

5 Issues for discussion

In this chapter we bring together some conclusions from the developmental and investigative work outlined in the first four chapters. The purpose is to draw out issues for discussion in the disability field in Australia, particularly during 1997 while evaluating the draft revised ICIDH and contributing to the development of the first National Community Services Data Dictionary.

5.1 Terminology and definition: the yin and yang of policy and data

Terminology has played a crucial role in achieving changed policy and perceptions in the disability field. Good terminology unearths and crystallises basic concepts. Ideally it is also stable and consistent enough to help people communicate.

Data definitions at best reflect the 'true' underlying concepts and are consistent with current terminology. Good definitions clarify key ideas and are capable of underpinning a range of complex data collections.

When terminology changes fast, data definitions tend to lag behind. When terminology is being used as an instrument of policy change, data definitions—by nature slower moving and frequently aligned to the policy status quo—may be seen to be part of a system needing reform.

Both roles are important: terminology as the flag bearer of vision and sometimes change; data definitions as the monitoring instruments. Ideally the roles are complementary but consistent, rather than competitive. Terminology which is flexible and data definitions which are more stable both make important contributions to our understanding of disability and the effects of disability policy.

Thus, data definitions should:

- reflect as far as possible the 'true' underlying concepts, but not necessarily change as frequently as terminology changes;
- be meaningful and acceptable to people with a disability; and
- relate to the way in which services are defined, so that service use can be monitored and related to needs and outcomes for people.

Population data collections and administrative data collections must develop in concert. If they develop separately, the needs of people (as evidenced in population surveys), cannot be related to data on services received. An obvious corollary is that administrative definitions should be able to be related to each other, as well as to population data.

Ideally, then:

- basic concepts are agreed;
- terminology and data relate to the same basic concepts; and
- data also relate to the policy and administrative framework.

However:

- terminology may evolve faster than do data definitions, which are (and probably should be) more stable (or conservative) than terminology;
- we use terminology to explore common ideas about basic concepts—which we have to hope are relatively stable.

Thus, the interrelationships between concepts, terminology and data can be complex and fluid. Differences among them—and the different pulls each may exert on the other—may be inevitable and may reflect a healthy, evolving system.

However, a fruitful evolution of data definitions should not leave too wide a distance from terminology on the one hand and service definitions on the other.

5.2 Key concepts and terminology

This section briefly discusses some issues about disability terminology in use in Australia, partly to lay them on the table for the public discussion of this paper, but also to suggest language for the discussion which follows in the next section. Promoting public discussion of terminology is one of the main purposes of this paper. Terminology should be as acceptable and meaningful as possible to the people involved, and enhance the debate about the basic concepts.

If the four key concepts of the draft revised ICIDH-2—impairment, activity, participation and environmental or contextual factors—are basic concepts which are recognised and used in Australia (and in section 5.3 we suggest that they are), then how well and how clearly are these concepts reflected in common terminology in Australia?³

Disability

Perhaps the most notable feature about disability terminology in Australia is the number of different meanings apparently attached to the word ‘disability’ itself. In many ways the word ‘disability’ has taken on an overarching meaning.

The term ‘people with a disability’, in the context of disability support services, actually often means people who are experiencing a participation outcome which requires intervention either in terms of personal assistance or environmental modification. In this sense, the term for the second dimension of the 1980 ICIDH—disability—has often been used when referring primarily to the third dimension—handicap.

‘Disability’ is also sometimes used in a shorthand allusion to both impairment and disability. Most of the Australian disability-specific legislation follows the CSDA in referring to something like ‘people with a disability that is attributable to an intellectual, psychiatric, sensory or physical impairment or combination of such impairments’. But in common terminology the two ideas are collapsed—the notion of a

³ Deciding the order of sections 5.2 and 5.3 vividly illustrated the interconnections between concepts, terminology and data (and administrative) definitions. It is hard to discuss a topic without agreeing on terminology first, but it is hard to agree on terminology until the topic and concepts are tested against a range of common usage.

'disability attributable to a physical impairment' becomes condensed into the term 'physical disability'.

These two uses or connotations mean that 'disability' as a term brings in three of the dimensions of the 1980 ICIDH—impairment, disability and handicap—and at times may be even more blurred. Perhaps reflecting these difficulties, 'disability' is seldom defined in Australian legislation.

