

December 2005 NACC Clearinghouse on ICF Messages

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1. WWW.ICFCONFERENCE.COM NOW HAS EXECUTIVE SUMMARY OF 2005 MAYO MEETING...

...and soon it will have the deadline of the call for papers for the 12th Annual NACC meeting on ICF to be held June 5 to 7, 2006 in Vancouver, British Columbia, Canada. The theme is "Living in Our Environment: The Promise of ICF". In this meeting, the Canadian Institute for Health Information and the National Center for Health Statistics, CDC, welcome you on behalf of the World Health Organization Family of International Classifications to the 12th Annual North American Collaborating Center (NACC) Conference on the International Classification of Functioning, Disability and Health (ICF). For more information, please contact: Julie Bazerly, Conference Coordinator, 12th Annual NACC Conference for ICF, c/o Canadian Institute for Health Information, Tel.: (613) 694-6844, Fax: (613) 789-2114, Email: conferences@cihi.ca. Check www.icfconference.com frequently for updates. Paul Placek's Executive Summary of highlights from the 2005 meeting at Mayo is now on this website.

2. UNITED NATIONS COMMITTED TO ICF USE

According to Mary Chamie, Chief of Demographic and Social Statistics in the Statistics Division at the United Nations (mchamie@un.org and mary.chamie@gmail.com), the UN recognizes internationally agreed classifications such as the ICF. The United Nations system must recognize all internationally agreed classifications for their frameworks. This is why international agreements are reached – to show consensus in concepts and classifications and to ensure harmonization of standards, concepts and methods. An explanation as to how the United Nations *Family of International Economic and Social Classifications* operate may be seen at <http://unstats.un.org/unsd/class/family/default.htm>. In addition to the agreement at the international level to use internationally agreed classifications, there are a number of national statistical offices, not all, that by law must incorporate the use of internationally agreed classifications into their legislation and statistical programs. Many do so, based on principle. This is why it was so important that the World Health Organization approved the ICF as an internationally agreed classification. The ICF may be seen at the UNSD statistical classifications website as an internationally agreed classification shown in the Inventory of the *Family of International Economic and Social Classifications* (<http://unstats.un.org/unsd/cr/family1.asp>), with a proper link to the WHO website for details on the ICF classification itself. The UN Statistical Commission took action several years ago when it recognized that an internationally agreed classification, the ICF, is now available for development of statistical methods and measurement. At the meeting of the Statistical Commission in 2003, the Commission approved for the first time, the collection of official national statistics of disability through the *UN Demographic Yearbook* system; emphasized the need to ensure the collection of internationally comparable disability statistics and encouraged the UN Statistics Division to work with the Washington Group on Disability Measurement to identify items for which statistical information on disability was comparable. The Washington Group is now formed to ensure the development of standardized statistical methods, while basing them on the international agreements thus far reached (<http://www.cdc.gov/nchs/citygroup.htm>). At that same time, the Commission advised the judicious and complementary use of the sources of disability statistics and information, namely, censuses, surveys and administrative records. To quote the Statistical Commission report, see E/2003/24 and E/CN.3/2003/34 located at <http://unstats.un.org/unsd/statcom/sc2003.htm>. With respect to the development of standards and methods for censuses, the ICF is now also incorporated into the text of the revised set of *Principles and Recommendations for Population and Housing Censuses* and has been proposed to be included in the update procedures of that document for the next round of population and housing censuses between 2005 and 2014.

3. FIFTY ABSTRACTS NOW AVAILABLE FROM WASHINGTON GROUP MEETING IN RIO

The 5th meeting of the Washington Group on Disability Statistics (WG) was held September 21-23, 2005, in Rio de Janeiro, Brazil, hosted by Instituto Brasileiro de Geografia e Estatística (IBGE), in collaboration with CORDE. About 50 abstracts and powerpoint summaries from the 5th meeting are now on the group's website

<http://www.cdc.gov/nchs/citygroup.htm>. Objectives for the 5th meeting were to: (1) Present work on continued development of the general disability measure; (2) Present work on the written protocols and plans for implementing the general disability measure, including lessons learned from regional workshops; (3) Present work on the development of extended measurement sets and the associated papers; (4) Discuss methodological issues related to proxy and nonresponse and to continue discussion of full population coverage; and (5) Discuss strategic issues. In the opening plenary of work to date by Jennifer Madans, she stated that at the first meeting held in Washington, DC in February 2002, the group "agreed to develop short and long sets of internationally comparable disability measures using the ICF as a framework" (with census questions a priority). A sixth meeting is planned in 2006. For more information on the 2006 date and location, contact Beth Rasch (Erasch@cdc.gov).

