WHO Collaborating Centre for the FIC in The Netherlands

rivm
National Institute for Public Health and the Environment

WHO Family of International Classifications (FIC)

NEWSLETTER

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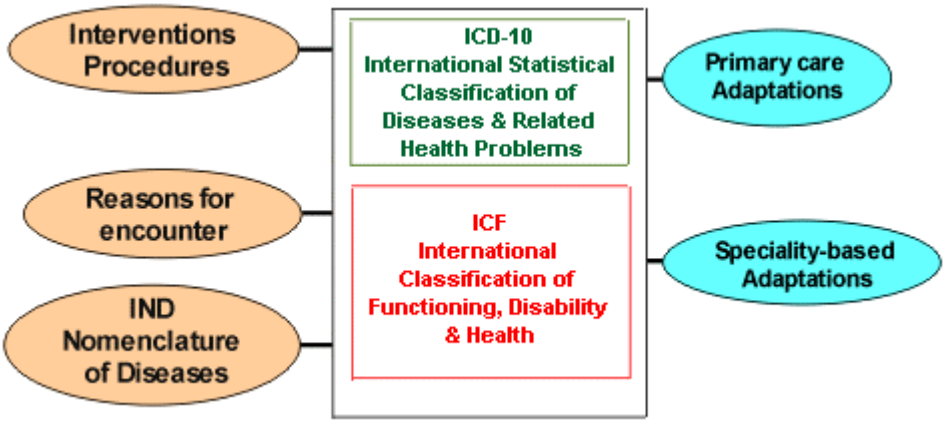
# From ICF to FIC

In Newsletter 10, the WHO Collaborating Centre announced as Dutch title for the ICF **I**nternationale **c**lassificatie van het menselijk (= human) **f**unctioneren. This title was published by accident on the title page of the book, published in April 2002, see page 21 for more information.
In consultation with the WHO in June 2002 it was decided to stick to the English title and an erratum page will accompany the first print run, changing the Dutch title into: ICF, Nederlandse vertaling van de (= Dutch Translation of the) 'International Classification of Functioning, Disability and Health'. In this way full credit is given to the intention of the WHO to mention all three core terms of the title. This solves the difficulty that no real Dutch equivalent for the term 'disability', as umbrella term, is available.

The 2001 Heads of Centres meeting in Bethesda (see page 2) was the first one explicitly dedicated to both, ICD and ICF, as the core of the Family of International Classifications (FIC). A picture of the WHO-FIC can be found on the following WHO home page: www.who.int/classification/




This change will also have consequences for the Dutch Centre and its newsletter. The centre will be called WHO-FIC Collaborating Centre. Its terms of reference and work plan will be published after the forthcoming redesignation. The former ICIDH Newsletter will not automatically change into an ICF Newsletter, but will be a Newsletter on the WHO-FIC, as you can see in the footer. However, this first issue is still dedicated to the ICF. See further our new website www.rivm.nl/who-fic



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# Editorial

*In spring 2001 the 54th World Health Assembly endorsed the International Classification of Functioning, Disability and Health (ICF) for international use. The acceptance of the ICF as the successor of the ICIDH meant the end of the ICIDH revision procedure which lasted several years with the contribution of many persons from all over the world, and the beginning of a lot of new actions as well.*

*The ICF was launched in Bethesda (Maryland, USA), preceding to the Heads of Centres meeting in October 2001. WHO presented the ICF in English as a full and a short version (pocket size), on cd-rom and 5 other language versions (Arabic, Chinese, French, Russian, Spanish). The WHO Conference on Health and Disability (April 2002, Trieste, Italy) offered the opportunity to pay international attention to the ICF and its possibilities. See this page for more information about the Bethesda meeting and the Trieste conference. ICF related information provided by WHO is to be found on:* www.who.int/classification/icf.

*Many centres and countries started ICF translation and implementation activities. We know of several translations already available or on their way, e.g. Czech, Dutch, German, Italian, Japanese, Slovenian,and several Nordic languages. To translate the ICF is a heavy task which takes a lot of time and energy. It gives a great advantage to those who don't have to translate because the adequate language version is provided by WHO, e.g. the North American Collaborating Centre spent two days on implementation issues during the 8th conference on ICF (June 2002, Toronto, Canada). See 'ICF around the world' in this newsletter.*

*Other international organizations gave attention to the ICF as well. The UN Statistics Division issued recently "Guidelines and Principles for the Development of Disability Statistics" (UN, New York, 2001, ISBN 92-1-161442-2) and integrated the concepts of the ICF as much as possible within the existing experience on the development of disabiliy statistics described in the publication. The UNSD disability database DISTAT with information on disability prevalence rates from national studies is organized according to the ICIDH, the influence of ICF will be considered (see http://esa.un.org/unsd/disability). The UN Washington City Group on Disability Statistics accepted the ICF as a framework for its work (see page 3).*
*At least three international journals will dedicate a full special issue to the ICF (see pages 3 and 4).*

# International Organizations

## World Health Organisation

### Meeting of Heads of WHO Collaborating Centres for the Family of International Classifications Bethesda (USA) October 2001

The most recent annual meeting of Heads of WHO Collaborating Centres for the Family of International Classifications was held in Bethesda, Maryland, USA from 21 to 27 October 2001. Details of discussions and work to be done are described in the full report of the meeting. Nearly one hundred papers have been presented. Both, report and papers, are available from the WHO website. The agenda items were:

- Implementation of ICD-10 Committee
- Subgroup on Training and Credentialling
- Update Reference Committee (URC)
- Mortality Reference Group (MRG)
- Electric Tools Committee (ETC)
- International Classification on Functioning, Disability and Health (ICF)
- Family Development Committee (FDC)
- Implementation of automated coding systems for mortality
- Terminology and mapping with ICD-10 (including SNOMED-CT)
- Guidelines for hospital morbidity coding
- Improving coordination of vital registration activiteis at the international and national levels
- Host centre presentations
- Presentation and discussion of scientific papers

Documents relating to ICF: 41, 47, 55, 58, 60, 64, 66, 68, 70, 87, 93, 96.

For information:
Papers to be found on
www.who.int/whosis/bethesda
Report of the meeting to be found on
www.who.int/whosis/icd10/collabor.htm

### WHO Conference on Health and Disability

A conference on Health and Disability organized by WHO in cooperation with the Italian Ministry of Health and the Italian region Friuli-Venezia Giulia was held in Trieste (Italy) April 18-20, 2002. Aim of the conference was to discuss disability within the context of health and the role of the ICF in improving information on disability and health.
The international conference was attended by 200 persons representing 75 countries. Topics of the programme:

- health and wealth of nations
- disabled and healthy?
- What is wrong with disability statistics?
- ICF and health information systems
- ICF in clinical practice
- ICF in surveys

Papers and report of the international conference will be available through the website: www.sanita.fvg.it

For a brief report on the preceding Italian conference (April 17, 2002), see elsewhere in this newsletter (Italy, Presentation of the Italian version of the ICF).

For information:
www.sanita.fvg.it

## United Nations

### UN Washington City Group on Disability Statistics

As a result of the United Nations International Seminar on Measurement of Disability (New York, June 2001) it was recognized that statistical and methodological work is needed at an international level in order to facilitate comparison of disability data cross-nationally. For this reason the UN Statistics Division authorized the formation of a City Group. The first meeting was organized in Washington by the National Center for Health Statistics (Feburary 18-20, 2002) and so the name of the group became to be: Washington City Group (WCG).

During the first meeting of the group attended by 58 participants from 30 national statistical offices of 30 countries and representatives of several national and international organizations the following objectives of the WCG have been agreed upon:
to guide development of a small set of comparable general disability measures for censuses and national surveys;
to recommend one or more extended sets of survey items to measure disability in population surveys or specialty surveys;
and to address methodological issues associated with disability measurement.

Derived from these general objectives the group decided for a next meeting to aim at:
Ad 1 completion of a matrix linking various purposes of disability measurement with question characteristics; evaluation of measures currently in use and test results;
Ad 2 exploration and discussion of sets of measures related to the general measures with special attention for activity (limitations) vs participation (restrictions) and environmental factors (ICF terms and concepts);
Ad 3 discussion of methodological areas like special populations (e.g. mental health problems) and use of administrative data (alone or in conjunction with census/survey data).

For information:
Papers and the full report of the first city group meeting are available through the website
www.cdc.gov/nchs/citygroup.htm

# International Journals

### Disability and Rehabilitation

A special issue of the International Journal Disability and Rehabilitation on ICIDH/ICF edited by Marijke de Kleijn - de Vrankrijker is being prepared and expected to be available by the end of 2002. Aim of this special issue is to show the use and role of the ICIDH up to now and the potential role of the ICF as the successor of the ICIDH. In several papers contributed by authors from all over the world attention is paid to a variety of aspects, applications and professions:
- Introductory paper by WHO (ICIDH revision process, rationale for the ICF and the needs that it serves in rehabilitation).
- The International Disability Rights Movement perspective and the ICF versus ICIDH.
- New and missing elements in the ICF: measurement of participation and the role of environment (both new elements) and the subjective dimension (missing element).
- Special populations (persons with mental disorders and children)
- Health care (allied health professions including nursing, rehabilitation, emergency services).
- Surveys, statistics and related issues.

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### Handicap – Revue de Sciences Humaines et Sociales, N°94-95: From ICIDH to ICF

The Summer 2002 issue of the quarterly *Handicap–Revue de Sciences Humaines et Sociales* (published in French, with English and French abstracts and table of contents), to come out in September, will be dedicated to the classifications of disability.
After an introduction by the French WHO Collaborating Centre on the revision process of the ICIDH (framework of an international normalization process ; national social policy issues at stake in the reception of a new paradigm of disability ; evolution of social representations of disability), the articles present sociological approaches of some theoretical, methodological and political issues that the new WHO classification raises.

