

March 2006 NACC Clearinghouse on ICF Monthly Message

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1. ABSTRACT DEADLINE EXTENDED TO APRIL 7 FOR VANCOUVER ICF MEETING

Due to a high number of requests, the deadline for abstracts for the North American Collaborating Center (NACC) ICF Conference has been extended to Friday, April 7. Take this opportunity to share your work at the 12th Annual NACC Conference on the ICF. Proposals must be received by April 7, and should address the theme "Living in Our Environment: The Promise of ICF". This is your chance to showcase your research, applications, programs, outcomes, challenges, successes and opinions on ICF. Presenters will find themselves in esteemed company: Opening the conference will be Vancouver Mayor Sam Sullivan, Tuesday, June 6. The Honorable Mike Harcourt — former B.C. Premier — will be the closing speaker on Wednesday, June 7. We are very pleased to announce the addition of a co-host — Statistics Canada — whose colleagues are well-known to both CIHI and the Canadian ICF arena. They bring a wealth of background and program ideas to this year's ICF Conference. Welcome aboard! Our Social Event this year will be dinner at the popular Dockside Restaurant, located on Vancouver's

Granville Island — an artist's haven housing a large public market, shops, theatres, galleries and restaurants. An evening of entertainment and the best of west-coast cuisine await you! The Dockside Restaurant is fully accessible, and fully-accessible transportation to and from the hotel is included. Tickets are \$75 CDN and anyone interested in taking part can select the "Social Event" option on the registration form. More information on the Social Event is available on the conference website at <http://www.icfconference.com/social.html>. Conference participants should also note that a block of hotel rooms at Vancouver's renowned Crowne Plaza Hotel Georgia has been reserved at a special rate of \$179 CDN/night. This historic hotel has become a social centre for Vancouverites and world travelers. The deadline for room reservations is Wednesday, May 3, 2006. Book your room early! For additional information or questions, please send requests to conferences@cihi.ca, or go to the conference website at <http://www.icfconference.com/>.

2. APPLICATIONS DUE APRIL 13 FOR CDC ICF DISABILITY GRANTS

Optional letters of intent were due March 13, but applications are due by the April 12 deadline for new disability awards to be made this year by CDC's National Center on Birth Defects and Developmental Disabilities. The Request for Applications is numbered CDC-RFA-DD06-004 and entitled "Intervention Research Grants to Promote the Health of People with Disabilities." In FY06, approximately \$2.3 million are available to support about five to seven R01 awards, and applicants can request funding for a project period of up to three years. Consistency with the ICF conceptual framework is stipulated. More information is available at: <http://www.cdc.gov/od/pgo/funding/DD06-004.htm>.

3. STONE UNVEILS PLANS FOR ICF "COMMUNITY OF PRACTICE"

In a February 8 presentation to the Interagency Subcommittee on Disability Statistics (ISDS), and a February 13 presentation to the ICF Subcommittee of the New Freedom Initiative, Professor John Stone from the University of Buffalo outlined plans for the new ICF "Community of Practice" (COP). He was and still is seeking advice on how best to implement the COP. Stone explained that this is the first year of a new five-year grant from NIDRR for CIRRIE-2, the "Center for International Rehabilitation Research Information and Exchange." Activities related to the ICF include cross-mapping to allow people to search the CIRRIE-2 and rehabilitation databases using ICF terms; sponsorship of ICF workshops based on the Procedural Manual and Guide for a Standardized Application of the ICF, developed by the American Psychological Association; and organizing the 2007 North American Collaborating Center (NACC) ICF Conference scheduled to take place in Niagara Falls, NY, on June 5-7, 2007.

The template for the ICF Community of Practice stems from a general set of characteristics that define such COPs. A community of practice is a group of people who share a common concern or a passion for an activity and attempt to do it better through interacting regularly. Three necessary characteristics are:

1. Domain – an identity defined by a shared common area of interest. Membership implies a commitment to the domain.

2. Community – in pursuing interest in a domain, members engage in joint activities and discussions and share information.
3. Practice – It is not merely a community of interest. Members are practitioners and develop a shared repertoire of resources, experiences, stories and ways of addressing recurring problems. This requires sustained interaction.

