



## WHO Family of International Classifications (FIC)

# NEWSLETTER

## 2017 WHO-FIC Annual Network Meeting Connecting Data for Health

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The 2017 Annual Meeting of the WHO Family of International Classification (WHO-FIC) Network will be held at the World Trade Center in Mexico City, Mexico, from 16 to 21 October 2017. "Connecting data for Health" has been identified as the main theme for the meeting this year.

The WHO-FIC Network, a network of WHO Collaborating Centres, NGOs, and selected experts, has been established since 1970 to support WHO's work on international classifications. The principal role of the WHO-FIC Network is to develop, update and revise, maintain and promote the implementation of the WHO reference health classifications, such as ICD (the International Classification of Diseases), ICHI (the International Classification of Health Interventions) and ICF (the International Classification of Functioning, Disability, and Health).

The meeting is hosted by the WHO Collaborating Centre for the Family of International Classifications in Mexico (el Centro Mexicano para la Clasificación de Enfermedades / Centro Colaborador de la OMS para la Familia de Clasificaciones Internacionales), with support by the PAHO/WHO Country Office and the WHO Regional Office in the Americas. This and other information, such as meeting timetable, registration form, venue and accommodation, can also be found at the meeting website:

<http://www.whofic2017.org/>



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## Editorial

*Dear readers of the WHO-FIC Newsletter, it is with mixed emotions that I present this newsletter to you. As this is the last newsletter in this style. Starting next year we will bring you relevant WHO-FIC news differently – the newsletter will go along with the digital era. It will become a sub-site of our Dutch WHO-FIC website (<http://www.who-fic.nl/en>). Of course, subscribers will still get the notifications of the newsletter in their inbox.*

*Another reason for reorganizing our newsletter is the ICF literature. As you may have noticed the amount of ICF literature is growing exponentially; it takes up more and more space of our newsletter. In this issue we have included almost 250 ICF references over the last year! That is why we intend to share our ICF literature database with you through our WHO-FIC website as well.*

*Despite the new format of bringing you WHO-FIC relevant news, we still need your active involvement. Because we need you bringing your WHO-FIC news to our attention! As for the newsletter at hand we have contributions on implementations of ICF in international context, we have a reflection on Professor Üstün's retirement from WHO and news from Statistics Netherlands regarding IRIS.*

*Enjoy reading, and let us know your WHO-FIC news!*

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## Retirement of Professor Üstün from WHO

Professor dr. T. Bedirhan Üstün has retired from the World Health Organization (WHO) after a 26-year career advancing international health policies and information standards for mental health, disability data, mortality and morbidity data. Prof. Üstün, who trained as a psychiatrist in his home country, Turkey, began his career at WHO in 1990 in the Mental Health Division. He conducted numerous large-scale epidemiological surveys, including the World Mental Health Surveys and World Health Surveys. From 1998 – 2016, Prof. Üstün led WHO's work on international classifications; in this capacity, he brought development of the International Classification of Functioning, Disability and Health (ICF) to a successful conclusion, led efforts to implement and use ICF and the International Classification of Diseases (ICD) on a global basis and formulated and led plans for the eleventh revision of ICD. During this 18-year period, Bedirhan, as he was widely known, developed the WHO Family of International Classifications (WHO-FIC) Network, expanding global participation in the Network and supporting the addition of related classifications.

WHO-FIC Colleagues remember Bedirhan for his vision, keen intelligence, enthusiasm, creativity and boundless energy. Dr. Cassia Maria Buchalla, former Head of the Portuguese Language Collaborating Centre in Sao Paulo, Brazil and Co-Chair of the WHO-FIC Education and Implementation Committee, recalls that she always admired the way he introduced new subjects. "The presentations he made at the meetings always called much my attention because he wove unusual images like the Tower of Babel to justify the need for classification, the periodic table (chemical elements) to show how the classification is important, the information paradox for the difficulties in the African continent, and so on. I use his ideas for my presentations very often."