A comparative analysis of the Quebec Classification ("Disability Creation Process") and the WHO's classification : an analysis of the anthropological models of disability, health and citizenship underlying these two classifications, by Henri-Jacques Stiker (Paris VII University).
From disadvantage to social participation : stakes and changes in the field of disability. What does the switch from an integration approach to a participation approach imply in terms of social policy, practice and expectations of the disabled person, by Serge Ebersold (Strasbourg University).
Converging and contradictory approaches of environmental factors in six classifications of health : ICIDH, ICF, ICD 10, DSM IV, Quebec Classification and the French Classification of Children and Youth Mental Disorders (CFTMEA), by Jean-Yves Barreyre (social science researcher).
Methodologies of assessment of the involvement and access to participation of the disabled person in special institution, using ICF, by Marc Brzustowski (National School of Public Health- Rennes)
From theory to practice : Consequences of the new disability paradigm for social policy in a European perspective, by André Gubbels (DG Employment and Social Affairs, European Commission)

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### Social Science and Medicine

Social Science and Medicine have agreed to publish a Special Issue on the ICF in the near future. The issue will be edited by Bedirhan Üstün and Jerome Bickenbach and consist of articles covering a wide range of ICF applications:

- The ICF: A new Understanding of Health and Disability, by T.B. Üstün, S.Chatterji, et al
- Demystifying disability through the context of the ICF? by R. Imrie
- The ICF Model of Disability: Implications for Disability Research by S.Chatterji, J. Bickenbach, et al.
- Environmental Factors in the ICF, by R. Hurst, J. Miller, and M. Schneider
- Mental Health and the ICF, by C. Kennedy and S. Chatterji
- International Classification of Functioning, Disability and Health (ICF): Toward a universal classification of disability in childhood by R. Simeonsson , M. Leonardi, et al
- Operationalizing ICF in a Clinical Setting by G. Reed and J. Lux
- ICF in Developing Countries by R. Thara, R. Vrasti, A. Chaker, J. Jelsma, M.A.Gomez, B.Ulug, Qiu Zhuoying
- Cross-cultural Variations in Perceived Thresholds for Physical, Mental and Substance use-Related Disabilities by R. Room and A. Pagila
- ICF and Social Policy by J. Bickenbach and David Gray

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# Other international contributions

### ICF from the perspective of deaf people

As deaf people around the world have not been informed about ICF (International Classification of Functioning, Disability, and Health) yet, it may be too early to describe their reaction. Instead I will use my knowledge of deaf people and their activities, acquired both during my visits to many countries, both developing and industrialized, and by reading monthly periodicals of the deaf to predict what reactions they will likely have. Here I must add that the monthly conference calls and occasional face-to-face meetings of DISTAB (a US-sponsored international committee on disability tabulations) in which I have participated through sign language interpreting services, expanded my understanding of the implications of ICF considerably.

ICF will certainly be welcomed by deaf people for several reasons. First, ICF has finally recognized hearing loss as a part of health. Like eye glass users, hearing aid or sign language users will not have to be viewed as unhealthy individuals or as medical cases any longer. They have for a long time been opposing the popular but still superficial assumption that the restoration of hearing would be required for health recovery. In fact, the life of most deaf people, including illiterate ones, has never been different from that of others in any daily activity except the activity of hearing. Knowing that their hearing loss is incurable, most deaf individuals, like other disability groups, have already accepted hearing loss as a non-threatening as a part of their health - a fact again confirmed by ICF. Hearing aids can be useful for those who have residual hearing and still desire to rely on hearing for participation. Those who have lost their hearing in late childhood or adulthood and those who still want to appreciate hearing for some reasons may want to use cochlear implants. These individuals have the right to believe that the restoration of hearing is important for their mental health. Since the restored hearing will never be identical to the congenital functioning hearing, they may again need emotional and social support from the more experienced ones.

Second, recognizing the importance of accessibility for participation in the social life for health maintenance, ICF has now included sign language, sign language interpretation, TV captioning, relay services for voice calls. In the past, deaf people had to visit their club weekly in order to share their disappointments, frustrations, thoughts, achievements and strategies for survival purposes. They knew that such social life was vital for their mental health. At that time, deaf people had no or severely limited access to daily communication in addition to mass media and telecommunication. In fact, both “isolation” and “silence” were the terms frequently used in their daily vocabulary. These words now are rarely used. Such accessibility has increased participation in societal activities and has also enabled deaf individuals to function BOTH within and outside their own group. In turn, it increases their self-confidence, self-reliance, or self-empowerment which again can reinforce their mental health.

Third, ICF will give deaf, deafened, and hard of hearing individuals a clear impression that hearing loss is neither a dead activity nor an end to the daily life because they can now acquire appropriate devices or services in order to increase their access to mass media, telecommunication and meetings where the use of hearing is prevailing. According to ICF, hearing, as an activity, must range from functioning to non-functioning. Most deaf people, however, prefer to be recognized as individuals identified with their own community, not as cases of hearing loss. In English and other languages where the capitalization of initial letters is permissible, the capitalized

"Deaf" has recently been adopted as a term.

Fourth, national organizations of the deaf will certainly recognize ICF as a powerful tool in their process of proposing policies or laws to the government and the parliament. ICF requires information about not only the numbers of persons with hearing ranging from functioning to non-functioning but also the use of hearing aids and interpreting services and the availability of TV captioning and relay services. This potential wealth of statistical information can enable deaf consumers not only to improve the quality of their proposals but also to make contributions to standardization.

Fifth, by having adopted the social and medical models of disability, ICF will soon expect organizations of the deaf or deaf individuals trained in the scientific inquiry to share their experiences and expertise with researchers. In this new way, deaf people and researchers will likely work together on the standardization of their terms or vocabularies. For example, "hearing impaired" - a term invented by researchers but now rejected by both deaf and hard of hearing people - is disappearing from the national vocabulary in many countries. Only two countries in Europe and probably in the world use "hearing-lost" instead of "deaf."

Before closing, we must keep in mind that like other official policies or laws, ICF will have to be revised and again revised whenever our understanding of health or disability increases. For this reason, both deaf people and health professionals have the obligation to improve the applicability of ICF by making health surveys periodically.

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# ICF around the World

## Africa

### United Nations Workshop on Disability Statistics for Africa

The United Nations Workshop on Disability Statistics for Africa was organized and sponsored by the United Nations Statistics Division (UNSD) and co-hosted by the Uganda Bureau of Statistics (UBOS) and the Population Secretariat of Uganda (Popsec). It was held in Kampala, Uganda, from 10 to 14 September 2001. The Workshop was attended by 30 participants from national statistical offices and government ministries responsible for making policies on disability matters. Eleven countries[1] were represented at the workshop.
The workshop was aimed at promoting the relevance of disability statistics in the African region through improved methods of measurement based on the WHO *International Classification of Functioning, Disability and Health (ICF)*[2] framework as well as concepts and definitions in the design of questions. The workshop also aimed at highlighting the importance of dialogue between users and producers of statistics in the planning and collection of data as a way to improve the reliability and utilization of data on persons with disabilities in policy formulation.
The workshop addressed methodological issues related to disability measurement, including the use of the ICF conceptual framework in disability measurement; use of the ICF concepts and definitions in developing questions on disability and classification of the produced data; identifying users' needs and dialogue among users and producers of disability data; special issues on formulating questions to assess disability; special issues in interviewing persons with disabilities; and special topics on disability with reference to women and refugees.

Lack of reliable and comparable data on disability in the African region was identified at the meeting as a critical bottleneck to effective planning and development of programmes for persons with disabilities. The meeting also stressed the importance of reliable information based on clearly defined concepts and definitions, and using appropriate instruments in the regular population and housing censuses and surveys. This is necessary for the mainstreaming of disability issues into the regular data analysis.

To promote the exchange of experiences between countries as well as regions, a review of the experience of the Asian and Pacific Decade of Disabled Persons (1993-2002) and of disability data in the ESCAP region was provided. This was done in recognition of the African Decade of Disabled Persons (2000-2009). The presentation included a discussion of the Decade's aims, agenda and target areas based on the *World Progamme of Action Concerning Disabled Persons*,[3] and of progress made in the implementation of the Asian Decade.

During the workshop, participants were introduced to the ICF as a conceptual framework for disability measurement and to its potential for application in data collection. The session drew attention to the low rates of disability prevalence in African studies and indicated how the use of the ICF framework in the development of questions, might provide a much broader definition of the population being identified as having disabilities. Use of the *ICF* in framing numerous areas of *The*

[1] Egypt, Ethiopia, Kenya, Namibia, Nigeria, South Africa, Sudan, Tanzania, Uganda, Zambia, and Zimbabwe

[2] *International Classification of Functioning, Disability and Health: ICF.* Geneva, World Health Organization, 2001.

[3] The World Programme of Action concerning Disabled Persons was adopted by the General Assembly in its resolution 37/52 of 3 December 1982.

*Standard Rules on the Equalization of Opportunities for Persons with Disabilities*[4] as elements of the Participation dimension was discussed and there were exercises focused on setting policy priorities using the *Standard Rules*, and then translating the elements into disability items for use in surveys. The *Integrated National Disability Strategy*[5] paper from South Africa was used as the model for policy development. Emphasis was placed on the inclusion of people with disabilities in the process, from policy identification to item development to methods of collecting data.

In the group sessions, participants developed questions to identify persons with disabilities, based on the ICF framework. The exercises included both data users and producers, and for many of the participants it was the first time for the two groups to work together. In the development of the questions, special attention was paid to the use to which the data would be put as a guide to what component of the ICF to include in the measurement. The questions developed by the participants, were used in group sessions to conduct live interviews on persons with various types of impairments. The live interviews provided the participants with a real life situation on how to interact with persons with disabilities in an interview, and also on how the interviewees interpreted and responded to the questions. The participants also had an opportunity to put into practice what they had learnt regarding (i) formulating questions that are ICF-based and that do not include potentially offensive terms, and (ii) special issues of interviewing persons with disabilities.

