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Editorial Board

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ICF-CY RELEASE

Children right's to live in a world without barriers WHO releases the classification of functioning, disability and health for children and youth

In Tunis, October 31, 2006 the WHO announced the release of the International Classification of Functioning Disability and Health – Children and Youth Version (ICF-CY), the first derived Classification from the ICF which was approved by the WHA in May 2001. The ICF-CY recognizes the developing child as a "moving target" and defines components of functioning, performance and environmental factors related to health and well being of children and youth. The ICF-CY was developed over a period of five years by a WHO Work Group consisting of Rune J. Simeonsson, Matilde Leonardi, Eva Bjork Akesson, Huib Ten Napel, Judith Hollenweger, Don Lollar and Andrea Martinuzzi in collaboration with professionals, parents, government officials and NGO's from many countries including AUSTRALIA, BRAZIL, CHINA, EGYPT, GERMANY, ITALY, JAPAN, KUWAIT, MACEDONIA, MEXICO, RUSSIA, SUDAN, SOUTH AFRICA, SWITZERLAND, SWEDEN, THAILAND, USA and ZAMBIA. Development activities were supported by a grant from the National Center on Birth Defects and Developmental Disabilities of the Centers for Disease Control and Prevention.

In developed as well as developing countries, children are at risk of deprivation of their rights in the form of denial of treatment, neglect, exploitation, discrimination and lack of access to services and supports. Previously, children's mental disorders could be documented with the ICD-10 tri-axial classification system, but there was no classification of function dedicated to children and youth. As a classification of functional components of health, the ICF-CY provides a common language to define children's functional needs and environmental barriers they face, yielding evidence of their rights for protection and access to care, education and services. Further, the ICF-CY can be used with ICD-10 and other diagnostic classifications to clarify the functional aspects of chronic illness and disabilities of infants, children and adolescents. As such, field trial findings and research applications have provided support for the comprehensiveness of the ICF-CY to capture aspects of growth and development of children at different stages of life and with different health conditions.

There is wide spread national and international interest in the promise of the ICF-CY as a classification for use in various settings serving all children. Of particular significance is the potential utility of the ICF-CY for policy sectors, systems and services that have previously not had an applicable classification. Social welfare, the legal system, public health and public education are sectors engaged in services and supports for children and will have for the first time, a classification system with direct applicability to their spheres of work and offering a standard terminology that can be shared across settings and disciplines.

To this end, the ICF-CY can advance the health, development and well being of children and youth through practices, policy and research sharing a common conceptual framework and language.

The ICF-CY is now being prepared for publication for its official launch in October 2007 in Italy.

