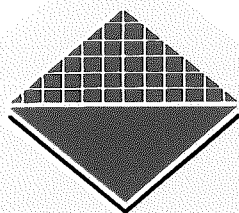


Measurement of disability: workshop proceedings

**Canberra, Australia
21–22 February 1994**



AUSTRALIAN INSTITUTE OF
HEALTH & WELFARE

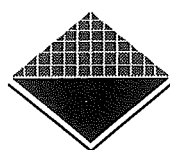
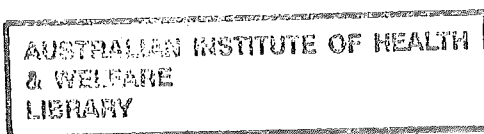
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Measurement of disability: workshop proceedings

Canberra, Australia
21-22 February 1994

Papers from a workshop organised jointly by the

Australian Institute of Health and Welfare
and the
NH&MRC Social Psychiatry Research Unit, Australian National University



Australian Institute of
HEALTH AND WELFARE
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Preface

We measure disability for many different reasons, and there are correspondingly different methods which have developed. There are also different approaches to the language with which we describe disability.

This workshop had two distinct purposes. It was designed to promote multi-disciplinary discussion of basic disability concepts, in particular those contained in the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), and to attempt to work towards greater consensus in the field in Australia, or at least towards a greater appreciation of the various perspectives. It was also designed to take advantage of the visits to Australia of participants at the 7th Meeting of the International Network on Health Expectancy (REVES) and of Professor John Cooper, University of Nottingham, who is carrying out further development of the ICIDH with particular emphasis on mental health and social role performance. The focus of his discussion was on measurement of disability in individuals, drawing together clinicians and allied health professionals with an interest in health status measurement.

The Australian Institute of Health and Welfare is a national research and statistics agency, with the responsibility to develop, disseminate and analyse national data in the fields of health and of welfare services. The Institute therefore has an interest in promoting greater consistency in data and the underlying concepts relating to disability.

The Social Psychiatry Research Unit is funded by the National Health and Medical Research Council to conduct research in the areas of social psychiatry and the epidemiology of mental disorders. These interests cover the social consequences of psychiatric disorders, and hence disability and handicap.

The papers contained in this publication were provided by participants during the workshop. Two additional papers, by Ros Madden and by Bryan Rodgers, are included to give some outline of the discussions which occurred during the course of the workshop.

Comments related to issues presented in these papers can be directed to the relevant authors or to the workshop organisers listed below (see list of participants for contact information).

Ms Ros Madden	Workshop Co-ordinator	AIHW
Ms Debbie van der Donk	Information Officer	AIHW
Ms Joanne Maples	Publication Co-ordinator	AIHW
Dr Bryan Rodgers	Co-convenor	SPRU

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Session 1.1 Concepts of impairment, disability and handicap

Overview of the Australian disability field

Heather Butow

Commonwealth Office of Disability, Canberra

Introduction

I don't believe it is possible to discuss the concepts of impairment, disability and handicap in Australia or elsewhere without doing so against the background of developments in the disability field in general.

Indeed, the links between the concepts of impairment, disability and handicap, the definitions and terminology applied to them, and the impact of policy developments on them are rather difficult to unravel. We all know that the policy response of government to the provision of disability services has changed focus and direction over time.

Something we're not always so conscious of is the key role played by language as both an indicator of change and as a tool in the change process. It's why the topic—measurement of disability—raises such an emotional response in the disability field. People with a disability know the power of language—at a personal as well as a policy level. Speakers after me will give you their perspectives.

What I'd like to do today is trace the links between language and policy. Certainly, the terminology and the definitions used to measure disability impact not only on the type of data collected, but also on how it is analysed and the range of policy responses possible.

The power of language

Descriptive terms used about people carry powerful images—positive and negative. In relation to disability, the terms used over time provide a good reflection of the attitude of the time towards disability. Retard, subnormal, cripple, lunatic, and deaf and dumb are just a few terms that are no longer acceptable.

Language used to identify categories of people creates images which in turn can offend or insult. Language and the images it generates can cause or exacerbate discrimination. This can occur through stereotyping, derogatory or imposed labels, omission, invisibility, or emphasis on difference.

Although discriminatory language is rarely used deliberately, its effect is not lost on those people to whom it is applied. Furthermore, many terms which at first appear to have scientific or professional credibility become associated with negative stereotypes and become derogatory and terms of abuse. We've all heard—and perhaps on occasions used ourselves—such words as 'retard' and 'spastic', to imply that someone is of little or no worth.

Linking language to policy change

Australia has been foremost in developing non-discriminatory language and using language to assist the policy development process as well as to reflect it. Let me illustrate this by walking you through some of the key events in disability reform since Federation.

In the early 1900s, most disabilities were considered to be a danger to society and many not susceptible to treatment. In 1927, the Royal Commission into Child Endowment or Family Allowances, declared that:

The unmistakably feeble minded, persons tainted with incurable forms of disease, or affected by other serious and transmissible defects, should be prevented from reproducing their species. People suffering from syphilis, deaf-mutism, or feeble mindedness should not be allowed to marry (Jones, 1990:36).

Although these concepts of disability have changed over time, early disability related legislation such as the *Sheltered Employment (Assistance) Act 1967* which provided for 'assistance by the Commonwealth towards the provision of sheltered employment and accommodation for certain disabled persons' still had both a very limited definition of disability and used the term 'disabled person', a description which in itself would now be considered pejorative.

Interestingly, 'disabled person' was defined as being either permanently incapacitated for work or permanently blind. Although this Act was replaced in 1974 by the *Handicapped Persons Assistance Act* the term and definition remained unchanged.

The Act also still supported centralisation of services and segregation of people with a disability from the rest of the community. The 1976 United Nations Declaration of the Rights of Disabled Persons was one of the first documents to articulate the view that people with a disability have the right to enjoy a decent life. This new understanding of disability has had enormous ramifications for identification and measurement of disability as well as policy responses and the language used. It has moved the focus to infrastructure development and human rights and put the solutions to problems in the economic and political spheres rather than health and welfare.

This deeper analysis of the situation of people with a disability includes concepts such as infringement and violation of rights rather than sickness and deficit. It also adds to our concept of disability by giving consideration to the disadvantage that occurs when people with a disability encounter cultural, physical, or social barriers that prevent their access to the various systems of society.

In 1981 the International Year of Disabled Persons (IYDP) served to direct community focus at people's abilities rather than their disabilities.¹ Under the banner of 'Break Down the Barriers', IYDP focused on 'full equality' and 'equity' for people with a disability.

Despite its reference to 'disabled persons', we learned from this year the importance of language in fostering positive attitudes towards and understanding about disability. You will all remember the word *disABILITIES*

1 The UN at this time had still not addressed the question of language. This was not to occur until 1992 in the debates surrounding the development of the UN Rules (see later).

with the *dis* slashed out. Nonetheless, in 1983 here in Australia, we were still referring to people with a disability as handicapped people.

It was at this time that the Federal Government commissioned the Handicapped Programs Review as a means of identifying what changes might be necessary to improve services and opportunities relevant to the needs of people with a disability. Not surprisingly, people with a disability took this opportunity to articulate their needs (essentially those enjoyed by other Australians): the right to a job, a place to live and a chance to lead an ordinary life. They rejected the notion of segregation and images of incompetence, illness and charity. The Review led to the enactment of the Disability Services Act in 1986—note the change in terminology and emphasis from ‘handicapped persons’ to ‘disability services’.

An objective of the Disability Services Act is to ‘further the integration of persons with disabilities in the community, and complement services generally available in the community’. The language of the Act was empowering in referring to ‘persons with disabilities’—people first; that they have a disability is a secondary consideration.

Unlike previous Acts, the definition of the target group is significantly expanded, since a disability is defined to:

- be attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of such impairments;
- be permanent or likely to be permanent; and
- result in a substantially reduced capacity of the person for communication, learning or mobility and the need for ongoing support services.

The Disability Discrimination Act was introduced in 1992. In this Act the definition of disability is very broad to ensure that no-one who is discriminated against because of a disability is left without a remedy because of definitional problems.

Measurement

I’m the first to admit that in the context of the move from a welfare to a rights focus, the translation of the policy intent into a useable definition on which to gather data becomes complex. However, not to do so—to continue to produce data based on historical definitions—is not only not relevant but also counter-productive. Too many misconceptions and inappropriate terminology still exist.

As you know, internationally, issues around disability and definitions are presently under review as there is some discontent with current terminology. It is claimed current terms reflect a medical and diagnostic approach and are too centred on the individual and may not adequately clarify the limitations of the wider community.

In Australia the data collected by the Australian Bureau of Statistics (ABS) is used as a basis for planning purposes. However, the ABS uses a similar approach to that used internationally. An alternative approach has been advanced in the United Nations Standard Rules on the Equalisation of

Opportunities for Persons with Disabilities.² The Rules were adopted by the United Nations in December last year. Australia had a key role to play in their development. The Rules:

- describe the rights of people with a disability; and
- spell out what governments can do to make things better for people with a disability.

Although still not totally acceptable to all people with a disability, the United Nations Rules at least distinguish between disability and handicap in a way that moves the focus to the impact of the environment on the individual.

'Mental' disability

I'd like to digress for a moment to the language often used to describe intellectual and/or psychiatric disability, that is 'mental' disability. I do so because, despite significant lobbying from the disability community and others, I understand the ABS still plans to refer to 'mental condition' in its 1996 Census of Population and Housing.

'Mental' is a good example of a term acquiring inaccurate associations and negative connotations. From a measurement perspective, not to distinguish between intellectual and psychiatric disability in a data collection exercise calls into question the useability of the data. Also, the range of negative terms beginning with mental—mentally deficient, mentally subnormal, mentally incurable—implying abnormality, disease and sub-humanity has reduced any professional and scientific credibility the term had.

Current developments

I'd like to conclude by briefly mentioning the Australian Disability Strategy currently being developed by the Office of Disability. The Strategy is about making sure that people with a disability can access all of the services available to the rest of the community—the transport system, telecommunications, the mass media, education, employment and so on.

It's not about providing special services for people with a disability. It's about recognising that people with a disability have the same right to opportunities as other citizens. The Strategy is based on the United Nations Standard Rules, mentioned earlier, and on the Disability Discrimination Act.

The Strategy will help put the objects of the Disability Discrimination Act and the United Nations Standard Rules into practice. It is a broad, long-term plan of action for governments to bring about equal opportunity for people with a disability. It is being developed in two stages.

The first stage, which began in May last year, covers Commonwealth Government functions and responsibilities. Its about to be considered by Federal Cabinet. Stage two will involve consultations with State and Territory Governments and the broader community. A national Strategy that goes across all levels of government and puts in place mechanisms to achieve national equal opportunity goals will be developed from this.

2 For the first time the United Nations has shifted in terminology from 'disabled persons' to 'persons with disabilities'.

Achievement against these goals will need to be measured and data based on the concepts embraced by the Strategy will be vital. Reliable data of this kind will put government decision makers in a position to develop rational policies directed to equalisation of opportunities and to assess the impact of those policies over time.

I hope that the considerations of this workshop will in some part assist in the necessary refocussing to enable data of this kind to be collected. I look forward to the outcomes of the workshop.

Reference

Jones, M.A. (1990) The Australian welfare state—origins, controls and choices. Allen and Unwin, Sydney.

Concepts of impairment, disability and handicap in the 1980 International Classification of Impairments, Disabilities, and Handicaps

The following material has been collated by one of the workshop coordinators, Joanne Maples, based on notes of a talk by Dr Michel Thuriaux, World Health Organization, and on the overheads provided.

Key concepts of disablement

'Disablement' is an often used catch-all term for three major concepts: impairment, disability and handicap. In general terms, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), published in 1980 by the World Health Organization, distinguishes them as below.

Impairments	Disabilities	Handicaps
<i>Organ</i>	<i>Person</i>	<i>Society</i>
Body structure/function	Activities	Roles

The ICIDH was developed as a tool to classify the consequences of disease, which are themselves classified in the International Classification of Diseases, the latest version of which is known as the ICD-9-CM (National Center for Health Statistics 1978).

The ICIDH defines impairment, disability and handicap, only 'in the context of health experience'. The definitions are presented later.

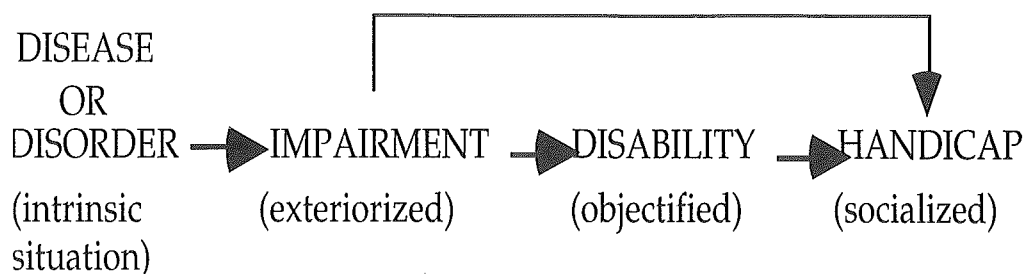
The classification is set out under the following headings:

International Classification of Impairments, Disabilities, and Handicaps—1980

Impairments	Disabilities	Handicaps
Intellectual	Behavioural	Orientation
Other psychological	Communication	Physical independence
Language	Personal care	Mobility
Aural	Locomotor	Occupation
Ocular	Body disposition	Social integration
Visceral	Dexterity	Economic self-sufficiency
Skeletal	Situational	
Disfigurements	Particular skills	
General sensory	Other restrictions	
etc		

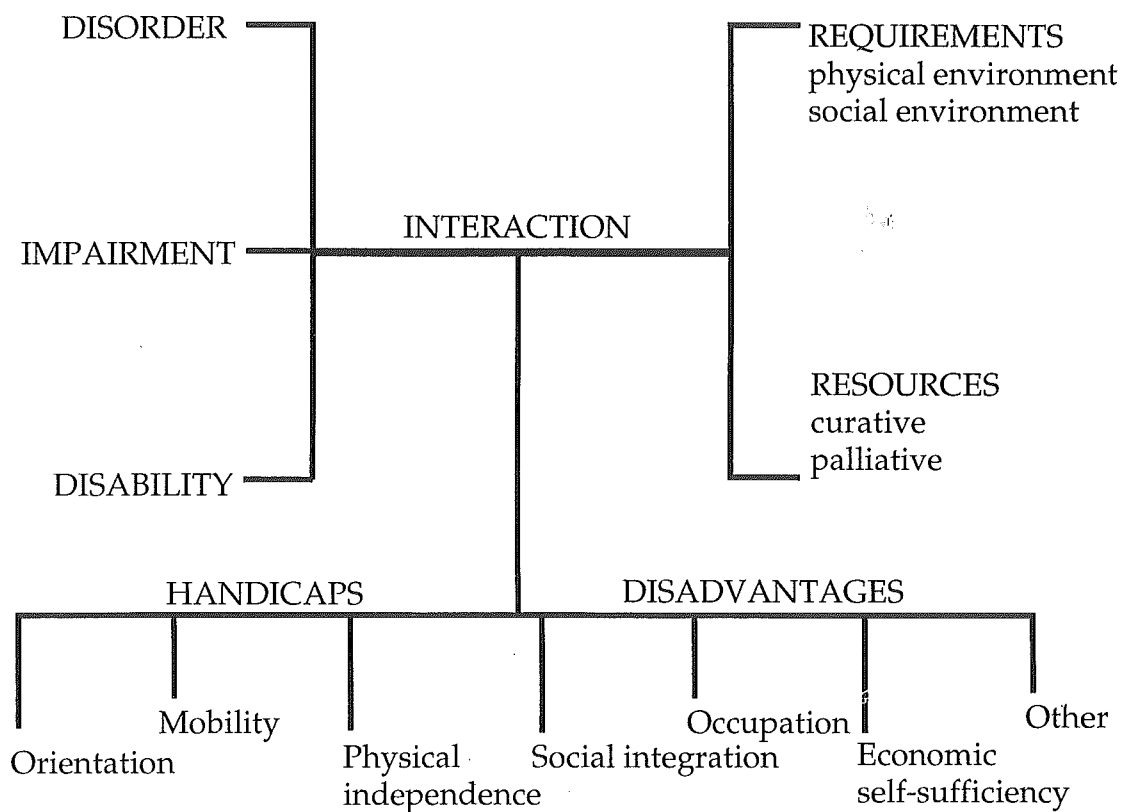
Disease, illness, health: theoretical models of the disablement process

The introduction to the ICIDH presents the following model of the consequences of disease.

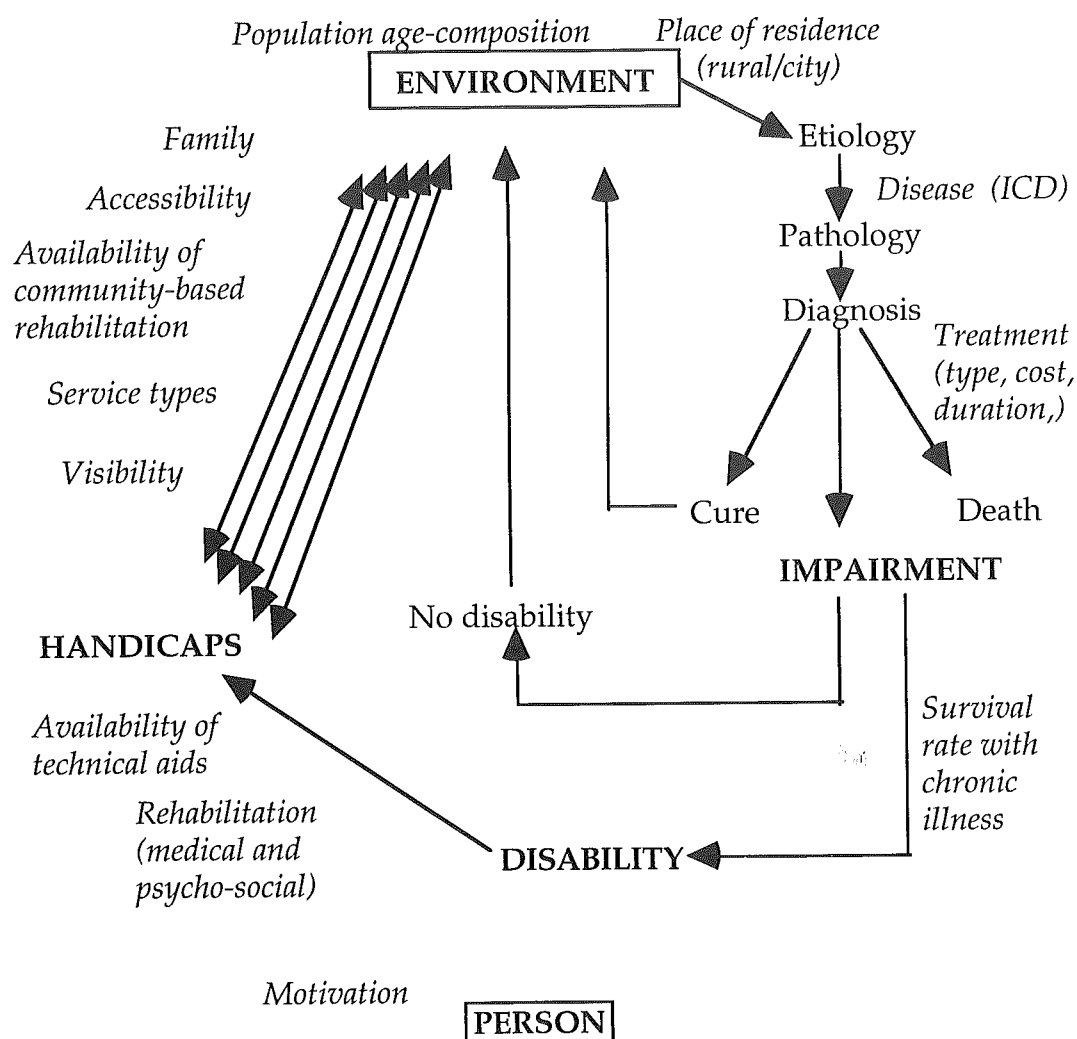


Source: World Health Organization (1980)

One model attempting to break down the apparent linearity of the process was developed by Badley (1987).



Another unifying scheme of the disablement process, developed by Minaire, is presented below. The biomedical model embraces the items on the right (including etiology, cure impairment and death). The ICIDH model is focused on the lower half of the diagram (including impairment, disability and handicaps). The situational model covers environment, handicaps and disability. The quality-of-life model is focused on handicaps only. The factors likely to modify (positively or negatively) the process of disablement are indicated in italics.



Source: Minaire (1992)

Impairment

ICIDH definition

'In the context of health experience, an impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function.

Note: 'Impairment' is more inclusive than 'disorder' in that it covers losses e.g. the loss of a leg is an impairment, but not a disorder.' (World Health Organization 1980)

ICIDH characteristics

'Impairment is characterised by losses or abnormalities that may be temporary or permanent and that include the existence or occurrence of an anomaly, defect, or loss in a limb, organ, tissue, or other structure of the body, including the system of mental function. Impairment represents exteriorisation of a pathological state, and in principle it reflects disturbances at the level of the organ.' (World Health Organization 1980)

Problems with ICIDH concept of impairment

- Discrimination between structure and function
- Overlaps with ICD
- Overlap with disability.

Impairment—ICIDH proposed definition 1993

Any abnormality of psychological or physical functions or of appearance.

Disability

ICIDH definition

'In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.' (World Health Organization 1980)

ICIDH characteristics

'Disability is characterised by excesses or deficiencies of customarily expected activity performance and behaviour, and these may be temporary or permanent, reversible or irreversible, and progressive or regressive. Disabilities may arise as a direct consequence of impairment or as a response by the individual, particularly psychologically, to a physical, sensory, or other impairment. Disability represents objectification of an impairment, and as such it reflects disturbances at the level of the person.

Disability is concerned with abilities, in the form of composite activities and behaviours, that are generally accepted as essential components of everyday life. Examples include disturbances in behaving in an appropriate manner, in personal care (such as excretory control and the ability to wash and feed oneself), in the performance of other activities of daily living, and in locomotor activities (such as the ability to walk).' (World Health Organization 1980)

Problems with ICIDH concept of disability

- General term
- Ability versus activity versus role
- Environment
- Causality: environment
- Overlaps with impairment/handicap?

Definition of disability—ICIDH proposal 1993

An interference with the performance of an activity by an individual in relation to the immediate environment.

Handicap

ICIDH definition

'In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on the age, sex, and social and cultural factors) for that individual.' (World Health Organization 1980)

ICIDH characteristics

'Handicap is concerned with the value attached to an individual's situation or experience when it departs from the norm. It is characterised by a discordance between the individual's performance or status and the expectations of the individual himself or of the particular group of which he is a member.

Handicap thus represents socialization of an impairment or disability, and as such it reflects the consequences for the individual—cultural, social, economic and environmental—that stem from the presence of impairment and disability.

Disadvantage arises from failure or inability to conform to the expectations or norms of the individual's universe. Handicap thus occurs when there is interference with the ability to sustain what might be designated as "survival roles".' (World Health Organization 1980)

ICIDH classification

'It is important to recognize that the handicap classification is neither a taxonomy of disadvantage nor a classification of individuals. Rather it is a classification of circumstances in which disabled people are likely to find themselves, circumstances that place such individuals at a disadvantage relative to their peers when viewed from the norms of society.' (World Health Organization 1980)

Problems with ICIDH concept of handicap

- Not fully developed
- Definition of a role
- Specification of disadvantages within society.

An international meeting to discuss the procedure for revising the ICIDH occurred in Washington, USA in December 1993. The expected date for revision

of the ICIDH 1980 will be 1999. One cross-cutting and three subject area groups were established covering:

- movement;
- sensory communication and perception; and
- mental and behavioural development.

The latter is proceeding to develop taxonomic guidelines.

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- Badley EM (1993) An introduction to the concepts and classifications of the International Classification of Impairments, Disabilities, and Handicaps. *Disability and Rehabilitation* 15(4): 161–178.

Copies of the ICIDH can be obtained from:

WHO Distribution and Sales Unit
20 avenue Appia 1211
Geneva Switzerland (Fax 41 22 7880401)

Progress on the development of the ICIDH is regularly reported in the Newsletter published by
WHO Collaborating Centre for the ICIDH
Nationale Raad voor de Volksgezondheid,
PO. Box 7100
2701 AC ZOETERMEER
The Netherlands

A copy of Newsletter 13, reporting on the Washington 1993 meeting, may be obtained by contacting the Disability Services Unit, Australian Institute of Health and Welfare, Canberra.

Session 1.2 Disability measurement in action

Use of the ICIDH from a population survey perspective

Jennie Widdowson
Australian Bureau of Statistics, Canberra

Introduction

The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) was originally presented as a trial framework to facilitate the recording and collection of data relating to the consequences of disease and to resolve problems which previously existed in attempting to classify impairments, disabilities and handicaps.

This classification was a first attempt to define the concepts of disablement in a 'common language' which could be used both for medical purposes and for statistical collection and avoids a partitioning between the medical and social consequences of disease.

In relation to the use of the ICIDH in population surveys, the classification needs to be evaluated from the point of view of whether it can be used to provide useful information and whether the concepts can be successfully operationalized for survey use.

Background

The ICIDH provides a conceptual model to describe disablement in terms of three interrelated events. These are:

- impairment, which may be described as something abnormal occurring within an individual (e.g. a disease, accident or abnormality). This does not necessarily imply that the individual is sick.

This may lead to :

- a disability, which describes the functional limitations of an individual or a restriction in performing certain activities as the result of an impairment. A disability is always measured in relation to the individual.

As a result, the individual may have:

- a handicap, which is a limitation or disadvantage which arises from the interaction of the individual and the social, physical or economic environment in which they live. A handicap can also be described as a loss of opportunity or barrier for an impaired person (e.g. a loss of opportunity with respect to educational attainment or occupational mobility or the inability to socialise, take care of oneself or move around adequately as a result of an impairment or disability).

Application of the ICIDH to population surveys

Population surveys on disability are used to produce data for policy making and planning. They need to be designed with the needs of users in mind as well

as the uses to be made of the data and should focus on the areas of greatest concern within the community.

Household data is collected in population surveys by interviewers who are trained to collect statistics in an unbiased and neutral environment, but they are not medically trained. Some data which is reported to interviewers may be less reliable than that obtained by trained professionals through a medical examination. However, as the information reported is only used to assign an individual to a category, much less detailed data are required than when medical assessments are made for legal purposes or for entitlement to government benefits.

The overall aim of a survey on disability is to obtain a reasonably accurate and objective assessment of the disablement of the population which is of use to a broad spectrum of users who may include academics, government and community organisations. It was not intended that the ICIDH should be applied in its full form in population surveys, but that it should provide a conceptual framework as a point of reference.

Most surveys on disability use the concepts set out in the ICIDH as guidelines, but there are a number of ways to operationalize these concepts to provide the information required by a particular country. As a result, there may be vast differences obtained from survey results by the use of different question wording or sampling methodology even though the underlying concepts remain the same.

The operational definitions used in a survey are based on the questions which are asked, and although they might broadly adhere to the concepts stated in the ICIDH, they may not be identical to the conceptual definition. However, there may be quite legitimate reasons for operational definitions to vary from the conceptual definitions, such as the need to produce statistics for a particular use by planners or researchers.

Disability can be identified and the level of disability determined by asking specific questions concerning an individual's abilities or lack of abilities to perform various tasks. These lack of abilities can also be ranked and scored to give a profile of disability and its severity as has been done in the United Kingdom in their survey of disability (Martin, Meltzer and Elliot 1988). Similarly, handicap and the severity of handicap can be identified by asking questions concerning barriers and restrictions encountered by an individual as a result of his/her disability.

