

10. ICF applications—examples

This section outlines some current applications in Australia, providing examples relating to:

- Applying the ICF to a national disability services data collection (Section 10.1)
- The use of the ICF framework in an allied health outcome measure: Australian Therapy Outcome Measures (AusTOMs) (Section 10.2)
- The ICF and classification for disability athletics (Section 10.3)
- The ICF and accident compensation in Australia (Section 10.4)
- The ICF and speech pathology (Section 10.5)
- The ICF and Rett Syndrome (Section 10.6)
- Classification of support and need (Section 10.7)
- Handicap Assessment and Resource Tool (HART) and the ICF (Section 10.8)
- The ICF and oral health (Section 10.9).

These examples have been contributed by different users who are acknowledged in the relevant section. The examples are included in chronological order – the order in which they were ‘discovered’ by and provided to the AIHW. They are included as interesting illustrations, often of work in progress, to encourage discussion and innovation. They are neither a complete nor an endorsed collection of current applications.

Section 6 on Environmental factors contains examples of applications that focus on this component of the ICF.

10.1 Applying the ICF to a national disability services data collection

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Introduction

This section describes the ways in which the ICF was used when redeveloping the main administrative national data collection used in the Australian disability services sector.

The CSTDA NMDS and its redevelopment

Specialist disability support services in Australia are provided under the Commonwealth–State/Territory Disability Agreement (CSTDA).⁶ This Agreement provides for a national program (\$2.5 billion in 2001–02) for people with disabilities who have ongoing support needs. The Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS) is both a set of nationally significant data items that are collected in all Australian jurisdictions (i.e. states, territories and the Commonwealth) and an agreed method of collection and transmission.

Since 1994, the CSTDA NMDS⁷ collection has provided funding bodies, service providers, consumers and other stakeholders with valuable information about services delivered under the CSTDA and the people receiving those services. Between 1994 and 2002, this information was collected on one snapshot day in each year of this period. From late 2000, the CSTDA NMDS was redeveloped in a joint project of the AIHW and the National Disability Administrators (NDA). The redeveloped CSTDA NMDS was implemented in the second half of 2002 and from 2002–03 will provide a range of data about all people with disabilities who receive a CSTDA-funded service in a year.

6 The 1991 and 1998 Agreements were known as the Commonwealth/State Disability Agreement (CSDA). The 2002 Agreement is known as the Commonwealth State/Territory Disability Agreement.

7 Between 1994 and 2002, the CSTDA NMDS was called the Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS).

Applying the ICF to the redeveloped CSTDA NMDS

The ICF was an essential tool in the process of redeveloping the CSTDA NMDS.⁸ The redevelopment exercise demonstrated three general ways the ICF can be used:

- *as a framework* to organise thoughts and ensure that major factors of interest are not omitted from the final data item or minimum data set
- as a set of classifications that can be used as a ‘smorgasbord’ for selecting the *domains* of most interest to stakeholders in the data to be collected via the final data item or minimum data set
- to provide *qualifiers* that assist the researcher to select a scale that is either directly related to an ICF qualifier or that ensures the data collected will map to an ICF qualifier.

In the case of the CSTDA NMDS redevelopment, the ICF Activities and Participation component and qualifiers were applied in two main areas:

- (a) support needs
- (b) participation outcomes.

The next two sections describe how the ICF was applied to the development of these data items.

Support needs

Background

A national indicator of disability support needs has been included in the CSTDA NMDS since its inception in 1994.

In 1999, as part of an initial review of the CSTDA NMDS, the AIHW undertook a project aiming to produce:

- a review of measures of ‘support needs’, the findings being related to policies, practices and developments in Australia in the disability field and in other closely related fields including the Home and Community Care program
- a presentation of options for data items which would encapsulate the main data needs and developments in Australia

8 Much of the data development for this project was done using the draft ICIDH-2. The final data items are, however, based on the ICF. To avoid confusion, this section is written as if the entire data development process was undertaken using the final ICF.

- a discussion of each option in relation to its relevance, quality, relatability to other developments, and comparability to national and international developments in population measures of disability.

The work undertaken for this project was subsequently advanced during the redevelopment of the CSTDA NMDS. The methodology of both the 1999 ‘support needs’ project and the 2000–02 redevelopment project are discussed below to illustrate the usefulness of the ICF in data development of this nature.

The project was not concerned with standardising the assessment of individuals at a local level. Rather it was about clarifying the concepts used to describe people’s support needs so that information gathered during assessment could be mapped to a national indicator (or indicators) and used for national comparison.

The ultimate objective was to develop options for a summary rating or indicator of support needs that was:

- comparable with population data, specifically data collected on individual support needs via the ABS Survey of Disability, Ageing and Carers;
- able to be used for mapping current state, territory and Commonwealth practices in as wide a range of services as possible⁹;
- consistent with current national data dictionaries and collections, thereby potentially increasing the potential for national comparability and reducing duplication in collection.

Methodology

There were a number of constraints or factors to consider in the search for a ‘support needs’ framework.

Firstly, it was essential that any support needs framework relate to the definition of ‘people with disabilities’ in the 1998 CSTDA as:

people with a disability attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these) which is likely to be permanent and results in substantially reduced capacity in at least one of the following:

- self-care/management
- mobility
- communication

requiring ongoing or episodic support.

9 The goal was to reflect enough of the language used in each jurisdiction to ensure that jurisdictions could translate the scales they use into an overarching scale (i.e. that the various types of language could be meaningfully calibrated into an overall scale to which their input could be mapped).

Secondly, as noted above, it was critical that the support needs framework be comparable with population data. This constraint implied that the framework would probably need to be a general support needs indicator, rather than a service-specific support needs indicator; that is, the framework would aim to indicate an individual's overall support needs, rather than their support in terms of services required.

Finally, it was also critical that the support needs framework relate as closely as possible to existing data standards and practice in the area of disability and related support services.

The AIHW therefore aimed for consistency with (and an ability to map to):

- the CSTDA definition of people with disabilities
- the 1998 ABS Survey of Disability, Ageing and Carers
- the National Community Services Data Dictionary Version 2.0 (then in draft)
- assessment tools currently in use in jurisdictions
- the existing CSDA MDS
- other major data collections, assessment tools, data development activities and concepts of relevance, wherever possible.

The issues surrounding 'support needs' were explored by:

- reviewing relevant literature including national and international data dictionaries and classifications
- examining a range of relevant Australian data collections
- investigating a number of well-known tools for assessing support need
- analysing information provided by jurisdictions, detailing policy directions and the assessment tools and frameworks currently in operation or under development
- synthesising this information to elucidate the major issues for discussion at an AIHW-NDA workshop in November 1999.

The AIHW then:

- undertook further research and analysis in accordance with the direction provided by the workshop
- developed a number of support needs data options for NDA consideration.

Using the ICF to develop a 'support needs' framework

Using the ICF as a framework

The ICF domains and scales were used as the framework to which all of the other classifications and tools described above were mapped; that is, the ICF

acted as a central, comprehensive framework and set of classifications in which to organise our comparative analysis and seek areas of commonality. The final support needs framework includes concepts that may be considered Activities and/or Participation (see Section 5 for further discussion).

Using the ICF as a 'smorgasbord' for selecting domains

Domains from the Activities and Participation component were selected, generally at the chapter heading level (e.g. Chapter 3, 'Communication'). All chapters within the Activities and Participation component were included in the support needs framework. However, in the following cases:

- ICF chapters were grouped (i.e. Chapter 1, 'Learning and applying knowledge' was combined with Chapter 2, 'General tasks and demands')
- ICF chapters were separated (i.e. Chapter 8, 'Major life areas' was separated into two separate items 'Working' and 'Education');
- a block from one ICF chapter was grouped with another ICF chapter (i.e. the block of 'Economic life' from within Chapter 8, 'Major life areas' was grouped with Chapter 9, 'Community, social and civic life').

Such grouping or separation was done only when it was either considered to be more meaningful/less onerous for service delivery agencies or to improve the degree to which the framework related to the ABS Survey of Disability, Ageing and Carers, the CSTDA NMDS, and other related classifications and tools. Examples were also included for each support needs domain or 'life area' in the support needs framework. These are selected categories from within each relevant ICF chapter (e.g. for the support needs life area 'self-care' the examples used are d510 washing oneself, d540 dressing, d550 eating and d530 toileting).

The selected domains and examples were tested with consumers, service providers and jurisdictions during the redevelopment of the CSTDA NMDS and refined where necessary.

Using the ICF to select qualifiers or scales

This was probably the most difficult aspect of the data development exercise. There was considerable consistency in the type of domains included in various classifications and tools examined during the 1999 'support needs' project. However, the scales used varied and sometimes related to the whole person and sometimes the person in relation to the specific service required.

The final selected scale relates directly to the ABS Survey of Disability, Ageing and Carers, enabling comparison with population data. The scale relates most closely to the qualifier concepts of 'difficulty and assistance with Activity' (in the *National Community Services Data Dictionary V2.0*; AIHW 2000) and

incorporates concepts of assistance both via personal assistance and/or via the use of aids or equipment (i.e. environmental factors).

The support needs scale also relates to the ICF performance qualifier for Activities and Participation:

The *performance qualifier* describes what an individual does in his or her current environment. Because the current environment includes a societal context, performance can also be understood as ‘involvement in life situation’ or ‘the lived experience’ of people in the actual context in which they live. This context includes the environmental factors – all aspects of the physical, social and attitudinal world which can be coded using the Environmental Factors component (WHO 2001:15).

The way in which the selected support needs scale relates to the ICF performance qualifier is outlined in Table 10.1. This scale also includes a further point ‘Does not need help/ supervision in this life area but uses aids or equipment’. This point does not map directly to the ICF performance qualifier. Instead it gathers additional information about one aspect of the individual's environment. This is consistent with the quoted statement from the ICF above.

Table 10.1: Mapping the CSTDA NMDS support needs categories to the ICF performance qualifier

ICF uniform qualifier	Support needs scale
NO problem	Does not need help/ supervision in this life area and does not use aids or equipment
MILD problem	Sometimes needs help/ supervision in this life area
MODERATE problem	Sometimes needs help/ supervision in this life area
SEVERE problem	Sometimes needs help/ supervision in this life area
COMPLETE problem	Unable to do or always needs help/ supervision in this life area
—	Does not need help/supervision in this life area but uses aids or equipment

The resulting support needs framework

Use of the ICF in redeveloping the ‘support needs’ area of the CSTDA NMDS resulted in the framework shown in Table 10.2.

Table 10.2: Support needs framework

How often does the service user need personal help or supervision with activities or participation in the following life areas?

The person can undertake activities or participate in this life area with this level of personal help or supervision (or would require this level of help or supervision if the person currently helping were not available)	1) Unable to do or always needs help/ supervision in this life area	2) Sometimes needs help/ supervision in this life area	3) Does not need help/ supervision in this life area but uses aids or equipment	4) Does not need help/ supervision in this life area and does not use aids or equipment	5) Not applicable
a) Self-care , e.g. washing oneself, dressing, eating, toileting					
b) Mobility , e.g. moving around the home and/or moving around away from home (including using public transport or driving a motor vehicle), getting in or out of bed or a chair					
c) Communication , e.g. making self understood, in own native language or preferred method of communication if applicable, and understanding others					
d) Interpersonal interactions and relationships , e.g. actions and behaviours that an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions					
In the following questions 'not applicable' is a valid response only if the person is 0–4 years old.					
e) Learning, applying knowledge and general tasks and demands , e.g. understanding new ideas, remembering, problem solving, decision making, paying attention, undertaking single or multiple tasks, carrying out daily routine					
f) Education , e.g. the actions, behaviours and tasks an individual performs at school, college, or any educational setting					
g) Community (civic) and economic life , e.g. recreation and leisure, religion and spirituality, human rights, political life and citizenship, economic life such as handling money					
In the following questions 'not applicable' is a valid response only if the person is 0–14 years old.					
h) Domestic life , e.g. organising meals, cleaning, disposing of garbage, housekeeping, shopping, cooking, home maintenance					
i) Working , e.g. actions, behaviours and tasks to obtain and retain paid employment					

Source: CSTDA NMDS Service User Form 2002

Participation outcomes

Background

A 'participation outcomes framework' was also developed as part of the CSTDA NMDS redevelopment project. The resulting draft framework is included here and is an additional resource for jurisdictions to include in the CSTDA NMDS and related materials, if desired. It is not included as a mandatory item in the national CSTDA NMDS.

