas of activity, Difficulty with activity, Assistance with activity**

| Area of activity                           | Difficulty with activity |   |   |   |   |   | Assistance with activity |   |   |   |   |
|--------------------------------------------|--------------------------|---|---|---|---|---|--------------------------|---|---|---|---|
|                                            | 1                        | 2 | 3 | 4 | 5 | 9 | 1                        | 2 | 3 | 4 | 9 |
| a3201 Changing body position from standing |                          |   | x |   |   |   | x                        |   |   |   |   |
| a3202 Changing body position from sitting  |                          | x |   |   |   |   | x                        |   |   |   |   |
| a3203 Shifting the weight of the body      |                          | x |   |   |   |   |                          | x |   |   |   |
| a4100 Walking short distances              |                          | x |   |   |   |   |                          | x |   |   |   |
| a4101 Walking long distances               |                          |   | x |   |   |   |                          |   |   | x |   |
| a4102 Walking on different surfaces        |                          |   | x |   |   |   |                          |   |   | x |   |
| a4201 Climbing                             |                          |   |   |   | x |   |                          |   |   | x |   |
| a4202 Running                              |                          |   |   |   | x |   |                          |   |   | x |   |

In addition, the Environmental factors classification may be used to indicate the type of assistance.

## Data elements for grouping disabilities

*'Disability groups' have been used in the CSDA MDS collection for some time (intellectual, physical etc). Support groups for people with disabilities are often organised by such disability groupings. Common experience as well as a particular cluster of health conditions, impairments, activity limitations, participation restrictions and support needs is the key to the existence of these groups; they want and frequently request data relating to members of the group.*

*The disability groupings have also been useful for providers of services to particular client groups with similar clusters of health conditions, impairments, activity limitations, participation restrictions and support needs. People with a particular range of skills that match to the needs of the people with disabilities can be employed.*

In the NCSDD two separate approaches are taken to grouping similar clusters of disabilities: an Australian national grouping and an international grouping. Before describing these groupings, the groupings in use up to this time are outlined.

### Main groupings in use

#### CSDA MDS grouping

*The CSDA, 1998, refers to its target group as people with a disability that is 'attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury. Or some combination of these which is likely to be permanent and results in substantially reduced capacity in at least one of the following:*

- *self care/management*
- *mobility*
- *communication*

*requiring ongoing or episodic support.'*

*The CSDA MDS data guide (1999) describes 'Disability group' as 'a broad categorisation of disabilities in terms of the underlying impairment, condition or cause, and reflects those impairments identified as significant in the CSDA.' As defined in the data guide, disability group is not a pure classification. It is based on grouping different concepts, namely cause (e.g. acquired brain injury), impairment (e.g. physical impairment arising from paraplegia) and condition (e.g. epilepsy). The categories do not contain all the detail that might be wanted in a more highly developed system. The CSDA MDS disability groups have been a useful way of talking about groups of people with similar clusters of needs. The specification of the groups arose from terminology useful to service users and providers, and was formulated specifically for the CSDA MDS collection.*

*In preparing data elements for the NCSDD, DDRAG advised that effort should be made to define disability groupings more rigorously.*

#### Four 'main' disability groupings

Four main disability groups are used regularly in Australian legislation and many administrative definitions. The Social Security Act (1991), AUSTUDY, Assistance for Isolated Children Schemes, Child Disability Allowance, Carer Payment and Mobility Allowance use three main groups – 'intellectual', 'psychiatric' and 'physical'. The Commonwealth Disability Services Act (1986) and eligibility for the Disability Support Pension include 'sensory' as an additional group. (The CSDA, as previously noted, includes 'neurological' and 'acquired brain injury' as additional categories.)

The same four groups ('intellectual', 'psychiatric', 'sensory' and 'physical') appear in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN, 1994). Where the sensory impairment group is not used it is assumed that sensory disabilities are included in the physical group.

## Other disability groupings

The Australian Bureau of Statistics (ABS) uses the term: 'Long-term condition' which is defined as 'a disease or disorder which has lasted or is likely to last for at least six months. Or 'a disease, disorder or event (e.g. stroke, poisoning, accident etc.) which produces an impairment or restriction which has lasted or is likely to last for at least six months'. Long term conditions have been coded to a classification based on the World Health Organization's International Classifications of Diseases, version 10 (ICD-10). 'Main condition' is defined as 'a long-term condition identified by a person as the one causing the most problems. When only one long-term condition is reported, this is recorded as the main long-term condition'. In the 1998 Survey of Ageing, Disability and Carers (ABS) health conditions are divided into mental and physical groupings with sub groups that align to the ICD-10 chapters.

