



**WORLD HEALTH ORGANIZATION**

WHO/HFS/CAS/C/03.22.1

Distr.: LIMITED

ENGLISH ONLY

**MEETING OF WHO COLLABORATING CENTRES  
FOR THE FAMILY OF INTERNATIONAL CLASSIFICATIONS**

Cologne, Germany

19-25 October 2003

**Title:** Annual report of the WHO-FIC Implementation Committee: ICF actions and draft workplan

**Authors:** Marijke W. de Kleijn – de Vrankrijker, co-chair

**Purpose:** for information in plenary and for discussion in committee breakout sessions

**Recommendations:** to discuss the draft workplan in the implementation committee meeting and to agree on a workplan for the near future

**This document is not issued to the general public, and all rights are reserved by the World Health Organization (WHO). The document may not be reviewed, abstracted, quoted, reproduced or translated, in part or in whole, without the prior written permission of WHO. No part of this document may be stored in a retrieval system or transmitted in any form or by any means - electronic, mechanical or other - without the prior written permission of WHO.**

**The views expressed in documents by named authors are solely the responsibility of those authors.**

## **Introduction**

This report relates to the actions of the WHO-FIC Implementation Committee concerning the ICF and to the draft workplan as a result of an informal meeting in St. Louis back-to-back to the NACC meeting June 19-20, 2003 in St Louis (USA).

## **Actions**

All Centres have been invited in advance of the St. Louis meeting to prepare a short report about ICF implementation activities in their country/region according to a list of issues (see annex 1) and to be prepared for a discussion about what should be done at the international level including priority setting for ICF implementation.

The face-to-face meeting was attended by representatives of the Australian, Dutch, French, North American (Canada and USA) and UK Centre and the WHO Regional Office for the Eastern Mediterranean. A one hour conference call was also attended by representatives of the Australian, German, Nordic and UK Centre and WHO Geneva. The meeting was chaired by Marijke de Kleijn (Dutch centre). The NACC centre was so kind to invite Patricia Welch-Saleeby to act as rapporteur.

The meeting agenda included three major items:

- 1 Presentations of short reports by centres about ICF implementation in their country/region, see annex 2;
- 2 discussion on ICF implementation issues to be addressed at the international level;
- 3 priority setting for ICF implementation issues at international level.

## **Draft list of priorities**

An informal draft report has been circulated among the participants. Because of the comments received we do not distribute the full report to the HOC meeting but it will just serve as an informal report for those who participated in the St. Louis meeting.

The draft list of priorities for international ICF implementation work is the main result of our 1 ½ days of discussions in St Louis. The list will serve as a base for discussions on the workplan for ICF in the WHO-FIC Implementation Committee. We will discuss the items for endorsement of centres and their willingness to participate in the work. It is intended to present after the committee discussions to the plenary meeting the final ICF implementation workplan for the near future.

## Draft Priorities for International Work

What	Immediate Action	Who	Endorsement of actions that are presented (Yes/No)	Which of these activities would your CC participate?
<p>1. Develop a method for collecting information on usage and implementation of ICF including a roster of experts relating to...</p> <p>Implementation strategy Translation and dissemination Coding A/P Qualifiers Training Surveys Clinical and administrative records Mapping Use of ICD and ICF</p>	Present draft plan in Cologne after email discussion with the group	WHO		
<p>2. Develop a plan for maintenance and updating that is consistent across WHO-FIC members</p>	Promised paper to be presented in Cologne including elements mentioned in our report	WHO		
<p>3. Define WHO-FIC in a box and a work plan for developing specific elements including best practices concerning...</p> <p>Implementation strategy Translation and dissemination Coding A/P Qualifiers Training Surveys Clinical and administrative records Mapping Use of ICD and ICF</p>	Agenda item for WHO-FIC implementation committee meeting in Cologne	WHO-FIC Implementation Committee		
<p>4. Examine the work plans of other WHO-FIC committees and how ICF work fits in</p>	To be introduced in the discussion in the Centre Heads or Planning Committee meetings about the WHO-FIC committee structure in Cologne	WHO-FIC Implementation Committee		
<p>5. Identify strategic forces and</p>	Paper prepared by	WHO-FIC		

opportunities at the national and international level that will drive implementation of ICF	Diane Caulfeild on process to stimulate discussion in the implementation meeting in Cologne	Implementation Committee		
6. Achieve international consensus on coding guidelines and standards including further definition of generic qualifier [begin with list identified in Brisbane]	Update Brisbane paper  Identify in Cologne who will contribute to this working group and define their tasks	WHO  Working group within the implementation committee		
7. Develop an overall training strategy for ICF addressing different types of users, including clinical coders and clinicians, etc. and at different levels, and train the trainers program for international use, including tools	Chair of the Training Committee will revise terms of reference in order to include ICF work and development of a strategic plan	WHO Sub-group on Training and Credentialing		
8. Explore relationships between clinical vocabularies and ICF and the possibility of developing standard maps	Jane Millar takes the lead on the paper to be presented in Cologne on SNOMED-CT and ICF	WHO-FIC Implementation Committee/Vocab Group		
9. Follow work on Subjective Dimension	The committee would like to stay informed about activities in this area (e.g. Australia, Japan) and therefore Marijke de Kleijn will contact Satoshi Ueda for status report in Cologne	WHO-FIC Implementation Committee		
10. Follow work concerning Derived and Related classifications (e.g. ISO9999, Children's Version, and ICECI).	Marjorie Greenberg will contact Rune Simeonsson to present results including examples and coding issues in Cologne regarding the Children's Version  Marijke de Kleijn will address ISO9999 and ICECI admission to the WHO-FIC in Cologne	WHO-FIC Implementation Committee		
11. Explore inclusion of ICF in	Jane Millar	WHO-FIC		

HL7 RIM as an agreed vocabulary	coordinating with Marjorie Greenberg and will report to the implementation committee after the September 2003 HL7 meeting	Implementation Committee		
---------------------------------	---	--------------------------	--	--

## Draft workplan

The table might be not clear enough, and for this reason we add some explanations for each item.