Communities of practice vary in size, and can contain a core group as well as ancillary members. Some communities are local and others cover the globe; some meet in-person and others on-line. Some are within an organization, and others have members from numerous organizations. Many of the elements of a community of practice are already in place with the ICF. The WHO holds meetings of experts, creating global coordination, currently mainly through the WHO ICF homepage at: <http://www3.who.int/icf/icftemplate.cfm>. The North American Collaborating Center conducts annual ICF conferences in the United States and Canada, described at: www.icfconference.com, and other WHO Collaborating Centers also pursue their own periodic ICF conferences on a regional basis. The NACC also sponsors this monthly electronic newsletter with 900 subscribers. However, there is a need for sustained *interaction*, which will be accomplished with three new interactive COP activities:

1. ICF FORUM – an *interactive* venue dedicated to fostering online “threaded discussions” of various ICF topics suggested by our moderator, expert of the month, or users;
2. ICF BULLETIN BOARD – instant posting messages and *interactive* queries needing short answers; and
3. ICF PRESENCE at Interagency Subcommittee on Disability Statistics (ISDS) teleconferences – a bi-monthly *interactive* presentation of an ICF topic at the teleconference, with abbreviated minutes of the ICF discussions compiled on the CIRRIE-2 website.

Stone announced that the COP message threads and discussions would be handled by Paul Placek, website architecture by Marcia Daumen, and overall direction by himself. There will be a "grand opening" announcement in a future Clearinghouse message and in other venues-- watch for it soon. Stone continues to seek input to make the COP useful, so contact him as follows: John Stone, Ph.D., Director, CIRRIE-2, University at Buffalo/SUNY, 515 Kimball Tower, Buffalo, NY 14214, tel (716) 829-3141 x125, or jstone@buffalo.edu

4. MCGILL ICF MAPPING GROUP SEEKS MORE COLLABORATORS

In the previous Clearinghouse message, we ran a piece entitled "Training: 11 Rules for Mapping Health Status Measures to the ICF." Group coordinator Carolina Moriello has since reported a very high level of continued activity. She notes that the Health Outcomes Research Group of the McGill University Health Centre (Principal Investigator, Dr. Nancy Mayo) is developing protocols for mapping health outcomes to the ICF, and that these are being developed in collaboration with Dr. Alarcos Cieza of the German WHO-FIC Collaborating Center's ICF Research Branch, based in Munich. Mapping activities are underway pertaining to the following copyrighted measurement instruments or intervention programs:

1. Stroke Impact Scale (SIS-16);
2. EuroQUOL EQ-5D;
3. Health Utilities Index (HUI);

4. Medical Outcomes Study 36-Item Short Form Health Survey (SF-36);
5. WHOQOL-Bref;
6. Community Health Activities Model Program for Seniors (CHAMPS);
7. Functional Autonomy Measurement System (SMAF);
8. Barthel Index of Activities of Daily Living;
9. Reintegration to Normal Living Index (RNL);
10. Older Americans Resources and Services Scale – Scale of Instrumental and Physical Activities of Daily Living (OARS-IADL);
11. Functional Independence Measure (FIM); and
12. Preference-Based Stroke Index (PBSI).

The McGill ICF Mapping Group is looking for colleagues to join this effort. Please contact: Carolina Moriello, MSc, School of Physical and Occupational Therapy, Division of Clinical Epidemiology, Royal Victoria Hospital, 687 Ave des Pins Ouest (R4.27), Montreal, Quebec, H3A-1A1, tel (514) 934-1934 x 36906, fax (514) 843-1493, or carolina.moriello@mail.mcgill.ca.

5. 38 PRESENTATIONS NOW AVAILABLE FROM AUSTRALIAN ICF MEETING; HOUGH REPRESENTS NACC

On February 6-7, 2006, the Australian Institute of Health and Welfare (AIHW) sponsored an ICF conference in Sydney, Australia entitled "Improving Information on Disability and Functioning: A Forum for People Who Need, Use, or Develop Information." The AIHW serves as the host for the WHO-FIC Australian Collaborating Centre. The Forum provided an opportunity for users to share information about the ICF and its implementation. The PowerPoint slide images from 38 presentations delivered at the Forum are available at:

<http://www.aihw.gov.au/eventsdiary/iidf2006/program.cfm>

Dr. John Hough from CDC's National Center for Health Statistics (NCHS) represented the North American Collaborating Center at the Australian Forum. He reported that about 125 persons attended, including representatives of five Australian states and territories, almost a dozen other nations, and several important disability advocacy organizations. John reported that a good proportion of the conference speakers and attendees included persons with disabilities. Moderators respectfully acknowledged the Native Australian Heritage of the ground on which the conference took place. Dr. Bedirhan Ustun, WHO Coordinator for Classifications and Terminology, presented a "stocktaking at five years" since the publication of ICF in 2001, an assessment of progress exhibited to date in the international implementation of the ICF. In Dr. Ustun's presentation, entitled "What is the Future of ICF: Synchrony or Anachrony?", he identified several important components of the "ICF Vision":

1. assertively placing the ICF within the spheres of health information systems;
2. progressing toward real on-line data capture and analysis of ICF-coded information;

3. developing ICF-oriented linkages to health information bases such as population-based registries, insurance systems, and sources of data which might ordinarily be ascribed to health services research; and
4. more demonstrations of feasibility of generating ICF data streams.

Professor Rune Simeonsson presented on the ICF-CY. John noted that a large number of Speech Pathologists and other communications specialists participated and also presented research papers. He reported that: "As a group, the Speech Pathologists cited the multi-dimensionality of both communication disorders and the ICF components applicable to disability experienced from those disorders. Professor Sharynne McLeod from Charles Sturt University in Bathurst, New South Wales, Australia, presented a detailed study of an application of the ICF to children with speech impairments. Professor Linda Worrall, a Speech Pathologist from the University of Queensland, deserves special congratulations for not only presenting her own ICF-oriented research, but also encouraging at least four of her doctoral students from the Communication Disability in Aging Research Center to present their own timely research on such applied ICF topics as "third-party disability" in spouses of older people with hearing impairment (Ms. Nerina Scarinci), environmental factors influencing the community participation of adults with aphasia (Ms. Tami Howe), ICF-coded barriers and facilitators in public bus transportation systems (Ms. Elizabeth Savina); and assessing communicative capacity in acute hospital settings (Ms. Robyn O'Halloran)." For more information about the AIHW Forum, contact John Hough at (301) 458-4437, or jph7@cdc.gov .

6. ALTMAN RETIRES FROM NATIONAL CENTER FOR HEALTH STATISTICS

Barbara M. Altman, a Sociologist who earned her Ph.D. degree from the University of Maryland, is retiring as Special Assistant on Disability Statistics at the National Center for Health Statistics at the end of April. Her career started at the University where she spent 12 years as the Director of the Sociology Undergraduate Office and as a Lecturer. While at Maryland, she organized courses on the Sociology of Disability and Disability Policy, and Barbara still maintains a role as an Adjunct Associate Professor, occasionally teaching at College Park. Her first government position was as a Senior Research Fellow with the Agency for Healthcare Research and Quality, where she was involved in the development of the disability components of the Medical Expenditure Panel Survey (MEPS). From the start, she has been concerned with disability issues, and in the course of her years with the MEPS, she particularly focused on standardizing measurement of disability in surveys. After coming to NCHS, she worked with the interagency committee involved in revising the measures of disability in the American Community Survey, and has had a key role in the Washington Group, an international group seeking to develop culturally-compatible measures of disability worldwide. In that role she has contributed to the use of the ICF conceptual framework in census and survey measurement. (See <http://www.cdc.gov/nchs/citygroup.htm> for a selection of Barbara's papers developed on behalf of the Washington Group.) Her disability research interests have focused on three areas: disability definition and measurement in survey data; access to, financing and utilization of health care services by persons with disabilities,

particularly working age persons and women with disabilities; and disability among members of minority groups. She is the author of numerous articles and book chapters on disability topics, and she is currently co-editor of the book series Research in Social Science and Disability, published by Elsevier. The fourth volume of RSSD, which examines measurement of disability internationally, based on the work of the Washington Group, is due to be published in 2006. She will be retiring to her writing, her garden, her grandchildren and some consulting. Contact information: Barbara Altman, 14608 Melinda Lane, Rockville, MD 20853, or b.altman@verizon.net .

