

WHO Collaborating Centre for the FIC in The Netherlands

Editorial Board Dr. Coen H. van Gool Dr. Willem M. Hirs Dr. Marijke W. de Kleijn-de Vrankrijker Drs. Huib Ten Napel Drs. Lany Slobbe

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Address

WHO-FIC Collaborating Centre
c/o Centre for Public Health Forecasting
National Institute for Public Health and the
Environment (RIVM), P.O.Box 1,
3720 BA Bilthoven, The Netherlands.
Telephone: 0031 30 274 2039/4276
Fax: 0031 30 274 4450
Website: http://www.rivm.nl/who-fic
E-mail secretariate: Lummy.Blomer@rivm.nl
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WHO Family of International Classifications (FIC)

NEWSLETTER

WHO-FIC Network Meeting 2011: Health Information is Vital

Cape Town: 29 October - 4 November 2011

The 2011 annual meeting of the WHO Network of Collaborating Centres for the Family of International Classifications will be held in Cape Town, South Africa, at the Southern Sun Cape Sun Hotel. The meeting will be hosted by the South African Medical Research Council (MRC).

'Health Information is Vital', is the theme for WHO-FIC 2011. It reflects the importance of accurate health information for effective health services, and the ongoing international drive to improve the registration of vital events (births and deaths), especially in countries with currently weak information systems for health (http://www.whofic.org.za/index.htm).

At http://www.who.int/classifications/network/meeting2011/en/index.html a provisional timetable and meeting agenda is available. Other meeting documents, such as papers, posters, and meeting reports will become available on this website as well. During the first five days of the meeting the Committee & Reference Groups convene. On Thursday November 3rd the meeting will be opened officially.

Please note that participation is on invitation only. You can find contact information, information about Cape Town, accommodations and social events at http://www.whofic.org.za/index.htm.



Editorial

Our newsletter 2011 number 1 was completely devoted to ICF experiences. This edition encompasses information regarding as much as possible members of the WHO Family of International Classifications (WHO-FIC).

Our oldest reference member is the ICD. In a lot of countries the tenth revised version (ICD-10) is in use. In the Netherlands this goes for mortality data registration but for morbidity the implementation of ICD-10 in all Dutch hospitals is running now. Being at this stage it is interesting to see how other countries carried out the introduction, and for this reason we invited our colleagues from Thailand to tell about their lessons learned. In the meantime the ICD is being revised again. Revision timelines, alpha and beta draft information and the new features of the ICD-11 are provided. The Australian Collaborating Centre organized a full day conference called "Towards ICD-11 for Australia" (July 1st 2011) in Sydney. Copies of all presentations from this event have been placed on the AIHW website, see also: http://www.aihw.gov.au/TwoColumnWideLeft.aspx?pageid =10737419473

The **ICF** as the second, but younger, reference classification meets a lot of interest and applications in several fields. A symposium organized by the University of Sydney called "Think before you measure" (June 29 – 30 2011) offered a possibility to get informed about ICF related matters. Presentations are available through: http://sydney.edu.au/health_sciences/health_systems_global _populations/think_before_you_measure/speakers.

We already mentioned the international interest in ICF as a base for the development of functioning and disability questionnaires in a previous newsletter. A comparison of the question sets developed by the UN Washington Group on Disability Statistics (short set) and the Budapest Initiative is presented for your information. A short explanation is provided as well.

Reference is made to the WHO World Report on Disability and its relationship with the ICF. And a few other ICF related contributions are included. In order to enable users to offer ideas for ICF updates WHO established an ICF update platform, see <u>https://extranet.who.int/icfrevision/</u>. Please note that you have to create an account first, which WHO has to authorize before you can login.

The newest reference member of the family under development is **ICHI**, the International Classification of Health Interventions. Why we need an ICHI as well as definitions, structure, content and planning of future work are described in a short informative contribution from the Family Development Committee. One of the WHO-FIC related members is the **ISO 9999**, Assistive products for persons with disability – Classification and terminology. A new version has been released July 2011. The main features of the new version and possible items for the next revised version in 2015 are described. Harmonization between the subdivision used in ISO 9999 and chapter 1 of the ICF Environmental Factors list will be part of the revision work.

Next time, we hope to be able to inform our readers about other related members, e.g. the International Classification of Patient Safety (ICPS) and the Classification of Traditional Medicine. Who wants to prepare a contribution?

For information:

Marijke de Kleijn-de Vrankrijker WHO-FIC Collaborating Centre in the Netherlands. e-mail: marijke.de.kleijn@rivm.nl

In Memoriam: Roberto Becker

Dear Colleagues,

We are very saddened indeed to hear of the loss of our friend and colleague Dr. Roberto Becker. He was held in great respect by his many friends and colleagues at WHO and in the network of WHO Collaborating Centres for the Family of International Classifications. All who had the pleasure and privilege to know him, both on a professional and on a personal level, will sorely miss him.

Dr. Becker has contributed over the past 35 years extensively and with great success to the work of epidemiology and health-related classifications in his role as Director of the Epidemiology Division of the National Secretariat of Basic Health Action of Brazil, and later in his role as regional advisor for disease classification and WHOFIC at WHO PAHO/AMRO. Dr Becker was among the leading experts in the implementation of ICD, ICD-O, and ICF, their use and maintenance.

The World Health Organization fully recognizes his contribution and his life-long commitment to global health through the international classifications and his contributions in the Americas, and other regions.

Our most sincere condolences go to his family at this difficult time.

Robert Jakob, on behalf of Bedirhan Üstün, the WHO CTS, and the WHO-FIC Network

For information:

Robert Jakob, WHO Geneva e-mail: jakobr@who.int

International Organizations

International Organization for Standardization

New version of ISO 9999 has been published

In July 2011 the new version of the international standard ISO 9999 Assistive products for persons with disability -Classification and terminology has been published. In ISO 9999 assistive products are classified according to their function. ISO 9999 is a related member of the WHO Family of International Classifications (WHO-FIC). This 2011 version replaces the 2007 version. Besides many smaller changes, an important change is the addition of a new class: 28 Assistive products for employment and vocational training, based on proposals of REHADAT, the German Information System on Vocational Rehabilitation.

