

## August 2003 NACC Clearinghouse on ICF Messages

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1. JUNE 1-4, 2004 - THE TENTH NACC CONFERENCE ON ICF IN HALIFAX, NOVA SCOTIA

Our colleagues at the Canadian Institute for Health Information, Diane Caulfeild and Kathey Cauley, have arranged to host the Tenth Annual North American Collaborating Center Conference on ICF. It will be held June 1-4, 2004 at the Westin Hotel. Look for the call for papers in a few months in your monthly email and on this website. The theme will be "A Research Agenda for ICF".

2. DOCTORAL DISSERTATION ON ICF

Susana R. Pereira is developing a doctoral dissertation in Portugal-University of O'Porto on "Classification of childhood disability in early intervention programs with the ICF", under the supervision of Professor Rune J. Simeonsson (Chair of the WHO Task Force on Children & Youth, University of North Carolina & University of O'Porto). For more information, contact her at [pereira@netmadeira.com](mailto:pereira@netmadeira.com) and phone number: (+351) 291771985 at Caminho do Pilar, 36 CB, 9000-309 Funchal Portugal.

3. ICF WORKSHOP HELD AT WORLD CONFEDERATION FOR PHYSICAL THERAPY

In June 2003, Jane Millar of the U.K., Catherine Sykes of Australia, and Janice Miller of Canada presented a 2-hour workshop on ICF at the WCPT in Barcelona. Over 400 physiotherapists attended the workshop. Participants were invited to submit written information on their

applications/uses of ICF. Janice has an electronic document which includes the contact information of respondents and ICF application categories and descriptions. The file has already been circulated to all the respondents to facilitate networking and information sharing for this group of physiotherapists. For more information, contact <millier.janice@sympatico.ca>.

#### 4. SEMINAR ON ICF AND INTERNATIONAL COLLABORATIVE RESEARCH HELD

A session on "ICF International Collaborative Research" was held at the July 23-24 meeting in Bethesda on "International Research in Disability", sponsored by the Center for International Rehabilitation Research Information and Exchange (CIRRIE). The session was as follows: Moderator, Jerome Bickenbach; "DISTAB: Overview of ICF and Disability Tabulations from the U.S., Canada, South Africa, Australia, France, and the Netherlands and Backcoding to the ICF: A Four-Year Collaborative Effort" by Gerry E. Hendershot; "How the Canadian Institute for Health Information relates to the Provinces, the World Health Organization, and the North American Collaborating Center" by Diane Caulfeild; "Italian Adoption of the ICF in the European Year of People with Disability (2003)" by Matilde Leonardi, MD; and "International Collaboration Mechanisms Leading to the ICF for Children and Youth" by Rune Simeonsson. The focus was on best international practices leading to successful collaborations in the field of disability research. The CIRRIE website is: <http://cirrie.buffalo.edu>. Their power points are at <http://cirrie.buffalo.edu/2003/agenda.html> and conference proceedings will soon be available at <http://cirrie.buffalo.edu/proceedings/conferencearchive.html#cirrie>. For more information, contact Marcia E. Daumen, CIRRIE Information Specialist, University at Buffalo, daumen@buffalo.edu tel: (716) 829-3900, ext. 146.

#### 5. NOTHING ABOUT US WITHOUT US

"Nothing About Us Without Us: Removing Barriers to Survey Participation by Persons with Disabilities" is the title of an article published by Gerry Hendershot in Survey Research, Volume 34, Number 2, 2003 (attached). It is also the focus of a conference on this topic to be held April 19-20, 2004 in Washington, D.C. The Interagency Committee on Disability Research's (ICDR) Subcommittee on Disability Statistics will sponsor this conference at the Capitol Hill Holiday Inn in Washington, D.C. to identify best practices in conducting surveys of people with disabilities. It is tentatively entitled "Best Practices for Surveying People with Disabilities". David Keer and Paul Placek, Co-Chairs of the Subcommittee on Disability Statistics working with a planning group of experts, developed this conference plan. They are now in the process of identifying presenters and participants who have expertise in the following areas: -inclusion of persons with disabilities in all phases of disability survey planning/design/interviewer training/implementation/dissemination of results (i.e., Participatory Action Research) -identification of barriers and facilitators to survey participation by respondents with disabilities, including legislation and policy -solutions and techniques for including respondents with disabilities in surveys, especially national surveys which provide statistics related to public policy on disability -description and evaluation of recent national surveys which have made substantial attempts to reduce barriers and

draw lessons from that experience for a statement of best practices - implementation of recent technological innovations in survey data collection, including CAPI/CATI, self-paced audio and video surveys, E-mail surveys, and Web-based surveys -assessment of the state of the art in survey design, emphasizing nonresponse bias and measurement of complex concepts, especially as they may affect disability-related statistics -development of standards and best practices to assure maximum participation by people with disabilities in surveys. Participants will include: representatives of federal agencies doing or using survey research, including member agencies of the ICDR; users and generators of survey statistics; disability advocacy and consumer organizations; and university and market researchers who conduct, or do secondary analysis with, survey research. Public and private sector standard-setting organizations will be invited. We will demonstrate universal and assistive technologies for data collection and show training videos. We will widely disseminate conference proceedings in a wide variety of accessible modes. Limited financial support is available to selected non-Federal presenters. Contact these Federal members of the planning group if you are interested in submitting an abstract or attending this conference. Please share this announcement with others who are doing work in these areas. Contact: David Keer, MA, National Institute on Disability and Rehabilitation Research/ED tel 202-205-5633; David.Keer@ed.gov; Paul Placek, PhD, National Center for Health Statistics/CDC tel 301-458-4437; PPlacek@cdc.gov; Juliana Cyril, PhD, National Center for Birth Defects and Developmental Disabilities/CDC tel 404-498-3014; JCyril@cdc.gov.

