

Editorial Board

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This Newsletter on the WHO-FIC, WHO Family of International Classifications, is a continuation of the ICIDH Newsletter, subsequently published by the former Dutch Classification and Terminology Committee for Health (WCC), 7 Volumes, the former Center for Standardization of Medical Informatics in Health Care (CSIZ), 1 Volume, and the WHO Collaborating Centre for the ICIDH, 4 Volumes.

Responsibility for the information given remains with the persons indicated.

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WHO Family of International Classifications (FIC)

NEWSLETTER

Volume 1, Number 1, 2003

From two to more FIC members

This second "Newsletter on the WHO-FIC" has three articles about classifications that are of interest for the Family of International Classifications:

- The ICECI on external causes of injury,
- The ISO 9999 on technical aids for disabled people, and
- The ICPC-2 on reasons for encounter, processes and diagnoses in primary care. Other potential members will be subject of following Newsletters, such as the Australian Classification of Health Interventions adapted for international use (ACHI-I), and the Anatomical Therapeutic Chemical (ATC) classification on medicaments. The question how to become a member of the FIC, at present only consisting of the ICD-10 and the ICF, is not easy to answer. Different approaches are circulating in the circle of the WHO-FIC Collaborating Centres and the WHO secretariat.

The concept of the Family was developed in 1987 and officially presented in ICD-10. A few Dutch attempts in the nineties to restart the debate on the Family concept to make it more operational, were internationally not successful. A new initiative was taken at the Heads of Centres meeting in Cardiff in 1999. A Family of health classifications working group was installed. Its terms of reference asked to review, establish the relevance, and clarify the concept of a family of health-related classifications. A first and second draft paper were discussed in 2000 and 2001, revealing at least six approaches:

- The WHO-FIC is a branch of a bigger UN Family of Classifications
- The purpose of the WHO-FIC is to allow the translation of health information into codes which facilitate the storage, retrieval, analysis, and interpretation of data and their comparison within countries over time and within and between countries at the same point in time.
- The WHO-FIC has to
 - be based on sound scientific and taxonomic principles,
 - be transcultural.
 - focus on multidimensional aspects of health,
 - etc
- The granularity level of the WHO-FIC is an intermediate level between very detailed vocabularies, such as Snomed CT, on the one hand and more coarse combination systems, such as DRG's and summary health measures, on the other.
- There are different memberships in the WHO-FIC: reference classifications (ICD-10 and ICF), derived classifications (the oncological ICD (ICD-O-3)) and related classifications (ICECI?).
- In order to enhance the Family there is a need for a protocol by which new member classifications are considered for particular applications or existing members for additional areas of application.

Still other approaches to the question wether a classification can become a member of the WHO-FIC are important, such as the ownership of a classification, copyrights etc. The final paper will be published by WHO. The reason why this crucial work of WHO-FIC Centres and WHO secretariat is summarized here, is to show the complexity of the membership authorization and the general principles that have to be coped with before WHO can decide upon a new member. Nevertheless, there is nothing wrong in nominating and discussing potential members, especially not if these classifications are already in use at a national or regional level.

The ICECI and ACHI-I were nominated as alpha-drafts (= open for internal comments of WHO-FIC Collaborating Centres) at the Heads of Centres meeting in Brisbane in October 2002. The ATC and ISO 9999 might be nominated as alpha-drafts in October 2003. The WHO/Wonca joint working group is aiming to take the ICPC-2 to the alpha-draft stage.

Editorial

This newsletter presents again a lot of news concerning WHO-FIC activities by international organizations and separate countries or groups of countries.

In October 2002 WHO and its centre heads met in Brisbane Australia for a week full of presentations and discussions concerning the core members of the Family of International Classifications and potential new members. Papers presented at this meeting are to be found at www.aihw.gov.au/international/who h oc . Several other activities organized by WHO or others in cooperation with WHO are reported in this newsletter, most of them relating to ICF (Trieste meeting, World Health Survey, core sets, ICF adaptation for children and youth) and some of them relating to other classifications. The United Nations Statistical Division is still actively involved in applications of the ICF in the field of surveys and

statistics; the UN Washington City Group (WCG) on Disability Statistics met twice and a short report on the work done so far is to be found in this newsletter.

In "FIC around the World" a bunch of reports from (groups of) countries regarding their experience, opinions and activities, most of them concerning ICF and a few concerning WHO-FIC. Some other regional activities might be of interest as well:

- German ICF newsletter entitled Schauflinger ICF-Brief, e-mail for information:
 M.Ueberle@Asklepios.com
- European Regional Conference of Rehabilitation International, Aachen, November 2002 including ICF presentations, for information: NOtte@cg-raad.nl
- French journal "Handicap, revue de sciences humaines et sociales" completely devoted to the ICF (nr 94-95, 2002) is available, e-mail address for information: ctnerhi@clubinternet.fr
- Swedish version of the ICF short version available on internet:

 www.sos.se/epc/klassifi/filer/icfkort.
 pdf; and complete version:

 www.sos.se/epc/klassifi/filer/icf.pdf

 Finally a supplement to the list of ICIDH/ICF references is included. We know of a related activity by Tora Dahl who drafted a list of references related to ICF which will be posted on the Nordic Centres website. For information: tora.dahl@tdcadsl.dk.

International Organizations

WHO and Collaborating Centres

WHO Conference on Health and Disability, Trieste Italy 17-20 April 2002

"Unless we measure health, we cannot manage and improve health systems. The ICF is the ruler with which we will take precise measurements of health and disability." This was the key message given by Dr Gro Harlem Brundtland, Director-General of the

World Health Organization in her opening speech during the WHO Conference on Health and Disability in Trieste, Italy from 17 – 20 April 2002. Over 70 countries registered for the conference, which was organized by WHO and hosted by the President of the Regione Autonoma Friuli-Venezia Giulia, Dr Tondo. Participants included Health Ministers or their representatives and other major policyand decision-makers from international and national health institutions; health-related agencies and non-governmental organizations.

They discussed the vision and measurement of health and disability and explored the perspectives for ICF implementation in their countries in a series of round table discussions, plenary sessions and technical meetings.

In the first round table philosophers and economists discussed *the "Health and Wealth of Nations"*. The presenters emphasised that health should be seen as a form of human capital and therefore good health is both intrinsically and instrumentally valuable. Referring to the work of the WHO Commission on Macroeconomics and Health it was

Macroeconomics and Health it was stressed that there is both, micro and macro-level evidence of the link between health and development. For example, increased height, a proxy for health status, is associated with higher wages and with better health, in the form of higher life expectancy. One of the very interesting aspects from an ICF perspective was to hear that in the absence of functional status data, economists who are studying the relationship between health and wealth of nation are using indicators like a person "height" as a proxy for health status.

What is the nature of health and its relationship with disability? This was the question at the center of the second round table discussion "Disabled and Healthy?". Presenters responded to this question by stressing the conceptual notions embedded in the ICF, namely that the conception of health and disability is based on the same domains of functioning, that disability is placed as a threshold issue

on a continuum of health and functioning for all people and should not be seen as a dichotomous category which applies to a certain minority group of people. Other points which were emphasized included the need to distinguish health state profiles (levels of functioning in core domains of health), from an overall health status (a summary measure of levels of functioning across all domains) and to distinguish between the description of a health state and the valuation of a health state for public health purposes The round table discussions were followed by two technical plenary sessions and two working sessions focusing on various topics related to the implementation of ICF. What is wrong with Disability statistics? was the topic of the first plenary session. Experts presented and discussed the multiple demands and potential uses of comparable health and disability statistics. They also identified the major problems of disability statistics as being the lack of a common framework, a very limited focus and domains which include only a few impairments; the use of an "a priori" definition of disability and nonexistent or weak linkage with health surveys. In that respect ICF can prove useful in improving cross-population comparability by providing a common framework, an inclusive focus and comprehensive domain coverage, an "a posteriori" definition of disability and a list of same domains for health & disability surveys.

The second plenary session focused on ICF and Health Information Systems (HIS). Presentations from developed and developing countries provided a comprehensive overview on the current status and future outlook of functional status data in HIS. The key messages which emerged from this presentations include the need for HIS to look beyond mortality and morbidity data and the utility of capturing functional status data using the ICF. The presenter identified the joint use of ICD and ICF and the development of ICF based data collection instruments as one of the major future challenges for the incorporation of ICF in HIS.