Preparations already being made for version 2015

The adaptation of ISO 9999 is an ongoing process. The New Work Item Proposal for version 2015 is already registered with ISO Central Secretariat in June 2011. The preparatory stage of this new revision will start with the registration as an approved new work item in October 2011. The publication of the final document is planned for August 2015.

The working group WG11, responsible for the revision, will meet in Tokyo in October 2011. During this meeting an inventory will be made of the changes that are necessary in the 2015 version. One of the tasks for the new revision is to indicate how to deal with components and composed products, acting as assistive products in the classification. Other tasks are to indicate the relation with and/or inclusion of general products in the classification, the revision of the classes 18 (Furnishings and adaptations to homes and other premises), 24 (Assistive products for handling objects and devices), 27 (Assistive products for environmental improvement, tools and machines) and 30 (Assistive products for recreation), and to consider a separate class for education, in relation to 04 (Assistive products for personal medical treatment) and 05 (Assistive products for training in skills).

Harmonizing ICF environmental factors with ISO 9999

A major task will be the harmonization between the subdivision of assistive products in chapter 1 of the list of environmental factors of ICF and the subdivision used in ISO 9999. In October 2010 the Family Development Committee (FDC) of WHO has recommended future joint work and collaboration between the technical experts of the Functioning and Disability Reference Group (FDRG) 'environmental factors' and ISO 9999 WG11 with the objective of harmonizing the two classifications in the content area of assistive products. ISO 9999, as a WHO-FIC related classification, should aim (agree) to have ontological linkages to the ICF as identified in an established content model to enable meaningful data exchange. The FDC supports the efforts of the FDRG to work towards alignment of ICF and ISO 9999 at an intermediate level of granularity (the level to be discussed and agreed at a later date). The Family Development Committee will designate a WHO-FIC Network representative to represent the Network in the ISO 9999 revision.

Project information

Stephen Lowe, Associate Project Manager of AbleData, USA, is the new chairperson of WG11. He is the successor of Tuula Hurnasti, researcher at the Injuries and Functional Capacity Unit of the National Institute for Health and Welfare (THL) in Finland. From the start the Netherlands Standardization Institute (NEN) administers the ISO/TC 173/SC 2 under which WG11 resorts. Due to a reduction of the budget, NEN has decided to relinquish the secretariat in 2011. With the start of the new revision of ISO 9999 the Japanese Industrial Standards Committee (JISC) takes over the secretariat.

For further information on the revision process: Mr Tsuyoshi Nakayama, nakayama-tsuyoshi@rehab.go.jp, secretary of ISO/TC 173/SC 2, Research Institute of the National Rehabilitation Center for Persons with Disabilities, Japan

For information:

Yvonne Heerkens, Chair of ISO/TC 173/SC 2 Dutch National Institute of Allied Health Care e-mail: woittiez.heerkens@planet.nl

International Classification of Health Interventions (ICHI)

Why an International Classification of Health Interventions (ICHI)?

The Family of International Health Classifications (WHO-FIC) includes 3 reference classifications: ICD, ICF and ICHI (under development). WHO had published the International Classification of Procedures in Medicine in 1978 for trial purposes, but it had not been updated. This forced some countries to develop their own intervention classifications which largely focused on medical and surgical interventions, and were not comparable. Others adopted a national classification, commonly the US ICD-9-CM Volume 3 (freely available, being replaced in 2013) or the Australian classification (proprietary). A European standard for classification of surgical interventions had been developed in the 1990s (pr EN ISO 1828), and several national classifications have followed this (France, Canada).

ICHI is being developed with a broad scope to include all types of interventions undertaken by providers in health

occupations, including medicine, surgery, diagnostics, primary care, allied health and rehabilitation, assistance with functioning, nursing, traditional medicine and public health. It will provide an international base for health policies to promote efficient provision of health services (eg, activity based funding).

Structure of ICHI

In 2006, work began to develop ICHI, led by the WHO-FIC Family Development Committee. ICHI will give a common framework to describe and compare the provision and effectiveness of health interventions, provide a classification of appropriate scope and detail to which countries may align their more finely grained national classifications, and make available a classification that can be used without adaptation in countries which do not wish to develop their own classification or use another country's coding system.

The following definition has been developed: A health intervention is an activity performed for, with or on behalf of a person or a population whose purpose is to improve, assess or modify health, functioning or health conditions. 'Why' a health intervention is performed, 'Who' performs the intervention, and 'Where' it is performed are all important, but can be classified using other classifications: e.g., Why is classified using the ICD or the ICF. There is no need to duplicate this content in ICHI.

The framework for ICHI is a categorical structure, a minimal set of domain constraints to represent a healthcare terminology in a precise domain with a precise goal. The structure is based on three axes, Target, Action and Means. Each Action has a Target and a Means. The Target axis includes anatomy and functioning domains. The latter are taken from ICF domains for body function, activities and participation, and environmental factors. Actions include diagnostic, therapeutic, managing, informing, assisting and preventing groupings. Means include surgical approach, imaging techniques and methods. All axes remain under review and will continue to be modified as ICHI content is put in place.

A content model has been developed to ensure that all concepts used in describing an intervention are systematically described. This includes concepts not included in the axes, such as devices and medicines, and provides links to other appropriate term sets.

ICHI Content Development

Once the structure was in place, content of the three ICHI axes was developed. In 2010, several volunteers used the axes as developed at that time to map a range of interventions from various existing classifications to the ICHI structure. A review of this material was considered at the 2010 WHO-FIC meeting, and a range of modifications to the axes were agreed. It was also agreed that ICHI would be developed at a level of granularity similar to ICD-9-CM Volume 3.

Because ICD-9-CM Volume 3 is freely available, it offered a good base for development of ICHI content. It was recognized that substantial updating would be required. At the 2010 WHO-FIC meeting, a sample chapter (heart interventions) was presented mapped against the ICHI axes, and it was agreed that this approach looked promising.

Alpha version development

In June 2011, 15 participants from nine WHO-FIC collaborating centres (representing five WHO regions) spent two weeks in Sydney to use all the ICD-9-CM content to develop the base for an alpha version of ICHI. Several sessions were held during the period for presentation of the material and for discussion of issues that had arisen. Many improvements were made to the draft axes as a result.