Dr. Richard Madden, who chaired the Australian Collaborating Centre for ten years and was the original Chair of the Network's Family Development Committee, notes that Bedirhan "followed up the approval of the ICF in May 2001 with the launch of the WHO-FIC Family at the 2001 meeting of Collaborating Centres in Bethesda, USA; the network of ICD and ICF collaborating centres became the WHO-FIC Network (and met together from that time forward). The need to use both ICD and ICF to describe health was included in the introductions to both ICD and ICF. In 2003, a WHO-FIC Council was established as the Network governing structure, along with a formalisation of the committee structure. That year, five related classifications were introduced to the Network, substantially expanding its coverage of health information and systems. Bedirhan's foresight in establishing the Family of Classifications has given a strong foundation for moves to integrate health information on individuals and populations to support health system integration and the Universal Health Care initiative." Richard also recognized Bedirhan's support for development of the International Classification of Health Interventions (ICHI) as WHO's third reference classification, along with ICD and ICF, and the need for ICHI, currently under development, to cover all aspects of the health system, including functioning and public health interventions.

Ros Madden, also of the Australian Centre and long-time Chair of the Network's Functioning and Disability Reference Group, remembers, "Those involved in the ICF development before 1995 would have been aware of Bedirhan Üstün as an enthusiastic and expert leader of the mental health task force in the process. Without WHO's decision in mid-1995 to ask Bedirhan to lead the whole development process, there would quite possibly have been no ICF, and certainly not in its present form. With one bold decision, he immediately brought diverse people and resources on board. This was the decision to bring Environmental Factors INTO the ICF, not left on the side-line – something that had been of concern and debate for some time. This makes it clear to ICF users that the environment affects people's experience of functioning and disability and must be accounted for in its measurement.

This was the beginning of the biopsychosocial model. Bedirhan raised funds for international testing, brought varied communities and dedicated experts into the development process, ensuring that there was a range of stakeholders formally involved. The ICF was a huge achievement and is changing practice around the world in measurement, statistics, policy and practice. For WHO and the WHO-FIC Network, Bedirhan was a leader of vision, of creativity, courage, enormous intelligence, tireless work and dedication to our common cause.”

The German ICF Research Branch recalls their long history of collaboration with Bedirhan and points to the ICF Core Set development and work on standardized reporting of functioning information as major achievements. Bedirhan co-authored numerous articles with members of the Research Branch on such topics as ICF Linkage Rules, assessing the impact of health conditions, harmonizing routinely collected health information and a minimal generic set of domains for rehabilitation.

Yukiko Yokobori of the Japan Hospital Association and current Co-Chair of the WHO-FIC Education and Implementation Committee greatly appreciates Bedirhan’s contributions to the implementation and use of international classifications in Asia. She recalls that he initiated regional activities at the WHO-FIC Network annual meetings and established the Asia-Pacific Network (APN) for the purpose of ICD implementation in 2006; in so doing, he built a cooperative structure to include ICD stakeholders and the WHO regional office. “As a result, we now have the strong network of International Classifications in Asia.”

Bedirhan’s support for the International Federation of Health Information Management Associations (IFHIMA) is remembered with gratitude by Margaret A. Skurka, Past President of IFHIMA. Margaret notes that he was instrumental in helping IFHIMA obtain status as a Non-Governmental Organization (NGO) in official relations with the WHO. With this status, IFHIMA sends representatives to WHO meetings and works closely with WHO on specific projects of particular concern or interest to WHO in the field of health records and health information. Over the past years, IFHIMA has collaborated with the WHO-FIC Network to develop and promote an international training strategy for coders. IFHIMA also manages the International Exams for Mortality and Morbidity Coders since 2015, directly as a result of prof. Üstün’s staffs’ efforts. Margaret also appreciates that, as a physician, Bedirhan has been a passionate and credible voice for the importance of accurate health care data, accurate death certificates and the importance of correctly coded data.