Suggested actions and ways forward, for inclusion in the international ICF implementation work program:

**Item 1:** Develop a method for collecting information on usage and implementation of ICF including a roster of experts relating to... (etc.)

- Develop a definition of implementation
- Develop a checklist of categories of implementation (e.g. use of ICF in surveys; clinical applications of ICF)
- These categories could be used to structure information on implementation presented on each Collaborating Center's web site
- Action: ask WHO to prepare a draft plan for discussion in Cologne, after further email discussion among members of this group

**Item 2:** Develop a plan for maintenance and updating that is consistent across WHO-FIC members

- Need for an agreed plan, to ensure that there is a consistent way of collecting information, comments and proposals relating to update/revision (although no action on maintenance and updating is anticipated in the near future)
- Develop a proposal seeking adequate WHO support for ICF maintenance and updating activities
- Action: ask WHO to produce a paper for Cologne outlining WHO's view of how maintenance and updating of ICF should be handled; the paper should take into account points made during discussions at this meeting (e.g. need for an approach that accommodates language differences; need for transparency of processes)

**Item 3:** Define WHO-FIC in a box and a work plan for developing specific elements including best practices concerning...(etc.)

- Make a list of what materials could be included be in the ICF part of the 'box'
- Make suggestions on what general WHO FIC information should be included in the WHO FIC box
- Action: further discussion by implementation committee at Cologne

**Item 4:** Examine the work plans of other WHO-FIC committees and how ICF work fits in

- This should be a topic for discussion in Cologne-how ICF fits into the terms of reference of each committee
- There is concern about ICF work being fragmented across different committees, as this creates resourcing problems for Collaborating Centres

- Action: await clarification of committee structure by WHO; make suggestion in Cologne that regular conference calls among committee chairs may be useful to better coordinate different strands of work

**Item 5:** Identify strategic forces and opportunities at the national and international level that will drive implementation of ICF

- This should be the subject of a brainstorming session in Cologne-SWOT analysis may be useful (i.e. identifying strengths, weaknesses, opportunities and threats)
- Action: Diane Caulfield to prepare a short paper to serve as a discussion starter

**Item 6:** Achieve international consensus on coding guidelines and standards including further definition of generic qualifier

- Request an update of the Brisbane paper on coding guidelines from WHO
- Form a working group to progress and draw together empirical work that is occurring at country level
- The working group should pay special attention to defining/calibrating the qualifiers
- Action: recruit members for working group in Cologne

**Item 7:** Develop an overall training strategy for ICF addressing

- Draw together an inventory of materials used for awareness raising and training (slides, user guides, etc)
- Examine the nature of training needs-who needs it and at what level
- NACC offered to lead this work; it will go forward under the auspices of the training committee, but with close contact with the ICF implementation committee
- Action: Marjorie Greenberg to revise terms of reference of training and credentialing committee to include more on ICF; ICF training to be on the agenda in Cologne

**Item 8:** Explore relationships between clinical vocabularies and ICF and the possibility of developing standard maps

- Action: Jane Millar (with input from Australia) to prepare a paper for Cologne on looking at the relationship between SNOMED CT and ICF

**Item 9:** Follow work on Subjective Dimension

- Stay informed about work going on in different countries
- Action: Marijke de Kleijn to ask Satoshi Ueda to provide a status report for Cologne on Japanese work

**Item 10:** Follow work concerning Derived and Related classifications (e.g. ISO9999, Children's Version, and ICECI).

- Stay informed about work going on, including ICF for children, mapping between ICF and ICPC, ICF and ISO 9999
- Action: Marijke de Kleijn to ask Rune Simeonsson for draft of ICF children's version, or a paper for Cologne on how the field trials are progressing

**Item 11:** Explore inclusion of ICF in HL7 RIM as an agreed vocabulary

- Action: Jane Millar to take this forward at upcoming meeting

## Annexes

1 ICF implementation issues for report and discussion in St. Louis

- 2 ICF implementation reports from Centres (Australian, Dutch, French, NACC, UK, EMRO, Italian)



## **Annex 1**

### **ICF implementation issues for report and discussion in St. Louis**

ICF implementation issues (derived from Bethesda/Brisbane discussions and the strategy and work plan)

- A implementation strategy including raising awareness
- B translation, dissemination and networking
- C coding guidelines including Activity/Participation delineation and validation of qualifiers
- D training including quality assurance
- E measurement and mapping (existing) tools to ICF, use of ICF in surveys, statistics, clinical and administrative records, inventory/compilation of use of ICF
- F maintenance and updating
- G WHO-FIC including ICF in a box, vocabularies
- H derived and related classifications
- I use of ICD and ICF together
- J subjective aspects of functioning and disability

Expected written information from Centres (attending the meeting or not)

For each issue A – J we expect to receive short information (two pages maximum) for

- what has been done in the country/region, what is available
- priority of the issue for international action
- what should be done at international level by who and how



## **Annex 2**

### **ICF implementation reports from Centres**

- **Australian**
- **Dutch**
- **French**
- **NACC**
- **UK**
- **EMRO**
- **Italian**

May 5, 2003

**Australian Collaborating Centre: ICF Implementation activities**



For health and welfare  
statistics and information  
6A Traeger Court  
Fern Hill Park  
Bruce ACT  
GPO Box 570  
Canberra ACT 2601  
Phone 02 6244 1000  
Fax 02 6244 1299  
<http://www.aihw.gov.au>

The Australian Institute of Health and Welfare (AIHW) is the Australian Collaborating Centre (ACC) for the WHO family of international classifications. The points below briefly set out the ACC's ICF implementation activities, both under way and planned for the future.

**A implementation strategy including raising awareness**

Development of the ICF Australian User Guide, with extensive input from key stakeholders in the Australian disability field, has been a major plank of the ACC's implementation strategy. The User Guide is an important tool for raising awareness of the ICF and its potential applications. Members of the ACC actively promote the ICF by giving presentations in various forums, whenever opportunities arise.