An analysis of the constraints of data collection systems emphasized weaknesses according to the system selected, as well as issues related to measurement error, disability definitions, and balancing the needs of data producers and data users. Issues related to cultural influences on reporting limitations were discussed, along with the substantially lower disability prevalence rates when using an impairment approach to identifying people with disabilities in censuses or surveys—that is, framing questions related to being blind, deaf, or mute. The probable underreporting of disability using questions, such as "Are you handicapped?", or "Are you disabled?" was also discussed.

Participants developed the following recommendations:

1 For the majority of the countries in the region, the census is the only source of information on the number of persons with disabilities and on the types of their disabilities. Countries are, therefore, encouraged to allocate funds for the inclusion of disability questions in population and housing censuses as well as in surveys.

2 There is a need to involve stakeholders in the process of developing data collection instruments to measure disability and in various activities in the planning process to collect, tabulate and dissemination data on disability. The participation and inclusion of persons with disabilities in the user/producer dialogue is highly recommended.

3 The ICF concepts should be used in the measurement of disability. This would encourage the use of common definitions and neutral terminology and would improve data comparability in the region. Training on the use of basic ICF concepts for statistics should be supported.

4 The following principles should apply in the design of questions to identify persons with disabilities:

- The questions should refer to activity limitations;
- The questions should ask for activity limitations in the context of a health condition;
- The questions should ask for type of activity limitation;
- The questions should allow the respondent to classify his/her degree or severity of activity limitation. Instead of response categories that include only yes/no options, response scale should be designed to include several response options, such as, none/a little/a lot; Yes, sometimes/Yes, often/No);
- The questions should include a time reference to distinguish between long-term and short-term limitations.

5 In light of the African Decade of Disabled Persons, there is need to strengthen and streamline the collection of data on disability into the general data collection system. Data collection should be aimed at the implementation of an identified policy concern. The United Nations Statistics Division (UNSD) and the United Nations Division for Social Policy and Development should provide guidance towards the realization of the objectives of the African Decade of Disabled Persons and of the Workshop.

6 Countries should maintain a network of persons involved in the measurement of disability in the region to facilitate the exchange of information on methodologies used and results obtained. In this regard, the UNSD should act as a facilitator.

7 Regional statistical institutions should take an active role in the implementation of objectives of the African Decade of Disabled Persons by fostering the networking of countries and experts in disability measurement in the

[4] Adopted by the General Assembly in its resolution 48/96 of 20 December 1993 and published under the title, *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (United Nations publication, Sales No. E.DPI/1454).

[5] Integrated National Disability Strategy, White Paper. South Africa, Office of the Deputy President, 1997.

region, with a view to improving methods of collecting disability data in the African region.

8 Awareness sessions about persons with disabilities should be included at workshops on disability statistics. Topics on awareness could include such issues as the portrayal and treatment of persons with disabilities, their rights, needs, potential, and obligations.

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## Asia

### Translations and regional conference

The Japanese translation of the ICF was made by the Japanese Ministry of Labor, Health and Welfare and expected to be published by the end of July 2002. The Chinese version is already available from WHO. We are not informed about other translations in the Asian region, but may be others are on their way as well.

The 12th Rehabilitation International Asia and the Pacific Regional Conference in conjunction with the Campaign 2002 to promote the Asian and Pacific Decade of Disabled Persons will be held in Osaka, Japan, October 21 – 23, 2002. In this Osaka Forum the RI Social Commission will have a seminar on October 22, 2002 with the topic "What is disability: recent development of the concept and its impact to policy and intervention". Attention will be paid to the changing concept of disability and to a critical apraisal of ICF and its impact.

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## Australia

### ICF in rehabilitation

To the heads of centres meeting in Bethesda October 2001 an Australian paper has been presented which can be of interest for the readers of our newsletter: Possible application of International Classification of Functioning and Disability and Health (ICF) in Rehabilitation by Catherine Sykes, Ros Madden & Jenny Hargreaves, the Australian Institute of Health and Welfare.

The paper presents a definition of rehabilitation and relates the different information needs of three phases of rehabilitation (Primary/acute, Secondary/medical and Tertiary/vocational) to the different components of the International Classification of Functioning, Disability and Health (ICF).
The paper looks at how some assessment tools commonly used as measures of rehabilitation outcomes can be mapped to ICF domains and the generic qualifier and also to the International Classification of Diseases (ICD). From this exercise it is apparent that the scope of the assessment tools is limited and it is suggested that tools to assess disability across the full range of domains of the ICF are yet to be developed.
The paper concludes that together the ICD and the ICF provide a framework for the collection of rehabilitation data. It is suggested that the key next steps for a rehabilitation data collection are to clarify and separate the different concepts for which information about rehabilitation patients is required; and to clarify the respective roles of ICD and ICF and other potential members of the WHO Family of Classifications. The ICD and ICF are freely available in six languages for use by countries without the resources necessary to access proprietary tools. There would be value in evaluating new rehabilitation tools, especially proprietary measures not widely available in the public domain, in the context of the ICD/ICF framework.

The full paper (document 58) may be accessed from the WHO website www.who.int/whosis/bethesda

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## Belgium

### ICF as a point of reference in the conceptualisation of chronic diseases

In the Western world there is a growing prevalence of chronic diseases (World Health Organisation 1997). The social prevalence of chronic diseases in family practice is 52%: one out of two patients visiting their GP, are confronted wit chronic disease either as patient or carer. (Knottnerus J.A. *et al.* 1992). People and patient organisations of all kinds are persuaded that the health care systems have a major role in organising and financing the care for chronic and depending patients. Managing these medical and health care problems will become a major challenge for the health care systems. Therefore the society, facing these problems, needs clear concepts. There is no linear correlation between the presence of a chronic disease on the one side and the need of care, finances or other support at the other side. This is in contrast with the perception in the population and the lay press that every person with a chronic disease is in big need of care and needs financial and other support.

One of the essential advantages of the ICF is the positive way one looks at human functioning. When a classification tool like ICF uses positive premises and the integration of physical, mental, social and environmental aspects of functioning, another attitude can be introduced in the world of health care.
In this perspective it is our opinion that the ICF can be worthwhile in the conceptualisation of concepts like chronic disease.

In daily practice and in multidisciplinary contacts it seems to be clear what chronic diseases are. However, there is a major problem of subjectivity or personal perception concerning what a disease is. Physicians and patients, although having the same sociological and cultural background, have a different perception of disease (Helman 1994). For chronic disease we use the definition of developers of the International Classification of Primary Care: *"A chronic disease in general practice is a period of care for a welldescribed disease lasting for a longer period. Its severity causes a reduction in acitivities which are perceived as 'normal' for the age and sex of the patient…. A long period is defined as longer than six months. De term' chronic' implies nothing concerning severity or stage of the disease".* (Okkes, Oskam, and Lamberts 1998)
In this definition there is an important reference to daily activities that are perceived usual and normal for the age and gender of the patient. The question arises how to describe (ab)normality. Here we strongly suggest to use the positive aspect of ICF as the main frame of reference.
*Chronic patients are people having a disease lasting for more than six months in a way they have, without treatment and medical follow up, major activity limitations and participation restrictions in the sense stated by ICF* (World Health Organisation 2001). It is clear that we make a distinction between patients with a chronic disease and chronic patients.
Managing chronic diseases/patients then covers all medical and paramedical acts and interventions to prevent further loss of body functions and body structures (domain 1 of ICF) as well as all social and psychological activities and interventions (domain 2 of ICF) to diminish the activity limitations and participation restrictions people experience by well described chronic diseases.

The development of a concept like chronic disease can be stimulated and marked by the premises of the ICF. When patients, carers, health care providers and policymakers will use the ICF paradigm, which in its essence is a competence model, as a point of reference, managing and financing the care for chronic patients will have another dimension. Efforts have to be done by policy makers, academic experts, clinical experts and all people involved in this field, to promote the paradigm shift that is proposed by the WHO by editing the ICF.

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# Czech Republic

## Czech ICIDH and ICF experience

The Czech Republic has participated in ICIDH work from 1982. From the very beginning there was a close cooperation with the WHO Collaborating Centre for the ICIDH in the Netherlands.

**Seminars**

Over the last ten years several national and international seminars have been organized concerning ICIDH and ICF. In 1992 the Department of Rehabilitation Medicine First Medical Faculty Charles University in Prague established a "WHO Collaborating Center for Rehabilitation for all" and organized two meetings (1994 and 1996) with international participation focusing at the IC IDH.
In cooperation with the Ministry of Health of the Czech Republic and professionals from Germany, the Netherlands, Hungary and Slovakia the Department of Rehabilitation Medicine First Medical Faculty Charles University in Prague organized a seminar about ICIDH and ICF (24 September 2001).
In collaboration with the Ministry of Health of the Czech Republic, the University of Cologne and the city Hospital of Cologne (Germany) the Department of Rehabilitation Medicine organized a seminar "The use of the International Classification of Functioning, Disability and Health of WHO. System, organization and funding of the rehabilitation in Germany and the Czech Republic" (26 March, 2002). And in addition a seminar "Rehabilitation at present" took place 27 March 2002.

**Rehabilitation**

The Ministry of Health of the Czech Republic published the guide „The activities of rehabilitation centers" in 1997 drawn up according to the ICIDH.
On the basis of the discussion between the Ministry of Labour and Social Affairs and the Ministry of Health of the Czech Republic on the 1st of July 1999, a working group was set up. Its goal was to propose a concept of the System of Rehabilitation in the Czech Republic and to prepare by May 2002 the Law of Rehabilitation in the Czech Republic based on ICF principles.