Since 2007, Bedirhan led the ambitious and multi-dimensional effort to revise the tenth revision of ICD, which had been finalized in the early 1990’s. The previous ten-year revision cycle for ICD had been extended in order to expand implementation of ICD-10 by member countries and

take advantage of the new updating process developed by the WHO-FIC Network. However, by 2004, it was agreed by the Network that the eleventh revision of ICD should be initiated. Bedirhan obtained support from the Japan Hospital Association and others to launch the revision process in 2007 and recruited experts from around the world to carry out the revision under WHO’s supervision. In addition to the goal of bringing ICD up to date with scientific advances and clinical practice, Bedirhan also undertook a major effort to align ICD with current technologies for classifications and health information and to link it with computerized health information systems. As mentioned by Vincenzo Della Mea, former Chair of the Informatics and Terminology Committee, Bedirhan’s accomplishments included bringing into a “concretely used resource, like ICD, concepts that in academia are always recognized as of importance (and) useful, enabling real electronic exchange,” but that normally are only tested in small applications. Vincenzo continues, “I refer to ontologies, ontology matching, etc; from this point of view, ICD-11 at its completion will be the central platform for exchanging meaningful data. He put enthusiasm on this, and while not everyone was equally enthusiastic, I have been infected too.” Others who responded to the questionnaire fielded by an Interim Assessment of ICD-11 in early 2015 also expressed enthusiasm for this component of the revision process and recognized Bedirhan’s visionary efforts.

The WHO-FIC Network congratulates professor Bedirhan Üstün on his many contributions to health and health information, thanks him for his support and friendship over the years and wishes him continued success in the years ahead.

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## ***International Organizations***

### **United Nations Statistics Division**

#### **Strengthening Disability Statistics in the 2030 Agenda for Sustainable Development**

##### **Introduction**

The 2030 Agenda for Sustainable Development (SDG) recognizes persons with disability (of whom more than 80 per cent live in poverty) as one of the vulnerable peoples and calls for their empowerment. The Agenda further commits that by 2020, to enhance capacity building support to developing countries, including for least developed countries and small island developing States, in order to increase significantly the availability of high-quality, timely

and reliable data disaggregated by among other things, income, gender, age, race, ethnicity, migratory status, disability (1). The United Nations Economic and Social Council (ECOSOC) in its resolution E/RES/2015/10, for the 2020 World Population and Housing Census Program, stresses that population and housing censuses are designed to generate valuable statistics and indicators for assessing the situation of various special population groups, such as persons with disability.

In the context of the 2030 Agenda for Sustainable Development and of the 2020 World Population and Housing Census Program, the United Nations Statistics Division (UNSD), with funding of the Department of Foreign Affairs and Trade (DFAT) of the Government of Australia, has relaunched its disability statistics program so as to enhance the capacity of national statistical offices to produce and disseminate good quality and fit-for-purpose statistics on disability for all-inclusive development planning and monitoring taking into account the situation of persons with disability.

As part of the program, UNSD is taking stock of the current state of affairs regarding the experience of countries in disability measurement in terms of:

- (i) how the data are collected,
- (ii) what data are collected, and
- (iii) available guidelines for disability measurement.

Through an analysis of the above and through an international consultative process, the relaunched program has as one of its expected accomplishments the review of the present and further development of international guidelines for measurement of disability taking into account existing measurement instruments, good national practices and country needs.

Country
Name and year of census
Definition of disability
Introductory phrase/question
Screening question
Disability question/items
Response categories
Other relevant items
ICF mapping tables
Observations concerning the content of parts of the questionnaires

Figure 1: analysis structure of census questions

For the international consultative process, six UN-regional meetings took place in which countries from the regions were invited. Meetings took place in Thailand, Barbados, Uganda, Oman, Kazakhstan and Chile. At each meeting participants were briefed on the 2030 Agenda and how disability is reflected therein and the 2020 World Population and Housing Census Program, the WHO's Model Disability Survey (MDS), UN-Regional Commissions' initiatives on disability, the Washington Group Short Sets (WG-SS) and the WHO International Classification of Functioning Disability and Health (ICF). The latter was combined with examples of a structured analysis of census questions on disability (Figure 1) from censuses of the 2010 round, focusing on how 'disability' has been operationalized in the census of each country.