**B translation, dissemination and networking**

The AIHW's international web portal has an ICF page and links to the WHO website and the ICF Australian User Guide.

The ACC is actively engaged in building partnerships with people and organisations interested in using the ICF in a wide range of fields, and offers advice and support to users.

The ICF Australian User Guide contains information on current and planned applications of the ICF in Australia. It also provides the basis for establishing a user network, and a way of sharing experience and knowledge, and putting users in touch with one another.

There has been interest in translating the User Guide for use in other countries.

**C coding guidelines including Activity/Participation delineation and validation of qualifiers**

The ICF Australian User Guide provides a set of draft criteria for delineating A and P, to complement the WHO definitions. It also recommends two approaches to delineating A and P in Australian applications:

- i. to designate some domains as activities and others as participation, allowing partial overlap (WHO option b); or
- ii. to use all domains as both activities and participation (WHO option d).

The User Guide also includes templates for recording users' experience with applying the A and P options, and with using the Environmental Factors classification.

ICF-based data elements have now been approved for inclusion in Australian data dictionaries—a means of promoting standardised use of the ICF in Australia (see 'Australian disability data elements', below).

**D training including quality assurance**

The ACC's approach to training is built around developing partnerships with people in specific fields

in Australia, and developing and adapting training materials to suit different needs and circumstances as opportunities arise. Several ICF PowerPoint presentations have been developed, and can be used with modifications to suit particular needs or circumstances.

#### **E measurement and mapping (existing) tools to ICF, use of ICF in surveys, statistics, clinical and administrative records, inventory/compilation of use of ICF**

Several mapping projects have been undertaken or are planned:

- Mapping disability support needs tools to the ICF
- Mapping aged care dependency data items to the ICF
- Mapping health terminologies to the ICF

The ICF framework has informed the structure and questions included in the national disability survey. The ACC is also represented on a group working towards collecting information on disability via the Australian census, and is advocating that the question or module developed should be consistent with the ICF.

The ICF has been used in the development of a support needs data item for the national disability services data collection, and a data item for a new national medical indemnity claims collection, on the primary body structure or function affected.

The ACC is represented on the Washington City Group and the DISTAB group.

#### **F maintenance and updating**

The ACC's primary focus is on maintaining and updating the User Guide. Australian experience in applying the ICF will be collected via the feedback templates in the User Guide, and the Australian ICF users network, and this material could make valuable inputs into any future work on updating the ICF, developing further coding guidance, etc.

#### **G WHO-FIC including ICF in a box, vocabularies**

The ACC chairs the WHOFIC Family Development Committee and is secretariat to an Expert Group on Health Classifications, established to develop an Australian Family of Health and Related Classifications, of which the ICF is a member.

#### **H derived and related classifications**

No major work on derived or related classifications is under way in Australia currently.

#### **I use of ICD and ICF together**

Work on using the ICD and ICF together is likely to go ahead in the context of a project on trends in morbidity and disability.

#### **J subjective aspects of functioning and disability**

The ACC has undertaken considerable work to develop a data element on satisfaction with participation for inclusion in the national community services data dictionary. 'Participation—satisfaction level' can be used to record a person's level of satisfaction with their participation, in relation to current life goals.

#### **Australian disability data elements**

Australia has developed national data dictionaries to operationalise national and international population health and welfare concepts and classifications, and uses them in its national data collections. The three main purposes are:

1. to ensure that data standards are maintained through the use of national and international standard classifications, as the basis for national data elements or building blocks;
2. to enable the data produced from different collections to be more readily compared and combined; and
3. to minimise the work for data providers who can build local collections using the national data elements and rely on being able to supply data to various funders in similar formats.

The Australian National Community Services Data Dictionary (NCSDD) Version 2.0 contains a set of

disability data elements, based on the ICIDH-2. Since the publication of the ICF in May 2001, AIHW has revised the disability data elements to conform to the ICF and relate, as far as possible, to relevant measurement concepts and tools. The set of revised disability data elements will be published in the NCSDD Version 3.0 later in 2003. The elements are:

Disability (data concept)

Functioning (data concept)

Activity—functioning, disability and health (data concept)

Participation—functioning, disability and health (data concept)

Assistance with activities and participation (data concept)

Body functions

Body structures

Impairment extent

Activities and participation domains

Activity – level of difficulty

Participation extent

Participation – satisfaction level

Environmental factors

Environmental factors – extent of influence

Disability grouping (a broad categorisation of disabilities in terms of the underlying health condition)

## **Dutch Collaborating Centre**

Marijke W. de Kleijn de Vrankrijker

### **A Implementation strategy**

- **NL**
  - Dutch translation
  - Website incl users reports
  - Information exchange (newsletter, reference list)
  - Presentations and articles on request
  - Users contact and conferences
  - Implementation itself not by centre (ICF team members involved)
- **International action need**
  - Clearinghouse by WHO + network

### **B Translation, dissemination, networking**

- **NL**
  - Translation by ICF-team published 2002
  - Book + CD-Rom
  - Dissemination of translation by professional publisher
  - Networking by Centre and ICF-team
- **International action need**
  - Exchange of experience by WHO + network

### **C Coding, A/P, qualifiers**

- **NL**
  - No coding guidelines actions, inventory of problems
  - A/P delineation done in practice
  - No qualifiers validation, development of own qualifiers (assistance, outlook)
- **International action need**
  - Inventory of use/problems of coding guidelines
  - Solution for coding problems presented in Brisbane
  - Inventory of A/P delineation in practice, evaluation of A/P delineation + consequences for ICF

### **D Training**

- **NL**
  - Website (English + Dutch), basic information set of sheets
  - Flyer (4 pages)
  - Presentations and articles on request
  - Decentralized special trainings (quality assurance?)
  - User guide (Australian?)
- **International action need**
  - Inventory (clearinghouse) of training material and manuals
  - How to guarantee quality and uniformity of understanding?
  - Train the trainers program

### **E Measurement**

- **NL**
  - Mapping existing tools to ICF
  - Use of ICF as checklist for development questionnaires
  - Use in clinical and administrative records
  - WHO-DAS, WCG, Eurostat, DISTAB participation
  - Inventory of use (website)
- **International action need**
  - Clearinghouse
  - Evaluation + recommendation of good instruments
  - WHO + network

## **F Maintenance, updating**

- **NL**
  - WHO-FIC centre in charge
  - Comments inventory (website)?
- **International action need**
  - Strategy paper by WHO
  - Electronic system and documentation of revision proposals + updates by WHO + network
  - Editorial board, CEN standard
  - Transparant process!!!!!!