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Editorial

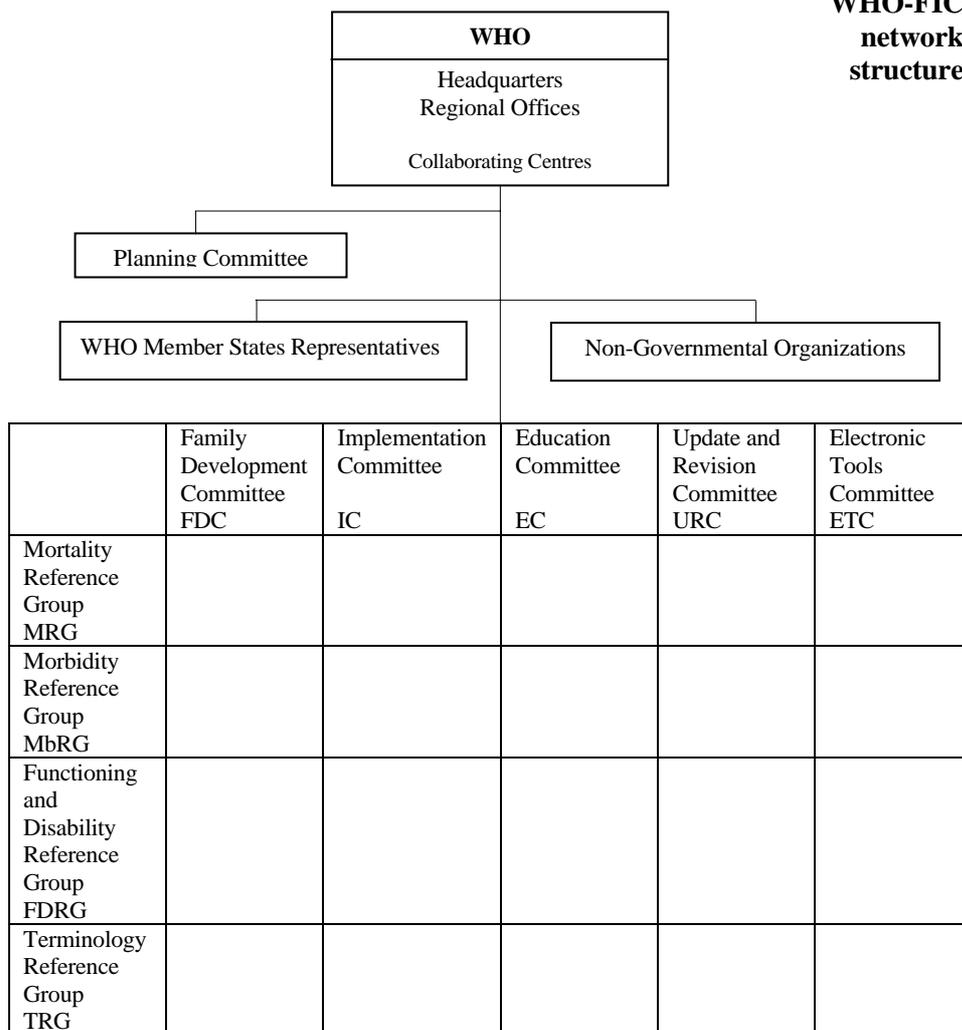
We wish all readers and colleagues a happy new year. We hope to be able to deliver you relevant information regarding the WHO-FIC members in 2007 as we did before. You are invited to send us your information concerning classifications, their applications, educational materials and related instruments in order to inform other interested persons through short papers in our newsletter.

The Dutch Collaborating Centre will work on the improvement of the ICF INFO database as was decided during the Tunis meeting last October-November, see following report which is the main part of this newsletter version.

Analogue to the newly created Asia-Pacific Network we are thinking of the creation of a European WHO-FIC network around the existing European Collaborating Centres in order to include European countries or language areas without a WHO-FIC Collaborating Centre. Anybody who is interested should contact Marijke de Kleijn (marijke.de.kleijn@rivm.nl).

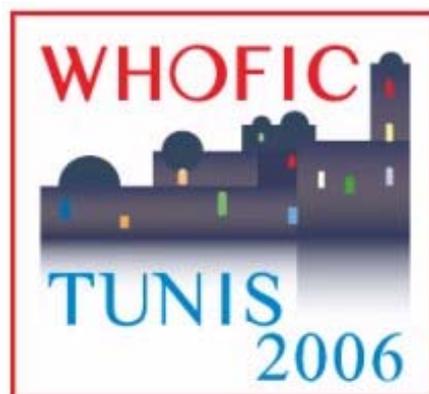
For those who are interested in the WHO's photo and video contest "Images of Health and Disability 2006/2007", we recommend to visit website: <http://www3.who.int/icf>. The winners of last year's contest can be found there as well.

WHO-FIC network structure



International Organizations

WHOFIC Network Meeting 29 October - 4 November



The meeting was attended by 112 international participants of ten WHO Collaborating Centres for the Family of International Classifications and representatives from Ministries of Health or National Statistical Bureaus from sixteen countries. All meeting papers are available at WHO web site, <http://www3.who.int/whofic/2006meeting/documentlist.html>. The views expressed in these papers are those of the named authors only and do not necessarily represent WHO's or WHOFIC Network's views.