Activity and activity limitation

The second dimension of the ICIDH now classifies a range of activities (which could possibly be carried out by any human being) and replaces the term 'disability' with the notion of 'activity limitation', which is classified in terms of the difficulty the person experiences with the activity and/or the assistance they need in performing the activity (see box 3.2).

Issues for discussion

- Are these new terms and ideas useful? Are they preferable to the 1980 disability classification? Are they in fact new or is the change simply a renaming and expansion?
- Is it accurate to say that it is now 'activities' which are classified? Is the definition accurate, or should it be phrased as 'area of functioning' rather than 'nature and extent of functioning'?
- Should the 'activity' classification be brought into line with more generic activity classifications such as those used in the time use surveys (which have an internationally agreed activity classification)?

Disablement

In the draft ICIDH-2 the word 'disablement' is used in two ways. First, it is used in the singular, as an overarching concept, much as 'disability' is now. Effectively, 'disablement' seems to replace 'disability' as a generic term in the ICIDH-2 draft. The word also still carries the notion of a 'process', as used previously.

Second, it is used as a term which is exchangeable with any of the three dimensions; thus a reference to 'disablements' could mean any of a number of effects relating to impairment, activity or participation. Used in this way it refers to the person affected, and appears to be used in the draft ICIDH-2 to dispense with the general term 'disability'.

Issues for discussion

- Are both these uses of the term 'disablement' in the ICIDH-2 clear and acceptable?
- Or do we prefer to accept disablement mainly in its current use, as a term for an overarching process?
- Is the effective replacement of the word 'disability' acceptable in Australia? Or do we prefer to retain the word 'disability' as the general personal descriptor—that is, use 'person with a disability' to refer to someone who has an impairment, activity limitation or participation restriction?

Handicap or participation restriction?

The word 'handicap' is widely perceived to be no longer an acceptable term among people with a disability and their advocates. It is understood that the term has fallen from favour largely because of the use of the word 'handicapped' to label people, and to see them only in term of this label—to fail to describe them as people first, with many capabilities as well as some disability.⁴

The draft revised ICIDH-2 proposes the ideas of 'participation' and 'participation restriction' as more accurately reflecting the key outcomes desired (see chapter 3).

It was reported at the ICIDH meeting in May 1996 that there is a view in some developing countries that a change in terminology (from impairment, disability and handicap) will be confusing in countries who are only just beginning to recognise the concepts and to separate disability policy from a more medical approach. There may be some international pressure to retain the word 'handicap'.

There appear to be mixed views in the United States. There has been a strong view in favour of replacing the word 'handicap', expressed for instance by North American participants at WHO meetings of ICIDH collaborating centres, who state that the word 'handicap' cannot be used in the United States or Canada. A more recent view, put in correspondence to WHO from members of a task force working on children's disability, has nevertheless been that the 1980 word 'handicap' and related concepts should be tested in the Beta phase.

Issues for discussion

- What is the preferred word in Australia—'handicap' or 'participation restriction'?
- How does the preferred word relate to the desired concept for the third dimension?
- Is the definition of 'participation' clear (see box 3.3)? Should it be preceded by 'in the context of disablement' or would this make the definition circular?
- Does the phrase 'in relation to impairments, activities, health conditions and contextual factors' clarify that the classification does refer to participation restrictions associated with 'disability'?
- Should the definition of 'participation refer' to 'activity limitations' rather than 'activities'?
- Are the participation domains or the handicap 'survival roles' preferred and why (see table 3.2 and appendix 3)?
- If the revised ICIDH adopts the word 'participation', is it satisfactory for Australian purposes? And should it be widely adopted into official data collections?

⁴ For similar reasons people in Australia are no longer usually referred to as 'disabled' because the label characterises the person solely in terms of one characteristic of many; the more acceptable term is now 'person with a disability'. Nevertheless, in the United Kingdom the term 'disabled' appears to be preferred, signifying that the person has been disabled by society rather than having an attribute of 'disability'.

Health

The 1980 ICIDH definitions have a standard preamble ‘in the context of health experience’ (section 3.2). Health interventions usually focus on individuals, and on shorter term medical interventions, so health-related terminology has perhaps been seen as irrelevant or even inimical to the development of disability services and the enhancement of rights and life opportunities for people with a permanent disability. Further, a concentration on clinical diagnosis (or grouping) rather than on needs is sometimes believed to lead to inappropriate resource allocation. Social and environmental improvements as well as services providing people with ongoing support have been sought instead, to enable participation and autonomy of the person involved.