## **G WHO-FIC in a box**

- **NL**
  - Dutch ICF electronically available incl database + browser
  - Information on use through website, newsletter, conferences
  - No vocabulary including ICF terms
- **International action need**
  - Electronic system by WHO
  - ICF and vocabularies relation by WHO

## **H Derived and related classifications**

- **NL**
  - Need for Dutch ICF operationalization for allied health professions, nursing and maybe rehab
  - ICF used for specifying ISO 9999 classification
- **International action need**
  - Childrens version! Elderly version?
  - Use of ICF in ISO 9999
  - No need for internationally agreed derived classification for professions
  - What about classifications such as ICNP?

## **I Use of ICD + ICF**

- **NL**
  - In practice: rehab, nursing homes, psychiatry, research
  - Core sets Stucki project
  - ICF + ICPC project Belgium/Netherlands
- **International action need**
  - Clearinghouse WHO + network

## **J Subjective aspects**

- **NL**
  - Involved in Japan study
  - ICF to be used for subjective and objective characteristics
  - Maybe some additional items
  - Addition of synonyms and layterms?
  
- **International action need**
  - Results of Japan study
  - Development of “will” qualifier (Nordenfelt)?

**Priorities for international action**

- **First priority: clearinghouse**
  - A implementation strategy
  - B translation, dissemination
  - C coding, A/P, qualifiers
  - D training
  - E measurement
  - I use of ICD + ICF
- **Electronic support for first priority**
  - F Maintenance, updating
  - G WHO-FIC in a box, vocabularies
  
- **Lower priority**
  - H Derived and related classifications
  - J Subjective aspects

**Catherine Barral**

**FRENCH WHO COLLABORATING CENTRE FOR ICF  
CTNERHI - 236 bis rue de Tolbiac - 75013 – Paris - France**

**French contribution to the international updates session  
and the WHO-FIC implementation committee meeting**

**PLAN:**

**1- Dissemination and networking**

**2- Use of ICF in surveys, studies and assessment instruments**

- Survey
- Studies
- Measurement and assessment instruments

**3- A/P delineation, coding guidelines and qualifiers**

- A/P delineation
- Coding guidelines and qualifiers

**4- Maintenance and updating**

**5- Subjective aspects of functioning and disability**

Integrating the social and individual models in a systemic approach, ICF appears as a useful vehicle for the dissemination of the disability perspective in France, complementary to the so far dominant medical and rehabilitative approach of disability.

National, regional and local initiatives using ICF are in increasing number in various domains:

- ICF training
- Use of ICF :
  - in surveys and studies
  - for description, assessment and measurement instruments
  - for the current reform of the legislation for persons with disabilities.

These various initiatives focus primarily on the issues of social participation and rights of persons with disabilities (in institutions and in ordinary settings) and environmental accessibility.

## **I- Dissemination and networking in France**

The French Collaborating Centre for ICF has set up an ICF trainers' training.

The training sessions include:

- a) An historical overview of the WHO classifications: from causes of death to human functioning
- b) A typology of disability approaches: five models (cf. Marcia Rioux)
  - Individual models: medical, rehabilitative
  - Social models : environmental, human rights
  - Systemic model : ICF and Quebec classification
- c) Presentation of ICF:
  - conceptual model
  - structure
  - qualifiers
  - coding (coding exercise on vignettes, discussion on coding guidelines)
  - historical, social and political determinants of ICF:
    - Social actors and lobbying (Independent Living, DPI)
    - Disability Studies
    - International and European norms and rules (UN, Council of Europe, European Union)
- d) French legislation on health and social action: main benchmarks.

These training sessions are intended for:

- governmental officers (health, social policies, surveys and statistics departments)
- national organisations of persons with disabilities
- national schools for public health and social work
- regional authorities in charge of social policies implementation
- regional organisations for disability surveys and training
- regional organisations for vocational integration (employers included)

- participants from Francophonie (Switzerland, Belgium, Luxemburg).

The trainees are provided with:

- a trainer's package: ICF (book), slideshow on CD Rom (100 slides divided in 4 modules), ICIDH-ICF bibliography
- an ICF website for trainers (in progress).

## **II- Use of ICF in surveys, studies and assessment instruments**

### **1- Survey (completed April 2003)**

**Long-term adult patients in psychiatric structures in the Ile-de-France region (Paris and the 7 surrounding administrative departments)** (J.Y.Barreyre, National Association of Centres for Disability Studies and Training / ANCREAI, 2003)

This survey, using ICD and ICF, is intended to address the questions raised by the mental health regional authorities and psychiatric staffs concerning (i) the adequacy of the global care provided to adult patients in long-term hospitalisations; (ii) the improvements to be made to meet the users' needs; (iii) the estimates in terms of creation of new and diversified community services for this population.

### **2- Studies**

**Using ICF for the assessment of practice in sheltered workshops** (D.Velche, CTNERHI, in progress)

The 1300 sheltered workshops existing in France show very diverse practices. The assessment of the types of services provided by these institutions intends to result in recommendations to improve the conditions of participation of the persons in the different domains of personal and social life and to tackle the necessary environmental transformations to achieve that goal.

Questionnaire based on a selection of items from the 9 life domains of the Activity/Participation classification and from the 5 chapters of the environmental factors.