In an analysis of the types of information on disablement collected by population surveys (Council of Europe 1990), it was suggested that disability surveys can be classified into two broad groups. Those which focus on impairment and disability produce output which is mainly concerned with functional limitation, while those which concentrate on disability and the resulting handicaps have their main focus on activity restriction. However, there may also be some overlap between these two types of surveys. The ABS surveys fall into the latter group, with a concentration on handicap and the limitation and restrictions on activity.

Difficulties with the concept of handicap

Interpretation of the concept of handicap into an operational definition has proved to be difficult because the original ICIDH definitions did not make a clear distinction between the application of the definition of disability and the definition of handicap. It is clear that the concept of disability applies to a person's abilities or lack of abilities while the concept of handicap is the result of these disabilities in most cases, but it is difficult to draw out this distinction when trying to devise questions for a survey to define these concepts. Because of the somewhat indefinite distinction made operationally between disability and handicap, it is possible to collect information on both disability and handicap and their level of severity, using essentially identical survey questions. However, disability must be analysed and expressed in relation to a person, while handicap should be measured in relation to the barriers or restrictions to the individual, caused by their environment and as a result of impairment.

The ABS surveys of disability and handicap

Australia was one of the first countries to try to apply the concepts of the ICIDH to population surveys. This was in the 1981 Survey of Handicapped Persons. Subsequent surveys in 1988 and 1993 used essentially the same definitions as the first survey.

The definitions developed in the 1981 survey were an attempt to translate the concepts of the ICIDH into questions which would be consistently understood by the persons responding to the survey. It would be too complex and time consuming to ask about an exhaustive list of impairments and disabilities. Therefore, as a result of testing, a list of 12 impairments/disabilities were selected as being the most significant to identify most people with disabilities in the community. These questions were used as a screen to identify respondents who would be asked further questions to identify the presence of a handicap.

Activities used in the assessment of handicap were chosen to be representative of various tasks which were used as indicators of difficulties or barriers experienced by persons with disabilities.

Handicap versus disability

When the 1981 Survey of Handicapped Persons was being developed the measurement of handicap and the associated level of severity was of prime importance to the users of data from this survey. Information on handicap was preferred to disability as current government programs were directed towards allocating funds based on handicap and away from services directed to a single disability type. The ICIDH was used as a starting point to identify handicap and the six major survival roles were investigated for use in the survey. During survey development it was realised that it was not easy to translate all these survival roles into questions which could be consistently understood by persons responding to surveys. It was decided that there would be no attempt to cover social and cultural integration or economic self-sufficiency because of the subjective nature of these handicaps. Five areas of handicap were considered to be feasible to measure and within the scope of the survey. These were self-care, mobility, communication, occupation and education. Tasks and activities selected to measure these areas of handicap were not an exhaustive

list, but were chosen as being the most representative and indicative for each area. It would be impossible to ask questions on all activities and tasks as this would be too time-consuming and would add unnecessary respondent burden.

Survey screening questions

In order to identify the target population for a survey of handicap and disability, the total population needs to be screened for their possible inclusion. A set of search questions was defined before the 1981 Survey, after discussions with user groups about their needs. The search list was originally based on a broad list of impairments, but after testing it was found that these did not identify everyone who should have been included in the target group.

Details of screening questions

Disabilities: functional limitation	Disabilities: activity restriction	Impairments	Chronic conditions
Loss of sight	Incomplete use of arms or fingers	Blackouts, fits and loss of consciousness	Long term treatment for nerves or an emotional condition
Loss of hearing	Incomplete use of feet or legs	Disfigurement or deformity	
Loss of speech	Restriction in physical activity		
Slow at learning or understanding	Difficulty gripping things *		
Help required due to mental illness			
Long term treatment or medication, but still restricted			
Long-term effects of head injury, stroke or brain damage *			
Restriction caused by other condition *			

* Added for the 1993 survey.

The final list included nine key disabilities and two key impairments which were known to lead to handicap. It was acknowledged that only the key disabilities and impairments should be identified because of the length of time required to collect more detailed information. In addition, one indicator of a chronic condition which may also lead to handicaps was included. It was necessary to include these additional indicators in the search list as, while some of these do not lead to a disability, they may result in a handicap.

This list of screening questions remained the same for the 1988 survey but three additional disability items were added for the 1993 survey. Although the initial screening questions are acknowledged to include items other than disabilities, they are used to produce a base population to be studied which has been broadly identified as the 'disabled population'.

Comparison of ABS and ICIDH classifications for handicap

The ABS classifies handicap by five dimensions while the ICIDH proposed seven. The ABS has not tried to collect data on orientation, social integration, economic self-sufficiency or 'other' handicap.

ICIDH handicap dimensions and ABS equivalents

Handicap	ICIDH handicap codes	ABS equivalent handicap
Orientation	—	not collected
Physical dependence	21, 23, 25, 26, 27, 28	Self-care—profound, severe, moderate, mild
Mobility	32, 33, 34–37, 38	Mobility—profound, severe, moderate, mild
Occupation	—	Occupation Schooling
Social integration	—	not collected
Economic self-sufficiency	—	not collected
Other	—	not collected

The physical dependence handicap specified in the ICIDH is broadly covered by the self-care handicap described by ABS with the levels of severity being equivalent to various levels of dependence specified by the ICIDH.

The ABS mobility handicap covers the same areas of mobility as the ICIDH specifications but makes a distinction between help needed and difficulty experienced, for any of the mobility tasks, while the ICIDH grades the handicap by the type of restriction (e.g. chair, room, dwelling etc.). This means that the two mobility handicaps are measuring a slightly different concept and functionality. However, the ABS definition was derived so that the basis for measuring severity was similar to that used in the self-care handicap and so that there was comparable scaling for deriving an overall measure of severity of handicap.

The occupation handicap in the ICIDH is used to describe the ability of an individual to occupy his/her time and so can measure both the restriction or barriers to education, unpaid work and recreation as well as employment. The ABS interpretation has been to apply occupational handicap only to employment activities for persons of working age and to use an additional schooling handicap which applies only to those attending school. This means that there is no measurement made of restrictions or barriers for non employment/school based activities such as household, recreational and leisure activities. In addition, there is no derivation of the level of severity of the occupation or schooling handicap, although, from the questions asked in the survey, this could be derived.

The communication handicap defined by the ABS does not exactly equate with any of the ICIDH descriptions of handicap, but is much closer to the description of speaking disability within the communication disability group. However, this was a particular area of interest to some users and, by relating

the questions asked to the amount of help required from other persons, it is not only matched in scale with the ABS mobility and self-care handicaps but was also defined as a barrier for the person.

Measurement of disability

The ABS has not previously produced any data on particular disabilities or any measurement of the severity of disability. However, sufficient questions have been included in the surveys so that data could be produced about all the main groups mentioned in the ICIDH except for behaviour disabilities, particular skill disabilities and 'other' disabilities. It is unlikely that data could be successfully produced via a population survey for these three disabilities as they are either too difficult to measure without a medical examination or they are too subjective.

ICIDH disabilities which could be derived from ABS data

Disability	ICIDH disability codes possible from ABS data
Behaviour	15
Communication	20, 21, 24, 25-27
Personal care	30-32, 33, 35, 38
Locomotor	40, 41, 42, 46
Body disposition	51, 52, 54
Dexterity	61, 63
Situational	70
Particular skill	none
Other	none

Limited data would be available concerning body disposition disabilities, dexterity disabilities and particular skill disabilities, while communication, personal care and locomotor disabilities would be quite adequately covered. It would also be possible to apply levels of severity for communication, personal care and locomotor disabilities.

Conclusion

It is generally agreed that the concepts put forward in the ICIDH provide a good framework for collecting data on impairments, disabilities and handicaps and most population surveys have been developed using the ICIDH framework. However, there are many problems in operationalizing these concepts into questions which are not subjective and are suitable for inclusion in a population survey. The suggestions made in recent papers (Chamie 1990; Council of Europe 1990) to improve the definitions of handicap and disability will hopefully allow these to be more easily collected in population surveys. Extending the definition of handicap to include environmental factors and dividing disability so that both functional limitations and activity restrictions can be measured should make the data more easily understood and more useful.

A number of differences have been identified between the ABS interpretation of the ICIDH concepts and the descriptions given as part of the framework. These differences were originally a function of user requirements. Any changes made for future surveys have to be considered from the point of view of both maintaining a comparable time series as well as trying to adhere as closely as possible to an international standard.

In addition, there are some areas not covered by the output from the ABS surveys. While it was never intended that all areas of the framework should be included in a population survey, it is possible that more extensive use could be made of the information already collected. It is intended to redress this in future proposed publications of data from the ABS disability surveys.

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Comparing the ICIDH with disability measures in national data collections for Australian aged care services

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The ICIDH was developed to assess the consequences of disease, in particular chronic disease. It is chronic diseases which most often result in disability and handicap in the elderly. This paper compares the ICIDH with assessment of the elderly in national data collections for Australian aged care services. At present there is no comparable measure of disability across aged care data collections. The potential advantages to using the ICIDH to standardise those data collections are explored here.

I will start by very briefly outlining the Australian government funded aged care system and showing where data is collected. I will then compare the conceptual classification of the ICIDH with these data collections before examining in more detail their comparison with the disability code of the ICIDH.

Australian Government aged care system

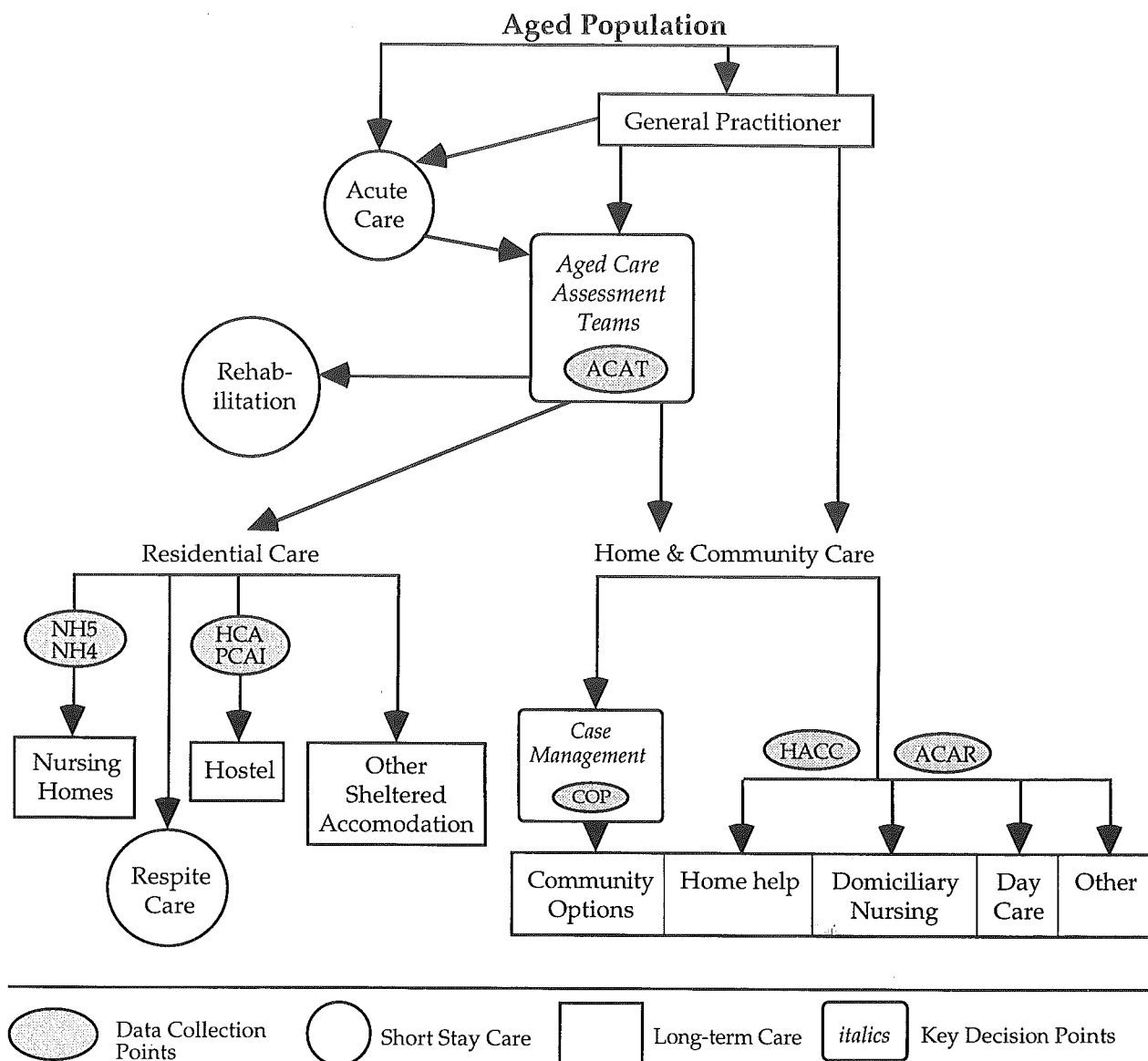
Figure 1 outlines the Australian Commonwealth Government aged care program. It shows that general practitioners and Aged Care Assessment Teams, or ACATs, usually determine whether there is a need for residential care or whether the aged person can be cared for within the community with the support of Home and Community Care (HACC) programs.

Increasingly, assessment of levels of dependency and disability are used to determine individual need for aged care services. Such assessments occur at various points in the aged care service network. The darkened ovals in Figure 1 indicate where data collections assessing disability and dependency occur.

Aged Care Assessment Teams (ACATs) have a major responsibility for assessment of the aged in need of care. ACATs are shown in the upper middle portion of Figure 1. ACATs assess all residents entering federally funded nursing homes and commencing this year will also assess all residents entering hostels. They also refer many elderly to home and community care services. ACATs are multi-disciplinary teams trained to assess the physical, medical, psychological and social needs of the frail and disabled aged and to assist them to access suitable services.

ACATs in each state employ a variety of assessment instruments and there is no standard assessment procedure. However, at the national level, a standard minimum set of 23 items has been determined that are extracted each six months from ACAT records in each state and from 1994 will be compiled into a national minimum data set.

Figure 1: Diagrammatic representation of Australian aged care service network showing points of national data collection.



Notes:

The diagram does not present all possible paths. In particular, it omits the sideways and backward paths.

For nursing homes, 18% are State government sector (AIHW 1993), and may not use the NH4 and NH5.

ACAT	Aged Care Assessment Team National Minimum Data Set
ACAR	Aged Care Assessment Record Pilot Project (Client Information, Assessment and Referral Record)
HACC	Home and Community Care client characteristics
COP	Community Options Projects client characteristics
HCA	Hostel Care Assessment Application Form (197A)
PCAI	Personal Care Assessment Instrument
NH5	Application form for Nursing Home Admission
NH4	Application form for Resident Classification

Further down the diagram in Figure 1 are the home and community care services. Data collections undertaken here are the Community Options Projects Client Characteristics (COP), the Home and Community Care Service Users Characteristics (HACC) and the Aged Care Assessment Record (ACAR). The Community Options data come from a survey of client characteristics. It is carried out approximately every six months in each state. The HACC data collection is a sample survey of user characteristics that is carried out annually for those persons who have received home and community care services within a specified one month period. The Aged Care Assessment Record is a pilot program and the first data collection was undertaken by consultants in September–October 1993 and currently no data are available.

For residential care services, entry to nursing homes and hostels is determined by ACATs using the NH5 form for nursing homes and the PCA form for hostels. These records are used to determine eligibility, and are available for each individual assessed for care. Once in residential care, the NH4, which is used to determine the Resident Classification Index (RCI), and the Personal Care Assessment Instrument (PCAI) are used annually to assess level of care to determine funding to the home.

The purposes of these national data collections are diverse. Residential care assessments are undertaken to determine both access to residential care and levels of federal government funding paid to the nursing home or hostel per resident. HACC and Community Options data collections are designed to provide a profile of clients accessing services to ensure that programs are meeting the government's access and equity requirements. The Aged Care Assessment Record is a pilot project testing the possibility of minimising the need for multiple assessments of elderly persons by providing an ongoing record for multiple service providers. ACATs provide the broadest assessment and are designed to meet several needs, but primarily to ensure that services are accessed by those who most require them.

Equally diverse is the training of the persons undertaking the assessments. ACAT and nursing home assessments are undertaken by trained, often medically trained, specialists in geriatric care. Hostel, HACC, Community Options and Aged Care Assessment Record assessments are carried out by a variety of service providers, some of whom are volunteers and many of whom have limited education and training.

The assessment of disability in each of these data collections, therefore, reflects both their diversity of purpose and the diversity of background and training of the assessors.

Comparison with the ICIDH

Table 1 presents the items used to assess disability and dependency in the Australian aged care services national data collections. These items are compared with the ICIDH and also with the Australian Bureau of Statistics 1993 Survey of Disability, Ageing and Carers (ABS 1993), the results of which have just been released. Not surprisingly, since their sole function is to measure disability, the ABS survey and ICIDH provide by far the most comprehensive measures.

Table 1: Disability items in National Data Collections for Aged Care Services, the ABS Disability, Ageing and Carers Survey 1993 and ICIDH
(see end of table for details of interpretation)

	Assessment		Home and community care		Hostels		Nursing homes			
	ACAT	ACAR	HACC	COP	HCA	PCAI	NH5	NH4	ABS93	ICIDH
Activities of Daily Living										
continence ^{1,2,3}	*		*	*		*	*	*	*	31
use of toilet ³		*				*	*	*	*	32.0
mobility	*	*	+transfers	*		*	*	*	*	40
transfers ³		*		*		*	*		*	46
stairs									*4	42
grooming		*								10.2 34
bathe/shower ³		*		*		*	*	+dressing	*	33
dress/undress ³		*		*	*	*	*		*	35
eating ³		*		*		*	*	*	*	38 38.1
falls							*			no
catheter/colostomy							*			30.2 30.3
foot care		*							*	34.3
personal appearance				*						10.2 34
personal hygiene					*					10.2 34
personal care (bathing, feeding)			*							
Instrumental activities of daily living										
take medicine				*	*				*4	no
shopping		*		*					*4	50.0
bank and shop					*					
money and finance				*					*	61.1
clean house		*	+meals	+laundry	*				*4	51.4 51.5
prepare meals		*		*	*				*4	50.2–8
do laundry					*					51.1 51.2 51.3
minor home maintenance		*		*					*4	no

Table 1: Continued

	Assessment		Home and community care		Hostels		Nursing homes			
	ACAT	ACAR	HACC	COP	HCA	PCAI	NH5	NH4	ABS93	ICIDH
telephone		*		*	*				*4	61.0
transport		*		*	*	public			*4	47
read					*				*4	26
write					*				*	28
Indicators of cognitive disturbance										
orientation	*						*			11
speech/ comprehension								*	*	20 21
communication			*	*		*			*	29
physical aggression						or verbal		*		19.4
verbal disruption								*		19.4
behaviour			*	*		*	*	*		19.4
wandering						*	*			13.5
sleep disturbance							*			no
motivation						*				18.0*
understanding of daily living tasks						*				
dementia				*					*	
Medical										
vision								*	*	25
hearing								*	*	23
primary diagnosis	*									
major medical diagnoses							*			
special diet					*	follows	requires			70.6 requires
rehabilitation support							*			
independence therapy								*		
skin integrity								*		
specialised treatments						*		*		

Table 1: Continued

Notes:

- * Indicates that an item measuring this activity is contained in the instrument
- 1 Items comprising the Barthel ADL Index are indicated in italics
- 2 Coded separately for bowel and bladder in the NH5, ABS Disability Survey and Barthel Index
- 3 Items comprising Katz Index of ADL
- 4 There are several questionnaires comprising the ABS survey. These items are not included in the questionnaire for the Establishment Component (hospitals, nursing homes, hostels, retirement villages).
 - Only items comparable with the aged care services data collections are presented for the ABS 1993 Disability Survey and ICIDH. These instruments contain many more items measuring disability that are not presented here.
 - Different scoring systems are used in each instrument. Although the same function may be measured, the coding system may not be comparable (see Tables 2 and 3).
 - For some items the concept of comparability is somewhat stretched. For example, in the ICIDH 'motivation' refers to 'interference with ability to work by virtue of severe impairment of drive' and in the PCAI refers to 'degree of resident's ability to initiate daily tasks and activities without regular direction from others'. While both these items measure motivation they are quite distinct. This is possibly the most extreme example of such incomparability.
 - The first digit of the D code of the ICIDH indicates the type of disability; behaviour (1), communication (2), personal care (3), locomotor (4), body disposition (5), dexterity (6), situational (7), particular skill (8), and other activity restrictions (9).

It must be kept in mind, however, when examining this table that although an item may be measuring the same function, comparison across data sets may not be possible due to different levels of measurement between the instruments and somewhat different wording of the items. Table 2 provides an example of the difficulty comparing items across instruments for one of the most commonly measured items, mobility. The ACAT item determines whether the person walks independently or not. The HACC item questions whether the person needs or receives assistance with mobility which is defined as walking and getting in and out of bed. Although the concept of mobility is comparable, you can see that it is operationalized in very different ways.

To my knowledge none of the instruments used in these data collections was based on the ICIDH, or developed with its concepts in mind. This assertion comes only from examining the instruments, however, as there is no public documentation of their genesis. They appear to have developed atheoretically as purpose-built instruments, as have many other measures of disability used in both research and practice (McDowell & Newell 1987). The basis of these instruments seems to be items from the Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) scales. However, standard examples of these scales, such as the Katz (Katz et al. 1963) and Barthel (Mahoney & Barthel 1965) Indexes, which have widely established validity and reliability (McDowell & Newell 1987; Research Unit of the Royal College of Physicians & British Geriatrics Society 1992), have not been replicated. The data collections reflect the purpose, background and narrow focus of their program areas. In contrast, the ICIDH deliberately departed from conventional assessment of ADL (Wood 1989).

Table 2: Items measuring mobility across data collections

Data source	Mobility item
ACAT	<i>Walks independently / Does not walk independently</i>
ACAR	Is assistance required with walking? <i>yes / no</i>

HACC	Does the person need or receive assistance with mobility (eg: walking, getting in/out of bed)? <i>yes / no</i>
COP	Can the person get around the house independently? <i>no need for assistance / some need for assistance / total need for assistance</i>
HCA	not assessed
PCAI	Mobility—refers to the degree and frequency of a resident's need for assistance to walk, or to use mobility aids such as walking frames and/or wheelchair if the resident normally uses these. <i>requires no assistance / requires individual supervision or some physical assistance on some occasions / requires individual supervision or some physical assistance on the majority of occasions / requires full physical assistance on the majority of occasions</i>
NH5	Mobility <i>walks unaided / walks with stick, frame, tripod / walks with the assistance of one person / walks with the assistance of two people / wheels self / wheeled by others / bed fast</i>
NH4	Mobility—refers to the degree and frequency of a resident's need for assistance with mobility and transfers. <i>requires no assistance or requires observation only; may use assistive devices / requires individual supervision or some physical assistance on some occasions / requires individual supervision or some physical assistance on the majority of occasions / requires total physical assistance on all occasions</i>
ABS93 (population component)	Do you ever need help to move about the house because of your condition? <i>yes / no / does not move about the house</i> Do you ever find it difficult to move about the house without help or supervision? <i>yes / no</i> Can you easily walk 200 m? <i>yes / no / does not leave home</i>
ICIDH	Walking disability: Includes ambulation on flat terrain. <i>not disabled / difficulty in performance / aided performance / assisted performance / dependent performance / augmented performance / complete inability</i>

Comparing the aged care data with the ICIDH raises several conceptual issues relevant to the national measurement of need in the elderly. First and foremost is that all the aged care data collections concentrate on the assessment of disability; none of them focus on impairment or handicap as defined by the ICIDH. They do not assess impairments as consequences of disease and, in fact, collect only the most rudimentary measures of disease itself. Their interest does not lie in the causes or even the immediate consequences of disease, but rather the practical consequences that affect daily life and personal care.

The omission of directly determining handicap is less understandable. While some assessment of handicap is either directly or indirectly undertaken at the time of assessment, this information is not included in the data collections. None of these data collections systematically assess handicap as outlined in the ICIDH. The problem of handicap is frequently avoided, or reduced to the disability level, because it is difficult to objectify and standardise the performance of roles and social disadvantage. However, it is this very factor that shows the social patterning of disablement and enables health and welfare resources to be directed to areas of greatest need (Bury 1987). The handicap measure of the ICIDH has been shown to correspond to type of care in Denmark, distinguishing between the elderly in residential, day home and sheltered housing (Dalgaard and Horwitz 1987). However, in an Australian nursing home the measurement of handicap was not continued after its six month trial because it was shown to be not useful (Last 1985).

This leads to two of the drawbacks of the ICIDH with national data collections: the time it takes to administer and the training needed for assessors. It often takes around 30 minutes for all the impairment, disability and handicap codes to be administered by a medically trained assessor (Jiwa-Boerrigter, van Engelen and Lankhorst 1990). This may be prohibitive for administrative national data collections. An essential ingredient to attain compliance in such data collections is brevity, meaning instruments that take only a few minutes (Butler, Fricke and Humphries 1993). Often these data are not collated at the time of assessment but as an added administrative burden. Short assessment instruments that take around three minutes to administer have, however, been developed for the disability code of the ICIDH (Jiwa-Boerrigter, van Engelen and Lankhorst 1990; van den Berg and Lankhorst 1990).

The second drawback is the training needed for assessors. Ford (1984) found that only medical officers trained in rehabilitation medicine and with experience in multi-disciplinary team work were able to interpret all the terms used when retrospectively coding medical records. As mentioned previously, data in hostels and home and community care services are sometimes collected by volunteers and generally collected by staff with limited training and education. Applying the ICIDH as it stands would be beyond the capabilities of these people.

Ford (1984) also found that physicians were most comfortable with the Impairment codes, physiotherapists with the Disability codes, and social workers saw the Handicap codes as useful. This raises an issue related to one of the main objectives of the ICIDH, which was to expand the outlook of those in specialist fields. While this is an admirable goal with many benefits, it is often impractical. Many data collections suffer because those working in the applied

field cannot see the relevance and benefits of gathering data beyond what suits their immediate needs in dealing with a patient. Diligent feedback of information can, however, help in this regard (Hoyes, Means & Le Grand 1992).

Assessing disability

Despite the advantages of a broader scope, the Australian aged care services data collections focus squarely on disability. It is, therefore, only items from the Disability code of the ICIDH that are presented in Table 1. The D code comprises nine types of disability: behaviour (1), communication (2), personal care (3), locomotor (4), body disposition (5), dexterity (6), situational (7), particular skill (8), and other activity restrictions (9).

Essentially all the items currently measured in the aged care data are contained within the D code of the ICIDH. Only falls and sleep disturbances, which are assessed in the NH5, and the minor home maintenance item that is important for some community care assessments are not directly assessed in the D code.

The ICIDH is obviously a much more sensitive and comprehensive measure of disability than the aged care data, which concentrate largely on personal care disabilities. To a lesser extent locomotor, communication and behaviour disabilities are also covered. Some body disposition disabilities are assessed but only those concerned with domestic disability. More specific dexterity and situational disabilities are barely touched by the aged care data.

The D code is also more sensitive in terms of its level of measurement. Disabilities can be measured at one, two or three digit level, with the two digit level the most commonly used and found to be more sensitive than the one digit level (Barrs & Dowell 1985). It is further recognised that disabilities are not threshold phenomena and that there is a graduation in performance. The D code has a supplementary digit that allows for recording the degree of disability on a seven point scale. Table 3 presents the categories of this scale and the corresponding categories for the aged care data collections. Many of the aged care data collections treat the disability items as threshold measures, although some do record up to four categories of severity or need for assistance. The D code also has a further seven point scale that can be used by those interested in rehabilitation or recovery potential. Such a dimension is not assessed in any aged care data collections.

