

OCTOBER 2005 NACC CLEARINGHOUSE ON ICF MESSAGE

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1. CONDOLENCES TO SCOTT CAMPBELL BROWN AND FAMILY

We are saddened to report that on October 25, 2005, Pat Brown, beloved wife of Scott Campbell Brown, died. She had been undergoing treatment for leukemia, but her sudden death came as a profound shock. Pat often accompanied Scott on his ICF trips, and she always conveyed a delightful disposition mixed with humor, bright-eyed innocence, and enthusiasm. If you would like to send Scott a card, his home address is 1792 Brooke Road, Stafford, VA 22554. Our thoughts and prayers are with Scott in this time of sorrow.

2. CIRRIE-2 FUNDED FOR \$2,500,000

CIRRIE-2 (Center for International Rehabilitation Research Information and Exchange-2) has just been funded by NIDRR for \$2,500,000 over five years, starting November 2005. CIRRIE-2 offers a comprehensive approach to address the needs of researchers, practitioners, and consumers for research-based information from international sources.

CIRRIE-2 will expand its existing Database of International Rehabilitation Research and will synthesize material from it to develop state-of-the-science digests for target audiences. Dissemination will involve multiple channels, including professional and consumer organizations who will serve as knowledge intermediaries. CIRRIE-2 will also develop an online, multi-lingual international encyclopedia of rehabilitation in English, Spanish and French, in cooperation with the Quebec Institute for Physical Rehabilitation. To support collaborative activities between the U.S. and other countries, CIRRIE-2 will conduct four types of international exchange programs involving researchers and technical assistance experts. These include a) short-term exchanges of individuals, b) institutional linkage exchanges, c) a program for Minority Serving Institutions and d) a program for information gathering for dissemination to U.S. audiences. The International Classification of Functioning Disability and Health (ICF) will provide the conceptual framework for CIRRIE-2 and be one of its principal themes. CIRRIE-2 will sponsor workshops on the ICF in cooperation with the American Psychological Association and the WHO North American Collaborating Center (NACC). CIRRIE-2 will conduct an international conference on the ICF in Year 2, in collaboration with the NACC. CIRRIE-2 will create a Community of Practice on the ICF, using its website for threaded discussions. The project also will cross-map the terms of the ICF to the terms in the thesaurus used to search the CIRRIE and REHABDATA databases, making it possible to search both databases using ICF terms. CIRRIE-2 will also develop new initiatives in the area of cultural competence for disability service providers. The project will target pre-service training for service providers within university programs. Its strategy is to create new curriculum materials tailored to four professional programs. The materials will be developed and tested by CIRRIE-2 in a university setting and then disseminated to university programs across the country. By the end of the project, CIRRIE-2 will develop a text book on this topic. It will also develop two new monographs and a second edition of the book, *Culture and Disability: Providing Culturally Competent Services*, published by SAGE Publications in CIRRIE-1. In Year 4 CIRRIE-2 will conduct an international conference on *Providing Culturally Competent Disability Services*, in collaboration with the Toronto-based Joint Centre of Excellence on Research on Immigration and Settlement. For more information, contact: John Stone, PhD, Director, Center for International Rehabilitation Research Information and Exchange, 515 Kimball Tower, University at Buffalo, State University of New York, Buffalo, NY 14214, jstone@buffalo.edu, tel 716-829-3141 x 125, fax 716-829-3217, web <http://cirrie.buffalo.edu>

3. 40 ICF PAPERS AT TOKYO HEADS MEETING

Click on <http://www3.who.int/icd/tokyomeeting/documentlist> for a list of about 72 country reports, papers, and poster sessions at the WHO Heads of the Family of International Classifications held in Tokyo (there are additional documents, agendas, etc.). Of the 72, 20 have ICF specifically in the title, and a similar number deal with ICF in some specific way. The ICF-related papers, in addition to annual reports of the Collaborating Centres and WHO-FIC Network committees, are as follows:

B.2.2 Ohashi Kensaku. Care Management Utilizing ICF and Social Work Practice

B.2.3 Diane Caulfeild, Paul Placek . ICF Tutorial and 11th Annual NACC Conference, Rochester, Minnesota. Mapping the Clinical World to the ICF