The working session on *ICF in Clinical Practice* and *ICF in Surveys* covered a wide range of conceptual and practical issues. For both settings the panel participants elaborated on the added value of ICF (e.g. complete description of clinical conditions, planning interventions, monitoring clinical outcomes, tracking change over time, relevance for users and providers) and presented ongoing development and implementation activities.

The conference proved to be a significant step towards a broad based and sustainable application of ICF. After three days filled with presentations and intensive discussion participants agreed that in order to obtain a more meaningful picture of health, data on function and disability needs to be incorporated. With regard to ICF they concurred with the Dr Brundtland's analogy of the ICF as the "Swiss Army Knife for health ministries, researchers and decision-makers."

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Application of ICF in the World Health Surveys (WHS) Program

Rationale, Objectives and Implementation of the WHS

Two major challenges face health policy-makers at the national and international levels:

- The need for reliable information that can be used to improve the health of the populations they represent.
- Increased international and national attention on the role of health in human and economic development which has resulted in increasing resources being committed to improving health in all settings. A national health ministry can only respond to these challenges if it has the capacity to monitor inputs, health system functions and outcomes. This requires in turn, good quality baseline

information on the way the health system is currently functioning, and on the outcomes expected from increased investment in the health system. Although routine Health Information Systems (HIS) can provide some of this information, they can not provide enough. Surveys can supplement this HIS data in ways that can facilitate the monitoring of health system performance and develop the baseline information required. Accordingly, WHO has developed and implemented both a survey program and a World Health Survey (WHS) that will compile comprehensive baseline information on the health of populations.

Objectives of the WHS

In response to the challenges described above WHO set out the following objectives for the WHS:

- to develop a means of providing low-cost, valid, reliable and comparable population health information;
- to build the evidence base needed to monitor health systems in order to determine whether they are achieving the desired goals; and
- to provide policy-makers with the evidence they need to adjust their policies, strategies and programs as required by the evidence.

Implementation of the WHS The WHS implementation is characterized by following components:

- World wide coverage: The World Health Survey is implemented in 73 countries across the WHO regions
- Modular approach:
 The World Health Survey offers a menu of choices of modules for various components including Health of populations; Risk factors; Responsiveness of health systems; Coverage, access and utilization of key health services; Health care expenditures; health insurance programmes; Mortality
 Different choices of survey methods:
- Different choices of survey methods. The World Health Survey provides a suite of different methods such as Household Face- to- Face Surveys; Computer Assisted Telephone

Interview (CATI) and Computer Assisted Personal Interview (CAPI).

- Conceptual foundation and sientific validation:

All the survey instruments have been developed after a rigorous scientific review of existing instruments and international consultations..

- Representative sample size:
 Depending on the needs of each country, sample size may vary between 1, 000 and 10, 000 for each country survey. Respondents are randomly selected and cover adult populations and younger people.
- Cross Cultural Comparability:
 The WHO Survey Programme has been developed with a view to cultural sensitivity and different techniques have been introduced to calibrate the self- reports of individuals on their own health and on how they are treated by the system.

How is ICF applied in the WHO Health Survey?

The ICF has been applied in the WHO Health Survey in two major ways: by providing the conceptual framework for defining health, and by providing a comprehensive set of health and health-related domains and representative item pool for the survey questionnaire in order to measure health states.

Measuring health in multiple domains

The item-generation procedure for the health module of the WHS involved two basic steps: first health domains were selected that comprehensively covered the entire area of health; secondly, items that adequately represented those said domains were selected. Each item, moreover, was assessed in terms of its validity, reliability, and cross population comparability. The health module of the WHO Health System was developed in light of this item generation process in the development of ICF and WHODAS II. For its part, the WHS had at its first objective the assessment of health in different domains as reported by people in general population. The Health States Descriptions section used in the WHO Multi Country Survey study comprised 63 items in 21 health and health-related domains. Based on this study

carried out in 61 countries the choice of domains for the WHS has been reduced to 8 "core" domains (vision, pain and discomfort, affect, sleep and energy, cognition, mobility, self-care, interpersonal interaction).

All recall questions are asked for last 30 days. The focus is the difficulty experienced by respondents in each of the domains in their actual environment. Thus, the emphasis in the surveys in observed performance as reported by respondents. A additional feature of the health module of the WHS is the use of vignettes to make adjustments to the self report. The vignettes are short descriptions of concrete levels of ability on a health domain, each of which the respondents are

domain, each of which the respondents are asked to evaluate. The vignettes serve to fix a given level of ability on a domain and the evaluations the respondents give to the vignettes allow WHO to measure the response category cut-points of these items in different populations and groups, and to adjust the responses to the health domains to make the data comparable across populations. There are four sets of vignettes in the WHS. All ask respondents to rate amount of difficulty in given domains on a five-point ordinal scale. The entire structure of the health module of the WHS, therefore, is built up the health domains and individuals items that are found in the ICF classification. In this sense, the WHS is grounded methodologically and in terms of content, to the ICF.

Implication of using ICF in WHS

The obvious advantage of using the ICF in this way for international health and disability statistics is that it increases the international comparability of these data. The WHS will be the most extensive international health survey ever conducted and will offer unlimited source of data for individual countries and the international research community. That all these data are comparable, by virtue of the link to the ICF, is of considerable value. In addition, each nation will be able to access the population norms that will be created from the resulting data from the WHS. These norms will also be expressed in ICF-compatible language, thereby increasing their usefulness and validity.

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International Classification of External Causes of Injury (ICECI)

The ICECI is a multi-axial, modular, hierarchical system for classifying external causes of injuries. It was designed to help researchers and prevention practitioners throughout the

prevention practitioners throughout the world to describe, measure and monitor the occurrence of injuries, and to investigate their circumstances of occurrence, using an internationally agreed set of data items and categories. An international consortium of organisations and individuals developed the ICECI.

The consortium has included leading providers and users of statistical information for injury prevention. Development was undertaken in close collaboration with WHO.

The ICECI is designed to complement

The ICECI is designed to complement the ICD-10 External Causes chapter, with which it has partial conceptual overlap.

After development and consultation on several drafts, field-testing and taxonomic review and subsequent revision, version 1.1 of the ICECI is now submitted for recognition as a *Related Classification* in the WHO Family of International Classifications.

The above is the abstract of a paper presented by James Harrison at the meeting of Heads of WHO-FIC Collaborating Centres in Brisbane, Queensland, Australia, 14-19 October 2002. The full paper (document 74) is available at:

www.aihw.gov.au/international/who_hoc For information:

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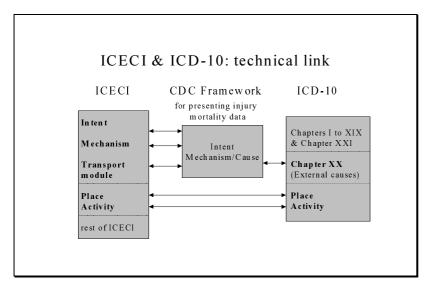


Figure 1: Technical link between ICECI and ICD-10

The Development of ICF Core Sets

From 31 January to 3 February 2003 the second ICF Core Set conference on Depression, generalized Chronic Pain, Obesity and Stroke took place in Kloster Seeon near Munich with the participation of a panel of 140 distinguished experts from 28 countries. This conference together with the 1st ICF Core Sets on musculoskeletal conditions that took place 26-29 April 2002 represents a cardinal event within the joint project "The Development of ICF Core Sets" conducted by the university of Munich and the WHO.

To improve functioning and health, we need tools to describe and measure it. Although a large number of health measures already exist, only the ICF provides us with a common international framework for describing and measuring health. The ICF is not intended to replace existing healthstatus measures, but to provide a common reference system. It is also important to understand that the ICF has been developed as an universal framework for functioning and health. Thus, the ICF needs to be adapted for use in medicine, among other fields. When applied in medicine, ICF Core Sets are both intuitive and practical. ICF Core Sets link the ICF to the condition oriented perspective and make the ICF feasible for clinical practice or research and health

reporting. Thus, the development of ICF Core Sets represents a decisive step forward in the provision of care for people with limitations in functioning and health all over the world. During the conference, a decisionmaking and consensus process based on the results of preliminary studies using empirical data from patients with one of the four health conditions under consideration (depression, generalized chronic pain, obesity and stroke), international Delphi surveys, and systematic reviews took place. Two primary outcomes were attained during the 1st and the 2nd ICF Core-

Set Conference:
- preliminary Core Sets for clinical assessment defined as lists of ICF domains that should be considered in

comprehensive, multidisciplinary assessment of functioning and health in patients with specific health conditions and

- preliminary Core Sets for clinical studies defined as lists of ICF domains that should be recorded in every clinical study in which the effect of an intervention on patients with specific health conditions is to be determined.