Conclusion

In conclusion, although the ICIDH does not provide a system for assessment, it does offer an agenda for items that should be taken into account (Wood 1987). While there is important debate about the exact location of items within the classification (Cooper 1993), there is agreement that a classification system that crosses the disciplines of medicine, rehabilitation and social welfare services is highly desirable. A consideration of all these areas can only help the frail and disabled elderly by encouraging a holistic consideration of their many and interrelated needs. What is more important, though, for the collection of data that informs policy makers and program developers, is the conceptual basis and sensitivity of the ICIDH, which may enable the needs of the elderly and the social patterning of need to be better elucidated. Specifically, a greater understanding of handicap would allow improved targeting of health and welfare services to those most in need.

Table 3: Levels of measurement

Data source	Number of levels	Description of categories for levels of measurement
ACAT	2	yes / no
ACAR	3	independent / with assistance / dependent (for tasks of daily living)
	2	yes / no (for tasks of self care)
HACC	2	yes / no
COP	2	yes / no
	3	no need for assistance / some need for assistance / total need for assistance
HCA	3	with assistance / with supervision / totally independent
PCAI	4	no assistance / supervision and physical assistance for some tasks / supervision and physical assistance for majority tasks / full physical assistance for majority tasks
NH5	3	independent / need assistance / dependent
	4	never / sometimes / occasionally / frequently
NH4	4	no difficulty or assistance / some difficulty or assistance / majority supervision / total assistance
ABS93	3	yes, easily / with difficulty / no
	2	yes / no
ICIDH	7	not disabled / difficulty in performance / aided performance / assisted performance / dependent performance / augmented performance / complete inability

Furthermore, embracing such a system of standardisation would enable national and international comparisons. Only with standardisation can a national picture of disability and dependency in the elderly which accesses the whole range of government funded services be produced. Uniformity of language, understanding and insight into the interrelationships of the consequences of disease is essential (WHO 1989). Australia is rightly proud of its aged care services and believes itself in the forefront of the provision of an adequate balance of care for the frail and disabled elderly, with the ICIDH this could be tested via international comparisons.

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Impairment, disability and handicap from a workers' compensation system perspective

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Introduction

One of the great advantages of the World Health Organization's *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH) schema of 'impairment', 'disability' and 'handicap' is that it introduces conceptual clarity within an area which is often characterised by woolly thinking and conceptual elision.

The major challenge, and why I welcome this workshop, lies in the task of giving greater operational significance to this theoretical triptych of concepts. Presently, the chief barrier to the adoption of the impairment component (derived largely from the *International Classification of Diseases* (ICD)), lies in the need of workers' compensation systems for the provision of scaled values to assessments of impairment. While the 'I' codes, like the ICD itself, provide a sophisticated taxonomy of impairments, they do not, with the partial exception of aural and ocular impairments, meet the requirement, which occurs in a number of areas of workers' compensation scheme operation, for quite precise ascertainment of levels of impairment.

It is for this reason that a number of workers' compensation schemes have adopted the American Medical Association's *Guides to the Evaluation of Permanent Impairment* (AMA Guides) (or a variation of it in the case, for instance, of Comcare) to serve this role. The evaluation process under the AMA Guides is divided up by organ system, with the Guides specifying the medical information required for the evaluation of the nature of the impairment under review. The particular impairment is then expressed as a percentage of the total body function that has been lost.

It is almost certain that the lack of precise scaling is the reason why the only recommended recourse to the ICD, of which I am aware, in relation to workers' compensation schemes in Australasia, is contained in the New Zealand Law Commission's review of the operations of the New Zealand *Accident Compensation Act* (Law Commission 1988). Indeed the proposal to resort to the ICD lay precisely in its taxonomic strength, with the Law Commission wishing to give greater clarification to the notion of 'personal injury', being one element of the entitlement touchstone of 'personal injury by accident' which underpins that country's pioneering, comprehensive, accident compensation scheme. The Commission saw a detailed schedule, based on the ICD, as capable of specific adjustment so as to include or exclude matters for scheme coverage [paras 165-6]. As well, it regarded the use of the ICD 'E' Code as providing the most authoritative base for gathering useful injury information [para 281].

While the determination of levels of disability, for benefit purposes, is a fundamental aspect of the operation of workers' compensation schemes, it is not a process which builds upon the ICIDH framework. Apart from the elements which apply in relation to the operation of Part B of the Comcare

Guide, used in the determination of non-economic loss (and largely derived from the *Guide to the Assessment of Rates of Veteran's Pensions*, issued by the Department of Veterans Affairs) Australian workers' compensation statutes remain wedded to an impairment-based approach. In regard to the disability and handicap components of the ICIDH framework, the only significant consideration of this structure within workers' compensation systems was conducted by a Working Group on Impairment/ Incapacity Assessment, in Victoria, which developed some 'Disability and Handicap Severity Scales' to assist the implementation of certain provisions of the *Accident Compensation (General Amendment) Act 1989*. The work of this Group is discussed later in this paper and the 'Disability and Handicap Severity Scales' developed by it appear as an Appendix to the paper.

The nature of workers' compensation systems

In order to place the discussion of 'impairment', 'disability' and 'handicap' within the realm of workers' compensation in its proper context, it is necessary to make some preliminary comments about the nature and role of workers' compensation itself.

Workers' compensation is, in many respects, a system in search of a principle. It emerged in the late nineteenth century as a 'no-fault' compensation system in response to the almost total inability for injured workers to obtain compensation for work injuries under the prevailing common law system. In its original Anglo-Australian conception, workers' compensation was devised as a limited amelioratory measure to assist workers in 'dangerous' industries. The operation of the English *Workmen's Compensation Act 1897*, which served as the model for the earliest Australian workers' compensation statutes, was confined to a number of defined classes of 'dangerous employment', namely factory, mining, quarrying and engineering employment, work on or about a railway and on or about any building which exceeded thirty feet in height.

The concept of general coverage of workers in all industries and occupations came with 1906 English Act with the major exclusion being an income test. The first Victorian workers' compensation statute, the *Workers Compensation Act 1914*, was (with the addition of the 'Table of Maims', derived from New Zealand legislation) copied from the English Act. The income threshold was removed in 1972. In the intervening sixty year period, coverage of the compensation statute was extended in a number of ways, including deemed employment (e.g. in respect of share farmers) and deemed coverage (e.g. in regard to journey and recess injuries). This incremental process of expansion was described by Judge Harris in his 1976 Report in terms of 'workers' compensation in Victoria [having] developed into an elaborate but rather disordered scheme for social security benefits'. Further expansion of the Victorian scheme occurred in 1985, followed by a fundamental reordering in 1992. The 1992 changes included the removal of journey claims from system coverage and substantial modification of the benefit structure.

What this encapsulated history reveals is that there are no natural boundaries to the operation of workers' compensation schemes. A further complicating feature is that Australia, Canada and the United States are the only three (out of 141) nations with major occupational disability compensation arrangements operative at the sub-national (i.e. state, territory or provincial) level. Thus, in

Australia, workers' compensation exists as ten different employer financed schemes of occupational injury and disease benefits which parallel a federally administered, taxpayer financed, system of social security. Apart from considerable variation in the major features (e.g. in terms of entitlement, levels of benefit, etc.) of the various State schemes, there is an ongoing debate as to the respective responsibilities (particularly in terms of the proper assumption of costs) between State/Territory workers' compensation arrangements and the federal social security system. The matter of cost shifting between these two areas was a significant issue in the recently released Industry Commission Report on *Workers' Compensation in Australia*.

One of the most intractable problems for workers' compensation schemes lies in the area of permanent partial incapacity and the manner in which they can avoid, particularly in times of economic downturn, becoming de facto unemployment insurance systems. That is, a worker's injury may result in a temporary removal from the labour market because of an inability to continue normal employment (temporary total incapacity). However, with time and treatment, the injury heals and the injured worker may be left with a residual permanent partial incapacity. This may leave workers unable to perform their original occupations but there may be other suitable employment which they could adequately perform.

In times of economic prosperity such jobs would be freely available and, having found such employment, the ongoing liability of the compensation system may be in terms of a payment to bridge (either wholly or in large part) the difference between the worker's earnings in pre-injury and post-injury employment. However, in times of economic recession, the state of the labour market means that such employment is not available to these workers (nor to many suitable workers with no residual disability). The question, then, lies as to the proper liability of the compensation system in regard to ongoing payments for persons in this situation.

The problem of boundary definition and the demarcation of responsibility is thus an endemic one for workers' compensation systems. It is into this area that concepts of 'impairment' and 'disability' (but only occasionally 'handicap') are often pressed into service.

Impairment

Measures of impairment operate in two broad areas of Australian workers' compensation practice. First, in terms of a specific benefit measure which relates to the type and level of impairment; secondly, as a threshold screening measure in relation to actual entitlement to a particular form of benefit (e.g. the ability to pursue a common law action for damages) or in determining the level (or continuing level) of benefits to which an entitlement already exists (e.g. the level of benefits for 'serious injury' under the Victorian *Accident Compensation Act*).

Compensation for impairment

The various Australian workers' compensation statutes contain an impairment table, commonly described as a 'Table of Maims'. This had its origins in the New Zealand *Workmen's Compensation Act 1908* and was reputedly the brainchild of the prominent jurist, Sir John Salmond. It was first introduced into

Australia in the 1910 Tasmanian workers' compensation legislation and, in time, was adopted in all jurisdictions. The table is essentially a ranking of impairments in one column with a corresponding compensation amount in the other column, such amount either being a specified monetary figure or a percentage of a prescribed maximum amount.

It is only in relatively recent times that the traditional 'Table of Maims' has been expanded from its original focus on loss, or loss of use, of sight, hearing, mental powers and members or sections of members. Indeed, until 1985, the only difference between the Table in the then Victorian legislation and that enacted in 1914 was the more particularised treatment of loss of digits in terms of individual phalanges. A period of expansion began with New South Wales adding facial disfigurement to their Table in 1964, followed by loss of taste or sense of smell in 1967, the physical loss of an eye in 1971 and the loss of sexual organs in 1980.

The next logical step, moving to a fully comprehensive impairment benefit has only been undertaken at the Commonwealth level, the *Safety, Rehabilitation and Compensation Act* (Comcare) and the *Seafarers Rehabilitation and Compensation Act* (Seacare), and in the Northern Territory (*Work Health Act*).

Screening device

A number of workers' compensation schemes have made a decision to limit access to certain benefits to the more severely injured workers, either on grounds of equity or of scheme efficiency, (i.e. the transaction costs as a percentage of total costs involved in the administration of minor claims). This can be seen, for instance, in the 30% impairment threshold (supplemented by a serious injury test) for the pursuance of a common law action for damages under the current Victorian legislation and in the 10% impairment threshold which operates in relation to Comcare's payments for injuries resulting in permanent impairment and compensation for non-economic loss under Division 4 of the *Safety, Rehabilitation and Compensation Act*.

In other situations, after entitlement to benefits has been established, some schemes employ an impairment test as a screening device for the determination of the *level* (or continuing level) of ongoing benefits. In this area, however, the concept of impairment is effectively being utilised to determine a matter of disability or incapacity. In other words, impairment is being used as a proxy for disability. This was the situation with the former section 93B of the Victorian *Accident Compensation Act*, in response to which the Tripartite Committee and the Working Group, whose operations are described below, were created.

Disability and handicap

Disability

The terminology used in workers' compensation schemes in relation to this question does not follow the ICIDH lexicography. Where the term 'disability' is used it usually refers to the ICIDH definition of impairment (see for example the definition of 'disability' in the *Workers Rehabilitation and Compensation Act* 1986 (SA), s. 3(1) and the *Workers' Compensation and Rehabilitation Act* 1981 (WA), s. 5(1)). The most commonly used term which equates to the ICIDH use of disability is that of 'incapacity'. Thus, for instance, the *Northern Territory*

Work Health Act 1986 defines 'incapacity' as 'an inability or limited ability to undertake paid work because of an injury'.

The crucial divide in this area lies in the terms of a duration and severity matrix: temporary as against permanent incapacity and partial as against total incapacity.

Duration of incapacity	Severity of incapacity
Temporary	Partial
Temporary	Total
Permanent	Partial
Permanent	Total

It is a crucial divide since weekly benefits of workers' compensation are payable to an injured worker during a worker's incapacity for work, and the level of such benefits varies according to whether the incapacity is regarded as total or partial in nature. Apart from the Victorian legislation, what precisely is meant by these terms has largely been left to judicial interpretation. The ruling High Court view is that 'incapacity' means 'physical incapacity for actually doing work in the labour market in which the employee works or may reasonably be expected to work' rather than physical incapacity resulting in actual economic loss [*Arnott's Snack Products Pty Ltd. v Yacob* (1985) 59 ALJR 215]. While this statement is generally valid for the various Australian jurisdictions, it was a view expressed in relation to section 11(2) of the *Workers' Compensation Act 1926* (NSW) and there may be some legislative qualification which affects its application in particular jurisdictions.

However, the general thrust of workers' compensation legislation, in relation to incapacity, is directed not to the injured worker's actual employment but to suitable or accessible employment. This is made clear in the Victorian legislation which does define both 'total incapacity' and 'partial incapacity'. These definitions are in the following terms:

'total incapacity' in relation to a worker, means an inability arising from an injury such that the worker is not able to return to work, either in the worker's pre-injury employment or in suitable employment; and

'partial incapacity' in relation to a worker, means an inability arising from an injury such that the worker is not able to return to his or her pre-injury employment but is able to return to work in suitable employment.

This particular focus is related to the matter discussed earlier, namely the question of system boundary definition. Thus the workers' compensation legislative provisions are often directed to measures which attempt to ascribe some notional earnings to a partially incapacitated worker, on the basis of their degree of residual capacity, or incorporates into the legislation a provision that the proper responsibility of the compensation system is to maintain benefits to such partially incapacitated workers for a prescribed period after which employer responsibility is discharged and benefits cease.

Handicap

The ICIDH notion of handicap is one which only intrudes interstitially into the operation of workers' compensation systems. It chiefly operates in terms of a modifier to the application of suitable employment provisions in respect to a particular worker's incapacity. Thus, in the recently enacted federal seafarers' legislation, it is provided that:

'suitable employment', in relation to an employee who has suffered an injury in respect of which compensation is payable under this Act, means any employment (including self-employment) for which the employee is suited having regard to:

- (a) the employee's age, experience, training, language and other skills; and
- (b) the employee's suitability for rehabilitation or vocational retraining; and
- (c) if employment is available in a place that would require the employee to change his or her place of residence—whether it is reasonable to expect the employee to change his or her place of residence; and
- (d) any other relevant matter.

[*Seafarers Rehabilitation and Compensation Act 1992*, s. 3]

This is the least developed area of workers' compensation system design and probably the most sophisticated attempt to deal with it occurred in relation to the Victorian study described below.

A Victorian case study

Background

Mention was made earlier as to the trigger point providing the effective demarcation of workers' compensation schemes from de facto unemployment insurance systems with respect to partially incapacitated workers. One such attempt was made in Victoria, under the former WorkCare scheme, with a provision which was contained in the *Accident Compensation (General Amendment) Act 1989*. This provided for the reduction of weekly payments of compensation from 80% to 60% of pre-injury earnings where a worker had been on benefits for twelve months, if:

the worker's level of impairment resulting from, or materially contributed to by, the injury would, if assessed according to the methods prescribed . . . be less than 15 per centum.

Due to concerns about the potential operation of this provision, since a 15% impairment can have radically different employment disability consequences between, for instance, a white collar professional and a manual labourer, the Government established a Tripartite Committee (i.e. with government, employer and union representation) to develop the 'prescribed methods' for the operation of this provision.

This task was delegated by the Committee to a technical Working Group on Methods Used to Create the Disability and Handicap Severity Scales for Assessing WorkCare Impairment Levels (1990) which was directed 'to devise a test for assessing capability for work which includes incapacity, disability/handicap for implementation from 1 January 1990'. The Working Group was given a number of directive guidelines, including a specific injunction to consider the ICIDH classifications, in arriving at a test which took account of both:

- the nature and extent of the work related injury; and

- the extent to which the impairment affects capability to work given the worker's personal circumstances (such as age, gender, ethnicity, disability, education and training, work history).

Sources

The Working Group, not surprisingly, settled on the AMA Guides as the best available method for assessing medical impairment. However, the interesting part of their endeavours lay in their search for national or international approaches to the measurement of work related disabilities which could be adapted for its purposes. Most existing approaches to disability were rejected as unsuited for the role of setting workers' compensation benefit levels on the grounds that they:

- related to general 'activities of daily living' rather than work related tasks;
- provided only broad levels of assessment (mostly for determining rehabilitation progress);
- were not comprehensive; and
- did not provide relative scores or levels between disabilities.

The two approaches which appeared to offer the greatest potential were the ICIDH and the British Disability Survey. The latter was a project of the British Office of Population Census, led by Jean Martin, which utilised the ICIDH to create a disability severity scale for use in a national survey of the prevalence of disability in Britain (Martin, et al. 1988). It also went some way to overcoming the ICIDH's weakness in not containing any real scaling or scoring of disabilities since it contained a statistically rigorous method for determining disability scores. Consequently, the Working Group developed a 'Disability Severity Scale' based on a comprehensive and mutually exclusive set of descriptors, drawn from the ICIDH, together with the British Disability Survey's methodology in ensuring statistical rigour in determining relative weights for each of the disabilities.

The third task of the Working Group was to find a measure of relative severity of handicaps in the labour market, through focusing on personal characteristics which were believed likely to have a significant impact on whether a person with a medical impairment and a disability could re-enter the workforce. The Working Group drew on two main sources. The first was from the *Accident Compensation (General Amendment) Act 1989*, itself, through the factors determining whether a job offer to a particular worker was 'unreasonable', namely questions of 'the worker's age, gender, place of residence, ethnicity, disability, education and training'. The second was the socio-economic circumstances affecting employment capacity identified, in a Social Security Review Issues Paper, in terms of 'age, sex, educational level and job qualifications, previous employment history, literacy' (Cass, et al. 1988).

Disability scales

There then followed an intensive period of refinement and testing in order to achieve operationally useful instruments, which were also of reasonably easy application, for measuring the severity of work-related disability and work related handicap. With respect to the disability scales, a panel, comprising an occupational health physician, a psychologist and two occupational therapists,

prepared a pool of disability descriptors (mainly drawn from the ICIDH) for operational testing. An original group of around 180 descriptors was reduced to 116 items in two pilot exercises. This involved a rigorous testing procedure. In the first round 88 judges, being persons recommended by members of the Working Group on the basis of their experience and expertise in relation to work related disability, were given a bundle of cards containing a description of an activity which an individual could not do or had difficulty in doing. They were asked to rate the disability according to severity of impact on an individual's ability to work. This first round activity involved over 10,000 individual judgments. This resulted in the establishment of relative disability severity within each disability category. What was then needed was a second round testing procedure to compare disabilities from different scales in order to create a single integrated scale across all 116 descriptors; otherwise there would be ten independent disability category scales which would not achieve the objective of comparing people with different types of disability.

In the second round, judges were required to assess the relative severity of the two disabilities from each scale rated highest and lowest on average in the first judging exercise according to the procedure used in the first judging exercise. From the mean scores of these highest and lowest items, a proportionate value on the new common severity scale was imputed to the other disability descriptors in the various scales. This scale ranged from zero to 100 with the measured range of actual items varying from 12 to 96. In relation to the question of the measurement of the relative severity of multiple disabilities, the model adopted in the British Disability Survey (namely, worst + 0.4 (second worst) + 0.3 (third worst)) was found, after testing on some 111 multiple disability case histories, to accord with clinical experience.

Handicap scales

The Working Group had no real precedents to guide them in terms of a measure for the severity of work related handicap. However, after an examination of the literature and statistics related to labour market disadvantage, mobility and long-term unemployment, together with consultation with officers of the Commonwealth Employment Service and the Victorian Department of Labour, a number of determining characteristics were recognised. These were:

- age
- years since last employed
- previous occupation(s) and accompanying skill levels
- language skills
- place of residence
- level of schooling
- gender

The Working Group decided that a handicap scale must look at profiles where combinations of characteristics were the salient feature rather than individual characteristics on their own. In order to overcome the logistical nightmare of such a task (e.g. if each of the seven characteristics had between two and four levels, over 800 profiles would be created) the Group developed a methodology

which created a smaller number of profiles, with adequate differentiation between profiles, with such profiles being mutually exclusive (i.e. a worker could fit into one, and only one, profile). Two vocational counsellors with extensive labour market placement experience and members of the Working Group developed 30 profiles ranging from those with only two characteristics (e.g. age, employment skills) to profiles with five characteristics (e.g. age, employment skills, language skills, years since last worked, place of residence). As with the disability severity scale, the emphasis was on the creation of a scale which encompassed the most severe to the least severe cases with adequate differentiation.

The testing was undertaken by judges selected for their expertise in placing disadvantaged workers in the open labour market. Some 26 judges (17 employment counsellors and 9 rehabilitation counsellors) with this experience were required to rate each of the 30 profiles on a 10 point scale according to the difficulty of re-employment after a year on workers' compensation. As a result of this testing, gender was excluded as a sufficiently differentiating characteristic and other profiles were amalgamated. This left 22 profiles which ranged from 9.5 to 1.2 on the 10 point scale.

Because the Working Party's terms of reference required them to retain a primary focus on 'loss of capacity for work' for compensation entitlement, it decided that the handicap factor should be used as a weighting on the disability score. Accordingly, the 9.5 to 1.2 scale was adjusted to provide for a maximum weighting of 1.5 on the disability score for the worst case profile to a weighting of 1 (i.e. no weighting) for the best case profile. The remaining profiles were adjusted proportionately.

Disability and Handicap Severity Scales

The results of these investigations were brought together in a booklet, *Disability and Handicap Severity Scales*, first edition, published by the Department of Labour in March 1990. The *Accident Compensation (Impairment) (No.2) Regulations 1990* (Regulation 6) specified that the disability/handicap rating of a worker had to be assessed in the manner described in the Scales.

The Working Group recognised the innovatory nature of its work and saw the need for active monitoring of its application and for further refinement with the benefit of experience and further testing. In fact, a review was undertaken by Rod O'Connor and Associates, in June 1991, the descriptors in need of revision were identified, and a process of testing, similar to that described above, undertaken. However, before a second edition of the Scales could be recommended and adopted, there was a radical recasting of the Victorian legislation, in late 1992, following a change of government, which had the effect of repealing the legislative provisions underpinning the disability and handicap scales. Consequently, this approach is no longer in use in Victoria.

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Assessment of work capacity within the Australian social security framework

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Historical background

Prior to July 1987 assessment of eligibility for the Invalid Pension was based on an assessment by a Commonwealth Medical Officer that an individual was '85% permanently incapacitated for work'.

There was concern by the mid-1980s that in many cases non-medical factors such as age, fluency in the English language, skills and recent work experience were having too great an influence when compared with impairment due to a medical condition or disability.

In July 1987 the Social Security Act was amended to change the qualification requirements for invalid pension. The new requirement specified an 85% permanent incapacity for work with at least 50% of the incapacity being directly caused by a permanent physical or mental impairment.

In order to assist in the assessment of permanent impairment the Australian Government Health Service (AGHS), which performs the medical assessments for the Department of Social Security (DSS), developed a set of impairment tables to provide a simple and consistent numerical evaluation of impairment. These tables were called 'Guide to the Assessment of Impairment for Invalid Pension' and were based on a set of tables developed by the Department of Veterans Affairs (DVA) in 1986 for the assessment of rates of Veterans' Pensions (GARP). The DVA tables had been derived from the American Medical Association Guide to the Evaluation of Permanent Impairment.

It should be noted that the AMA tables are designed primarily as an aid to compensation assessment and revolve around the concept of 'whole person impairment'. This concept was continued into the DSS tables, which were then used to provide a quantitative measure of impairment as it effects capacity to work.

The Guide was intended to provide an accurate, systematic and uniform assessment tool which ensured that all assessments were conducted on the same basis Australia-wide in a nationally consistent manner.

Since their introduction in 1987 the Guide has been subject to an ongoing process of evaluation and review. Late in 1987 a review committee chaired by Professor Ann Woolcock reported on the Guide and made suggestions for improvements. Reliability and validity testing was carried out in 1991 by the AGHS and again, suggestions for improvements implemented. Further changes were the result of both AGHS and DSS experience in the use of the Guide and recommendations arising from consultation with various welfare and disability groups. Special tables have been included to allow assessment of drug and alcohol abuse, gynaecological conditions and conditions where pain is a major contributor to incapacity for work.

The Tables have thus developed over time to increase the emphasis on loss of functional capacity as it affects an individual's ability to work rather than simply loss or abnormality of psychological or physiological function.

The current revision was renamed 'Tables for the Assessment of Impairment for Disability Support Pension' and these Tables were incorporated into the Social Security Act in November 1991. There are, in all, 27 tables, some of which are based on particular body systems, some of which are diagnosis based and some of which are function based. When more than one impairment is present, separate scores are allotted for each and total impairment obtained by combining the separate ratings through a Combined Values Chart. Assessing medical officers are provided with instruction on the use of the Tables. Use of the function based tables is preferred to the diagnosis based tables whenever possible.

Some of the descriptors of functional loss contained in the Tables currently in use would be more appropriately described as disabilities within the WHO definitions. However, disability must be based on impairment, and it is felt that it remains overall more accurate to describe the Tables as dealing primarily with the assessment of impairment. The alterations that have been made since their introduction have increased their relevance and applicability to assessment of impairment specifically as it impacts on capacity for work. This is the only purpose that these Tables are intended to serve, and they should not be used for any other purpose. In their current form they are quite unsuitable for use to assess 'whole person impairment' for compensation purposes.

The Tables do require some instruction and training in their use. They are currently utilised by medical officers of the AGHS as part of the overall assessment of applicants for the Disability Support Pension (DSP). A network of approved medical practitioners conducts the examination in country areas and the documentation is then forwarded to the AGHS for oversighting and allocation of impairment rating.

The Disability Reform Package

In the 1990 Budget the Government introduced the Disability Reform Package, which aimed to improve targeting of payments and to link payments with programs of vocational assistance. Despite the changes of 1987, interpretation of the invalid pension eligibility rules by appeal bodies had led to it to a large extent becoming a defacto unemployment benefit for people with relatively minor medical problems, but other non-medical labour force disadvantages.

The DSP is targeted to those people whose principal labour market disadvantage is due to a significant impairment and consequent disability, resulting in a continuing inability to work without the provision of special supports.

This targeted approach to DSP eligibility is needed to ensure that benefits go to those whose need is greatest and in the case of labour market programs those who stand to derive an acceptable level of long-term gain.

From November 1991 the Invalid Pension was replaced by the DSP. The new legislation specified two medically related criteria:

- a minimum impairment of 20% using the Tables (which were incorporated into the legislation)

- an ongoing inability to work for the next two years as a result of this impairment.

Applicants may be determined as meeting these criteria on prima facie grounds (by DSS staff) or referred to the AGHS for medical examination.

Welfare and disability advocacy groups have been critical of the introduction of a minimum impairment threshold or 'gate'. They felt that the assessment of impairment was being used as a surrogate for assessment of work related disability. Impairment was considered unsuitable for this purpose because it measures only the reduction in a person's physical and mental functions without necessarily making any meaningful connection with the person's ability or otherwise to work.