Editorial rules used in the content construction process were documented. Examples include: choosing anatomy rather than function as the Target when the intervention is medical, surgical or diagnostic; where an intervention includes several actions, the main action or the first one mentioned should be selected; actions undertaken as part of a more comprehensive action should not be separately coded.

ICHI coding exemplified

Three examples illustrate the ICHI method and coding structure:

Cryotherapy of corneal lesion: ABE LD AA 01

Target	ABE	Cornea
Action	LD	Reattachment
Means	AA	Open approach

Reconstruction of intracranial vessel: AEA LF AA

Target	AEA	Intracranial artery
Action	LF	Reconstruction
Means	AA	Open approach

Mobilization of spine: FKC HH AH

TargetFKCMobility of bone functionsActionHHManual therapyMeansAHExternal

Initial discussions were also held in Sydney on the inclusion of functioning interventions and public health interventions in ICHI. A further meeting on functioning interventions was held in Italy in September 2011. It was agreed that the functioning content of ICD-9-CM Volume 3 needs substantial expansion and updating to be suitable for ICHI, and further work on interventions for rehabilitation and mental health interventions has been commissioned.

Future Work

The Cape Town WHO-FIC meeting in 2011 will review the alpha content that has been developed, along with the updated axes and editorial rules, and discuss outstanding issues. It is planned that an alpha version be available as

soon as possible. Use of an iCAT platform (developed for the ICD-11 revision) for ICHI is being examined, so that there will be a robust platform for input from a wide range of experts.

A limiting factor in ICHI development is the availability of resources. Work to date, including content development, has been done by WHO-FIC collaborating centres on a voluntary basis. This approach should be sufficient to receive input on the alpha version to produce a beta version. Field testing will require specific commitment of resources. The retirement of ICD-9-CM Volume 3 may assist in identifying resources as affected countries seek replacement classifications. Moves towards an international casemix grouper, which would depend on ICD-11 and ICHI, provide a strong business case for finalisation of ICHI.

ICHI development to date demonstrates the strength of the capacity provided for classification development by WHO-FIC collaborating centres, and conversely the limited resources that are available to these centres for activities that are not directly linked to national agendas. Great thanks are due to the many volunteers who have assisted to date and additional interest is always welcome.

For information:

Richard Madden University of Sydney, Australia e-mail: richard.madden@sydney.edu.au

World Health Organization

World report on disability

The first ever World report on disability, produced jointly by WHO and the World Bank, suggests that more than a billion people in the world today experience disability.

About 15% of the world's population lives with some form of disability, of whom 2-4% experience significant difficulties in functioning. The global disability prevalence is higher than previous WHO estimates, which date from the 1970s and suggested a figure of around 10%. This global estimate for disability is on the rise due to population ageing and the rapid spread of chronic diseases, as well as improvements in the methodologies used to measure disability.

Disability associated with unfavorable outcomes

People with disabilities have generally poorer health, lower education achievements, fewer economic opportunities and higher rates of poverty than people without disabilities. This is largely due to the lack of services available to them and the many obstacles they face in their everyday lives. The report provides the best available evidence about how to overcome barriers to health care, rehabilitation, education, employment, and support services, and to create the environments which will enable people with disabilities to flourish.

Nine recommendations

The report ends with a concrete set of nine recommended actions for governments and their partners:

1: Enable access to all mainstream systems and services.

2: Invest in programmes and services for people with disabilities.

3: Adopt a national disability strategy and plan of action.

- 4: Involve people with disabilities.
- 5: Improve human resource capacity.

6: Provide adequate funding and improve affordability.7: Increase public awareness and understanding about disability.

8: Improve the availability and quality of data on disability.9: Strengthen and support research on disability.

This pioneering World report on disability will make a significant contribution to implementation of the Convention on the Rights of Persons with Disabilities. At the intersection of public health, human rights and development, the report is set to become a "must have" resource for policymakers, service providers, professionals, and advocates for people



with disabilities and their families.

The report can be found at:

http://www.who.int/disabilities/world_report/2011/en/index. html.

For information:

Coen van Gool WHO-FIC Collaborating Centre in the Netherlands. e-mail: coen.van.gool@rivm.nl

Washington Group on Disability Statistics

Update on the work

Since 2001, the Washington Group on Disability Statistics (WG) has developed, tested and adopted a short question set of disability questions for use on national Censuses (WG-SS; see page 6 and 7, short set questions are underlined). The questions reflect advances in the measurement of disability and use the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) as a conceptual framework.

PREA	MBLE			
WG (Short Set questions are UNDERLINED)	BI – Mark 2			
<i>Interviewer read:</i> "The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM."	<i>Interviewer read:</i> "Now I am going to ask you some [further] questions about [your/his/her] general mental and physical health. These questions deal with [your/his/her] ability to do different daily activities, as well as with how [you have/he has/she has]			
VISION				
VIS_1 Do you wear glasses?	VIS_1 Do you wear glasses?			
VIS_2 Do you have difficulty seeing [<i>if VIS_1 = YES:</i> even when wearing your glasses]? Optional Vision Questions	VIS_2 Do you have difficulty seeing [<i>if VIS_1</i> = <i>YES</i> : even when wearing your glasses]?			
 VIS_3 Do you have difficulty clearly seeing someone's face across a room [<i>If VIS_1</i> = <i>YES</i>: even when wearing [your/his/her] glasses]? VIS_4 Do you have difficulty clearly seeing the picture on a coin [<i>If VIS_1</i> = <i>YES</i>: even when wearing [your/his/her] glasses]? 				
[Note : Countries may choose to replace "the picture of a coin" with an equivalent item 1				
HEA	RING			
HEAR_1 Do you use a hearing aid?	HEAR_1 Do you use a hearing aid?			
HEAR_2 Do you have difficulty hearing, [if HEAR_1 = YES: even when using a hearing aid(s)]? Optional Hearing Questions (WG only)	HEAR_2 Do you have difficulty hearing, [<i>if HEAR_1 = YES:</i> even when using a hearing $aid(s)$]?			
HEAR_3 How often do you use your hearing aid(s)?	HEAR_3 Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [<i>if</i> HEAR_1 = YES: even when using your hearing $aid(s)$]?			
HEAR_4 Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [<i>if</i> $HEAR_1 = YES$: even when using your hearing aid(s)]? HEAR_5 Do you have difficulty hearing what is said in a conversation with one other person in a noisier room [<i>if</i> $HEAR_1 = YES$: even when using your hearing aid(s)]?	HEAR_4 Do you have difficulty hearing what is said in a conversation with one other person in a noisier room [<i>if HEAR_1</i> = <i>YES:</i> even when using your hearing aid(s)]?			
MOB	ILITY			
MOB 1 Do you have difficulty walking or climbing steps?	MOB_1 Do you have difficulty walking or climbing steps?			
MOB_2 Do you use any equipment or receive help for getting around? MOB_3 Do you use any of the following?	MOB_2 Do you use any equipment or receive help for getting around? MOB_3 Do you use any of the following?			
A. Cane or walking stick? B. Walker?	A. Cane or walking stick? B. Walker?			
C. Crutches?	C. Crutches?			
E. Artificial limb (leg/foot)?	E. Artificial limb (leg/foot)?			
F. Someone's assistance?	F. Someone's assistance?			
G. Other (please specify:)	G. Other (please specify:)			
1. Yes 2. No [For each A-G] MOB_4 Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [without the use of your aid]?	1. Yes 2. No [For each A-G] MOB_4 Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [without the use of your aid]?			
<i>NOTE: Allow national equivalents for 100 metres.</i> MOB_5 Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks [without the use of your aid]?	<i>NOTE: Allow national equivalents for 100 metres.</i> MOB_5 Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks [without the use of your aid]?			
NOTE: Allow national equivalents for 500 metres. MOB_6 Do you have difficulty walking up or down 12 steps? MOB_7 Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block, when using your aid?	NOTE: Allow national equivalents for 500 metres. MOB_6 Do you have difficulty walking up or down 12 steps?			
MOB_8 Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks, when using your aid?				

