

MARCH ICF CLEARINGHOUSE MESSAGE

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1. ABSTRACT DEADLINE EXTENDED TO APRIL 18 FOR JUNE 16-19, 2003 NACC ICF MEETING. Everyone who has an interest in the ICF will want to participate in the Ninth Annual NACC Meeting on ICF to be held June 16-19, 2003 in St. Louis, Missouri. There are three important deadlines: April 18 for abstracts (see '03 Call for Abstracts), May 1 for registration and optional \$20 Mississippi Riverboat cruise & dinner, and May 16 for the deeply discounted \$135 hotel rate at Chase Park Plaza. The draft NACC ICF St. Louis agenda is also attached (NACC STL Agenda). You must make your own Chase Park Plaza reservation and reference "NACC on ICF", and the \$135 rate will be honored the nights of June 16-19. Thanks to Independence Technology, there will be wonderful complimentary dinners June 16 (at the hotel) and 18 (on the Mark Twain paddlewheeler boat), and five star lunches June 17 and 18. Why not start your visit to St. Louis on June 16 with a complimentary dinner of chicken Florentine and spicy jumbo shrimp or herb-encrusted filet of beef with pinot noir demi-glace and sautéed Maryland crab cake with citrus beurre blanc? Note that the ICF NACC meeting which ends at noon on June 19 will include a session on "International Updates". We are very excited that a Heads of ICD/ICF Implementation Committee will be meeting June 19-20 and that we will receive the benefit of their early arrivals in our "International Updates" session. You will not want to miss the June 18 trip to Hannibal, Missouri and the dinner cruise on the Mark Twain riverboat, so get your registration and \$20 in by May 1.



2. ICF BREAKOUT AT JULY 21-22 NIH MEETING. There is an ICF breakout session at July 21-22 "Conference on Physical Disabilities Through the Lifespan". The conference will be held at Natcher Conference Center/NIH in Bethesda, Maryland. There is no charge to register. Logistics are being handled by IQ Solutions: hkott@iqsolutions.com. CME credits will be offered. Ms. Hope Levy Kott is their conference coordinator, (301) 984-1471. For questions about the program itself, which is attached as "AgendaJuly..." contact Dr. Michael Weinrich at (301) 402-4201. There is an ICF breakout session, as follows:

PARTICIPANTS:

- Organizer, Chair: Paul J. Placek, PhD
- #1. Rune J. Simeonsson, Ph.D., M.S.P.H. "Adapting a Version of the ICF for Children and Youth"
 - #2. David B. Gray, Ph.D. "ICF and Adults with Mobility Impairments: Research Implications for Linking Person and Context"
 - #3. Jean Kozak Ph.D. "ICF Applications to Canadian Alzheimer's and Dementia Data: Emerging Research Issues"
 - #4. Geoffrey M. Reed, Ph.D. "Proposed ICF Research Agenda for Professional Organizations: Implications from the ICF Procedural Manual and Guide for a Standardized Application"

#5. Gerry Hendershot, PhD. "Using Survey Data to Study Aging with a Disability: The Need for Standardized Coding of Disability Domains and Levels of Functioning"

Several hundred top disability experts are expected. See the attachment "AgendaJuly" for more of the topics.

3. ONE EUROPEAN ICF EXPERT NEEDED. There may be an opportunity to travel an ICF international survey representatives (TRAVEL COVERED) to come to Washington, D.C. July 23-24 for a conference on International Collaborations and talk about "best international collaboration practices" as it relates to ICF. Paul Placek has this session slot which he has agreed to arrange for John Stone, the organizer. This session will be 9am -11:30am on Thursday July 24. The new Center for International Rehabilitation Research Information and Exchange is hosting the meeting, and its website is <http://cirrie.buffalo.edu/>. Paul Placek's contact is John Stone, PhD, Director, Center for International Rehabilitation Research Information and Exchange (CIRRIE), in Buffalo, New York. Email: jstone@buffalo.edu. Paul Placek is organizing this session, so you will need to contact him first to be a part of it <pjp2@cdc.gov>. They expect 70 participants. This meeting is being piggybacked on to a major (hundreds of participants) NCMRR/NICHD/NIH July 21-22, 2003 meeting "Disabilities Through the Lifespan" to be held in Bethesda, Maryland (a few miles from D.C.). I organized an ICF breakout session in it, and have attached the entire agenda (AgendaJuly).

4. WASHINGTON CITY GROUP TO MEET IN BRUSSELS OCTOBER 14-15, 2003. A 3/24/03 Announcement of Washington City Group in Europe was made by Claudia Ciattaglia <claudia.ciattaglia@istat.it>: Dear colleagues, The Italian National Institute of Statistics (ISTAT), which plays an informal coordination role for the Washington City Group (WCG) in Europe, would like to inform you that the next meeting would take place in Europe as it was proposed during the first WCG meeting held in Washington (18-21 February 2002). It was indeed proposed to have this meeting in Europe because the Council in its Decision of 3 December 2001 has declared 2003 as the European Year of People with Disabilities. The Washington City Group is now tentatively scheduled to be held in Brussels on October 14th and 15th, 2003. We will send you more detailed information in due course, but please, mark already these two days in your calendar, Sincerely, Roberta Cialesi and Elena De Palma.