The feasibility and validity of these preliminary Core Sets will be tested by experts from all over the world. The steps involved in this process will be conducted by the "ICF Research Branch of the WHO-FIC Collaborating Centre in Germany" and the WHO.

The importance of the ICF and the ICF Core Sets for the improvement of functioning and health and of the patient's perspective and the multidisciplinary management of functional limitations was emphasized by the attendance of a number of presidents, vice presidents, or board members of different international organizations at this conference. Partner organizations of the project represented at the conference included: The International Society of Physical and Rehabilitation Medicine, The Austrian, German and Swiss Society of Physical Medicine and Rehabilitation, The German Society for Rehabilitation Research and The Swiss Physical Therapy Association. The 3rd ICF Core Set Conference on

chronic ischaemic heart disease, obstructive pulmonary diseases, diabetes mellitus and breast cancer will take place from 30 May - 2 June 2003.

For information about the project as well as registration forms for the next conference:

Prof. Gerold Stucki and Dr. Alarcos Cieza, University Hospital Munich, Department of Physical Medicine and Rehabilitation, Marchioninistr. 15, 81377 Munich, Germany, phone 0049 89 7095 4284, fax 0049 89 7095 8829, e-mail: Alarcos.Cieza@phys.med.uni-

Alarcos.Cieza@phys.med.unimuenchen.de

Adapting the ICF for child health systems

With increased concerns regarding childhood morbidity, particularly in the developing world, there is a need for a universal tool that can describe health conditions and their consequences unique to the developing child. This presentation describes the process of preparing an adapted version of the ICF to classify functional characteristics, disability and environmental factors of children that can be used in conjunction with the ICD-10 for documentation in child health systems.

The ICF for children is based directly on the ICF organization (Body Functions/Structures, Activities & Participation, Environmental Factors) with the hierarchical structure of chapters, blocks and categories complementary with the main volume. Content applicable for children will be retained with information to be added taking the following form: (a) modifying existing descriptions; (b) assigning new content to unused codes; (c) modifying inclusion/exclusion criteria; (d) use of 2nd, 3rd or 4th qualifiers as appropriate

A WHO work group is convening over two years to (a) develop drafts of the ICF for children; (b) test draft versions; (c) identify needed instruments and (d) prepare a final version for publication in 2004. This presentation will provide a status report of the work group activities based on recent meetings in Trieste, Italy and Vasteras, Sweden. 2002.

The above is the abstract of a paper presented at the meeting of Heads of WHO-FIC Collaborating Centres in Brisbane, Queensland, Australia, 14-19 October 2002. The full paper (document 41) is available at:

www.aihw.gov.au/international/who_hoc
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WHO and Wonca

Relations between ICD-10, ICF and ICPC-2

A first article with basic information on the ICPC-2 and its possible relations with ICD-10 and ICF was published in this Newsletter on the WHO-FIC, 1(2002)1, pp 13-15. This second article deals with the work of the WHO/Wonca joint working group on the relations between ICD-10, ICF and ICPC-2.

The joint working group reported to the Wonca International Classification Committee (WICC) in September 2002 and to the WHO Heads of Centres through the Family Development Committee (FDC) in October 2002.

The figure illustrates that the ICPC-2 can be used in three modes in primary care: as a reason for encounter classification, as a diagnostic classification and as a process classification.

The working group concluded that the ICPC-2 does not cater for the

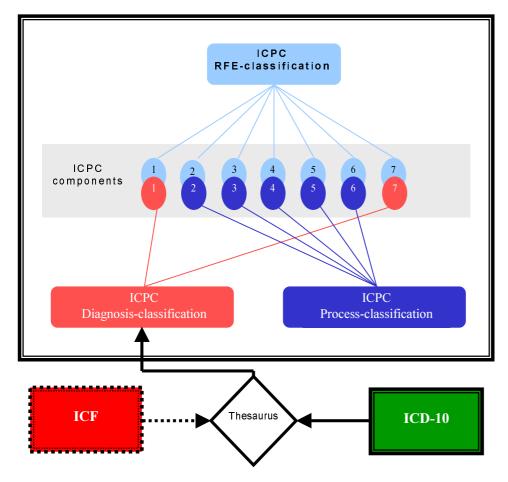
classification needs in community based "primary health care". The group recommends that the ICPC-2 will be included in the Family of International Classifications (FIC) as the reason for encounter classification (RFE). In the RFE-mode all seven components of ICPC-2 are involved which allows WHO to use ICPC-2 concepts in future updates of ICD-10 and its derived classifications. It allows Wonca to describe the terminological relations in the ICD-10/ICPC-2 thesaurus for the part of the diagnostic concepts involved in both classifications e.g. components 1 and 7 of ICPC-2. The diagnostic components of ICPC may cover the need for a primary care diagnostic classification of health data, especially those needs of family doctors.

The working group recommends that the FDC and the WICC will work together towards a common solution for a diagnostic primary care classification. The relation in the thesaurus between ICPC-2 as a diagnostic classification and ICD-10 is now in a stage where practical work can be done by several participants. A further customisation of the four language ICD-10/ICPC-2 thesaurus will allow others to be involved. The coding of process with ICPC-2 is not meant to be anything more than superficial and its use depends to a considerable extent on national conditions. It is unlikely that primary care providers other than family doctors, such as nurse practitioners and barefoot doctors, will find the coding of process of ICPC-2 (nor the ICN for that matter) sufficiently geared to their professional needs.

The working group considers ICF an important tool to describe problems of functioning in primary care patients and recommends focusing first on the relation of ICF with ICPC-2 in its diagnostic mode.

The Centre Heads of the WHO-FIC Collaborating Centres recommend that the WHO/Wonca joint working group will continue its work. A draft of five tasks awaits approval by WHO:

- The possibility of using/developing ICPC-2 for a broader primary care classification needs to be studied.



- ICPC-2 & ICF relation must be examined.
- The Wonca comparative study of ICPC-2 and the Swedish primary care version of ICD-10 be reported. Other countries are invited to do comparative studies.
- FDC should make recommendations for the development of a primary care classification.
- Needs of developing countries must be analysed.

The joint working group will meet on 27 April 2003 in the Netherlands, preceding the meeting of the Family Development Committee on 28/29 April 2003 in Leiden.

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International Organization for Standardization

Technical aids for persons with disabilities – Classification and terminology (ISO 9999)

In 1992 the International Organization for Standardization (ISO) published the first edition of the international standard "Technical aids for disabled persons – Classification" (ISO 9999: 1992). Because of the need for improvement the classification has been revised twice since its first edition. The most recent version is the second revision (third edition) accepted by ISO and CEN in 2002. The classification includes technical aids used by persons with disabilities, especially produced or generally available. In the set of definitions use is made of ICIDH terminology; in the next version ICF terminology will be included in the definitions and other consequences of the ICF will be envisaged.

Technical aids (including software) are being classified according to their function. The classification consists of three hierarchical levels and the codes consist of three groups of two digits each. The current version includes eleven chapters (first level). Besides the explanatory text and classification itself, a conversion table between 2nd and 3rd editions and an alphabetical index are provided.

The above is the abstract of a paper presented at the meeting of Heads of WHO-FIC Collaborating Centres in Brisbane, Queensland, Australia, 14-19 October 2002. The full paper (document 91) is available at:

www.aihw.gov.au/international/who_hoc

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United Nations

Washington City Group on Disability Statistics

Introduction

The Washington City Group (WCG) was established by the United Nations to enable the international community to develop agreement on the nature of a general measure of disability for use in the world community. The first meeting was held in February, 2002 in Washington, DC.

Objectives:

- 1. Develop a small set(s) of general disability measures suitable for use in censuses, sample based national surveys, or other statistical formats.
- Recommend one or more extended sets of survey items to measure disability, related to the general measures, to be used as components of population surveys or as supplements.
- 3. Address important methodological issues associated with the measurement of disability.

The above is the abstract of a paper presented at the meeting of heads of WHO-FIC Collaborating Centres in Brisbane, Queensland, Australia, 14-19 October 2002. The full paper (document 33) is available at:

www.aihw.gov.au/international/who hoc

Second meeting

Last January the second meeting took place in Ottawa. Main topics of the programme and presented papers:
- disability measurement matrix,

7

- overviews of General Disability
 Measures (in developing countries, in
 Europe and in other developed
 countries).
- several presentations concerning recent disability surveys and use of available disability data,
- methodological issues, implementation of MEHM (Minimum European Health Module) items, measurement of participation and environmental factors.