7. UPDATE ON THE WASHINGTON GROUP ON DISABILITY STATISTICS

Beth Rasch and Barbara Altman are noted for their work on the Washington Group on Disability Statistics (WG), which uses the ICF conceptual framework in prospective census and survey measurements. At the March 8 meeting of the Interagency Subcommittee on Disability Statistics, Beth provided an update on this activity. The fifth meeting of the WG was held September 21-23, 2005, in Rio de Janeiro, Brazil, hosted by the Brazilian Institute of Geography and Statistics (IBGE) in collaboration with the National Coordination Office for the Integration of People with Disabilities (CORDE). This event brought together representatives from 31 countries, three organizations representing persons with disabilities, and five international organizations. The meeting was preceded by the second of two workshops organized by the WG intended to prepare representatives from several countries in Africa, Asia, and Latin America to conduct the WG pre-test of the short set of questions on disability. The WG is organized through workgroups, whose current tasks include:

1. considering suggested revisions to the short measure and accompanying statement of rationale (the short measure may be further revised based on pre-test results which are pending);
2. revising the implementation documents and assisting countries in carrying out the WG pre-tests;
3. developing a blueprint for extended measurement sets; and
4. planning analyses of the WG pre-tests.

Presentations and papers from all of the WG meetings are available on the group's website: <http://www.cdc.gov/nchs/citygroup.htm>. The sixth meeting will be held in Kampala, Uganda on October 10-13, 2006. A major focus during that meeting will be review and discussion of the results of international pre-testing currently underway in over a dozen countries. For more information on the 2006 meeting, visit the WG website or contact Beth Rasch at (301) 458-4248, or Erasch@cdc.gov.

8. MACDONALD-WILSON COMPLETES DISSERTATION USING ICF

Last spring, Kim MacDonald-Wilson completed her dissertation toward earning the Doctor of Science degree in Rehabilitation Counseling at Boston University, using the ICF. The title is: "Feasibility of a self-report interview of mental functions in the International Classification of Functioning, Disability and Health (ICF): Cognitive

interviewing with persons with work disabilities due to psychiatric conditions." Excerpts from her dissertation abstract follow:

"The Mental Functions chapter of the ICF contains a number of items that include cognitive, emotional, and interpersonal functions as well as symptoms that have been found to be related to vocational outcome for people with psychiatric disabilities, but is not designed as a stand-alone assessment instrument. This study investigated the question, 'What is the feasibility of using the Mental Functions Chapter of the ICF Checklist as a self-report interview with people with psychiatric disabilities?'

Methods: Sixteen research participants were recruited to conduct cognitive testing of a self-report version of the Mental Functions Chapter of the ICF Checklist. Respondents were interviewed in person using a semi-structured cognitive interview protocol about their understanding of interview questions, item definitions, and process of responding to questions. Data was qualitatively analyzed using a content analysis approach to identify problematic questions and to suggest modifications.

Results: Cognitive testing improved the questions about Mental Functions so that most items were easily understood by people with psychiatric disabilities. All questions required at least minor changes and more than half of the items were deleted due to problems in comprehension, decision process, or response process. Higher-level mental functions were not useful as screening items for proceeding with the detailed third and fourth level sub-items and were deleted. Many complex cognitive functions were not directly relevant to work or were difficult to understand even with significant revision and were deleted, such as global psychosocial functions, consciousness, experience of self and time. Questions that were easiest to understand were physiological functions such as energy and drive and maintenance of sleep, emotional functions such as appropriateness and range of emotion, and some specific cognitive functions such as sustaining attention, retrieval of memory, and calculation. The resulting survey contained 52 questions, reduced from 127 items in the original mental functions chapter.

Conclusions: Mental Functioning and Work is a 52-item self-report survey based on the Mental Functions chapter of the ICF that people with psychiatric disabilities could consistently understand to report problems in cognitive and emotional functions in work situations."

For more information, contact: Kim MacDonald-Wilson, Sc.D., Assistant Professor, Rehabilitation Counseling Program, University of Maryland, Department of Counseling and Personnel Services, 3214 Benjamin Building, College Park, MD 20742, tel (301) 405-0686, or kmacdona@umd.edu.