4. NATIONAL COUNCIL ON DISABILITY ENDORSES ICF FOR CENSUS USE

Check out the latest National Council on Disability report to the President and Congress at http://www.ncd.gov/newsroom/publications/2005/pdf/progress_report.pdf. National Disability Policy: A Progress Report, December 2003 - December 2004. The report has a publication date of November 17, 2005 and on that day was transmitted by Chairperson Lex Frieden to President Bush and to the President Pro Tempore of the U.S. Senate and the Speaker of the House. The document has 204 pages and 13 chapters. Chapter 1, Disability Statistics and Research, recommends that Congress adopt legislation requiring the Census Bureau to report to Congress the estimated number of people with disabilities, and Recommendation 1.1 states in full: "NCD recommends that the Interagency Committee on Disability Research undertake an intensive assessment of the feasibility of applying the principles and organization underlying the World Health Organization's International Classification of Functioning, Disability and Health to the formulation of Census questions". NCD member Dr. Joel I. Kahn, who was a plenary speaker at the most recent NACC ICF at Mayo Clinic in Rochester, and who has attended a number of ICF meetings, was undoubtedly influential in this part of the report. Joel was in the "spotlight" of a previous Clearinghouse message, and can be reached at 513-983-4727 (tel) or at kahn.ji.1@pg.com.

5. WHO WEBSITE NOW HAS ICF-CY, 2005 DISABILITY PHOTO CONTEST WINNERS, AND 2006 PHOTO CONTEST RULES

Go to the ICF homepage <http://www3.who.int/icf/icftemplate.cfm> for a downloadable ICF-CY and to view winners of "WHO Photocontest - Images of Health and Disability 2005". Here you can browse the ICF and ICF-CY, view the 2005 photo contest winners, and obtain information about the 2006 contest. First prize is \$1,000, and the closing date for entries is March 31, 2006. For the first time in 2006, children up to 12 years old and teens age 13-17 will be entered in their own age groups. There is no entry fee, and there are three submission categories: color photos, black and white photos, and digital photo art. You can also order ICF books, view training materials, obtain the ICF checklist, check out the beginner's guide, and obtain information about the WHO FIC (Family of International Classifications) Network.

6. FIM DEVELOPER CARL GRANGER CROSSWALKS UDSMR TOOLS TO ICF

The Uniform Data System for Medical Rehabilitation (UDSMR) has developed a series of functional assessment measures covering childhood to adult, and inpatient and outpatient (www.udsmr.org). The UDSMR is the most widely used system in the world for documenting the severity of patient disability and outcomes of medical rehabilitation. Dr. Carl Granger is an architect of this system. He states that their outpatient themes are the broadest as they cover physical functioning, cognition, pain experience, mood, social interaction, role participation, spirituality, and satisfaction with treatment. The attached file (booklet) contains most of the items which they have available and illustrates the relationships between the ICF items and the items used by the various instruments created by UDSMR. It is 38 pages and it is entitled: "Comparisons of FIM Items, LIFEWare Items, PAR-PRO Items, and Wee-FIM Items and ICF". Dr. Granger approved this dissemination, and is considering participating in the Vancouver ICF meeting in June 2006. Contact information is as follows: Carl V. Granger, MD, Professor, Rehabilitation Medicine, University at Buffalo, 270 Northpointe Pkwy, Ste 300, Amherst, NY 14228, Phone: 716 817-7800, FAX: 716 568-0037, email: cgranger@udsmr.org.

7. INTERAGENCY SUBCOMMITTEE ON DISABILITY STATISTICS (ISDS) INCLUDES ICF TOPICS

The ISDS periodically includes an ICF topic in its monthly videoconference/teleconference meetings, but at its January 11, 2006 meeting, three ICF topics were presented: (1) Rune Simeonsson, rjsimeon@email.unc.edu, "Overview of the Status of the International Classification of Functioning, Disability and Health version for Children and Youth (ICF-CY)"; (2) Don Lollar, CDC, "Application of the ICF-CY for Early Intervention in Georgia"; and (3) Scott Brown, OSEP, scott.brown@ed.gov, "Potential Use of the ICF-CY in the Early Intervention Handbook". The ISDS is a Subcommittee of NIDRR's Interagency Committee on Disability Research. For over 20 years, the meetings have always been on the second Wednesday of each month from 1:30-3:00pm e.s.t. To receive notices of future meetings and to have access to archived minutes from over five years of previous meetings, send an email to: Chad Lamb at clamb@cessi.net. You will then be invited to one of the videoconference sites, or you can teleconference and participate interactively by telephone: International callers must pay toll and call USA 1-210-406-2131. Within the US, the toll free number is 866-705-0982; PASSCODE: 4539672#.