Using the ICF to develop a 'participation outcomes framework'

Using the ICF as a framework

The overall goal of the CSTDA is to enhance the quality of life for people with disabilities by assisting them to live as valued and participating members of the community. Thus, quality of life and participation are critical concepts in terms of measuring outcomes for individual consumers. Participation is defined in the ICF as 'involvement in a life situation'. Participation is taken to mean not just 'doing' an activity, but also having an autonomous role and experiencing real involvement and satisfaction.

The ICF concept of participation is thus consistent with the philosophy of the CSTDA, the Australian Disability Service Standards and the UN Standard Rules on Equalization of Opportunity for People with Disabilities. Thus, the Activities and Participation component of the ICF appeared to be a useful starting point for developing a framework that related to all of these philosophies.

Using the ICF as a 'smorgasbord' for selecting domains

A range of life domains was selected from the Activities and Participation component. These domains were selected in discussion with consumers and funding departments and attempt to relate to the areas of most interest to consumers as well as the overall focus on human rights in the CSTDA.

Domains from the Activities and Participation component were selected, generally at the chapter heading level (e.g. Chapter 6, 'Domestic life'). However, in the following cases:

- particular aspects of ICF chapters were drawn out into the participation life area (i.e. Chapter 3, 'Communication' was used in total but the block called 'Conversation and use of communication devices and techniques' was drawn up into the heading to increase its prominence; Chapter 4, 'Mobility' was used in total but the blocks on 'Walking and moving' and 'Moving around using transportation' were drawn up into the heading to increase their prominence)

- ICF chapters were separated (e.g. Chapter 8, 'Major life areas' was separated into two separate participation life areas, 'Participation in education, work and employment' and 'Participation in economic life'),
- some ICF chapters were not referred to in the participation module (i.e. Chapter 1, 'Learning and applying knowledge', Chapter 2, 'General tasks and demands' and Chapter 5, 'Self-care').

Examples were also included for each participation life area. These are selected categories from within each relevant ICF chapter or block (e.g. for the participation life area 'Domestic life', the examples used are d610 acquiring a place to live, d620 acquisition of goods and services, d630 preparing meals, d650 caring for household objects and d660 assisting others).

Using the ICF to select qualifiers or scales

Two scales are included in the 'participation outcomes framework':

- 'Extent of participation' (judged by service provider or assessment process)
- 'Satisfaction with participation' (judged by consumer, with advocate if necessary) in relation to duration, frequency, manner or outcome.

These are the qualifiers in the *National Community Services Data Dictionary Version 3* (AIHW 2003a) and are based on quite extensive research and development. The first qualifier is, essentially, the generic ICF qualifier. The scales also enable data collated using the participation outcomes framework to be related to some population data collected via the ABS Survey of Disability, Ageing and Carers. The use of the different scales, together with the context in which the component information is gathered (e.g. through client satisfaction surveys), makes it clear that the participation outcomes framework is a framework for collating information about participation rather than activities.

How to use the participation outcomes framework

It is important to note that the draft participation outcomes framework is not a proposed question that would appear on a form:

- The framework indicates output and concepts rather than the precise wording that would be used in questions. Separate mechanisms would be used to gather information from consumers and service providers.
- The separate recording for the service provider and person is in line with the established principle that quality of life measures should be based on both 'objective' and 'subjective' measures.
- If adopted, there would need to be user guides. Such guides would explain the ICF framework, including the importance of environmental factors. This could bring in social attitudes, i.e. the 'valued members' aspect of the CSTDA goal.

Thus the participation framework acts as multi-purpose 'participation module' and is proposed for use as a broad outcome indicator meaningful in the CSTDA field. It could be used in the course of service administration when conducting satisfaction surveys, discussing people's overall goals and developing individual service plans (e.g. in case management reviews); and in assessing overall quality of life.

As with support needs there are many measures and instruments relating to quality of life and satisfaction. However, based on work done during the development of the ICF, it is considered likely that these will map to the 'participation framework' (see also Section 5 for a discussion of measurement of Participation). The way the 'participation framework' might relate to other existing (or future) information and planning processes is illustrated in Figure 10.1.

It is important to note that this sort of this participation framework would aim to look at outcomes relating to a whole person, across life domains. The outcomes at this broad level (e.g. satisfactory participation in domestic life) would be difficult to attribute to specific service interventions. However, information about them could be very useful at a general or program level: e.g. to answer questions about the quality of life for people with disabilities (accessing CSTDA-funded services) and to consider priorities for action. Information could also be useful for planning services to meet people's participation goals.

The resulting participation outcomes framework

Use of the ICF in developing the area of participation outcomes in the CSTDA NMDS resulted in the framework shown in Table 10.3.

Table 10.3: Draft 'participation outcomes framework'

Life area	Extent of participation (judged by service provider or assessment process)	Satisfaction with participation (judged by consumer, with advocate if necessary) in relation to duration, frequency, manner or outcome
	<ol style="list-style-type: none"> 1. Full participation 2. Mild participation restriction 3. Moderate participation restriction 4. Severe participation restriction 5. Complete participation restriction 	<ol style="list-style-type: none"> 1. High satisfaction with participation 2. Moderate satisfaction with participation 3. Moderate dissatisfaction with participation 4. Extreme dissatisfaction with participation 5. No participation 6. No participation and none desired
<p>Participation in communication and conversation (e.g. producing and receiving spoken, nonverbal, formal sign or written messages, involvement in conversation, discussion with or without use of communication devices and techniques)</p>		
<p>Participation in mobility within the home and community environment (e.g. changing and maintaining body position; carrying, moving and handling objects; walking and moving; moving around using transportation)</p>		
<p>Participation in domestic life (e.g. acquiring necessities such as a place to live and goods and services; household tasks such as preparing meals; caring for household objects and assisting others)</p>		
<p>Participation in interpersonal interactions and relationships (e.g. relating with strangers, formal and informal social relationships, family and intimate relationships)</p>		
<p>Participation in education, work and employment (e.g. informal education, preschool, school, vocational and higher education; work preparation such as apprenticeships; acquiring, keeping and terminating a job, remunerative or non-remunerative employment)</p>		
<p>Participation in economic life (e.g. basic and complex economic transactions, economic self-sufficiency)</p>		
<p>Participation in community, social and civic life (e.g. community life, religion and spirituality, recreation and leisure, political life and citizenship, human rights)</p>		

Source: CSTDA NMDS Network Guide, 2002

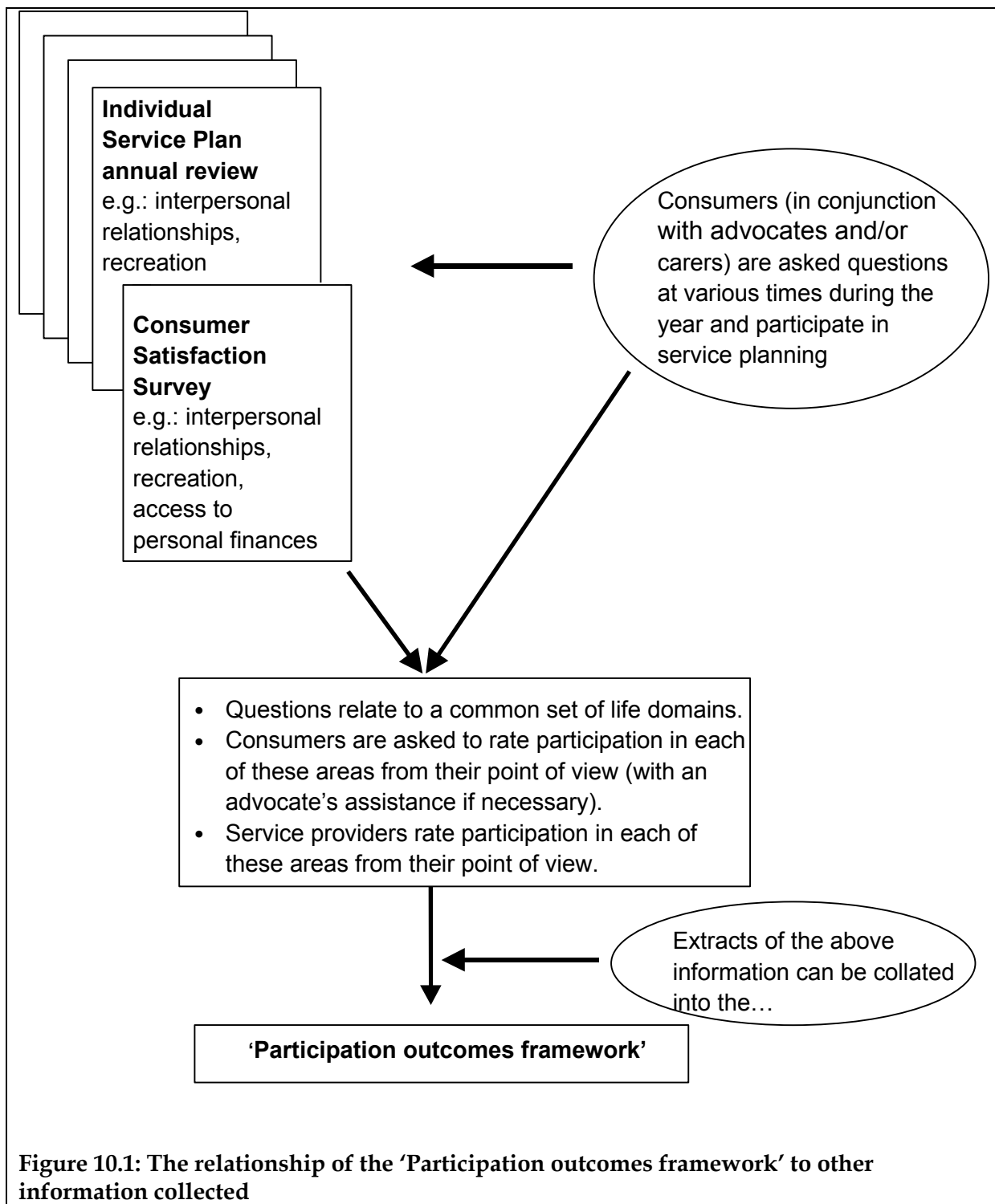


Figure 10.1: The relationship of the 'Participation outcomes framework' to other information collected

10.2 The use of the ICF framework in an allied health outcome measure: Australian Therapy Outcome Measures (AusTOMs)

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Introduction

This section provides a brief overview of the way in which the framework and key concepts of the ICF were used in developing an Australian tool to measure therapy outcomes – the Australian Therapy Outcomes Measures (AusTOMs). This tool is based on the Therapy Outcomes Measures (TOM) developed in the United Kingdom by Professor Pam Enderby and colleagues. As well as drawing on the concepts of the ICF, AusTOMs incorporates descriptors developed by Australian clinicians using focus groups and a modified Delphi survey.

AusTOMs—using the ICF in an Outcome Measure

The AusTOMs project is a Commonwealth-funded initiative that aims to develop a valid and reliable measure of therapy outcomes for use in the allied health disciplines of speech pathology, occupational therapy and physiotherapy. The project team is based at La Trobe University, Bundoora, Victoria and is working with allied health clinicians both within Victoria and across Australia on the development of the measure.

While there has been a clear focus in outcomes literature on evaluating medical interventions, there is also a growing body of literature on the

outcomes of allied health professions (Benjamin 1995). There is a focus on measuring outcomes not just by assessing an impairment, but by assessing areas that may be more important to clients i.e. functional and societal limitations (Barr 1995). It is recognised, however, that there is not a clear linear relationship between a person's impairment, their limitations in everyday activities, and their level of disability or social limitation (Enderby 1997).

The AusTOMs tool uses the ICF as a basis for the headings and concepts of three out of four domains; thus, clinicians measure changes in clients' Impairments, Activity Limitations and Participation Restrictions, as well as a fourth domain, Wellbeing/Distress.

Each domain is rated on an ordinal scale with six defined points, where 0 = most severe, and 5 = no difficulty. To improve the sensitivity of the scales, clinicians are able to make half-point ratings (e.g. 1.5) to show that a client is performing somewhere between the defined points (e.g. between 1 and 2). Thus the domains effectively represent eleven-point ordinal scales. Each domain is independent of the others, so that a client may show no progress in one domain, while demonstrating great progress in another.