COMMUNICATION				
	NOTE: Communication questions were not originally included in the BI-M1 set. This domain has been adopted for inclusion by the Budapest Initiative Task Force members at the 3-5 November 2010 meeting. This section may be omitted, at			
	country's discretion.			
COM_1 Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?	COM_1 Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?			
COG	ITION			
COG_1 Do you have difficulty remembering or concentrating?	COG_1 Do you have difficulty remembering or concentrating?			
Optional Cognition Questions				
COG_2 Do you have difficulty remembering, concentrating, or both?COG_3 How often do you have difficulty remembering?COG_4 Do you have difficulty remembering a few things, a lot of things, or almost				
everything?				
SELF	-CARE			
SC_SS Do you have difficulty with self care, such as washing all over or dressing?				
UPPE	R BODY			
	NOTE: Upper Body questions were not originally included in the BI-M1 set. This			
	domain has been adopted for inclusion by the Budapest Initiative Task Force			
	country's discretion.			
UB_1 Do you have difficulty raising a 2 liter bottle of water or soda from waist to	UB_1 Do you have difficulty raising a 2 liter bottle of water or soda from waist to			
eye level?	eye level?			
UB_2 Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?	UB_2 Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?			
AFFECT (ANXIETY AND DEPRESSION)				
NOTE: Proxy respondents may be omitted from this section at country's discretion.				
Interviewer: If respondent asks whether they are to answer about their emotional states after taking mood-regulating medications, say: "Please answer according to whatever medication you were taking."				
ANX_1 How often do you feel worried, nervous or anxious? ANX_2 Do you take medication for these feelings?	ANX_1 How often do you feel worried, nervous or anxious? ANX_2 Do you take medication for these feelings?			
ANX_3 Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?	ANX_3 Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?			
DEP_1 How often do you feel depressed?	DEP_1 How often do you feel depressed?			
DEP_2 Do you take medication for depression?	DEP_2 Do you take medication for depression?			
DEP_3 Thinking about the last time you felt depressed, how depressed did you feel?	DEP_3 Thinking about the last time you felt depressed, how depressed did you feel?			
PA	AIN			
NOTE: Proxy respondents may be omitted from this section at country's discretion.				
Interviewer: If respondent asks whether they are to answer about their pain when taking their medications, say: "Please answer according to whatever medication				
PAIN 1 In the past 3 months, how often did you have pain?	PAIN 1 In the past 3 months, how often did you have pain?			
PAIN_2 Thinking about the last time you had pain, how much pain did you have?	PAIN_2 Thinking about the last time you had pain, how much pain did you have?			
FATIGUE				
NOTE: Proxy respondents may be omitted from this section at country's discretion. TIRED_1 In the past 3 months, how often did you feel very tired or exhausted?	TIRED_1 In the past 3 months, how often did you feel very tired or exhausted?			
TIRED_2 Thinking about the last time you felt very tired or exhausted, how long did it last?	TIRED_2 Thinking about the last time you felt very tired or exhausted, how long did it last?			
TIRED_3 Thinking about the last time you felt this way, how would you describe the level of tiredness?	TIRED_3 Thinking about the last time you felt this way, how would you describe the level of tiredness?			

In 2010 the WG finalized efforts to develop an extended set of disability questions to be used as components of population surveys, as supplements to surveys, or as the core of a disability survey (WG-ES, see page 6 and 7). Development of this extended set of questions began with a review of existing question sets already in use in other surveys (national or research) with the goal of expanding upon the six WG short set domains (vision, hearing, cognition, mobility, self care, and communication) to include additional functional domains (upper body functioning, affect, pain, and fatigue) and more information per domain (for example, functioning with and without assistance).

WG Extended Set testing

In collaboration with the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), the extended question set was cognitively and field tested in six UNESCAP countries (Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines and Sri Lanka) with additional cognitive testing in Canada, the United States and South Africa. Further cognitive testing was also carried out by the Granada Group consisting of France, Germany, Italy, Portugal, Spain, Switzerland and the US.

Budapest Initiative questionnaire

The Budapest Initiative (BI), a joint effort of WHO, UNECE, Eurostat and a number of interested countries, has developed a short form questionnaire to provide the basis for comparable standardized information on population health focusing on health state. The questionnaire, the Budapest Initiative – Mark 2 (BI-M2), can be used to produce internationally comparable estimates of the measurement of health state (see page 6 and 7). The BI-M2 is a subset of the WG Extended Set, and testing of these questions coincided with the WG-ES testing.