WHO-FIC network structure

The meeting served to review and update as necessary all elements of the WHO Family of International Classifications and the work of the WHOFIC Network, including Centres themselves, five committees and four reference groups. Each of the committees and reference groups presented an

annual report of its activities. All reference groups had their initial meetings ahead of the Network meeting. The newly founded reference groups reviewed their terms of reference and discussed possible membership and provisional work plans in addition to their primary tasks in the field of classification and terminology. The plenary meeting heard the progress reports of the various reference groups, and cleared them for implementation. The basic documents defining the role and general governance of the reference groups will be available on <http://www.who.int/classifications/network/en/>.

Challenging the Information Paradox

The main focus of the presentations was on the contributions of the international classifications to challenging the information paradox. An initial meeting of the Asia-Pacific network immediately preceded the meeting, and this initiative was, warmly welcomed by the Network.. Efforts at country level were highlighted by five country reports. A panel of international experts shared their insight as to how the issues raised could best be addressed.

International Classification of Diseases (ICD)

A database for the implementation has been updated by data compiled with a condensed questionnaire based on the ones that have been used for implementation surveys over the past 40 years. It includes also questions about updating ICD and barriers to implementation. An online version is in preparation. The information in this base will assist efforts to improving health information in individual countries. Initial analysis and a round table discussion of experts indicate that an understanding of the importance of health information at population level and commitment from high level decision makers of the single countries are an essential prerequisite to succeed in implementation.

Tools for implementation that are currently under development, include an electronic training tool for classification that can be used online and offline for self learning. The materials will also allow for a paper-based training. In future steps a coding tool and a registration toolkit will be added to facilitate implementation. Previous experience has shown that implementation support and development of such strategies are an overwhelming task with a view also on regional and cultural differences. As a result a regionalisation should be a way to overcome these obstacles. As a first step in this direction an Asia-Pacific Network has been created and nine countries attended the first meeting of this subgroup of the WHO-FIC Network. A thorough implementation assessment will be carried out in single countries. This will allow to gather in depth information to complement the implementation database. Next meeting of the A-P Network will be in Japan September 2007 to systematically plan for the assessment. It is expected that similar Networks for other regions, especially Africa, could allow greater focus on implementation and enhance the value of the knowledge of the global WHO-FIC network at regional and local level.

. ICD- XM

A first comparison of four national modifications of ICD for clinical use has been made. Some common parts were highly refined by several of those modifications - the hot spots. This will provide input to the work for the revision of the ICD. Having access to modifications already in place in other countries would also do such necessary changes in the same fashion in an other country. A large part of the preparatory work consisted in bringing the different tables into one single format for comparison. In the discussions it was agreed the countries to send their modifications in a standard format, ClaML light. The maintenance platform for the ICD will allow the representation of multiple modifications to the ICD at all levels of the classification. Collecting the codes and the titles of the nationally

adapted categories in ClaML format (see Electronic Tools Committee) will allow to use the platform for the creation of the ICD-XM.

. ICD-10 French 2007 edition

The ICD-10 French edition Volume 2 has been compiled with the support of the French Collaborating Centre. Volume 1 will be ready late January. The work on the alphabetical index is scheduled to started end of December. The whole work should be ready for print by end of April 2007.

. ICD-O in French

All parts of the work have been translated into French and have systematically been revised. The errata have been incorporated. A few edits in the introductory part are still necessary and will be made by end of November. Publication will be in late February '07.

Updates to ICD

WHO is in the midst of preparing for the printing of the third edition of ICD-10, and as such have made modifications to the Introduction in Volume 1. A new page 'Updates' outlines where one can find the complete listing of the updates and their sources on the WHO website. The third edition of ICD-10 will include all the major updates for 2006 as well as the minor updates that are to be implemented in January 2007. The Education Committee is starting the process of certification of trainers for coders. The certification is designed to assure a minimum standard for the education in the field of coding. It was clearly stated that this cannot be used to replace national diplomas and education programmes. This can not be a substitute to existing better education programmes. Better education allows for better coding. A preliminary version of the 'Maintenance and Publication Tool for the WHOFIC Classifications' has been demonstrated in the Electronic Tools Committee. The software development effort will continue in DIMDI and WHO and it's planned to distribute a beta version in the next WHOFIC Network meeting. It's decided to have 2(3) conformity levels of producing the ICD in ClaML.