So called 'Impairment' groups are proposed in the draft Australian standard data set for rehabilitation. These are described in the Uniform Minimum Data Set for Medical Rehabilitation, a data collection developed in the USA with the purpose of collating data from specialist units for outcomes assessment. The Impairment codes are actually diagnostic groups based on the ICD. These groups are also used in the Australian National Sub-Acute and Non-Acute Patient Classification (AN-SNAP).

Diagnostic information is used in both cases to create groupings.

## Conclusion – two disability groupings for the NCSDD

After considerable developmental work, mapping and discussion, it was concluded that there are advantages to using both a refined version of the CSDA MDS groups and the 'four main groups'.

- both groups are useful;
- for most detailed applications in Australia there are advantages in using the CSDA MDS groups, as they have been developed in partnership with the field over some years, and have proved useful;
- there are advantages in presenting the 'four main groups' for collections which require less detail or which require international comparison; and
- it will be important to relate the two resulting groupings.

Aspects of the main groupings already in existence have been conceptually combined so as to provide two groupings which:

- relate to the current CSDA MDS grouping which has evolved and is useful;
- relate to the four main groupings mentioned in the legislation and administrative definitions;
- relate more explicitly to the ICIDH and demonstrate the multi-dimensional nature of each grouping or classification; and
- relate to the ICD and health condition.

The results are tabulated in Table 5. This table provides explanatory background for the use of the data elements:

- Disability grouping – Australian national
- Disability grouping – International

Table 5 locates the two groupings in the sphere of the WHO health-related classifications, ICIDH and ICD, while preserving relevance to practical applications by consumer groups and disability-related services in Australia. Related to each Disability grouping are key features of each of the dimensions of ICIDH as well as examples of the relevant ICD chapter headings. By reading the descriptions in the table it should be possible to select the appropriate class for a particular disability.

**Table 5: A description of Australian National Disability Groups and International Disability Groups according to concepts present in the ICD and ICIDH-2.**

| DISABILITY GROUPINGS                                                                                                         |                                                                                                                                                                                                             | CONCEPTS USED IN MAKING THE DISABILITY GROUPINGS                                                                                                                                                                    |                                                                                                                                                                 |                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                                                   |
|------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Australian National Disability group                                                                                         | International Disability Group                                                                                                                                                                              | Health Condition - by ICD-10 <sup>1</sup> Chapter                                                                                                                                                                   | Body structure and function/impairment (ICIDH-2 Beta-2 draft, 1999) <sup>2</sup>                                                                                | Activity/Activity limitation (ICIDH-2 Beta-2 draft, 1999) <sup>2</sup>                                                                                                                                                                       | Participation/ Participation restriction (ICIDH-2 Beta-2 draft, 1999) <sup>2</sup>                                                                                                                                                                                                                           | Environmental factors & pattern of support needs                                                                                                                                                                                                                                                                                  |
| Intellectual<br>Autism including Asperger's syndrome<br>Specific learning/ Attention Deficit Disorder<br>Developmental delay | Intellectual/learning<br>The inclusions are based on the AAMR <sup>3</sup> definition. Including learning disabilities in this grouping is an expansion of the scope of the AAMR definition.                | Certain conditions originating in the perinatal period<br>Congenital malformations, deformations and chromosomal abnormalities<br>Mental & behavioural disorders. Sections F70-79<br>Mental retardation for example | "Intellectual functioning significantly sub average" (AAMR). That is impairment of mental functions (ICIDH-2).<br>Level of impairment may be relatively stable. | "... fundamental difficulty in learning and performing certain daily life skills" (AAMR). That is a range of ICIDH-2 activity limitations.                                                                                                   | "The limitation in adaptive skills occurs in the context of community environments" (AAMR). That is a range of ICIDH-2 participation restrictions.                                                                                                                                                           | "... is indexed to the person's individualised needs for supports." (AAMR).<br>Level of support tends to be relatively consistent over a period of time, but may change in range and intensity with changes in life circumstances.<br>Range of environmental factors (ICIDH-2) required for optimal functioning may be extensive. |
| Psychiatric                                                                                                                  | Psychiatric<br>Psychiatric disability includes recognisable symptoms and behaviour patterns associated with distress that may impair personal functioning in normal social activity (WHO,1993) <sup>5</sup> | Mental & behavioural disorders. Numerous ICD sections including Mood (affective) disorders, Neurotic, stress-related and somatoform disorders and Disorders of adult personality and behaviour.                     | Impairments of global mental functions<br>Impairment of specific mental functions<br>Level of impairment may vary over time                                     | In general, people with a psychiatric disability may perform Activities; however, there may be changes in level of performance during the course of the condition. Activities such as self-care and interpersonal activities may be limited. | People with psychiatric disability may experience many areas of Participation restriction, especially in 'social relationships', 'community social and civic life', 'work and employment', and 'education' (ICIDH-2).<br>The extent of participation restriction may vary during the course of the condition | Environmental factors such as social attitudes and knowledge may be important. The supports needed by people with psychiatric disability may be extensive in range, but required with intermittent intensity. Intensity may increase with exacerbations in the level of impairment                                                |