Based on the results of the cognitive and filed testing from both the UNESCAP region and the Granada Group, the BI recently shared the BI-M2 with Eurostat as a possible question set for the 2014 version of the European Health Interview Survey (EHIS). This would facilitate both international comparability on the individual domains and the computation of summary measures of health state. Developmental work and testing is continuing; particularly to develop questions for domains (e.g., learning) that are not included in the WG/BI sets.

Results of the UNESCAP cognitive and field tests are available online at: http://www.unescap.org/stat/disability/analysis/

For information:

Jennifer H. Madans National Center for Health Statistics, USA Washington Group on Disability Statistics e-mail: JMadans@cdc.gov

International Classification of Diseases (ICD)

Towards a new ICD in 2015

The Australian Institute of Health and Welfare (AIHW), in its role as the Australian Collaborating Centre for the WHO's Family of International Classifications, hosted "Towards ICD-11 for Australia" to announce the World Health Organization's (WHO) development process for the International Classification of Diseases.

The ICD is being revised to reflect the advances in health sciences and better fit the users' needs including its use in computerized records and health information systems. The ICD revision will pass through alpha and beta stages. Alpha stage refers to initial authoring with the scientific experts. Beta stage refers to collaborative authoring by the interested parties and field testing.

ICD Revision Timelines:

Open ICD-11 Alpha Browser to the
public for viewing
Open ICD-11 Alpha Browser to the
public for commenting
Open ICD-11 Beta to the public –
commenting, field trials and translations
Present ICD-11 at the World Health
Assembly

ICD-11 alpha information

The Alpha draft is updated daily as the work progresses and is intended to show the new features and content to stakeholders early in the process. A caveat is clearly displayed on all pages of the Alpha draft, reminding stakeholders that the alpha draft is incomplete, should not be used for coding at this time, and has not yet been approved by the Topic Advisory Groups (TAGs), the Revision Steering Group (RSG) or WHO. The alpha-draft can be viewed online at: http://www.who.int/classifications/icd11/

ICD-11 beta information

WHO will engage with interested stakeholders to participate in the ICD revision process. Individuals will be able to:

- Make comments
- Make proposals to change ICD categories
- Participate in field trials
- Assist in translating

New ICD-11 Features

ICD-10 does not accurately reflect all advances in health sciences. ICD-10 was released in 1990 and has since been adapted by many countries. However, much has changed in the past twenty years in the medicine and health-care industry is not incorporated to a satisfactory level. In addition, with the advent of computerization in health care delivery and records ICD did not serve this purpose.

Information Technology readiness

Many countries are transitioning to represent the medical records in computerized settings. ICD is planned to be ready for use in electronic health records systems. For this purpose ICD is being linked to SNOMED CT and other standard terminologies. In addition, ICD mortality information is gathered through vital registration, verbal autopsy and other applications. Using information technology which require standard identifiers ICD will serve new applications for mortality reporting.

Content Model

To enable computerization reason for ICD Content Model is a structured framework, representing the ICD knowledge in a standard way, allowing computerization. Each ICD entity, for example a disease is defined by "parameters" that represent different dimensions of the entity such as synonyms, signs, symptoms and other features.

- 1. ICD Entity Title
- 2. Classification Properties
- 3. Textual Definitions
- 4. Terms
- 5. Body System/Structure Description
- 6. Temporal Properties
- 7. Severity of Subtypes Properties
- 8. Manifestation Properties
- 9. Causal Properties
- 10. Functioning Properties
- 11. Specific Condition Properties
- 12. Treatment Properties
- 13. Diagnostic Criteria
- Each parameter is then filled in by standard value sets.

Definitions

All ICD entities will have definitions or key descriptions of the meaning of the category in human readable terms to guide users. Short or limited definitions (100 words or less) will appear in the print version of the ICD-11, while detailed definitions will appear in the online version. Definitions will be compatible with the content model and diagnostic criteria.

Topic Advisory Groups

Topic Advisory Groups are content experts in a given ICD domain. They serve as the advisory body for specific issues which are key topics in the update and revision process. They function similar to an Editorial Board of a scientific journal to plan the peer review process and advise WHO in all steps leading to the revision of topic sections of ICD in line with the overall revision process.



Input from all Stakeholders

WHO aims to engage all experts and stakeholders in making comments, making proposals and taking part in field trials. The Content Model gives experts the opportunity to make structured input, allowing users to directly participate in the revision process. Expert and stakeholder input will of course be subjected to a scientific peer review process guided by Topic Advisory Groups (TAGs).

Internet Based Platform

Using a "Collaborative Authoring Tool" known as iCAT, interested stakeholders can participate in the revision process using an internet-based platform. iCAT is open year-round to allow users to browse continuously updated information.

Field Trials for Use-Cases

Two types of field trials will be carried out during the Beta phase: inter-rater reliability tests and bridge-coding tests. Inter-rater reliability tests the information on a case (live or medical record) and will be coded by two different people to see whether they concur on the same code. Bridge-coding tests will check the information on a case (live or medical record) and will be coded in ICD-10 and ICD-11 to see whether both systems yield the same codes.

Multi-lingual representations

The ICD as an international standard has to be multilingual. The previous ICD was developed in English first and then translated manually. This is called Multilingual representation, not a Translation. The aim is to represent equivalent concepts rather than word-by-word translation. Building from experience in previous ICD translations in multiple languages and using the ICD-11 Content Model with standard terminologies, ICD-11 will have computerized assistance for its development in multiple languages with human experts verifying concept equivalence.

The priority will be on 6 Official United Nations Languages: English, French, Spanish, Russian, Chinese and Arabic plus German and Portuguese. Other languages will be at the request of WHO Collaborating Centers in different language areas.

ICD-11 Browser

The ICD-11 Browser allows the public to browse and search all ICD-11 entities, including all aspects of the content model. Users can search and browse the foundation layer or various linearizations. The Browser will be open in September for commenting by the public.