**Translation**

ICF was translated into the Czech language by the end of February 2002. The translation was funded by Department of International Relations of the Ministry of Health. Prof. Pfeiffer, the emeritus head of the Department of Rehabilitation Medicine the First Medical Faculty Charles University, translated the full classification. The Ministry of Health

published the ICF in paperback in March 2002. Participants of seminars and members of professional organizations (of psychologists, physical therapists, occupational therapists, speech therapists, social workers) received the translation for comments.

**National committee**
A national committee for cooperation with WHO under the leadership of deputy minister of health Michael Vít MD was established on the basis of the proposal by Olga Švestková MD. Members of this " Committee WHO for ICF" are representatives of the Ministry of Health, the Ministry of Labor and Social Affairs, the Ministry of Education, the Government Committee for People with disabilities, representatives of the Medical Faculty of Charles University and of the Czech Medical Association of Rehabilitation and Physical Medicine. Two representatives from Slovakia (Assoc. Professor Miroslav Palat MD and Maria Orgonasova MD) became the close co-workers of the committee. Because the Czech and Slovakian language are so close to each other we can cooperate even during the translation process.

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## Denmark

### ICF as framework in developing better information about functioning, on patients with traumatic head injuries-after discharge from intensive rehabilitation setting

**Introduction**
By discharge from rehabilitation setting, many patients with severe traumatic head injuries and relatives report on poorly coordinated intervention in a complex social sector. The county of Frederiksborg, Denmark, was given extensive funds from the Danish ministry of Social Affairs, in order to make an intervention study to develope the quality of information and coordination between sectors. One of the crucial determinants for better information and coordination between professionals, are identified as the different professional languages. The disciplinaryspecific terminology does not seem to provide the nessecary information, for identifying the patients needs after 1st discharge. This paper will concentrate on the ICF perspective.

**Purpose of the study**
The purpose of this intervention study is to make a better coordinated intervention for patient with traumatic brain injuries after 1st discharge, with the use of ICF as framework.

**Methods**
ICF was used as framework in the development of an electronic record, which follows the patient after discharge. The record is updated by each professional, who is in contact with the patient. Multidisciplinary teams identified 46 items from ICF, considered as most important variables for describing the current functioning. Assessment is done by 1st discharge from special rehabilitation setting.

**Initial results**
The structure of ICF and the defintions on item level seem to meet the need of professionals to create a meaningfull and uniform professional language about functioning in the multidisciplinary team. Difficulties with using the qualifiers are identified and special coding conventions has been designed especially for this study, as the suggested coding conventions from the ICF, Final Draft, was considered not to be applicable for this intervention study.
The study is ungoing, and the electronic record is still under development. Monitoring procedures over the coming 2 years. Hereafter it will be considered as a tool, which can be implemented into other rehabilitation settings, in order to give better information between sectors about the patients needs after discharge.
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The full paper presented to the Bethesda meeting (October 2001, document 47) may be accessed from the WHO website: www.who.int/whosis/bethesda

## Germany

### ICF: the German experience

This paper is a revised version of a presentation given at the seminar „The International Classification of Functioning, Disability and Health, ICF (ICIDH-2), WHO", Ministry of Health of the Czech Republic, Praha, 24 September 2001

**The German view**
"Disability" is not an abstract term for it concerns human living. Thus, if we talk about disability we are actually thinking of the evaluation and prevention of disability, as well as overcoming disability. Moreover, we also have in mind human rights, as well as social, disability and rehabilitation politics.

"Disability" is a health-related term. That means the disability process begins with a health problem, for example a disease, disorder, injury, or trauma. Independent of the health problem an individual may then experience disability as a phenomenon in its own right, which hinders him or her in performing activities he or she wants to do, or in living an independent life, and the disability process may develop a momentum of its own. For this reason, "disability" is a phenomenon which is to be regarded over and above any existing bio-medical health problem.

Traditionally, a severe abnormality of a body structure or a loss or deviation of physiological or psychological functions were viewed as a disability. The old conflicting positions: "An individual is disabled" and "an

individual becomes disabled", are now dialectically resolved by the bio-psycho-social model of the World Health Organisation (WHO), which underlies the International Classification of Functioning, Disability and Health (ICF) from 2001. Within this model a disability of an individual is defined as the negative result of the interaction between both his or her health problem and his or her contextual factors (environmental factors, personal factors). The relative weight between both these factors may vary from 0 % to 100 %, depending on the nature of the problem. Theoretically, there is only one case in which disability is independent of contextual factors, namely, if the disability remains the same in any set of contextual factors.

In the ICF disability is defined as any restriction of functioning. "Functioning" is the basic term of ICF. It includes all aspects of functional health within the three dimensions (1) body functions (including the psychological area) and structures of the organism, (2) activities of an individual and (3) participation of an individual in life areas, e.g. working life. Environmental factors, in particular, may facilitate or hinder participation. Inversely a disability can be reduced or eliminated not only by rehabilitation activities but also by improving the environmental conditions. For this reason, both rehabilitation and disability politics should be co-ordinated. Otherwise, rehabilitation cannot achieve its aims, namely those of improving abilities and improving participation. Both aspects of the ICF are considered in the German Social Code No. IX (SGB IX) of 2001 and the Antidiscrimination Act of 2002.

**Participation in the revision process of the ICIDH**

The WHO first published a classification of functional health restrictions in 1980. It was called "International Classification of Impairments, Disabilities and Handicaps", for short: ICIDH. Since that time more than 3000 papers on ICIDH have been published; but practical experience and theoretical considerations made it necessary to revise the original ICIDH. The revision process started in 1993 and the result of the process, the ICF, passed the Assembly of WHO in May 2001.

It must be admitted that in spite of the efforts of rehabilitation experts such as Professor Jochheim, former President of Rehabilitation International, who tried to introduce ICIDH in Germany, the classification was slow to receive general recognition. The first translation was published in 1989 in the German Democratic Republic. After the Re-union a revised version of the translation was worked out in co-operation with Austria and Switzerland. This version - with a supplement of 16 papers on ICIDH - was published in 1995. Since then a large number of experts, particularly those working in rehabilitation, have taken note of the ICIDH, and, of course, controversial discussions constantly take place regarding its meaning, purpose and practical relevance within the field of rehabilitation.

When the second translation of the ICIDH was published in 1995, the revision of the classification was already underway - a process in which Germany took part. The VDR promoted the revision process and supported the German activities financially. The Department of Rehabilitation Sciences of the VDR co-ordinated the activities for the German speaking countries. A German Working Group on ICIDH has been established which includes associations of people with disabilities as well as societies, ministries in the fields of rehabilitation, rehabilitation physicians and representatives of other professional groups. A large group of professionals translated the so called Beta-1 version and Beta-2 version of the ICHDH-2 (working title of the ICF during the revision process). This group was now very experienced in the translation of WHO English so that the ICF could be translated within three months. All translation work was done without royalty. We then published the comparison of both, the original ICF and the draft of its German translation in internet (www.vdr.de, rehabilitation, ICF) for public correction and remarks in January 2002. This procedure was very successful. The results were discussed at the Consensus Conference on the German translation of the ICF in February 2002, and many of the correction proposals were adopted. Moreover, linguistically difficult terms and phrases of the original ICF were translated back into English by a native speaker (physiotherapist) in order to check the translation. Over years we had discussed several translations of the ICF term "functioning" because in German there is no proper analogue which can be applied to human beings. Finally, the representatives of Austria, Switzerland und Germany decided to translate it in the sense of "ability to function", German: "Funktionsfaehigkeit", and to use it only as a technical term of the ICF. We, however, are not happy about both, the English term and the German translation. During the translation process several mistakes or uncertainties were detected in the ICF (e.g., b4200: see WHO recommendations; b7201 – b7203) which should be eliminated in a second edition of the ICF.

**Applications in Germany**

Due to the fact that the ICF has been published by WHO just recently, application of the classification in Germany can only be discussed on the basis of the ICIDH of 1980 – although it can be said that the ICF is already making itself felt.

The following represents some of the German experiences to date.

The ICIDH or ICF respectively has been taken in account in the following areas:

1. The legal definition of disability of the Severe Disabled Persons Act is based on the Model of Consequences of Disease of the ICIDH.
2. The ICF (ICIDH) plays an important role in the training for the medical field "Physical Medicine and Rehabilitation".
3. The ICF (ICIDH) is also included in the curricula of the medical

specializations “Social medicine”, and “Rehabilitation”.

4. In 1996 the Federal Ministry of Education and Research and the German Pension Insurance initiated the joint research programme “Rehabilitation Sciences”. The programme has an overall budget of 40 Million Euro. The programme includes some projects dealing with the ICF. One project aims at the development of disease specific ICF check lists.
5. The model of consequences of diseases (ICIDH) is part of the rehab quality insurance programme of the German Pension Insurance. This programme has been introduced in 1994.
6. The German Health Insurance applies the ICIDH when granting both the prolongation of rehabilitation measures and Caring Insurance benefits.

**The new German Social Code No. IX (SGB IX)**

The new German Social Code No. IX (SGB IX) from 2001 – Rehabilitation and Participation of People with Disabilities – was developed during the revision process of the ICIDH. It is based on the bio-psycho-social model of the ICF, and it explicitly uses the word “participation”, German: Teilhabe. However, the historically rooted special features are also taken into account, for instance, individuals who are threatened by disability in principal have the same social rights as individuals with disabilities.

In the German Social Code No. IX (§ 2) the terms “disability” and “threatened by disability” are defined as follows:

> An individual has a disability if his/her body function, intellectual ability or mental health deviate from the typical state of an individual of the same age for more than six months with high probability, and thus his/her participation in the societal life is restricted. He/she is threatened by disability if the restriction is expected.