Health is defined by the WHO as ‘a state of complete physical, mental and social well-being’ (WHO 1946). This holistic definition may soften the perceived ‘clinical’ focus of health, but does not clarify the scope of the ICIDH classification.

ICIDH-2 retains the preamble ‘in the context of health condition’ (section 3.5). This preamble may be considered desirable, for example, in widening the ambit of disability in Australia beyond ‘impairment’ and ‘activity limitation’ to include the HIV virus under the Disability Discrimination Act.

Issues for discussion

- Does the inclusion of the preamble ‘in the context of health condition’ widen or narrow the scope of ICIDH-2?
- Is widening or narrowing the effect desired?

Level of support needed—‘severity’ concepts

The notion of ‘support needs’ appears to be a familiar one in Australia, especially when considering access to disability support services, and the type of assistance needed. The ABS disability survey collects national data on support needs in activities of daily living (self-care, mobility and communication). A wider variety of supports than just activities of daily living is envisaged in the ‘participation’ domains of the revised ICIDH-2, which also include social relationships, education work and leisure, economic life and civic and community life (table 3.2).

Measures of support needs may be used to ‘assess’ people’s need for services or assistance. Such measures, if not validated by all parties, can be seen as inappropriate and even oppressive. Where measurement methods change over time, or vary among related services, they may be seen as arbitrary. But without publicly transparent eligibility criteria and ranking criteria, rationing (which exists in the provision of most public services) becomes informal and unaccountable. Thus, some indicator of support needed is a tool for monitoring equitable access to disability support services.

The use of undefined terms such as ‘substantial’ and ‘significant’ in many Australian services definitions (chapter 4) allows administrative discretion on ‘relative need’, that is, informal rationing. A measure of support needed, if not defined, is likely to creep in undefined, thereby limiting public accountability.

Need

The word and concept of ‘need’ is present in a number of service definitions in Australia (and in some of the proposed qualifiers for ICIDH). Its presence in the main

population disability survey in Australia enabled the estimation of unmet demand for disability support services (Madden et al. 1996).

All people have needs, and much has been written about the nature of human need (see, for instance, Bradshaw 1972; Doyal & Gough 1991). People are often obliged to express these needs or take other action to satisfy them. One of these actions may be to seek help or a service. People seeking a service to satisfy their needs are generally required to express their need in terms of the service definition, and to provide some information to the service giver (see chapter 1). If the person does not need the service, no information is given.

It is understood that some people object to the use of the word 'need' as implying some 'deficit' in the person expressing the need. Again, this is an issue for public discussion. However, if the word is unacceptable, views should also be expressed on the implications of rejecting the idea of 'need'.

Issues for discussion

- Are the notions of 'need' and 'support needs' acceptable in Australia?
- If they are unacceptable, what concept or idea should replace the idea of 'need'? Or can we do without one?
- If there is a view that the idea is not required, how can we describe the rationale and process by which services are requested and supplied (and related information collected)?

Qualifiers for 'participation'

Five key concepts have been suggested in the course of developing qualifiers for the new third dimension of the ICIDH: satisfaction with manner of participation (difficulty), satisfaction with outcome of participation, contextual facilitator (or barrier), personal support needed, difficulty experienced by the person, and extent of participation. These proposals are described in section 3.6.

'Satisfaction with participation' seems a particularly useful concept, reflecting the key notions of empowerment and autonomy—satisfaction should be in relation to the person's own goals.

Issues for discussion

- Is the 'satisfaction with participation' metric a useful qualifier of participation dimension?
- Which are the two or three least useful of the five qualifiers set out in Section 3.6 and why?
- How can the 'extent of participation' in relation to norms be judged for any one person?
- Does it matter that the concepts of 'difficulty' and 'assistance' are suggested as qualifiers for both 'activity limitation' and 'participation'? Is there a distinction or does this lead to confusion?

Combining a number of impairment scores

A single, global measure of impairment for a person has become an important measure for social security payments in Australia.

Issues for discussion

- Is a method for combining individual impairments, activity limitations or participation restrictions needed in the ICIDH?
- Are Australian methods used by the DSS and DVA worth placing into the international arena for review in this context?

5.3 Key concepts and data definitions: is the ICIDH a possible cornerstone for Australian data definitions?

Terminology was related to key concepts in section 5.2. In this section, data definitions are related to key concepts, by reflecting on how the definitions discussed in chapter 4 relate to the proposed ICIDH. The approach is to see if the draft ICIDH-2 works in the Australian data context and, if not, what would be better. The purpose of the section is to attempt to draw out issues for public discussion.