For information:

Sara Cottler, WHO Geneva e-mail: cottlers@who.int Bedirhan Üstün, WHO Geneva e-mail: ustunb@who.int

FIC around the World

Japan

Decline of Functioning in Elderly Persons two Months after the Great Earthquake in Japan

A great earthquake of magnitude 9.0 attacked the northeastern part of Japan on March 11, 2011, followed by a strong tsunami and the meltdown of Fukushima Daiichi Nuclear Plant. This triple disaster has caused great damages to the local communities, including 15,733 people dead, 4,462 missing (as of August 27, 2011) and at least 83,951 evacuated to temporary shelters. In addition, functioning of the survived people was found to have declined considerably. For example, a month after the disaster we conducted an on-site check-up of functioning in 102 healthy elderly (65 years or more) persons in Sendai City, who were staying in temporary shelters during day. It revealed a remarkable decline in mobility and/or self-care, which was observed in 64 persons (62.7%). Among the individual activities, gait declined in 47.1%; standing up from the floor (necessary for living in traditional Japanese houses and particularly in the temporary shelters) in 35.3%; climbing up and down steps in 24.5%; and self-care in 15.7%. These results were reported to the WHO-FIC FDRG meeting in Sydney, June 2011. The present study was planned to look at the situation after two months and look for the causative factors.

Methods and Participants

The place of study was the township of Minami-Sanriku, one of the most severely damaged communities, with a population of 16,817, which suffered 551 people dead and 437 missing after the disaster. The participants were 141 elderly persons (52 males and 89 females) with no previous problems in activities, who were staying in 35 temporary shelters of the town during the day (total number of accommodated persons were 2,935).

Instruments

Semi-constructed interviews on 60+/-2 days after the earthquake were held by public health nurses using 'Checklist for Disuse Deconditioning'. This checklist is based on ICF and consists of eight questions on the states of major activities before and after the disaster. Its purpose is to identify the declining of functioning (mainly activities) in a short time. The additional information such as pre-existing chronic disease, new disease/trauma, the time-course of appearance of decline of activities etc. were also collected. The results were analyzed statistically, including a logistic correlation analysis.

Results

Decline in Mobility and Self-care: In total, mobility and/or self-care declined in 59 persons (41.8%). Gait (a450)

declined in 36.9% (gait alone in 12.1%), self-care (a510-560) in 17.7% (alone in 9.9%), climbing up and down steps (a4551) in 16.3% (alone in 0.7%), standing up from the floor (a4104) in 12.1% (alone in no one).

One of the merits of 'Checklist for Disuse Deconditioning' is to ask questions not only on the 'qualitative' aspects (grades of independence) of the activities, but also 'quantitative' ones (frequency, duration etc. of the activities). One of the 'quantitative' questions is about the bodily motion during daytime, which had considerably decreased in 67 persons (47.5%) compared with 'before the disaster'. For example, 104 persons (73.8%) were in the top rank ('Moving much also outside home') before the earthquake, but after it only 54 remained so. Out of the initial 104, 23 moved down to the second rank ('Moving much in the home'), 24 to the third ('Sitting almost always'), and three even to the last but one ('Lying down sometimes'). No one was in the lowest (fifth) rank ('Lying down almost whole day') before, but after the disaster one person moved down there from the third rank.

Logistic Regression Analysis showed that the factors influencing the decline of mobility and/or self-care were, in the order of strength of influence, 1) the reduction in bodily motion during daytime (Odds Ratio (OR): 23.25 and 95% Confidence Interval (CI): 7.89-87.62), 2) disease/trauma after the earthquake (OR: 12.90 and 95% CI: 1.98-112.32), and 3) bodily motion at present (OR: 4.40 and 95% CI: 2.00-11.03). All three were highly significant.

Conclusion

The above results strongly suggest that the decline in mobility and self-care in the essentially healthy elderly population after the disaster is mostly due to 'Disuse Deconditioning' (Disuse Syndrome), caused by the inactive lifestyle forced by drastic changes in environmental factors. The prevention and early detection of the decline in functioning and early intervention to it must be incorporated to the health policy at the time of disasters.

Yayoi Okawa MD, National Institute for Longevity Sciences, Japan Kayo Takimura MD, Ministry of Health, Labour and Welfare, Japan

For information:

Emiko Oikawa Ministry of Health, Labour and Welfare, Japan e-mail: oikawa-emiko@mhlw.go.jp

North America and The Netherlands

ICF-CY Improvement Suggestions

At the Oregon Institute on Developmental Disability, we use the ICF-CY for development of a profile to help

teachers and therapists compose the annual educational plan (known as an IEP in the US) for students who use augmentative and alternative communication (AAC); that is, students who communicate by means other than conventional speech. The ICF-CY is particularly well suited for this group because AAC specialists already use a participation model. Additionally, unlike other systems for describing communication function, the ICF-CY separates speech function from communication function. Yet, there are no existing educational planning tools for this population that utilize a participation model.

While the ICF-CY is an excellent compendium of descriptors for health, education and social services that has the capability to change the way the world thinks about disability, we recognize that it is a work in progress that will no doubt undergo repeated revisions and fine tuning as it is embraced by practitioners and researchers worldwide.

From the perspective of our research on communication disorders (funded by a generous grant from the Institute for Education Sciences, US Department of Education), we have found that the communication portions of the ICF-CY would benefit from some elaboration and reorganization. As we gleaned items for our profile, we found communication items that are either missing, redundant or in need of rewording. We generated the following notations which we offered to Yvonne Heerkens of the Dutch Institute of Allied Health Care, our Dutch counterpart, for their review (review notes in italics).

Redundancies:

i. d300's (communication) and b167 (mental functions of language)

In the Dutch derived version for speech therapists we have elaborated b167. Subclasses are available for pragmatic functions, semantic functions and form functions (phonology, syntaxis, morphology) for both the reception of written and the reception of spoken language. According to our understanding these functions can be separated from the activities described in d3 communication.

ii. Play addressed to varying degrees by both d880 (more detailed) and d9200

There is an overlap, probably caused by the fact that play was already in the ICF under the heading recreation and leisure, but for children play is much more that just recreation and leisure. Reading the two classes it seems that d9200 is more about playing together certain games; while engagement in play, d880, is about playing with materials and objects like playing with a doll or a dinky toy. Especially the use of the term 'game' in both classes is confusing. iii. b163 (p.56) basic cognitive functions has for inclusions "representation, knowing and reasoning" which are either addressed in other codes or not defined adequately:
a. representation=using symbols d3351, d3352, p.147; *I* agree that the inclusions are not defined properly, but *I* don't think that representation is the same as producing signs etc.