Third meeting

The participansts formulated the following objectives for the third full meeting:

- Based on the matrix to identify one or two purposes for which cross national comparison of data makes sense.
- To identify (the underlying construct for) the general measure(s) (level of impairment, activity, participation and/or environmental factors) needed in relation to the identified purposes.
- To conclude about methodological issues related to the general measure(s).
- Preparatory discussions about the more detailed measures needed for the chosen purposes (see A) in relation to the general measures.
- Discussion on general methodological issue: population coverage and groups which are often excluded in surveys (children, institutionalized population, homeless, etc).
- To conclude about the use of current disability data for the time being.
- To define next steps.
 The third meeting is expected

The third meeting is expected to take place in October 2003 in Brussels.

For information:

General information and papers http://www.cdc.gov/nchs/citygroup Jennifer Madans, e-mail: JMadans@cdc.gov

Renée Langlois, email: <u>langren@statcan.ca</u> Marijke W. de Kleijn – de Vrankrijker, email: <u>marijke.de.kleijn@rivm.nl</u>

FIC around the World

Asia and Pacific region

Presentation on ICF at a meeting for Deaf Leaders from the Asia/Pacific Region

The following contribution is the description of a presentation on ICF by Yerker Andersson at the regular meeting of the Regional Secretariat in Asia/Pacific of the WFD. This meeting was held in Osaka, Japan, October 17-19. About 14 countries were represented.

Established in 1951 and recognized as a non-governmental organization by the United Nations a few years later, WFD has regional secretariats in eight geographical or political areas (European Union, Asia and the Pacific, Central Europe, Eastern Europe and Middle Asia, South America, Central America and the Caribbean, Eastern and Southern Africa and the Arab Region). Depending on the availability of financial support, the secretariats meet once a year or every second or third year to discuss the concerns of deaf people in their areas. They are supported and managed by the national federations of the deaf who have successfully secured government grants for this purpose. At present over 120 countries are represented in WFD. The Scientific Section of WFD has a long list of experts in different areas. More information about this federation can be found in the website

www.wfdnews.org.

Aware of my involvement in the activities of DISTAB, a US-sponsored international research group, the Japanese Federation of the Deaf asked me to share information about ICF and its development with deaf leaders from the Asia/Pacific region. Since all the delegates were deaf and also since my presentation was limited to 1 ½ hours, my presentation focused on hearing both as a body function and as an activity and environmental factors such as sign language, TV captioning, text telephones, relay services, flashing signals. How these health components interacted also was explained. Some of

those terms that were of special interest to deaf people were found in the current version of ICF to be incorrect or misleading. For example, the use of "sign language" was not consistent in the English, Spanish and French versions of ICF. "Formal sign language" in the English version might imply that everyday language should not be recognized. "Sign language" now is a common term in almost all English-speaking countries "Lenguaje de signos convencional" in the Spanish version would probably suggest that the use of sign language should be based on agreement or sanctions. Besides, most Spanish-speaking countries have different opinions on the apparently identical terms of "lenguaje" and "lengua." "Langage des signes" in the French version might seem simple but "langue des signes" is more preferrable in several French-speaking countries.

My blend of easily understood signs adopted from different sign languages and Japanese signs which has been developed since 1949 and the creation of similes and paraphrasing for illustration purposes were helpful. Fortunately, as most of the delegates were familiar with the variations among signed languages in the world, they could understand my explanations or descriptions.

In addition to this special topic, the historical development of ICIDH and ICF and the involvement of international disability organizations and experts with disabilities were described briefly. After my presentation, the questions asked by the delegates focused mostly on the application of ICF as a resource to the development of policies on human rights. At the end, I urged the delegates to increase the involvement of national federations of the deaf and deaf experts in their countries in the implementation and, if necessary, future revisions of ICF in cooperation with health professionals and researchers.

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Australia

ICF Australian User Guide

To promote the use of the ICF in Australia, the Australian Collaborating Centre is developing an ICF Australian User Guide. The User Guide is intended to be a complement to the ICF classification, to assist Australian users to understand the classification, to inform them about current and potential applications and to provide advice on 'getting started'. It is aimed at those wanting to find out more about the practical use of the ICF in Australia or considering or planning to use the ICF

The Guide has been designed to be fully consistent with the ICF. The ICF itself, at various points, reflects optional approaches. This User Guide aims to guide the Australian user in their approach to the ICF, including options.

The User Guide is currently a work-inprogress. It is intended that a web version will be available by the end of 2002, followed by the publication of a hard copy and a revised web version in mid-2003.

The above is the abstract of a paper presented at the meeting of Heads of WHO-FIC Collaborating Centres in Brisbane, Queensland, Australia, 14-19 October 2002. The full paper (document 78) is to be found at:

www.aihw.gov.au/international/who_fic At the time of the presentation of this paper it was intended that a web version would be available by the end of 2002, followed by the publication of a hard copy and a revised web version in mid-2003. In the meantime a web version of the guide (version 0.5) is available as a public draft for comment and discussion, see http://www.aihw.gov.au/disability/icf_ug

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Belgium and the Netherlands

FIC invitational conference

The WHO-FIC Collaborating Centre in the Netherlands is organising an invitational conference, entitled "*How are you?*", on 2 May 2003 at the

RIVM in Bilthoven. It is meant for users of the international classifications of diseases and related health problems, and functioning, disability and health in Belgium and the Netherlands. The answer to the question in the title of the conference might be positive or negative, general or specific, and will be covered most likely by one or more classes of the classifications. The classifications, ICD-10, ICF, and ICPC-2 (see Newsletter 1(2002)1 pp 13-15) are translated in Dutch and published – at least - on CD-ROM. The ICECI on injuries is still in development. The formats in which these classifications are available for users will be discussed in the plenary morning session. The Netherlands ICT Institute in health care (NICTIZ) will clarify its role regarding the use of the classifications and derived applications and it will also report on an assessment study of Snomed CT.

Two parallel afternoon sessions will deal with the ICF and ICD (incl. ICPC-2 and ICD-O-3 in Dutch). Uses of the ICF will be discussed in rehabilitation. primary care, nursing, allied health professions, mental health, eligibility assessment, and technical aids. Uses of ICD will relate to cancer registries, mortality statistics, gastro-enterology, peadiatrics, trauma information systems and the relation of the Dutch DRG (=DBC) system with ICD. Purpose of the conference is to join these and other initiatives using (parts of) international classifications in different kinds of information services and information products. A report of the invitational conference will be delivered to the next WHO-FIC Heads of Centres meeting in October 2003 in Cologne, Germany. The conference is also the starting point of a more encompassing evaluation of the uses of international classifications in 2003/2004 in the Netherlands and Belgium. Its purpose is again a conference, planned for mid 2004, to discuss the role of international classifications as the 'backbone' of all information services and information products on health status.

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Netherlands

ICF in nursing: possibilities explored

Introduction

Nurses around the world focus on health related functioning. Together with patients, they manage, relieve or solve the problems that result from diseases. Yet nurses have no tradition of using the International Classification of Functioning, Disability and Health (ICF). Moreover, many nurses are not aware of the existence of this WHO classification.

As with other care providers, not all nurses feel the need to use classifications or standardized terminologies. Many patient records around the world are filled with straight forward everyday language. Although easy to use, its variety and unclear definitions often contribute to confusion. Sloppy use of terms as 'down', 'tense', 'depressed' or 'anxious' for one and the same patient can hinder communication among nurses and between nurses and other care providers and can lead to unfocussed nursing interventions. Nurses who are aware of this problem often use mono-disciplinary nursing classifications. Whereas these classifications can contribute to a better understanding among nurses, they were not developed to promote clear communication between disciplines. For this reason a Dutch project 'ICF in nursing' was undertaken.

Goal

The purpose of the project was to explore the usefulness of the ICF for nursing practice. More specifically the goal was to explore possibilities of developing applications for nursing and multi-disciplinary practice and to evaluate the use of these ICF-based applications in hospital based patient care.