Why use ICF

The AusTOMs project is based on more than ten years of research into outcome measures in allied health, carried out by Professor Pam Enderby, now Dean of Medicine at Sheffield University, UK. Enderby and others developed and rigorously tested TOM, a system of measuring therapy outcomes in the National Health Service (Enderby 1997; Enderby et al. 1998). This system was based on the ICIDH, the predecessor of the ICF.

When in Bristol, Enderby studied the notes of 350 speech pathology cases and discovered that speech pathology goals could be related to the three areas described in the ICIDH – impairment, disability and handicap (Enderby 1992); that is, the domains of the ICIDH were particularly applicable to speech pathology clinicians because these were the areas where they set goals. For example, a speech pathology clinician might aim to increase the client's range and rate of oral movement (impairment goal), increase the client's ability to communicate using speech (disability goal) and increase the client's use of communication to participate in classroom activities (handicap goal).

Enderby felt that there was a fourth category of goals in therapy, not explicitly covered by the WHO ICIDH classification. These goals related to the client's wellbeing. These are feelings of distress or anxiety, which clinicians may hope to alleviate during therapy (Enderby 1992).

The AusTOMs team, in consultation with clinicians, felt that the ICIDH framework was also relevant to speech pathologists, occupational therapists

and physiotherapists in the Australian clinical context. The framework offers a way of describing 'health', and is relevant to all three allied health disciplines. It is because the framework is applicable across all disciplines that the team was able to create a tool that may be used to compare outcomes across disciplines. AusTOMs also provides clinicians with a common language when comparing outcomes. Rehabilitation services often involve many professions working with the same client. Without a common language for describing outcomes, clinicians are hampered when sharing information about client progress; many, even within the same profession, commonly use dissimilar language to relate goals and outcomes (Enderby 1997).

Developing the AusTOMs scales

Stage 1: Examining the measure in the Australian context

The project team at La Trobe University examined the UK Therapy Outcome Measure (TOM) scales. The terminology on these scales was updated to reflect the ICF vocabulary, using 'impairment', 'activity limitation' and 'participation restriction'. A core scale was developed for AusTOMs, from which to develop profession-specific scales.

New scale headings, more appropriate to Australian clinical practice were proposed. In speech pathology and physiotherapy, these scale headings represent an impairment, e.g. impairment of 'voice' or 'fluency' for speech pathology, or impairment of 'musculoskeletal movement related functions' for physiotherapy. In addition, physiotherapists decided to use the ICF terminology for body functions and structures as their card headings. Occupational therapists, on the other hand, developed their scale headings to reflect the 'activity limitation' domain; it was felt that this domain best reflected the focus of occupational therapy intervention. Occupational therapy scale headings were based on the ICF headings for activities and participation, e.g. 'learning and applying knowledge'.

Stage 2: Developing scale descriptors

Once the scale headings were decided, descriptors were developed for each point in the ordinal scales. The research team held focus groups of clinicians across Victoria in each profession for this part of the project. Clinicians were asked to provide detailed terminology to describe impairments and activity limitations under each disorder heading. For example, speech pathologists were asked to provide a written description of what zero (0) (the most severe difficulty) might include for a client with a 'voice impairment'.

Speech pathology and physiotherapy groups focused on developing specific descriptors for 'impairment' and 'activity limitation' domains. Occupational therapy groups, on the other hand, concentrated mainly on the 'activity limitation' domain.

The project team then sought input from clinicians across Australia in determining the face validity of the scales. The scales were sent out in a modified-Delphi (two round) survey to speech pathology, occupational therapy and physiotherapy clinicians across Australia. This was done using the National Allied Health Casemix Committee membership. More than 600 returns across the three professions were received. The scales were modified on the written advice of responding clinicians, and a second round of surveys was sent out for confirmation of the changes.

The research team also sought the views of consumers (clients) during development of the scales. Consumer groups were contacted, and representatives attended a focus group at La Trobe University. Consumer feedback and advice on terminology were particularly useful for the development of the Participation and Wellbeing domains of the scales.

Stage 3: Training clinicians

Fourteen health-care sites in Victoria were recruited for the project data collection. Speech pathologists, occupational therapists and physiotherapists across these sites, all of whom had agreed to participate in the project, were required to attend standardised training sessions in the use of the AusTOM scales. The inter- and intra-rater reliability of the scales were assessed.

Stage 4: Data collection

Data collection on 500 clients per profession, across 14 sites in Victoria, was undertaken during the 6 month period from October 2002 to March 2003. During that time, clinicians were asked to rate clients at the beginning and at the end of a period of therapy, using AusTOMs. Clients were asked to rate their own health using the EuroQol (EQ-5D) measure of health status. This measure has been used widely across Europe and has an accepted Australian version. The score was then correlated with each domain of AusTOMs and the correlation with the EQ-5D was used to assess the concurrent validity of the AusTOM scales.

Data analysis took place at La Trobe University, Victoria. Allied health staff on each site submitted their data entry sheets (standardised forms) to the research team who entered the data onto a centralised database. In total, data from over 1000 interventions across all three professions were received. The data were

used to examine the usefulness of AusTOMs as a valid and reliable tool for assessing outcomes in allied health intervention.

Data analysis shows preliminary evidence for the validity and reliability of the AusTOMs scales. Clinicians have been enthusiastic in their contribution to its development, and have generally reported that the tool is quick, easy to use, and clinically useful.

10.3 The ICF and classification for disability athletics

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Introduction

It has been widely advocated that four of the classification systems currently used in disability athletics (i.e. track and field) should be replaced by a single, unified classification system. The purpose of this module is to:

- provide a brief overview of classification in disability athletics
- establish a rationale for basing a single, unified system on the language and structure of the ICF
- provide specific examples of how the ICF can be applied to enhance the utility and taxonomic integrity of a single unified system.

This module is based on a published paper entitled *Taxonomic Theory and the ICF: Foundations for a Unified Disability Athletics Classification* (Tweedy 2002).

Overview of classification in disability athletics

Sport plays an important role in the lives of people with a disability, providing a valuable, self-directed means of enhancing rehabilitation and long-term health, as well as offering opportunities for recreation, social interaction, and the pursuit of athletic excellence. In 1948 the first Stoke Mandeville Games for Paralysed Individuals, forerunner of the modern Paralympic Games, were held (Vanlandewijck & Chappel 1996). Recognising that competitors would experience differing degrees of disadvantage in sport, the Games were organised so that athletes experiencing similar degrees of disadvantage competed against each other. The aim was to make competition fair, so that athletes who experienced greater disadvantage in sport were not precluded from success. For example, people with quadriplegia competed against each other and did not have to compete against people with paraplegia. The methods for placing athletes into groups were based on conventional medical assessment procedures.

Disability sport now includes people with a wide range of health conditions and impairments, and systems of classification remain a vital yet controversial feature of disability sport (Sherrill 1999; Vanlandewijck & Chappel 1996)

playing an important role from international sport to local 'come and try' days. In general, the purpose of disability sports classification systems is twofold (Tweedy 2002):

- to define eligibility
- to ensure competition among eligible athletes is fair (i.e. that athletes are not precluded from success solely because of the disadvantage they experience as a result of their impairment).

Athletics (i.e. track and field) is one of the most popular organised sports for people with disabilities. This section focuses on four of the systems currently used in disability athletics at the Paralympic Games and many other national, state and local competitions throughout the world. The systems are those of the Cerebral Palsy-International Sport and Recreation Association (CP-ISRA 2001), the International Stoke Mandeville Wheelchair Sports Federation (ISMWSF 1995, 2000) and the International Sports Organisation for the Disabled (ISOD 1993). The latter has one system for amputees and one system for 'les autres'¹⁰. Table 10.4 presents a brief synopsis of people who are currently eligible to compete under the auspices of these organisations.

For a number of years it has been advocated that the four systems presented in Table 10.4 be replaced by a single, unified system. Such a move would streamline the process of classification, as well as provide an opportunity to improve taxonomic integrity and eliminate inconsistencies and ambiguities that currently exist.

Table 10.4: Health condition / impairment eligibility criteria for four of the disability athletics classification systems used at the Paralympic Games.

Organisation	Eligible participants
Cerebral Palsy-International Sport and Recreation Association (CP-ISRA)	People with '...a diagnosis of non-progressive brain damage with motor dysfunction such as cerebral palsy, traumatic brain injury, stroke or similar conditions' (CP-ISRA 2001, Section 1.3). Ineligible are people with intellectual impairment without motor function and people with motor dysfunction that does not have a cerebral origin (CP-ISRA 2001, Section 1.5).
International Sports Organisation for the Disabled (ISOD—Amputees)	People with '...acquired amputations and dysmelia resembling acquired amputations' (ISOD 1993, Section I, Chapter 4.2.1) but not 'dysmelia not resembling acquired amputations' (ISOD 1993, Section I, Chapter 4, Comment #1).
International Sports Organisation for the Disabled (ISOD—les autres)	People with '...locomotor disabilities regardless of diagnosis' (ISOD 1993, Section I, Chapter 4.3.1). Ineligible persons include those with 'severely reduced mental capacity...heart, chest, abdominal, skin, ear and eye diseases without locomotor disability' (ISOD 1993, Section I, Chapter 4.4.1).
International Stoke Mandeville Wheelchair Sports Federation (ISMWSF)	'...persons suffering from spinal cord injury or with a disability which can functionally be equated to a spinal cord injury...' (ISMWSF 1995:2). Historically has included people with spina bifida and polio.

¹⁰ *les autres* is a French term meaning *the others*.

Why base a disability athletics classification on the ICF?

Taxonomically, the ICF and the current disability athletics systems are very closely related. They are all classifications of the functioning and disability associated with health conditions, although they vary considerably in terms of breadth of scope.

The ICF is a very broad classification. Its universe encompasses all aspects of human health and some health-relevant components of wellbeing. It is not only about persons with disabilities, but all persons. The framework of the ICF organises information into two parts (Functioning and disability; and Contextual factors) and their respective components and domains (WHO 2001). This framework is used to describe the universe of the ICF, providing a structure for the meaningful organisation of information (WHO 2001).

In contrast, the disability athletics classifications are very narrow in focus. Their collective universe is limited to people with certain health conditions and/or impairments (see Table 10.4) and to those aspects of human health that relate directly to the activities within the athletic disciplines (i.e. running, jumping, throwing and wheelchair racing). In other words, the scope of the athletics classification systems can be fully described by a small number of the Body functions and structures and Activity domains of the ICF (expressly discussed later in this section).

Linking the development of the highly specific disability athletics classification system to the broad classificatory framework of the ICF has the potential to improve the utility of both systems and to advance understanding of the functioning and disability associated with health conditions.

It would be beneficial to base a unified disability athletics system on the ICF because the ICF provides a well-constructed, taxonomically sound structure and uses standardised definitions that are actively promoted, widely utilised and have been translated into several different languages. Use of the ICF as framework for a unified athletics classification would minimise ambiguity, enhance conceptual clarity and maximise understanding, particularly among non-English speaking stakeholders in the international disability sport community.

Conversely, the ICF benefits from wide use; justification for the development and maintenance of broad classificatory frameworks such as the ICF depend on their widespread application (Fleishman & Quaintance 1984). Moreover, if the ICF were used in the development of a unified athletics system, there would be potential to expand and develop specific domains within the ICF. For example, a new unified disability athletics classification system could expand and enhance relevant Activities codes, specifically those for running (a4552), jumping (a4553), throwing (a4454) and wheelchair propulsion (a465).

Empirical evidence suggests that such 'fractionalising' enhances the usefulness of primary categories in broader, more general systems such as the ICF (Fleishman & Quaintance 1984).

Using the ICF to develop a unified disability athletics classification

Using the ICF, the purpose, structure and language of the four current disability athletics systems have been identified. The remainder of this section identifies areas of weakness in the four current systems and indicates how the language and structure of the ICF could be applied to overcome these weaknesses in a unified disability athletics classification.

Defining eligibility by health condition/impairment type

The clarity and effectiveness of the eligibility criteria presented in Table 10.4 are compromised by use of terms that are not standardised, such as 'functionally be equated' (ISMWSF system), 'similar conditions' (CP-ISRA system), and 'resembling' (ISOD amputee system). For example, it is surely a matter of debate as to which disabilities can functionally be equated with spinal cord injury. Such potential areas for debate would considerably weaken the integrity of a unified system.