There are a wide range of services in Australia, both specific and generic, of relevance to people with a disability. Many of these services use apparently different definitions of disability and related concepts for their own purposes, usually via eligibility criteria for the service. The administrative definitions generally define a subset of people with a disability for whom a service is provided, rather than defining disability. These various administrative definitions dictate the way with which services are administered and described, and the data emanating from them. However, the larger the reach of service, the more the administrative definition is likely to influence perceptions of disability.

Australian statistical and administrative definitions were mapped onto the ICIDH-2 framework in chapter 4. Not only were the four basic ICIDH-2 concepts frequently present and distinguishable, but the gaps in the definitions became apparent—for instance the infrequent reference to environmental or contextual factors as well as the general absence of definition of ‘disability’.

The separation of the broad notion of ‘disability’ (or ‘disablement’?) into four concepts appears useful for understanding and analysing processes which are occurring. Disability service information must necessarily include the notion of ‘participation’, which is affected by the environment and society at large, and is also a prime purpose of disability support services. It also seems essential to separate this concept from the more personal measures of impairment or activity limitation. Using this approach, we might be able to comment that, with certain changes to services, a certain percentage of people with impairment or activity limitation have improved their participation outcome. A number of disability initiatives are aimed at social and environmental effects. To the extent that the Australian environment becomes more appropriate to people with a disability, there should be a lowering of the apparent need for support services. The success of these approaches needs to be evident from the statistics, otherwise there is a risk of not knowing what has worked and efforts in important areas may be relaxed.

The revision of the ICIDH has strived to make the classification more relevant and acceptable to people in the field, in particular by responding to criticism that the 1980 version did not adequately reflect the importance of environmental factors.

The role of carers has gained increasing public recognition in recent years. Informal care, provided by family and friends, provides the majority of the assistance received

by people with a disability (ABS 1995; AIHW 1995a). This contribution is recognised by governments which provide some support to carers, chiefly in the form of financial support or respite. Thus, collecting information on informal care as well as formal services is also an important part of providing a national picture of assistance to people with a disability.

Chapter 4 tests the ICIDH-2 concepts in the administrative context. It is also vital to test them in the wider community. Do these concepts reflect the way in which people in the field think about disability? Does the ICIDH provide a framework which helps relate key questions in the field to data definitions which might help answer these questions?

Issues for discussion

- What are the key questions that people in the disability field would like to see answered by the provision of quantitative data? Does the ICIDH help us frame these questions?
- Do the four new draft ICIDH-2 dimensions—Impairment, Activity (limitation) and Participation (restriction)—work in the disability field at large, particularly among people with a disability?
- Is the conclusion of chapter 4 reasonable—that the four new ICIDH concepts do provide a useful framework into which to fit Australian statistical and administrative definitions?
- Do the participation qualifiers enable improvements in participation to be monitored at a personal and also a socially aggregated level?
- Do the concepts of the ICIDH-2 support collecting data about carers?

5.4 Core questions for disability data?

This section further explores the possibility that the ICIDH-2 concepts provide a workable framework on which to build some key questions and output for disability data in Australia. The ultimate aim is to draft a range of related or consistent data items and questions, as options for use or reference, to promote national consistency of disability data. These suggestions are formulated in response to the high demand for nationally consistent disability data (see chapter 1) and to ensure that key disability data items are reflected in the National Community Services Data Dictionary now being developed (see chapter 2).

Core output: the first digit of ICIDH-2 dimensions?

If the ICIDH-2 is a reasonable framework for key disability definitions and classifications, then core output from data collections should provide information on the first digit classifications of the three main dimensions—Impairments, Activities, and Participation.

These dimensions are defined in boxes 3.1, 3.2, 3.3. The first digit codes are given in appendix 3. The five possible qualifiers for participation are set out in section 3.6.

Purposes and nature of collection

Before considering draft questions capable of producing this output, it is useful to review the types of purposes of each ICIDH-2 dimension in various current collections (see chapter 4).

Broadly, the ICIDH-2 concepts of impairments and activities (or activity limitations) are currently used in Australia to:

- screen people into population surveys or the ambit of services, that is, to define the broad group of ‘people with a disability’;
- define and name specific disability groupings in legislation and related service collections and in common terminology; and
- enable the collection of data on impairments and activity limitations.