|                                                   |                                                                                                                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                             |                                                                                               |                                                                                             |                                                                                                              |                                                                                                                                                                                                                                 |
|---------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Deaf-blind<br>Vision<br>Hearing<br>Speech         | Sensory/Speech<br>This group is based on the specific needs of people with impairments of eye, ear and related structures. Though the areas of participation affected may be diverse the environmental factors needed to change participation are specific to this group. Speech has been located in this group because of its association with hearing disability. | Diseases of the ear and mastoid process<br>Diseases of the eye and adnexa                                                                                                                                                                                   | Impairments of the eye, ear and related structures.<br>Level of impairment relatively stable. | Activity limitation in areas of communication primarily                                     | Participation in mobility for vision, communication, and areas where interaction with community is involved. | Availability of a specific range of environmental factors will affect the level of disability experienced by people in the sensory/speech grouping. Once in place level of support tends to be consistent.                      |
| Physical<br>Acquired brain injury<br>Neurological | <b>Physical/Diverse<sup>4</sup></b><br>The common features of this group are the presence of a common impairment, which may have diverse effects within and among individuals. E.g. ABI - impairment of brain structure leading to diverse effects on activity and participation depending on severity and location of impairment of brain.                         | Congenital malformations, deformations and chromosomal abnormalities<br>Diseases of blood and blood forming organs and certain disorders involving the immune system<br>Endocrine, nutritional and metabolic diseases<br>Diseases of the circulatory system | Impairments may affect any or multiple areas of body structure or functioning.                | As any area of the body may be affected, any or multiple areas of activity may be affected. | All or several areas of participation may be restricted for persons with physical disabilities.              | Environmental factors may have a significant effect on participation outcomes for people with physical disability. Support needs may not be specific, but related to areas of participation restriction or activity limitation. |

|  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                                         |  |  |  |  |
|--|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|--|--|--|
|  | <p>Arthritis – impairment of joint function leading to diverse effects on activity and participation depending on severity and number of joints involved. The following conditions can be included in the physical/ diverse class.<br/>Paraplegia, quadriplegia, muscular dystrophy, motor neurone disease, neuromuscular disorders, cerebral palsy, absence or deformities of limbs, spina bifida, arthritis, back disorders, ataxia, bone formation or degeneration, scoliosis etc.</p> | <p>Diseases of the respiratory system<br/>Diseases of the skin and subcutaneous tissue<br/>Diseases of the musculoskeletal system and connective tissue<br/>Diseases of the genitourinary system<br/>Symptoms, signs and abnormal clinical and laboratory findings not elsewhere classified<br/>Injury, poisoning and certain other consequences of external causes</p> |  |  |  |  |
|--|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|--|--|--|

1 World Health Organisation 1992 International Classification of Diseases and Related Health Problems: Tenth Revision Geneva, World Health Organisation

2 World Health Organisation 1999 International Classification of Functioning and Disability Beta-2 draft. Geneva, World Health Organisation

3 American Association on Mental Retardation 1992 Mental Retardation: Definition, classification, and system of supports. Washington DC, American Association on Mental Retardation

4 The reason that neurological, ABI and physical can be grouped in the physical/diverse group is the presence of common impairments of structure, which result in diverse patterns of activity limitations, participation restrictions and support needs.

5 World Health Organisation (WHO) 1993. The ICD-10 classification of mental and behavioural disorders: diagnostic criteria for research. World Health Organisation, Geneva