**Applying the concepts of ICF to bring forward the needs of elderly dependant users of nursing homes and to adapt the system of care** (K.Chauvin, National School for Public Health, in progress)

The ongoing reform of the financing of nursing homes for the elderly dependant in France has lead to questioning the current forms of assistance to dependency. This local study intends (i) to identify the needs of elderly people on the three levels of impairments, activity limitations and participation restrictions as perceived by old persons themselves, who live in a nursing home; (ii) to identify the environmental factors that come into play; (iii) to suggest improvements of the care system.

**Contribution of the French CC to DISTAB:** comparison of 5 national surveys on disability.

### **3- Measurement and assessment tools**

#### **Global assessment scale of autonomy (J.Y Barreyre, C.Peintre, ANCREAI, 2003)**

Based on 9 domains (including environmental factors) of ICF (including the 6 used in the WHO-DAS II) and 52 questions (with explanatory cards), the questionnaire is available in three forms (professional, self-report, proxy). This measurement instrument is part of a system of information intended to inform about specific environments needed to perform a particular activity.

**On going reform of the national disability nomenclatures and assessment guidelines** used for the orientation of adults and children with disabilities and attributions of allocations (using ICD and ICF). A study group associating our research Centre on Disability (CTNERHI), the department of Social Affairs and the French Commission of health nomenclatures is currently working at integrating participation and environment factors in the different health nomenclatures and disability assessment scales based on ICD and ICIDH.

We agree with the Nordic Center about the usefulness of a collaborative effort of the WHO CCs on the issue of measurement and assessment instruments.

### **III- A/P delineation, coding guidelines and qualifiers**

#### **1- A/P delineation**

As there is no implementation of ICF as such in France so far, nor specific tests of the different ways of using the A/P classification, we do not have empirical data to contribute to the clarification of this issue. However in the survey, studies and assessment tools using ICF, the A/P classification is used with full overlap (no delineation), and the distinction between activity and participation is based on the use of the qualifiers: capacity measuring activity and performance measuring participation, as suggested by WHO. This option reflects a tendency in France, not a generalised rule.

By reducing activity to capacity and participation to performance, this option brings the conceptual segmentation of ICF back to that of the ICIDH, familiar to the French classification users. This option shows also that in the absence of clear definitions of the concepts of activity and participation, the users may thus be driven to choose the operational distinction that qualifiers offer.

**N.B.:** A number of classification users (social work, institutions) still prefer using the Quebec classification (CDP) considered clearer and easier to use regarding its segmentation and more consistent conceptually.

#### **2- Coding guidelines and qualifiers**

A number of questions raised at Bethesda and Brisbane meetings (cf. Jane Millar's UK report, but also Nordic and Australian Collaborating Centres reports) will be usefully clarified when WHO's project of

publishing a "separate set of coding guidelines as an independent document or as part of training material" (B.Üstün, Brisbane, 2002) comes to reality.

A number of other questions still rely on complementary definitions and explanations that are missing so far, such as:

- definition of "construct"
- redundant definitions of 'performance' and 'participation': the qualifier has the same definition as the dimension it is supposed to measure
- by definition, capacity is not applicable to participation: capacity being understood in a uniform environment, participation in the usual environment
- 'capacity with assistance' and 'performance without assistance' require further explanations

#### **IV- Maintenance and updating**

- The updating of the ICF WHO website and WHO instruments (WHO-DAS II and ICF Checklist) would be quite helpful.
- We need to be better informed about the follow up of decisions taken at the annual CC meetings (see above).
- There is also a need for an improved (and maybe more formalised) circulation of information about the implementations and uses of ICF, their purposes and products. Or are they generally too country specific?
- There are already quite a number of corrections to be made to the French translation of ICF: typo errors but also terminological improvements. To whom can they be addressed?

#### **V- Subjective aspects of functioning and disability**

So far, the place of "judgement" passed by the person on his/her impairments, his/her activity limitations, his/her participation restrictions and on the role of environment – the subjective evaluation of situations of disability and of disabling situations- is not properly taken into account, whether in surveys (for statistical and epidemiological purposes) or in assessments of disability situations (for social interventions purposes).

But what do we mean by “subjectivity” as opposed to “objectivity” in the matter of disability?

How and what is to be taken into account relatively to ICF?

Including in a possible list of "Personal Factors" a set of general subjective characteristics that would require being trans-culturally applicable, seems neither too feasible, nor desirable.

Instead, a way of including individual judgement in each dimension of the ICF could be considered.

#### ***Subjectivity as an added value by the person to weight the answer to a functional item***

a system of coding that would indicate the value that the person attributes to a functional item (whether impairment, activity limitation or participation restriction).; this value would qualify the weight of the consequences of disability for the person

For example:        I cannot do ... but I don't care

I cannot do ... but I wish I could  
I cannot do ... but I would need it

If we are to consider the adjunction of such a scale in ICF, reference to the scales of subjective health could be helpful.

***The "meaning" of a situation for the person rather than "subjectivity"***

An emphasis put on "subjectivity" entails a risk of reducing a situation to psychological factors and of bringing back insidiously disability to an individual matter and approach. We would rather orient the reflection towards the issue of the meaning of a lived situation by the person, as a dynamic interaction between social, cultural and psychological elements (cf. Fougeyrollas P. 1998, n° 9, p.58-59; Ravaut J.F. and Robine J.M. ....)

***Impact of social representations and norms on subjectivity***

Belonging to a particular social group (religious, ethnic, cultural, etc.) implies that the values and norms of the group influence individual preferences and their hierarchy.

For instance, in the French Disability survey (INSEE-HID, 1998-2000), most often disabled persons attribute their activity limitations or participation restrictions to their impairment (conforming to the current dominant individual approach of disability). It is possible that an update of this survey in a few years from now, when the role of environment has been more acknowledged shows an imputation of the limitations to environmental obstacles rather than to intrinsic characteristics.

## **North American Collaborating Center: ICF Implementation Activities**

The WHO Collaborating Center for the Family of International Classifications for North America is housed at the National Center for Health Statistics, Centers for Disease Control and Prevention, USA, and works closely on ICF implementation issues in the US and Canada with the Canadian Institute for Health Information.