Use of the clearly defined, mutually exclusive ICF codes could be used to help define eligibility and improve the clarity of the system. For example, the codes b710–b799 (Neuromusculoskeletal and Movement-Related Functions), s110–s199 (Structures of the Nervous System), and s710–s799 (Structures Related to Movement) best describe the populations covered by the four current systems and would be the most appropriate starting point.

Defining eligibility by 'minimum disability'

In each of the current disability athletics systems, it is possible for an athlete to have a health condition or impairment type that satisfies eligibility criteria but to be ruled ineligible on the grounds that he or she does not meet other criteria, commonly called 'minimum disability' criteria. In column 2 of Table 10.5 the criteria used by each of the current systems are presented. In the lexicon of the ICF, the term 'minimal disability' does not accurately describe the eligibility criteria stated by the respective organisations. Column 3 of Table 10.5 presents a more accurate description of each of the criteria. In a unified system it would be important to ensure that the descriptor used for this area of classification was stated accurately in terms consistent with the ICF.

Column 4 of Table 10.5 presents the rationale that each organisation presents for establishing minimal disability criteria. There are obvious discrepancies

and gaps in the rationale establishing minimal disability criteria in each of the current systems, highlighted by the fact that no rationale is offered by ISMWSF. A necessary prerequisite for the establishment of a unified system would be documentation of a sound rationale for and description of minimum disability criteria stated in terms consistent with the ICF.

Table 10.5: Characteristics of the current disability athletics classification systems

Organisation^Φ	*Minimum disability criteria	Description of current minimum disability criteria in ICF terms	Purpose or rationale for minimal disability criteria	Method for placing into classes
Cerebral Palsy - International Sport and Recreation Association (CP-ISRA)	'If an abnormality can only be detected by a detailed neurological examination and impairment of function is not clearly evident during classification and does not obviously impact on sports performance, then the athlete is not eligible for competition' (CP-ISRA 2001, Section 1.3).	Minimal body function impairment, as well as minimal activity limitation	'seeks to provide sports opportunities for individuals... whose level of neurological impairment disadvantages them in training for, and competing in, sports' (CP-ISRA, 2001 Section 1.1)	Neurological examination including the Ashworth scale (Ashworth 1964) and evaluation of muscle tone together with generic and sports specific tests of activity limitation. 8 classes available
International Sports Organisation for the Disabled (ISOD—Amputees)	'Minimal handicap...[is] amputation through or above the wrist joint' (ISOD 1993, Section I, Chapter 4.2.3). No lower limb criterion identified.	Minimal body structure impairment	Aims to ensure that only athletes with an impairment that prevents them from 'participating on reasonably equal terms' with able-bodied athletes are included, thereby maintaining the credibility of the disability sport movement (ISOD 1993, Section I, Chapter 4.1.1)	Classified according to the limb(s) affected (upper or lower), how many limbs have been affected, and how much of the limb has been amputated (e.g. above knee, below elbow); 9 classes available.
International Stoke Mandeville Wheelchair Sports Federation (ISMWSF)	ISMWSF grades the strength of 54 muscle groups on a scale of 0 to 5 (0 = total lack of voluntary contraction; 5 = normal contraction). Maximum points for lower limbs is 80; athletes who score 70 points or less are eligible. No upper limb criteria are specified.	Minimal body function impairment	No stated rationale	Muscle grading together with generic and sports-specific tests of activity limitation. 8 classes available for field events, 4 classes for track events.

^Φ The ISOD 'les autres' system is not presented in this table or included in the analyses based on this table. This is because the 'les autres' system has a very weak conceptual basis, a fact highlighted by the current IPC policy of using the 'les autres' system to define eligibility but not to place athletes into classes. Instead, athletes who are permitted to compete in disability athletics under 'les autres' criteria are placed into classes using the Amputee or ISMWSF systems.

Clarifying conceptual basis of classification

To ensure the conceptual basis of the current systems of classification are not significantly altered or lost in the development of a unified system, they need to be clarified. This example illustrates how the ICF can be used for this purpose. A précis of the methods used for placing athletes into classes is presented in column 4 of Table 10.5. In general, the conceptual basis of each of the current systems is quite clear and logical. When eligibility of an athlete for a system of classification is defined in terms of the type of health condition or impairment, then the methods used to assess the impairment will be relatively uniform, allowing comparison of results and providing a sound basis for grouping athletes into classes.

A misconception about the conceptual basis of these systems is that they classify (or control for) the *extent of impairment of an athlete*. However this phrase is taxonomically inconsistent with the ICF, being predicated on the outdated notion that activity limitation is *caused by* impairment. The phrase implies that, by measuring impairment, the activity limitation experienced by a person can be predicted. In the ICF, the impairment and activity dimensions are interdependent (WHO 2001:18, Fig. 1); impairment does not cause activity limitation (WHO 2001). Moreover, the ICF removes the ambiguity previously associated with the term *impairment*, using it only to describe limitations in the domains of body structure or body function. *Activity limitations* (not impairments) refer to difficulties experienced by a whole person; therefore, the term *whole-person impairment* (used in some quarters of disability sport) is not valid in the ICF lexicon. Although a range of methods can be used to quantify the impairment of discrete structures or functions, it is not a simple matter of converting an amount of impairment into an amount of activity limitation. The process of evaluating how much a given quantity of impairment will affect the activity of a whole person must begin by defining the activity.

To illustrate, Person A and Person B may both have spinal cord lesions that paralyse 50% of their musculature, resulting in the same total score using the ISMWSF muscle chart. Quantitatively, these persons could be said to have the same extent of impairment. However, if the distribution of the paralysed muscles is spread over the upper and lower body (including the small muscles of the hand) in Person A and restricted solely to the lower body in Person B, then it is likely Person A will be less impaired in the activity of walking/running, but more impaired in the activity of throwing a ball, than Person B is. In this case, a correct restatement of the comparison of Persons A and B is that Person A experiences less activity limitation in walking and greater activity limitation in throwing a ball than Person B does.

As identified in Table 10.5, the current disability athletics systems take account of both observable activity limitation and assessment of impairment. If a

unified system is to remain consistent with the conceptual bases of current classification processes (as interpreted using the ICF framework), then its definitive role should be estimation of the *extent of activity limitation resulting from impairment*. Assessment of impairment alone is not sufficient because the effects of impairment only make sense when interpreted in light of a specific activity. Assessment of activity limitation alone is not sufficient because there are many factors other than impairment that influence activity limitation. Based on the extent of activity limitation resulting from impairment, eligibility can be decided, and eligible athletes can be placed into classes with athletes who experience similar extent of activity limitation to enable fair competition.

Improving social sensitivity

Each of the four current systems of disability athletics classification refers to the process of classifying athletes, thereby making people the units of classification. A more contemporary and socially sensitive view of classification argues that people should not be characterised solely in terms of a classification (WHO 2001). Accordingly, the ICF does not classify people. Rather, the unit of classification is categories within each domain. Adoption of ICF categories as the units of classification in a unified disability athletics system would be consistent with the purpose of the system while improving social sensitivity.

Conclusion

This section outlines how the broad, generalisable taxonomy and standardised language of the ICF may be used to expose inconsistencies and clarify the conceptual bases of the current systems and thus to provide guidelines for developing a new unified system of classification. Such a system will be effective in achieving its intended purpose.

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10.4 The ICF and accident compensation in Australia

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Abstract

This paper briefly describes the Australian accident compensation system, with particular emphasis on its process of impairment classification, assessment, and entitlement to damages. It argues that this process is fundamentally flawed, and suggests that the framework provided by the ICF may provide a starting point for future development.

Accident compensation in Australia

Individuals who sustain an injury in Australia may be eligible for a variety of benefits under Accident Compensation, a set of statutory and common law systems generally under the jurisdiction of states and territories (as distinct from the Commonwealth).

More than \$10 billion per annum (about 1.5% of GDP) is collected in premiums and paid in benefits under the various schemes encompassed by accident compensation:

- Workers Compensation (ten statutory schemes)
- Motor Transport Compensation (eight statutory schemes)
- Public Liability Insurance (generally private insurance)
- Medical Indemnity Cover (medical defence and private insurance)
- a variety of self-insurance and pooled arrangements.

The structure of the schemes has been under constant review during the past 20 years in terms of both benefit entitlement and also underwriting structure. Almost invariably, scheme review has followed either cost escalation, leading to affordability issues for premium payers, or perceived inadequacy of benefits, leading to rights issues for injured parties.

Again, almost invariably, these catalysts for reform have been linked in some way to instability, inappropriateness or lack of confidence in the process or method of assessment of impairment or disability.

Eligibility for compensation

For 'no fault' type schemes, *eligibility* for compensation is broadly linked to the circumstances or place of occurrence, e.g. 'in the workplace', 'out of the use of a motor vehicle'. All of Australia's workers compensation systems have at least some no-fault benefits, as do three of our eight motor transport compensation systems.

For 'common law' type schemes, *eligibility* for compensation is contingent on the ability to establish that the injury for which compensation is claimed was due to the negligence of a third party ('the plaintiff'). All of Australia's public liability insurance (including medical indemnity) is based on common law principles. All of our motor transport compensation systems have at least some common law entitlements (in five out of eight this is the only entitlement). All but three of our ten workers compensation systems have at least some common law entitlements.

In some cases these over-riding eligibility criteria are supplemented by *thresholds* or 'entry points', usually based on an assessment of impairment or disability; i.e. eligibility for damages is contingent on meeting a certain percentage of disability. The determination of whether or not this threshold is reached follows a similar process to the assessment of entitlement to damages, described in the next section.

Assessment of compensation entitlements

The nature of the scheme (common law or no-fault) also generally determines the way in which benefits are determined.

Common law

For common law schemes, compensation is generally available for the following major classes of 'heads of damage':

- *Economic loss (past and future)*, requiring an assessment of the extent to which the injury has resulted in a reduced capacity to engage in employment, and so earn income, and for how long this incapacity will remain
- *Care costs (past and future, medical, hospital, attendant care, therapy, aids and appliances)*, requiring an assessment of the treatment, equipment and personal care which will be required to (as far as possible) overcome the disabling affects of the injury
- *General damages (also termed 'non-economic loss' or 'pain and suffering')*, requiring an overall assessment of the significance of the disability or impairment arising from the injury, normally compared to a 'worst possible case', or some other 100% entitlement.

The method of determination of these measures is left to a judicial process i.e. a judge or magistrate who makes a once-and-for-all award based on evidence from a variety of medical and other experts representing both sides of the argument (plaintiff and defendant). There is generally no specified instrument or benchmark to guide this process, the major argument in favour of this being that the subjective power of the judge allows an appropriate consideration of individual circumstances. Damages are payable by way of a single lump sum. In a large majority of cases the common law matter does not receive a judicial verdict at all. The settlement for each head of damage (and in total) is agreed between plaintiff and defendant lawyers, based on precedent judgements leading to a decision about the amount they would expect the matter to be awarded. Therefore the 'assessment' process is even further removed from any rigorous and structured basis.

In my view there are at least four major problems with the subjectivity of the common law assessment process:

- The process has little scientific basis or structure in terms of the concepts of impairment, disability, and incapacity,
- The process is litigious and slow and effectively encourages claimants to prolong their incapacity to maximise financial reward,
- There is only very rough equity between claimants; it is not unusual for very similar claimants to be awarded very different amounts of compensation,
- The process has been found to be unstable at a macro-level. Over time it seems that the balance of judgement gradually moves in favour of the claimant. Hence the convention of what constitutes any 'percentage' incapacity, disability or impairment becomes less and less severe by any objective measure. The result is cost pressure on the scheme, and usually a major review, which typically leads to some short-term restriction on judicial power or some artificial threshold or reduction in entitlements.

Statutory benefits

For no-fault schemes, compensation is generally payable according to statutory benefit rules.

Again the compensation is of three main types:

- *Income replacement benefits (either total or partial)*, which is normally contingent on an assessment of ability to return to usual employment or modified employment ('suitable duties')
- *Medical and care benefits*, usually paid on a 'reasonable and/or necessary' type basis

- *Non-economic loss (or 'permanent impairment', or 'pain and suffering')*, which has a similar meaning to that of the common law equivalent.