Disability advocacy groups have also been critical of the use of doctors to perform these assessments. The use of doctors, they argue, denotes a 'medical' or 'deficit' model and fails to focus on the abilities of people with a disability. They feel that other health professionals are often more appropriate for certain kinds of disability, e.g. psychologists for intellectual disability or psychological problems and physical therapists for musculo-skeletal disabilities.

The need, under access and equity principles, to provide the same assessment process everywhere in Australia, including extremely remote areas, is another important consideration which makes medical officers more suitable than other health professionals. In addition, recent research has shown that over 90% of applicants for the DSP are under active medical treatment. Many have multiple interacting medical conditions and some have an uncertain diagnosis or prognosis. Most of these people do not have a single stable disability, but have a chronic illness. For the assessment of chronic illness a medical practitioner is the most suitable choice.

The Minister for Social Security therefore agreed to a further review of the Tables, involving external medical and other experts, to improve their accuracy and relevance to assessment of loss of work capacity, and to the appointment of consultants to advise on the development of a possible alternative rating system to measure work capacity.

Review of impairment tables

The Committee which performed the Review was chaired by a representative of the DSS and included medical and allied health experts from Sydney, Melbourne, Brisbane and Adelaide as well as representatives of AGHS. The medical expertise represented on the Committee covered rehabilitation medicine, neurology, psychiatry and drug and alcohol dependence. After initial consultations with all relevant medical associations and medical colleges a workshop was held in Sydney in March 1993 and invitations were extended to specialists recommended by the Committee.

The Tables were examined and discussed sequentially with the invited experts attending the sessions devoted to the Table(s) covering their field of expertise. The session on each Table was structured to focus discussion on the appropriateness of the Table's descriptors to the purpose of assessment of impairment as it related to capacity for work.

The result was a revised set of Tables with descriptors which described the effect of impairments specifically on the capacity to work (i.e. work related impairment).

The draft Revised Tables were then circulated to all those colleges of medicine and professional associations whose fields of expertise are represented in the Tables. Further refinements to the Tables have taken place as a result of responses received from this consultation process.

The Report of the Committee containing the Revised Tables has now been submitted to the Minister for Social Security for consideration by Government.

Development of the work ability tables

AGHS was funded in the 1990 Budget to appoint consultants to advise on the development of a work capacity rating system as a possible replacement for the Tables for the Assessment of Impairment for Disability Support Pension.

The consultants conducted a review of Australian and international research literature on the assessment of impairment, disability and handicap. This indicated that although the assessment of impairment is well developed and widely used in Australia and internationally, there are few models available for the assessment of disability and handicap.

Focus groups were held involving Commonwealth Medical Officers, representatives of disability advocacy groups, experts in psychiatric and intellectual disability and people with special expertise in rehabilitation and work placement to discuss a wide range of issues concerning the assessment of impairment, disability and handicap.

As a result of this consultative process the consultants considered that impairment assessment should be retained and improved as a component of the overall assessment, but that the assessment also include a quantitative rating of work ability to complement the current purely qualitative work capacity assessment. The consultants have been developing specific Work Ability Tables as a tool in this process.

These Tables are based on a view, confirmed by the literature and focus groups, that there are a small number of core work abilities that impact crucially upon the overall ability to work. The Work Ability Tables, which are currently in final draft form, reflect the literature, the views of key informants, and have undergone multiple revisions in the light of consultation and comments. Demonstration of an underlying impairment is central to the valid use of the Work Ability Tables, and for this reason they are designed to be used by a medical practitioner, as are the Impairment Tables.

The current legislation already requires that both a significant impairment (of 20% or greater) and an ongoing inability to work must co-exist in order to render an individual eligible for DSP. The Work Ability Tables codify this aspect of the current assessment so that it may be more rigorous, consistent and transparent and also used in the development of rehabilitation and/or retraining programs.

The Work Ability Tables are due to be presented to the Disability Task Force in the near future prior to being considered by Government.

The current state of assessment in Australia

All applicants for DSP are required to provide a report from their treating general practitioner (or medical specialist). In some cases it is clear, or 'manifest', from the treating doctor's report and the applicant's statement that the individual is 'manifestly' unable to work and DSS staff do not require any further assessment to grant DSP. All other cases are referred for independent assessment by the AGHS.

The AGHS assessment is based upon:

- a medical history and relevant examination of the client;
- the treating doctor's report;
- specialist reports (if provided);
- a self assessment module provided by the client;
- impairment assessment using the Tables;
- qualitative assessment of current and future work capacity; and
- qualitative assessment of rehabilitation/retraining potential.

Assessment has now become a complex procedure requiring considerable skill. The Expert Committee who assisted in the most recent revision of the Impairment Tables feel strongly that impairment assessment must remain rigorous and be professionally administered. The nexus between the individual's medical condition, the resulting impairment and the subsequent impact on work ability requires skill and experience in vocational assessment. These skills are not a focus of undergraduate medical education, nor are they easily gained in general practice. Work capacity assessment properly forms a small subsection of the recognised specialty of occupational medicine. Assessment must focus on the potential of the individual, and what special support needs must be met to assist him or her to (re)join the workforce.

Because of the very large number of clients who have to be examined and assessed, and the need to contain costs, the time spent on each assessment must necessarily be limited and is normally no longer than an hour. If the examining doctor feels unable to come to a conclusion further medical evidence may be requested from a treating practitioner, or an independent specialist consultation and opinion may be obtained. These options are only invoked in rare cases.

Looking to the future

The Revised Impairment Tables and the Work Ability Tables have yet to be considered by government. At this stage they are nothing more than options which may or may not be found acceptable. Any implementation would be subject to the usual processes of evaluation and review over time.

If the Revised Impairment Tables are accepted and implemented then the assessment process will be focused even more specifically on the impact of impairment on the person's capacity to work without special supports. If the Work Ability Tables are accepted and implemented then the existing qualitative assessment of work capacity will include a semi-quantitative component. This would render this aspect of the assessment more reliable, consistent and transparent.

The AGHS is currently examining a possible assessment tool which uses a range of descriptors to quantify rehabilitation potential. If this tool proves suitable it might also be incorporated into the assessment process at a later date.

As disability advocacy groups have emphasised the importance, from their perspective, of self assessment by the individual concerned, one of the options being considered is to expand the current applicant statement into a more detailed 'Impact Statement' which will give each applicant the opportunity to explain how his or her disability affects ability to work. Most importantly, it may enable the individual who has the disability to highlight more effectively the assistance that he or she feels is needed to gain entry to the workforce.

Session 1.3 Disability and health

An overview of the relationship between disability and health

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Summary

- The development of Activities of Daily Living (ADL) measures of functional status and the International Classification of Impairment, Disabilities, and Handicaps (ICIDH) were important moments in the construction of disability, independent of biomedical disease models.
- It is argued here that models proposed by various authors, like situational handicap and social factors in disability, are best seen as examples of quality of life models rather than as separate models.
- Structural equation models of quality of life are advancing our understanding of the multi-dimensionality of disability, handicap and quality of life and of the relationships between the dimensions.
- The addition of a desirability ratings to disability states, for example in Quality Adjusted Life Years (QALY) measures and severity ratings in Disability Adjusted Life Years (DALY) measures, is an attempt to develop the measures for health decision-making. The validity of desirability ratings and the possibility of constructing a uni-dimensional measure of quality of life are in dispute and yet to be proven.
- The ICIDH concepts are essential parts of the quality of life model but in need of development in dealing with mental health. As well the concept of handicap in the model requires complete redefinition to deal with both physical and mental health.

Introduction

Disability refers to the ability of an individual to function physically, psychologically and socially, and the problems and needs that arise from less than maximal function. The physical aspects of disability are clearly open to biomedical categorisation and the psychological aspects can be described by psychiatric diagnoses. However many social aspects of disability do not fit easily into health definitions nor is the physical environment in which people function well measured in medical or psychiatric studies.

From a social perspective, disability indicates a set of problems related to performance of social and economic activities, consequent burdens upon family and society, and the problems at the larger level for social harmony. Disability is 'environmentally conditioned' so that the impacts of various disabilities differ according to the supportiveness of different environments. In some cases the environment may be the primary cause of the inability to function, with some medical condition playing only a minor role. Disabilities are not only

environmentally conditioned but they are buffered in a variety of ways with aids and appliances, medications and forms of social support. Consequently it is difficult in some cases to map global definitions onto the lived experience of disability.

Social perspectives on disability were important to its emergence as a policy issue. As Pope (1984:589) observed:

As long as disability does not threaten the norms and values of the group, or its social and economic viability, disability is an unfortunate personal event—not a social problem.

In past times disability was indeed 'an unfortunate personal event' and it remains so in many poorer regions of the world. In societies with welfare states, the historical trend has been away from a passive acceptance of disability as an 'act of God, gods or nature' fitted into cultural beliefs and values of the group, towards a program of identifying and controlling the social and individual problems of disability. This program for managing disability has led to a parallel interest in its measurement. This has implied a progressive redefinition of the relationship between health and disability.

Minaire (1992) proposed that the definition of health has shifted over the past 30 years from 'survival', to 'freedom from disease', to 'the individual's ability to perform daily activities' and lastly to 'well-being or quality of life'. This is a useful heuristic device for organising complex historical processes defining health. The focus on 'quality of life' as the goal of health is generally supported. He also proposed that there are four models of the relationship between disability and health, namely:

- the biomedical model;
- the ICIDH (International Classification of Impairments, Disease and Handicap) model;
- the situational handicap model; and
- the quality of life model.

There can be little dispute that the first two are essential models of the relationship between health and disability. However I will argue that Minaire (1992) does not clearly distinguish situational and quality of life models from the ICIDH model. All three models, excluding the bio-medical model, lay claim to be 'quality of life' focused. Since the ICIDH model is a classification system rather than an analytical model, it assesses quality through disability and handicap measures. So it will be argued here that the ICIDH, situational handicap and quality of life models are all versions of the quality of life models with different emphases on contributory factors.

There is also a body of literature omitted from Minaire's taxonomy, namely models of health and disability which attach preference or severity weights to health expectancies, like Quality Adjusted Life Years (QALYs) or the global burden of disease models developed for the World Bank (1993). This adds the dimension of desirability or severity weights to the conception of health. It highlights what is in dispute, namely the essential components of a model of quality of life.

The redefinition of the relationship between disability and health had a number of important stages:

- the biomedical model of disease;
- the development of ADL measures of functional status;
- the development of the ICIDH distinct from the ICD codes;
- debates over the contribution of social and environmental factors to disability and health-related quality of life; and
- debates over the measurement of 'desirability' of disability states as components of health.

The first two models presented by Minaire will be reviewed here since they set the baseline for discussions. The debate over social and environmental factors will be discussed as will the possibility for including these various factors in quality of life models. Finally the models adding preferences to disability measures will be critically discussed.

The biomedical model

The biomedical model of health and disability is expressed in the sequence:

etiology → pathology → manifestation e.g. disability

Certain diagnoses or lesions for example arthritis, are known to be associated with a high probability of disablement. Some symptoms, such as chest pain, chronic cough, or intermittent claudication, consistently reduce activities of daily living that people can perform. Other indicators such as blood glucose levels, or levels of service use are also associated with higher levels of disability.

While some illnesses or conditions, physical and mental, produce declines in these functions, there is no direct correspondence between presence of a chronic disease and the person's ability to function. More generally the concept of disease accounts for only a part of the variance in health status, the amount depending on the particular concept of health status. The limitation of this as a general approach to disability and health is that diseases are neither invariable nor universal. Not only negative anatomical, biochemical and physiological variables need to be considered but also particular physical, cultural and social factors.

The development of disease does not simply incapacitate a person in a mechanical sense, rather it affects the individual's capacity and performance as a participating member of a highly interdependent group. Thus the bio-medical sequence is particularly awkward for dealing with mental illness. Taking even a limited approach to the person as a social being means taking into account a person's roles, relationships and attitudes to illness as part of the process of the disability (Williams 1987). Given this limitation of the biomedical model, specific diseases provide a well defined portal of entry to the disability process that is a useful predictive factor in demographic and epidemiological studies.

The ICIDH model

The development of ADL (Katz et al. 1963) and instrumental activities of daily living (IADL) measures (Lawton and Brody 1969) was a major step in the separation of disability measurement from diagnosis of disease. These measures operationalised disability as functional status in basic hygiene, self-care and household tasks. The absence of a direct emphasis on social function

in ADLs beyond activities essential for daily living was notable. This was the source of some difficulties with the incorporation of mental health into disability models.

The separation of the ICIDH classification from the World Health Organization (WHO) International Classification of Disease (ICD) classification system in 1980 was the next major development in defining and measuring the process of disability. To deal with the multi-factorial nature of disability, that is psychological, social and medical aspects, the WHO developed the ICIDH in 1980 (see Wood 1989). This classification rearranged the categories of disease according to their disabling potential rather than according to the nature of the underlying morbid anatomical processes. The classification itself was a conceptual and measurement advance based on earlier work of Nagi (1965) as well as ADL developments. Subsequent debates have clarified the options for defining the relationship between disability and health.

The essence of the approach is presented in the framework:

disease)	
accident)	→ impairment → disability → handicap
abnormality)	

The terms were defined as follows.

- *Impairment*: any disturbance to the body's mental or physical structure or functioning. The impairment is characterised by a permanent or temporary loss or abnormality of psychological, physiological or anatomical structure or function in a tissue, organ, limb, functional system or mechanism in the body.
- *Disability*: a reduction or loss of functional capacity or activity resulting from an impairment. Disability is characterised by excesses or deficiencies of customarily expected behaviour or functions, and represents the identification of impairments through their effects on everyday activities.
- *Handicap*: the social disadvantage resulting from an impairment and/or a disability, entailing a divergence between the individual's performance and status and that expected of him by his social group. Handicap therefore represents the social and environmental consequences of impairment and disability.

Thus impairments were focused on organ functions and structures, disabilities on activities and handicaps on extent of limitations in the performance of social roles. In this model diseases, accidents and abnormalities are exteriorised in impairments, objectified in disabilities and socialised in handicaps.

The impairment codes were innovative in attempting to provide an exhaustive list of organ or system malfunction complementing the listing of diseases in the ICD codes. The disability scores departed from the conventional assessment of activities of daily living to emphasise similarities for analysing connections between specific disabilities and impairments. Disability was originally defined as a limitation in function customarily expected of the body or its parts or restrictions in activity consequent upon impairment. This definition was soon modified so that functional limitations were classified as impairments to clarify the boundary between impairment and disability. The handicap classification

involved the development of a new ordinal scale but the problems associated with this concept were not successfully resolved.

The criticism of the first version of the classification centred on conceptual and nomenclature problems and the weakness of the nomenclature of handicaps. The Australian Bureau of Statistics using a preliminary version in its early pretests found that impairments were practically indistinguishable from disability. It used a mix of one health condition, two impairments and nine disabilities in screening for disability in its surveys. There were also problems in clearly separating concepts of disability and handicap and an inherent bias in the screening for disability towards the more visible conditions. Gut and visceral disorders are under-rated as handicaps because they are not visible disorders. Finally it is generally accepted that the arrows suggested in the original model are unhelpful. For example, the progress may be reversed. A woman becoming widowed, a social role handicap, may become disabled in performing activities and develop psychological impairments. The transitions between levels are complex and may flow in all directions.

The lack of visibility of mental health disability like that associated with dementia, depression, anxiety states, schizophrenia, eating disorders and personality disorders, was also a concern, possibly arising from an over-emphasis on physical disability in the model. With psychological impairments the initial nomenclature was regarded as weak and subsequent modifications are proposed to improve this. The practical problems of separating categories are probably even more complex in the case of mental health. Dementia, a disease, leads to multiple impairments of social function, disability and handicap in the biomedical model. However it is usually only diagnosed when disability exists and hence impairment is inseparable in practice in surveys from the disease and disability.

The problem of social roles

Social theorists criticised the apparent focus in the ICIDH on handicaps as the characteristics of individuals rather than of social interactions and environmental situations. They rejected the notion of handicap as an individual disadvantage arising from impairment or disability. Some argued it was a limitation arising from the fact that an individual was confronted by physical, social, and cultural barriers preventing access to the various systems of society (Williams 1987).

Wood (1987) was sensitive to the tendency to individualise and over-medicalise disability but has defended the ICIDH on these grounds. He rejects the 'over socialisation' of disability as a social conspiracy or resulting from social oppression (Wood 1989). This neglects the 'spring' from which disability arises, either wholly or in part, namely some health condition. Various social factors contribute to the role impact of health related disability but this is a different concept from social disadvantage which is entirely socioeconomic.

The distinction between types of disadvantage is a practical one. It can be made between a limitation in job access caused by sight loss to one caused by lack of opportunities related to occupying a lower social class position. While the individuals may be similarly disadvantaged in outcomes, the different causes of this require very different policy responses and interventions. Health related disability is a useful category and can be separated from general social

disadvantage. This reasserts the relevance of the redefined connection of disability and physical health without losing the notion of disability within a broader concept of disadvantage.

In an attempt to clarify this point further Wood makes the distinction between roles and tasks (1989:118):

Tasks may be the prerequisite for a role but they are not sufficient cause to be regarded as constitutive of the role; to that extent there is a causal relationship between the two ... There is complex mediation between task and role, to which individual behaviour and attitudes contribute as well as resources and social opportunities and restrictions.

This point has led others to attempt to confine the handicap category to limitations of social role performance. Role is a useful concept but the attempt to limit handicap to evaluations of social role performance raises more questions than it answers. Who defines what roles are relevant for assessment of handicap in a politically dynamic and multicultural society like Australia? For example does it matter that a disabled woman is unable to fulfil all traditional female roles? Can she express her own rating of role performance? Mental health specialists have problems with self-report of adequacy of social role performance because of potential delusions or incompetence of the respondent. Roles, however, are dynamic and changing in most modern societies. People occupy multiple roles and have the capacity to substitute dissatisfying ones with satisfying roles to achieve an overall satisfied state. The rigid definition of roles produces a real risk that conservative role definitions can be influential in redefining impairments and disabilities to fit this narrow version of roles.

While generally supporting the ICIDH, the notion of handicap has proven troublesome. It may be better to delete it completely and simply have an extended range of disability with mild to moderate severity. An estimate of the impact of disability on quality of life can be provided by respondents if required, or another person where they are not competent. Further if there is interest in the care giver or social burdens that arise from an individual's inability to perform certain activities, then there are a range of measures of care giver burden. In this model impaired function, arising from some medical phenomenon, leads to inability to perform activities with varying degrees of severity. Disabilities affect individuals self assessed quality of life and may also have effects on care givers and providers of support which can also be measured. This type of thinking is already in use in Australian Aged Care Assessment and in research on disability among the aged as will be discussed in the next section.

Environmental factors

Minaire (1992) among many others has noted that handicap is the result of the encounter between disability and an environmental situation. He sees situational disablement as having three levels: individual, situational and environmental. He categorises situations into macro-situations (school, housing, family life, professional activities etc.) and micro-situations (driving, moving around, opening doors etc.). Situational disablement tends towards a balance between individual, situational and environmental inputs and outputs

to the disablement process. It implies the integration of the individual into an environment and of the environment into personal experience.

This approach, particularly the situation level of effects, cuts across the social dimension of disability already discussed. It is confusing to use different terms for the same phenomena, so social aspects of 'situational' handicap are best confined to the discussion of social factors in disability and health.

The unique contribution of this perspective is to emphasise the environmental aspects of disability which are not easily measured by self-report of individuals. They generally require more thorough environmental assessment of specific locations. Minaire correctly reported that much of this is situational and difficult to generalise across populations. It is precisely because of this variability that it is often uneconomic to collect specific environmental information in surveys, but it remains an important aspect of disability.

Environmental factors are generally part of quality of life models in the field of ageing. Lawton (1983) has defined four intersecting domains of the quality of life: psychological wellbeing, behavioural competence (disability), objective environment and perceived quality of life (see Figure 1). This fits the revisions of the ICIDH suggested above, namely to limit it to disability, i.e. behavioural competence in Lawton's model. A model of 'successful ageing' has also been developed by Baltes and Baltes (1990) which incorporates interaction with the environment as an element of success in maximising function. It defines success in ageing as 'selective optimisation with compensation'. This emphasises individual motivations, along with the use of aids and the selection of age-friendly environments. The environment is treated generally rather than by measuring specific environmental features. The environmental perspective in the 'successful ageing model' is not part of a separate view of health and disability but rather just one element in a complex mix of factors related to quality of life. The Lawton model demonstrates the position taken here, namely that the environment contributes to disability (behavioural competence) and to perceived quality of life. Given this, it is not helpful to construct a separate model of environmental or situational disability.

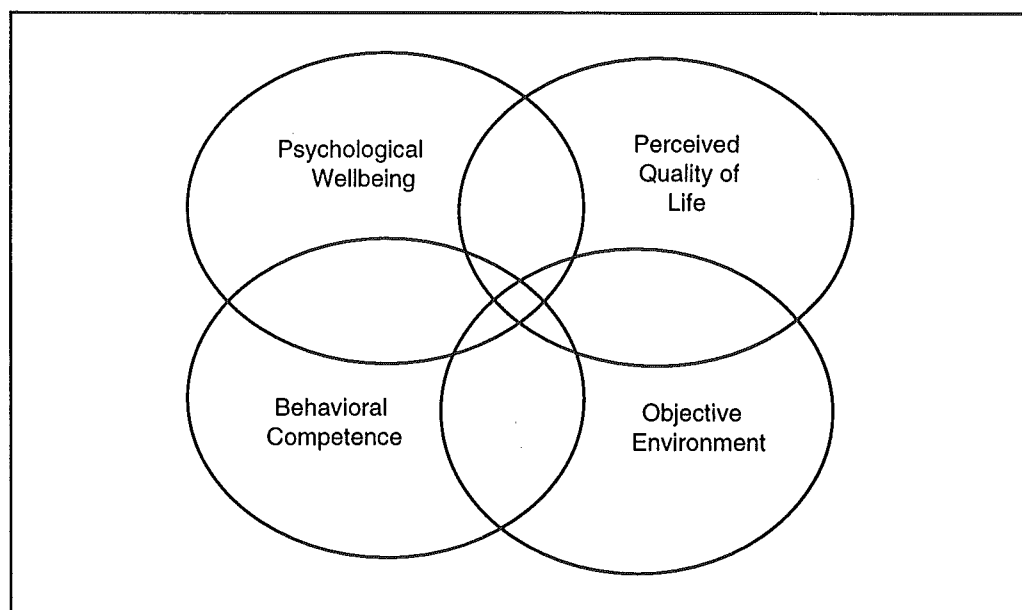


Figure 1: Lawton's Four Sector Quality of Life Model

The Quality of Life Model(s)

The quality of life thinking emphasises the multi-dimensionality of health and disability and embeds them in a broader notion of wellbeing or happiness (see Figure 1 as an example). It is sometimes focused on the analysis of the structure of health status when it deals exclusively on health related quality of life. Wood (1989:117) clearly describes the ICIDH as part of this perspective, in that disability *inter alia* contributes to quality of life.

I will focus on discussions of quality of life for one population group, the aged, since issues differ between population groups and the aged bear the major burdens of disability and handicap in the community. The first attempts to model quality of life were studies of determinants of perceived health status using single equations (Fillenbaum 1979). ADL type measures of disability were major predictors of self-rated health and quality of life. More recently Liang (1986) and Johnson and Wolinsky (1993) have used structural equation techniques to model health status. This allows not merely identification of direct effects but also the interrelationships of illness, disability and handicap. Such models cover a limited range of underlying dimensions and none of the models were based on a comprehensive causal model of health status.

Liang and colleagues developed structural models of self-rated health which use the accepted division of activities of daily living into physical and instrumental and limited measures of health, for example numbers of current illnesses, numbers of medications and numbers of services used. This lack of specific detail about health may be a consequence of the constraints of the method rather than a preferred position on modelling illness.

Johnson and Wolinsky (1993) have used a more specific set of constructs in an attempt to model health and disability more precisely (see Figure 2). First they describe disease as multi-dimensional rather than as a simple count. This reflects the more global impact of diseases like cardiovascular disease compared to specific impacts of musculo-skeletal diseases. Next they separate disability into upper and lower body disabilities to unmask the effects of diseases, like cerebrovascular diseases which affect both compared to musculo-skeletal diseases which may affect only lower body disabilities. Lower body disabilities include walking half a mile, up ten steps, standing, stooping, and lifting 25 pounds. Upper body disabilities included sitting for more than two hours, reaching over the head, reaching out and grasping objects with the fingers.

Next functional limitations are divided into three: (1) basic, closely matching the original ADLs; (2) household, closely matching IADLs; and (3) advanced ADLs which separate out those items tied to cognitive capacity or mental functioning. Advanced ADLs—namely difficulties with eating, managing money and using the telephone—largely reflect cognitive dysfunction, which goes part of the way to incorporating mental health into the model. The authors propose that cardiovascular, cerebrovascular as well as upper body disability affect all three ADLs. Others, such as dementia, affect advanced ADLs only and lower body disabilities are likely to effect basic and household disability but not advanced ADLs.

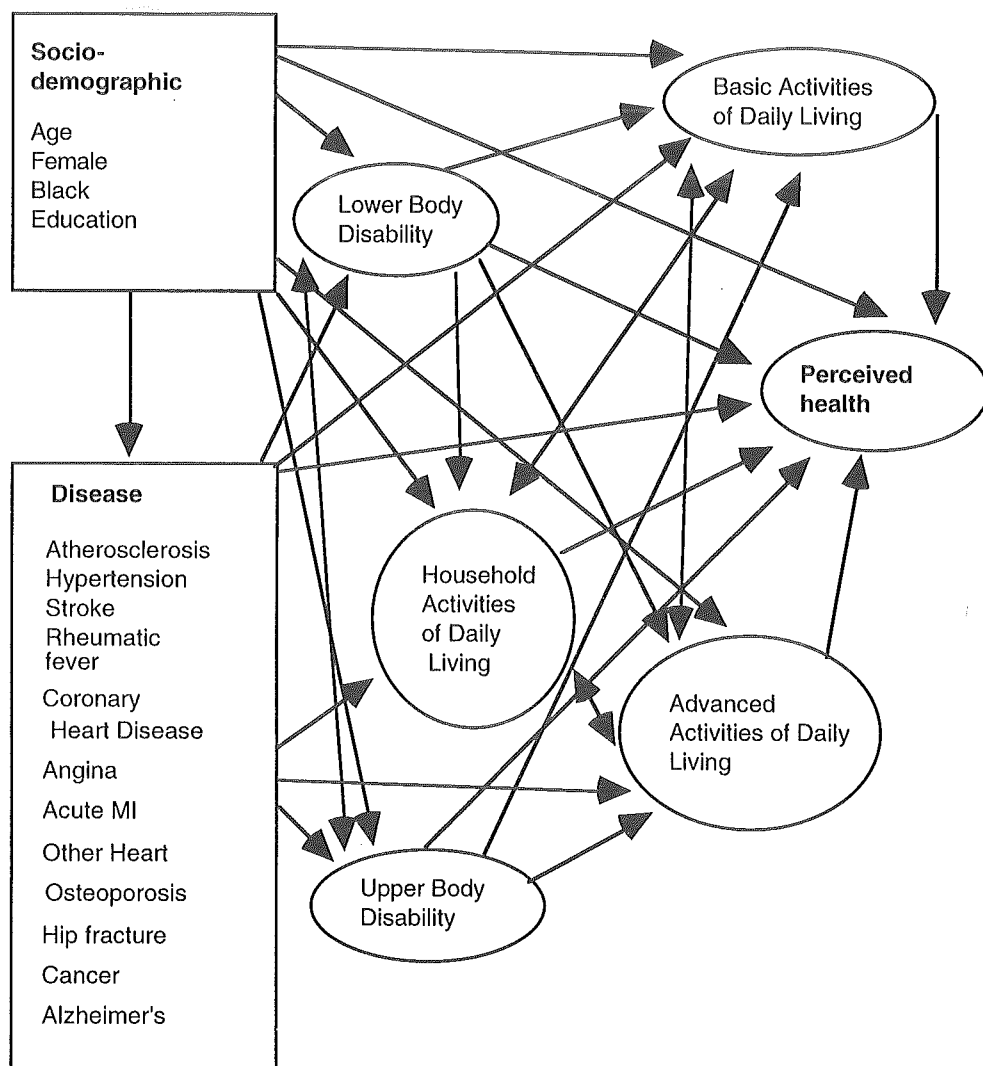


Figure 2: *Johnson and Wolinsky's Model of Health and Disability*

The conclusions from analysis of data from the US Longitudinal Study on Aging are that diseases are best treated separately and that, as well, disability and functional limitation are also best treated as multi-dimensional. Coronary heart disease, hardening of the arteries and hypertension have global effects on all dimensions of health status. Osteoporosis influenced UBDs and LBDs but its effects on functional limitations was limited to basic ADLs. Having a fractured hip was more pervasive, affecting household ADLs in addition to UBDs and basic ADLs. This elaborate mapping of health and disability gives a more precise sense of the connections between specific health conditions and specific disability consequences without the limitations of working with only one specific disease.