### **A. Implementation strategy including raising awareness:**

Raising awareness of ICF and its potential uses is a major focus of the NACC implementation strategy. *At the December 5, 2002 ICF Meeting with U.S. Federal agencies* sponsored by the Interagency Committee on Disability Research, WHO and UN representatives asked federal agencies to consider possible applications of ICF in statistics, data, policy and programs. At this meeting, a paper by Cille Kennedy "Federal Agency Funding of ICF Initiatives" was distributed; the full paper is in the NACC Clearinghouse on ICF.

*ICF presentations* have been made in the U.S. in 2003 by Placek, Hendershot, and Greenberg to: the Northeast Disability Research Consortium in Boston, MA; the Social Security Administration in Baltimore, MD; the Agency for Health Care Quality in Rockville, MD; and the Medical Subcommittee of the Interagency Committee on Disability Research in Rockville, MD. In Canada, Diane Caulfeild made a presentation to the Ontario Round Table on ICF and its application in Return to Function/Return to Work for people with disability.

*ICF book purchase and distribution* – The NACC has purchased and distributed hundreds of ICF Pocketbooks and Redbooks.

*Annual NACC meetings on ICF....* The 9<sup>th</sup> NACC meeting will be held in St. Louis, MO, on June 16-19, 2003, and the 10<sup>th</sup> one will be in Halifax, Nova Scotia in June 2004.

*A paper "Strategy for Implementation of ICF in the U.S."* was prepared by Ray Seltser and Gerry Hendershot and presented at the 8<sup>th</sup> NACC Meeting on ICF last year in Toronto. It proposed a comprehensive program of research by major U.S. Federal agencies. This paper will be input to a NACC research agenda for ICF; it is hoped that such an agenda will attract funding for pilot and demonstration projects.

### **B. Translation, dissemination and networking**

*Translation...* CIHI worked with WHO to create the Canadian French translation of ICIDH-2 Beta-2 full version in 2000; this was used in the development of the French ICF book.

*Dissemination...* The *NACC ICF Clearinghouse* activity began with NCHS staff in Fall 2002, with a monthly informational announcement to a primarily U.S. and Canadian email "group" of over 300 persons every month. It also includes a 2002 contract with Washington University. Join the NACC Clearinghouse on ICF at

<http://www.cdc.gov/nchs/about/otheract/icd9/icfhome.htm>

Read the Oct. '02 - Current '03 Monthly NACC Clearinghouse on ICF messages at

<http://www.cdc.gov/nchs/about/otheract/icd9/icfactivities.htm>.

CIHI has a hotlink to the clearinghouse, and Diane Caulfeild participates actively in the activity.

**The NACC Clearinghouse on ICF Brochure and Tabletop Exhibit** have been prepared, and are available now for general use. A total of 2,500 brochures have been printed. Six smaller tabletop exhibits suitable for airline carry on will be printed next month and put out on loan to anyone conducting workshops or exhibiting at meetings.

### **C. Coding guidelines including A/P delineation and validation of qualifiers**

NCHS funded a *contract* with Dr. William Reynolds to review empirical, conceptual, and theoretical evidence available to date and evaluate the four WHO options for delineation of A&P. He will make a presentation on his findings at the June 2003 NACC Meeting and submit a paper following the meeting. In June 2001, NCHS funded CIHI to undertake a similar effort, and this paper is available on the CIHI website. The NACC welcomes information on how other countries are addressing the A/P delineation, as well as broader coding issues. Greater international consensus on coding guidelines and standards is needed.

### **D. Training including quality assurance**

Training tools are a high priority with the NACC. The NACC Head chairs the Subgroup on Training and Credentialing of the WHO-FIC Implementation Committee and will work with the ICF experts in the network to develop an international work plan for ICF training and credentialing. Three training tools have been developed by the NACC. **First, Code ICF** is web-based training on ICF. Feedback was solicited in the Trieste and Toronto meetings, and it is scheduled for completion this year with installation on the WHO website shortly thereafter. Check out the draft and still unreviewed version of Code ICF at: <http://wsroom.westernu.edu:8080/icftraining/index.html>

**Second, the ICF Videos project** involves producing instructional videos from expert interviews on ICF, which were videotaped in October 2001 at the Heads of ICD/ICF Meeting in Bethesda October 2001. The four videos are on ICF use by consumers, ICF applications in surveys and clinical areas, historical development, and conceptual/issue areas. The videos will be previewed in St. Louis. Selected clips are in Code ICF. The videos will be distributed free in several formats.

**Third, the ICF Curricula in North American Colleges and Universities project** involves assembling model U.S. and Canadian college and university curricula which used ICF in the Fall 2002 semester, testing out a model curricula with ICF, and preparing a report for the June 17-19, 2003 ICF NACC meeting in St. Louis. The curricula will be distributed freely starting immediately. Quality assurance issues were considered in the *HCFR* articles discussed elsewhere.

### **E. Measurement and mapping (existing) tools to ICF, use of ICF in surveys, statistics, clinical and administrative records, inventory/compilation of use of ICF**

**Mapping (existing) tools to ICF...**The NACC notes with interest the American Psychological Association's project headed by Geoff Reed, *Procedural Manual and Guide for a Standardized Application of the ICF*. It is a collaborative effort of APA with eight U.S. professional associations. The NACC is supportive of this effort. McMaster University School of Occupational Therapy has established that there is a good fit between ICF and OT assessment tools.

**In surveys...**DISTAB represents a study by U.S., Canada and four other countries of ICF use in surveys. Since 1999, five countries (U.S., Canada, South Africa, Netherlands, France) have been active in an NCHS/CDC-led project to develop methodologies and statistical tables to backcode disability data from their five national disability surveys to the ICF. About one year ago, Australia joined the effort. This project is called "DISTAB" because DISability TABulations are produced for

study and possible publication. The DISTAB group meets by phone monthly (3<sup>RD</sup> Wednesday each month) and in-person annually in conjunction with selected ICF meetings. Paul Placek writes the monthly minutes. The group's broad aims have been to develop methods to produce more comparable national disability statistics from national censuses and surveys using the ICF framework, and to study how disability survey methodology can be improved. DISTAB's work spawned United Nations work in ICF and surveys, and establishment of the Washington City Group, which has held meetings in Washington and Ottawa. DISTAB maintains close contacts with the Washington City Group and presents its results there. A methods paper is due to be published very soon. **CDC surveys and research...**National Health Interview Survey and Behavioral Risk Factor Survey have included questions on functioning and environmental factors using ICF framework. CDC sponsored several research projects that developed community checklists and measures to assess broad range of environmental barriers for adults and children.