The project

The possibilities of using the ICF in nursing practice were explored in a large, hospital based project in the Netherlands. The university hospitals of Amsterdam (AMC), Groningen (AZG) and Nijmegen (UMCN) joined forces with the National Centre for Nursing and Care (LEVV) in order to plan and perform the project. The project was co-coordinated by the Nursing Science department at the UMCN and was sponsored by the Dutch Council for Health Insurances. Usefulness of the ICF was explored in ten subprojects in nursing practice. The subprojects focused on several patient groups (e.g. stroke patients, patients at psychiatric wards, patients at surgical wards, geriatric patients) and several elements of the care process (e.g. assessment, nursing diagnoses, multidisciplinary communication, discharge). In most subprojects the development, implementation and evaluation of ICF based applications for nursing and multi-disciplinary practice were the central focus. In total, the subprojects involved 45 experts, 190 care providers, and 150 patients in the development of applications for patient care (e.g. assessment forms, care records). These applications were implemented at 35 hospital wards or outpatient clinics and evaluated using information from 40 experts, 300 care providers and 450 patients.

Results

The results of the project are derived from the evaluations of those involved in 1) development of ICF based applications for practice, 2) the implementation of these applications on wards and at outpatient clinics and 3) the evaluation of these applications by designated users.

- Results from application development Large sections from all components of the ICF were used in the development of applications for practice. Only in the classification of body structures, some parts were omitted. In most cases. codes at the three-digit level were selected for the applications. In some cases items were missed. For instance, many respondents involved in the development of practice tools commented on the lack of specific terms and codes for patients' moods. Likewise, respondents reported difficulties in finding useful terms to describe the many relevant aspects of wounds. On a higher level, many struggled with the use of neutral terms,

whereas nurses in practice are used to describe 'problems'. Furthermore, the use of qualifiers was often discussed. In many cases it was decided to add or alter qualifiers. A common problem with the ICF qualifiers was the absence of a digit for 'potential problems'. The need for coding potential problems was often reported, since nurses focus on risks that patients encounter (risk of malnutrition, risk of falling etc.). Although all workgroups reported some of these difficulties, it was largely felt that the ICF provided terms to describe next to all relevant aspects of human functioning. In most cases terms were evaluated as being clear, useful and well defined.

- Implementation of ICF-based applications

In the implementation of the ICF-based applications many minor and non-ICF specific problems were encountered. The implementation was sometimes hindered by the fact that for many nurses it was the first time ever they used the ICF. This implied that introducing the ICF and monitoring the use of the newly developed tools took ample time and effort. Although most applications could be used without in depth knowledge of the classification, it was generally felt that understanding the essence of the ICF and its components was needed.

Nurses and other care providers who

- Users' evaluations

reflected on the use of the practice applications gave positive evaluations on the whole. It was commented that using the ICF applications contributed to a more complete insight into a patient's functioning. Furthermore, the users thought that usage of the applications improved clear communication between care providers from different disciplines. The use of the ICF applications did not trigger the use of ICF terms in other elements of the care process than those applications specifically focussed on. If, for instance, a tool aimed at ICF-based assessment, ICF terms were not automatically used in other sections of the patient's record.

Whereas the applications were seen as clear cut and useful, users often

thought of the ICF itself as rather complex and abstract. Once the users were more experienced however, the central components of the classification were seen as a valuable framework in assessing human functioning.

Discussion

The project can be seen as a multiple cases study in which many potential applications of the ICF were developed and pilot tested. As such, the project was successful and resulted in insights that were not previously available. A major limitation of the project was its hospital focus. The results could be different for applications in other areas such as home care or nursing home care.

It is concluded that the ICF is very relevant to nursing care; it covers a large majority of the aspects of human functioning relevant to nurses. Furthermore, it is concluded that some elements of the classification need more detail in order to be relevant to nursing care. From a nurses' point of view, the provided qualifiers need to be reconsidered. Not only was the option of 'potential problems' missed, the phrasing of the qualifiers and the use of percentages were often seen as abstract and not very relevant to

everyday patient care.

The ICF, although not yet perfect in every aspect, can be seen as a classification with great relevance and potential to the nursing discipline. Therefore the use of the classification among nurses should be promoted. While teaching the ICF in nursing curricula and implementing the applications from this project, new applications should be studied and nurses should be encouraged to become involved in future revisions of the classification.

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AAMR's 10th edition of 'Mental Retardation: definition, classification and systems of supports' compatible with ICF

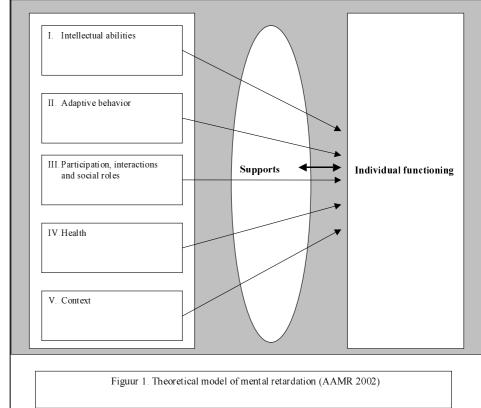
The American Association on Mental Retardation (AAMR) has a long history of formulating and disseminating manuals on the definition, terminology and classification of 'mental retardation' (MR). Throughout the years, this publication became a comprehensive and internationally recognized

Table: Relation between the five AAMR dimensions of functioning and the basic concepts of the ICF model of functioning

$ICF \rightarrow$	Health Condition	Body Functions &	Activities &	Participation	Contextual factors
AAMR-2002		Structures			(environ- ment)
Dimension I					
(intellectual		*			
abilities)					
Dimension II					
(adaptive			*		
behavior)					
Dimension III					
(participation,				*	
interactions &					
social roles)					
Dimension IV					
(health)	*	*			
Dimension V					
(context)					*

reference book for conceptualization, diagnosis and assessment of intellectual disability. The previous ninth edition of the manual (1992) presented a fundamental change of perspective. Mental retardation (MR) was no longer defined as an intellectual defect but as a state of functioning; the manual formulated a multiperspective view of functioning; functioning was conceived within a social-ecological paradigm as the interaction of the individual with the environment; and it focussed on supports. Although there was no reference to the WHO ICIDH, the 1992 manual obviously leaned on a similar paradigm. Recently, in May 2002, the AAMR published the tenth edition of the manual. In preparing this completely revised edition, the AAMR has carefully studied both the ICIDH and the development of the ICF. Although the 2002 manual is focussed on the understanding of the specific disability of MR, it brings the model and classification approaches closer in line with the ICF model of functioning and disability. As a result, the new model of MR that constitutes the framework for diagnosis, assessment as well as for designing supports for persons with MR, is now compatible with the ICF. For the purpose of diagnosis, MR is defined as "a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. The disability originates before age 18." The following five assumptions are essential to the application of this definition: 1. Limitations in present functioning

- 1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
- 2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor and behavioral factors.
- 3. Within an individual, limitations often coexist with strengths.



- 4. An important purpose of describing limitations is to develop a profile of needed supports.
- 5. With appropriate personalized supports over a sustained period, the life functioning of the person with MR generally will improve. (p. 1)

For assessment and classification purposes, the new model (figure) encompasses a multidimensional approach that deliberately has been designed to be consistent with the ICF model of disability. The five dimensions represent different perspectives towards human functioning that are interrelated and interdependent. The model shows the central role of Supports that – along the same dimensions – affects functioning. Supports are resources and strategies that aim to promote the development, education, interests and personal well-being of a person and enhance individual functioning. The table shows the relation between the AAMR dimensions of functioning and the ICF building blocks. Because of the importance of the concept of intelligence in MR, the first AAMR dimension of functioning is restricted to this particular mental function (ICF

domain b117). The AAMR dimension of Adaptive Behavior is congruent with the ICF dimension of Activities, whereas the AAMR dimension of Participation, Interactions and Social Roles is similar to the ICF concept of Participation. The AAMR Health dimension represents Health Conditions as well as relevant domains of the Body Functions and Structures component of the ICF. The AAMR Context dimension is completely similar to the ICF component of Environment and leaves open the inclusion of Personal Factors (that are not explicitly discussed in the AAMR model).

The multiperspective view is also reflected in a new multifactorial model of etiology. Chapter 8 of the manual addresses the interaction of biomedical, social, behavioral and educational risk factors and their implications for assessment and prevention.

Supports are rooted in both a contextual and egalitarian view of human functioning. Chapter 9 elaborates on sources, functions and intensity of needed supports. Supports are the tools for intervention in MR on

an individual, organizational as well as a societal level.

The compatibility between the AAMR model and the ICF is important to facilitate interdisciplinary and international communication about MR, not only in clinical situations but also in matters of policy and in the organization of supports. As the role of the environment in understanding and enhancing human functioning and disability is becoming more acknowledged, more disciplines (such as law and public administration) and more generic public services (e.g. health care, transportation, housing, media) are getting involved. Effective communication and concerted action between all those concerned is of paramount importance. In this respect, the ICF compatibility of the AAMR's conceptualization of MR is an important step forward. Chapter 7 of the manual addresses in length the relations of the 2002 model with the ICF, the ICD-10, as well as

References

the assessment of MR.