Thus, impairments and activity limitations are:

- the key to screening questions in the major services and in the ABS survey;
- also a screen for ICIDH, so that a participation restriction is not picked up unless associated with impairment or activity limitation;
- the key to the CSDA MDS ‘disability groups’ (for instance ‘physical disability’);
- the basis of a possible census question;
- located in ‘person characteristics’ in the AIHW information model (see appendix 2).

Data on the participation dimension are usually collected to present a fuller picture of the person’s situation (in some detail as in the ABS survey) or as a central part of service provision (in focused detail). Specific services concentrate on different aspects of participation, for instance, the person’s likelihood of participation in work (as in assessment for the Disability Support Pension) or the person’s need for living assistance (as provided by a disability support service).

How the ICIDH-2 output could be produced

This subsection sets out a number of questions, in increasing detail, which could be used in various types of data collections—the more disability-specific collections enabling the greatest level of detail, and the large, more general collections demanding a shorter set of questions.

A minimum solution—questions for the census and some generic service collections

In late 1996 the ABS convened a meeting in Canberra, of interested stakeholders to discuss a possible census question relating to disability. There is great interest in this possibility, so as to be able to refine estimates of disability prevalence for small areas (for planning purposes) and for small population groups (especially Indigenous peoples).

An ABS draft, based on the New Zealand census question, was further refined during the meeting to (among other things) make it align to the complete activities dimension of the ICIDH-2:

CQ1. Do you find it difficult or impossible, or do you need or receive help:

- seeing, hearing or recognising things?
- to do everyday activities such as eating, dressing or moving around?
- to communicate or socialise with others?
- to do activities that people your age usually do (work, school, leisure, handling money)?
- to learn, understand or remember things?

CQ2. Is this because of your (or the person's):

- long-term health condition?
- short-term health condition?
- age?
- disability? OR impairment or injury of body part or function?⁵

These questions, or something similar, are being tested and further developed by the ABS and discussed with ABS user groups to examine their possible use in the next census.

Their brevity means that they could also be used in generic service collections aiming to identify people with a disability, in a manner consistent with the census. If it were important to focus on one particular activity area, for instance, education, this could be split from its grouping with other areas.

Issues for discussion

- Are these questions likely to lead to meaningful data?
- Could these questions also be used for generic service data collections wishing to identify people with a disability?
- How can these questions be made clearer to people responding?

Questions for population surveys and disability specific data collections

Questions for population surveys and disability specific data collections would be similar to the minimalist census questions, but would:

- allow more specificity by providing lists (or prompt cards) showing all activities for CQ1 and all 'conditions' and 'impairments' for CQ2; and
- allow for information on participation and contextual factors.

Thus, CQ1 and CQ2 could be supplemented by similar questions based on the Participation dimension of ICIDH-2:

DQ3. Are you restricted in your participation in the area of:

- work, education, leisure?
- social relationships?
- financial transactions and economic life?
- communication, including writing?
- eating, dressing or moving around?

⁵ The response options for CQ2 are not mutually exclusive, and will hopefully be refined in ABS testing.

(This draft has not been refined to make it clear to survey respondents; it is simply framed to reflect the full participation dimension.)

DQ4. For any area where your answer was yes:

- what assistance do you need (insert personal support categories)?
- what changes do you need in the people or things around you (insert contextual facilitator/barrier categories) to make it easier for you to participate in this area?
- how satisfied are you with your level of participation (insert categories for satisfaction with outcome of participation)?
- how satisfied are you with the process, how difficult is your participation (insert 'process/manner' categories)?

Further work by the AIHW is planned, to map these questions on to the definitions and collections outlined in chapter 4 (and map in the reverse direction) so as to check the viability of these proposals. Work with the CSDA minimum data set network could result in the tighter use of CQ1 and CQ2 in naming the 'disability groups' in that collection; some information relating to DQ3 and DQ4 is already in the collection.

Discussion of the proposal could help to formulate firm proposals for adoption in administrative data collections.

ABS disability survey

The importance of the ABS disability survey as a national data source is such that it will remain a key focus of conceptual development of data on disability in Australia.

The operationalisation of new ICIDH-2 concepts—if practical and acceptable—into the disability population survey will be largely the responsibility of the ABS. If their developmental and consultative work proceeds in parallel with the work flowing from this paper, consistency can be achieved. The ABS survey has influenced this work and its ongoing development will continue to do so.