8. BUFKA OF APA SPEAKS AT KYUSHU UNIVERSITY IN JAPAN

At the invitation of Dr. Jiro Okochi at Kyushu University in Fukuoka, Dr. Lynn Bufka of the American Psychological Association spoke on "Clinical Use of the ICF by Multidisciplinary Health Professionals." Her October 24, 2005 talk was attended by students and professionals from the Departments of Psychology and Rehabilitation. She described the ICF Procedural Manual which she, Geoff Reed, and others have worked on for so long, NIDRR's funding of ICF research, the Office on Disability's ICF

Subcommittee, among other things. Lynn is Director, Professional Development Demonstration Projects, at the American Psychological Association in Washington, DC and her email is LBufka@apa.org.

9. SPOTLIGHT ON DR. JOHN HOUGH

Each month we “spotlight” someone who has made a difference with the ICF. This month we focus on Dr. John Hough, who joined the Classifications and Public Health Data Standards staff under Marjorie Greenberg within CDC’s National Center on Health Statistics in October, 2005. John says: “If the *Spotlight* is designed to describe someone who has made a difference with the ICF, at this stage I can’t honestly say I’ve done much more than simply learn about the ICF, hopefully to become one of its most proficient advocates for justifiable application. Due humility is warranted. Nevertheless I’m privileged to have joined the NCHS Classifications and Public Health Data Standards Section, and this community of researchers, so as to be able to contribute more thoroughly to the development and dissemination of the ICF. As evidenced by my testimony, personal interaction and intervention have provided me with my fundamental understanding of our disability topics. I’m hoping to return the favors by providing the same kind of interaction within this growing community of investigators, and hopefully to participate in broadening this ICF ‘Big Tent’ even more.”

John is an epidemiologist who started his career in Public Health in 1984. “I’d have to say that my earliest considerations about disability in our families or in society arose during my childhood, when my maternal grandmother, an amputee as a result of diabetes, annually visited my family in Florida, and my dad would re-build a truly homemade wooden wheelchair ramp to accommodate her entry and exit from our home. It was a perfect system --- until she needed to accompany us to the supermarket, our church, or elsewhere. I recall many of our family outings being short-circuited because of our collective inability to overcome what today we would call ‘environmental barriers.’ Even though I know she meant it humorously, each time such an impediment arose, my grandmother would say something to the effect of ‘I guess they just don’t want me in there,’ which to a child in a formative period really suggested that, indeed, there were some people or places that really didn’t want disabled people to come and participate.”

“I would attribute my academic and professional interests in disability policy to three of my earliest professors at the University of California, Berkeley, School of Public Health, where I earned the Master of Public Health degree in 1984. All three are deceased now, but I want to honor them here by name: William H. Bruvold, Ph.D., M.P.H.; Frank Falkner, M.D., F.R.C.P.; and Octavio I. Romano, Ph.D.. Each of them either had a visible disability or a child with a disability. In one lesson or another, in the classroom, their faculty offices, or out in the field conducting Behavioral Science research, in retrospect I can remember many distinct lessons about disability. Once, within the rubric of a course on Evaluation Research Methods, Professor Bruvold engineered a field experiment among myself and a half-dozen other M.P.H. students at an inner city San Francisco high school, in which we were to use a Likert-scaled instrument entitled the ‘Attitudes Toward Disabled Persons Scale’ to measure whether high school students’

perceptions about disability might change after viewing a short movie about accommodation and physical barriers. Not unexpectedly, the experiment yielded no effect. Nevertheless it was a valuable experiment from the viewpoint of learning about pre- and post-test evaluation methods. But in the subsequent classroom session, Professor Bruvold said these quite memorable (though paraphrased) words: ‘Sometimes it’s the attitudes about a person with a disability, rather than the disability itself, that makes the situation worse for that person.’ That remark certainly stayed with me. Similarly, Professor Romano wrote and lectured about the somewhat philosophical theme that chronic illness or disability renders our humanity with a kind of cleansing or cathartic understanding, that even though harsh, illness should be welcomed and appreciated, and rather than avoided *per se*, illness could be seen as a necessary, desirable component of the human condition. This theme isn’t too different from that more publicly asserted by Susan Sontag in her famous book Illness As Metaphor. These ideas from faculty members surely influenced my thinking, especially in Berkeley at that time, the birthplace of the Independent Living Movement, where I met many disabled friends and from which I began to understand disability and disability policy in uniquely political economic terms.”