b. "knowing" is not defined;

c. the term "reasoning" is addressed as problem solving d175 p. 138, *Idem, I don't think that reasoning is the same as problem solving, although it can be a part of problem solving.*

iv. reading: b16701, d166, d140, d325; writing: d345, d145, d170, b16711. See pp. 137, 145-147, and 136-137. *See i (redundancies), i (missing) and v (needing reworking)*

Missing:

- i. Codes for pragmatic aspects of language. Pragmatics refers to a set of skills for the use of language that must be present for competent communication. Suggestion: remove either item b1672 Integrative Functions of Language or item d355 Discussion; replace with delineation of multiple pragmatic aspects of language. *As indicated we have included the pragmatic, semantic and form functions under b167.*
- ii. Test taking (or does d8202 include this?) *Test taking in a school situation d8202, in a vocational training situation d8252 and in higher education d8302.*iii. Comprehension of single words

I agree; learning to comprehend single words is probably in d133; but comprehension as such might be included in b167.

 iv. Syntax and semantics are not well addressed for either language acquisition or use of language.
 As indicated we have included the pragmatic, semantic and form functions under b167.

Needs reworking:

i. d455 Moving around (p.157) and d450 walking should not be separated. Walking is a differentiated form of d460.

There is indeed a problem in the whole block d450-d469; there are different ways to go from one place to the other or to move around: such as walking, running, crawling, climbing, swimming, skating, skiing, diving, riding. There are three categories with respect the use of (assistive) products:

• for some of the activities an assistive product can be used when there are limitations in performing the activity (such as a walking stick when there is a problem in balance during walking), but still the activity itself can be done; the products are additional

- activities that can only be done using a certain product (these are not assistive products), e.g. skiing and skating (although there are e.g. adapted skies) but also for bicycding and driving you need a bicycle or a car; the products are inherent to the activity
- There are alternative activities which can be done as a substitute for activities that are severely limited; e.g. when walking is severely limited people can use a wheelchair to go from one place to the other; they have a limitation in walking, but not in riding a wheelchair. These differences must be taken into account when rearranging chapter d4.
- ii. Cognitive development would be better organized using Piagetian model.
- iii. Attention items should be together in the learning and applying knowledge. b140 items should go with d160 items.

We agree there is an overlap between b1400 and d161 and between b1402 and d160.

- iv. B 156 items (Perceptual Function) should be in b 200's Sensory functions, not b100's Mental functions.
 As we understood perception is a function of the brain and not of the senses, although the difference might not be all that clear. Perception is about the interpretation of the stimuli; a patient with a stroke might have problems in recognizing a face without having impairments in visual functions.
- v. Syntax, currently d 1331 and d 1332 in Learning and applying knowledge, should be in either **Mental functions** (b 167) or in **Communication** (d 300's). The decision to make basic learning a separate block has introduced several problems like the one that is mentioned, but also between reading and learning to read and writing and learning to write (as indicated earlier). Learning is more a 'phase' (better be included using a qualifier) than a different class. There is a specific problem when learning is in the activity classification but what is learned is in the classification of functions: e.g. mental functions of language (b167) and acquiring language (d133).
- vi. Use of the words **acquiring** and **learning** is confusing. The definition of some of the "acquiring" items includes the term "learning."

I agree.

vii. Sections on communication, d 300's, needs more parallel structure between "receiving" and "producing" items. For example, "receiving" has items for simple and complex messages, but we don't have any such delineation in "producing" items.

We think that the differentiation between simple and complex is 'too simple'. We propose to replace this by a distinction between the literal (explicit) meaning and the figurative (implicit) meaning of messages both in producing and understanding of messages.

viii.We recommend a complete reworking the communication section, so that it reflects current models of language form, content and use.*We agree, but including b167.*

Conclusion

It is notable that the two groups of researchers have independently found many similar opportunities for elaboration and revision within several sections of the ICF-CY to make them more useful for practitioners in the field communication disorders. This coincidence of suggested revisions across two languages and cultures points to the benefit of recruiting practitioners worldwide for the ICF-CY revision process. The above notations are mainly suggestions for specific items. As we worked with the ICF-CY, we felt that the entire tool would be much easier to use for all ages and levels of functioning if it reflected a developmental sequence across all domains of human functioning. We hope that this will be a primary goal in the revision process for ICF 2.

For information:

Sandra A. M. Steiner, MA, CCC-SLP Oregon Institute on Developmental Disability Oregon Health & Science University, USA e-mail: steinesa@ohsu.edu Yvonne Heerkens, Chair of ISO/TC 173/SC 2 Dutch National Institute of Allied Health Care e-mail: woittiez.heerkens@planet.nl

Thailand

Lessons Learned From Implementation of ICD-10 in Thailand

Implementation of ICD-10 in Thailand

Thailand has been using the International Classification of Diseases and Related Health Problems – ICD since the year 1950 [1]. We used ICD-7, and later ICD-8, for mortality coding and statistics before ICD usage for morbidity coding and statistics began in 1963. ICD-9 was used during 1980-1993 before implementation of ICD-10 in 1994.

Training of clinical coders

Despite the Ministry of Public Health announcement of ICD-10 implementation in 1994, formal ICD-10 training for clinical coders did not start until 1997. First ICD-10 training for trainers workshop was conducted under guidance of the Australian ICD Collaborating Centre with Sue Walker as a

main teacher. Now we have a basic ICD training workshop and an advanced ICD training workshop. ICD-10 training in Thailand created huge amounts of ICD-10 clinical coders within 15 years. Until now, more than 20,000 clinical coders were trained. Unfortunately, training demands never decrease, due to high turnover rate and deficiency of clinical coders in hospitals.

Creating of awareness and asking for co-operations from medical doctors

Medical doctors play a major role as creator of input sources for ICD coding. So we needed to give medical doctors the most important key knowledge, being how to write good diagnosis summary and death certificate. The guideline on how to write good diagnosis summary and death certificate was created in 1998. The Ministry of Public Health published and distributed the guideline to all medical doctors in Thailand in 1999.

Development of coding quality improvement system

ICD coding quality has been monitored by the Ministry of Public Health since 1999 after discovery of a high percentage of ill-defined cause of death in Thailand mortality statistics [2]. We found two major coding quality problems: incorrect codes and missing of comorbidity/complication codes. So we started coding quality improvement system in 1999. The system included medical records and death certificate audit, re-training medical doctors and clinical coders when needed, and certified coders program. This methods improved outcome of ICD coding quality significantly [3].