5. MARCH 28 NEDRC MEETING FEATURED ICF. About 60 persons attended a meeting in Boston on March 28, and the meeting focused on disability survey methods and ICF. NEDRC stands for Northeast Disability Research Consortium, and this was its first meeting. After stimulating presentations and discussions, a listserv was developed and collaborations planned. The morning presentations included a panel on "Applying the ICF (International Classification of Functioning, Disability and Health) to surveys" which included: Moderator: Don Lollar, Centers for Disease Control and Prevention; Marjorie Greenberg, National Center for Health Statistics; and Alan Jette, Boston University. Paul Tupper moderated the lunchtime discussion, it was decided to set up a listserv and continue NEDRC meetings. An afternoon panel covered "Examining methodologies to include hard-to-reach populations in disability survey research" which included: Moderator: Lisa Iezzoni, Harvard Medical School; Augustine Augbolue, Health

Education and Allied Lifelines Foundation; Mari-Lynn Drainoni, Center for Health Quality, Outcomes and Economic Research; and Gerry Hendershot, GH Consulting. The third and final panel was on "Use of ICF in Clinical Settings", chaired by Marjorie Greenberg, Head, WHO Collaborating Center for the Family of International Classifications for North America. She stated that the goal was to identify research and clinical partners in the Northeast to pilot test ICF in clinical settings as a common language for coding and reporting functional status, and establish a working group to design the pilot studies and seek funding. Other presenters were Lisa Iezzoni, M.D., Professor of Medicine, and Harvard Medical School: "Why should we capture ICF routinely in clinical settings?" Alan Jette, Professor and Dean, Sargent College of Health and Rehabilitation Sciences, Boston University: "Mapping existing assessment tools to the ICF", Gerry Hendershot, PhD, "The German Stucki Project", and Paul Placek, PhD, the American Psychological Association (Reed) Project.

Within days, Dr. Mary Cerreto, Ph.D., Associate Professor of Family Medicine, Boston University Medical School, set up the NEDRC listserv and most of the 60 attendees registered within a day or two. NEDRC represents a consortium of people involved in or with studies in the field of disabilities. Initially brought together by the Massachusetts Department of Public Health, the listserv welcomes members involved in the numerous facets of research in the field of disabilities --- people with disabilities and their family members and people across all disciplines working in areas relevant to people with disabilities. Such areas include, but are not limited to, the provision of health care, health economics, aging, health disparities (e.g., racial/ethnic disparities, socioeconomic disparities), mental health, health services, epidemiology, lifespan issues, prevention and wellness, disease management, surveys, classification issues, women's health, early intervention, employment, health policy, education, long-term care, self-determination, transition, health quality, outcomes, health statistics, health care provider training, federal and state government issues, adaptive environments, alternative communication, assistive technology, advocacy, and special health needs. The listserv welcomes members at all levels of experience in research, including students. The goals of the NEDRC listserv are to provide a place for the: (1) identification of research in the field of disabilities being conducted by various people and organizations throughout New England; (2) sharing of information; (3) building of research partnerships across disciplines, colleges, universities, and organizations; (4) development of working groups on particular topics of interest; and (5) announcement of NEDRC events and other events of interest to NEDRC members. The group is open to all; just send an email to Mary C. Cerreto, Ph.D. [Mcerreto@aol.com].

6. Spotlight on Marjorie Greenberg, Head, WHO Collaborating Center for the Family of International Classifications for North America (see photo). The Collaborating Center: (1) Represents the United States and Canada in international activities related to study and implementation of the ICF; (2) Works with U.S. researchers conducting ICF studies and evaluations; (3) Disseminates information about ICF and potential applications and (4) Collaborates with Canadian researchers through the Canadian Institute for Health Information (CIHI). Marjorie introduced the idea of an ICF Clearinghouse in June 2002 at the Eighth Annual

North American Collaborating Center Meeting in Toronto. Since then, the contract has been implemented with NCHS staff and Washington University; monthly messages have been sent out since October 2002. Marjorie points out: "The North American Collaborating Center ("NACC") established a NACC Clearinghouse on ICF to facilitate information exchange, with an emphasis on ICF information in the United States and Canada. This effort is consistent with our terms of reference and an exciting opportunity to share information about applications of ICF in North America. With ICF approval by the World Health Assembly in May 2001, a flurry of national and international activity has occurred. While a relatively small cadre of revision experts have kept themselves informed, large groups of prospective users have now entered the scene. The NACC has typically had annual conferences to keep ICF experts and consumers informed, but now there is a need for more regular information exchange and technical assistance. It is essential that all stakeholders be up-to-date, given that there is new major ICF activity in government, professional associations, universities, service providers, and consumers. I am really pleased with the functioning of the NACC ICF Clearinghouse so far and that we have over 250 subscribers in a few short months. I want to thank Paul, Linda, Diane, David and Trish for doing a terrific job in launching the Clearinghouse."

On a personal note, Marjorie is known around the office as "Mother Greenberg" because of the interest she takes in staff members. She was nominated by staff members and received the 2002 NCHS Director's Award for Managerial Excellence. She has been with NCHS since 1982, and also serves as Executive Secretary to the National Committee on Vital and Health Statistics, which is the external advisory committee to DHHS on health information policy. Her areas of interest and expertise include health data standardization, uniform health data sets, health classifications, data policy development and evaluation policy. Marjorie is a founding member of the Public Health Data Standards Consortium, which represents the interests of public health and health services research in data standards setting processes

(<http://www.cdc.gov/nchs/otheract/phdsc/phdsc.htm>). She also serves as the Consortium's federal representative to the National Uniform Billing Committee. She received her bachelor's degree from Wellesley College and a master's degree from Harvard University. She and her husband George have two children, Josh (a banker married to Mindy) and Debbie (a teacher), dogs Moses ("the ICF doggie") and Monty, cat Lily and two birds. Yes, that's Bedirhan Ustun with Moses, after the Heads of ICD/ICF meeting in Bethesda. Marjorie is looking forward to seeing everyone in St. Louis.