This will simplify the task for certain ICD modifications for which the full ClaML version cannot be generated due to the lacking level of granularity.

ICD Revision

Currently revision activities have been started in:

Mental Health

- in collaboration with the International Networks of WHO Mental Health Department;

Oncology

- in collaboration with the International Networks of the WHO /IARC;

External Causes & Injury

- in collaboration with the ICECI group, and related WHO departments;

Rare Diseases

- in collaboration with Orphanet

A Revision Steering Committee (RSC) is being formed and an outline of Terms of Reference has been drafted. Possible membership has been discussed. The RSC will include the heads of the working groups for each major area of ICD revision and the chairs of Planning committee, Update and Revision Committee and Family Development Committee as well as some terminology /ontology experts. Initial meeting of the revision steering committee has been planned for 17-18 April 2007 in Japan.

Morbidity Reference Group (MbrG)

At the Tunis meeting of the WHO-FIC Network the MbrG was established.

The objective of the group is to improve international comparability of morbidity data and the application of ICD in morbidity by analysing and integrating needs deriving from statistics (e.g. hospital data), casemix (e.g. DRG systems) and clinical documentation (e.g. clinical terminology and electronic health records).

A database for listing national applications of ICD for morbidity purposes will be set up. There is some overlap with the implementation database, see above. The two bases will be brought in line and could be merged. Existing clinical modifications will be handed to WHO in a standard format "ClaML Light". These files will include the codes, titles, a language tag

and a few other attributes. They will be merged in the maintenance platform located at WHO. The authors of the national modifications will deliver the updated files on an annual basis.

The group discussed the ICD revision process and supported the development of separate views of ICD-11 for mortality and morbidity.

International Classification of Functioning, Disability and Health

ICF Implementation

The meeting reviewed the progress on the strategic directions for ICF implementation:

1. Health and Disability Statistics: The WHO/UNESCAP project on

improving disability statistics was completed. The project involved 20 countries from the Asia-Pacific region and provided the following outcomes:

- Following the development and field testing in five pilot countries a ICF based question set for use in census and surveys was recommended for the UNESCAP region;
- Development and publication of ICF Disability Statistics Training Manual;
- UNSIAP established a 5-day Training Course on Disability Statistics based on the ICF framework.

2. Health outcome measurement: The ICF based WHO Disability Assessment Schedule II (WHO DAS II) have been adopted as outcome measure in the WHO Projects such as the Global Programme to Eliminate Lymphatic Filariasis and in the Tsunami Recovery Impact Assessment and Monitoring System.

The meeting noted the increased importance of health outcome measurement in information paradox countries. In this context it was stressed to promote actively the inclusion of the ICF framework and related assessment instruments like WHO DAS II as an outcome measurement in disease programme and health initiatives. In collaboration with the Occupational Health Unit in WHO the establishment of a Health and Productivity data consortium using the WHO Health and Productivity Questionnaire (WHO HPQ) is explored.

3. Disability Evaluation: Progress in aligning the disability certification

process with the ICF framework was reported from ongoing projects in Greece, Germany, Tunisia and the US. Progress was also reported from ICF applications in the areas of education as well as labour and employment.

4. ICF implementation support: The meeting recommended to review and further improve the **ICF INFO database**. The final version of the database will be hosted on the WHO FIC website with linkages to a mirror website in each of the Collaborating Centres. In a second step criteria and an approach will be developed to identify lessons learned and best practices in implementation of ICF. This quantitative analysis will contribute to the development of implementation guidelines and advice.

ICF Training and Education

The meeting took note of various ICF Training and Education initiatives and material. Two main work streams were recommended:

- to create an inventory of ICF Training and Education initiatives on the WHOFIC website in connection with the ICF INFO database
- to develop a generic ICF training application in conjunction with the WHO FIC education tool

A site with a compilation of existing materials for training and information will be set up, in connection with the ICF INFO database. Only materials used on WHO meetings will be put there. This will assure a certain level of quality and consistency with the principles of ICF.

Future steps include a revision of the materials, the compilation of core curricula and finally the compilation of reference training materials in line with the technology in use for the WHO ICD training tool.