In clinical and administrative records... *In a landmark report issued in June 2001, the National Committee on Vital and Health Statistics of HHS (which advises the Secretary of HHS) recognized the significant value of functional status information and identified the ICF as the only viable candidate for a code set for classifying functional status in clinical and administrative records. Shortly thereafter, the Center for Medicare and Medicaid Services (formerly, Health Care Financing Administration) invited NCHS to organize and edit a special issue on functional status in Health Care Financing Review. ICF is covered in some detail in several of the eight articles of the special issue. Paul Placek and Gerry Hendershot served as guest editors. This HCFR issue is due out in July 2003. McGill University is undertaking an investigation into the integration of ICF into the Electronic Health Record. The Continuing Care and Rehab department of CIHI is undertaking the development of National Indicators for Home Care, which incorporate the impairment section of ICF to identify why clients are going into Long Term Supportive Home Care and Maintenance Home Care.*

**Inventory/compilation of use of ICF...** We have just learned that the Consolidated Health Informatics Initiative, one of 24 eGov initiatives in the United States, will be forming a team to identify candidates for a disability vocabulary and make a recommendation to adopt one for federal use in exchanging clinical data. Paul Placek will represent NCHS on the team and will support the ICF framework as the framework for determining what a disability terminology needs to include.

**Inventory/compilation of use of ICF...** *We recently completed the Patient Medical Record Information standards questionnaire distributed by the U.S. National Committee on Vital and Health Statistics, done under the directive of the Health Insurance Portability and Accountability Act of 1996. NCVHS is evaluating PMRI terminologies as candidates for a set of clinical data standards for DHHS adoption. The NACC would welcome systematic collection by WHO of information on ICF applications.*

## **F. Maintenance and updating**

The NACC strongly encourages that a "Maintenance and Update" WHO-FIC Committee be established for ICF, with a structure parallel to the ICD Committee.

### **G. WHO-FIC including ICF in a box, vocabularies**

Preliminary checks with the National Library of Medicine at the National Institutes of Health reveal that no classifications are included in Mesh. However, NLM is planning to put ICF (and ICD-10, and the oncology classification) into UMLS (Unified Medical Language System). Once in UMLS, a disability search in Mesh would result in a referral to UMLS. However, we understand that any agreement would be with WHO and NLM, and would not involve the NACC.

### **H. Derived and related classifications**

The NACC has not undertaken work in this area, but notes NCBDDD/CDC's support of the *ICF for Children and Youth*.

### **I. Use of ICD and ICF together**

The NACC has not undertaken work in this area, but notes Rune Simeonsson's papers on this topic with children's' data. This should be an area for future growth.

### **J. Subjective aspects of functioning and disability**

The NACC has not undertaken work in this area, but notes with interest the collaborative work of Trish Welch Saleeby with the Japanese Collaborating Center.

## **UK WHO Collaborating Centre**

### **WHO Family of International Classifications Implementation Committee**

#### **Implementing ICF – UK perspective**

##### **Introduction**

This short paper discusses implementation issues derived from Bethesda and Brisbane and the strategy and workplan, as well as the meeting in Lieden in the specific ICF sessions, pertinent to the UK. Most of the points are what we see as needing to happen and would form part of our implementation plan. Most of the work needs to be in parallel and we are also keen to share work done by other centres to avoid reinventing the wheel.

From a standards perspective, ICF has not been approved for use in the NHS in England and, as such, any implementation plan would contribute to this approval process – and approval process requires extensive piloting and implementation guidances, which is consistent with the aims of the WHO FIC implementation work. Adequate funding and resourcing has to be recognised, however.

##### **a. Implementation strategy**

We feel there is 2 pronged approach to the health side of implementation in the UK:

- In the healthcare arena in the UK, there are a number of drivers which could start to use ICF framework – conceptually and for statistical information. The National Service Frameworks for Mental Health, Older People, Children and Longer Term Neurological conditions all have elements which look beyond the original diagnosis and look at wider and longer term care delivery. These all require underpinning information collection to monitor progress – hence ICF framework is required at point of delivery of care and statistically to monitor performance against care standards set.
- In parallel, we have to ensure that functioning is included as part of the core information collected at the patient interface – thus it needs to be fed into national work on the core patient record. This work will include influencing healthcare professionals education/training. The suggested process which needs to be developed is the collection of functional information using clinical terminology, and the ICF framework, and then coders mapping across to the classification for statistical purposes.

This national approach is essential to ensure that all the other elements follow as itemised further in this document. It is recognised that this excludes the Social care end and this dialogue needs to happen too.

The UK would also point out that WHO setting strategic targets for ICF related information, with timescales of 5 years, associated with their evaluation of healthcare delivery across the world would be a major driver for implementation nationally. It is also felt that it would ensure the mapping was

undertaken within SNOMED Clinical Terms, which is likely to be the clinical terminology of choice in the UK and a number of other countries.

Thus we see that strategic drivers can be on a country basis, WHO basis and also European basis, and would suggest that the Implementation Group start to map this out.

### **b. Dissemination/networking**

This requires resourcing and the drivers in (a). It is clear that there is a lot of interest in this classification and the conceptual framework it offers. There are pockets of activity throughout the country – we need to have a mechanism to understand this. However, with that contact comes a need to have a national picture and approach.

### **c. Coding guidelines etc**

As there has been no further work from the WHO in response to the work the UK undertook across collaborating centres, we would expect to refine these further internally alongside use in pilot sites. With regard to the use of qualifiers, using the clinical terminology at the point of collection will introduce this concept. The requirements for statistical and therefore aggregated information will influence how we deal with aggregation of the information.