It is vital that population data be able to be related to service data and that census questions on disability produce estimates compatible with population survey questions.

How to produce consistency once questions are drafted

The National Community Services Data Dictionary (discussed briefly in chapter 2) will be a major vehicle for promoting consistency of disability data. It is hoped that the first draft of this Data Dictionary will be released in 1997, but work such as suggested in this paper will take longer to develop and agree (and can be included at a later time). The definitions in the national data dictionary might be accompanied by different illustrative questions designed to show (as suggested above) how relevant questions would look in:

- a lengthy population survey;
- a population census;
- an administrative data collection relating to disability support services; and
- an administrative data collection relating to generic services, where the main purpose may simply be to identify the person with a disability.

The shortest set of questions will be required for use in the census and in some generic service collections (administrative and population surveys other than the specialist disability survey). This short 'identification module' should be consistent with ABS screening questions for the disability survey.

5.5 How to move towards consistency in Australia

This discussion paper has been prepared on the assumption that it is desirable to move towards greater consistency of disability data in Australia. Calls for greater consistency in definitions have been made over a number of years, and the greater usefulness and power of more reliable national data sets appears to be widely acknowledged.

The paper also, in reviewing nationally significant definitions and collections, has tended towards the conclusion that the draft ICIDH-2 may provide a useful framework for more consistent administrative and data definitions. The ICIDH-2 concepts appear to reflect the general approach of Australian service definitions, and have attempted to embrace ideas and criticism put forward by the wider disability field. In chapter 4 it was found to provide a useful framework for comparison and identifying gaps.

An attempt has been made in section 5.4 to use the draft classification to move on to the next step, and to draft some basic common questions which might be used in Australian data collections. Are these draft questions usable? acceptable? Will they help answer the key questions identified (by discussants) in section 5.3? It is unrealistic to expect that differences among administrative definitions can be eliminated, but the gradual evaluation and adoption of such questions, based on an international classification system, may minimise differences in data collections.

The National Community Services Data Dictionary and Information Model

Moves towards greater consistency of data definitions are occurring across the community services field (see chapter 2). The development of a National Community Services Data Dictionary is a high priority in the national work plan established, reflecting the need across the whole community services sector for greater consistency in data definitions and rationalisation of data collections. Potentially this greater consistency will have benefits not only within a diverse field such as the disability services field, but also for organisations and people working across a number of different community services (for instance non-government organisations acquitting funding from several different government programs). The parallel development of both an information model and a data dictionary is planned for 1997 and 1998.

Recognising the value of information models in clarifying ideas, aiding communication and setting priorities for data development—as well as the complexity of developing a much needed data dictionary for disability services—the AIHW began in 1996 to develop a draft Disability Information Model. The first draft resulted from a workshop with the Disability Data Reference and Advisory Group, who have maintained a watching brief over its subsequent development. Further work has now produced a

first draft of a Community Services Information Model (included and described in appendix 2). The four draft ICIDH-2 concepts informed the development of the model. Recommendations arising from the discussion of this paper will inform these national developments.

Issues for discussion

- Is there reason not to work towards greater national consistency in disability data?
- Does the draft Community Services Information Model include concepts which reflect the main issues in the field (in particular, provide a framework for answering the key questions which discussants identify in section 5.3)?
- Are the draft questions in section 5.4 relevant to the key issues in the field? Can they be used to underpin key data collections relating to the population needing services and those receiving services? Are they worded in an acceptable way? Are they relatable to important current collections? Could they be useful elements in a National Community Services Data Dictionary?

5.6 What next?

This paper is to be available in the following additional formats:

- Full version and plain English version available at the AIHW Home Page (<http://www.aihw.gov.au>);
- Full version and plain English version available on diskette, on request to the authors;
- A plain English version will be available on audio cassette, probably after being read on Print Handicap Radio.

You are invited to respond to the issues raised in this paper in a number of ways:

- by responding to the questionnaire on the website (<http://www.aihw.gov.au>);
- by responding to the enclosed questionnaire;
- by writing to the authors at the AIHW.

In addition nominees of DDRAG will be invited to a specific discussion. Other people interested in attending a discussion can indicate their interest in the questionnaire.

Following this feedback, a final paper of conclusions will be published. These conclusions will be used to inform the Australian response to WHO on the draft ICIDH-2, and the work of the Institute in formulating a National Community Services Data Dictionary.