As mentioned above in the ICF the term “disability” is defined as follows:

> A disability is any restriction of functioning.

The disability terms of the ICF and of the German Social Code No. IX differ from each other. The most important differences are:

1. The ICF term includes individuals who have problems in body structures/functions or in performing activities without restrictions in participation.
2. The ICF term refers neither to the concept of age equivalence nor to duration.

Rehabilitation offers the best means of preventing or overcoming disability. On the other hand, when one looks at the German Social Code No. IX, individuals with disabilities form only one of the groups of people for whom rehabilitation services are intended. § 4 lists all the groups of people who are targeted for rehabilitation services. The common feature of these groups are that their members are (1) threatened by restriction of participation or (2) that they are restricted in participation. Services for participation include all necessary social services in order:

1. to prevent or to overcome disability or to reduce the consequences of disability,
2. to prevent or to overcome restrictions of earning capacity or caring needs or to prevent premature payment of social benefits or to reduce current payments of social benefits,
3. to secure participation in working life according to the individual’s abilities and learning,
4. to foster comprehensively personal development and to facilitate or to make easier the participation in societal life and the management of an independent and self-determined life.

Only number 1 refers to disability in the sense of the German Social Code No. IX. Number 2 refers to two social risks: the Social Pension Scheme insures the risk of earning capacity restrictions, and the Social Caring Scheme insures the risk of caring needs.

For short, the groups formed by the numbers 1 to 4 are called “rehab potential”. Figure 1 shows the differences between the approaches of the ICF and that of the German Social Code No. IX.

1. The rehab potential only overlaps with the ICF term “restriction of functioning”, the general definition of disability. This can be attributed to two reasons. (1) “restriction of functioning” doesn’t include “impending participation restriction”. (2) The ICF term includes individuals who have problems in body structures/functions or in performing activities without restrictions in participation. In the rehab potential an existing or impending participation restriction is necessary.
2. All other terms – “restriction of participation”, “disability” according the German approach, and “Severe Disability”, a special feature of the German approach – are subsets of both the “rehab potential” and the “restriction of functioning”. Moreover, the term “disability” in the German approach is a subset of the ICF term “restriction of participation”, the special definition of disability.

**Further action in Germany**

The bio-psycho-social model of the ICF has already found high acceptance in Germany. Particularly the introduction of environmental factors and the idea of personal factors are welcomed. Several rehabilitation facilities have used the model and the chapters of the revision version Beta-2 as guidelines for documenting their interviews with rehabilitation patients. The experiences are encouraging. However, it is already recognized that coding with the ICF will be difficult and time-consuming. Thus, the practicability of the ICF should be improved. Training in the use of the ICF will be absolutely essential.

Another point should be stressed, namely that in contrast to the ICIDH,

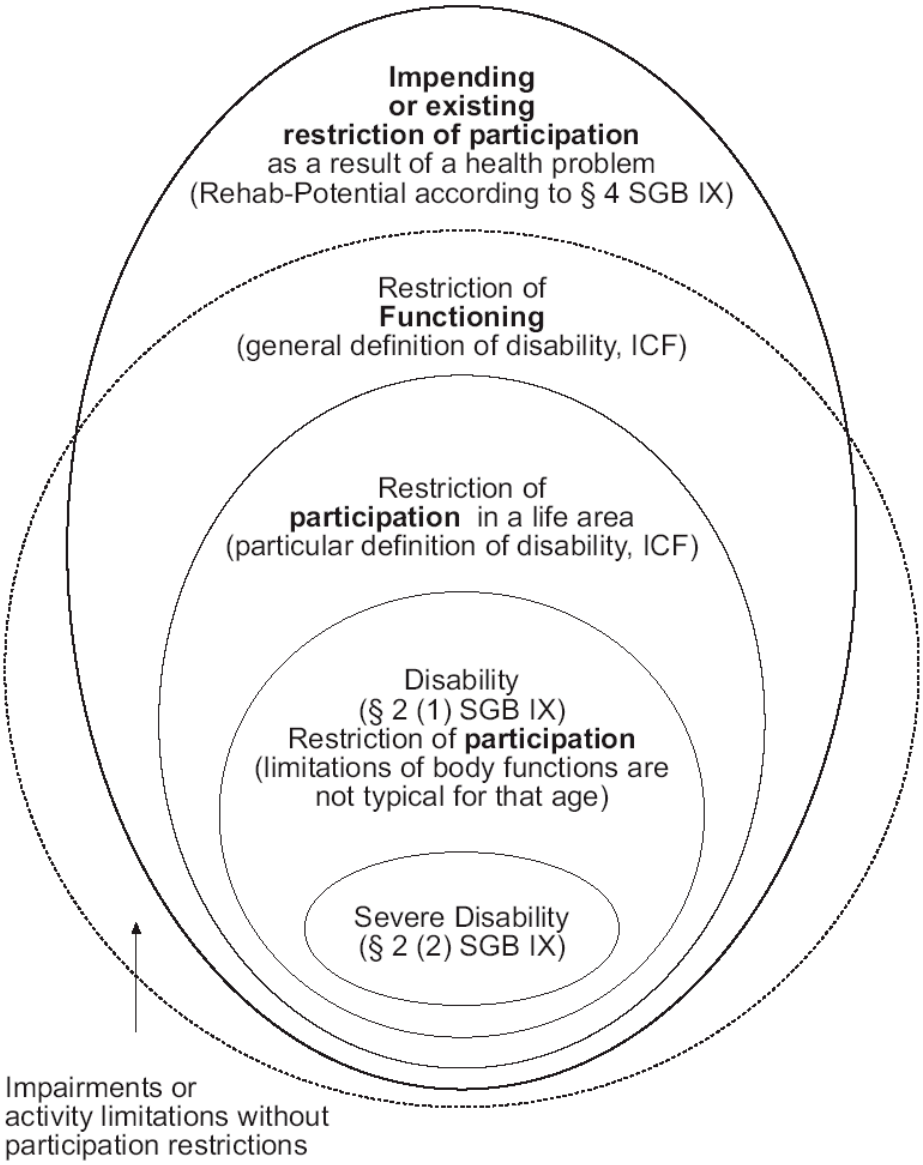
the ICF only contains neutral terms. Many of our physicians in rehabilitation complain about that. Obviously they also need to be able to express the signs and symptoms of restrictions of functioning in negative terms and in this respect they feel that the ICIDH was more helpful. We will have to deal with this problem.

While both, the concept of activities and the concept of participation, are clearly understood some of us have severe problems with the operationalization of both concepts. We have to deal with these too.

Our next steps are as follows:

1. It is necessary that users of the ICF will be trained. For this reason we will develop training material. This material will include numerous case vignettes which reflect German needs. The case vignettes will be worked out by many experts in the fields of rehabilitation and disability. We will publish this material in internet (www.vdr.de) for public access and download.
2. Disease specific ICF check lists will be worked out within research projects. These lists shall be practically used particularly in rehabilitation facilities for diagnostics of functioning, planning rehabilitation measures and evaluating rehabilitation measures.
3. Finally, we are considering developing a German adaptation of the ICF which will capture the German situation with regard to rehabilitation and assessing disability more precisely, because our highly sophisticated health and social system has a lot of features which are hardly covered by the ICF. Moreover, we shall try to incorporated the negative terms of the ICIDH into the inclusions and exclusions of the ICF as far as possible.

**Fig. 1: Disability: ICF and German Social Code No. IX (SGB IX) (Rehabilitation and Participation of People with Disability)**

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## Italy

### Presentation of the Italian version of the ICF

On the 17th April 2002 the Italian version of the "International Classification of Functioning, Disability and Health" (ICF) was presented at the "International Conference on Health and Disability". This conference was promoted by the World Health Organisation in collaboration with the Ministry of Health and the Italian region Friuli-Venezia Giulia.
and evaluation of the ICF, through the creation of the "Italian Disability Network". This consists of 25 organisations (universities, research institutes, hospitals, associations for disabled persons, public and private rehabilitation centres etc), experts (researchers, statisticians, academics, workers in this sector), civil servants and politicians from various ministries, and persons with various health conditions and their families.

The day was full of contributions from both representatives of regional and national public institutions (Ministers, undersecretaries, assessors), experts and researchers. After presentation of the national and regional picture with respect to the most relevant laws and provisions in the area of health and disability, and presentation of the new classification of health and disability, various points were made which generally highlighted:

- innovative aspects of the ICF, in that it not only addresses disability but also the related health and wellbeing of each individual;
- the cultural revolution inherent in the new classification, which regards disability as a result of a combination of factors (with particular attention to the role of health conditions in interactions with environmental factors) and not as a condition attributable to the individual;
- how the final version of the ICF, now accepted by 191 countries as the international standard for measurement and classification of health and disability, was reached;
- the close relationship between ICD (International Classification of Diseases) and ICF;
- potential uses of the new classification in clinical and statistical fields and in socio-sanitary policy planning;
- the need for definition of tools and methods of ICF application in various areas (clinical and rehabilitative, epidemiological, statistical, administrative, and policy programming).

Additionally, the project "Sistema Informativo sull'Handicap" (Information System on Disability), promoted by the Ministry of Welfare and implemented by ISTAT (the Italian National Statistics Institute) since 2000 was presented.
In Italy, as in most other countries, there is not complete picture (data and information) of disability. It cannot therefore be precisely stated how many disabled persons live in Italy, their disability types, their level of social integration, or the fulfilled and unfulfilled needs of the disabled persons and of their relatives.
The main goal of the "Information System on Disability" Project is to overcome this lack of information by creating a coordinated and integrated statistical database on disability, utilising all available data from several different data sources (Surveys, Archives, Database systems) and by promoting other actions to stimulate new investigations and surveys in sectors and thematic areas where data is currently lacking.
The website www.handicapincifre.it was created to allow diffusion of available data to various interested parties (from politicians to workers in the sector, from associations for disabled persons to individual citizens). The site can be accessed by disabled persons and is available in both Italian and English. Data can currently be consulted sorted by a system of pre-defined indicators, however a data interrogation system is in development which will enable the user to effect personalised researches.
Comparison with the ICF domains has highlighted various thematic areas and aspects which, in spite of integration of data from diverse sources, are still unaddressed by surveys and other data collection methods. To cover this lack of information Istat is carrying out other activities as part of the project such as a register of information sources on disability and handicap at the various institutional levels involved and a survey on disabled persons which utilises the ICF as its conceptual reference.