A key problem in the UK at the moment is Data Quality, and it is an opportunity to get work done properly from the beginning

### **d. Training**

This element has to be in tandem with the strategic drivers. The approach to training for ICD 10 is a model, but there is much more fundamental work to be done with healthcare professionals on starting to work with agreed language – so we need to introduce both the framework and the language principles pre-registration and post-registration levels. So there is wide education and training strategy to be developed.

Materials will be piloted in parallel at the same time as work is going forward with strategic drivers and healthcare record work

Jane Millar, Janice Miller (Canada) and Catherine Sykes (Australia) recently presented a 2 hour workshop to about 500 Physical Therapist (Physiotherapists) at a world conference in Barcelona, which was very successful. The approach was as follows:

- What is a health classification... Why do we need it?
- The new ICF... What's in it, how can we learn about it?
- How can ICF be applied to PT and our other colleagues?
- Who is using it and how could it help our practice?

Feedback indicated that our approach was good one and we are happy to make the slides more widely available. We included some practical work so that we developed their understanding further – not just on the classification itself but why we need agreed language.

#### **e. Surveys and mapping existing tools**

The WHO has adopted separate strategies for the implementation of the ICF in surveys and for clinical use. We agree with this approach. Our concern is that there does not appear to be global strategy for the use of ICF in national surveys. We feel that it is not appropriate to backcode old survey data into ICF codes. I am sure you appreciate there is a vast amount of work required in generating a survey instrument based on a classification. Howard Meltzer feels that the Europeans are progressing well in getting a questionnaire based on activity, participation and environment. This has come from European Disability Measurement project and the new work currently carried out by EuroREVES. Therefore, we feel more positive that things are moving in the right direction. Therefore, the development work is certainly being carried out under Eurostat contracts and this will feed into the Washington City Group meetings, and the work being done there.

#### **f. Maintenance and updating**

We feel there has to be central decisions about this through Collaborating Centres and WHO – and it might be a generic policy for all WHO FIC approved classifications, with specific elements relating to each classification. This is something UK has wanted from the beginning. We have the mechanisms then to deal national implementation of this.

#### **g. WHO-FIC in a box / vocabularies**

We ask that the implementation committee agree what this means, ie the specific items which make up this ‘box’. Then, we can develop a grid for each classification and tick off what has and has not been developed. Thus gives direction for work – WHO FIC and nationally.

With regard to vocabularies, a clinical vocabulary has already been discussed as the preferred approach to actual collection of information at the interface with client in the healthcare arena in the UK. However, we need to ensure that mapping work is done from the preferred clinical terminologies so that aggregated information is available for the different purposes – which have yet to be defined!

We have no views on the other points within the UK at this point. There are a few extra points that came out of Lieden which needs to be included in discussions:

- The need to establish a method for capturing the uses and implementations of ICF
- Examine the workstreams within the other WHO FIC committees and establish whether there should be similar work items related to ICF eg register of experts
- The emphasis on the pin-pointing the strategic drivers, and the UN was sited
- A training session prior to the start of the Cologne meeting was discussed and needs to be planned in St Louis

- The implementation plan should focus on sharing of resources coordinated planning across countries where possible

**Jane Millar, 2003**

## **WHO Regional Office for the Eastern Mediterranean (EMRO)**

Amina Elghamry provided information on implementation activities and issues.

Unfortunately we have not attended these meetings. We don't have an advisor. We missed a long period of contact with Collaborating Centres. We must start at the beginning. We want to be oriented to the background to help us face this challenge, to participate, and to know the situation. I am here for the first time to be exposed to the duties and the committees. So I consider my participation to be oriented to the situation with all of the Centres. We are dealing with 23 countries. Originally Arabic speaking but dealing with English and/or French language.

We started translating ICF into Arabic language. But until now we have not been in the process of

ICF. How can we participate in this process? How can we activate in EMRO region?

Discussion followed the presentation:

Recommendation that there should be an Arabic Collaborating Centre established. Region can determine where but Cairo makes sense. Or perhaps, Tunisia?

## **Disability Italian Network Report: ICF Implementation activities**

This is just to inform you that the Disability Italian Network, DIN, the scientific group that is implementing ICF use and WHO-FIC in Italy, has developed the Italian implementation strategy in collaboration with Ministry of Welfare, and some of the Regional authorities. Since the Italian translation (April 2002) we have been overwhelmed by requests from all the Country and WHO has been constantly updated about the incredible success of this classification in the Italian setting. We have a national training plan and we are preparing a national inventory of ICF use, as well as needs for its use, in different settings. Some sectors in Italy will start a systematic ICF, ICF checklist and WHO-DAS 2 use: mainly rehabilitation and work and we have a working group at the Ministry of Health that is discussing about our invalidity pension system and legislation and how this will have to change introducing ICF.

A group of architects in Milan has developed a project and build some apartments basing all the technological applications on ICF, so we have an "ICF based" building. We have been collecting all the publications done in Italian journals and all the articles that are related to it. They are in Italian. The Agenzia Regionale Friuli Venezia Giulia, which organized the World Conference on Health and Disability in Trieste last year, is developing a national ICF web site that will have all these information as well as all the Italian legislation related to disability and links to all WHO, WHO-CC, European Union related sites and other international ICF and WHO-FIC's worksites. You might also be interested to know that in these weeks it is under discussion at the Italian Parliament a new law on long term care for people with special needs based on ICF and that this law will use WHO-FIC as conceptual framework.

Hope this information can be added to your discussion. Best regards.

Dr. Matilde Leonardi, neurologist, paediatrician  
Co-ordinator  
International Scientific Research and Disability Project  
DIN coordinator and WHO liason  
Scientific Direction  
Italian National Neurological Institute C. Besta  
Via Celoria 11  
20133 Milan  
Italy  
Tel: +39 02 2394 511/ 498  
Fax: +39 02 2363973  
E-mail: [leonardi@istituto-besta.it](mailto:leonardi@istituto-besta.it)