Desirability and severity of states of disability

There is increasing interest in desirability or severity measures in models of quality of life so that the disability measures more readily indicate priorities for action. There is a confusing practice among health economists of describing desirability or utility ratings as measures of quality of life. The position taken here is that quality of life is broader than utility as already described.

Kaplan (1982, 1993) and others at the University of California, San Diego have developed what they call a quality of life model, the General Health Policy Model. The model defines health status as mortality, morbidity, preference for different functional states (utility) and duration of stay in specific health states. The key contribution of this model is the addition of utility measures of the different desirability of health states. Full function is rated as one and death as zero and other states falling between the extremes are rated using surveys among groups representative of the population.

In terms of models of the relationship between health and disability the novelty in these models is the addition of a dimension of desirability to the disability state. They create common units, QALYs, in which to make decisions about health interventions and resources. Health decisions are then made on the basis of expressed preference or utility. For example Oregon State USA used the Kaplan techniques in allocating medical resources.

A different approach to the demand for common units for decision-making can be found in the development of DALYs for the World Bank (1993)

Development Report 'Investing in Health'. Disability incidence was derived from community surveys or, failing that, from expert opinion. Six classes of severity of disability were assigned to disability states. The weights were developed by consensus among experts in international health. Each expert voted on the weight to be assigned to the entire class not to individual disabilities in that class. The class was given a severity weight according to the average of the expert votes. Class 2, as an example, included most cases of leprosy and half the cases of pelvic inflammatory disease and was given a severity weight of 0.22. Class 4 included 30% of cases of dementia and 50% of blindness and it was given a weight of 0.6. To produce the DALYs, death and disability losses were combined and a discount rate of 3% applied so that future years of healthy life were valued at progressively lower levels.

Age weights were also applied so that years of life lost at different ages were given different relative values rising steeply from zero at birth to a peak at 25 years and after that declines with age. The formula used was $[ka \exp(-Ba)]$ where $B=0.04$ and $a=\text{age}$. This produces a pattern so that the death of a newborn baby girl represents a loss of 32.5 DALYs, a female death at age 30 the loss of 29 DALYs and a female death at 60 represents the loss of 12 DALYs. It is important to note that these DALY calculations were intended for use to determine which programs should be funded in which countries on the basis of the DALY gains. It remains to be seen how such ratings would be used in countries with age discrimination legislation.

There are disputes on rating methods between economists who require that the scaling method be true to the axioms of choice in traditional game theory and psychologists who seek to establish scale properties. A fundamental problem is the relationship of both to the way ordinary people think about health. The criticisms which QALYs have focused on the validity of the ratings of desirability (Carr-Hill and Morris 1991), and serious challenges to the validity of survey methods for rating desirability of disability states, have been expressed by Browne and Burrows (1992). In Australia, focus group discussions about the EURO-QUAL (a desirability measure like Kaplan's) revealed that evaluations and choices necessary for this measure were not understood by

most Australians. They could not validly express preferences within the choices proposed. Another problem in the general population is that people who have had a condition, e.g. surgery for breast cancer, tend to provide more positive evaluations of life with the condition than people who have not had it. This raises the problem of how people can rate states of which they have no experience.

As well as the issue of whether 'desirability' is a stable and measurable phenomenon, there is an issue about the appropriateness of health decision-making being based on single unit 'utility' measures. Components of health are indeed related, as described in a quality of life model, but they may not be reducible to uniform units in a single dimension. It seems more likely that health-related quality of life is multi-dimensional and health decision-making may just have to cope with that. If a single measure is required then global measures like self-rated health can be used but at the cost of lack of precision.

Single unit scales like those of Kaplan inevitably legitimate trade-offs between numbers of minor conditions and death. For example there is a point in these measures where it is assumed by the ratings that a person would rather be dead than have a long period with the common cold. Some would regard such trade-offs as absurd. In specific situations trade-offs do need to be made but a general system for that may be neither practical nor ethically justified.

The problems with the DALYs are also clear. The attempt to focus on disability and health expectancy rather than survival is a welcome development. However the severity weightings are invalidated even though they are based on expert opinion. First, expert opinion is unlikely to reflect popular opinion. Second, different groups of experts may produce different weightings, and World Bank decisions on loans for health projects may be significantly affected by alterations to the weights. This is a serious concern when these measures are specifically designed for health decision-making. If ratings do not truly measure population preferences then policy decisions will be wrongly made.

Conclusion

The development of the ICIDH concepts and measures has been important in redefining the relationship between disability and health. More needs to be done in improving these measures particularly in the area of mental health and the category of handicap could be removed from the classification altogether. The debates over social and environmental determinants of disability and handicap have also raised concerns about aspects of the classification. We need to distinguish the need for improvements in the classification, for example by inclusion of items more sensitive to environmental factors, from creating new models of disability. The ICIDH as a component of health related quality of life provides the best route to understanding and measuring disability and health.

The integration of ICIDH measures into multi-dimensional quality of life models is the new direction for research activity. Structural equation models are beginning to provide useful generalisations of relationships between concepts. Further work is needed on more specific relationships to make sense of these generalisations. The attempt to advance these models by creating a single utility dimension to facilitate decision in public policy is more controversial. The validity of the ratings of different states of disability needs to be established before this process is generally used.

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Profiles of people with a disability for policy evaluation: outline of a project

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Introduction

Currently at TNO Prevention and Health we are starting a research project to develop profiles of handicapped persons for policy evaluation, for short 'handicap profiles'. The general purpose of the research project 'handicap profiles' is developing a method to get an insight into the consequences for the handicapped of policy from both national and local authorities. Its goal is to distinguish and describe a limited number of 'typical' subgroups in the handicapped population, that can be used to forecast and/or monitor the integral effects of policy on the life situation of the handicapped. This includes not only specific policy on the handicapped but also general policy on working, housing, transportation, etc.

Why?

A number of measures have been taken and will be taken, of which the outcome for the handicapped is very uncertain. Among others it concerns:

- cost reduction and control (higher and/or new contributions of the handicapped)
- decentralisation of the legislation (from national level to local level)
- reduction of the use of certain services and insurances.

Especially it is difficult to see how people with a handicap will be affected by the cumulative effect of several measures taken at the same time.

How?

Currently the first phase of the 'handicap profile' research is in progress. In this first phase the following activities will be carried out:

- literature study and expert interviewing;
- inventory of available information and defining a basic data set needed to develop the profiles;
- demonstrating the possibilities of 'handicap profiles'.

This phase should show if the development of 'handicap profiles' is feasible. It should yield a GO/NO GO for the next phase, a research program on the development of 'handicap profiles'.

Present stage of the research

Literature study:

Little or no directly relevant literature has been found. Most relevant seem 'panel' approach experiences. The expert-interviewing is being started at this moment. As documented previous experience with this approach is scarce, we hope the audience in this workshop will share with us their experiences with related approaches.

Handbook on disability statistics

Another project relevant to this workshop that is carried out in cooperation with the Netherlands Central Bureau of Statistics (CBS) and the United Nations Statistical Division (UNSTAT) by TNO Prevention and Health, is the development of a handbook for both disability information in censuses and household and institution surveys on disability.

The handbook will be based on existing handbooks such as:

- Handbook of population and housing censuses (UN, 1992);
- Handbook of household surveys (UN, 1984); and
- Training Modules for Household Surveys on Health and Nutrition (WHO, 1988);

and on regional experiences from Canada, United Kingdom, Spain, Fiji, Japan, China, Australia, etc. Much of this information is available via Distat info (UN).

The first draft of this handbook will be discussed with a limited number of referees and external contributors early June 1994. The second draft will be discussed in November/December 1994.

Session 1.4 Towards greater interdisciplinary understanding in Australia

Measurement of disability: a consumer perspective

Paul Creedon

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Before I start my talk, let me give you some information about myself and where I come from. I have practiced as a Social Worker for some 10 years, and I am also a member, and sometime employee, of Disabled Peoples' International—Australia (DPI (A)), which is the national peak group representing all people with a disability. DPI (A) is run by people with a disability with a very clear charter to ensure that we, i.e. all people with a disability, have access to the same rights and power enjoyed by other members of the community.

My task today is to talk to you about the views of people with a disability to measurement of disability. I will talk primarily about assessment of disability, rather than data gathering, because assessment is often more 'real' to people with a disability and it is usually what defines the presence of disability for survey purposes. However the concepts of empowerment and control are as relevant for surveys as they are for assessments.

Let me start by saying that assessment is something that people with a disability, or medical condition, or injury know a lot about. Indeed for many of us it is something that takes up an enormous amount of our time and energy, and the time and energy it takes up is often not justified in terms of outcomes.¹

Before I get on to the issues about outcomes however, perhaps I will define what I mean by assessment so we are all working from the same information base.

Assessment, in my view and in this context, is any task or activity designed to gain information from an individual or group of individuals with a disability to achieve a particular purpose. These can be either formal or informal. This would therefore include such things as a Wechsler Adult Intelligence Scale (WAIS-R) psychological assessment, a MODAPTS physical assessment, a medical check up, an assessment of flexibility, a literacy or numeracy assessment, a hearing test, etc.

Many of these assessments lead to some form of decision or activity, indeed many consumers have major decisions which control their lives made on the basis of these assessments:

1. For the remainder of this paper I will tend to describe people with a disability as consumers, because in the context of this workshop they would generally be consumers of your assessment or other services, notwithstanding the fact that you may well be contracted to provide a service to another client, e.g. the Department of Social Security, which may have its own interests.

- they will be used to determine if you should be allowed to make your own decisions;
- they will be used to determine what kind of education you get;
- they will be used to determine if you get a disability pension or not;
- they will be used to determine what if any services or training you are eligible for;
- they will be used to determine what if any transport assistance you are eligible for;
- they will be used to determine whether you can live independently, where you live, who you live with, and what support you get;
- they will be used to determine what equipment you require; and
- they will be used, well I think you get the picture.

Assessments then, have an enormous impact in every life area for many consumers. Unfortunately, all too often it is someone else making the decision, and the decision is based on information which is neither available nor accessible to the consumer.

Assessment has the capacity to promote equity, to facilitate consumers having control over their own lives, and to empower consumers to live full lives in the community. Unfortunately, assessments rarely have these sorts of outcomes for consumers. In my view, this is partly the fault of the assessment tools themselves—with their jargon, rating scales and percentile evaluations.

Additionally, assessment tools are often unrelated to real life as experienced by most people. The problems presented in many assessments are not the sort of problems people face in their day to day lives, yet it is the things they face in their daily lives that allow them to make sense of themselves in comparison to the rest of the world. In other words, many assessment tools create artificial environments to test a person's response or capacity to a real environment. While this may allow the assessor to save time, equipment, etc. it does not help the assessee to see the usefulness and value of assessment.

Largely, however, it is the traditional process of assessment which is to blame for the lack of value to consumers. It is the process which is used in the vast majority of settings whether in hospitals or offices, whether in institutions or in the community, whether formal or informal, and whether by 'professionals' or by 'non-professionals'.

In this traditional assessment process the consumer is an outsider, a 'subject' to be studied. They come into an assessment area and they are told to do something, often with limited instruction, and the assessor diligently takes notes, marks boxes, draws circles, or uses some other mysterious code to record results. The consumer may have had the process explained to them beforehand, but still they are an outsider. This is because it is generally seen as something that the assessor is doing to achieve a particular purpose, and often the belief by assessor and assessee alike, is that consumers wouldn't really understand the results anyway.

Let's look now at what that purpose often, or perhaps even usually, is.

Assessment generally is to tell the assessor something, predominantly they are used to make some sort of diagnosis, to measure something, to reach some

form of objective determination, to classify and categorise behaviour, or needs, or symptoms into some recognisable format. And it is this classification that distinguishes the assessor as 'skilled', that is, possessing some expert knowledge about the consumer and the world in general, and the assessee as 'unskilled' that is not possessing, and perhaps unable to possess, this expert knowledge about themselves.

Unfortunately the process of assessments, and the purpose of assessments combined, while they may lead to very good outcomes for assessors in terms of knowledge, understanding and classification, usually have very poor outcomes for consumers. In other words, the understanding that is now possessed by the assessor is rarely transferred or transferable to the consumer, so the consumer has none of this understanding or knowledge, but has often experienced a very strong restatement of their powerlessness in the system.

So, by now you are probably saying to yourselves—'what does he want us to do—stop assessing?!!!' Well, the answer is no—I don't want you to stop assessing, what I want you to do is change the way in which you assess and re-evaluate the reasons why you assess.

As I said earlier, assessments have the capacity to promote equity, to facilitate consumers having control over their own lives, and to empower consumers to live full lives in the community. But assessments can only do this if you conduct your assessments in a non-traditional way so that consumers are no longer outsiders, and if you make the purpose of your assessments to empower and inform consumers rather than, or at least as much as, anyone else.

OK, so your next question is probably along the lines of 'but how do we do that?!!!' Let me outline how one organisation has done it while saying that their method will not necessarily solve your problems, nor will it necessarily meet your needs, so it's the underlying philosophy rather than the content that is important.

The organisation is Heta Inc., in South Australia, and it conducts a range of services—predominantly employment related—for people with a disability. It uses this assessment process with all disability groups, physical, intellectual, psychiatric, sensory or acquired brain injury, mainly modifying the type and degree of support where necessary.

Heta used to conduct its assessments in a traditional manner and with the purpose of finding out what sort of work a person could do. In recent years the manner of assessment has changed dramatically (I will discuss this shortly), and the purpose of assessment has changed from finding out what work a person can do, to empowering the consumer to match their vocational interests with their potential skill areas themselves. Heta calls this process a Circuit Assessment.

The assessment process still uses standardised assessments, like the Purdue Pegboard or the Raven's Progressive Matrices, etc. but it involves consumers testing themselves and their peers and then relating these results in a concrete manner to their interests and the labour market.

Consumers begin the process by investigating their broad interest areas themselves, and then determining what sorts of skills are required for those types of jobs. This is by both self investigation and peer review.

Consumers are also given pre-assessment training to prepare them for the process and the language and meaning of assessment.

They then undertake a series of assessments where they time themselves, score themselves and then determine what their skills are in relation to the general population. Of course this is done with the supervision and support of a person appropriately qualified—but the consumer controls the process.

The next step is where the consumer relates what they have learnt about their skills and abilities with what they already knew, and then to the labour market and their interest areas, and to try out their skills in real work environments.

The final step is where consumers prepare (with appropriate support) their own skills report which they present to a case conference.

As such, this process assists consumers to build on their knowledge of themselves and therefore on their ability to make their own realistic decisions about their future. In this way it meets the purpose of this particular assessment, that is to empower the consumer to match their vocational interests with their potential skill areas themselves.

Now, I am not advocating this particular process as the panacea to all the problems of assessment for people with a disability.

However, I am saying that assessments generally for consumers are currently of little or no real value to them regardless of their intellectual or reasoning skills. I am advocating that you look carefully at your purpose for assessment, the process you are using and that you find and create 'real life' assessment tools that allows consumers to relate to the assessment from their own perspective.

If you are serious about providing a service for the consumer—the person with a disability—then your purpose must be to empower them to make their own decisions by assisting them to learn for themselves. And any of you who have compared what a person learns by 'being told' versus what they learn through experience will know that the latter is far more effective.

And any of you who truly conduct assessments with this sort of purpose in mind will know that a traditional form of assessment process will not achieve the desired outcome.

I urge you, when you are reviewing the talks and discussions of today and tomorrow, to consider not whether you will make your assessments of value to consumers, but how you will make them of real value to consumers.

Measurement of disability: a service provider perspective

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Introduction

ACROD is the peak council in Australia of non-government organisations providing services to people with disabilities. We have around 430 organisational members at present, ranging from very small groups to very large service organisations, in both rural areas and in the capital cities. We also have many individual members and professional bodies in the rehabilitation field. Our members work with people with all types of disability.

As service providers we are involved with methods of assessment, measurement and classification from several angles:

- for individual assessment and development of individual programs;
- for planning and staffing purposes within our agencies;
- for accounting to government as a major funding body, about what services we provide, to whom, and what the outcomes are; and
- for knowledge about numbers of people with various disabilities and needs in our regions and in the whole community, for planning and lobbying purposes.

In this paper I will make some general comments on concepts and terminology; provide perspectives from the point of view of the service provider on measurement and classification tools, in particular the International Classification of Impairments, Disabilities, and Handicaps (ICIDH); and I will give a specific example of how one large service provider (Yooralla) has developed a classification system to suit its own purposes, using the ICIDH as a base.

I have canvassed opinions on assessment and measurement systems, and in particular the ICIDH, from providers of various types of services, ranging from providers of medical and therapy services in hospital rehabilitation settings, to providers of services in the community—employment, accommodation, recreation, and so on.

Many service providers are not at all familiar with the ICIDH. Many are aware of its use and adaptation for the Australian Bureau of Statistics five-yearly surveys of disability, and of various other systems of assessment and classification used for purposes such as eligibility for benefits, employment assistance, etc.

Many providers, however, even if they are not familiar with the details of the ICIDH, are steeped in the concepts basic to the ICIDH, such as those related to functional disability and handicap in performance of various roles (intra and interpersonal, at home, work, leisure etc.), concepts which are basic to their professional training and practice.

Some service providers have struggled with setting up assessment and classification systems themselves, for their own agency's purposes; some have used the ICIDH as a starting point.

Whether familiar with the ICIDH or not, all service providers have something to say about the difficulties of assessment, and the difficulties of definitions and terminology.

Concepts, definitions and terminology

Basic concept of norms

No amount of fiddling with the language used in the ICIDH or any other classification of disability will save us from facing the much more basic question 'What are the norms?' Over time and across cultures, what is considered normal or abnormal may change, but there will still be norms. A group of profoundly deaf people may say they have neither a disability nor a handicap, as they are perfectly self-sufficient in their own group, with their own language. So what is an impairment, disability or handicap may at times be quite subjective, and it can shift over time; we still need to be wary therefore of classifying people.

ICIDH terminology an improvement on pre-1980 usage

Usage of the terms 'impairment', 'disability' and 'handicap' as defined in the ICIDH was less stigmatising and patronising than earlier usage, particularly the way the word 'handicapped' had been used in the past. The pre-1980 use of the terms still persists in the community and in the media, and service providers play an active role in educating people to ensure correct usage.

Part of the problem is the practical need to find short concise descriptions. Thus, for example, we still have great trouble with adjectives and nouns on signs and in other situations where brevity is important. I recently saw two signs in Sydney: one indicated an accessible route for wheelchair users by a sign 'Disabled Access'; around the corner from this was an older sign, 'Handicapped Access', presumably a relic of former times. We always hear of 'disabled parking' and 'disabled toilets'; a sign in Perth has come up with the term 'paraplegic toilet'.

The old use of the term 'handicapped' was very demeaning, and essentially wrote off a whole person in all areas of life. The definitions and terms in the ICIDH do allow for the fact that a person's disability may lead to handicap in specific areas or situations, e.g. a disability in walking may lead to handicap in mobility but not in other areas. Interventions by service providers and the community by, for example, providing modified vehicles or ramps or lifts, aim to reduce that level of handicap.

Current terms

We commonly speak nowadays of four, sometimes five, major types of disabilities: physical, sensory, psychiatric, and intellectual, with a smaller fifth category of 'acquired brain damage' often being added because the disabilities do not neatly fit into the other broad groups. When we break down 'sensory disability' further, we commonly say 'including hearing impairment and vision impairment'.

Problems still in terms for psychiatric and intellectual disability

Over the years since 1980, terminology has changed, partly through attempts to find more acceptable terms, and partly through attempts to find more general terms to cover a whole range of different disabilities, so that no groups are left out. This is probably how we have come to use the term 'psychiatric disability'—partly because the word 'mental' led to confusion with the now discarded term 'mental retardation', and also was seen as stigmatising. So 'psychiatric', not a term used in the ICIDH classification at all, was used to describe disabilities resulting from psychological, emotional, and behaviour impairments.

In a similar way, the term 'intellectual impairment' is used in the ICIDH classification, but not 'intellectual disability', the accepted term in Australia now used by service providers, government, and consumers.

Useful distinction between impairment, disability and handicap

The ICIDH has provided, and still provides, a useful conceptual framework in which to study disability. Its definitions, and the distinction between the terms 'impairment', 'disability' and 'handicap', assist staff in disability agencies to see their role more clearly. The ICIDH framework successfully combines elements of a clinical, diagnostic approach, in which the impairment can usually be clearly defined, with the more consumer-focused approach which looks at the whole person functioning in daily life activities, in a household, work, family, and community.

The 'disability' and 'handicap' scales (or modified versions of these) can assist service providers to pinpoint in what way they hope to reduce disability and handicap by providing a particular service.

A knowledge of a person's 'impairment' (a word rarely used by service providers except in relation to hearing impairment and vision impairment) or disorder or illness or diagnosis or cause of a disability, carries with it certain general knowledge of the sorts of disabilities usually linked with that type of impairment. The 'impairment' is often taken as a useful starting point, from which a service provider (whether a therapist, job trainer or recreation worker) aims to reduce consequent disability and handicap.

Separation of the terms 'disability' and 'handicap' was especially useful. For example, in raising government and public awareness of issues affecting people with a disability, the concept of the 'handicapping' effect of the environment (e.g. inaccessible buildings or transport) put the responsibility for removing barriers in the lap of designers and legislators, rather than with people with disabilities.

Some problems in definition at individual level

Service providers working with people with physical and sensory disabilities seem to have far fewer problems with definition and classification than people working in the areas of intellectual disability, psychiatric disability and head injury or acquired brain damage.

Obviously some impairments are more observable and reliably measured and described than others. It is in the areas of intellectual and psychiatric impairment where accurate assessment and description is most difficult: opinions and judgments of assessors will vary; perceptions are often not

confirmable by the person being assessed; the use of IQ tests has been criticised for many years for their unreliability, particularly with young people or with people with severe levels of impairment; behavioural 'impairment' may be contextual, and reduced or aggravated by certain social situations.

In the same way, the disability section of the ICIDH is more useful for the more easily identifiable and measurable disabilities, such as in communication, personal care, locomotion, and dexterity, which are testable, repeatable and largely objective, and where both the assessor and the assessed are able to agree on the description and level of the disability. Service providers are becoming more and more wary of making judgments about areas such as social disability or the quality of relationships.

Some problems in definition at population level

There is a lot of disquiet in organisations providing services for people with intellectual disability about the continuing difficulty in identifying people with intellectual disability at population level (such as in ABS Survey of Disability, Ageing and Carers). Perhaps this is partly due to our ongoing confusion between what is impairment and what is disability, and partly through the difficulty in asking the right questions in a household survey.

Service providers' needs for assessment/classification tools

The writers of the ICIDH correctly state that users will need to establish their own classification systems to meet their own needs.

The needs of service providers for assessment and classification systems relate to the following (these needs overlap with the needs of therapists, government, health services, etc.).

- Working with the individual—what is the diagnosis or impairment, what are the needs, and what should the individual rehabilitation plan include?
- The needs of the agency, such as determining the types of staff required for particular types of service and levels of support.
- Government accountability—maintenance of data on types and levels of service provided to people with various types and levels of disability over a particular period.
- Measuring need in a community or a population, for planning purposes, and to target improvements. Needs studies are especially useful for getting a picture of particular groups that have previously been poorly identified, or about which little has been known.

At individual level

With some impairments (e.g. spinal injury, vision impairment) knowledge of the type and location of the impairment may serve as a useful general indicator of the severity of disability that a person will experience, and serve as a predictor to the amount of support and type of services that may be required. (This is said with some reservation, however, as this sort of prediction is probably more useful at an aggregated agency level, as there will always be exceptions. It may prove more useful for planning an agency's staffing needs than for planning a program with an individual.)

With other impairments, head injury being one example, knowledge of the impairment is not always a reliable predictor of a person's disability, so will not

assist a provider in planning an individual program, or in predicting the amount of support that may be required.

Nor, for any type of disability, are details of impairment and level of disability necessarily good predictors of 'handicap' and need for support. A person with a 'mild' disability may at times be 'severely handicapped' or vice versa, depending on the coping skills of the person, and depending on the amount of support available from family, or the availability of technical aids and appliances.

Most assessment tools are based very much on functional ability to perform activities of daily living. Service providers use a large variety of assessments, based on the context, i.e. assessment of functioning against the actual skills required for work, for living in a household etc.

At times these assessments of ability/disability will be far more detailed in certain areas than in the ICIDH. For example, Headway's Adult Development Program to assist people after head injury uses an assessment of skills in various areas associated with living independently in the community.

Assessment for use of public transport goes right down to details of reading a timetable, paying the fare, ability to cope if the stop is missed, etc.

At agency level—a classification example using the ICIDH as a base

When planning a new consumer data base several years ago, Yooralla Society of Victoria, a large non-government organisation whose services include therapy, accommodation, employment services and training, recreation, and information, closely examined the ICIDH for its potential application. They decided that the ICIDH itself was inappropriate. However, it provided a useful framework from which the agency devised a classification system more appropriate to its needs. Lynette Moore, General Manager, Children's and Adults' Independence Services at Yooralla, has provided information about this system, and I thank her for her assistance in the preparation of this paper.

The data base had the following elements:

- **Diagnostic categories:** 55 disorders, grouped under five major headings, based on the International Classification of Diseases (ICD), with more specificity in those disorders more prevalent in the agency's consumer group.
- **Functional disabilities:** 11 categories, based on the nine major disability codes in the ICIDH, with more detail on daily living activities than in the ICIDH.
- **Support required:** seven categories, based on the ICIDH severity scale for disability, but more positively oriented to 'support required' than to the more negative 'severity of disability'. A category for 'supervision' (as opposed to assistance) was added, as this was important for the agency's planning of staffing for accommodation services.
- **Reasons for requesting service:** 12 categories relating to the daily living activities in which development or support is being sought from the agency, based loosely on the ICIDH seven classifications of handicap, but oriented to needs rather than limitations.

Funding and government accountability

As Yooralla point out, many services are moving to unit-based funding mechanisms, with some units being funded on a per capita basis, with different levels of funding applying to different levels of consumer need. Governments are increasingly concerned that services are provided efficiently, that they are targeted to those in greatest need, that resources are spread equitably among different disability groups, that overservicing does not occur, and that agencies are more accountable to government.

