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

Brisbane, Queensland, Australia  
14-19 October 2002

**WHO CONFERENCE ON HEALTH AND DISABILITY**  
**17-20 April 2002, Trieste, Italy**

**Report of the Meeting**

by

**Classification, Assessment, Surveys and Terminology Team (CAS)**  
**World Health Organization**

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## **Wednesday 17 April 2002: Italian day**

## **Thursday 18 April 2002**

### **Welcome**

Renzo Tondo, President Regione Friuli Venezia Giulia and meeting host

### **Opening**

Girolamo Sirchia, Italian Minister of Health

Gro Harlem Brundtland, Director General, WHO

- It is very important for all of us to appreciate the importance of the work to place disability within the overall framework of health.
- ICF is the common international framework for describing and measuring health at both individual and population levels.
- The work to develop and promote the ICF has allowed WHO to set norms and standards, promote the basic global values of health, equity and inclusion, and provide countries with tools and advice to improve their health policies and the performance of their health systems
- ICF is based on the value of inclusion, and on a universal model of disability. It rejects the view that disability is a defining feature of a separate minority group of people.
- Health is the ability to live life to its full potential.
- By adopting ICF as a basis for its policies and legal framework, countries therefore subscribe to an inclusive, equitable and humanistic view of health. They accept the right of disabled to be a natural part of society.
- With the ICF countries will be able to monitor their policies and services to meet their international responsibilities of the equalization of opportunities for persons with disabilities.
- ICF provides the framework for health services, by measuring health outcomes to monitor and assess the effectiveness of health interventions. It meets the urgent demand for instruments to measure the performance of health interventions and health systems.
- WHO has already adopted ICF as the basis for its World Health Survey Program: Member States are encouraged to follow this example by making their health information systems and survey programs consistent with ICF.
- ICF will also be the tool for measuring the effectiveness of interventions funded by initiatives such as the Global Fund to fight AIDS, Tuberculosis and Malaria.

- With the ICF, countries will be able to identify factors such as education, transportation or housing, both as determinants of health and social factors influenced by improvements in health. These links further support the relationship between health and economic development.

### **Round Table I: Health & Wealth of Nations**

**Chairman:** David Evans

**Speakers:** Girolamo Sirchia, David Canning, David Evans, Giuseppe Nisticò

- Good health is both intrinsically and instrumentally valuable and evidence of the latter is the link between health and development.
- Health is a form of human capital: healthy people are more productive.
- There is both micro evidence of the link between health and development (e.g. height, a proxy for health status, is associated with higher wages) and macro evidence (e.g. countries with better health, in the form of higher life expectancy, have higher levels of GDP and increased life spans change life-cycle behaviour, education, retirement, savings).
- The WHO Commission on Macroeconomics and Health concluded that improving health will: release scarce resources from promotion, prevention, treatment and rehabilitation to use elsewhere; increase the time available for work and leisure; increase people's economic productivity per hour; and increase investment by improving a country's ability to attract investment.
- The balance of evidence suggests that improving health of children leads to better educational performance.

### **Round Table II: Disabled and Healthy?**

**Chairmen** Daniel Wikler

**Speakers:** Marijke W. de Kleijn, Jerome Bickenbach, Andre Gubbels, Giampiero Grifo, Yerker Anderrson, Antonio Guidi, Qui Zhouying, Chris Murray

- There are several conceptual puzzles about the nature of health, including whether health and disability are overlapping concepts.
- ICF offers an appropriate conceptual framework for knowing what changes in legislation and government programmes, including dealing with discrimination, lack of equal opportunity and violation of human rights, that affect persons classified as "disabled" are most effective in bringing about desired increases in their societal

participation.

- WHO is committed not only to the conceptualisation and measurement of health for the generation of evidence for health policy, but also to the de-stigmatization of the notion of ill-health by incorporating functioning into the concept.
- We understand health to be a separate concept from well-being, although of intrinsic value and instrumental for well-being.
- For health state description and measurement, WHO requires a conception of health as comprising of domains of functioning of the human body and mind, and as such an attribute of an individual (which can be aggregated to describe and measure the health of populations).
- By distinguishing health state profiles (levels of functioning in core domains of health) from an overall health status (a summary measure of levels of functioning across all domains), we can see why an individual with a functional decrement in one domain, but no other problems, might well describe themselves as ‘disabled, but (otherwise) healthy’.
- We must distinguish between the description of a health state and the valuation of a health state for public health purposes.
- By separating health from well-being, and operationalizing health for description and measurement, WHO is able to generate the evidence to link health with other aspects of well-being, such as human, or economic, development.

## **FRIDAY 19 April 2002**

### **Plenary Topic 1: What is wrong with Disability Statistics?**

**Chairman:** Bedirhan Üstün

**Speakers:** Michael Wolfson, Mary Chamie, Jennifer Madans, Gaetan Lafortune, Helen Nviiri, Alicia Bercovich, Somnath Chatterji

- There are multiple demands and potential uses of comparable health and disability statistics, including 1) monitoring health progress over time for different populations; 2) planning for health and social services and related expenditures; and 3) evaluating the outcomes of health and disability policies.
- Statistics on disability, internationally, have been hampered by the lack of an officially agreed upon international classification. There is an almost 60 fold difference in the prevalence rates of disability across different national surveys that have been back-coded to the ICIDH 1980.

