

NACC Clearinghouse on ICF-August 2005 Messages

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SHARE YOUR ICF ACTIVITIES WITH OTHERS! SEND YOUR ANNOUNCEMENTS TO DR. PAUL PLACEK AT PJPLACEK@DMV.COM OR CALL 410-643-2817. THANK YOU.

1. NIDRR'S PROPOSED FIVE-YEAR PLAN EMBRACES ICF

John H. Hager, Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education, recently sent out an announcement on the National Institute on Disability and Rehabilitation Research's (NIDRR) Long-Range Plan for Disability and Rehabilitation Research. NIDRR's Director is Steven James Tingus. Hager asked that people with disabilities, their families and advocates, and researchers and service providers review and comment on a draft long-range plan prepared by the federal government's key agency for disability and rehabilitation research. In its plan, the National Institute on Disability and Rehabilitation Research (NIDRR), an organization within OSERS, emphasizes five "domains" as areas for expanded research efforts in the next five years in support of people with disabilities: employment; participation and community living; health and function; technology for access and function; and disability demographics. The new plan will help focus NIDRR research on new approaches for defining, measuring, counting and categorizing disability; new research issues; and new methods for conducting and managing research. The proposed plan was published in the Federal Register in a supplementary section on July 27, 2005, and is accessible at <http://www.ed.gov/legislation/FedRegister/other/2005-3/072705d.html> FR Doc 05-14741, [Federal Register: July 27, 2005 (Volume 70, Number 143)], [Page 43521-43555]. The comment period closed August 26, 2005. The following excerpts are verbatim:

"Definitions of Disability - ...Prevailing definitions of disability used by Federal agencies do not reflect the new paradigm of disability concepts because the Federal definitions typically stress limitations and do not mention the potential role of accommodations or environmental conditions. The field of disability and rehabilitation research also continues to lack a widely accepted conceptual framework to identify and measure disability. The newer conceptual frameworks all focus on some continuum that progresses from etiology through disease, impairments and functional limitations, which, when combined with external or environmental conditions, may cause deficits in the performance of daily activities or desired social roles. The latest proposal for classifying disability is the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization (WHO), and last revised in 2001. A diagram of the ICF classification schema can be found at <http://www.cessi.net/longrangeplan/icf.htm> ...The ICF represents a revision of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), which was first published by the WHO for trial purposes in 1980. Developed after systematic field trials and international consultation, it was endorsed by the Fifty-fourth World Health Assembly for international use on 22 May 2001 (resolution WHA54.21). <http://www3.who.int/icf/intros/ICF-Eng-Intro.pdf>. ...The ICF allows one to view disability as a dynamic interaction between the person and the environment. ICF's diagram of its classification schema depicts the multiple interactions of the person with the environment, and the various aspects of the person. The ICF provides a method for organizing measures of function, activity, participation and environmental context. NIDRR and many of its partner agencies are considering the appropriateness of applying the ICF to U.S. populations, and are engaged in assessments of the necessary measurement tools and data systems (page 43527)."

On page 43546, The Context for Disability Demographics, the proposed plan states: "A lack of standardized definitions, terminology, coding, classification, and measurement of disability and functioning often limits generalization of research findings. Extending use of research findings or population trends to inform policy or clinical interventions is limited due to the difficulty of extrapolating knowledge about disabilities that is gathered from a disparate range of data sources, classification and coding systems, and measures of disability. For example, it is important to estimate future potential demands on rehabilitation systems, but existing population data sources do not adequately provide for planning, development and evaluation of rehabilitation services and population trends. The ICF, which is described elsewhere in this plan, is a coding system that promises to allow the assessment of disability as a dynamic interaction between the person and the environment."

On page 43547, the NIDRR Research Agenda states: "To be useful for policy, research, programs, and services, data must be grounded in an appropriate organizational framework, such as the ICF. The ICF is a scheme organized around function, activity, participation, and environmental context. To evaluate the potential uses of the ICF, a

variety of measurement tools and data systems must be examined in addition to further evaluation of the implications of the classification system for U.S. populations. When the Long Range Plan is approved as final, this Clearinghouse will announce it.

2. CODE ICF WORKS

In last month's message, we said that it was still on the Western University website. If you tried to access it, and failed to get in, it may have been temporarily down due to work on the servers at Western University, so try again if you had problems last month. The CODE ICF address is still <http://wsdb.westernu.edu/icftraining/>. We note that one of the developers of CODE ICF, LeeAnne Carrothers, has taken a new job at Chapman University in Orange, California. We wish her well, and we know that Western University will miss her.