Statutory benefits of the first two types (income and medical) are usually payable periodically for as long as entitlement continues. The judgement of when this entitlement begins and ends, and to what extent, is usually made by a medical practitioner based on his or her own experience.

Statutory benefits for non-economic loss are usually paid in lump sum form, with entitlement based on the application of an *impairment guide* or table, of which there are several in use in Australia. There are two main types of such tables:

- *tables of entitlements for specified impairments or 'maims'* – usually in respect of the loss of (or loss of the use of) a body part. These have been developed by individual schemes; and
- *whole Person assessments of impairment*, most commonly using the guidelines of the American Medical Association (4th or 5th Edition).

Disputes over the assessment of entitlement to statutory benefits are heard by a variety of appeal mechanisms, ranging from a judicial process (not unlike the common law) to a binding expert medical panel.

The assessment process in respect of statutory benefits is far superior to that in common law jurisdictions, but still has four major problems:

- For income support benefits, the assessment of incapacity is arbitrary, subjective, and without a well-developed framework to consider the injured person, his or her functional potential, and the mechanical and attitudinal qualifiers required to return to employment
- For medical and care benefits, the process of referral and the assessment of need for ongoing treatment is also arbitrary in most schemes. There are only broad developments in recommended clinical pathways and evidence-based medicine
- For non-economic loss, the process in some schemes has been found to be unstable at a macro-level, for the same reasons as common law is. This problem appears to be assisted by use of the American Medical Association Guides, which place more discipline on the assessment process
- The continued use of 'impairment' as the basis for non-economic loss, however, causes problems for equity reasons. The great benefit of the common law is its desire to differentiate disability from impairment at an individual level (although I would argue it does this imperfectly).

Potential of the ICF in accident compensation

The underlying objective of accident compensation is to provide 'indemnity', i.e. to restore the injured person, as far as possible, to his or her pre-injury condition. In concept, one would imagine that the compensation process should be attempting to define and measure the outcome of the injury in terms of restrictions relative to the pre-injury state and to take steps to modify those restrictions.

However, the process of assessment and compensation described above is arbitrary, unstructured, litigious and focused on monetary compensation rather than facilitated recovery of function. This process has been shown to be unstable and to require constant review. It is also, arguably, detrimental and inequitable to individuals who have sustained an injury.

The ICF potentially provides a basis for clarifying and strengthening the framework for classification, assessment and modifications in the field of accident compensation, leading to a more robust and appropriate compensation system.

Classification

The dimension of body structures and functions provides a more appropriate starting point than the insurance concept of 'impairment' for describing the physical sequelae of an injury or disability.

Assessment

The dimension of activity provides a rigorous framework in which to develop metrics of the insurance concept of 'capacity' in the context of potential for achieving a more positive outcome. This is particularly the case when one combines it with the participation dimension, which can lead directly to the prognosis for future development, such as return to work or social independence.

Modification

The qualifiers to the participation dimension provide a direct parallel with the notion of 'suitable duties' or 'aids and appliances', which are part of the compensation language.

Limitations of ICF

The main limitation of the ICF in providing a framework for assessment and management in accident compensation is the work that will need to be done in moving beyond this framework. The ICF has been developed in a health and

disability paradigm, which historically has operated independently of accident compensation in Australia, and vice versa.

For progress to be made in this area, concerted efforts are needed on both sides. This requires a significant commitment by accident compensation authorities to acknowledge the potential of the ICF and its family of classifications. It also requires sponsors and advocates of the ICF to recognise the commercial realities of accident compensation and to assist in developing more targeted classification and assessment instruments.

The other challenge for the use of the ICF is the transition from a 'framework' to the development of assessment instruments suitable for use at an individual claimant level (e.g. for body structure and functions , activity, and participation). Such instruments will be necessary to improve resource allocation for accident compensation and other statutory entitlement systems.

10.5 The ICF and speech pathology

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Introduction

The Communication Disability in Ageing Research Unit (CDARU)¹¹ has been using the ICF and its predecessors in the education of speech pathologists and audiologists, in clinical practice with older people with hearing impairment and aphasia, and most predominantly as a research tool. The CDARU is based within the Department of Speech Pathology and Audiology at The University of Queensland and the directors are Dr Louise Hickson, an audiologist, and A/Prof Linda Worrall, a speech pathologist. The CDARU have used both the conceptual framework and the classification scheme, and both of these are now discussed under the headings of teaching, clinical applications and research uses.

Use of the ICF in teaching

The conceptual framework of the ICF is introduced to speech pathology and audiology students early in their first year. It is used to frame discussions about communication disability, particularly in relation to speech pathology and audiology assessments and treatments. The framework is used in more detail in a series of aphasia management lectures and in a module about ageing and aged care. A/Prof Linda Worrall and other staff from the CDARU coordinate these modules. They use the framework to provide a structure for lectures and an overview of clinical practice in this area, and students are also examined on the interpretation of the ICF for people with aphasia and other age-related disorders.

In audiology, the ICF is used extensively in teaching as a framework for rehabilitative audiology. The effects of hearing impairment on the lives of people with hearing impairment are described using the ICF terminology, and students are encouraged to consider rehabilitation options for clients in light of their impact on Body Functions and Structures, Activities and Participation. Details about the ICF are provided initially in didactic lectures, and students are subsequently required to apply the ICF in a series of modules about

11 CDARU's web site is at: <<http://www.shrs.uq.edu.au/cdaru>>

rehabilitation for complex cases, e.g. an older person living in an aged care facility, a person experiencing major negative psychosocial consequences of hearing impairment.

Use of the ICF in clinical practice

Staff in the CDARU run student clinics for groups of people with aphasia (and other acquired neurogenic communication disorders) at The University of Queensland, and the Geriatric Assessment and Rehabilitation Unit of the Royal Brisbane Hospital. In an effort to guide students (and many clients) to think more broadly than the impairment level, the Participating in Choice (PIC) approach was developed (Worrall & Davidson 2000). This approach was an extension to the Activity-based Functional Communication Therapy Planner (Worrall 1999). The PIC approach to clinical management begins with an unstructured interview with the client about his or her communication needs. The main question is 'What do you hope to achieve by coming to speech therapy?' The client's goals are then classified according to the ICF components. This process assists the student to choose an assessment and treatment approach that is not only relevant to the client, but also uses an approach suitable to the goal. For example, if developing further social relationships is a goal, then social model approaches may be the first choice for this type of goal rather than impairment-based approaches; that is, the client may be introduced to support organisations or group sessions before syntax retraining occurs.

In audiology rehabilitation practice, students are required to use an audiology tool that is similar to the PIC in many ways. With the Client Oriented Scale of Improvement (Dillon et al. 1997), the clinician works with the client to develop a set of prioritised goals for the rehabilitation process. Clients are asked what they would like to achieve and these goals become the focus of the intervention that follows. Outcomes of the rehabilitation process are assessed in relation to these goals. Client's goals should be as specific as possible (e.g. to understand the guest speaker at the social club meeting) and may relate to Body Structure and Functions, Activities and Participation.

Use of the ICF in research in communication disability

A number of publications of the CDARU team have used the ICF as a conceptual framework or have investigated the validity of the classification scheme. Two of the books that have been written (Worrall & Frattali 2000; Worrall & Hickson, in press) use the ICF framework to structure information and explain the use of the ICF to speech pathologists and audiologists.

Dr Louise Hickson and A/Prof Linda Worrall have also obtained a number of large research grants to evaluate interventions based on the ICF. Examples include a project funded by Blue Care to examine the effectiveness of the Participation Enablement Program (PEP) for older people in aged care facilities, and a current project funded by the National Health and Medical Research Council to examine the effects of the Active Communication Education (ACE) program for older hearing impaired clients. Outcomes are measured at each level of the ICF in both of these projects.

The ICF has also been widely used as a framework for postgraduate work. Dr Madeline Cruice used the ICIDH-2 in her doctoral studies to examine the relationship between communication disability at the Impairment, Activity Limitation and Participation restriction levels to overall quality of life. Bronwyn Davidson and Brigitte Larkins also used the ICF in their doctoral studies, which involved examining the everyday communicative activities of people with aphasia and people with a traumatic brain injury through participant observation. Patrick Stark's masters research project examined the impact of hearing aid fitting on both the person with hearing impairment and his or her significant other, using the ICF framework. Robyn McCooey used the ICF as a rationale for developing the Inpatient Functional Communication Interview as part of her Masters studies. The results of several students' participant observations of everyday communication activities in people with aphasia, traumatic brain injury and hospital in-patients were then used to examine the validity of the chapter on communication in the Activities and Participation component of the ICF (see Worrall et al. 2002).

Two other PhD students in the CDARU are using the ICF framework. Tami Howe is using the Environmental Factors hierarchy to examine communication accessibility for people with aphasia, and Nerina Donaldson is examining the issue of third-party disability in spouses of older people with hearing impairments. The team has also been collaborating with Dr Travis Threats who was the American Speech-Language Hearing Association's liaison for the revision of the ICIDH-2 but is now involved in developing the American clinical manual for the ICF.

Selected key publications of the CDARU involving the ICF or its predecessors are listed for further reference. A full list of all ICF-related publications is available from the authors.

Selected key publications:

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10.6 The ICF and Rett Syndrome

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Introduction

Rett syndrome is a relatively rare but serious brain disorder most often affecting girls. Generally, the early development of an infant with Rett syndrome appears normal. However, some time in the first 6 to 18 months of life, the normal pattern of childhood development does not continue (Kerr & Witt-Engerstrom 2001).

In most cases there is a loss of communication and hand skills with the subsequent development of unusual hand movements. In the long term, most children are no longer able to talk, and many find it difficult or are unable to walk. Other clinical features include poor head growth, epileptic fits, spinal curvature, abnormal breathing patterns, and gastrointestinal and sleeping problems. Rett syndrome is, therefore, usually associated with severe intellectual and physical disability, and girls with this condition commonly suffer from considerable health problems. Despite this, however, many parents remark that over time girls may appear to improve in their social awareness and communication skills.

Rett syndrome is a genetic disorder and has recently been shown to be associated with mutations in the methyl-CpG-binding protein 2 (*MeCP2*) (Amir et al. 1999). The *MECP2* gene is on the X chromosome. However, despite these recent genetic advances, there is still little information available about the natural history of the disorder, and we do not know which factors (in the girl, her family and her broader environment) are related to prognosis.

The principal aim of the Australian Rett syndrome research program, which began in 1993, was to define a population based cohort, that could be used for subsequent clinical and epidemiological studies and followed prospectively (Leonard et al. 1997). Baseline data on communication, mobility, symptoms and classification have been gathered since 1993 on individuals as they are enrolled in the cohort. In 2000, data were collected on functional ability in daily living, behaviour, hand function, medical conditions and use of health, therapy and education services (Colvin et al. 2003). In addition, parents used a calendar system to report the occurrence of medical, other health and therapy appointments for the duration of that year. Molecular testing for the presence

of *MECP2* mutations has also now been undertaken on more than 80% of cases, with mutations identified in approximately 70% of cases.

The research program has several aims:

- to assess the burden of Rett syndrome on the affected individual, their family and the community
- to determine which factors contribute most to this burden and which factors may alleviate this burden by determining:
 - how functional ability, behavioural score and medical/health burden at specific ages is influenced by a range of environmental and genetic factors
 - how the outcome for the family, in terms of quality of life, is influenced by the child's genetic characteristics, family functioning, support and resources.

Thus the components of the ICF –

- Body Functions and Structures
- Activities
- Participation
- and contextual factors (Personal and Environmental Factors)

provide a conceptual framework for investigating the broadest aspects of disability and functioning in Rett syndrome.

Body functions and structures

A number of body functions and structures studied in the Rett syndrome research program are relevant to the ICF:

- mental functions/nervous system
- sensory functions/eye, ear
- voice and speech functions
- functions of digestive, metabolic, and endocrine systems
- genitourinary/reproductive functions
- neuromusculoskeletal and movement-related functions
- functions of the skin and related structures.

The ICF framework provides the capacity to identify variation in body function and structure.

In our long-term follow-up studies, we specifically inquire in our parental questionnaire about medical conditions associated with Rett syndrome (e.g. scoliosis, digestive disorders, and epilepsy). During our 1-year intensive

calendar study, parents reported on their daughters' health on a daily basis, which allowed us to gain a window into the day-to-day life of a girl with Rett syndrome.