- There is a need for functional status information for health and social statistics. However, data from different sources present problems of comparability; there are also conceptual, technical and institutional barriers to collecting and analyzing data on functional status.
- When health is viewed as a continuum with a decrement in health understood as a disability, the challenge is in identifying the most appropriate methodology for measuring this threshold across surveys, clinical practice and social policy needs.
- ICF can prove useful in improving cross-population comparability by providing clear operational definitions of domains, unambiguous coding guidelines and a framework that can be demonstrated to work in surveys and clinical applications. When the ICF is used as the framework to conceptualise disability and to operationalise survey questions, where disability is a threshold on a continuum of health, the variation in disability rates is within acceptable limits that have face validity.
- The ICF has achieved important successes as a successor to the ICIDH, including less stigmatizing language, inclusion of environmental factors, and a more realistic appreciation of causal relationships. However, work on the ICF is in progress especially with regard to the development of more formalised assessment strategies that are linked to this framework.
- ICF is a promising basis for collecting disability data in developing countries.

## **Plenary Topic 2: ICF and Health Information Systems**

**Chairperson:** Marjorie Greenberg

**Speakers:** Ed Sondik, Michael Wolfson, Richard Madden, Myint Htwe, Mounkaila Abdou, Roberto Becker

- The major health surveillance and statistics programs in the US are undergoing considerable change and a continuing priority for the US is the reduction and eventual elimination of disparities in health status defined by race, ethnicity, income or other demographic variables.
- The ICF's emphasis on multiple dimensions which together describe the many aspects of how individuals function in their environment is an important step in the requisite characterization of health. There needs to be a link to risk factors within the ICF framework in order to examine the relationship between these and health currently and in the future.
- It is a challenge is to find ways to summarize the complex ICF framework to enable data collection on population health using surveys and similar data drawn from administrative records.

- Interest in the development of health information systems across the whole of Canada's health system is at an all time high; to be useful, the ICF needs to be operationalized into well-tested, practical data collection instruments at a variety of levels of detail.
- WHO in SEA Region will provide assistance in promoting ICF for health information systems WHO assistance in promoting ICF in the context of HIS activities, if there is national commitment to its use.
- There is need to sensitizes health and disability programme managers on the usefulness of ICF, and to develop partners among collaborating centres, research institutes, insurance companies and NGOs.
- The ICF is an essential part of the Australian Family of Health and Related Classifications, which is currently being developed. The Family of Classifications is congruent with the Australian Health Performance Framework, and is an important part of the Australian health infrastructure.
- In Africa, the challenge is to integrate ICF in the existing health information systems, and create of culture of information conducive to a wide use of ICF.

### **Working session 1: ICF in Clinical Practice**

**Chairmen:** Paul Garfinkel

**Speakers:** Rachel Jenkins, Paul Garfinkel, Cille Kennedy, Gerold Stucki, Rune Simeonsson, Jayne Lux, Gretchen Swanson

- There is no doubt about the potential value of ICF in clinical practice: ICF emphasizes a broad view of health; it helps inform the clinician about domains not always considered; it profiles more fully the functional components of clinical conditions; it enables planning interventions, matching interventions to clinical profiles, and identifying the focus of intervention.
- ICF can help to structure baseline information from various perspectives of the multi-disciplinary team, that complements ICD, encourages thinking beyond a medical model, and encourages broad treatment planning.
- ICF can be used to re-evaluate functioning in specific domains, monitor the individual's progress, and track the effectiveness of treatment.
- ICF can help in setting intervention targets and permits measurement of outcome along multiple dimensions.
- There is a need to advance ICF by making it more user friendly, tailor-made to specific user needs, clinically relevant, easier to use, and cross validated to established

instruments.

- It is valuable to develop a generic core set and selected core sets in functional domains for mental health, rehabilitation, etc., as well as for different health conditions to be used in minimum data sets and to determine how much of the variance will be explained by the generic core set and how much by the more specific core sets.
- For the future, we need to continue to develop a standardized application manual at different levels of detail; develop and test generic and specific core sets; develop the child version of ICF; cross validate with other measures currently in use; develop primary care versions; disseminate information widely to increase clinicians' awareness, educate people involved in policy development and professional education, and partner countries advanced in ICF development with those that are less developed.

### **Working session 2: ICF in Surveys**

**Chairman:** M. Abdou and M. Htwe

**Speakers:** Sowarta Kossem, Jennifer Jelsma, Mitchell Loeab, Renee Langlois, Montserrat L. Cobo, Elena de Palma, Howard Meltzer, Ros Madden, Juergen Rehm, Paul J. Placek, Bedirhan Üstün

- Presentations showed the feasibility of using the ICF framework and individual domains.
- Thus far there has been a strong focus on use of activity limitation although there is a growing concern and interest in using participation and environment codes as well.
- There are interesting examples of different ways of using the framework, e.g. collecting data on all levels of functioning/disability, and combining ICD and ICF; collecting data on capacity, performance and environmental facilitators and barriers; collecting environmental factors data which is limited in scope to technical aids and personal assistance; and back-coding /cross-walking existing surveys to ICF framework .
- Importance of linking data collection to policy needs and ensuring data fits the purpose intended and is used in policy development.
- There is a need to look at the gap between the experience of disabled people compared to non-disabled, moving away from just asking disability survey questions to disabled people.
- Areas that are still weak in disability surveys is the inclusion of mental health aspects of disability, institutionalised populations and children.

- Setting thresholds should happen after the data has been collected rather than building into the questionnaire.
- ICF framework is good for pushing collection of data on participation and environment.
- There is still much development work to be done on ICF to get proper tools (e.g. how to measure environment, guidance on personal factors)
- Important to link disability and health surveys more directly and ICF makes this easier.