Compiling a basic information course will be a first step in this direction. It will be carried out under the lead of the Brazilian Collaborating Centre.

ICF Children and Youth version

After finalization of the review process the meeting recommended the adoption of ICF-CY as a derived classification to the WHO-FIC family, see also the press release on page 1,2.

ICF Updating

Within the new Functioning and Disability Reference Group an ICF update task group was established.



G. Stucki, co-chair of the DRG reporting to the plenary

Under WHO CAT leadership the task group will provide the following deliverables with the first year:

- ICF Update platform up and running (principles, information rubrics, cycle, software application)
- Update proposals in ICF-CY identified and submitted.

International Classification of Health Interventions (ICHI)

It was discussed whether ICHI should be considered to be a related classification rather than one of the core WHO classifications. To avoid confusion with interim draft proposed versions its name might be changed. Fully aware of the unmet need of the international community, though, the meeting felt that work should start to capture selected key domains where a classification of interventions is needed and elaborate the structuring principles that should govern their integration in a future international classification, possibly around a backbone to which modules could be connected. The suitability of knowledge representation models, such as those underlying CCAM, should be thoroughly assessed for possible adoption. It was recognized that all forms of health interventions should be included. Several candidate priority modules were mentioned, such as those relevant to the work of the Health Metrics Network and the short list of sentinel interventions developed under the European Hospital Data Project. It was suggested to perform the work in an Interventions Work Group under

the FDC that should report to the WHOFIC meeting in 2007 and 2008.

Terminology Reference Group

The meeting was briefed on the exploratory steps taken by WHO with a view to establishing an International Terminology Network. It was clearly indicated that the planned activities under the aegis of WHO are designed to make the Organization responsive to the needs of the Member States. According to Bedirhan Üstün a Terminology Reference Group could explore the possible synergies between classifications and terminologies, as well as multilingual knowledge representation. The meeting recognized that the tasks in this field far exceeded the capacity of individual developers and that cooperative action would be beneficial to all. It was also recognized that any existing product was short of being a perfect solution and that there would be a need to bring together a suite of products to improve the current solutions.

The meeting reviewed brief presentations of work undertaken in various parts of the world. Under the aegis of the European Union, where more semantic interoperability solutions are crucial given the cultural and linguistic diversity of its Member States, various projects have been funded.

Next meetings in 2007

The candidate Italian Collaborating Centre informed the meeting that it would be ready to host the next meeting of the WHOFIC Network from 28 October to 3 November 2007 in Trieste, Italy. The central theme proposed will focus on Information Power: owning and sharing information.

In view of the burgeoning activities of the Asian WHOFIC Network, the ICD Office, Ministry of Health, Labour and Welfare in Japan invited the planning committee to hold its midyear meeting in Kyoto from 19-20 April 2007.

For information about this meeting contact:

Robert Jakob, WHO-CAT team, Geneva
jakobr@who.int, or have a look at the WHO classifications website
<http://www.who.int/classifications>

International conference on disability and classification, from concepts to action, 26-27 October 2006, La Marsa, Tunisia

After nearly 30 years of conceptual debates aiming at defining disability and its components, one has entered a new era, that of applications of the classification. Thus, in the framework of the general theme of the annual meeting of the WHO-FIC network "Challenging the information paradox", this conference aimed at

- gathering experiences of applications and uses of the classification [ICF and DCP (Quebec classification)] with a particular focus on transition countries
- for framing the collection of disability data and developing statistical and administrative information systems (disability questions in censuses, population surveys, data recording)
- for designing observation and assessment tools focusing on living conditions and needs of disabled persons
- as a conceptual framework for designing and planning public policies (social, health and health related intervention programs, compensation systems, ...), with particular attention paid to Community Based Rehabilitation
- discussing applications results and their comparability, methods used and their limits, incidence in the social field
- inviting stakeholders of the region to join the French speaking network on disability measurement and setting up further North-South collaborations.