### Mapping to ICF

The disability questions/items and response categories have been 'mapped' to ICF categories and ICF-Qualifiers, as shown in the example table below:

Disability questions/items	ICD	ICF-Function	ICF-Structure	ICF-Activity	ICF-Participatio ←	ICF-Environmental Factors
<b>Do you have difficulty</b>						
seeing even wearing glasses or lenses		b210*				e1251*
hearing even if using hearing aids		b230*				e1251*
walking or climbing stairs				d450*	d4551*	
remembering or concentrating		b144*	b140*			
Self-care				d5*		
bathing				d510*		
dressing				d540*		
communication				d3*		
understanding others				d310- d329		
being understood by others				d330- d349		
permanent or temporary job				d8502 d8501		

\* indicates that there is a corresponding item in the WG Short Set

Response categories	ICF-Qualifiers?
no difficulty	.0 NO problem
some difficulty	.1 or .2 MILD/MODERATE/FAIR problem
yes, great difficulty	.3 SEVERE problem
cannot do at all	.4 COMPLETE problem
don't know	

The tables with the mapped items to the ICF have been grouped by geographic region and also for all regions combined. This will provide information about the most common items per region and for all regions combined. From this a possible set of items for international comparability of data on functioning/disability could be derived.

All meetings followed the same structure of sessions: (i) *Collection of data on disability through censuses, surveys or administrative sources: National examples* This session was aimed at providing information on national experiences regarding: the questions used to measure disability, reasons for the choice of questions, testing of the

questions, experience in how the questions worked in the field, use of proxy respondents, translation of questions, use of scaled response categories, topics on which data were collected, sample size, geographical level at which results are available, etc. Each country was invited to present their own way of data collection, purpose of collection and to also take part in the discussions following the presentations.

*(ii) Data needs and availability for monitoring and reporting for:*

(a) SDG disability indicators; and (b) national needs  
This session covered presentations on data needs for generating disability-related SDG indicators for global monitoring. Country presentations discussed the extent to which countries are able to produce data for monitoring and reporting for the SDGs, and for national monitoring, including on existence of national policy frameworks, coordination mechanisms for producing and utilizing the statistics on disability, identifying data gaps, as well as on challenges experienced by countries in generating the required data.

*(iii) Strategies for promoting national production of data on disability and their utilization for policy purposes*

This session was conducted through group discussions and aimed at identifying a strategy or steps to be taken to ensure: generating reliable and good quality data on disability that are fit-for-purpose, and to utilize the data for monitoring progress towards inclusion of persons with disability in development programs. Some of the issues for the discussions and inclusion in the strategy included:

- (a) existence of a mandate for collection and compilation of data on disability,
- (b) national frameworks for monitoring the situation of persons with disability,
- (c) identifying main users of disability-related statistics,
- (d) promoting utilization of disability data for policy purposes,
- (e) identifying key producers of the data on disability in national statistical systems,
- (f) existence of national coordination mechanisms,
- (g) strengthening national capacity to produce fit-for-purpose statistics (from diverse sources) for national, regional, and global monitoring and reporting.

In the final session concluding remarks were made, based on the outcome of the discussions on next steps in developing this area of statistics, including on provision of technical support to countries.

## Results

As mentioned in the introduction, the results and accomplishments of all regional consultations, the analysis of all available 2010 census round questions on disability, as well as the outcomes of the group discussions, are expected to provide input into the review of the present and further development of international guidelines for

measurement of disability taking into account existing measurement instruments, good national practices and country needs.



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2. 2020 World Population and Housing Census Programme Economic and Social Council resolution E/RES/2015/10, adopted on 10 June 2015.

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## Washington Group on Disability Statistics

### Overview of Data Collection Tools Developed by the Washington Group on Disability Statistics and their Recommended Use

Questionnaire modules developed by the WG are designed to be easily incorporated into ongoing national data collection systems, in topic specific surveys and are also widely used in programmatic and research data collections. This overview describes the currently available WG data collection tools and how they relate to each other so that users can select the most appropriate tool for their needs.