We develop and try to perfect measures for certain uses, including planning of individual programs and staff services at agency and higher level. Once such measures are available, there is a risk that they will be used for resource allocation, when they are not suitable for that purpose. It would be unwise for funding bodies to try to develop the ICIDH into a system like the 'diagnostic-related groups' (DRGs) used for hospital funding, as the issues of deciding funding levels using DRGs for long-term care in hospitals are far from resolved.

The ICIDH is particularly relevant to 'input', i.e. to the consumer's situation and needs, and to what resources and assistance are available to reduce the level of disability and handicap. It is not an assessment of 'output'. Any attempt to compare different service providers giving ostensibly the same service, as a basis for funding, would be fraught with difficulties. Development of performance or output indicators is a large but different issue also facing service providers.

The different levels of government and different departments must work together to ensure consistency in data collection and reporting requirements. This is particularly important when agencies are trying to ensure that they minimise administration costs and, in turn, maximise the use of their funds for direct service delivery. It is immensely frustrating for agencies that, as government departments implement funding mechanisms which have very low levels of administrative funding built in, their requirements for data collection and reporting have risen dramatically.

At population survey level

One of the roles of national peak disability bodies is to identify gaps in services. How many people are there who have Alzheimer's Disease? How many have acquired brain damage? What are their needs? Are there neglected groups who don't form their own lobbies? Are any groups under-serviced?

The ABS are responsive, through their user group, to the needs of service providers for numbers and data about people in certain categories. They have attempted in their 1993 survey to identify more precisely people previously poorly identified, including people with dementia, people with acquired brain damage, and people with certain dexterity disabilities.

Future directions

Agencies, now more than ever before, must have good databases operating. Government departments must work closely with agencies and with consumers to ensure systems are consumer focused and consumer friendly.

To be of use to service providers today, any assessment or classification system has to take account of the following aspects.

- It has to be specific to the agency's consumer group.
- It should use language and concepts that are positive rather than negative. Thus, assessing a level of severity according to level of 'support needed' is preferable to assessing 'dependent performance' and reflects a major shift in how agencies view their consumers and their role in relation to consumers, as well as how consumers view themselves.
- It should take account of the fact that standard practice today is for consumers to complete data forms themselves, or with the assistance of an advocate, and to 'own' the record, including having a copy of it. Gone are the days of professional staff rating and categorising consumers without their knowledge and input. Furthermore, the consumer's opinion on his or her particular support needs and priorities is usually more important for the eventual outcome than the staff member's opinion.

Finally, service providers are keen to work cooperatively with government, research bodies, and people with disabilities, to improve the quality of data collected at community and population levels, in an effort to fine tune the definitions and terminology and to gain a better picture of needs, especially in the areas of psychiatric and intellectual disability.

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Session 2.1 ICIDH and mental health

Options for consideration in the revision process of ICIDH (1980)

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Introduction

It is clear from the literature of recent years on the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), published by the World Health Organization in 1980 (and referred to here as ICIDH-80), that the basic idea of using a tri-partite scheme for the description of the consequences of illness has found favour, and that the three concepts—impairment, disability and handicap—have been widely accepted as useful. At the same time, however, application of the system in practice has often revealed problems. The principal difficulties have arisen from overlap between the three classifications, in that a number of items are present in two of the classifications and some are present in all three. The degree of overlap present in ICIDH-80 and the many inconsistencies between the definitions of the three concepts and the content of the respective classification mean that, strictly speaking, the term 'classification' is not justified. The scheme is better regarded as containing three useful lists, which form a promising start in the progress towards classifications.

This commentary is written by a general psychiatrist so the special needs of persons in the mental health services have naturally been kept in mind, but it should be noted that it is only with respect to the Impairments section of ICIDH-80 (or a similar but revised version) that the requirements of mental health workers are likely to be different from the requirements of their colleagues in physical medicine. So long as the concept of impairment remains basically the same, this section will always have parts on physical impairments that are obviously different from the parts on psychological impairments. But the sections on both disabilities and handicaps are not clearly divided in this way, since disabilities and handicaps (as defined in either ICIDH-80 or the modifications discussed here) require the same descriptors for all types of subjects. For instance, if a person cannot go out of the house (a disability) and so cannot perform a particular job of work (a handicap), these need to be described as such; in these two sections of ICIDH it makes no differences to the description of the consequences of illness whether the original illness is physical, such as paralysed legs, or psychological, such as agoraphobia. The categories covering these particular instances in the Impairments sections would, of course, be quite different from each other.

In other words, although this document is written by a psychiatrist, most of the points discussed will be seen to be relevant to users of ICIDH or its successor in all types of health services.

As a preliminary to the detailed discussion that follows, it is presumed that the main aims of ICIDH are as follows:

1. To develop a descriptive system that allows the assessment of the ways in which diseases, illnesses or disorders interfere with what an individual can do.
2. To describe this interference at three levels of organisation, namely:
 - a) interference with functions (e.g. of organs or limbs). These interferences with functions are *impairments*;
 - b) interference with purposeful activities of the whole person interacting with the immediate environment. These interferences with activities are *disabilities*; and
 - c) interference with actions at a more complex level, involving social interaction of various types, such as interference with role performance. For the moment these will still be referred to as *handicaps*.
3. To achieve 1. and 2. by means of three classifications, rather than being limited to 'useful lists'.
4. To provide lists or classifications of external factors which interact with impairments, disabilities and handicaps (for instance, physical barriers, administrative processes, and personal attitudes).
5. To provide guidance about methods of assessment, at more than one level of detail.

Implications of these aims

If these aims are accepted, it is useful to discuss briefly what is implied in them. During this early stage of the revision process, if different or additional aims are adopted, these need to be examined in a similar fashion.

Aim 1: To develop a descriptive system that allows the assessment of the ways in which diseases, illnesses or disorders interfere with what an individual can do.

In this document, impairments are limited to interferences with performance of functions, and losses and abnormalities of structure are not included. Discussion here is therefore confined to interference with the performance of functions. However, there is no special problem in including abnormalities and losses of structure in impairment so long as it is stated clearly that the Impairments section has two conceptually different parts, each requiring its own classification.

Aim 2. To describe the interference at three levels of organisation.

Why keep to three levels—why not have more? Since we are dealing with interference with the whole range of human behaviour, from part-functions through the activities of the whole individual to social interaction, a case could perhaps be made for using many levels. But three is convenient and easy to remember and has worked well for most users of ICIDH. Anybody who becomes familiar with ICIDH-80 in detail (or with any other system which grapples with the complexities of human behaviour) soon comes to realise that a large number of possible levels of organisation can be identified. Nevertheless, these levels tend to fall into fairly natural groups, and the three broad sections chosen for ICIDH-80 are a familiar and practical compromise. The lesson to be learned is that in the revised system, it will be helpful to

comment about some of the more obvious subdivisions of the three main groups. To do so should be reassuring to the users, and will illustrate that the boundaries in the revised system are more clearly established.

If impairments are restricted to interference with functions, and it is assumed that handicap is something to do with the social level of performance (implying interaction beyond the personal purposeful activities around which the concept of disability is centred), then it is possible to envisage a three-part system of which all three parts share the common feature of being types of interference with performance—that is, performance of a function in the case of impairment, performance of a personal purposeful activity in the case of disability, and performance of something at the social level in the case of handicap. This simplified scheme is easy to think about and to understand, and is discussed as 'IDH-93' in the next part of this document.

Aim 3. To achieve these aims by means of classification.

In order to justify being called a classification, each section of ICIDH must follow some basic rules. The concept that is the basis of each section must be described (best done to begin with by one or more narrative paragraphs, identifying not only its essential characteristics, but also commonly associated features). This should be accompanied by clear statements about what each concept is not, so as to emphasise the need to clarify boundaries throughout the development process. The eventual need for a brief formal definition in which every key word or phrase is carefully chosen (and further defined in an additional set of statements) should be kept in mind by having several draft options, but lengthy deliberations about these are best left for the final stages. In the initial stages of revision, the longer 'working definition' accompanied by both inclusion and exclusion statements is more useful.

Aim 4. To provide lists or classifications of external factors.

The need for these has been agreed by users of ICIDH-80 for several years, but a decision is needed as to whether they should be included as an integral part of the revised scheme, or provided as separate documents for use alongside it.

Aim 5. To provide guidance about methods of assessment, at more than one level of detail.

It should be possible for the revised scheme to be accompanied by guidance about how to apply the concepts and classifications to methods of assessment. Examples of draft assessment schedules need to be developed, which can guide users towards the development of more detailed and extensive assessment schedules for local use. The ICIDH cannot be expected to include assessment schedules and methods that can immediately be used in widely different circumstances, but some common principles and basic methods could be outlined and discussed. It would be particularly valuable for some of these comments and discussions to focus on the need for more than one level of detail in the application of the concepts of ICIDH. The methods required for large-scale population surveys or the summarisation of regional and national data are quite different from the requirements of researchers and clinicians operating at the level of the individual. Nevertheless, all can have a common conceptual base within ICIDH, and the ways and means of providing this need to be examined.

Issues of special interest for mental health work

Most of the patients encountered in physical medicine have obvious impairments or disabilities, so it is natural for attention to be focused on these by the medical professionals involved. But in mental health work, the most obvious problem with many of the patients is their inability to perform their social roles; they do have impairments and disabilities but these are often of a more subtle and not very obvious type. It is therefore natural for mental health workers to want to see interference with social role performance in a prominent place in a descriptive system, based upon a classification of social roles. At the moment in ICIDH-80, items describing social role performance occur in both the Disabilities and the Handicaps sections, but neither set of items are in sufficient detail to provide individual profiles over a number of conventionally recognised social roles. A single section (with options for more detail) is required, as noted later.

The assessment of psychological impairments is of great importance in mental health work, and must have adequate and appropriate coverage for the revised ICIDH to be attractive to the professionals in the disciplines concerned. The Impairments section of the ICIDH-80 poses many problems for mental health workers. The content, the arrangement and also some of the terms used all have some aspects which are very different from conventional practice in psychiatry and clinical psychology.

A fairly radical revision of this part of the Impairments section is needed, but without changing the central aspects of the concept upon which it is based.

ICIDH-80 and the WHO Schedules—DAS and PIRS

At the same time as the final draft of the ICIDH-80 was in preparation, the staff of the WHO Division of Mental Health were preparing interviewing and rating schedules for use in an international collaborative study on disability in psychiatric patients (Jablensky et al. 1980). There was some interchange of ideas with Dr P Wood, and several sections of the WHO Psychiatric Disability Assessment Schedule (DAS) dealing with interference with social role performance were incorporated into the final version of ICIDH-80 (they were, however, placed in the Disabilities section, as categories 17 'Family role disability' and 18 'Occupational role disability' rather than in the Handicaps section where the definition centres around 'fulfilment of a social role'). The Psychological Impairments Schedule (PIRS) contains ratings of a wide variety of psychological and psycho-motor impairments.

In summary, these two schedules are congruent with the concepts of ICIDH-80, but their content was selected so that almost all of the overlap between the three classifications of ICIDH-80 was avoided. The schedules have now been used successfully in several large international collaborative studies, and have proved to be applicable in several different cultures and languages. Their success reinforces the general conclusion that the concepts of ICIDH are useful, so long as their practical application is made easier by the removal of overlap and inconsistency.

IDH-93: a discussion document with a simplified ICIDH-80

Over the last few years there has been an increasing interest in the assessment of disability in many countries, together with the closely related topic of

assessment of the quality of life. Experience as a collaborating investigator in the WHO studies using the DAS and PIRS schedules has made it clear that it is now time to improve the schedules, and also to revise the scheme containing their underlying concepts. The advent of the next version of the International Classification of Diseases (ICD-10), and the recent decision to include the revised version of ICIDH as an official chapter of the overall ICD-10 family of documents give the revision process added importance. With these issues in mind, a discussion document, entitled IDH-93 for unknown reasons other than likely convenience, was prepared in 1993. This was done partly out of personal interest, and partly at the request of (and with some assistance from) the Division of Mental Health of WHO in Geneva.

The first draft of IDH-93 is a set of papers totalling over 50 pages, so it is not reproduced here. It has been sent to a limited number of interested persons by the Division of Mental Health, and has been presented as a discussion paper at several meetings. It was discussed in detail at an informal multi-disciplinary meeting organised by the Division of Mental Health in Mannheim (June 28–30 1993) and was discussed further at another informal meeting in Paris (October 25–27 1993). The main differences between ICIDH-80 and IDH-93 are now summarised.

For the purposes of this discussion, IDH-93 can be regarded as a simplified version of ICIDH-80. (This is true enough for immediate practical purposes, but IDH-93 is also derived from a classification of normal behaviour developed in outline some years ago (Cooper 1990); this was produced as a guide to thinking about ways of classifying disability, on the grounds that a classification of deficiencies in normal behaviour is most likely to be useful if based upon a classification of normal behaviour.)

Box 1: IDH-93 definitions of impairment, disability and handicap

These short definitions are for use in the context of health experience.

*An **impairment** is any interference with the performance of a normal psychological or physical function, including appearance.*

*A **personal disability** is any interference with the performance of a normal purposeful activity in relation to the immediate environment.*

*A **role handicap** is any interference with the performance of a normal social role.*

The performance referred to is that of a healthy individual whose age, sex, educational, social and cultural setting will determine what range and variety of functions, activities and social roles should be expected, and what level of performance should be regarded as normal.

IDH-93 can be regarded as illustrating what happens if the simple rules of classification are applied to ICIDH-80, and the boundaries between the three concepts defined more closely. It differs from ICIDH-80 in two principal ways:

1. All three concepts in IDH-93 are narrowed down so that they are defined only in terms of interference with the performance of a task. The tasks being performed are, of course, of different levels of complexity, assessed in different contexts in the three parts of the system, as in ICIDH-80.
2. The content of each classification is limited strictly to categories that meet the definition. There is no overlap, and the three parts are designed for use as a linked system.

ICIDH-80			
Title	Impairment	Disability	Handicap
The <i>definitions</i> centre around:	structure or function (organ)	activity (person)	role (a social phenomenon)
The <i>content</i> , however, refers to:	many structures + many functions + some activities + a few social role performances	some functions + many activities + some social role performances	some functions + some activities + some social role performances
The overlap interferes with use as a linked system, but the more comprehensive content of each part encourages use separately.			
IDH-93			
Title	Impairment — physical — psychological	Personal disability	Role handicap
The <i>definitions</i> centre around:	function	activity (person)	social role
The <i>content</i> , consistently, refers to:	functions	personal activities	social roles
Designed without overlap, for use as a linked system, and the three parts can be used separately if required.			

Figure 1: Some important differences between ICIDH-80 and IDH-93

The implications of these differences are as follows.

Firstly, abnormalities and losses of anatomical structure are not included as impairments in IDH-93, whereas they were present in ICIDH-80. There are, of course, many reasons to have satisfactory ways of describing and classifying abnormalities and losses of anatomical structure, but there is little to be gained by including them in this scheme. If they are included, then the diverse and extensive lists of impairments do not rest comfortably under the title of 'classification'. Two distinct classifications are needed: one of losses and abnormalities of structure, and one of abnormalities of functions (a substantial number of which are a direct consequence of the losses and abnormalities of structure).

Secondly, the concept and the definition of *role handicap* in IDH-93 are simpler than those of *handicap* in ICIDH-80. Many users of ICIDH-80 have found it difficult to understand how the definition, the characteristics, and the classification of handicap fit together (World Health Organization 1980, page 183). Handicap is first described in the definition as 'a disadvantage which ... prevents the fulfilment of a role'. This is followed by a statement that the classification is not one of disadvantages, but of circumstances that place individuals at a disadvantage. The classification that follows contains many

items that refer to the performance of individuals, in ways that appear to have already been covered in the classifications of impairments and handicaps.

It seems preferable to limit the concept and definition of handicap to what in ICIDH-80 is said to be its main characteristic, that is, the difference between the actual performance of a social role and the performance that would normally be expected. There is also something to be gained, at least for the moment, by using a double title 'role handicap' to emphasise that social role performance is what is being referred to. A classification of social roles is needed, which is used for assessing the ways in which the individual does or does not achieve the performance expected of him in the roles which are appropriate for him. These assessments indicate the ways in which he is handicapped.

Thirdly, a revised ICIDH based upon these same principles would be much easier to use as a linked system that allows the performance of an individual to be recorded at the three levels of the system, thus making possible an examination of how the three levels may be related. An item of behaviour, or lack of it, found in one part of the scheme is not present in other parts, but its consequences or causes may be found in the other parts expressed in different terms at a different level of complexity. In addition, each of the three parts can be used separately, if it is required to describe the individual at only one level (which is often the case).

Box 2: Outline of a classification of social roles

<i>Family roles</i>	<i>nuclear extended</i>
<i>Occupational roles</i>	<i>external to household household educational</i>
<i>Leisure roles</i>	<i>external to family within family organised sports, etc.</i>
<i>Community roles</i>	<i>social political religious</i>
<i>Sexual roles</i>	
<i>Other</i>	

Use of a system with these properties is of potential interest for detailed clinical assessments of individuals, for instance in examining the number and pattern of impairments, disabilities and handicaps for groups of individuals with different diagnoses. It is striking, for example, that schizophrenic illnesses usually produce a number of interferences with performance at all three levels, suggesting that a quite pervasive disturbance is present that starts at the most basic levels. In contrast, states such as bereavement reactions and character disorders have most entries in the system at the role end, and may produce only a few entries of an unusual type at the level of impairment. We know for other reasons that these disorders are of different natures, and it is of interest that they come out so differently on this sort of scheme.

Assessment of social role performance

It is worthwhile discussing this, because it has been evident in recent discussions that some users of ICIDH-80 are uncomfortable with the idea of assessing the performance of social roles due to the relatively large cultural influences on both the numbers and types of social roles expected of individuals. It is true that cultural variations in social role performance are more obvious than they are for functions and activities, but the difference is quantitative and not qualitative. There are also cultural effects (due to differences in upbringing and education) upon the repertoire of an individual for both functions and activities; it is just that they are more obvious for social role performance. To recognise these variations and to assess an individual while taking them into consideration requires the same type of knowledge and judgement from the professional person making the judgement as does, for example, the range and power of leg movements in a child compared to those of an elderly person. Different standards and contexts of judgement are applied to different individuals, but knowledge of these differences is well within the capability of an experienced and appropriately trained health worker.

In this discussion, the double term 'social role' will be used to avoid confusion with the way 'role' by itself is used in ICIDH-80.

There are a great many definitions of social role in the literature, but they all share the following key concepts and features.

- A social role is a type of position or status in a social group.
- The members of that social group have specific expectations about how a person occupying a particular social role will behave towards other members of that group. For most social roles there is a set of core behaviours that are obligatory, plus some others that are optional extras.
- A person in a social role shows that he occupies it by interacting with the other members of the group according to their expectations, so enabling them, by means of the same interactions, to fulfil their own (reciprocal) social role.

To use an explicit example of father and son, to fulfil the role of father, a person must interact, in ways appropriate to the cultural group, with his son. The interaction, such as talking to or playing football with the son, also allows the son to express his role of son towards the father. To put this in another way, the performance of a specific or named social role is manifest in reciprocal interpersonal interactions.

Most people have several social roles, and a single count-up of how many social roles a person is or is not performing, compared to a previous occasion or compared to what the family and friends expect or hope for, can in itself be a useful indicator of social activity or status. Each social role usually has several components (or 'Sub-role activities' in IDH-93 terms). For instance, the sub-role activities that make up a role such as father are likely to vary a great deal from one culture to another, but it is usually easy to establish for each culture or group what the expected behaviours for a father are. In addition, a person's social roles vary with age, but again there is usually no special problem in determining what is expected of, say, a child or a grandparent in a particular group. It is, of course, usually necessary to do this by asking both the person

concerned and others who are in close contact with that person, but to do this is no different from what is required in many other types of individual medical and social assessment.

Widespread experience with the DAS schedule in several international collaborative studies has shown that social role performance can be assessed with no more trouble than, for instance, the mental and behavioural state. In practice, two levels of assessment emerge, one global and another more detailed. In the way the DAS has been used up to now, these two levels of enquiry have been combined, in that it has been left to the discretion of the interviewer to decide what level of detail to use. This decision can usually be seen to depend upon whether the initial response indicates a good social role performance or a poor one. It is often clear from the start that the subject of enquiry has a good social role performance, and in such cases there is little point in going into great detail. But when a poor performance is described, it is usually worthwhile finding out which parts (i.e. which sub-role activities) of the expected role behaviour are deficient.

The global level of assessment is often very simple and rapid to do, since it consists of asking just one or two general questions about the subject, say a husband, of his wife. The wife is asked something like 'Is your husband a good husband?—Is he doing what is expected of him with respect to you and the children and his work?'. The reply of the wife may be little more than 'Yes, he is a good husband'; this can be expressed as a rating and is for some purposes an important item of information. This type of assessment views the husband through the eyes of the wife, but she knows the family and cultural context in which to judge the husband's performance. The interviewer/rater is also assumed to be familiar with these contexts, and will also make allowances in the rating for a professional judgment of the wife's abilities as an informant. There are therefore many complex and relative value judgements involved in this type of rating, but the situation is no different from many other clinical situations in which a professional health worker makes a global or overall assessment of the change in a patient's clinical state—using the same type of contextual knowledge and judgements.

The more detailed level of social role assessment is appropriate for assessing poor social role performance, for following the progress of an individual over time, or for comparing the content of social roles in different cultural groups. It involves inquiring about each of the various behaviours expected of a person in the social role in question, in detail. In the current DAS, some general guidance is given about likely 'sub-role behaviours', but these are expressed in general narrative form and it is left to the interviewer to decide how many questions to ask and what level of detail to use. Uses can be foreseen for a pre-prepared list of the behavioural components of the main social roles, such as husband, wife, son, daughter, wage earner, sexual partner etc. specified after discussion to arrive at agreed local and individual expectations.

To have available sections of a revised ICIDH in the form of items or ratings which allow the assessment of social role performance does not, of course, imply any obligation to use them. The ICIDH must attempt to be comprehensive overall, but any particular user will be likely to select for use only parts of the whole system. (There may also be support for designing the

layout of most parts of ICIDH so that two levels of assessment are provided (or at least suggested).)

Further definition of boundaries between the three concepts

Several options need to be discussed in the near future, and their implications examined before final decisions are made. For IDH-93, the main extra points are as follows.

The boundary between a function and an activity is identified by stating that a function does not involve purposeful use or manipulation of the immediate environment. For instance, to measure the power of contraction of a muscle or the range of movements of a joint is to measure functions (and any deficiencies are impairments). The results of these assessments are useful concepts, and are expressed without direct reference to the immediate environment, although, of course, this was involved in the process of measurement, as was a person acting in one of a variety of different possible roles. If what is being assessed is how a person uses joints and muscles to walk across the room or climb stairs, interaction with the environment is a necessary part of what is being assessed, and the object of assessment is an activity; any deficiency will be a disability.

The boundary between disability and role handicap is identified by stating that an activity does not involve interaction with another person in the reciprocal performance of their own named social role. It can, however, include interaction with another person as an 'impersonal other' when, for instance, the individual concerned needs another person with whom to perform an activity, such as a conversation, but the identity of the other person or the social role that they are performing at that time is not relevant to the assessment. Having a conversation while learning a new language is an example—a person's ability to do this can be assessed with a wide variety of other persons speaking that language, and their individual identity or social role is not a part of the result of the assessment. In contrast, to assess a mother's ability to carry on a conversation with her daughter as an important part of performing her role as a mother can be done only by assessing a conversation between the two, and with the concept of the mother's role very much in mind all the time. In this latter context, what is being assessed is a part of the mother's social role performance, and not just an activity.

These are just two examples of the sort of additional statements and examples that are needed to clarify the boundaries between the concepts. More than what is given above is needed, but the examples are sufficient for the purposes of this paper.

It is well worthwhile exploring the implications of several options for boundary definition. For instance, if an activity, and therefore a disability, is defined as including the social interactions required for social role performance, the third component of the scheme is left empty (this is assuming that the rules of classification have been applied, and thus distributing the categories under Orientation Handicap, Physical Independence Handicap and Mobility Handicap to their correct places in Impairments and Disabilities). This gives options of either having a two-part scheme composed of only *impairment* and *disability* (but in which *disability* is very large and would need several clear subdivisions), or having a three-part scheme in which the third part would be the

lists or classifications of external factors that have been the subject of discussion for so long.

Future users of ICIDH will probably not mind very much which one of these and other possible options are chosen, so long as the result is clearly described and the reasons for the decisions are given.

Conclusion

The above discussions are sufficient to illustrate that definitions and concepts in a scheme such as ICIDH can be changed if there are good reasons, but that the consequences of the changes need to be worked through with the definition of boundaries very much in mind if the result is to be a practical proposition. The principal difference between the options discussed above and sections of the ICIDH-80 is that these options follow some simple rules of classification.

Perhaps the most important point to be made in conclusion is that in spite of the above rather lengthy discussion about definitions and boundaries, the great majority of individual items in a scheme such as ICIDH can be found a place without trouble.

There is no need to wait for these issues of classification to be resolved first, before getting on with the essential work of:

- assembling groups of items needed for purposes of assessment;
- devising operational definitions for them; and
- testing their reliability and usefulness in clinical situations.

If an item of behavioural assessment is important clinically or administratively, then it needs to be developed for use irrespective of its eventual place in the overall scheme.

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Session 2.3 The relevance of ICDH to mental health in Australia

ICIDH and mental health

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The ICDH was developed in the 1970s as an extension to the International Classification of Diseases (ICD). The principal reason for its development was that the users of the ICD (health planners, clinicians monitoring changes at an individual and population level, persons advocating the needs of the disabled, medical records services and other observers of health care consumption) felt that the ICD:

- did not sufficiently cover the impact of the disorder on the individual and the society in which he lived; and
- was unable to describe the heterogeneity of the clinical expression of a disorder, and its variable evolution in different individuals and in different societies.

The ICD is based on a medical model which assumes the following sequence:

aetiology → pathology → manifestation

This model does not reflect either the reasons for which the person makes contact with the health system or his ability to function as a normal individual. In the field of mental health these issues are of particular importance as the main target of therapeutic intervention is often to reduce disability rather than to 'cure' the illness. In the ICDH model may be seen a supplement to the ICD which conceptualises the consequences of diagnosed illness according to the model:

disease → impairment → disability → handicap

Let us briefly consider each of these in a mental health context:

Impairment

In the context of health experience, an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.

An impairment is generally considered to comprise a deviation from some norm in the individual's biomedical status. Woods himself refers to impairments as 'the exteriorisation of a health problem'. This idea may be easily understood in the case of physical disease where impairment is visible and may be easily classified as either absent or present e.g. the loss of an eye, swelling of a joint, spots on the face and so on. In mental health, impairments are abstract constructs such as cognition and self-awareness which cannot be visualised as Woods suggests and must be measured by reference to deviation from a norm. The coexistence of these quite different types of signs have led

many users of ICIDH to argue for a separate impairment section for physical and mental disorders.

Disability

In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

While impairment concerns parts of the body, disability is concerned with compound or integrated activities e.g. bathing, dressing, feeding. Unlike the impairment section, most of the disabilities relating to physical disorders are easily applied to mental health. A number of disabilities have, however, also been included which are related to mental dysfunction only. Some of these may seem curious to persons unfamiliar with psychiatric disorders e.g. dropping lighted matches on the carpet disability.

Handicap

In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual.

Handicap is relative to other people and therefore highly dependent on social values and environmental factors. This section is of particular importance to mental health as it is in their relationships with others that persons with mental disorders often suffer the most. Furthermore we know that many mental disorders, in particular many of the so-called neurotic disorders, are culturally specific and that social tolerance of psychiatric symptoms is far more variable than for physical disorders.