 Luckasson, R., Brothwick-Duffy, S., Buntinx, W., Coulter, D., Craig, P., Reeve, A., Schalock, R., Snell, M., Spitalnik, D., Spreat, S., & Tassé, M. (2002). Mental Retardation: Definition, Classification and Systems of Supports. Washington: American Association on Mental Retardation.

the DSM-IV. It also discusses the use

and limitations of applying the ICF to

 More information on the manual is available at <u>www.aamr.org</u>

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ICF from the perspective of postmeningitic children

Bacterial meningitis is an infection of the central nervous system, affecting approximately 15 per 100,000 children per year in The Netherlands. About 10-15% of the children who survive bacterial meningitis has severe adverse outcomes such as sensorineural hearing loss, paresis, seizures, and mental retardation. In the previous decade, cognitive, academic, and behavioral problems have been reported to exist in approximately 20% of the postmeningitic children several years after recovery. In 1998 we started a large Dutch study to determine the incidence of adverse consequences of bacterial meningitis for academic achievement and behavior and to gain more insight into the severity of these problems and possibly underlying neuropsychological impairments. We found that the long-term incidence of academic and behavioral limitations (as established with a comprehensive neuropsychological assessment) was 32% in postmeningitic children. Children with academic and behavioral limitations performed generically poorly on measures of cognitive functioning, speed, and motor steadiness, rather than showing impairments in specific neuropsychological domains. To characterize our findings in the right perspective, we took advantage of the recently published ICF concepts. A disablement model was considered inappropriate. The notion of 'impairment' was applicable to indicate problems in body function or structure. For example, hearing loss was described at the level of impairments. The notion of 'activity limitations' appeared to cover difficulties that pertained to the execution of activities. For example, academic under-achievement could best be classified as belonging to the level of 'limitations'. The choice between the levels of impairments and limitations resulted from ample discussion. We argued that the academic and behavioral problems of these children had to be described on the level of 'activity limitations' because the children were definitely underachieving in our academic achievement tests, whereas neuropsychological assessment revealed no deficits in specific neuropsychological domains. Hence, the problems could not be interpreted as related to body function. The clinicians in our research group were not familiar with the concepts of the ICF. Initially, they preferred the notion of 'academic and behavioral

problems' instead of 'academic and behavioral limitations'. Nevertheless, the members of the group became convinced that 'limitations' expresses the severity of the problems of the postmeningitic children appropriately, and it was decided to use the ICF terminology. Have others met similar problems, and, if so, how have they dealt with them?

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North America

Dissemination of ICF

There is a need in North America for more regular information exchange and technical assistance on ICF. Therefore, the North American Collaborating Center has sponsored five distinct efforts aimed at ICF dissemination, all supported by contracts. First. CODE ICF is webbased training on ICF. Feedback has been widely solicited in the Trieste and Toronto meetings and it is scheduled for completion late in 2002 with installation on the WHO website shortly thereafter. Second, NACC ICF Clearinghouse activity begins with NCHS staff in Fall 2002, with a monthly informational announcement to a primarily U.S. and Canadian email "group". It also includes a new 2002 contract with four components:

- 1) Identification and Typology of ICF Users in North America;
- 2) Marketing;
- 3) Training and Technical Assistance; and
- 4) ICF Conference Support. *Third, 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 ICF use by consumers, ICF applications in surveys and clinical areas, historical development, and conceptual/issue areas. Selected clips are in CODE ICF. Fourth, 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. Fifth, the Spring 2003 issue of Health Care Financing Review will feature ten articles (plus several commentaries) on capturing functional status, and several of them will examine the feasibility of using the ICF as the code set for that purpose.

The above is the abstract of a paper presented at the meeting of Heads of WHO-FIC Collaborating Centres in Brisbane, Queensland, Australia, 14-19 October 2002. The full paper (document 40) is available at:

www.aihw.gov.au/international/who hoc

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DISTAB update

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. This project is called "DISTAB" because DISability TABulations are produced for study and possible publication. The DISTAB group meets by phone monthly and in-person annually in conjunction with selected ICF meetings. One publication on methodology has been accepted for publication, and another paper with comparative tables is in draft form. DISTAB's work stimulated a United Nations Seminar on the Measurement of Disability Statistics in June 2001 and a follow-up to that, the Washington City Group meeting in February 2002. DISTAB's current

effort to code environment and participation items to ICF from surveys is a City Group recommendation. Australia has just joined DISTAB and has provided documents and tabulations. The DISTAB group works closely with the United Nations Statistics Division, which is now using the ICF in its statistical program to backcode surveys and censuses. The management of multiple drafts of documents produced from six national surveys by about 15 survey experts has become a substantial task as the group continues its work, and so the group now has its own password-protected website for document management.

The above is the abstract of a paper presented at the meeting of Heads of WHO-FIC Collaborating Centres in Brisbane, Queensland, Australia, 14-19 October 2002. The full paper (document 39) is available at:

www.aihw.gov.au/international/who hoc

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Sweden

Disability, Action Theory and ICF¹

From a general scientific point of view, I find the ICF to be an attempt on the part of the medical and health sciences to move outside the health-disease dimension and to theorize about the place of the human body and human activity in the environment, and in particular the confrontation with society. The concepts to be used here are not medical, nor are they simply biological; they do not, with the exception of some of the concepts of impairment, belong to natural science. They are concepts belonging to the humanities and the social sciences. The theoretical basis for the development of these concepts is action theory. Action theory has its proper place in philosophy and it has been particularly developed among philosophers who deal with the arts

¹ This is a short version of a paper presented at the XIV European Congress of EUMASS, 13-15 June 2002, Oslo

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and social sciences, see, for instance, von Wright (1971) and Davidson (1980). In all sciences where action is a central concept, action theory must be central. And now action has become central in some of the sciences of health care.

Unfortunately, however, the WHO has in its conceptual development hardly acknowledged the existence of the field of action theory and has therefore not systematically used insights gained in philosophical action theory.

Introduction to action theory

The concept pair that I will introduce is: capacity--opportunity. A capacity can be understood as a person's inner possibility for action. The capacity is what a person's inner resources permit him or her to do. By inner resources I mean the biochemical, physiological and psychological conditions inherent in the person. The opportunity, on the other hand, is the person's outer or external possibility. It includes factors that surround the person: physical as well as psychosocial, cultural as well as legal. To take an example: the inner resources of a Volvo mechanic permit him to engage in his craft, to use his hands in the way he wishes. The external arena, the workshop, gives him the opportunity to use the tools necessary. The rules of the company and the laws of the country permit him to have the work he has and they constitute the ultimate opportunities for him with regard to this set of activities. Together the mechanic's capacity and opportunity for engaging in his craft form his whole possibility for action. The amalgamation of a person's capacity and opportunity is sometimes called the person's practical possibility for action. Capacity plus opportunity is the person's practical possibility for a particular action.

That there exists a practical possibility on behalf of an agent for an action F, however, does not necessarily mean that the agent actually performs the action F. I have, for instance, now the practical possibility of leaving my office. I have both the inner capacity and the external opportunity; nothing prevents me from leaving the office. However, I am not going to leave it at this moment. Why not? The answer is

simply that I do not want to leave the office now. There is a *lack of will* on my part. The will is thus a crucial notion in all action theory. But the will is quite absent in the theory of the *ICF*.

On the notions of activity and participation in the ICF

The *ICF* has introduced two action categories, Activity and Participation. These two categories have been understood to form two ontologically distinct categories in some earlier proposals, for instance in the Beta 2-document and the Prefinal document from October 2000. In the final version of the *ICF* the categories of Activity and Participation are in a sense amalgamated into one ontological category covering the same domain. Still, they constitute two distinct concepts given two different definitions:

- An activity is the execution of a task or an action by an individual.
- Participation is involvement in a life situation.

Ouestions can be asked both about the intended amalgamation of the two categories and about the halfheartedness of this amalgamation. There cannot be any activities performed independently of any environment. All action must be involvement in a life situation. But what, in that case, is the point of the distinction? When one looks closer it becomes evident that the notion of activity is normally supposed to cover the "capacity aspects" of an action, whereas the notion of participation is supposed to cover the "performance aspects" of the same action. The notion of capacity is characterized in the terms of the activity definition: "The capacity qualifier describes an individual's ability to execute a task or an action." And: "The performance qualifier describes what an individual does in his or her current environment. Because the current environment brings in a societal context, performance as recorded by this qualifier can also be understood as "involvement in a life situation...", p.214. And involvement in a life situation is included in the very definition of participation.