The assessment of intellectual function is particularly difficult to assess in Rett syndrome because of the apraxia and communication difficulties associated with this disorder. However, we have used the WeeFIM (as is described subsequently in the activities and participation sections) to obtain an estimate of cognitive functional ability (Leonard et al. 2001). Neurological functioning is of particular interest as two-thirds of girls with Rett syndrome suffer from epilepsy (Glaze et al. 1987). In our study, parents document the occurrence of epileptic seizures, which will allow us to categorise their seizure profile.

Visual and hearing function have not been specifically assessed in our research program as these are thought to be normal in Rett syndrome. However, autonomic functioning (in particular involving respiratory and cardiovascular systems) is of interest as it is thought that there is a neurologically mediated disturbance in these areas (Julu et al. 2001). Parents describe the nature of breathing disorders (e.g. hyperventilating) and patterns of occurrence. This has the potential to impact on their growth as it is thought that the 'work' of hyperventilation (or deep breathing) is associated with high levels of energy expenditure (Motil et al. 1994). In addition, clinical studies carried out by our colleagues at the Children's Hospital at Westmead (Sydney) will involve the use of the 'Autonomic Monitor' to specifically test this function.

The investigation of digestive system functioning is relevant to Rett syndrome because girls with this condition are commonly affected by gastro-oesophageal reflux disease and constipation as well as growth problems (Motil et al. 1999). Our questionnaires include detailed questions about feeding patterns including the quantity of meals and the time taken to feed. As well as assessing digestive system functioning, we also attempt to assess the way in which these functional problems can be overcome to optimise the subject's wellbeing as well as minimise the burden on families and carers. One example is the use of PEG (percutaneous endogastric tube) insertion to increase caloric intake, decrease feeding time and improve weight and overall health.

The presence of scoliosis, which may be treated by physiotherapy, bracing and/or surgery, is an example of abnormal body structure that affects up to half of girls with Rett syndrome (Stockland et al. 1993). We are currently undertaking a study to assess the impact of these treatments on the progression of scoliosis and on the functioning of girls and women with Rett syndrome. In addition, structural impairments affecting mobility can be overcome with the use of aids such as wheelchairs and walking frames. We

are attempting to quantify the use of these aids and identify any problems or restrictions to their access.

The structural and functional deficits associated with Rett syndrome often require hospitalisations for the purpose of managing acute medical conditions as well as operative procedures to correct problems. These hospitalisations result in a burden on the health system as well as the families who are caring for their children during the illnesses. We are attempting to quantify the impact that this population has on the health system, in terms of hospitalisations, medical visits and allied health services, by analysing data collected from the 'daily calendar' is completed by parents.

Finally, the genetic make-up of an individual can be considered to be part of body structure. As described above, our epidemiological study also includes the mutation status of each individual and the extent to which they have skewing of the X chromosome.

Activities

Our questionnaires include sections about the individual's activities in a number of domains relevant to the ICF:

- activities of learning and applying knowledge
- communication activities
- movement activities
- self-care activities
- domestic activities
- interpersonal activities
- performing tasks and major life activities.

The subject's ability to perform practical, day-to-day communication activities is assessed using the WeeFIM. This is a functional independence measure that we have used to measure independence in activities of daily living taking into account the help and assistance that may be required. Items include the extent of comprehension and ability to verbalise. We also have information about the subject's ability to communicate at all stages of her life, e.g. before she went through regression. Parents are asked to describe equipment used to aid communication.

Mobility is also formally assessed using the WeeFIM, which covers locomotion, toilet/bath and shower transfers and chair/wheelchair transfers. Ability to manipulate objects with the hands is an item of interest in our research because one of the hallmark features of this disorder is loss of functional hand use. We use the hand apraxia score to attribute a value to the

degree of functional hand use (Burd et al. 1990). Furthermore, the use of hand preference in Rett syndrome has also been studied in depth as a result of information collected from parents (Umansky et al. in press).

Activities of self-care are again assessed using the WeeFIM. Specific questions are devoted to bathing, dressing, grooming and toileting. Parents document their daughter's ability in this domain and, as well as scoring her on a predetermined scale, they include extra written information about how she carries out these activities. We include questions about puberty and menstruation in our long-term study to assess sexual development in this population, as this has implications for self-care and parental management. As already indicated, feeding and meal times are important elements of our research because of the practical implications to the child and family. Parents document the quantity of food provided, preparation procedures and mealtime routines. Information about specific equipment used with meals to facilitate feeding and oral functioning is also requested.

Girls and women with Rett syndrome are obviously unable to take an active role in traditional domestic activities such as shopping, meal preparation and housework. However, parents and carers may make an effort to include the girls and women where possible in these activities, e.g. by including them in shopping trips and having them in the kitchen during meal preparation so that they can feel part of the activity. We recognise the potential therapeutic benefit of these activities and parents are therefore able to document them in a section on day-to-day therapy.

In some cases, communication, movement and interpersonal activities have been assessed using a video protocol, whereby families and therapists record the subject performing, where possible, a number of structured tasks. These procedures are preferably conducted in a familiar setting, e.g. home or school to maximise functional ability.

Participation

Our questionnaires include sections about the child's or young adult's participation in a number of domains relevant to the ICF:

- personal maintenance (i.e. self-care)
- mobility
- exchange of information
- social relationships
- home life and assistance to others
- education
- community, social and civil life.

By the nature of their disability, girls and women with this condition are not usually able to participate in work, employment and economic life in the traditional manner.

The extent to which subjects can take part in their personal maintenance is assessed using the self-care domain in the WeeFIM. In addition, parents are able to give quantitative answers about their daughter's ability to care for herself. In general, a subject is usually limited in her ability to participate in personal maintenance but may be able to ease the burden on caregivers, e.g. by indicating when she is soiled. Participation in nutrition is usually limited because of the severity of the disorder, but parents are able to document choice making at meal times, e.g. through use of photographic cards or actual foods. Taking part in a range of therapy services (e.g. physiotherapy, occupational therapy, music therapy, hydrotherapy) can be considered to be participation in health. Using the calendar system, parents documented participation in health services over a period of 1 year during 2000. The extent to which subjects take part in therapy may be influenced by many factors. In our studies, we have found that therapy participation varies according to severity of disability, age and maternal education (Moore 2002).

Mobility is an important area of functioning in girls and women with Rett syndrome because it is often compromised, resulting in a decreased ability to participate in the community (Kerr & Witt-Engerstrom 2001). We have collected specific information about subjects' abilities to mobilise, whether they can do so independently, or by being supported or fully aided with equipment. Mobility is of central importance, and information has been sought about parent's attempts to modify the home environment and their vehicles for this purpose.

Participation in exchange of information can be difficult to assess. Again, the WeeFIM covers social involvement by quantifying the degree of assistance the girls and women require to express their needs and feelings. In addition, the use of communication devices in Rett syndrome is documented in the follow-up study. As well as objectively quantifying the degree of functionality in this domain, parents are able to describe the way in which their daughter communicates e.g. facial movements, gestures. This is closely related to the development of social relationships and ultimately to participation in community, social and civil life. The challenge is to find ways of communicating that will maximise the involvement of subjects and their families. The relationship between the girl/woman and her siblings is explored.

Participation in home life and assistance to others is obviously related to the degree of disability in Rett syndrome. Respondents indicate the accommodation-living situation in the questionnaire. Increasingly, young

women with Rett syndrome are gaining access to group homes and supported living with the assistance of government organisations. This is allowing these women to take on a role in a home environment with like-minded peers.

Participation in education by girls and women with Rett syndrome has undergone significant change during the past 10 years in keeping with shifts in philosophy and policy in special education. In our follow-up studies, parents have been documenting the educational setting as well as the amount of aide support for their daughters. Parents are asked to provide further information about their degree of satisfaction with their child's school arrangements. Furthermore, the participation in informal educational activities (e.g. in the home setting) is included.

Participation in community, social and civic life is an important element of life for children and women with Rett syndrome. Parents have documented participation in family events, religious events such as First Holy Communion, school events such as sports carnivals, and ethnic celebrations such as St Patrick's Day. Participation in recreation and leisure activities will also be specifically included in the upcoming parental questionnaire. This will include activities such as swimming, horseriding and attending cinemas.

Participation facilitation can be related to the extent to which therapy and education professionals are informed about Rett syndrome. Participation restriction is also likely to be related to a number of factors. These include the physical disability and immobility associated with Rett syndrome, which impede access to events/activities. In addition, participation in life situations can be somewhat impaired because of communicative disabilities associated with the disorder and parents' lack of resources for overcoming this aspect of the disability (i.e. communication devices). The attitudes of service providers are also important.

The Australian Rett syndrome research program is based on a biopsychosocial model which integrates aspects of both medical and social models of disability and functioning. The investigation of environmental factors such as equipment and support available to individuals and families and the social capital of the communities in which they live is likely to be integral to understanding the burden of this disorder. The program will use the ICF framework to identify those factors determined to be most beneficial and cost-effective in optimising health, function and quality of life for the affected child and her family.

10.7 Classification of support and need

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Supports Classification and Assessment of Needs Instrument

Work is currently under way on a project to develop a new system for classifying and assessing the support needs of people with disabilities. This is a collaborative project between The University of Sydney, the Royal Rehabilitation Centre Sydney (RRCS) and the Centre for Developmental Disability Studies (CDDS). It is a 3-year project (2002–04), with funding provided through a competitive Australian Research Council grant, with contributions from industry partners RRCS and CDDS.

Rationale

People with a disability (and their families and advocates) now expect to take part in ordinary everyday activities such as leaving home, moving house, joining and retiring from the workforce, developing relationships and raising a family. Providing support to enable people with a disability to live and work within the community is now an accepted part of Australian life. Varying types and intensities of support may be needed for some or all of these activities. In the face of a marked population increase of people with a disability (on average 14% annually or seven times the population growth over the past 5 years) a scientifically sound valid, and reliable needs assessment and support planning system is urgently needed.

All jurisdictions in Australia are grappling with the need to provide rational allocation of limited resources based on support needs, in an era of growing demand for services. Moreover, there is ample evidence in Australian and international literature that a better system is required for assessing the support needs of people with a wide range of disabilities and to translate

those needs into responsive and individualised service delivery (e.g. Schalock 1999). Providing such services with the available resources is a significant government challenge. Already 42% of people needing support are receiving some form of assistance from formal service agencies (ABS 1999). Existing demand (at least 58% of those needing support on 1998 figures) and growing demand (estimated at around 3% per year with the ageing of the population) indicates that a more effective and empirically sound system is required to ensure the resources available reach those most in need in the Australian population.

The support needs classification and assessment system

The project is developing an innovative, rigorous and robust system of identifying and classifying support needs based on the conceptual framework of the ICF (WHO 2001). In line with this framework, the project conceptualises disability as a dynamic state typically incurring restricted function due to:

- the interaction of the person (their health condition including impairment)
- the activities they desire to do (and any difficulties in carrying these out)
- environmental and personal factors (restrictions on participating in the community, e.g. physical access, discriminatory attitudes, particular background of an individual's life and living).

Hence, an individual's functioning in everyday life is the result of a complex relationship between these three components.

The aim of this new system for support needs assessment and classification is to reliably identify the type and intensities of support needed, taking into account the complex interactions that characterise disability (WHO 2001). A valid system will overcome the limitations of existing instruments that either overestimate (lack of sensitivity) or underestimate (lack of specificity) the support needs of people with a wide range of disabilities in varying situations.

The system comprises:

- procedures to involve the person with a disability and those most familiar with the person in identifying and assessing needs
- reliable methods of observing and assessing support needs in situ
- valid measures to identify support needs in a range of life activities, and which take into account the interactive effects of health condition (and impairment), desired activity and context (including environmental and personal factors).

The system is unique in that the person with a disability and people relevant to that person (i.e. the person themselves, parent/s or carer/s, advocate, and key service providers) complete the assessment together in the person's living

environment. They are able to consider the person's hopes, dreams, likes and dislikes, as well as the difficulties and barriers he or she experiences in attempting to fulfil personal goals. This contrasts with the current situation where assessment is typically done 'to' or 'on behalf of' people with disabilities by (well-meaning) professionals often in unfamiliar settings (consulting room or institutional environment) without the benefit of information from those closest to the person with a disability.