Furthermore, we established a certified coders program in 2006, which will assess each coder's competency and certify him/her based on level of achievement. We use recommendations from the WHO-FIC Education Committee [4] to classify coders as entry level, intermediate level and expert level. For entry level we do not certify, but for intermediate and expert level the coder must pass coding examination before getting the certificate. During 2006-2010, six intermediate level examinations were conducted; around 400 coders out of 1,000 coders passed the exam and got the certificate issued by the Ministry of Public Health. We plan to conduct first expert level certification in 2012.

ICD-10-Thai Modification in 2000

Modification of ICD-10 in Thailand happened after the ICD office discovered that some medical doctors in Thailand added more terminal digits to ICD-codes to make it "more specific". Because ICD-10 did not include codes of common diseases in Thailand (for example: necrotizing fasciitis, green pit viper poison snake bite, Dengue shock syndrome etc.) and doctors demands increased very fast, the Ministry of Public Health, in co-operation with medical schools, medical associations and other stakeholders, started an ICD-10-Thai Modification in 2000. After pilot testing for four years, the Ministry of Public Health adopted ICD-10-

TM to be used in morbidity coding in Thailand from 2005 onward [5].

Lessons learned from implementation of ICD-10

Looking back into the past, we could identify four key success factors for ICD-10 implementation:

1. Manage the process of change of all key-implementation elements.

Resistence to change occurred every time we tried to introduce a new way of working, including ICD-10 implementation. Before the first ICD-10 training course, we had to convince the Ministry administrators about the importance of ICD-10 coding in mortality and mortality statistics, about the need for mass training of clinical coders, and about the role of medical doctors in relation to code quality. In addition, we had to change the way clinical coders did ICD coding from browsing a list of diagnosiscodes, to standard volume 3 and volume 1 based coding. We had to change the way the doctors wrote diagnosis summaries and death certificates, and we had to implement the new medical record and coding audit system into hospitals. All these developments need good change management.

2. Co-operation with all stakeholdes organizations in the country.

Since the implementation processes affects all doctors, clinical coders, hospitals and some organizations - both public and private sectors - a network must be formed. The Ministry of Public Health did great on networking with medical schools, medical association, the World Health Organization-Thailand office, re-imbursement agencies. The sense of belonging established in the network will also facilitate future updating and maintenance works of the ICD in Thailand.

3. Creation of new leaders in all levels.

ICD-10 leaders were created since the first ICD-10 training for trainers in Thailand. This group of trainers became resource persons and lecturers, some were retired but most of them are actively co-operating with the Thai Health Coding Center. Most of the certified coders help the center on answering coding questions in the website via web-board or web-forum. These leaders have good attitudes on the importance of ICD in the health information system and can promote future activities on implementation of ICD to outsiders or new-comers.

4. Keep going.

Just keep putting efforts on implementation! This work in Thailand and we hope it will work in other countries as well.

Surprisingly, changes in hardware and software technology had little impact on successful implementation of ICD-10 in Thailand during the past 15 years. This may due to the fact that we could not use the computer to do the ICD-coding instead of human coders as well as we could not use the computer to do good diagnosis summary instead of medical doctors. However, if software developers can produce programs that could perfectly do the mentioned tasks correctly, then we may use the program in implementation of ICD in the future.

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Wansa Paoin, Mailwan Yuenyongsuwan Thai WHO-FIC Collaborating Center Ministry of Public Health, Thailand

For information: Wansa Paoin Thai WHO-FIC Collaborating Center Ministry of Public Health, Thailand e-mail: wansa@tu.ac.th

Australia

Using the ICF to understand sexuality and Cerebral Palsy

In my doctoral thesis entitled Making Sense of Sex with People with Cerebral Palsy I explored how people with Cerebral Palsy construct their own sexuality and the salience of the socio-sexual schema which are involved in this process. The study aimed to address three questions; 1) the relative salience of public, interactional and private sexual schema in the construction of sexuality for people with Cerebral Palsy, 2) how people with Cerebral Palsy construct sexual participation and particularly sexual spontaneity, and 3) how people with Cerebral Palsy describe their sexuality. This project utilized a hermeneutic phenomenological approach to explore these questions. For this research, seven in-depth, semi-structured interviews were conducted with five men and two women with moderate to severe Cerebral Palsy. In doing so, my dissertation aimed to build on research to fill the gap between how sexuality and disability is constructed external to the individual and how the individual constructs their own sexuality.

Within my dissertation, participant data indicated that how people with Cerebral Palsy perceive sexual experiences with others (interactional) is the most influential factor in the construction of their sexuality. In hindsight, the Activities and Participation component of the ICF may have supported the hermeneutic phenomenological approach used within my thesis. As such, the results could have been systematically described and interpreted in terms of participants' perceptions of their performance and capacity in each of the nine domains (i.e., learning and applying sexual knowledge, sexual communication, domestic life, self care, etc.).

In addition, my thesis indicated that public influences were the second most important factor in the construction of sexuality by people with Cerebral Palsy. In this respect contextual factors, particularly environmental, could have been useful in interpreting participants' perspectives on the influence of society on their sexuality. Namely, participant assessments of their performance as a sexual member of their society and their sexual capacity to execute actions (e.g., sexual intercourse) and tasks (e.g., pleasing one's sexual partner) may have been a better indication of societal influence on their constructions of sexuality.

Finally, the results of my research indicated that private influences were the least influential factor in the construction of sexuality within people with Cerebral Palsy. In retrospect, the personal factors as described by the ICF may have proved handy in deciphering the influence of an individual's life and living (i.e., gender, race, age, upbringing, coping styles, social background, past and current experiences, etc) on their sexuality. For example, private influences may play a more important role than indicated within my thesis if they had been explored and interpreted with the ICF in mind. While participation, environment and individual experiences were addressed within the discussion of my dissertation the formalized and systematic construction of the ICF may have provided a stronger foundation upon which the results of my research and their interpretations could have been based.

For information:

Tinashe M Dune, PhD Australian ICF, Disability and Rehabilitation Research Program, Faculty of Health Sciences, University of Sydney, Australia e-mail: tinashe.dune@sydney.edu.au

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