### The WG Short Set of questions

The first tool developed by the WG was a short set of 6 questions designed primarily for inclusion in Censuses. The tool was developed in response to the stated need of member countries for a short module that could be added to decennial censuses, which in many countries can be the sole or most reliable means of collecting population-based data. Because of the restrictions inherent in the census format, the module had to be short and parsimonious. While developed initially for censuses, the brevity of the module is also well suited for inclusion in surveys for the purpose of disaggregating outcome indicators by disability status. To maximize international comparability the question set obtains information on difficulties a person may have in undertaking basic activities that apply to people in all

cultures and societies and so are universally applicable. Difficulties in these basic activities in a non-accommodating environment are associated with a higher risk of participation restrictions. When analyzed in conjunction with other information collected on censuses and surveys, it is possible to compare whether difficulties in basic activities are associated with participation restrictions or if the necessary accommodations have been made so that all persons can fully participate in society. This definition is in keeping with the UN CRPD and its goal of full and effective participation and inclusion in society (Article 3).

Due to the need to keep the module short, only a single question per functional domain could be included. The final set of questions includes difficulties seeing, hearing, walking or climbing stairs, remembering or concentrating, self-care, and communication (expressive and receptive). It is acknowledged, therefore, that the short set of six questions would not identify all persons with all types of difficulties in basic activities. However, evidence shows that using these questions covering major functional domains identifies the large majority of people with disabilities, and so is useful for making inferences about the characteristics of people with disabilities in the population and their outcomes that are critical for policy planning and evaluation. To identify the remaining people, a more extensive set of questions is needed, for example the WG Extended Set summarized below. The short set does not include functional domains of importance to children (see section on WG/UNICEF Module on Child Functioning). The short set is recommended for data collections in 1) censuses where space is very limited; 2) surveys where some information that is obtained on all or multiple members of the household/family is used to describe the total population (such as labor force surveys); and 3) broad-based household surveys that cover a wide range of topics where information is obtained on all household/family members (e.g., living standard measurement surveys or household income and expenditure surveys).

The short set is not optimal for reporting on children for two reasons. First, as described above it will not identify children with many developmental issues, and second because the questions will not necessarily be answered by the primary caregiver. If the Module on Child Functioning cannot be incorporated into ongoing data collections due to design requirements or other restrictions, the information resulting from using the Short Set on children should be limited to the population 5 years and older. The results would reflect functioning difficulties only in the Short Set domains included. Evidence has shown that this would be an underestimation of functioning difficulties in this subpopulation, and this should be documented when reporting results.

### **The WG Extended Set of questions on Adult Functioning**

Upon completion and adoption of the Short Set, the WG embarked upon the development of an Extended Set that

would allow for the collection of additional data on domains of functioning (for the adult population 18 years and above) that were not included in the Short Set; for example, affect (anxiety and depression), upper body functioning, and pain and fatigue. In addition, the question set begins to explore the connection between functioning and the environment through the inclusion of questions on the use of assistive devices and personal assistance in the mobility (walking) domain.

The Extended Set of questions on Adult Functioning is intended for population-based household surveys (demographic and health surveys-DHS, household income and expenditure surveys-HIES, etc.) or as part of a larger disability survey, and is recommended in health surveys and surveys that focus specifically on disability. The WG Short Set of questions is embedded into the Extended Set. Including the short set each year on ongoing surveys and the extended set on a periodic basis is one way to reduce burden but assure that information on all functional domains will be available.