Thus, there is no talk of activities performed in the current situation and no talk of a capacity to be involved in a life situation. The matrix is not filled, so why this multiplicity of concepts? Why distinguish between activity and participation, when the job needed is done by the qualifiers capacity and performance?

The basic confusion in the *ICF* can be resolved in a radical way. The uniform category activity/participation could remain uniform throughout and simply be called: action. Activity/participation could then simply be replaced by action. An action can be qualified in many ways relevant to the context of rehabilitation. We can talk about the ability or capacity to perform the action, both in a standard environment and in specified environments. We can talk about the opportunity to perform the action and we can discuss whether such an opportunity exists today or whether it can be easily created. And we can ask whether the action is ever performed by the individual, even if he or she has the full ability and opportunity of performing it in the current situation.

The very broad action category can also be subdivided in many ways, according to different dimensions. One subdivision can be made in terms of simplicity and complexity. There are some simple actions, sometimes called basic actions, to which I shall return, which are of particular importance for the medical profession, viz. those actions which almost exclusively consist of bodily movements (performed in a certain context). These could be singled out as a special category. But the idea of juxtaposing activity as the execution of a task and participation as involvement is not, I think, comprehensible. All activities, i.e. all actions, entail some involvement in the external world. Let me now comment on the choice of qualifiers in the *ICF*, the capacity qualifier and the performance qualifier. Given the analysis I have previously given, it would have been more natural to choose a capacity and an opportunity qualifier. But the manual seems to suggest that we should classify people according to what they

actually perform on a particular occasion. Observe: we are supposed to classify what people *in fact* do, not what is possible for them to do. But is this a task for a medical classifier? Should the medical classifier primarily be concerned with how people decide to steer their lives, should they be concerned with people's interests and inclinations?

Above I claimed that capacity and opportunity are not sufficient for the performance of an action. In order to actually act one must first *intend to act* or *want to act*. And in this respect people differ very much without there necessarily being anything for the institution of health care to consider. Some people are active and want to do a lot of things, whereas others want to do little. As a result there is a great difference in their actual performance. But, normally, there is nothing of medical interest behind these differences.

A benevolent interpretation of the intention of the constructors of the ICF is that they have mainly had in mind such tasks as most people *need to fulfil* for managing their daily life. Thus, it may have been presupposed that people want to act in the specified manner. Or, if they, in extreme cases, do not want to perform these actions, they still have to perform them. We can have in mind such actions as eating, sleeping and performing basic hygienic activities. I do not wish to deny that it can be of medical interest to know whether a person actually performs such fundamental activities as are necessary for his or her survival. But clearly this is only a minor part of what people do. There are many activities/participations as classified in the *ICF* that it is not necessary or even reasonable for everybody to perform in a regular manner.

Thus, it is much more neutral and clear to introduce the opportunity category as the supplementing qualifier. This is not to deny that with some fundamental actions it is crucial to ascertain that these are actually performed by a particular individual.

Concluding remarks

I have introduced a number of insights and notions from philosophical action theory in order to resolve a few remaining unclarities in WHO's conceptual framework with regard to functionings and disabilities. Let me summarize my major claims:

- 1. Every action or task is performed in a physical (normally also a social and cultural) environment. This must then also hold for activities in the sense of ICF and cannot be anything peculiar to performances as interpreted in the ICF.
- 2. If no environment is explicitly referred to there must be some environment presupposed. Often this environment is assumed to be of a standard kind.
- 3. The ICF not only deals with capacities and disabilities. It also deals with and classifies the actual performance of actions. As I have shown such classification entails the existence of a will on behalf of the agent. The ICF contains no systematic treatment of the concept of will.

References

- Davidson, D, Essays on Actions and Events, Oxford 1980
- International Classification of Impairments, Disabilities, and Handicaps (ICIDH), Geneva (WHO) 1980
- International Classification of Functioning, Disability and Health (ICF), Geneva (WHO) 2002
- Nordenfelt, L, *On Disabilities and Their Classification*, Studies on Health and Society 1, Linköping 1997
- Nordenfelt, L, *On the Nature of Health*, 2nd (revised) edition, Dordrecht 1995
- Nordenfelt, L, Action, Ability and Health: Essays in the Philosophy of Action and Welfare, Dordrecht 2000
- Von Wright, GH, *Explanation and Understanding*, London 1971

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Supplement List of ICF References

This is the 17th supplement to the list of ICIDH/ICF references published in September 1994

2078

1st World Congress of the International Society of Physical and Rehabilitation Medicine, abstract book, 7-13 July 2001

2082

Actieprogramma uitgavenbeheersing hulpmiddelen Ministerie van VWS 2000

2075 Achterberg T van

Een unforme verpleegtaal is een utopie in: TVZ, Tijdschrift voor verpleegkundigen (2001)8 pp 240-242

2114 Achterberg T van

Over onderzoek en oorbare zorg, 2002, 32 p

2094 Bakker A, Balkom AJLM v, Dyck R v

Angststoornissen in: Handboek Arbeid en Belastbaarheid, o.r.v. Willems JHBM, Croon NHT, Koten J-W, 1997 pp 1-44

2117 Barral C, Roussel P

De la CIH à la CIF. Le Processus de révision in: Handicap, revue de sciences humaines et sociales, (2002)94-95, pp 1-24

2123 Barreyre J-Y

Appréhension des facteurs environnementaux dans les classifications des maladies, des handicaps et des fonctionnalités: convergences et contradictions in: Handicap, revue de sciences humaines et sociales, (2002)94-95, pp 133-148

2050 Becher, JGSSJM

Measurement of impaired muscle function in upper motor neuron syndromes: method and clinical applications

proefschrift VU, Amsterdam 2000

2095 Beckung E, Hagberg G

Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy

in: Dev Med Child Neurol, 44(2002)5, pp 309-316

2080 Bent N, Jones A, Molloy I [et al]

Factors determining participation in young adults with a physical disability: a pilot study in: Clinical Rehabilitation (2001) 15, pp 552-561

2074 Brug Y van der, Frederiks C [et al]

De ICIDH en de verpleegkunde in: TVZ, Tijdschrift voor verpleegkundigen, (2001)9, pp 275-278

2084 Brug Yvd, Jongerden I

ICIDH in de verpleegkunde LCVV (2000) 18

2102 Buntinx WHE

De "caring community". Tussen hoop en vrees in: NGGZ-nieuws, april 2002, pp 7-12

2092 Butcher RL

Teaching spasticity and weakness from a dynamic systems perspective: part II in: Neurology Report, 25(2001)3, pp 106-114

2090 CIHI

Analysis of ICIDH-2 Impairment Coding Using a National Rehabilitation Database, 2001, 25 p

2091 CIHI

Development of Mutually Exclusive Lists for Activities & Participation: WHO International Classification of Functioning, Disability & Health, 2001, 56 p

2115 CIHI

Comparative Evaluation of the Beta-2 ICIDH-2 and the Disability Creation Process in: Human Development, Disability and Social Change 11(2001)1, pp 6-25

2083 CTNERHI

Beta-2 draft testing report, 2000, 64 p

2099 Desrosiers J, Noreau L, Rochette A etc.

Predictors of handicap situations following post-stroke rehabilitation

in: Disabil and Rehabil, 24(2002)15, pp 774-785

2087 Dijk AJ van

On Rehabilitation Medicine proefschrift, 2001, 242 p

2055 Dijkers MPJM

Measures of social outcomes in disability research tools of disability outcomes research in: Arch Phys Med Rehabil, 81(2000)12, pp 63-80

2076 Downie RS, Macnaughton RJ

Images of health

in: The Lancet 351(1998)March 14, pp 823-825

2124 Ebersold S

Le champ du handicap, ses enjeux et ses mutations: du désavantage à la participation sociale in: Handicap, revue de sciences humaines et sociales, (2002)94-95, pp 149-164

2089 Fougeyrollas P

ICIDH and Environmental Factors International Network, 9(1998)2-3, 87 p

2109 Fougeyrollas P

La classification québecoise du processus de production du handicap et la révision de la CIDIH in: Handicaps et Inadaptations, Les Cahiers du CTNERHI (1998)79-80, pp 85-103

2110 Fougeyrollas P, Noreau L

The next challenge of international standardization; the issue of validation of measurement NACC, May 2002, 6p