The two day conference was organised around seven topics

- What does "disability" mean today?
- Surveys on disability in different cultural contexts
- Disability Statistics: methodological issues
- Classification: tools to serve public policies and people's rights
- Comparability of disability data: available tools
- Classification and clinical and rehabilitation practices

- Dissemination, promotion and training to disability classification

27 Papers in English or French reported applications of the classification in

- national disability surveys in Afghanistan, France, Kosovo, Morocco, Southern African region (Malawi, Namibia, Zimbabwe); education focused instruments and surveys (OECD in Gabon and Ethiopia)
- administrative and clinical data recording (Australia); rehabilitation programs monitoring (Tunisia, Algeria, Quebec)
- legislation (France, Tunisia)
- international programs (UN, WHO, African Decade for disabled people, Handicap International)

Over 100 persons attended the conference, with a significant participation of stakeholders from Algeria and Tunisia.

Main results

1. A general acknowledgement of the systemic approach of disability that places the disability issue in the broader scope of development beyond health

The definition of disability as the interaction of the person and her environment (material, social and political) has become a common reference. It has significant implications in terms of (i) broadening the field of disability and stakeholders beyond the medical and medico-social ones including town planning, transportation, education, employment, culture,...; (ii) acknowledgement of PWDs' expertise and their inclusion in debates, research, policy making. Complementary to the progress accomplished regarding the definition of disability, the UN convention on the rights of persons with disabilities (forthcoming) puts the stress on the shift from social rights to civil rights. The evidence at the world level of a close link between disability and poverty, disability and education, places the issue of disability within the broader scope of development beyond that of health.

2. Surveys: why countries with the heaviest disability burden show the lowest disability prevalence rates?

All surveys presented have common features (whether in industrialized or emerging countries) that witness the impact of the systemic model:

- population based
- main objectives:
 - numbering the types of disability: impairments, activity limitations, but also participation restrictions. However environmental factors remain insufficiently investigated, most often limited to close environment (technical and human aids, home adaptations)
 - living conditions
 - assessment of needs
 - for awareness raising and monitoring the implementation of relevant policies
- include two phases: a general investigation applied to all population, followed by a more thorough investigation on impairments, activity limitations, participation restrictions on a target sub-group (screened with different methods)
- the previously commonly used dichotomised coding opposing a population of disabled persons to that of non disabled is replaced by gradual scales of severity, measuring disability on a continuum. A more flexible method that allows to define more or less extended populations according to the question to deal with.

High variations of prevalence rates were partially due to questions wording, demographic structures, cultural differences, attitudes and practice. But these causes are insufficient to give account of the observed variations; a matter that needs further reflexion.

Whatever the explanations, these variations question the relevance and usefulness of looking for global prevalence rates.

Accounting for subjectivity

The issue of the objectivity of self declaration surveys has been raised, as well as the problem of understanding the questions for persons with low level of education.

Subjectivity ranges from ignorance of one's own capacity to participate when asked to expertise of one's own experience.

An issue that deserves further investigation.

3. Classification: tool to serve public policies and people's rights

ICF becomes a reference for the development of public policies and legislations (France, Tunisia), but the interests and economic stakes of three types of stakeholders – policy makers, professionals, civil society – impact diversely on the use of information collected.

Resistance to the systemic model

- Policy makers: a resistance due to the fear of expending compensation measures that include environmental factors
- Professionals: resistance to change in institutional settings

The role of civil society and in particular disabled persons for social change

Evidence was brought that existing information (statistical, administrative or clinical) are often kept unused in emerging countries. Civil society and persons with disabilities in the first place need training to conceptual tools and data to get hold of them, forge an identity as pressure groups and use them on the public scene.

Expectations regarding the UN Convention

The compelling measures contained in articles 31 and 32 of the UN Convention are expected to support civil society's action and inspire public authorities.

4. National and international comparability of data

- OECD presented a method for comparing institutions (school) and resources allocated according to the type of disability.
- R.Simeonsson presented a comparison of tools to diagnose disability in childhood and the capacity of ICF CY to describe disability in childhood in a dynamic perspective of developmental evolution
- the Australian module FRHOM: an instrument of routine data recording on functioning that will allow for comparisons in time and between institutions.