B.2.6 Marjorie S. Greenberg, Marijke de-Kleijn. Report on ICF Workshop Thailand

B.3.1. Stephanie Weber, Egbert van der Haring; Susanne Bröenhorst, Michael Schopen, Pieter Zanstra. Maintaining Medical Classifications in XML – ClaML redefined for use with WHO-FIC classifications

B.3.2 Stefanie Weber, Susanne Bröenhorst, Michael Schopen Maintenance and Publication Tool for WHO-FIC Classifications - a status report

B.3.4 Diane Caulfeild. From Paper to Database - Exploring an Electronic Database Environment for ICF

B.4.2 Rune J. Simeonsson, Matilde Leonardi, Eva Bjorck-Akesson, Judith Hollenweger, Don Lollar, Andrea Martinuzzi, Huib Ten Napel. The ICF-CY: a derived classification for children and youth

B.4.4 Niels Bentzen, Anders Grimsmo Proposals for future collaboration between WHO-FIC and Wonca/WICC.

B.5.1 Yayoi Okawa, Satoshi Ueda, Kenji Shuto. The Utilization of ICF in National Legislation and Policies in Japan

B.5.3 Satoshi Ueda, Yayoi Okawa, Kenji Shuto. Clinical Application of ICF to National Medical Insurance and Personal care Insurance

B.5.4 Matti Ojala, Kristina Bränd Persson, Martti Virtanen. Implementation of a questionnaire to collect information on the use of qualifiers, rating scales and assessment protocols with ICF

B.5.5 Sykes C. Madden R. Williams KA functioning and related health outcomes module: the tool and testing

B.5.6 Richard Madden, Ros Madden, Ching Choi, Ken Tallis, Wen Xingyan. Use of ICF in health information systems and surveys

B.5.7 Ros Madden. ICF: why collaborate?

B.5.8 Marijke W. de Kleijn – de Vrankrijker, WHO-FIC IC co-chair. Annual report WHO-FIC Implementation Committee concerning ICF

B.5.9 ICF Structured Collection of Comments

B_5-B_2-2 Care Management Utilizing ICF

I.2 WHO Business Plan for Classifications

P.1.10 Nenad Kostanjsek, Bedirhan Üstün. Questions for Disability Statistics Overview and preliminary results from WHO/UNESCAP field tests

P.1.12 Lozano R, Soliz P. Measurement of disability in Mexico - A different approach

P.1.13 Lozano R, Soliz P. Describing health state by measuring health domains

P.2.11 Catherine Sykes on behalf of the ICF team. A functioning and related health outcomes module

P.2.12 Leonardi M, Raggi A, Frare M, Martinuzzi A. ICF-DIN Training for EU MHADIE project. European experience on ICF training

P.2.13 Catherine Sykes on behalf of the ICF team. Metadata standards for functioning and disability in Australia

P.2.17 Nenad Kostanjsek, Bedirhan Üstün. ICF: a multi-dimensional approach for measuring health and disability.

P.2.18 Tai Takahashi, Jiro Okochi, Nenad Kostanjek. Health measurement using the ICF. Test-retest reliability study of ICF codes and qualifiers in geriatric care

P.2.19 Tai Takahashi, Jiro Okochi, Nenad Kostanjek. Development of ICF Illustration library.

P.2.20 Nenad Kostanjsek, Bedirhan Üstün. Cross-walking assessment tools to ICF Update on the work in progress

B Ustun WHO Report 2005 (powerpoints)

4. ICF PAPERS AT APHA

Originally scheduled for New Orleans, the American Public Health Association Meetings have been rescheduled for December 10-14, 2005 in Philadelphia. There are at least six ICF papers on the program:

1. ICF for children and youth (ICF-CY), Rune J. Simeonsson, University of North Carolina, rjsimeon@email.unc.edu
2. Using the ICF to measure community factors affecting physical activity, Elaine G. Gerber, PhD, American Foundation for the Blind, gerber@afb.net
3. Measuring childhood disability: The International Classification of Functioning, Disability and Health (ICF) and the CSHCN Screener in the Medical Expenditure Panel Survey, Kristen Hill, Massachusetts General Hospital for Children, kshill@partners.org
4. Measuring Disability Among the Elderly in the Community--An application of ICF Kristine A. Mulhorn, University of Michigan-Flint kmulhorn@umflint.edu
5. Housing and health among low-income adults with physical disabilities: A focus group approach, Pei-Shu Ho, pei-shu.ho@medstar.net
6. Participation and Environment Measurement Systems--PARTS and FABS, David Gray, Washington University, grayda@msnotes.wustl.edu

From December 19, 2005 to February 13, 2006, abstracts may be submitted for the November 4-8, 2006 APHA meeting to be held in Boston.