9. ATRA ENDORSEMENT OF ICF NOW ON WEB

The American Therapeutic Recreation Association (ATRA) press release announcing the Association's position statement endorsing the ICF is now posted at:

<http://www.atra-tr.org/newsreleases.htm> . The direct link is at:

<http://www.atra-tr.org/Press%20releases/ATRA%20ICF%20statement%20Newsrelease%20.pdf>.

ATRA now "supports the use of ICF language and terminology in recreational therapy practice guidelines, standards of practice, curriculum development, public policy, international relations, and research." The press release closes with this statement by ATRA President Dr. Bryan P. McCormick: "Our Association is pleased to endorse the International Classification of Functioning and sees it as a valuable tool in our treatment services."

10. APA MONITOR HIGHLIGHTS ICF MANUAL

Visit the American Psychological Association (APA) website at <http://www.apa.org/monitor/jan06/changing.html> to read the latest *APA Monitor* update on current activities associated with the Procedural Manual and Guide for a Standardized Application of the ICF: A Manual for Health Professionals." The article is entitled "Changing health care's focus: A newly released APA draft manual aims to transform the way health professionals approach health care", by Zak Stambor of the *APA Monitor* staff (Volume 37, number 1, January, 2006). The article includes substantive quotes by Lynn Bufka, Geoffrey Reed, David Peterson, Marjorie Greenberg, and Susanne Bruyere.

11. SPOTLIGHT ON LYNN BUFKA

Each month we try to "spotlight" someone who has made a difference with the ICF. For more than three years, Lynn F. Bufka has been doing exactly that -- making a difference at the American Psychological Association (APA), located in Washington, D.C. Before coming to APA, Lynn earned her Ph.D. degree in Clinical Psychology (APA Approved) from Boston University in 1996. Her Clinical Psychology Internship was at the Brockton Medical Affairs Medical Center, which is affiliated with the Harvard Medical School. She was already well-published in major psychology journals and had taught such courses as Cross-Cultural Psychology, Case Management, and Adult Psychological Assessment, at Boston University. Since November, 2002, Dr. Bufka has been Director of Professional Development Demonstration Projects, within the APA Practice Directorate. In this capacity, she is responsible for the design, management, and coordination of large-scale projects that demonstrate the value and benefits of integrating psychological knowledge, services, and methodology in areas of expanding opportunities for professional psychology. One important focus of Lynn's work has been on facilitating adoption and implementation of the ICF within health care practice. The ICF is especially relevant to psychological practice because most psychological interventions are designed not only to reduce symptoms but also to increase individual functioning. Lynn believes that systematic clinical classification of information about functioning using the ICF will enable individual psychologists and other health care providers to use

universal nomenclature to describe their work and the needs of their clients. To enable consistent application of the ICF, the APA has spearheaded an effort in collaboration with WHO and several national associations of health professionals (e.g., APTA, AOTA, ASHA, ATRA, NASW) to complete the Procedural Manual and Guide for a Standardized Application of the ICF. Lynn is setting up interactive, on-line review and comment for the Manual, and all interested individuals are invited to participate. Lynn has given many ICF presentations and taught a number of ICF workshops, and she and her APA colleague Dr. Geoffrey Reed have recently partnered with Professor John Stone to conduct ICF workshops under the CIRRIE-2 initiative. (Geoff Reed was "spotlighted" in the December, 2003 ICF Clearinghouse newsletter, and John Stone was "spotlighted" in the October, 2005 ICF Clearinghouse newsletter.) Lynn provided important information about the Manual in the January, 2006 *APA Monitor* article entitled "Changing health care's focus: A newly released APA draft manual aims to transform the way health professionals approach health care," cited above. Lynn is married, lives in Silver Spring, Maryland, and plays soccer in a women's competitive league. She says she has a "great kid in first grade and a beloved dog," and with her husband says: "We will travel to virtually any foreign destination for a wedding, including Scotland, Australia and India!" Contact information is as follows: Lynn F. Bufka, Ph.D., American Psychological Association, 750 First Street, NE, Washington, DC 20002-4242, tel (202) 336-5869, or LBufka@apa.org

Be sure to send news of your ICF activities to Paul J. Placek, Ph.D., at PJPLACEK@VERIZON.NET or call him at 410-643-2817. We will share your news with 900 ICF Clearinghouse subscribers.