5. Community Based Rehabilitation

The systemic approach of the Quebec classification applied to CBR programmes in Algeria and Tunisia

showed that interventions within the environments of the persons:

- bring about a redefinition of professional roles in a multidisciplinary perspective instead of hierarchic
- support families to face school and other local authorities with specific demands.

In conclusion

This conference has fulfilled its objectives by showing that classifications are used as conceptual and methodological guidelines for collecting data, planning public policies, designing and monitoring intervention programmes, whether in Northern or in Southern countries. The conference ended with a workshop intended to discuss North-South collaborative projects. It was attended by 30 people among which Algerians, Tunisians and representatives of the Secretariat of African Decade for Disabled Persons (Mohamed Fall) and WHO/DAR (Allana Officer).

For information:

The conference was organised by the Ctnerhi (Collaborating centre for ICF in French, <http://www.ctnerhi.com.fr>) and the French Federative Institute of Disability Research, [http://rfr-handicap.inserm.fr/](http://rfr-handicap.inserm.fr)
Email: C.Barral@ctnerhi.com.fr

ICECI

Portuguese version ICECI

The International Classification of External Causes of Injury (ICECI), version 1.2, has been translated into Portuguese and can be downloaded from the ICECI homepage, <http://www.rivm.nl//who-fic/ICECIeng.htm>. Its title is: Classificação Internacional de Causas Externas de Lesões (CICEL).

ICECI website

The original domain name, www.ICECI.org, is obsolete. All relevant international information on ICECI will be maintained by the WHO-FIC Collaborating Centre in the Netherlands.

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ISO9999

The ISO work group in charge with updating and revision of the related WHO-FIC member ISO9999 classification met in Berlin last October 2006.

Items for discussions were:

- finalization of the ISO9999 2006 version (FDIS) named: Assistive products for persons with disability – Classification and terminology;
- cooperation with GMDN;
- classification of multifunctional products;
- relationship between ISO9999 classes and ICF classes (document available for comments).

For information:

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Participants in the Berlin meeting

FIC around the World

Germany

Classifying of disability. Discourse Analysis of the International Classification of Functioning, Disability and Health (ICF)

The subject of this study is how the notion of disability is conceptualized in the ICF. In general disability is distinguished from normalcy; in the ICF disability is the opposite term of functioning. Health is not defined in the ICF. Since health seems to equate functioning it is arguable whether disability is an antonym to health as well. Due to the fact that the ICF belongs to the Family of International Classifications it is a powerful, multipurpose instrument designed to be used in an international context, in different disciplines and for various

purposes. Therefore it is important to analyse how disability is conceptualised in the ICF; not only by the definition but throughout the classification. To understand the significance of the ICF, first the history of WHO Classifications is considered, especially the development process of differentiating between disease and disability.

The ICIDH followed the “consequence of disease”-approach. In contrast to this, a “biopsychosocial” approach is used in the ICF. By integrating the medical and the social model of disability in the ICF the WHO attempts to achieve a synthesis of these opposing models. Regarding the conceptualisation of these models disability is viewed in different ways: one centres on the physical body and the other on the social environment. To analyse the conceptualisation of disability in the ICF the process of attempting this synthesis is reconstructed. Viewing the biopsychosocial approach critically, internal ambiguities are identified. Therefore one has to examine how far the different understandings of disability relate to a one-dimensional or to a pluralistic conception of normalcy, to normative (social, medical or juridical) norms or to normalistic (statistically based) norms. In distinguishing different conceptions of normalcy reference is made to the theory of “normalism” that has been developed by the German literary scholar, Jürgen Link (1999)*. As a provisional result the ICF represents a pluralistic understanding of disability and normalcy which is relevant for its many applications in different disciplines and for various purposes.

* Jürgen Link: *Versuch über den Normalismus. Wie Normalität produziert wird, Opladen 1999, 3. Auflage (Essay on normalism: how normalcy is produced)*

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The Netherlands

Development of 'IMPACT', an ICF-based instrument to measure activity limitations and participation restrictions

The consequences of traffic accidents can be serious, both for the victim and for society. Available data about consequences of traffic accidents in The Netherlands mainly concern numbers of deaths, hospitalizations and costs. However, figures about the long-term disability consequences (impact on activities and participation of the persons involved) of traffic accidents are sparse.