A trained facilitator guides the assessment meeting(s) to identify personal goals and activities (such as where and how the person wishes to live, work and spend their time) and what is required to achieve these in the most effective and practical way. The facilitator's role is to encourage differing views to be openly debated in order to develop an action plan that is responsive to the individual's preferences, and that is constructive, achievable, and acceptable to all. This assessment process may last up to 2 hours or require an additional meeting to achieve an agreed record of the individual's personal goals and the type and amount of support required to achieve these on a daily basis in activities and participation domains such as self-care, domestic life, mobility and transport, communication, interpersonal interactions and relationships, health management, emotional and behavioural management and home and community living.

Application of the concept of support has been further guided by the conceptual model of support in the Mental Retardation Definition, Classification and Systems of Support, 9th and 10th editions (AAMR 1992, 2002). This support outcomes model directly links support resources (including the person with a disability and others, technology and services) with the functions of support (e.g. receiving assistance with finances or work, or with home living activities, friendship, instruction) and, the intensities of the support required. Intensities of support considers time duration, time frequency and intrusiveness measures, and allows assessment of whether support is only required occasionally (intermittent); is time- or occasion-specific (limited); is needed over an extended period (extensive); or is of a frequent, intensive and possibly life-sustaining nature (pervasive). This model is based on a 'best fit' assumption; that is, a match between the supports needed and the type and intensity of the support provided results in desired outcomes such as achieving personal goals in key life activities, increased personal satisfaction and enhanced quality of life. A multi-dimensional scoring system is used for key activity and participation domains, with the level of intensity of support needs identified using the categories intermittent, limited, extensive and pervasive.

The system has been trialled extensively for people with an intellectual disability in residential environments. Currently, work is being undertaken to

trial the system among individuals from a range of disability types and across diverse environments.

Expected outcomes

The proposed project will demonstrate:

- the multidimensional and dynamic nature of the support needs of people with disabilities
- the reliability and validity of the proposed support needs assessment and classification system across a wide range of disabilities
- the training and protocols required to ensure proposed system is reliably implemented in diverse settings
- ways that the proposed system can be directly linked with service planning and resource allocation.

10.8 The Handicap Assessment and Resource Tool (HART) and the ICF

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Background

The Handicap Assessment and Resource Tool (HART) was developed in the early 1990s, at a time when the ICIDH was in use. The HART aims to assess 'personal care handicap'. In the ICF, the concept 'participation restriction' replaces 'handicap'. The HART measures just one small part of overall health status – the personal care element of participation (Figure 10.2). This part is critical to decision making about admission or discharge from hospital. It can also help to judge the effectiveness and, hence, the efficiency of various in-patient and community-based rehabilitation programs.

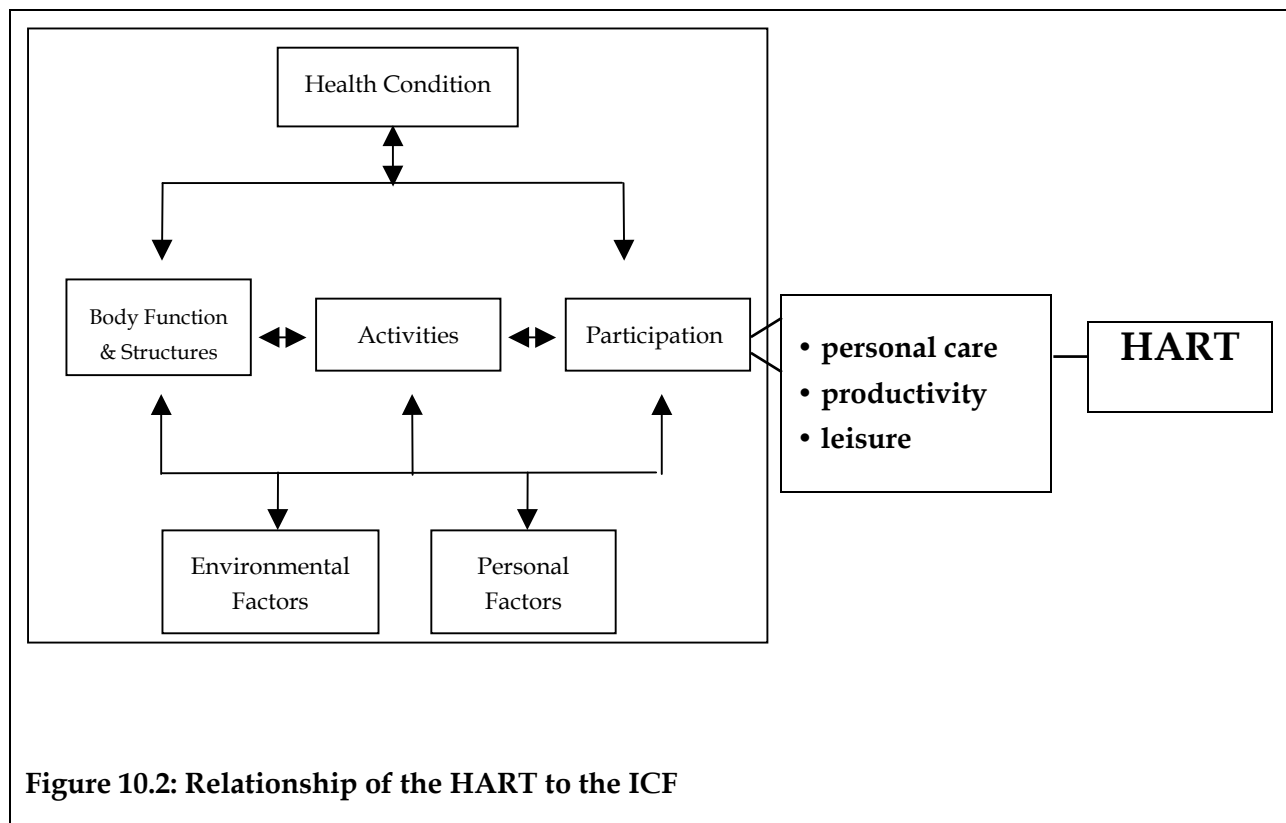


Figure 10.2: Relationship of the HART to the ICF

Rationale

The list of items that could be included from the ICF to reflect participation in life in general is large, as it includes items that relate to personal care, to productivity and to leisure. The HART selects from the very large set of possibilities by measuring just one aspect of participation or participation restriction – personal care. Personal care is defined by the HART as including the following ‘domains’: clothing, hygiene, nutrition, mobility, safety, residence, supports.

Purpose

The purpose of the HART is to establish which areas pose problems for people regarding their personal care, despite their own efforts and those of their usual supports. The HART does not primarily seek to establish what people can do alone. The HART captures what people can do or get done for them in their ‘usual environment’ with the ‘usually available help’ regarding aspects of existence that are vital for survival.

The HART is a practical tool designed to be used by clinicians as part of their usual practice. It provides a time-efficient means of comprehensively assessing participation restriction in personal care in a way that assures the quality of such assessments. It also provides a means of recording and summarising clinical observations. This enables information to be transferred for clinical purposes and for health-service management.

The assessment of functional status to identify areas of need is central in planning the management of people’s difficulties. In community settings, functional assessment could identify people’s unmet needs in the area of personal care (‘participation restrictions’) so that these could be attended to. In hospital settings, the HART could aid the discharge planning process by providing a comprehensive assessment of patients’ functions given the support systems available to them and taking into account their physical domiciliary environment.

Consider, for example, people who have had a stroke and cannot prepare their meals alone. In this case, they could not be discharged from hospital to live alone. However, if someone is always willing and able to provide their meals, then they have no problem with this aspect of personal care. If they have no other participation restrictions in personal care, as defined by the HART, they could be discharged from hospital to the assessed settings. For the purposes of determining whether they can live in the assessed environments, it does not matter that they cannot prepare their meals alone. The HART helps to obtain and collate the information required to make such decisions. The HART also provides a means of conveniently recording the aspects of personal care for

which help is required. Changes in the identified aspects of care that occur as part of the natural recovery process or as a result of rehabilitation can be used to demonstrate improvement; conversely, increased assistance is evidence of deterioration. This can be used to demonstrate the effectiveness of health-care services.

Clinical use of the HART

Clinicians can use the HART to determine and summarise their patients' participation restrictions in personal care (Figure 10.2). Unresolved participation restrictions are made explicit, which helps goal setting for management. In complex cases, the structured assessment ensures that no critical components are forgotten and that quality assurance is maintained in health care processes. The HART also provides a convenient way of communicating patients' personal care restrictions.

There are many questions the HART may help clinicians and managers to explore:

- How many participation restrictions in personal care do patients initially have?
- What types of participation restrictions in personal care are present?
- In the service provided, what are the patterns of change in activity limitations and in participation restrictions in personal care?
- What factors delay change in these activity limitations and in personal-care participation restrictions, and which of these barriers could be readily altered?
- For individual patients, does the participation restriction in personal care justify (continued) in-patient care?

Change in participation restrictions in personal care during episodes of health care can reflect the effectiveness of interventions. Once effectiveness is known, efficiency can be judged. Judgements of effectiveness and efficiency are critical components of quality improvement processes for clinicians and health-service managers. The use of the HART ensures information about participation restrictions in personal care is gathered in a standardised fashion, thus allowing comparisons between different services and practices. This can help in evaluating programs and identifying barriers to optimal practice.

10.9 The ICF and oral health

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Introduction: functioning, disability and oral health

Oral diseases have a substantial impact on the wellbeing of individuals and populations because of several special features of the structure and function of the mouth. From an early age, the mouth and face have powerful influences on psychological wellbeing and social interactions. Craniofacial conditions such as facial clefts, although rare, have profound psychological and sociological significance for children and families. The ability of dental decay to cause excruciating pain has been recognised since antiquity, and toothache continues to be a highly prevalent and disabling condition, even in an era of modern dental care. Although conditions such as dental decay, gum disease, dry mouth and tooth loss have much more subtle impacts on wellbeing, they are highly prevalent and hence contribute to a substantial burden of oral disease within the Australian population. In 1996, dental caries, complete tooth loss and periodontal disease featured among the five most prevalent conditions in the Australian population (AIHW 2002c).

For many individuals, the impact of oral conditions on wellbeing is a private experience, endured from day to day. Yet this 'silent suffering' creates a substantial impact on the population. For example, in her introduction to the US Surgeon General's Report on Oral Health, Donna E. Shalala, (then) Secretary of Health and Human Services declared, '...oral health problems can lead to needless pain and suffering, causing devastating complications to an individual's wellbeing, with financial and social costs that significantly diminish quality of life and burden American society' (US Department of Health and Human Services 2000). Documentation of the population burden of oral disease has become possible only in the last decade, as dentistry has developed research methods to assess more comprehensively the nature and consequences of oral disease. Much of the research has been stimulated by the WHO's development, first, of the ICIDH (WHO 1980) and, more recently, the ICF (WHO 2001)

The purpose of this section is to review the conceptual and methodological approaches to measuring oral health within the evolving frameworks of the ICIDH and ICF. Recent findings are presented from national surveys

conducted among the Australian and UK populations. The section concludes with recommendations for assessment of oral health using the ICF framework.

Measures of oral health using ICIDH and ICF frameworks

Since the early twentieth century, dental researchers have made detailed epidemiological assessments of oral health using a predominantly clinical focus on disease and tissue destruction. For example, Dean and colleagues in the United States Public Health Service developed the DMF index in their groundbreaking studies of the relationship between dental decay and levels of fluoride in drinking water (Dean et al. 1942). The DMF index, a measure of a person's history of dental decay, is recorded by a trained dental clinician who examines the teeth of study subjects for clinical signs of decay (D), previous treatment of decay by a filling (F) or previous extraction due to decay, leaving a missing (M) tooth. There are comparable clinical indices that measure gingival inflammation, periodontal tissue destruction, dental trauma, occlusal (orthodontic) irregularities, and temporomandibular disorders.

By the 1970s, in response to broader concerns that many clinical indices of general health status were not responsive to population measures of health service provision, Cohen & Jago (1976) advocated the development of 'sociodental' indicators to capture non-clinical aspects of oral disease. They argued that sociodental indicators were necessary to broaden the narrow focus that had emerged within oral epidemiology, which emphasised only the clinical parameters of disease, and therefore failed to document the full impact of oral disorders within populations.