2066 Fougeyrollas P, Noreau L, Boschen KA

Interaction of Environment with Individual Characteristics and Social Participation: Theoretical Perspectives and Applications in Persons with Spinal Cord Injury

in: Topics in Spinal Cord Injury Rehabilitation 7(2002)3, pp 1-16

2051 Fox AV

Phonologically disordered German-speaking children in: American Journal of Speech Language Pathology, 10(2001)3, pp 291-307

2056 Grunberg M

Eval'kine outil d'evaluation en masso-kinesitherapie in: Kinesither Sci, 407(2001), pp 37-42

2119 Gubbels A

Un changement de paradigme pour les politiques européennes relatives au handicap? in: Handicap, revue de sciences humaines et sociales, (2002)94-95, pp 43-50

2096 Heerkens Y, Berg P v d, Steen C v d

Verslag fase 2: van het project 'Ergotherapie, logopedie en fysiotherapie in de zorg voor mensen met een verstandelijke handicap' ELF-project, Heerkens Y, Berg P van den, Steen

CWM van der, NPi etc. 2002

2057 Hermann KM

Relationships among selected measures of impairment, functional limitation, and disability in patients with cervical spine disorders in: Phys Ther, 81(2001)3, pp 903-914

2113 Holleman G, Achterberg T v, Frederiks C

Toepassingsmogelijkheden van de ICIDH binnen de verpleegkunde, overkoepelende studie van tien separate projecten naar de toepassingsmogelijkheden van de ICIDH, december 2002, 32 p

2093 Holt KG

Teaching spasticity and weakness from a dynamic systems perspective: part I

in: Neurology Report, 25 (2001)3, pp 102-105

2122 Institut canadien d'information sur la santé

Évaluation comparative de la version Bêta-2 de la CIH-2 et du Processus de production du handicap in: Handicap, revue de sciences humaines et sociales, (2002)94-95, pp 111-132

2070 Jelsma J, Weerdt W de, Cock P de

Disability Adjusted Life Years (DALYs) and rehabilitation

in: Disabil and Rehabil, 24(2002)7, pp 378-382

2059 Kennedy N

The effect of a period of rehabilitation in a rheumatic diseases unit

in: British Journal of Therapy and Rehabilitation, 8(2001)1, pp 29-36

2106 Klerk MMY de

Rapportage gehandicapten 2002 SCP, juli 2002

2097 Law M. Baum C. Dunn W

Measurement in occupational therapy In: Measuring occupational performance: supporting best practice in occupational therapy, 2001, pp 3-19

2081 Lo R [et al]

Cross-cultural validation of the London Handicap Scale in Hong Kong Chinese, 2001, pp 177-185

2060 Lollar DJ

Measures of outcomes for children and youth in: Arch Phys Med Rehabil, 81(2000)12, pp 46-52

2107 Lollar DJ

Public Health and Disability: Emerging Opportunities in: Public Health Reports, 117(2002), pp 131-136

2079 Madden R

Participation and environment: out of the melting pot and into ...?

UN seminar on measurement of disability, 2001

2077 Miles M

ICIDH meets Postmodernism, or 'Incredulity toward Meta-Terminology Disability World, 2001, 7 p

2086 NCVHS

Classifying and Reporting Functional Status NCHS, 2001, 21 p

2108 Nordenfelt L

Disability, Action Theory and ICD X!V European Congress of EUMASS, June 2002, 6 p

2065 Noreau L, Fougeyrollas P, Boschen KA

Perceived Influence of the Environment on Social Participation Among Individuals with Spinal Cord Injury

in: Topics in Spinal Cord Injury Rehabilitation, 7(2002)3, pp 56-72

2085 Oostendorp R

Tussen praktijk en wetenschap: de uitdaging voor de paramedische zorg inaugurale rede, 2001, 51 p

2118 Organisation mondiale de la santé

Vers un language commun pour le fonctionnement, le handicap et la santé. CIF: Classification internationale du fonctionnement, du handicap et de la santé in: Handicap, revue de sciences humaines et sociales, (2002)94-95, pp 25-42

2088 Picavet S

Public Health Questions on Physical Disabilities and Musculoskeletal Conditions proefschrift, 2001, 148 p

2053 Pierce D

Untangling occupation and activity in: Am J Occup Ther, 55(2001)2, pp 138-146

2100 Raman S, Levi SJ

Concepts of disablement in documents guiding physical therapy practice in: Disabil and Rehabil, 24(2002)15, pp 790-797

2104 Robine J-M, Jagger C, Egidi V

Selection of a Coherent Set of Health Inicators, A First Step Towards A User's Guide to Health Expectancies for the European Union Euro-REVES, June 2000

2105 Robine J-M, Jagger C, Romiau I

Selection of a Coherent Set of Health Inicators, Part II Final report Euro-REVES, June 2002

2068 Rochette A, Desrosiers J, Noreau L

Association between personal and environment factors and the occurrence of handicap situations following a stroke

in: Disabil and Rehabil, 23(2001)13, pp 559-569

2067 Roelofsen EE, Lankhorst GJ, Bouter LM

Simultaneous development and implementation of the Children's Rehabilitation Activities Profile; a communication instrument for pediatric rehabilitation in: Disabil and Rehabil, 23(2001)14, pp 614-622

2103 Roelofsen EE, The BA-M, Beckerman H, Lankhorst GJ

Development and implementation of the Rehabilitation Activities Profile for children: impact on the rehabilitation team

in: Clinical Rehabilitation, 16(2002), pp 441-453

2120 Rossignol C

La "Classification" dite CIF proposée par l'OMS peutelle avoir une portée scientifique?

in Handicap, revue de sciences humaines et sociales, (2002)94-95, pp 51-94

2061 Rumpt J

De theorie van het bewegingscontinuum in: Ned Tijdschr Fysiotherapie, 111(2001)2, pp 38-42

2072 Schuntermann M

Internationle Klassifikatio der Funktionsfähigkeit, Behinderung und Gesundheit (ICF) der Weltgesundheitsorganisation (WHO) -Kurzdarstellung

in: Phys Med Rehab Kuror, 11(2001), pp 229-230

2098 Spencer J, Hersch G, Shelton M etc.

Functional outcomes and daily life activities of African-American elders after hospitalization in: Am J Occup Ther, 56(2002)2, pp 149-159

2121 Stiker H-J

Analyse anthropologique comparée de deux classifications: Classification internationale du fonctionnement, du handicap et de la santé (OMS) et Classification québécoise dite Processus de production du handicap (Société canadienne pour la CIDIH) in: Handicap, revue de sciences humaines et sociales, (2002)94-95, pp 95-110

2073 Stucki G, Cieza A, Ewert T

Die Perspektive der Rehabilitationsmedizin zur ICF in: Phys Med Rehab Kuror, 11(2001), pp 231-232

2064 Stucki G, Cieza T, Ewert T [et al.]

Application of the Internationale Classification of Funtioning, Disability and Health (ICF) in clinical practice

in: Disabil and Rehabil, 24(2002)5, pp 281-282

2101 Svestkova O

Conceptual framework for rehabilitation in the Czech Republic: a proposal in: Disabil and Rehabil, 24(2002)15, pp 798-801

2097 Tenenbaum A, Rivano-Fischer M, Tjell C,

The quebec classification and a new Swedish classification for whiplash-associated disorders in relation to life satisfaction in patients at high risk of chronic functional impairment and disability in: J Rehab Med, 34(2002)3, pp 114-118

2069 Tschala-Katumbay D, Edebol Eeg-Olofsson K [et al]

Impairments, disabilities and handicap pattern in konza, a non-progressive spastic para/tetraparesis of acute onset

in: Disabil and Rehabil, 23(2001)16, pp 731-736

2071 United Nations

Guidelines and Principles for the Development of Disability Statistics

Statistics on Special Population Groups Series Y no. 10 (UN), New York 2001

2112 Verhoeven JD

Van ICIDH naar ICF: consequenties voor claimbeoordeling en kansen voor reintegratie in: TBV, 10(2002)11, pp 328-331

2111 Willems, H, Kleijn-de Vrankrijker MW de

Work Disability in the Netherlands: Data, Conceptual Aspects, and Perspectives in: J Occup Environ Med, 44(2002), pp 510-515

2116 Wright M, Garcia LJ, Neault MJ, Fergus SL

Use of the Disability Creation Proces Model (DCPM) in the Evaluation of Language of Dementia in: Human Development, Disability and Social Change, 11(2001)1, pp 36-49