3. SEPT. 8 ICF-CY MEETING IN ATLANTA

On September 8, from 10am to noon the NCBDDD/Disability and Health Team is hosting a seminar entitled "Diagnosis and Function: Complementary Public Health W.H.O. Classifications" in Atlanta at Executive Park 12, Conference Room 1002. This seminar will review the findings of the World Health Organizations' Child/Youth Taskforce on the International Classification of Functioning for Children and Youth. Presenters include Matilde Leonardi, Judith Hollenweger, Eva Bjorck-Akeeson, Rune Simeonsson, and Huib ten Napel. For questions regarding meeting content, please contact Don Lollar (DLollar@cdc.gov, 404-498-3041), For questions on logistics, contact Theresa Kanter (tkanter@cdc.gov, 404-498-3042).

4. WASHINGTON GROUP ON DISABILITY STATISTICS MEETS SEPT. 21-23 IN RIO

The 5th Annual Meeting of the Washington Group on Disability Statistics will be held September 21-23, 2005 in Rio de Janeiro, Brazil. The annual meeting will be preceded by the second regional workshop of the Washington Group (September 19-20, 2005), which is the venue for informing local countries about the Washington Group general measure on disability and the planned pre-testing. There will be 10 sessions over the three days. Session 5 focuses on conceptual issues and will include a discussion of what it means to use ICF as the framework for Washington Group work and a discussion of language issues related to disability measurement. In Session 8, the United Nations Statistics Division will present information on the collection of national disability statistics from population and housing censuses and related national surveys and administrative registers. In Session 10, the Steering Committee chair will lead a discussion on planning next steps, and objectives for the 6th meeting in Uganda will be established. For more information, contact: Beth Rasch, PT, MS, National Center for Health Statistics, Phone: 301-458-4248, Email: ERasch@cdc.gov.

5. ICF ACTIVITIES IN BRAZIL

Cassia Maria Buchalla reports that in July, a 16 hour ICF course with powerpoint presentation was held in Sao Paulo. It included a beginners guide and a collection of 20 exercises. The next course will be in October in Curitiba, Paraná (a state in the south of Brazil). She also reports that they are working on a project to apply the ICF in the Family Doctor Program, which includes consumers with disabilities from the community to be longitudinally followed. There are groups in Sao Paulo testing the ICF core sets (stroke and rheumatoid arthritis). In Northeast Brazil, the University of Rio Grande is applying the ICF in a stroke project. She also reports that University of Minas Gerais researchers have two main projects on ICF-- one of them is related to analysing data on physical and occupational therapy, and the other is on occupational health. Furthermore, one of Dr. Buchalla's students is involved in building an instrument to apply the ICF in rehabilitation after knee surgery, and another is building a core set on HIV/AIDS using interviews and focus groups. For more information, contact: Cassia Maria Buchalla, WHO-FIC Center for Portuguese, Sao Paulo - Brazil, Email cmbuchal@usp.br.

6. FELICIANO ICF PRESENTATION

Harry Feliciano made an ICF presentation at the August 2-5, 2005 Annual Uniform Data Systems for Medical Rehabilitation (UDS MR) Conference on August 4th . His title was "Going Beyond Diagnosis: Documenting Reasonable and Necessary Inpatient Rehabilitation Facility Services". UDS MR's focus is on the inpatient rehabilitation environment, and they asked Harry to discuss Palmetto GBA's use of the ICF for that patient population. This conference is held annually in Buffalo, and is designed to provide subscribers of all of the UDS MR adult product lines an opportunity to learn about general topics that impact the rehabilitation industry. Topics typically include government regulations, reimbursement systems, clinical information (coding, scoring, and documentation), technical information, outcomes, quality, and research. The 2005 conference agenda is at http://www.udsmr.org/buf_agenda.php. Harry is at: Harry Feliciano, MD, MPH, Director, Part A Medical Affairs, Palmetto GBA, (803) 763-5007, Email harry.feliciano@palmettogba.com.

7. EUROPEAN UNION PROJECT INVOLVES ICF

On August 5th, Matilde Leonardi announced EU Project MHADIE. EU project 6FP-MHADIE is the short title for "Measuring Health and Disability in Europe" The website is www.mhadie.it. The EU project objectives are:

- 1) to use the ICF model as the structure for analyzing existing general population health surveys and education statistics data
- 2) to show that the ICF model is adequate for describing and measuring patterns of disability in clinical samples of selected conditions in different countries cross-sectionally and over time as well as feasible and useful in clinical and educational sectors
- 3) to produce policy recommendations and guidelines concerning how the existing sources of data can be harmonised with the ICF model.