The day of the official presentation of the Italian ICF version concluded with the relevant ministries undertaking to promote respect of the rights of disabled persons and define policies which protect the health of all citizens. Finally, the invitation was extended to identify, with the collaboration of various national and international organisations, promotional and training courses to favour adoption of the ICF in its various fields of application both abroad and in Italy.

Experts' reports and results of the "WHO - Conference on Health and Disability" will shortly be available at www.sanita.fvg.it

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## Netherlands

### The International Classification of Primary Care (ICPC) and its potential relations with ICF

#### Introduction

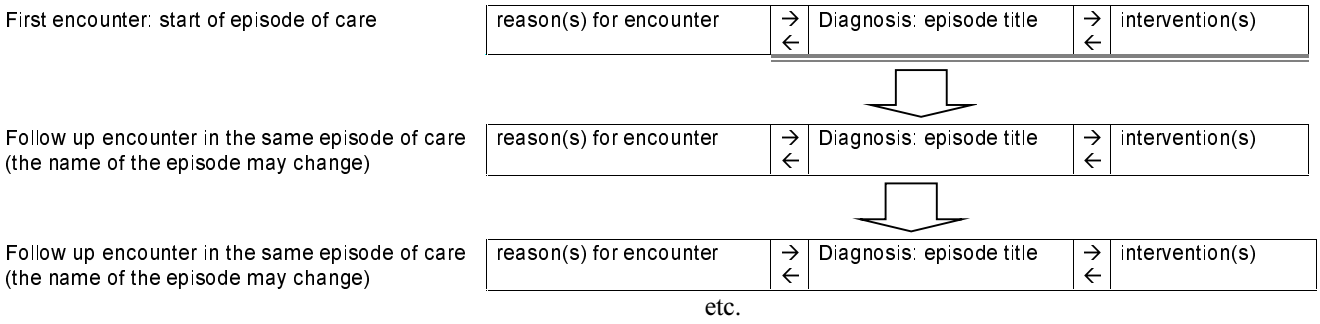
ICPC (the International Classification of Primary Care) orders the international domain of family practice, and is the designated primary care classification of the World Organisation of Family Doctors (Wonca), now available in over 20 languages. In the Netherlands, as is the case in other countries, ICPC is mandatory for use in electronic

patients records (EPRs) in family practice. In order to further enhance the practical use of ICPC, the Dutch Ministry of Health is currently financing a collaborative project of the Transition Project of the Department of Family Practice (Division Clinical Methods & Public Health, Academic Medical Center – University of Amsterdam) and the Dutch College of General Practitioners (NHG). In the course of the project, close cooperation has been established with the WHO Collaborating Center for the ICIDH (now ICF) and ICD-10 in the National Institute of Public Health and the Environment (RIVM), and with the Departments of Family Practice at Ghent University and the Free University of Brussels, Belgium.
In this project, a full mapping between the Dutch ICPC-2 and the Dutch ICD-10 is used to create a large thesaurus for semi-automatic double-coding of diagnoses in EPRs, also serving the goal of improving the electronic communication of patient information between primary and secondary/hospital care. Additionally, part of this project focuses on establishing potential relations between ICPC-2 and the ICF. Within the Dutch family practice context, this could have direct practical use for the cooperation of family physicians with physiotherapists and community nurses.
In this contribution, the potential practical relations between ICPC-2 and ICF are further explained on the basis of a description of ICPC. The Dutch Collaborating Center would welcome any reactions providing further information, suggestions and/or practical experiences with regard to the position of ICF within family practice/primary care.

**ICPC: a brief description**

This classification provides codes for the description of the content of encounters in an episode of care structure: the patient's reason(s) for encounter, the doctor's diagnosis, and the intervention(s). Since diagnoses may change over time (e.g. from flu to bronchitis, to pneumonia, to bronchial carcinoma), it is essential to link data belonging to one problem. Therefore at the heart of ICPC data is the *episode of care*: a health problem from its first presentation to a health care provider until the completion of the last encounter for it. An episode of care encompasses all encounters, respectively contact elements related to that health problem (fig 1).

Fig 1 Core elements for coding encounters in an episode of care structure with ICPC




ICPC is a biaxial classification system. Seventeen chapters with an alpha code referring to a body system/problem area form one axis; seven components (rubrics with a two-digit numeric code) form the second. An ICPC code consists of an alpha for the chapter, and of a two digit numeric code for the rubric within the chapter and component structure (fig 2).

Fig 2 ICPC structure: 17 chapters, 7 components

| Chapters⇒ Components ⇓ | A | B | D | F | H | K | L | N | P | R | S | T | U | W | X | Y | Z |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Symptoms and complaints | | | | | | | | | | | | | | | | | |
| 2. Diagnostic, screening, preventive | | | | | | | | | | | | | | | | | |
| 3. Medication, treatment, procedures | | | | | | | | | | | | | | | | | |
| 4. Test results | | | | | | | | | | | | | | | | | |
| 5. Administrative | | | | | | | | | | | | | | | | | |
| 6. Referrals and other reasons for encounter | | | | | | | | | | | | | | | | | |
| 7. Diseases | | | | | | | | | | | | | | | | | |

Chapters:
A: General and unspecified
B: Blood, blood-forming organs and immune mechanism
D: Digestive
F: Eye
H: Ear
K: Circulatory
L: Musculoskeletal
N: Neurological
P: Psychological
R: Respiratory
S: Skin
T : Endocrine, metabolic and nutritional
U: Urological
W: Pregnancy, child-bearing, family planning
X: Female genital
Y: Male genital
Z: Social problems

ICPC reflects the characteristic distribution of reasons for encounter, diagnoses and interventions in family practice. All frequent reasons for encounter, diagnoses, and interventions (roughly: occurring at least once per 1000 patients per year) have a separate code; less frequent diagnoses/reasons for encounter are, therefore, relatively often included in a 'ragbag' rubric: a miscellaneous collection of symptoms and complaints, of interventions or of diseases. As opposed to disease classifications, ICPC caters for the classification of the typical questions patients bring to family doctors, i.e. not only symptoms, complaints and diseases, but also social and daily life problems, fears, and requests for advice, medication, examination or referral etcetera. In order to provide the necessary additional clinical detail, ICPC has been mapped to ICD-9(-CM), and to ICD-10.
For coding *reasons for encounter*, all rubrics from all components may be used; a reason for encounter may be: a symptom or complaint (component 1): e.g. I have a cough: R05; a request for an intervention (components 2-6): e.g.: I need a new prescription for my asthma (R50); or a disease (component 7): e.g.: I am here for my hypertension (K86). For coding a *diagnosis*, all rubrics from components 1 and 7 may be used, which include all diagnostic categories. If needed, additional diagnostic detail can be derived from ICD-10; e.g., by coding: ICPC-2 code K72, cardiovascular neoplasm, together with ICD-10 code C45.2, mesothelioma of pericardium. For coding an *intervention*, all codes from components 2, 3, 5 and 6 may be used: examination of ear (H31), referral to a cardiologist (K67).

**Relations with ICF**
Rubric –28 in ICPC is 'limited function/disability NOS (not otherwise specified)', and provides in all chapters the opportunity to incorporate two chapters of ICF: body functions and body structures, thus replacing the 'NOS'. The 'body' chapters follow the same pattern in both classifications. Selected diagnostic classes of ICPC can be related with selected limitations from the ICF chapter 'Activities and Participation' on the basis of empirical data from family practice, physiotherapy, and nursing. Although in principle all aspects of activities and participation can come up in the course of practically every episode of care, still, a probability distribution of the most likely concurrences will greatly enhance the practical use of ICF in EPRs structured with ICPC.
At this moment, no direct relation of ICPC with the chapter 'Environmental factors' is foreseen. The work on the relations between ICPC and ICF is currently shared between the Departments of Family Practice at the Universities of Ghent ('Body functions' and 'Body structures') and of Amsterdam (`Activities and Participation').

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# North America

## NACC meeting

The 8th North American Collaborating Center Conference on ICF was held June 2-4, 2002 in Toronto, Canada. Seventy-four persons, mainly from Canada and the USA, some from other countries as well e.g. Brazil, Denmark, Germany, Netherlands, Switzerland, and representatives from WHO, attended this interesting ICF conference.
After opening and keynote addresses individual and panel presentations represented a broad scope of information in the following six themes:
- Strategies for ICF
- ICF Conceptual and Issue Areas
- ICDF Surveys
- ICF for Clinical Practice
- Capturing & Coding Functional Status Information
- Basic ICF Research

During the breaks there were demonstrations of Code ICF (draft interactive training programme) and a video of the Heads of Centres meeting in Bethesda, Maryland, USA, October 2001.

Postings of presentations and other papers are available through the website. The report of the conference is expected to be available in August 2002.

For information:
1. Go to the CIHI website http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=home_e
2. Select "News and Events" from the About CIHI box.
3. Scroll down until you reach the Events Section.
4. Continue scrolling until you reach the Proceedings of Past Events section.
5. Select the hotlink - The 8th North American Collaborating Center Conference on ICF. This will take you to the conference page, with presentations and papers which can be viewed in PDF Format. These presentations and papers can be saved and printed, but cannot be edited or changed.