#### 6. CONSOLIDATED HEALTHCARE INFORMATICS, SNOMED, AND ICF

Paul Placek and Marjorie Greenberg are participating in a new Disability vocabulary work group under the Consolidated Healthcare Informatics Initiative (CHI), one of 24 e-Gov initiatives. The Consolidated Healthcare Informatics (CHI) Initiative has the goal of enabling health data interoperability across federal health care enterprise, via federal adoption of standards, in sync with the health care industry. Progress includes adoption of HL7 messaging standards for multiple administrative and patient care related areas, NCPDP for retail pharmacy transactions, IEEE 1073 messaging standards for connectivity, DICOM for images, and LOINC for laboratory result names. A number of domains are currently under consideration under the CHI Initiative. The Disability Work Group will be assessing coverage of SNOMED CT, ICF and other classifications. An ASPE-sponsored study conducted by Mayo Clinic recently evaluated content coverage provided by SNOMED CT, ICF, and ICNP, as well as by the MDS, for content recommended by domain experts in three quality domains of pressure ulcers, chronic pain, and urinary incontinence. The most complete coverage was found for SNOMED CT. Specific coverage percentages provided for the three domains pressure ulcers, chronic pain, and urinary incontinence, respectively, were as follows: SNOMED CT 77%, 92%, and 95%; ICNP 16%, 3%, and 4%; ICF 18%, 9%, and 4%; and MDS 70%, 8%, and 8%. There was also an evaluation of the content coverage provided by SNOMED CT, ICF, and ICNP for the entire MDS. SNOMED CT had a complete match for 46% and partial match for 45% of the MDS. ICF had a complete match for 2% and partial match for 39% of the MDS. ICNP had a complete match for 12% and partial match for 50% of the MDS. The complete study is available from Jennie Harvell in the Office of the

Assistant Secretary for Planning and Evaluation,  
Jennie.Harvell@HHS.GOV.

#### 7. WIN \$1,500 IN WHO 2003 DISABILITY PHOTO CONTEST

Prizes for "WHO Photo Contest "Images of Health and Disability 2003"  
are as follows:

1500 US-Dollars + one set of ICF publications

2nd Prize

1000 US-Dollars + one set of ICF publications

3rd Prize

500 US-Dollars + one set of ICF publications

4th - 20th Prize

100 US-Dollars + one set of ICF publications

Further information on this contest and the display of awarded photos  
from last year's photo contest can be found on the ICF website:

[www.who.int/classification/icf](http://www.who.int/classification/icf). Photographers are invited to  
photograph the notions of health and disability in a variety of ways:  
showing how people live with a disease, injury or health condition;  
striking contrast on a theme like "Disabled and Healthy?", or "Who is  
disabled?"; showing disability from the body, person or societal  
perspectives; illustrating key conceptual features: What is health? Can  
we measure health? Disability as universal human experience, which cuts  
across mental and physical conditions; SPECIAL THEME: This year "mental  
health" has been designated as a special theme. The best photo that  
depicts mental functioning disability and health will be given a  
special award. Photos may focus on parity of mental health with  
physical health and emphasize the relevance and importance of mental  
health. There are three categories of submission:

1. Colour photographs (prints only)
2. Black and white photographs (prints only)
3. Black and white or colour digital photographs (electronically  
generated or manipulated images)

In each category up to ten photographs may be submitted for prizes.  
There is no entry fee and the closing date for entries is 31. December  
2003. The entry rules are attached. For more information, contact:  
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and Terminology (CAS) Department of Health Financing and Stewardship  
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website: <http://www.who.int/classification/icf>

#### 8. SPOTLIGHT ON DEB STEWART OF MCMASTER

Debra Anne Stewart, MSc., BSc.OT is an Occupational Therapist and  
Assistant Clinical Professor at McMaster University in the School of  
Rehabilitation Science in Hamilton, Ontario, Canada. Several years ago  
she completed a challenging piece of work entitled "Development of  
Mutually Exclusive Lists for Activities and Participation: WHO

International Classification of Functioning, Disability and Health". She presented that work at a North American Collaborating Center meeting in New York in the Summer of 2001. Last year she published "The International Classification of Functioning, Disability and Health: Implications for Occupational Therapists" in *Occupational Therapy Now*, July/August 2002, 17-21, 2002. This year, she is working on "Mapping of the Canadian Occupational Performance Measure and the WHO ICF" with colleagues Anne Carswell, Sue Baptiste, and Mary Law. She is part of a private practice with several other occupational therapists who provide community-based occupational therapy services to families of children and teens with special needs. This is what keeps her "grounded" --working with families is her 'raison-d'etre'. It's the parents and the teenagers who provide her with the best evidence and support for a social model of health and function that emphasizes person-environment interactions and participation! On the personal side, Deb is a gardener at heart, walking (outdoors) is her second favorite activity, and camping is a close third. She lives in Mississauga with her husband and two teenagers...her daughter is 19 and just finished her first year of university, and her son is 16 in grade 11. And then there is the dog Joey who clearly sees himself as one of the 'pack' (if not the dominant member at times). Last year, she and her husband had their first big trip to Scandinavia and took a Baltic Sea cruise. We hope to see Deb in Halifax at next year's NACC meeting! Contact Deb at [stewartd@mcmaster.ca](mailto:stewartd@mcmaster.ca).