The ICIDH (WHO 1980) provided the impetus for a revolution in the conceptual basis and empirical methods for evaluating oral health. In his application of the ICIDH framework to oral health, Locker (1988) proposed a framework for measuring oral health that extended beyond the confines of clinical indices of disease activity and tissue destruction embodied in the DMF index. Importantly, Locker's model also expanded the scope of ICIDH to include certain feeling states (e.g. pain and psychological discomfort) which are prominent consequences of oral disease. Locker also elucidated subcategories of the ICIDH definition of disability, describing concepts of physical disability, psychological disability and social disability. It is an intriguing footnote to history to observe that some of those same concepts have now been embodied in the ICF definitions of Activities and Participation and that pain (previously excluded from ICIDH) has now been classified as a Body Function within the ICF. Specific references to the oral cavity within the current ICF classification (WHO 2001) occur for seven body functions (b28010, b5100–b5105) and five Body Structures (s3200–s3204). The mouth and face are

involved directly in six forms of Activities and Participation (d330, d5201, d550, d560, d5701, and d7105).

These theoretical developments were matched by a surge in methodological work by researchers around the world who developed instruments to measure oral health and its consequences. Researchers from different countries used various phrases to describe the underlying concepts being measured, including 'social impact of oral disease', 'subjective oral health status', 'oral health related quality of life' or simply 'oral health'. However all of the questionnaires captured, to varying degrees, concepts described in the ICIDH (WHO 1980), Locker's refinement of the ICIDH for oral health (Locker 1988) and, as it turns out, the ICF (WHO 2001). By 1996, when the first international conference for methodological research in this area was held, no fewer than eleven standardised questionnaires had been developed and undergone testing for reliability and validity (Slade 1997a). In a subsequent international conference, new measures of oral health were described that were targeted towards young children and specific clinical conditions such as dry mouth and oral cancer (Inglehart & Bagramian 2002).

While it is beyond the scope of this section to review all of the measures described above, Table 10.6 summarises the features of questionnaires that assess multiple dimensions of oral health described in ICIDH/ICF frameworks and which have been used in clinical research or population studies. Questionnaires range in length, from 3 to 56 items and consequently they vary in the scope of dimensions measured. Although not shown in Table 10.4, most of the questionnaires inquire about the negative consequences of poor oral health, and hence are consistent with the orientation of the ICIDH. However, the Dental Impact Profile (Strauss & Hunt 1993) and UK Oral Health Related Quality of Life questionnaire (McGrath & Bedi 2001) ask about positive and negative consequences of oral status, as embodied in the ICF.

Examples of results from studies that have measured oral health within an ICIDH/ICF framework

In a review of 14 cross-sectional studies of adults, Slade (2002) reported that the following factors consistently have been associated with poorer subjective oral health status: fewer teeth, more diseased teeth, more extensive periodontal disease, other untreated dental conditions, unmet treatment needs, a pattern of episodic/emergency dental visits to treat dental problems, and lower socioeconomic status. In the US, non-whites generally report poorer oral health compared with whites. Slade (2002) also reviewed five clinical studies in which improvements in subjective oral health were found following general dental treatment, replacement of missing teeth, treatment of

temporomandibular (jaw joint) disorders, and surgical treatment for oral cancer.

One of the most comprehensive measures of oral health status, the 49-item Oral Health Impact Profile (OHIP), was developed in Australia (Slade & Spencer 1994a). A shorter, 14-item version OHIP-14 questionnaire has also been developed (Slade 1997b). OHIP questionnaires have been used to assess oral health in 25 studies, ranging from international comparative population surveys through to randomised clinical trials. For example, in a study of community-dwelling South Australians aged 60+ years, 6.6% of those who had one or more teeth reported that they had experienced discomfort while eating because of problems with their teeth, mouth or dentures (Slade & Spencer 1994b). Other impacts reported by at least 10% of people with teeth included difficulty chewing and avoidance of foods; under 5% reported adverse impacts of oral health on social roles and interpersonal relationships. However, people with no remaining natural teeth were approximately twice as likely to report these impacts. In a 2 year follow-up of people who had one or more teeth, Slade (1998) found deterioration in reported oral health status among three hypothesised high risk groups: people who experienced tooth loss during the two-year period; people who usually visited the dentist because they had problems; and people who reported financial hardship in obtaining dental care.

A comparison of OHIP responses among older adults in South Australia, Ontario (Canada) and North Carolina (US), found that tooth loss was consistently associated with high OHIP scores, indicating more frequent adverse impacts on oral health (Slade et al. 1996). Interestingly, there were larger differences in OHIP scores between whites and African-Americans within the US sample than between the three countries, and while those differences diminished in multivariate analyses that controlled for clinical measures and dental visits, African-Americans continued to have the highest levels of impact. This finding lends support to the ICF framework by suggesting that socioenvironmental factors (e.g. social and cultural influences) influence oral health and its social impact. Furthermore, the results indicate the effects of social and cultural diversity may be greater between race groups in North Carolina than between the other countries studied. Consequently, these results lend support to the expanded conceptual model of ICF, in which socioenvironmental factors (i.e. people's living circumstances) interact with the personal dimensions of functioning and disability.

Other researchers have used the OHIP to compare subjective oral health status and generic health status, with the results suggesting that oral health is perceived as a distinct dimension within general health. For example, in a

study of adolescents in New Jersey, Broder et al. (2000) found only weak to moderate correlations between OHIP scores and the SF-36, a widely used measure of subjective health status. Importantly, the SF-36 was not associated with clinical oral status, whereas the OHIP was. Nonetheless, the OHIP was not intended to serve as a screening tool for identification of dental treatment needs, and a study of Canadian adults found that it had poor sensitivity and specificity in predicting the need for dental restorations, periodontal (gum) treatment and dentures (Locker & Jokovic 1996). In two clinical trials comparing treatment for complete tooth loss using the OHIP questionnaire, patients receiving implant-retained dentures had significantly greater improvements in subjective oral health status than patients receiving conventional dentures (Allen et al. 2001; Awad et al. 2000).

Recent findings from national surveys of oral health using the OHIP

The short version OHIP-14 questionnaire has been used in two recent surveys of samples representative of the adult populations in Australia and the UK. This permitted for the first time, a comparison of subjective oral health status between representative populations using a standardised, multiple-item instrument. The prevalence of adverse impacts among dentate adults was markedly similar in the two populations, with 18.2% of the Australian sample and 15.9% of the UK sample experiencing one or more items 'fairly often' or 'very often' during the preceding year. In fact, regional variation in prevalence within the samples was greater than that between the two populations. Conspicuous in the Australian sample was the significantly greater impact reported by people with no natural teeth remaining (23.9%). Although the prevalence of impacts varied only marginally between populations, dentate Australians reported a significantly greater mean number of impacts and perceived greater severity of impacts than their UK counterparts as measured by the sum of affirmative responses to items. The higher impact response of Australians was not distributed equally across all items, but rather was centred on two specific dimensions categorised as pain (aching, pain on eating) and physical disability (diet unsatisfactory, interrupted meals). The former is classified as a domain of the Body Function component within ICF, and the latter is consistent with the Activities/Participation and Body Function components of the framework.

Tooth loss was associated with subjective oral health deficits in both populations and was independent from the effect of age. However, the relationship between tooth loss and impact was neither monotonic nor consistent between populations. In the Australian sample, retention of 25 or more teeth was associated with significantly less impact, whereas in the UK a decreasing gradient in impact was observed with increasing levels of tooth

retention past a threshold of 16 teeth (Figure 10.3). The effect of social and cultural determinants on outcomes was apparent when the Australian sample was categorised according to country of birth (Australia, UK/Ireland, other). Investigation of age and tooth loss associations with OHIP scores for immigrants born in the UK and Ireland revealed almost identical patterns to those observed in the resident UK population. Despite substantial progress in the field of health inequalities, the reasons for such cultural differences and the role of social factors in their development remain to be clarified.

Recently, data from the UK survey were used to evaluate the potential causal pathway among dimensions of oral health defined in Locker's theoretical model (Locker 1988), on which the OHIP was based. Consistent with the ICIDH, Locker's model proposed a series of links connecting dimensions of oral health in a hierarchy, beginning with impairment, and progressing to more debilitating impacts of functional limitation, discomfort and pain, through to disability, and ultimately to handicap. Examination of the combination of survey responses generally supported Locker's model with the majority of response patterns conforming to the theoretical hierarchy. This was not the case however for 10.3% of adults. In almost all of these cases, responses included pain and discomfort *in addition to* functional limitation, indicating a pathway that was not delineated in Locker's model. Accordingly, pathways were revised to omit combinations of dimensions that were not prominent in both the Australian and UK population, and incorporate those reported combinations that were unspecified in Locker's hierarchy. The latter comprised Impairment with Disability, Functional Limitation with Pain or Discomfort, and Pain or Discomfort with Handicap. The modified model highlights the pivotal role of pain in escalating the impact of oral conditions to more debilitating levels. While Functional Limitation alone was not causally linked to Disability or Handicap, in the presence of pain or discomfort, lower grade impacts could advance to these more serious threats to wellbeing.

This finding has implications for tertiary prevention interventions that target symptomatic conditions to avert disability or handicap. For example, if these same patterns of subjective oral health observed in national cross-sectional studies could be confirmed to have causal associations, it would suggest that many aspects of diminished oral function are self-limiting in the absence of pain. Furthermore, as a 'case study' of the WHO theoretical framework of health, these results from oral health imply that pain may play a central role in mediating transitions among subcategories of the ICF domains of Activities and Participation.

Conclusions

In the last decade, significant progress has been made in measuring oral health within an ICIDH/ICF framework.

- The OHIP is one of the few measures of oral health that incorporates the social dimension of health thoroughly. Historically it has used the ICIDH conceptual structure and remains well aligned to the new concepts of the ICF.
- The OHIP-14 has been used effectively to measure adverse impacts of oral health on wellbeing in national population surveys.
- The population distribution of conceptual dimensions within the OHIP suggests that oral pain plays a central role in mediating transitions among subcategories of the ICF domains of Activities and Participation.
- New work is under way to develop measures suitable for children and other population subgroups
- While some other questionnaires of subjective oral health have captured positive dimensions, they have not been adopted so widely, and methodological problems in measuring both positive and negative consequences using those questionnaires need to be resolved.
- Additional work is needed to move beyond classification and quantification in population health surveys to evaluate interventions that may improve health outcomes captured in an ICF framework.

Table 10.6: Questionnaires measuring subjective oral health status

Questionnaire (authors)	Dimensions measured	No. of questions
Sociodental Scale (Cushing et al. 1986)	Chewing, talking, smiling, laughing, pain, appearance	14
RAND Dental Health Index (Dolan et al. 1991)	Pain, worry, conversation	3
General Oral Health Assessment Index (Atchison & Dolan 1990)	Chewing, eating, social contacts, appearance, pain, worry, self-consciousness	12
Dental Impact Profile (Strauss & Hunt 1993)	Appearance, eating, speech, confidence, happiness, social life, relationships	25
Oral Health Impact Profile (Slade & Spencer 1994a)	Function, pain, physical disability, psychological disability, social disability, handicap*	49
Subjective Oral Health Status Indicators (Locker & Miller 1994)	Chewing, speaking, symptoms, eating, communication, social relations	42
Oral Health Quality of Life Inventory (Cornell et al. 1997)	Oral health, nutrition, self-rated oral health, overall quality of life	56
Dental Impact on Daily Living (Leao & Sheiham 1996)	Comfort, appearance, pain, daily activities, eating	36
Oral Health-Related Quality of Life (Kressin et al. 1996)	Daily activities, social activities, conversation	3
Oral Impacts on Daily Performances (Adulyanon et al. 1996)	Performance in eating, speaking, oral hygiene sleeping, appearance, emotion	9
UK Oral Health Related Quality of Life questionnaire OHQoL-UK(W)© (McGrath & Bedi 2001)	Eating, appearance, speech, breath odour, social life, romantic relationships, confidence, sleep, mood	16

Note: Slade and Spencer defined 'handicap' based on the framework described for ICIDH (WHO 1980). With the publication of the ICF framework (WHO 2001), the terms 'Activities and Participation' replace the formerly used terms 'impairment', 'disability' and 'handicap'.