Applications in mental health

Let us consider briefly some of the possible applications of the classification in the field of mental health:

Establishing the long-term individual and social consequences of disease

The ICIDH may be used in a clinical setting as a supplement to clinical notes. A standardised description of the impact of the disorder on the patient's everyday life will thus be available which may be more sensitive to clinical change than descriptions of symptoms and signs, and may also be valuable in determining therapeutic goals. In the case of schizophrenia for example, adding an ICIDH code to the ICD diagnosis will indicate rapidly the more urgent adjustment problems confronting the individual such as impairments of speech pressure, body image disorder, obesity and false perception, and disabilities of work stress tolerance and disturbance of self-presentation. Severity ratings may also be given so that these impairments and disabilities may become points of reference for evaluating the impact of therapeutic intervention.

Planning the management of chronic mental disease

It is a well known fact in psychiatry that the same disorder may engender extremely variable patterns of disability and dependency in different individuals depending on factors such as their pre-morbid personality, availability of social support, coexisting pathologies, age, social class, type of clinical management and so on. This is particularly true in elderly populations where multiple pathologies are common so that age and diagnosis alone are

insufficient indicators of service needs. Let us take for example the case of two women both in their eighties with arthritis and mild cognitive difficulties—the first has no active social network and is confined to a chair in a nursing home, the other is living in the community with family and is celebrating her 84th birthday by taking a first trip in an ultra-light.

We used a functional disability scale based on ICIDH disability and handicap sections to study elderly persons diagnosed with severe senile dementia scoring less than zero on the Mini-Mental State Examination. Scale scores range from zero to 186. A very wide, almost bi-modal distribution of scores can be seen. Thus while the clinical indicator used, the MMSE, suggests that this is a homogeneous group, in terms of service needs they are clearly very different, ranging from bed-ridden to independent for some activities of daily living if help is provided.

Describing the circumstance of individuals with a disease in different social settings

In mental health the social setting of the patient is often an important determinant of adjustment to the disorder, its clinical course and management. For example, the admission of an elderly dementing person into a long-stay hospital is far more commonly due to social intolerance or social isolation rather than for medical reasons. Using the ICIDH to record information relating to social integration may not only be useful in predicting the need for institutional care before the crisis occurs, but at a research level increases our understanding of the role of non-medical factors in the evolution of chronic mental disorder.

Evaluation of the impact of health care policies and specific therapeutic programs

The ICIDH may be used as the basis of evaluation studies and as such is a far more sensitive indicator to change than the presence or absence of a disorder. By using ICIDH a clearer picture may be obtained as to the mechanism by which a therapeutic program has had its effect enabling the differentiation of biological, psychosocial and environmental factors. For example, we used the disability and handicap scale described above to compare two forms of care for the dementing elderly (long-stay hospitals and communal living). The results suggested that while type of care had no impact on the progression of the disorder or life-expectancy, clear differences were seen in the evolution of disabilities. Here we see the example of mobility from the mobility sub-scale—the hospital patients becoming confined to chair or bed at a much earlier stage than those in communal care.

Determining staff requirements

Staffing requirements for institutions are commonly based on the number of patients and the type of disorder without reference to disability levels. As health care strategies in western countries generally aim to maintain persons with mental disorders as long as possible in the community the profile of institutional residents tends to change towards greater severity and multiple pathologies. Failure to take such changes into account rapidly leads to staff burn-out, poorer standards of care, and at worst, patient abuse. The ICIDH may provide a standardised method of identifying and classifying disability levels

which may be used in the justification of demands for changes in staff : patient ratios.

A point of reference for the standardisation of health surveys

As life expectancy increases, particularly at higher ages, so does the prevalence of the major chronic diseases. Increasing concern is thus being expressed by researchers in the field of population health that western countries may be heading towards what has been described by Kramer as a pandemic of mental disorders and their associated disabilities. Mental health surveys are thus now interested in looking beyond prevalence estimates to increasingly focus on population disability levels in order to predict service needs more accurately. Unfortunately there is little standardisation between countries and often even between repeat surveys within the same country. The ICIDH provides a useful conceptual framework for the standardisation of terminology and for the preparation of survey questionnaires which may facilitate international comparisons.

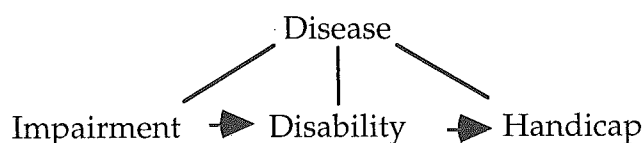
A basis for the determination of social security allowances and compensation claims

Both public and private benefits for the chronically ill are covering a widening array of mental disorders but the basis for determining need in most cases is highly inadequate, depending largely on diagnosis and income. In France, for example, financial aid to modify housing conditions for a disabled person is determined by diagnosis and the present state of their house without reference to the actual disabilities of the person. In providing an internationally acceptable standardised classification of the consequences of illness, ICIDH has an important role to play in determining sickness benefits.

Shortcomings in the mental health context

Difficulties in the application of ICIDH in the mental health context have been discussed at a series of meetings held between WHO and a group of consultants consisting of psychiatrists, psychologists and psychiatric epidemiologists. A number of problems have been identified by this group.

The first problem relates to the ICIDH model itself which assumes a causal, linear relationship between disease, impairment, disability and handicap. In the area of mental health in particular the relationship may be two-way, e.g. depression leading to social isolation which in turn intensifies depression. Additionally the three concepts do not necessarily proceed one from the other in a linear progression, e.g. a person formerly suffering from a mental disorder may continue to be handicapped by stigma although the disorder itself is no longer present. It has thus been proposed to modify the model to:



In this way impairment, disability and handicap may be related independently to the underlying disorder with the possibility of a two-way interaction.

A second issue relates to the problem of the relationship between the mind and the body. Interestingly, all organs of the body are included in the impairment section of ICIDH except the brain and central nervous system. No provision is made for the recording of the central nervous system abnormalities which may underlie a mental or behavioural disorder. It thus adheres strictly to the view that psychiatric disorders are purely mental phenomena and that a link cannot be made between an impairment to the brain and resulting cognitive, behavioural and personality disturbances. Psychiatry, it is true, has always rested on the assumption of mental causes; as specific psychiatric disorders are explained in terms of underlying nervous system dysfunctions they will probably disappear into the domain of neurology. However it is important that, as neurological research is now beginning to isolate possible biological markers of many psychiatric illnesses, the possibility of being able to record central nervous system impairment should be made possible.

Moreover, within ICIDH the so-called 'mental' functions represented are at times overlapping and inconsistent. As an example, language comprehension is classified as an impairment whereas difficulty in understanding speech is classified as a disability. Categories within a classification system must, by definition be mutually exclusive otherwise it cannot be considered a classification but rather, as John Cooper has pointed out, a series of lists. Many of these difficulties arise because, in the case of mental illness, impairments are usually defined in terms of their associated disabilities, so it is not surprising that there is considerable overlap between the concepts.

Thirdly, disability in mental health is often likely to be a function of both functional and cultural factors which need to be differentiated and split between categories of the classification. An example of this is 'parenting', presently considered a disability. Parenting includes a wide range of behaviours both biologically and culturally determined. For example the schizophrenic mother's inability to recognise or maintain eye contact with her child is a true disability at the individual level whereas failure to play with the child or show affection in a manner appropriate to the culture constitutes a social integration handicap.

Fourthly, there are also a number of more specific shortcomings in ICIDH relating particularly to mental health. For example there is no method of recording fluctuating performance in the severity ratings, communication disability does not stipulate that the communication should be appropriate, and it is not presently possible to differentiate the consequences of treatment as opposed to the consequences of the disease itself, e.g. extra pyramidal signs occurring as a result of anti-psychotic medication. These and a number of other problems will hopefully be corrected in the revision of the classification.

The overall impression that one has on using ICIDH is that psychiatry is really a secondary application. To be fair, the classification has been compiled by a rheumatologist, and it is in this area that it clearly works best. The ICIDH clearly has an important place in mental health but revisions are needed if it is to be used by professionals in this field. Looking for example at the section on cognitive disability we find that intellectual impairment is considered to consist of IQ, thinking and memory, while learning is classified separately under language impairments, and disabilities of psychomotor function, behaviour,

attention and volition are all classified on the same level in yet another section entitled 'other psychological impairments'. Cognitive psychologists have clearly not been involved in this strange ordering of things.

Mental health professionals have until recently shown relatively little interest in the classification, and it is in this area that its developers have experienced the most difficulty. On the other hand the disinterest of mental health workers is to some extent understandable. The ICIDH has obliged many other branches of medicine, such as rheumatology and cardiology, to see disease in an entirely new perspective in which severity is not defined by risk of mortality but rather in terms of its consequences for the quality of life of the individual. In psychiatry this is 'old hat'. Most psychiatric illnesses are defined in the first place by their impact on behaviour and social functioning (disabilities and handicaps). A large part of ICIDH for psychiatrists and psychologists is thus to some extent already embodied in ICD itself.

Increasing interest is now being shown in the area of mental health as the full potential of the classification has begun to be appreciated—in particular for the standardisation of terminology regarding the social consequences of mental disorders and the possibility of having a comprehensive yet culturally portable classification system for research purposes. The success of ICIDH in mental health very much depends on the willingness of persons to use it and communicate their experiences and difficulties to Michel Thuriaux at the WHO office.

Measurement of psychiatric disability

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Good mental health care services should identify the problems presented by each patient, diagnose the disorder carefully, then measure symptoms, disability and risk factors, and should provide treatment until the consumer no longer has the disorder, or the symptoms, or any disability, or any enhanced risk of developing the disorder again. The aims of a fully functioning service are listed in the box below.

Box 1: Background to defining a consumer outcomes measure

Consumers with mental disorders have the right to expect:

1. That the clinician or unit attending their needs is competent and experienced in the treatment of their disorder.

Measures: A description of the role is publicly available in information sheets and on public notices.

2. That their intake procedures are defined in terms of who can refer, how appointments are made, the characteristics of patients to be accepted, and the assessment procedures.

Measures: Explicit referral policy. Information sheet about the mechanism for making appointments and their costs. Inclusion and exclusion criteria for patients. The assessment procedures should include: (i) an intake interview with an experienced clinician; (ii) a confirmation of the clinician's diagnosis either through a second opinion or through the use of a structured diagnostic interview or both; (iii) measurement of symptom profile, disability and risk factors, all conducted using reliable and valid rating scales or questionnaires.

3. That the process of treatment is standardised in that diagnosis specific treatment protocols are available, protocols are consistent with best practise, there is quality assurance over process, and patients confirm that their treatment was delivered as promised in a satisfactory and courteous manner.

Measures: (i) Treatment protocols should be written and used by all clinicians to guide treatment. (ii) These protocols should be reviewed by outside consultants and be consistent with best practise. (iii) During treatment there should be quality assurance to ensure that treatment is delivered as planned, and that the response to the treatment is as expected. Aberrant responses to treatment should trigger immediate clinical review.

(iv) At the end of treatment an independent person should review that treatment was delivered as planned and that it was delivered in a manner that was satisfactory to the patient.

4. Outcome is measured at post-treatment and at follow up, that arrangements for appropriate continued care are made and effected.

Measures: The assessments of diagnosis, symptoms, disability and risk factors mentioned earlier are repeated post treatment and at appropriate follow up intervals. Persons who still meet criteria for the diagnosis are reviewed, as are those who are still symptomatic, disabled or have significant risk factors, to decide whether additional treatment is indicated or desired.

While these criteria may appear to be excessive from the view of many service providers, from the consumer's point of view they are not. Consumers want the best possible treatment delivered as accurately and as promptly as possible and continued until they are better. The idea of rationing, being provided with less

than optimal treatment because resources are scarce, has no meaning. Each consumer wants the best treatment now. They are happy to comply with diagnostic and assessment procedures—provided that the primary purpose of such procedures is to improve care. In the final analysis, consumers are interested in the reduction of disability so that they can get on with their lives. Getting better is all that counts.

There are many consumer outcome measures available; but they are seldom used routinely. In order to develop standard or agreed consumer outcome measures which *will* be used, three steps are necessary. First, a review of the literature and consultation with the mental health industry's providers and consumers (the stakeholders) needs to be undertaken to identify the many measures that currently exist, and the practicality of their implementation. Second, the areas in which new measures need to be developed should be identified. Third, thought needs to be given to the clinical environment in which the regular completion of such measures will prove to be the natural thing to do.

Twenty-eight per cent of the Australian population will, in any year, have symptoms that meet criteria for a mental disorder. They are the potential consumers, the more chronic and disabling their condition the more they are likely to seek treatment, and the more long-term their needs. In terms of treated prevalence, i.e. the 3.5% of the population treated by the mental health and drug and alcohol services (the providers), we think that two thirds will suffer from anxiety and depressive disorders, one sixth from substance use disorders, one twelfth from schizophrenia and one twelfth from the other disorders. Anxiety and depression are the principal causes of disability and hence measures will have to be sensitive to those disorders. The main consumers of services will be those who are most disabled and those who have multiple diagnoses. Therefore any measure of symptoms and disability that is used will have to be sensitive to all common disorders. Like others, we do not think that mental health services have any remedy for ordinary human unhappiness and see no reason why disability measures designed for use with the consumers of the mental health services should necessarily extend to the measurement of unhappiness, alienation, victimisation or to any other broad issue.

Any measure of psychiatric disability that is in routine clinical use will also inform about the efficacy and efficiency of a health service. It will be used in this way by *all* stakeholders, from administrators through providers to consumers. Even though the main use should be by clinicians to improve their care, measures will be used by administrators to assess the efficiency of a service, and by consumers and their families to communicate their needs and satisfaction with treatment.

Consumer outcome measures should be:

1. brief, in that they do not detract from clinician patient consultation time (there is no point in accurate assessment of disability if one's predicament is not understood);
2. able to be used naturally in the course of routine clinical care (this is where the new computerised clinical information systems will make such measurement relatively effortless);

3. reliable and valid (i.e. they have to measure consistently what they claim to measure);
4. sensitive to change in an individual (thereby informing both patient and clinician whether the desired goal is being approached); and
5. able to measure:
 - the average load on a service (thereby identifying the needs for staff);
 - the change produced by that service (i.e. effectiveness of the service); and
 - the productivity or efficiency of a service (i.e. such measures could be used to inform casemix calculations).

Population outcomes measures such as prevalence of disorders or the suicide rate, while relatively reliable and valid, are very coarse measures of change, benefit, load or performance and tell us nothing about the disablement due to mental disorder. Individual consumer outcome measures which assess impairment, disability and handicap related to an illness are more complicated. Impairment is hard to measure so that it contributes information that is independent of diagnosis and symptom severity. We are unaware of any such scales appropriate for use in mental disorders. Handicap (e.g. unemployment, homelessness) is the result of the interaction between disability and societal pressures and is hard to measure in a way that is other than time and site specific. Disability in its widest sense is all about quality of life and level of functioning. It may be appropriate therefore that consumer outcome measures are centred around measures of disability and should be an intrinsic part of any measures of outcome. Other aspects of the human predicament like quality of life, consumer satisfaction or empowerment are also important. However reliable and valid measures of these other domains might have to remain separate—certainly measures of such concepts exist—to be used in special situations. It is a matter worth thinking about, but one must be constantly aware that a 10 item scale may be completed routinely whereas a 110 item scale will be mostly ignored. Or said in another way, if the average clinical consultation takes 30 minutes then three minutes spent on assessment might be acceptable, given the possible gains, whereas 25 minutes on assessment and only five minutes on the patient's needs is certainly not acceptable.

There are a large number of disability and quality of life scales in the literature and some of these are listed in Table 1.

Table 1: *Measures of disability*

Measure; Authors	Format	Target group	Reliability	Validity
Brief Disability Questionnaire (BDQ); Von Korff, Ustun, Ormel, Kaplan, & Sartorius (1993)	eight items; self-rated; administration time: 10 mins	Primary care patients	Internal consistency: $\alpha=0.88$ (n=5,604; 15 centres)	Correlation with: GSDS = 0.47; activity limit. days = 0.50; GHQ (depression) = 0.30; (n = 5,604; 15 centres)
Groningen Social Disabilities Schedule (GSDS); Wiersma, de Jong, Kraaijkamp & Ormel (1990)	Semi-structured interview (patient or informant); eight social roles; administration time: one hour	All adults; mental health and primary care patients	Inter-rater: $k=0.93$ for the eight social roles (n=107)	Overall score discriminated between patients living in the community, in sheltered accom., and in the hospital (n=96). Change in scores was concordant with change in severity of psychiatric illness (n=285)
Psychiatric Disability Assessment Schedule (DAS); World Health Organization (1988)	Semi-structured interview (informant and patient); 97 items; social behaviour and social roles; administration time: ?	Patients with a mental disorder	Inter-rater: $k=0.63$ to $k=1.00$ across six parts in three centres (n=512)	Profiles distinguished between a group of schizophrenics and a group of controls (n=56)
DSM-III-R Global Assessment of Functioning Scale (GAF); American Psychiatric Assoc. (1987)	Clinician rating (scale from 1–100); psychological, social and occupational functioning; current level and highest level in the past year	Patients with a mental disorder	Inter-rater: $k=0.75$ (n=321) and $k=0.08$ (n=316) in two DSM-III field trials	?
Main Problem Questionnaire; Andrews	Item; self-rated	Patients with a mental disorder	?	?

There is a need for a review which notes the characteristics of each scale and examines the psychometric properties of the measures; that is, their applicability, acceptability, reliability and validity. At a minimum, good measures should be brief and easy to use, have demonstrated and acceptable levels of internal consistency, inter-rater and test-retest reliability, content, criterion and construct validity. Measures do not have to be complex to be useful. For example, one measure which appears to hold promise is the Brief Disability Questionnaire (BDQ; Von Korff, Ustun, Kaplan, & Sartorius 1993). This eight item, self-rated questionnaire which measures disability as defined by ICIDH, has been shown to have acceptable internal consistency ($\alpha=0.88$) and validity ($r=0.47$) when compared to a much longer semi-structured interview (the Groningen Social Disabilities Schedule; GSDS; Wiersma, de Jong, Kraaijkamp and Ormel 1990) in a large sample (n=5604) of primary health care patients stratified and weighted for mental disorder across 15 centres. A validation study of the BDQ (using the GSDS as the criterion measure) in specialist mental health services is urgently needed. These two measures represent the extremes of practical measurement. Final selection of a standard measure for Australian health services will probably lie between these extremes, short enough to be practical yet enough to be informative.

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Psychiatric disability measurement and casemix

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Earlier this year a project was commenced as part of the implementation of the National Mental Health Plan to develop a methodology for the development of national consumer outcome measures which are compatible with the objectives of the National Mental Health Policy.

At the same time as this development is proceeding, the Commonwealth Casemix Program has, as part of its agenda, the development of casemix classifications and funding alternatives for mental health services.

With this focus on outcomes, service classifications and funding in the mental health area, a fundamental interest has to be how to measure and classify psychiatric disability. In terms of outcomes for consumers, a major dimension of outcome is the difference between degree of disability on entry into an episode of care and the degree of disability on exit.

Casemix classifications do not necessarily have to contain disability or outcome measures. The primary criteria for determining casemix categories are that they group together episodes of care that:

- are resource homogeneous;
- have similar clinical features or management procedures;
- form classes of episodes with sufficient numbers of cases to be useful for service management and quality comparison purposes; and
- are classified based on data that is readily available.

However, level of disability is usually at least implied by the clinical descriptors or categories that form part of most casemix classification structures.

Whether or not outcome measures are part of the classification directly, they figure prominently in considering relative quality of services being provided. Reduction in disability levels is here again an important variable with casemix classification in comparative quality analyses and service evaluations. The converse of disability reduction is functional gain or improvement.

Two main casemix classifications are currently in use in hospital mental health service provision in Australia.

The Australian Diagnosis Related Groups (AN-DRGs) classification is applied to acute inpatient episodes of care and currently includes nine mental disease and disorder classes and six alcohol/drug related classes. The factors that are used to determine AN-DRG grouping are: diagnoses that explain admission (ICD-9-CM), procedures performed (ICD-9-CM), discharge outcome and patient age group.

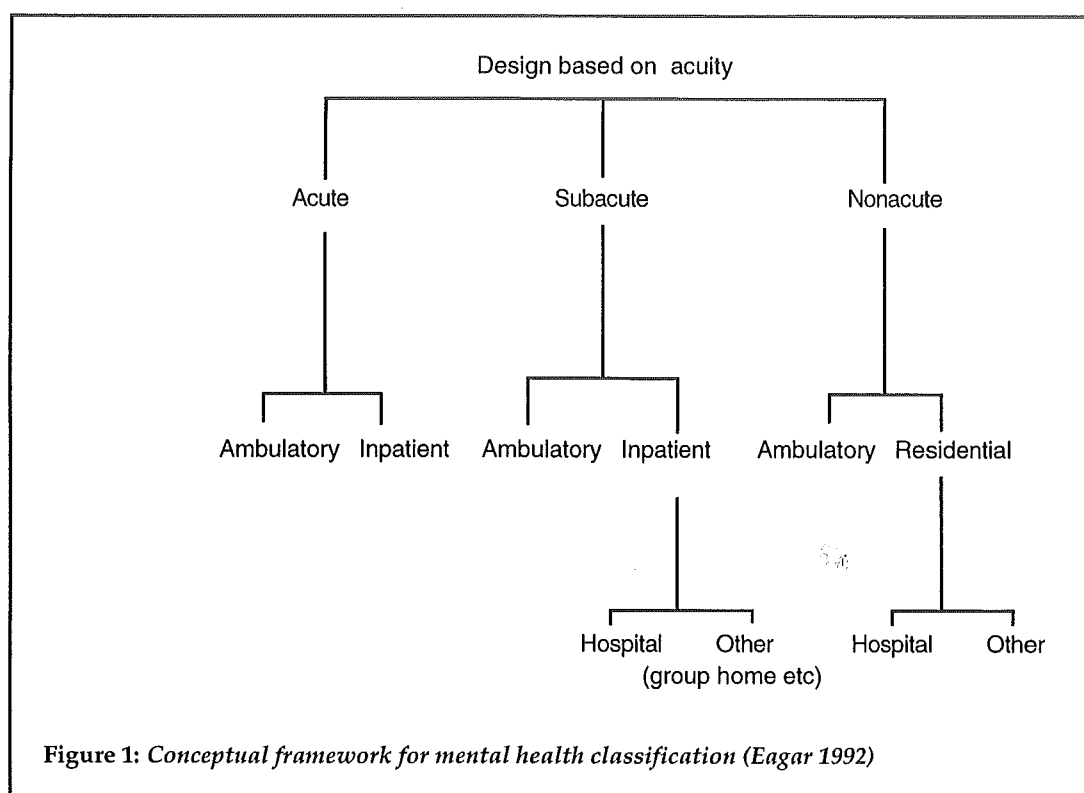
Private hospitals currently claim per diem payments for psychiatric services. A crude classification called 'Psychiatric Programs' is used to determine the per diem rates payable to hospitals by private health funds. This is based largely on the mix of services to be provided to the patient and is not linked directly to the presenting level of disability or diagnosis.

Considerable criticism has been directed to the adequacy of psychiatric AN-DRGs in explaining the costs of psychiatric episodes of care. This criticism relates largely to the psychiatric diagnoses being considered poor predictors of intensity and length of stay even in acute care settings. This limitation is even more problematical when dealing with long stay episodes in specialised psychiatric units and episodes of care across multiple settings.

Mental health casemix classification issues

Some of the main issues and constraints in the design of a mental health classification system for Australia have been recognised as follows.

- The need for a conceptual framework and standard definitions. Various models are available but there is no general agreement at this point. A framework that is currently widely understood and proposed by Eagar (1992) is at Figure 1.



- The need to work within the policy framework of the National Mental Health Policy including the nature and method of delivery of mental health services and the move to mainstreaming of these services.
- The need for applicability across treatment settings in order to:
 - promote managed care;
 - allow for valid comparisons of outcome, cost and patient mix and severity; and
 - create incentives consistent with the National Mental Health Policy.
- The need to serve uses other than purely payment applications in designing mental health casemix classifications. For example, it may be preferable to fund some components of mental health services on a patient

or capitation basis rather than on an activity basis. This may be particularly so where the patient is likely to receive multiple services over an extended period of time. However, outcomes have to be measurable in categories that are comparable between optional approaches as part of routine evaluation of services.

- The need to improve AN-DRG accuracy so that they better explain the length of stay of acute cases in non-specialised settings and to develop alternative classifications for cross-setting, specialised unit and non-hospital care.
- The need for more accurate and complete morbidity and resource utilisation information for the development of suitable classification systems.
- This includes the need for a more detailed diagnosis and coding standard than ICD-9-CM. DSM-III-R has been proposed as a more comprehensive and useful nomenclature particularly in relation to its axis five which offers an assessment of psychological, social and occupational functioning.

As these issues are being considered and responded to, development of the AN-DRG classification continues, including, in the short term, modifications to MDCs 19 and 20. The modifications currently proposed for version three of AN-DRGs are shown at Table 1b.

Table 1a: *Diagnosis-related groups—versions 1 and 2*

DRG	Number	ALOS 1-50	Standard Deviation	Coeff. of variation	%
830 O.R. procedure with principal diagnosis of mental illness	49	15.8	13.8	0.88	1
831 Acute adjustment reaction and disturb. of psychosocial function	860	7.1	8.1	1.13	13
832 Depressive neurosis	1,264	9.5	9.3	0.97	19
833 Neuroses except depressive	549	7.6	8.4	1.10	8
834 Disorders of personality and impulse control	240	12.2	13.0	1.07	4
835 Organic disturbances and mental retardation	715	13.4	10.3	0.77	11
836 Psychoses	1,877	14.8	12.1	0.82	28
837 Childhood mental disorders	65	6.6	7.6	1.15	1
838 Other mental disorder diagnoses	66	13.3	14.1	1.06	1
433 Substance abuse and induced mental diagnosis	97	4.3	6.1	1.43	1
434 Drug dependence	192	5.0	7.6	1.51	3
435 Drug use not dependence	812	7.3	8.5	1.15	12
TotalTotal	6,786				

Table 1b: AN-DRG version 3 (proposed)

DRG	Number	ALOS 1-50	Standard Deviation	Coeff. of variation	%
1 Schizophrenia	388	14.4	12.5	0.87	6
2 Paranoia & acute psychotic reaction	406	11.8	10.1	0.86	6
3 Major Affective disorders	1,088	16.2	12.5	0.77	16
4 Other affective and somatoform disorders	1,219	9.7	9.3	0.96	18
5 Anxiety disorders	708	6.9	7.9	1.14	10
6 Eating disorders and obsessive compulsive disorders	137	17.1	14.3	0.84	2
7 Personality disorders and acute reactions	936	7.4	8.5	1.15	14
8 Mental disorders originating in childhood	17	7.9	7.9	0.99	0
9 Alcohol intoxication and withdrawal	324	4.0	4.5	1.14	5
10 Drug intoxication and withdrawal	57	5.6	6.3	1.12	1
11 Alcohol abuse and dependence	566	7.7	8.7	1.13	8
12 Other drug abuse and dependence	130	8.3	10.9	1.31	2
13 Alzheimer's senile dementias and other organic mental disorders	813	13.4	10.6	0.79	12
Total	6,789				

Other work is being carried out in the development of minimum national data set specifications including financial and costing information. This information is to be collected across different patient settings and is linked to developments with the National Health Information Agreement and the National Health Data Dictionary.

Research entailed in the development of useful casemix classifications includes the following.