The WHO International Classification of Functioning, Disability and Health (ICF) provides a detailed scheme to describe the consequences of disease or disability. Early 2004, a literature search was performed to reveal instruments that provide a comprehensive measurement of (all or several) activity limitations and participation restrictions according to the ICF. The following resources were used: Pubmed (Medline), Cinahl, Online contents (database of Maastricht University), Cochrane (evidence based medicine), databases of the Dutch Ministry of Transport, Public Works and Water Management, Dutch Paramedic Institute, references in publications and search machines on the internet.

The literature research did not reveal a suitable ICF-linked instrument. Therefore, we developed IMPACT (ICF Measure of Participation and ACTivities) as a measure for the consequences of traffic accidents based on the ICF.

In order to keep IMPACT of reasonable size and also to cover all 21 sub-domains of ICF Activities and Participation, we decided to develop an two level instrument .

Level 1, the screener, is one to one connected to the ICF activity and participation sub-domains. Most sub-domains are covered with one item, some needed a few additional ones. Level 1 has 18 activity related items and 15 participation related items.

People can indicate themselves as having no, minor or major limitations or restrictions on the different domains. Level 2 contains 23 different modules, all having approximately 14 items (there are 23 modules instead of 21, because we divided the large domain of Self-care into 3 separate modules). People only fill out those modules related to the 'positive' scored items in the screener (level 1). The modules related to screener-items where people score 'no limitation/restriction' are not filled out. This limits the number of items respondents have to score. The items and format of level 2 are based on the questionnaire 'SIP-136' (Sickness Impact Profile), a widely used, validated and reliable instrument. Other instruments and ICF-categories were used for developing necessary additional items.

Pilot testing Level 1

To test the first draft of Level 1 for applicability and content validity, it was administered to a group of victims of a traffic accident with different diagnoses (n=11) and to a panel of (rehabilitation) professionals. The participants were asked to fill out Level 1 in the presence of a researcher. Afterwards questions were asked about the content (for example: are items missing or unnecessary, are the given examples clear?) and about the feasibility for self-report (lay-out, options for answers). The professionals tested level 1 and gave their response in a mailed questionnaire.

Pilot testing Level 2

All 23 modules of Level 2 were reviewed by professionals in rehabilitation medicine, therapy or research. A total of 17 reviewers took part and each examined 6-8 modules so that each module was reviewed by 5-6 persons.

We adjusted IMPACT based on the results of the pilot tests.

Validation and reliability study of IMPACT

In 2006 a validation and reliability study was conducted in which 988 subjects were asked to participate, and 276 respondents (victims from traffic accidents) were actually were involved

(28%). The following aspects of IMPACT were tested:

- The test-retest reliability: Respondents were asked to fill in level 1 of IMPACT twice (4 weeks interval);
- Convergent validity: Responses to level 1 of IMPACT were compared to responses to the WHO-Disability Assessment Schedule (WHODAS);
- Sensitivity and Specificity: Comparing responses of level 1 and level 2 of IMPACT;
- Construct validity: factor analysis and internal consistency analysis of response patterns.

The results of the study showed that Level 1 of IMPACT is sufficiently valid and reliable, and that the validity and reliability of Level 2 is not yet fully established. More data are required to be conclusive on this aspect and to establish the sensitivity and specificity of IMPACT. These data are obtained in a pilot implementation of IMPACT that will start in January 2007. The main aim of the pilot implementation study is to implement IMPACT in professional organisations that provide care and services for traffic accident victims (revalidation institutes, insurance companies) in order to show the added value of IMPACT for the services they provide. At the same time the data that will be obtained, are used for further improvement of IMPACT. Results will be available in 2008.

Although IMPACT is developed with the consequences of traffic accidents in mind, it is a more general instrument to assess activity limitations and participation restrictions, regardless of the underlying cause. Plans are made to implement IMPACT as an instrument in an experimental situation to assess the need for care and other resources for elderly people and persons with disabilities.

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