5. ICF CONFERENCE IN SYDNEY FEBRUARY 2006; ICF MODULE

The Australian Institute of Health and Welfare will be holding a forum on 'Improving information on disability and functioning' on 6-7 February 2006 in Sydney. As well as the overall aim of the forum—to improve information on functioning and disability—another main aim is to provide an opportunity for people interested in/or using the International Classification of Functioning, Disability and Health (ICF) to get together and share ideas and experiences.

Speakers from a broad range of disciplines and with varied experience will be presenting at the forum, including representatives from the World Health Organization, Australian and international universities, non-governmental organizations, consumer groups and public and private agencies. A draft program and registration details can be found at <http://www.aihw.gov.au/eventsdiary/iidf2006/index.cfm>. If you are interested in attending please register soon, as places are limited to the first 150 people who register.

Note also that the Australian Institute of Health and Welfare has recently released a report that may be of interest to the ICF world entitled '*A functioning and related health*

outcomes module: Testing and refining a data capture tool for health and community services information systems'. The Functioning and Related Health Outcomes Module (FRHOM) is a compact module that can provide a summary that reflects the person's current status across all components of functioning as defined in the ICF. The report intends to inform people interested in improving information on human functioning across a wide range of fields, and/or interested in testing the FRHOM. The report can be found at www.aihw.gov.au/publications/index.cfm/title/10196.

For more information, contact Kate Williams, Functioning and Disability Unit, Australian Institute of Health and Welfare, tel 02 6244 1119, fax 02 6244 1069, kate.williams@aihw.gov.au

6. NEW FREEDOM INITIATIVE MEETING CONTINUES ICF TOPICS

The ICF Subcommittee of the New Freedom Initiative, under the leadership of Dr. Margaret Giannini, Director, HHS Office on Disability, continues to hold monthly meetings with a focus on ICF. The NFI Committee <http://www.hhs.gov/newfreedom/> was established by the Office on Disability to monitor and promote activities of the NFI, which has these goals: increase access to assistive and universally designed technologies; expand educational opportunities; promote home ownership; integrate Americans with disabilities into the workforce; expand transportation options; promote full access to community life; and support sound health care policy for people with disabilities. The ICF provides a standard language for the description of these goals. The October 11 meeting included a discussion by John Stone of his new CIRRIE-2 grant (see item 2 above) and presentations by David Peterson and many of the authors of ten ICF papers in *Rehabilitation Education* (Vol. 19, Number 2 & 3, 2005). The November 8 meeting will focus on ICF papers presented at the Tokyo Heads Meeting (see item 4 above).

7. VALLUZZI TAKES ICF JOB AT NCBDD/CDC IN ATLANTA

Congratulations are in order for Janet Valluzzi, who on October 15, 2005 took a key ICF position in Atlanta, where she will work with ICF experts John Crews and Don Lollar, among others. Her new address is: Disability and Health Team, National Center for Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, 1600 Clifton Road, NE, MS-E-88, Atlanta, GA 30333, tel 404-498-3057, fax 404-498-3050, jgv6@cdc.gov. She will continue to co-facilitate the NFI Subcommittee on ICF meetings chaired by Dr. Giannini (see item 7 above).

8. HOUGH TAKES ICF JOB AT NCHS/CDC IN HYATTSVILLE

Dr. John Hough has accepted a senior ICF position within the Classifications and Public Health Data Standards Staff (CPHDSS), Office of the Director, National Center for Health Statistics, CDC. He began his new position on October 31. John formerly worked on the Disability and Health Team, National Center for Birth Defects and Developmental Disabilities, CDC, and at the National Institute on Alcohol Abuse and Alcoholism, Division of Epidemiology and Prevention Research, National Institutes of Health. He has master's and doctorate degrees in public health with majors in

epidemiology, health services and policy analysis and experience as a health scientist, researcher and administrator in related fields. He will be working with Marjorie Greenberg, CPHDSS and the North American Collaborating Center on disability classification and ICF. Although Marjorie still misses Paul Placek (who continues to bring you these Clearinghouse messages), she is thrilled that John has joined her staff!