- Further evaluations for longer term use of classifications used internationally other than those reviewed to date. Hindle and Harris (1993) canvass some 40 classifications or instruments which could have some application (see Box 1).
- Testing of alternative classification models including their elements of:
 - activities of daily living;
 - functional dependency;
 - symptom levels;
 - quality of life; and
 - career issues.
- Particular attention to options for measurement of activities of daily living and functional dependency regardless of which classification system is finally developed.

- Consideration of inclusion of extended care and extra-mural services into classifications of mental health services, and consideration of an episodes of illness classification and program funding rather than an episode of care, or treatment encounter.

Box 1: Classifications or instruments which have some application to casemix (modified from Hindle 1993)

ICD	<i>International Classification of Diseases</i>
ICD-9-CM	<i>International Classification of Diseases. ninth Revision. Clinical Modification</i>
ICHPPC	<i>International Classification of Health Problems in Primary Care</i>
DSM	<i>Diagnostic and Statistical Manual for Mental Disorders</i>
DSM-III-R axis	<i>version 3 of DSM</i>
	1. <i>Clinical syndromes</i>
	2. <i>Developmental and personality disorders</i>
	3. <i>Physical disorders and conditions</i>
	4. <i>Severity of psychosocial stressors</i>
	5. <i>Psychological, social and occupational functioning</i>
DSM-IV	<i>version 4 of DSM (due 1994)</i>
ICIDH	<i>International Classification of Impairments, Disabilities, and Handicaps</i>
EADLM	<i>Extended Activities of Daily Living Measure</i>
QUALY	
FSQ	<i>Functional Status Questionnaire</i>
CMBS	
CPT-4	<i>United States version of CMBS</i>
OPCS	<i>United Kingdom version of ICD-9-CM</i>
READ Clinical System	
PAIS	<i>Patient Acuity (or Dependency) System</i>
GDS	<i>Geriatric Depression Scale</i>
APACHE	<i>Acute Physiology and Chronic Health Evaluation system</i>
FRG	<i>Function Related Group (for rehabilitation)</i>
CRG	<i>Clinically Related Groups</i>
CRG	<i>Cost Related Groups</i>
DCG	<i>Diagnostic Cost Groups</i>
ADRG	<i>Alternate Diagnosis Related Groups</i>
Refined DRG System	
SII	<i>Severity of Illness Index</i>
CSI	<i>Computerised Severity Index (Horn)</i>
CPSI	<i>Computerised Psychiatric Severity Index</i>
PMC	<i>Patient Management Categories</i>
DS	<i>Disease Staging</i>
PPC	<i>Psychiatric Patient Classes (Ashcraft et al.)</i>
LPPC	<i>Long-stay Psychiatric Patient Classification (Fries)</i>
RUG	<i>Resource Utilisation Grouping</i>
RUG-3	<i>version 3 of Resource Utilisation Grouping</i>
AVG	<i>Ambulatory Visit Group</i>
APG	<i>Ambulatory Patient Group</i>
PAC	<i>Products of Ambulatory Care</i>
ASWS	<i>Ambulatory Service Weighting System</i>
EDG	<i>Emergency Department Groups</i>
AAC	<i>Australian Ambulatory Classification (121 classes, including five psychiatric)</i>
ACG	<i>Ambulatory Care Groups (51 final classes)</i>

Funding services by outcomes

In developing funding approaches that introduce incentives to achieve the aims of the National Mental Health Policy, a primary goal has been set to achieve positive consumer outcomes for people who have a mental disorder and consequent psychosocial disability. The policy clearly states that priority in resource allocation should be given to those people with severe mental health problems and mental disorders.

Casemix is seen as an important tool in enabling management of resources to these ends. It provides a fundamental bridge between measuring effectiveness of alternative service provision and linking effectiveness to resourcing.

Information on relative service effectiveness and efficiency is required in decisions about funding levels for alternative services, substitution of new for old services and pricing. Such information requires accurate, consistent patient classification including available disability measures, a clear typology for services and accurate service costing. These are the key ingredients of an effective casemix classification.

Developing the classification

Given the priorities and goals outlined above, the casemix classification required will need to address the following.

- The cross setting care characteristics of services targeted by the National Health Plan. It will need to cover community care services as well as institutional care services.
- Cross health care sector differences in servicing patterns, e.g. large number of patients in the public sector are continuing users of mental health care services.
- Identification of characteristic service utilisation patterns over time. These are likely to be linked to diagnosis, disability, demographic or environmental variables.
- Accessing data sets that will enable classification variables to be identified. Data requirements include availability of case registers with a unique number across sites, ability to conduct a longitudinal review over say a five year period on service utilisation patterns, ability to validate and further develop resource consumption data accuracy prospectively.
- Other complexities such as service provision advantages and disadvantages across multiple settings, disagreements about treatment goals and approaches among providers, lack of uniformity in treatment inputs across providers and settings.

The classification will also need to be robust to alternative funding models. For example it will need to be applicable to examining the outcomes and service utilisation patterns of a population based funding approach as compared with a casemix based funding approach.

Disability measurement casemix applications

Consumer outcome has to be measured if the goals of the National Mental Health Plan are to be achieved. This requires the development of standardised

national mental health consumer outcome measures. The primary areas that have been suggested are:

- ADL levels;
- quality of life;
- symptom scales;
- social independence; and
- career issues.

In terms of national statistics, really simple measures that can be used routinely at entry to and exit from the mental health care system are being sought. The UK outcome targets which have been suggested are to:

- reduce suicide in the general community;
- reduce suicide in the mentally ill; and
- improve level of functioning.

Measurement of disability is central to the last of these and a research and development strategy is now needed to identify or design a standardised measure of functioning. This should be simple to administer and give a reliable measure of functional improvement outcomes in the areas of:

- independence;
- social functioning; and
- symptom levels.

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Disability measurement and health care funding for people with a disability

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The argument:

- We are in the middle of a revolution.
- People with the most disadvantages are most at risk.
- We lack ideas and measurements to defend those most in need.

Casemix is a good idea because:

- It controls for patient variability, in order to identify provider variability.
- It funds in accordance with patients' needs, not providers' costs.
- It thereby encourages equity and cost/effectiveness.

Casemix must be done well. For example, it can't:

- depend only on principal diagnosis, highest-ranking procedure, and highest-ranking other diagnosis;
- ignore functional dependence; or
- ignore social factors.

DRGs don't work for:

- people with chronic conditions;
- people who are socially disadvantaged;
- those least able to defend themselves; or
- patients who are more expensive.

DRG-based funding in USA

- US Medicare has 35 million beneficiaries and 10% of those are disabled.
- Co-payments per family were \$3,300 in 1991 and rising.
- ProPAC says the real concerns are quality, access, outcome.
- The delivery system is disjointed.
- The poorest areas have reduced access to care.
- The poor have lost access to post-discharge services (Zeitler et al. 1990).
- Resources have been reduced for patients in geriatric units, especially for patients with complications due to chronic problems (Berenson and Pawlson 1990).
- The incidence of injuries due to poor medical care correlates with age and disability.
- These people have twice the risk and are more likely to receive negligent care (Brennan et al. 1990).

- The expected costs per day for disabled elderly increased in proportion to ADL score.
- These increased costs are not reflected in payments (Liu, McBride, and Coughlin 1991).

Problems with casemix for people with disability

- Casemix classifications don't take adequate account of number and severity of comorbidities.
- People with comorbidities (especially disability) have poorer outcomes.
- They also have more in-hospital complications (Greenfield et al. 1992)
- Patients with disabilities cost more, take longer to treat.
- DRG based funding encourages hospitals to find patients who are easy and cheap to treat.
- Disabilities are poorly measured (Batavia 1993).

What to do:

- Fix DRGs.
- Build episode of illness casemix classifications.
- Fund for outcome, not just production.
- Iso-utility, not just iso-resource.

At the moment, an episode of illness might encompass APG, rehabilitation, DRG, HOMEC.

Funding models:

Per day for therapy
and maintenance



Per day for
maintenance



Per case for
functional gain



Conclusions

- There are lots of ways of measuring performance of a health care system.
- The key measure, however, is how well it cares for the most disadvantaged.
- We should be proud of what we've done thus far.
- We should be scared of what we are about to do next, in the name of economic rationalism.

Additional papers

Notes on the workshop discussion

Ros Madden

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These notes are intended to indicate some of the main issues discussed during the two days of the workshop, in response to the papers presented. Issues relating to mental health are more specifically covered in Bryan Rodgers' notes.

Purposes and methods in measuring disability

The workshop was designed to be a multi-disciplinary gathering and part of its value lay in the revelation of diversity among aims and approaches in defining and measuring disability.

Different viewpoints represented at the workshop were provided by:

- people representing people with a disability, whose purpose in measuring disability is often to indicate the level of need for services and to make a better match between the individual's self-identified needs and abilities and the service offered;
- providers of support services, whose purposes in measuring disability include providing supports appropriate to the needs and abilities of services users, prioritising the use of resources, and comparing the resources and successes of their service with those of other services;
- funders and planners of broad disability programs, whose primary purpose in measuring disability is to assess the relative need for resources among groups of people with differing disability types and service types, and to identify unmet (absolute) needs;
- people responsible for the administration of legislation outlining the rights of people with a disability, who may prefer to use broad measures and definitions of disability in order to protect people who may be disadvantaged by exclusion;
- people responsible for income security policy, including the social security and compensation fields; these administrators may prefer definitions which clearly define the criteria for and limit the number of people included in their programs;
- clinicians, whose need may be to gauge more precisely the nature and severity of disability in order to devise the most appropriate intervention, or to make comparisons of the efficacy of various treatments;
- national and international statisticians whose purpose in measuring disability is to be able to compare data across service types and across national and international boundaries; the measure of disability may then be an outcome measure of an intervention (often a health or community service intervention), an indicator of need for support or treatment, or a

benchmark which enables the collation or comparison of data from several different sources.

Approaches to measuring disability are closely related to approaches to defining and classifying disability, and the workshop discussion ranged over all three areas—definition, classification and measurement.

The different purposes which exist for defining and measuring disability may produce different approaches in deciding on the method of measuring disability. For instance the Disability Discrimination Act in Australia promotes self-identification, both of disability and of need, and sets out a very broad definition of disability. In contrast are definitions of disability aimed at defining and possibly restricting entitlement, for instance to social security or compensation payments.

Models of services may also influence the definition. A 'welfare' model may emphasise the person's deficits and the service's support qualities, whereas a 'rights' model of service may emphasise the person's capabilities and aim to remove barriers which inhibit the person's achieving their potential.

In areas such as the safety and compensation fields, causation of an injury or condition (or even 'fault') is a factor in basic descriptions, as well as impairment, disability and handicap. The compensation system can thus also be contrasted with the welfare system since, while the former is concentrating on 'fault' and causes, the latter concentrates on 'needs'. An emphasis on 'cause' may also exist where the goal is to enhance public health efforts by the prevention or diminution of certain risks, or where the goal is to make statistical predictions of future patterns or rates of disability.

The compensation system and to a large extent the income security system focus assessment and services on one particular facet of disability or handicap, namely the ability to perform paid work, and on the level and duration of any disability. These systems aim for a measurement of income earning disadvantage. This task is made more difficult because there is not necessarily a direct relationship between the impairment, the overall level of disability and the level of work ability.

Systems providing income support can create incentives for people to be classified as having a disability. For instance, within the social security system in Australia the Disability Support Pension may involve less ongoing assessment than the Unemployment Benefit and it was suggested by some workshop participants that this creates something of an incentive for a person to be classified as having a disability rather than being unemployed. Within the compensation field, the common law approach is widely recognised as prolonging the duration and level of disability, by making its decisions slowly, after the condition has stabilised; these behavioural effects of the definition itself are known as 'functional overlay'. As a general principle, the methods of assessment should not increase people's perception of the level of disability.

A useful system of definition and measurement should focus on needs and provide an aid to decision making—and should not, for instance, lead to estimates which show a very large proportion of the population as having a disability, while not indicating what proportion need some form of support. 'Need' should be objectively measurable and administratively possible, according to the workshop discussion. An indicator of 'severity' is thus an

important ingredient of, or at least adjunct to, a system of disability definition or measurement, to enable the comparison of needs, and also to help prioritise other related services, for instance safety and public health measures which are designed to minimise the incidence and severity of disability.

The individual and the expert: the value of self assessment

The paper presented by Paul Creedon of Disabled Peoples International stimulated discussion and acknowledgment of the link between the methods of assessment and the decision being made as a result of the assessment—who makes decisions and whom are they for?

The individual being assessed needs to see the purpose of assessment.

Assessment can promote equity and empowerment if the individual concerned is involved in the assessment and has an understanding of the underlying purpose of the assessment. The process of assessment is often, however, seen as a process controlled by an assessor, especially if scales of measurement have a great deal of jargon and do not relate to people's circumstances and concerns as they themselves see them. Both the process of assessment and its purpose, if determined and controlled by the assessor, disempower the individual being assessed.

The practice of some employment services which involve people with a disability in their own 'assessment' was outlined to the workshop. The person with the disability is involved in preparing their own report and in setting their own goals. Training and support are then offered to help them reach these goals.

Some professionals would recognise this model in the process they themselves experience in peer review and professional development.

At the level of national statistical collections, the role of consumers in defining the data to be collected is equally important. Adele Furrie of Statistics Canada described the development of the Canadian statistical collections and the importance of consumers in defining 'disability' and the data to be collected. The definition of disability and its operationalisation were major issues in the Canadian statistical development, since there can be as many definitions as there are programs and services. The data base of Statistics Canada now includes information on barriers, needs, and socio-demographic characteristics for the population with a disability.

The importance of self assessment was generally recognised by the workshop, as well as the utility in asking global questions along the lines of: 'how are you?'

The International Classification of Impairments, Disabilities, and Handicaps and its development

The World Health Organization's International Classification of Impairments, Disabilities and Handicaps (ICIDH) is based on the following definitions:

Impairment: *In the context of health experience an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.*

Disability: *In the context of health experience a disability is any restriction or lack (resulting from an impairment) of ability to perform an*

activity in the manner or within the range considered normal for a human being.

Handicap: *In the context of health experience a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual (World Health Organization 1980).*

As well as providing a basic classification of these concepts, the ICIDH contains supplementary 'gradings' relating to severity of disability and outlook scales.

The ICIDH is in the process of revision—a process which will probably lead to a revised version in 1999. A first meeting on the revision of the ICIDH was held in Washington in 1993. The revision is being done on three planes—impairment, disability and handicap, with various collaborating centres throughout the world taking on a specific content area for revision, for instance, movement, sensory and communication, behaviour and development.

The ICIDH is published in 15 languages and is quite widely used. The classification is well known in some spheres in Australia and little known in others.

The use of the ICIDH in Australia

Reviewing the aged care field in Australia, Debra Rickwood found little consistency in the data items employed to record levels of dependency, even among nationally provided services. She suggested that the ICIDH would be useful as a checklist or framework for people devising data collection instruments. A pool of related instruments could be developed, recognising that not all service providers need to look at all aspects of disability.

Helen McAuley, reviewing the disability services field, found that, while the specific codes of the ICIDH were not widely used there was a general familiarity in the field with the concepts of impairment, disability and handicap.

Similarly, the broad concepts of impairment, disability and handicap reflected terminology and basic concepts in the fields of compensation and social security, but the ICIDH itself did not provide a framework on which to base measurement in these fields. Alan Clayton and Jo Mazengarb described developments in the fields of compensation and social security in Australia, where the need for greater consistency in measuring disability among thousands of clients had led to developments emanating from the American Medical Association's *Guides to the Evaluation of Permanent Impairment*.

Jenny Widdowson of the Australian Bureau of Statistics described the use of the ICIDH in national surveys.

Discussion of the ICIDH

The ICIDH was contrasted with the International Classification of Diseases (ICD), which relates more directly to clinical experience and assists clinical thinking and decision making. One of the problems to be overcome in the further development of the ICIDH is to bring together more closely those people defining the ICIDH and those people wishing to applying it.

The workshop discussed some directions for the possible further development of the ICIDH.

There are overlaps in the way impairment, disability and handicap are operationalised in the classification. Because of these boundary problems and other structural problems (a suggested lack of cohesiveness or coherence) the ICIDH was considered by some to be not yet a true classification system.

Problems with the impairment definition include:

- the adequacy of discrimination between structure and function;
- the overlap with ICD; and
- the overlap with disability.

While impairment is the deviation from the norm in biomedical status, handicap is highly dependent on social and environmental factors. The preamble to the handicap classification in the ICIDH states:

It is important to recognize that the handicap classification is neither a taxonomy of disadvantage nor a classification of individuals. Rather it is a classification of circumstances in which disabled people are likely to find themselves, circumstances that place such individuals at a disadvantage relative to their peers when viewed from the norms of society.

Handicap is recognised to be the result of the encounter between disability and the environment. There is a resulting discontinuity between impairment and handicap in the ICIDH.

'Handicap' in particular was seen to need further development, in terms of its definition, classification and rating. Because it is by definition a social construct, there is difficulty in establishing an international standard enabling comparison among different societies and cultures. The concept of 'handicap' has encountered great difficulty in translation to various languages.

A recognition of the environmental influence on handicap needs specific recognition, for instance in the identification of barriers, of appropriate interventions and of the outcomes of interventions.

There was discussion of the need for a fourth dimension in (or perhaps adjunct to) the ICIDH, relating to the environment and to the barriers (including discrimination) contributing to the individual's experience of disability and handicap. This idea, of a fourth dimension relating to external factors/environment, appealed to several participants. It was suggested, however, that such a development would have to be localised within different countries, perhaps within a broad international framework, rather than attempting an international standard on factors which would vary strongly from country to country.

Despite the understanding of the social context which defines handicap—and the recognition that environment not only affects handicap but can also affect disability—the ICIDH concepts are defined specifically 'in the context of health experience'. A number of participants pointed out the importance not only of recognising that the ICIDH is set out 'in the context of health experience' but also of retaining the notion of impairment as underlying or accompanying disability and handicap. Otherwise, according to one workshop participant, disability is purely socially constructed and 'becomes a matter of choice'; then

there is no accompanying basis for constructing the desired indicators of severity and need.

If the ICIDH is to be an international standard it needs to provide replicable measurements. If it is too specific to context and culture it becomes too difficult to make comparisons across contexts.

Conclusion

The workshop reached no formal conclusions, but it seems fair to say there was a lively interest in achieving an international standard of definition, classification and measurement, which not only enables comparison across countries, but which contains concepts robust enough to be used in different disciplines and for different purposes in the one country. It was generally thought that the ICIDH needed greater promotion in Australia, in order to foster the search for a national and international standard.

There was great interest in the capacity of the ICIDH to be a multi-disciplinary tool. A system is needed which is conceptually coherent and applicable for all the people whose perspectives and purposes were outlined above. The ICIDH needs to be part of a common language and provide common elements to these different purposes.

The WHO representative, Michel Thuriaux, urged those attending to make specific suggestions for improvements to the ICIDH.

Copies of the ICIDH can be obtained from:

WHO Distribution and Sales Unit
20 avenue Appia 1211
Geneva Switzerland (Fax 41 22 7880401)

Progress on the development of the ICIDH is regularly reported in the Newsletter published by:

WHO Collaborating Centre for the ICIDH
Nationale Raad voor de Volksgezondheid,
PO. Box 7100
2701 AC ZOETERMEER
The Netherlands

A copy of Newsletter 13, reporting on the Washington 1993 meeting, may be obtained by contacting the Disability Services Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra City, ACT, Australia 2601

Notes on the workshop discussion: mental health

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Introduction

The second day of the workshop focused on disability and mental health. As made clear in John Cooper's opening paper, the fundamental issues involved in the revision of ICIDH and in deriving measures of disability are similar in the areas of physical and mental health. There are, nonetheless, some important differences in emphasis between the two domains, and it is helpful to acknowledge these.

- For certain mental health problems the criteria for diagnosis require some level of disablement, including social role handicap, e.g. dementia or mental retardation.
- The clinical assessment of severity of many psychiatric disorders (within diagnostic categories) is often made, at least in part, by reference to the degree of associated impairment, disability and handicap.
- Contact with services for mental health problems arises in many instances because of disablement, particularly at the level of social role handicap. For example, alcohol abuse/dependence may be undetected or tolerated by others until it leads to family or work problems or involvement with the police. Similar pressures apply to self referral.
- With mental disorders, it is usually the case that functional impairments are not observed directly. Either self report is necessary or impairment is inferred from higher level performance.
- In the treatment of mental disorders, the primary goals are often to achieve satisfactory levels of performance, especially at the level of social roles, rather than to effect a cure.

None of these issues is unique to the mental health field, but their importance is more marked and, consequently, there is particular concern within the mental health professions to establish acceptable systems for the classification and assessment of disability. Not surprisingly, there is a history of the development and use of disability measures in this field and two examples, the WHO Psychiatric Disability Assessment Schedule (DAS) and the Psychological Impairments Schedule (PIRS), are referred to in John Cooper's paper.

The program for the second day of the workshop allocated considerable time for discussion. Whilst some debate took its lead from the topics covered in preceding papers, there were recurrent themes throughout the day and some arguments were developed over the course of several sessions. The final session of the day was an open discussion led by Karen Ritchie and Scott Henderson, which brought a focus on problems in the use of the 1980 ICIDH and invited suggestions for the planned revision of the classification. The following summary does not attempt to follow the temporal order of these discussions, rather it picks out the main points raised in respect of classification systems and methods of assessment, and hopefully indicates key areas of consensus and contention.

Three levels of classification

There was substantial agreement on the value of distinguishing the three levels of impairment, disability and handicap established in the ICIDH. The importance of clarifying the boundaries between these levels conceptually, and of achieving greater correspondence between this structure and the detailed classification was also widely accepted.

There was little discussion of other possible elements in a revised classification system. Only passing reference was made to structural (as distinct from functional) impairment, although the development of neuro-imaging and more sophisticated electroencephalogram (EEG) techniques is likely to make an impact in the area of mental health. The classification of 'external factors' (which has a parallel in the more narrowly conceived Axis IV classification of psychosocial and environmental problems within DSM-IV) also received less comment during the second day than the first, but the mention that was made of the important influence of environment on the link (or lack of it) between disability and handicap suggests that this would be a valuable area of endeavour, whether or not it is incorporated into the main body of the revised ICIDH.

Cultural determinants of social roles

The most contentious element of the classification system was social role handicap, on account of the cultural determination of 'normal' social roles. This concern arises with respect to both a system of classification and methods of assessment.

System of classification

A balance can be struck between a classification system's utility and its range of applicability. It is not difficult to envisage a classification which makes allowance for age in the determination of handicap in, say, the role of father, where there are very different expectations for fathers of young children, of independent adult children, and of children who act as carers for the parent, but it appears harder to encompass the range of roles fulfilled by elderly parents in different societies. A detailed classification is less likely to be valid across different cultures, but a broader classification will inevitably group together diverse constituents and will have little practical utility.

Methods of assessment

It was generally accepted that methods of assessment must take into account cultural norms. (This also applies at the levels of impairment and disability.) It was not so clear how specific such norms should be. Are country of residence, historical time, sex, age, ethnic group and position in the family sufficient for defining norms, or should education, marital status, socioeconomic status, employment or other personal factors be taken into consideration? Any disagreement about the appropriateness of norms for an individual will also impinge on assessment. Social roles are expectations of behaviour by self, other individuals and society and a consensus is not guaranteed. For example, is it sufficient to base the role performance of a 'wife' on reports from her husband or are the expectations of the woman herself to be taken into account? Cases of discrepancy between sources may require integration or arbitration by someone who is necessarily bound by societal expectations.

Classifications of disease and disability

Some concern was expressed over the distinction between disease and disability when formulating respective systems of classification. In reply, it was pointed out that the two systems are conceptually distinct and that overlap in content, most notably between symptoms and impairments, does not pose a problem for the use of either system. It was also acknowledged that disability plays an important part in assessments of the severity of many psychiatric disorders.

Disability in the context of health experience

The issue of the definition of impairment, disability and handicap as arising 'in the context of health experience' was touched on at several points during the meeting.

At a practical level, it was pointed out that clinicians make judgements about the underlying causes of disablement all the time, but there are no guidelines for decision making by non-clinicians. In such circumstances the underpinning of disablement by 'health experience' appears to be largely implicit and, particularly if a subject acts as their own informant, may rest upon personal decisions about the status of illness or disease. In survey research, the necessary link between health experience and disability might not be formally assessed, and it is not evident how the extent of disablement, especially social role handicap, can be apportioned between health and other experiences, such as socioeconomic disadvantage or racial prejudice.

At the conceptual level, there was mention of running the model of 'impairment can lead to disability which can lead to handicap', backwards, when changes in social role, e.g. those resulting from bereavement, precede or precipitate illness. This appeared to obviate any necessity for disablement to be dependent on disease, injury or other biomedical abnormality. There was subsequent discussion of freeing up the traditionally held linear relationships between disease, impairment, disability and handicap, to permit reciprocal relationships, and the point was made that handicap (such as arising from stigma) can persist after recovery from mental disorder. This seemed to erode further the requirement of the ICIDH definition.

This issue of defining and operationalising 'the context of health experience' was unresolved.

Applicability to different target groups

As well as the desirability of a system of classification appropriate for a wide range of populations, there was also recognition of the need for a variety of assessment instruments for different target groups, e.g. different age groups, preferably with equivalent measures across such groups.

Self assessment

The issue of self assessment had arisen on the first day of the workshop. On the second day, it was pointed out that self assessment may be inappropriate in some circumstances or may simply be unreliable or inaccurate. A parallel was drawn with using a question on whether a subject was intelligent rather than an IQ test. The value of task based assessments in some circumstances was pointed out, and it was clear that this approach was already in use, either

formally or informally, in various existing assessment procedures. At the same time, there are circumstances where individuals are seen as the most valuable informants on their own condition, and this is true when assessing impairment and disability associated with some psychiatric disorders. There are also examples where assessments have called on subjects and other informants in combination.

Capacity and performance

The ability of people with disablement to circumvent difficulties, either by their own strategies or by depending upon others, was discussed. A simple example of this is for those with impaired manual skills to wear clothes without buttons and shoes without laces or buckles. With some methods of assessment these difficulties are under-reported and, while it may be appropriate that handicap is not identified, the omission of instances of impairment and disability can be problematic. The design of methods of assessment needs to take account of this distinction between capacity and usual performance.

The value of 'gating' in assessment

A proposal for the possible simplification of methods of assessment is to consider the efficacy of 'gating' procedures. Provided there is a strong and consistent relationship between underlying severity of disablement (within specified domains) and meeting individual criteria used in its measurement, the assessment can be simplified by using gating items, whereby negative responses lead to omission of a block of subsequent items. An alternative procedure, based on the same principle, is to list items in each domain in order of severity and identify the point on this (Guttman) scale which best matches the subject's performance. Such procedures have value in being less time consuming, but it is necessary to establish their validity by confirming the underlying assumptions in the appropriate population and in sub-groups within that population (e.g. different age groups).

Suggestions for enhancing the appeal of a revised ICIDH

A number of suggestions were made as ways of increasing the likely acceptance of a revised ICIDH and encouraging its use as a basis for methods of assessment.

- The need for a classification which satisfies a range of users, including clinicians, consumers, planners, those evaluating services and statisticians, was reiterated.
- The revised ICIDH should be more user friendly, and the adoption of simpler language and an improved structure would be welcomed.
- The use of the ICIDH as a basis for presenting research findings would be encouraged by examples of its successful application. There appear to be very few (if any) existing reports that have utilised the ICIDH in this way.
- The formulation of instruments of assessment based on the ICIDH classification could be facilitated by the offer of expert WHO opinion on such instruments during their development.
- Although the ICIDH is well known in the disability field, the revised classification and any methods of assessment derived from it could benefit from greater promotion.

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