You need to have Adobe Acrobat Reader installed on your computer in order to view these files. For those who do not have this software, please click on the following hotlink and follow instructions on how to download your free acrobat reader http://www.adobe.com/products/acrobat/readstep2.html

# Sweden

## ICF and Social Policy

Social Policy is a concept that denotes such conscious efforts of a society as programs and planned activities to prevent social problems, to increase health, welfare and social security and as well to contribute to equality. Health care policy could be seen as part of the social policy or as a separate area beside the social policy domains dealing with welfare and security. Here, I will discuss the use of ICF in social policy areas outside the traditional health care.

ICF is presented as a multipurpose classification that should serve various sectors by offering a common language for the communication between users from different professions. WHO indicates that already the earlier classification has been used 'as a social policy tool – in social security planning, compensation systems and policy design and implementation'. An important innovation in ICF is the introduction of the contextual factors, especially the environmental factors. One chapter in the list of environmental factors covers services, systems and policies, which offers an opportunity to assess their importance and influence as barriers or facilitators in relation to activities and participation of a person. Services, systems and policies are specified for social security (code e570), general social support (e575) and health (e580). What is then the meaning of a social policy tool? To talk about a tool gives an idea of an instrument but the classification is not an instrument but a classification of dimensions and concepts. Therefore, the topic is to discuss how useful the classification is in planning, developing, using or evaluating social policy programs.

ICF is presented as using a 'biopsychosocial' model in order to try to avoid the shortcomings of the 'medical model' and the 'social model' of disability as they tend to see disability either as a mere personal problem or as a socially created problem alone. ICF also underlines the importance of the universalistic view that moves away from the perspective of persons with disabilities as a minority group. Disability is part of normal variation. Every dimension, every concept variable exist from functioning to disability and the classification may in principal be applied on all individuals, in all cultures. *However, the suggested qualifiers are only supposed to grade the disability and give no idea about how to grade functioning.*

The question now is in which respects could the ICF be used and useful in social policy? Of course, this discussion will mainly deal with social policy of relevance for persons with disabilities and not social policy from all possible aspects. The usefulness of ICF in developing and applying disability policy and general social policy will depend on the possibility to focus on the equalization of opportunities for persons with disabilities. The change of perspectives in the new ICF offers an opportunity to focus on persons as citizens instead of as patients. The general model includes participation as a central concept and the inclusion as well of the contextual factors makes the model well suited for social policy planning and evaluation. *However, the fusion of 'activities' and 'participation' into one component will weaken the emphasis to use participation as a central concept of the classification.*

In clinical use, the medical model may still dominate. Even if the medical model does not necessarily deny the influence of other factors, the model is acting in a way that mainly is directed toward the intrinsic factors, but as the individual functioning exists in a social environment, it is necessary to include both the individual and the environmental factors in order to understand the functioning. *It must be important to develop a more clear distinction between activities and participation.*

All political planning and policy need to be based on the knowledge about existing problems through secure data about the situation. As the classification becomes generally accepted, the ICF will give concept definitions that could be used in population surveys. However, the general acceptance depends on the relevance of the model behind the classification. The model will decide how relevant the population data will be. Health and welfare cover physical, mental and social dimensions and have to be described in a context relation. The *new concept of participation will then be very important to frame the consciousness of full participation and equality as the main goal of all social policy.* Therefore, national population surveys based on the concepts of ICF may give a good and coherent information for social policy planning.

Social policy programs are mainly aimed to give support, help, service, care, advice etc. according to given rules and legislation. This is given to individuals with special needs or rights. There are many reported examples of problems in such activities that may be easier through the use of ICF.
A difference in judgment between patient and nursing/medical staff,
A difference in the perspective on the problem that is the subject for the measures. Such differences could exist between different professionals, between professional and client, between clients etc.
Persons in charge of the administration of the social policy programs may have double roles, partly to represent the the society and partly to give service to the clients,
Persons with the direct contact with clients normally have no high status in the organization but they have the responsibility for the administrating of the service program. How individualized assessment will be used and what right to make an individual decision according to the very special situation of this client has the official person? An alternative strategy could be to assess the individual according to established rules for the eligibility to a certain service or measure. It is a choice between control by established goals or control by established rules.

Hopefully, ICF may give a frame of reference that could enhance the dialogue between the professionals and the clients. An early criticism from the international disability organizations toward ICF was that such a classification could mean an instrument for professional patronizing or even oppression. Therefore, it has been a conscious intention to make the revised classification as understandable as possible for different categories of users. In an ongoing small field study about self assessment of persons with physical disabilities, the topic is to investigate how persons with disabilities themselves want to

describe their own situation in the contact with social policy authorities. It seems that ICF offers new opportunities through the new dimension of participation and the environmental factors. It will be very important to have the self-assessment of the clients concerning his/her participation in the relevant domains of life as the full participation often is expressed as the ultimate goal for social measures. *A systematic assessment of environmental factors might give fruitful knowledge for future general preventive measures.*

Individual needs versus equal rights vor everyone? There may be legal demands on clear criterias. Some legislation include rather specified rules but other legislation gives the legal frames. The applications should then guide the use of the legislation through precedents.
However, there is definitely a dream that some social programs should be able to work more flexible and see to the individual needs. This requires an agreement about the general principles behind the program, which should counteract suspicion about discrimination and maltreatment. Maybe ICF could give such an accepted way of assessing and describing individual situations, not only diagnosis but functioning in a context.

Evaluation of social policy programs is required in one of the UN Standard Rules on Equalization of Opportunities for Persons with Disabilities. The ICF offers then a frame of reference for such evaluations as the dimension of participation may give indication on the effectiveness of the measures in order to fulfil the standard rules. *The revised classification ICF could offer through the universalistic perspective, the bio-psycho-social model, the introduction of the concept 'participation' and the inclusion of a list of environmental factors to be seen as facilitators or barriers, new opportunities to plan and execute social policy programs according to individual needs.*

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# USA

## Developing a Procedural Manual and Guide for a Standardized Application of the ICF by Health Care Professionals

The American Psychological Association (APA) has been closely involved with the World Health Organization's (WHO) revision of the International Classification of Functioning, Disability and Health (ICF), joining the development efforts in 1995. As an outgrowth of this involvement and the relationship that has been developed, APA and WHO are collaborating in the development of a *Procedural Manual and Guide for a Standardized Application of the ICF (Manual)* for health professionals.

Two primary goals of the Manual are to: 1.) provide a standard approach to using the classification for health service applications, including but not limited to, standard clinical interpretations of ICF concepts, case examples for the codes employed by ICF, and assessment information relevant to each qualifier and 2.) provide multi-disciplinary health professionals with the guidance necessary for reliable, valid, and clinically useful classification using the ICF system in both text and interactive versions.

The APA-WHO collaborative project commenced in early 2001 with the formation of an interdisciplinary drafting team comprised of representatives from occupational therapy, speech-language pathology and psychology. The drafting team is currently undergoing expansion to include representatives from nursing, medicine, physical therapy, audiology, social work, therapeutic recreation and vocational rehabilitation. To date, the drafting team has written the first five chapters of the Manual and in the process, has developed clinically based guidance that further clarifies the definitions of ICF items and the interpretation of the qualifiers, standard environment, current environment and other concepts outlined in the classification system.

The following conceptual and operational issues are anticipated when the ICF is implemented in clinical settings. The drafting team continues to develop and refine clinically useful approaches for addressing these issues and a few examples are highlighted. Over time, consensus regarding these and other approaches will need to be achieved to allow for the consistent implementation of the ICF.

### Distinguishing Codes

In some cases, the behaviors described in ICF item definitions for select codes within and across domains cannot be distinguished clinically (e.g., severity rating for certain body function (b) codes and the capacity rating for a corresponding (d) code). An example of this issue arises when attempting to distinguish b140 Attention functions from the capacity to focus attention (d160 Focusing attention). If a given application of the ICF necessitates the use of both the (b) and (d) codes, a possible solution for use in cases where codes cannot be distinguished, might be to record the same qualifier values for each. Specifically, the first (severity) qualifier for b140 would be the same value as the second (capacity) qualifier for d160. This solution is not to say that there is no difference between the body function code for attention and the d code for attention, but it is to say that the distinction cannot be made clinically.

In other cases, some codes appear to be overlapping, but can be clearly differentiated if further guidance and operational examples are provided. Examples include: d1550 Acquiring basic skills vs. d1551 Acquiring complex skills and b1302 Appetite vs. b1303 Craving vs. b530 Weight maintenance functions. The additional guidance that is being developed for

inclusion in the APA-WHO Manual will greatly enhance the reliable and valid use of these codes as they are applied in clinical settings.

**Qualifiers**

In order to implement the qualifiers, clinically based definitions of "capacity" and "performance" need to be developed and endorsed. Likewise, to understand the assessment of an individual's capacity with and without assistance, as called for by the second and third qualifiers, it is important to describe what is meant at the clinical level. In many cases, it will not necessarily be informative, nor will it often be safe in many clinical environments, to withhold *all* devices and other forms of assistance (e.g. supervision, contact guarding, verbal cues) while conducting an assessment. For example, most would agree that when conducting an assessment of listening comprehension, it is neither practical nor informative to do so after removing a client's hearing aid. So then, how can the second qualifier be interpreted so that it is clinically meaningful? One approach might be to allow the use of certain types assistance if that assistance does not directly facilitate performance of the functional area being assessed. For example, in the case of bathing, the use of a wheelchair might be permitted when coding "capacity without assistance" because it is not a device that directly facilitates bathing. Conversely, a long handled sponge or a tub bench would not be permitted, as these are devices that more directly facilitate this activity. Although this approach may be challenging to implement, it would enable clinicians to more meaningfully compare capacity with and without assistance and to document the impact of targeted types of assistance and devices on capacity.