9. TORA DAHL CONTINUES ICF WORK

Tora Dahl of Denmark was a "regular" at international ICF meetings, and she is now director of a five-year research program with intervention to people with low back pain and "sicklisted". The intervention is very careful health examination, information and empowerment for people to handle their fear and distress, and assisting them back to the workplace, having dialog with the company on the conditions on returning to work. ICF is the core frame of reference, and she is coding their clinical database into ICF categories where possible. There are 350 patients in two intervention groups. Back injury patients have many activity limitations/restrictions in participation because of pain, fear and social withdrawal. Her new contact information is: Tóra H. Dahl, MPH, OTD, Roennehaven 9, DK-8520 Lystrup, Denmark, <tora.dahl@tdcadsl.dk>.

10. LINKOV OF U. PITTSBURGH VISITS LITHUANIAN ICF EXPERTS

Faina Linkov, PhD is a postdoctoral research associate working under the direction of Katherine Seelman, former Director of NIDRR. As a part of her trip to a NATO-funded advanced research workshop to Lithuania, Dr. Linkov met with several leaders in the field of health and rehabilitation in Lithuania. This included a meeting with Dr. Albinas Bagdonas of Vilnius University, the ICF expert who translated the ICF into Lithuanian in 2004. Future steps in the implementation of ICF in Lithuania include: scale validation and standardization, development of the ICF working group, and improved collaboration with other disability research centers. For more information, contact Faina Linkov at FY11@pitt.edu. Dr. Seelman can be reached at kds31@pitt.edu.

11. CONTINUE TO SHARE YOUR ICF NEWS WITH PJPLACEK@VERIZON.NET

Over 800 persons interested in the ICF receive these monthly announcements about ICF activities. Share *your* ICF activities with the group by contacting Dr. Paul Placek at PJPLACEK@verizon.net, or by calling him at 410-643-2817. Join the NACC Clearinghouse Listserv by contacting him or Linda Washington at LRWashington@cdc.gov. Previous messages since October 2002 can be viewed at <http://www.cdc.gov/nchs/about/otheract/icd9/icfhome.htm>. About one-fourth of our subscribers are government, one-fourth are university-based, and half are commercial users. By country, three-fourths are U.S., one-fifth are Canadian, and the rest are other international.

12. SPOTLIGHT ON JOHN STONE

Each month we "spotlight" someone who has made a difference with the ICF, and this month we focus on Dr. John Stone. Item 2 above attests to John Stone's success in winning a \$2.5 million grant from NIDRR for CIRRIE-2, with ICF being a key component. John managed and directed CIRRIE-1, which also had important ICF activities. The mission of CIRRIE-2 (Center for International Rehabilitation Research Information and Exchange) is to facilitate the sharing of information and expertise between rehabilitation researchers in the U.S. and those in other countries (<http://cirrie.buffalo.edu>). The CIRRIE-1 project developed a database of 25,000 published articles on rehabilitation research conducted outside the U.S. Also as part of the CIRRIE-1 project he served as the Editor of a 12-volume monograph series on the cultures of persons with disabilities who have immigrated to the U.S. from other countries, as well as a newly published book, *Culture and Disability: Providing Culturally Competent Services* (SAGE Publications). Stone is a Clinical Associate Professor in the Department of Rehabilitation Science at the State University of New York at Buffalo. Prior to joining the faculty of the University of Buffalo, he worked for 17 years as a faculty member in several universities in Brazil. In 1991 he returned to the U.S. where he became Dissemination Director of the Center for Assistive Technology at the University at Buffalo and its NIDRR-funded Rehabilitation Engineering Research Center on Aging. He is also a former Peace Corps Volunteer (India, 1967-69). Since 1999 he has been directing the CIRRIE project. John's PhD is from Florida State University in 1976. John currently teaches graduate courses on "Functional Limitations and Disability", and "Academic Writing and Presenting". He is a member of the faculty of the PhD Program in Rehabilitation Sciences and has served as Coordinator of Grant Development and conducted workshops on grant development. He speaks fluent Portuguese and Spanish. Contact information: John Stone, PhD, Director, Center for International Rehabilitation Research Information and Exchange, 515 Kimball Tower, University at Buffalo, State University of New York, Buffalo, NY 14214, jstone@buffalo.edu, tel 716-829-3141 x 125, fax 716-829-3217, web <http://cirrie.buffalo.edu>