### **The WG/UNICEF Module on Child Functioning**

To address the unique situation of children, the WG embarked upon the development of a separate module that would specifically address child function. This work began in 2009 and UNICEF joined the collaboration in 2011. The survey module follows the same principles as the earlier modules: to determine ‘disability’ through a series of questions on difficulty functioning that would place a child at risk of participation restrictions in a non-accommodating environment. The module is split into two sub-modules: one for children 2-4 years of age; and another for children 5-17 years of age. Domains of functioning include: seeing\*, hearing\*, walking\*, communicating\*, cognition (learning\* and remembering), self-care (feeding and dressing), upper body functioning\*, behavior\*, emotions (anxiety and depression), coping with change, focusing attention, playing\* and relationships.<sup>1</sup>

Six of the domains mirror those included in the WG Short and Extended sets of questions. The module on child functioning is recommended for use in surveys that either focus on children, or that contain modules that focus on one or all children in the household. The child functioning module should always be used in surveys that focus on education. The domains included in this module address the unique situation of children and are critical for understanding participation in educational activities which is children’s primary activity and which will have major impacts on their lives as adults. Information obtained using only the short set will not provide information on these key domains. The respondent should be the child’s mother or primary caregiver.

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<sup>1</sup> \*domains for children 2-4 years of age. All domains with the exception of playing and upper body functioning are relevant for those 5-17 years of age.

## Modules under Development

The WG is working with partners to develop two modules that focus on participation and the barriers and facilitators that affect level of participation. The WG and UNICEF are developing an inclusive education module that would be used in conjunction with the module on child functioning. This module will focus on measuring barriers & facilitators to education by children with and without disabilities. Data are collected under four main domains related to the environment and within the context of school participation: attitudes, school environment (including getting to school, accessibility and affordability), and a set of questions designed for children currently out of school. The WG is working with ILO to develop a module on employment. Questions for selected domains from the extended set are used in conjunction with the short set questions and information on work related barriers and facilitators to address issues related to full participation in work.

## Supplementary Material

Implementation guides for each WG tool provide detailed information on how to construct the disability indicator; and analysis guides provide information on how to relate the information produced using the different tools on the same study population. The data collection tools were developed to meet user needs and reflect the need to balance requirements for a very short set of questions for some purposes against the need for more detail for other purposes and for specific age groups.

For more information visit our updated website:  
<http://www.washingtongroup-disability.com/>

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# ***FIC around the World***

## Netherlands

### Statistics Netherlands joins IRIS Core Group

Since 2013, Statistics Netherlands (CBS) uses IRIS for the production of cause-of-death statistics. IRIS is the name of software for the automated coding of causes of death. The software enables a user to code all the medical expressions on a cause of death certificate and to select an underlying cause of death, defined as the disease or disorder (natural cause of death) or the circumstances (external cause of death) starting the causal chain of morbid events leading directly to death. The cause-of-death statistics is a tabulation of these underlying causes of death.

Apart from Belgian, Cyprus, France, Germany, Luxemburg, Czech Republic and Sweden, The Netherlands is one of the eight European member states using IRIS for the production of cause-of-death statistics.

The United States of America started to develop software for automated coding of medical entities (ACME) in the 1970s. ACME found its way to Canada, Australia, the UK, and some European countries such as Italy, Hungary and Norway as well. Around the year 2000, Lars Age Johansson (Sweden) en Gerard Pavillon (France) made this software suitable for non-English speaking countries. To date, the governance of IRIS is maintained by DIMDI in Cologne, Germany. Countries or organizations considering the use of IRIS or using IRIS can join a so called IRIS user group. The IRIS user group gathers each year in September to exchange user experiences and to discuss future developments of the software.

To date, IRIS is further developed by the so called IRIS core group (CG). Germany, France, USA, Italy and Hungary are IRIS CG members. Every year, there is a new release of IRIS in January, containing the latest ICD10 updates for coding causes of death and improvements of the software.

In November 2016 Statistics Netherlands joined the IRIS CG. The tasks of Statistics Netherlands will be:

- Testing of IRIS prototypes before release of a new version;
- Review of the IRIS decision tables for coding or selection of the underlying cause of death;
- Instruction and training of IRIS users;
- Contributing to the user manual of IRIS.

For these tasks Statistics Netherlands will allocate Jan Kardaun (M.d.), Peter Harteloh (M.d.) en Suzan van der Aart (programmer).

By participating in the IRIS CG, Statistics Netherlands aims to contribute to the development and use of software for automated coding of causes of death, and to the quality of the software and thereby to the quality of cause-of-death statistics.

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