“My interests in disease classification arose, strangely enough, from first-hand experience with *procedure coding*, of all things! My first employment in Public Health was as a survey researcher with the California Medical Association (CMA) in San Francisco, and I landed in a position that involved the long-term revision of a seminal CMA publication entitled the California Standard Nomenclature, the CSN, which historically had been the forerunner of today’s Current Procedural Terminology (CPT) series published originally by the American Medical Association. Working with CMA physicians for nearly two years, we updated and revised the CSN, which really gave me appreciation for the breadth, exhaustiveness, and authoritativeness that are essential in procedural nomenclatures, and by analogy, in disease or disability taxonomies. I regret to report, though, that all our work on the CSN was for naught: one by one, California health insurers adopted the machine-readable CPT to align themselves with insurers nationwide, such that the CSN now resides firmly on the dustbin of history!”

After a stint as a hospital Quality Assurance Director, I returned for doctoral studies in Epidemiology and Health Policy, again at the U.C. Berkeley School of Public Health. I’m proud that my field residency experiences exposed me to working both for CDC and in health policy development settings: I served as an Association of Schools of Public Health summer intern at CDC’s NIOSH in Cincinnati, and later for a full year as a California Assembly Fellow, working as a legislative analyst for both an Assembly and the Assembly Health Committee in the lower house of the California Legislature. I earned the Doctor of Public Health degree at Berkeley, and in 1996 began a two-year post-doctoral fellowship in CDC’s Prevention Effectiveness program, through which I was assigned to the then-named Disability and Health Program, now organizationally located in CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDD).”

“It wasn’t long before I met and enjoyed Drs. Don Lollar, Joe Hollowell, Mike Adams, and the late Pierre Decoufflé, all of whom contributed as CDC pioneers to the revision of the ICIDH-2 during the 1990s. I owe each of these outstanding professionals a debt of gratitude for taking the time to shepherd me into these fields, to which I had obviously had some fundamental exposure but not yet in the context of the importance of what would become the ICF. (We might all agree that it’s hard to learn about disability classification or the ICF on one’s own or simply by reading about it: having a set of personal invitations to consider these weighty topics made all the difference for me.) As a Health Scientist at NCBDDD, I was honored to be able to serve some of the most prolific contributors to the disability field, through CDC’s extramural funding program to state health departments and universities related to health promotion among populations with disabilities. Beyond Atlanta, I count myself fortunate to have been exposed to the contributions to the ICF rendered by our former NCHS colleagues Dr. Gerry Hendershot and Dr. Paul Placek (whose position I filled), and by our many academic and WHO partners, including Drs. Rune Simeonsson, Gale Whiteneck, David Gray, and Bedirhan Üstun, all of whom have had important influences on my understanding of the ICF and, perhaps more importantly, its rightful place alongside the ICD within our compendium of tools that accurately classify health-related conditions.”

Between 2002 and 2005, I served as a Health Science Administrator within the National Institutes of Health (NIH), National Institute on Alcohol Abuse and Alcoholism (NIAAA) in Bethesda, Maryland, first in its Health Services Research Branch and then in its Division of Epidemiology and Prevention Research. In that capacity, I worked as a Project Officer on a large portfolio of NIAAA extramural research grants and clinical trials, although none had anything to do with the ICF or disability classification. For enabling me to retain some currency in the ICF topics during that period, I have to applaud all our colleagues who have contributed to the development of this ICF Clearinghouse and its Newsletter, including Drs. Placek and Gray, Patricia Welch Saleeby at Washington University, Jan Valluzzi, Linda Washington, and Marjorie Greenberg at CDC, and others, all of whom have helped to generate this community of ICF researchers, under a ‘Big Tent’ large enough even to include wayward epidemiologists at NIH! I can attest that this Newsletter is worth waiting for, and provides an enormously valuable service during these early years of ICF implementation.”