In the case of the performance qualifiers, performance is often variable across the different current environments encountered by individuals. The question arises as to whether performance should be coded according to best or worst levels? Is it possible to derive an "average" performance rating and if so, how useful is that for purposes of treatment planning? In the case of clinical assessment, one possible solution is to code the first qualifier in the context of the current environment that is most appropriate to the assessment (e.g., presenting problem or focus of clinical attention). This may be the environment in which the problem is most prominent (e.g., work settings for speech fluency disorders as opposed to the relaxed home setting with family members). This approach may be different from that used in surveys where coding typical performance *across* environments may be appropriate.

**Standard Environment and Current Environment**

Definitions for standard and current environments need to be developed if these concepts are to be implemented consistently. Health professionals are trained to establish environments that are appropriate to the evaluation of a given area of human functioning and to approximate characteristics of acceptable assessment environments when the situation calls for greater flexibility. At the clinical level, then, the definition of a standard environment is not really a complicated issue, *provided that it is clear to the health care professional that what is meant is an assessment environment appropriate to the assessment of capacity for the particular behavior being assessed.* This is likely to be more of an issue in attempting to generalize capacity ratings across settings, cultures, or countries.

However, even with definitions, additional implementation issues arise and are being addressed. If a current environment is temporary, such as an inpatient rehabilitation facility, should that be considered the current environment or is it the standard environment, or both? How is the coding that reflects functional levels achieved in one current environment distinguished from the functional levels achieved in a different current environment, particularly when these comparisons have meaningful clinical implications?

**Assessment Methodologies**

Many ICF codes do not represent unitary aspects of human functioning. That is, a single code frequently includes many facets of functioning. Therefore, it is not realistic to assume that 1:1 mapping is possible between standardized tests and most ICF codes. Rather, what is more likely is that multi-modal approaches (e.g. psychometric measures, clinical interviews, direct observation, key informant interviews) will best serve users as a basis for communicating assessment results through the ICF system. However, the mapping of standardized tests and other formal measures to the ICF system *will* highlight areas of functioning for which assessment instruments are not currently available and will be useful for purposes of identifying areas in which new assessment instruments or clinical approaches are needed.

Development of the APA-WHO *Procedural Manual and Guide for a Standardized Application of the ICF* has afforded the opportunity to convene health professionals from many disciplines to identify and evaluate the detailed issues that arise when preparing to implement the ICF. The approaches formulated thus far will likely be modified as additional comments are obtained and as clinical use of the system begins. The ICF is a tool that holds great potential for fully describing the facets of human functioning and development of the Manual is a natural next step for implementation of the system in clinical settings.

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## Cognitive Testing of Disability Questions about Environmental Barriers to Participation

### Introduction

In spring of 2001 staff of the Division of Health Interview Statistics asked the NCHS cognitive lab to test questions for the 2002 Health Interview Survey (NHIS). The questions will be used to collect data for the Healthy People 2010 Objectives. Healthy People 2010 is an initiative of the Department of Health and Human Services to prevent disease and promote health by setting measurable "objectives" with baselines and targets. Among the questions were some related to Objective 6-12 which is: "Reduce the proportion of people with disabilities reporting environmental barriers to participation in home, school, work, or community activities." The questions were based on a module developed by Craig Hospital with concepts from the new International Classification of Functioning, Disability, and Health (ICF). While the Craig Hospital questions had not been designed to provide data for Objective 6-12, they did provide a tested list of environmental barriers. An environmental barrier can be anything in the social or physical context that impedes or prevents a person's desired participation. With this broad a concept it was hard to develop a small number of questions that encompass the objective. Moreover, the questions need to be asked of everybody in the NHIS, both with and without disabilities.

### Methodology

We recruited 18 lab participants through personal contacts, flyers, and newspaper advertisements. Six people used wheel chairs, five used walkers and/or canes, one used a hearing aid, one wore a leg brace. Fourteen participants had a variety of conditions such as cerebral palsy, spinal stenosis, fibromyalgia, post polio syndrome, glaucoma, phobia, rheumatoid arthritis, and depression. One man had a leg amputation, one was blind in one eye. Because the NHIS questions are also going to be asked of people without disabilities, we recruited four participants who had no disabling conditions. We wanted to find out how well the questions would work with the general NHIS sample.

### Findings

The original questions had a variety of technical problems to address. A more basic conceptual problem also became evident. Only one of the participants had a clear idea of what was meant by environmental barriers to participation in activities. It became clear to us that we would need to develop a shared meaning for the construct before we could ask about perceived barriers to participation.

In the cognitive lab we tried a variety of alternative questions to solve both the technical and conceptual problems and finally settled on the module shown below for the NHIS.

The questions begin with an introduction that defines "barriers to participation" and lists the four settings in which memories are likely to be stored—at home, at school, at work, or in the community. A flashcard will be presented and the interviewer will read the barriers aloud while the respondent reads them in print. If any question is answered with Yes, two follow-up questions will establish which barrier pertains to the setting and how often it occurs.

### Revised questions for 2002 NHIS

The next questions are about your surroundings at home, school, work, or the community, and possible barriers that might limit or prevent your activities. FR: SHOW FLASHCARD A20 By barriers we mean things such as building design, lighting, sound, household or workplace equipment, crowds, sidewalks and curbs, transportation, attitudes of other people, and policies.

DIS.040 Thinking of your HOME SITUATION, do problems with any of these things on the list NOW limit or prevent your participation in home activities or household responsibilities?

(1) Yes (DIS.050)
(2) No (DIS.070)
(7) Don't know {blind} (DIS.070)
(9) Refused {blind} (DIS.070)

DIS.050 Which ones? (Probe: Any others?)
(1) Building design (stairs, bathrooms, narrow or heavy doors)
(2) Lighting (too dim to read, signs not lit, too bright, too distracting)
(3) Sound (background noise, inadequate sound system)
(4) Household or workplace equipment hard to use
(5) Crowds
(6) Sidewalks and curbs
(7) Transportation
(8) Attitudes of other people
(9) Policies (rental policies, eligibility for services, workplace rules)
(10) Other barriers
(77) Don't know {blind}
(99) Refused {blind}

>DISHMOFT<
DIS.060 How often do these things limit or prevent your participation in home activities? Would you say always, often, sometimes, or rarely?

The questions are repeated for the three other settings: school, work, and community. Thus, there are a minimum of 4 and a maximum of 12 questions.

### Discussion and conclusion

Developing and testing health survey questions is an iterative process, especially when trying to operationalize anything as conceptually complex as Objective 6-12. We will seek feedback from NHIS interviewers about how well the questions work and we will look at the data when it is available. More pretesting and field work may be necessary.

We recognize that by measuring things we may change them. Objective 6-12 calls for an assessment of perceived barriers and speaks of reducing the

proportion of people who report environmental barriers. Paradoxically, as the population becomes aware of the concept of environmental barriers to participation, they may report more occurrences, rather than fewer, at least initially. It will be interesting to follow the trend in sequential surveys.
A copy of the full paper presented to the Heads of Centres meeting in Bethesda October 2001 can be had from Bwilson@cdc.gov.

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### Advertissement of Bohn, Stafleu van Loghum

***The ICF,* now available in Dutch**

In cooperation with the Dutch WHO-FIC Collaborating Centre, Bohn Stafleu Van Loghum is publishing the Dutch translation of the ICF. After an extensive test phase and meticulous translation, the Dutch-language edition of the International Classification of Functioning, Disability and Health (ICF) is now available as a book with accompanying CD-ROM.

ICF, successor of the ICIDH – International Classification of Impairments, Disabilities and Handicaps - during its earlier phase of development, is a framework of WHO classifications providing a standardised terminology tool to describe human functioning and the problems which may arise therein. It is intended for widespread use, in the field of healthcare as well as in the world of education, labour and social security. The ICF is also used in the fields of legislation, policy-making and management, surveys and statistics. For example, the ICF provides the care provider with a standard common language with which to describe specialised concepts and to communicate univocally about these concepts both within and outside the healthcare sector.

The ICF classifies aspects of human functioning which may be related to a health problem and defines the different health-related components. The work complements that of the International Classification of Diseases and Related Health Problems: ICD-10 supplies terms for diseases, conditions and other health problems, while the ICF provides terms to describe human functioning from the various perspectives summarised below.

This publication comprises four classifications, an introduction, various appendices and an alphabetical index, which the reader/user will find useful for a wide range of applications.

Editorial notes justifying the translation, are those of the WHO-FIC Collaborating Centre in the Netherlands. These notes do not necessarily represent the views of WHO.

The contents of the book are available on the accompanying CD-ROM in the form of a PDF file and a special search programme, a so-called classification browser. For ICT use an XML version of the text is provided.

## The classification structure of the ICF:

**Body functions:**
- Mental functions
- Sensory functions and pain
- Voice and speech functions
- Functions of the cardiovascular, haematological, immunological and respiratory systems
- Functions of the digestive, metabolic and endocrine systems
- Genitourinary and reproductive functions
- Neuromusculoskeletal and movement-related functions
- Functions of the skin and related structures

**Body structures:**
- Structures of the nervous system
- The eye, ear and related structures
- Structures involved in voice and speech
- Structures of the cardiovascular, immunological and respiratory systems
- Structures related to the digestive, metabolism and endocrine systems
- Structures related to genitourinary and reproductive system
- Structures related to movement
- Skin and related structures

**Activities and participation:**
- Learning and applying knowledge
- General tasks and demands
- Communication
- Mobility
- Self-care
- Domestic life
- Interpersonal interactions and relationships
- Major life areas
- Community, social and civic life

**Environmental factors:**
- Products and technology
- Natural environment and human-made changes to environment
- Support and relationships
- Attitudes
- Services, systems and policies

ICF

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This is the 16th supplement to the list of ICIDH references published in September 1994.


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