Further information about participants, objectives, expected results etc. are available on

the web or from Dr. Matilde Leonardi, Neurologist, Paediatrician, Director, HEADNET Research group: Public Health Disability ICF, Scientific Coordinator and WHO liaison "ICF in Italy Project", EU-MHADIE Project Coordinator, Direzione Scientifica, Istituto Nazionale Neurologico Carlo Besta, Via Celoria 11, 20133 Milan, Italy, Tel: +39 022394 2511/2521, Fax 02 2363973, e-mail:leonardi@istituto-besta.it.

8. AUSTRALIA TO HOST ICF MEETING FEB. 6-7, 2006

An ICF meeting will be held in Sydney, Australia, February 6-7, 2006 with a range of interesting speakers including Dr. Bedirhan Ustun. The program should be on the AIHW website within a few weeks: <http://www.aihw.gov.au/>. For a thorough discussion of Australia's ICF-based activities, check out <http://www.aihw.gov.au/disability/index.cfm>. For more information about the meeting, contact Ros Madden, Australian Institute of Health and Welfare in Canberra, Tel 02 6244 1189, Email ros.madden@aihw.gov.au.

9. SPOTLIGHT ON STEVEN JAMES TINGUS, MS, CPHIL

Each month this Clearinghouse message spotlights a North American who has "made a difference" with ICF. In fact, the WHO slogan for ICF is: "To make a difference, measure the difference with ICF". Steve Tingus is highly deserving of that recognition because the agency which he directs has proposed to explicitly select the ICF for its official definition and measurement of disability. The acceptance of the ICF definition in his agency's Long Range Plan is just the most recent of his ICF achievements. As Chair of the Interagency Committee for Disability Research (ICDR), he has encouraged open discussion of ICF issues. The ICDR is the parent committee to a number of the Subcommittees, and several of the Subcommittees have held formal ICF conferences. Steve has an illustrious past. Four years ago, he was appointed by President George W. Bush as Director of the National Institute on Disability and Rehabilitation Research (NIDRR). NIDRR is a component of the Office of Special Education and Rehabilitative Services (OSERS) within the U.S. Department of Education (ED). By statute, Tingus Chairs the Interagency Committee on Disability Research (ICDR). In 2002, Tingus was appointed by Secretary Paige to lead ED's New Freedom Initiative (NFI) efforts and Chair the ED New Freedom Initiative Workgroup. The Department-wide workgroup promotes, facilitates, and coordinates policies, programs, and activities across ED, as they relate specifically to the implementation of the President's NFI. Prior to his appointment as Director of NIDRR, Tingus was the Director of Resource Development and Public Policy for the California Foundation for Independent Living Centers, Inc. (CFILC) and its non-profit project, the Assistive Technology "AT" Network. During his management of the AT Network, Tingus was recognized as a strong voice for the disability community, fighting for equal access to employment, health care, education, housing, and transportation. He testified on state legislation affecting disability policy issues ranging from special education, Medicaid eligibility guidelines, home modification and universal design, assistive technology, and long-term care. Prior to joining CFILC in 1998, Tingus was appointed in 1995 by Governor Pete Wilson to serve as his Health Care Policy Analyst for the California Department of Health Services (DHS). As public liaison and legislative expert

for DHS, one of the largest state departments, he represented DHS at interagency meetings and helped the Director design and implement initiatives pertaining to long-term care and disability policy. Tingus earned a Bachelor of Science degree in 1985 from the University of California, Davis, in Biological Sciences, and also earned a Master of Science degree in 1990 and a Candidate in Philosophy degree (Ph.D. ABD) in Physiology in 1994. During 2003, Tingus received the “Best New Freedom Individual” Award from the Jim Mullen Foundation—fellow nominees included Judge Ann Burke, David B. Gray, Christopher Reeve, and Pat Scherer —this award honors the individual whose efforts have the most extraordinary impact on people who have a disability . He also received the National Spinal Cord Injury Association’s Gil Moss Award—this award honors outstanding contributions enhancing the quality of life for people with spinal cord injuries. Five years ago, Tingus contributed to the development of the NFI. The NFI is the blueprint for current Federal policy supporting individuals with disabilities. On February 1, 2001, just two weeks into his administration, President George W. Bush invited Tingus to the East Room of the White House to introduce him in unveiling the NFI before members of Congress and the press. The ICF world should be grateful to Steve Tingus for his many contributions to disability science and policy, and for having his agency formally embrace the ICF in its Long Range Plan. Contact Mr. Tingus as follows: Steven James Tingus, M.S., C.Phil., Director, National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC 20024-6122, Direct Line: (202) 245-7549, NIDRR's Main Line: (202) 245-7640 Fax Line: (202) 245-7630, Cellular Phone: (202) 365-7941, E-Mail: Steven.Tingus@ed.gov.