

NACC Clearinghouse on ICF - December 2004 Messages

1. NACC CONFERENCE ON ICF JUNE 22-24, 2005 AT MAYO CLINIC IN ROCHESTER, MINNESOTA
 2. CODE ICF ON ITS WAY TO WHO
 3. ICF VIDEOS AVAILABLE SOON
 4. JANUARY 18 DEADLINE FOR OPPORTUNITY FOR PUBLIC COMMENT ON ICF, DISABILITY AND REHABILITATION SERVICE ISSUES IN HEALTH INFORMATION TECHNOLOGY AND ELECTRONIC HEALTH RECORDS
 5. DISABILITY STUDIES QUARTERLY ARTICLE ON ICF
 6. MARY LAW USING ICF IN CANCHILD PROJECT
 7. NEW ICF PAGES AT <http://www.who.int/classifications/en/>
 8. PAUL PLACEK RETIRES JANUARY 3, 2005
 9. SEND ICF CLEARINGHOUSE INFORMATION TO MARJORIE GREENBERG
 10. SPOTLIGHT ON NANCY MAYO
-

1. NACC CONFERENCE ON ICF JUNE 22-24, 2005 AT MAYO CLINIC IN ROCHESTER, MINNESOTA

Registration information will soon be available at the www.icfconference.com website for the 11th World Health Organization (WHO) North American Collaborating Center (NACC) Conference on the International Classification of Functioning, Disability and Health (ICF) in Rochester, Minnesota, June 22-24, 2005. The WHO Collaborating Center for the Family of International Classifications for North America ("NACC") is housed at the National Center for Health Statistics, Centers for Disease Control and Prevention and works in close collaboration with the Canadian Institute for Health Information (CIHI) and Statistics Canada. Our conference theme is "Mapping the Clinical World to ICF", and abstracts of papers and posters will soon be invited which focus on this theme. Clinical applications of the ICF will be emphasized in all plenaries and concurrent sessions (e.g., mapping various types of clinical data to the ICF, developing clinical assessment tools based on the ICF). The science of mapping (e.g., sources of error in mapping, computational advances enabling machine processing of clinical data) and uses of "mapped" clinical data for research and policy will also receive emphasis in relation to the ICF. Abstracts on related ICF topics also will be considered. The deadline for submitting abstracts of papers and/or posters is March 31, 2005. Participants will be notified of the status of their abstracts by mid-April. Additionally, on June 21, there will be a Pre-Conference Tutorial to provide training on the structure and uses of the ICF. The tutorial will focus on clinical and administrative applications of the ICF, and methods for mapping to and from the ICF. Questions about abstracts and scientific aspects of the conference may be directed to Marcy Harris harris.marcelline@mayo.edu or Diane Caulfield dcaulfeild@cihi.ca. Registration is \$100 USD for the tutorial and \$200 USD for the conference, or \$250 USD for both. Mayo Foundation is accredited by the Accreditation Council for Continuing Medical

Education to provide continuing medical education for physicians. Mayo Foundation designates this educational activity for a maximum of 21 category 1 credits toward the AMA Physician's Recognition Award. Each physician should claim only those credits that he/she actually spent in the activity. Psychologists also are covered under this accreditation. Mayo Continuing Nursing Education is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation. Participants can earn up to 21 accredited nursing contact hours. Other health care professionals will be provided a certificate of attendance for requesting credits in accordance with state nursing boards, specialty societies, or other professional associations.

Questions about continuing education credits may be directed to Martha Hoag hoag.martha@mayo.edu (507-266-5045). Questions about registration, facilities, and special accommodations for persons with disabilities may be directed to Martha Hoag hoag.martha@mayo.edu (507-266-5045) or Julie Beinborn beinborn.julie@mayo.edu (507-266-0737).

2. CODE ICF ON ITS WAY TO WHO

Under development for several years at Western University through contracts with NCHS, the web-based training called Code ICF has been approved by NCHS and is now under review by WHO. The plan is for it to stay on the Western University website at <http://wsdb.westernu.edu/icftraining/> until installed on the WHO website. Check it out! It now includes a great site map. If you log into the new Code ICF Training site, you'll note that there is a link at the top of the page for a Site Map. The site map includes every html page on the site, and can be expanded or collapsed as needed. Please create your own account to browse Code ICF. Bear in mind that it is a "Draft, Under Review", and will probably undergo continuous and regular updates. For information on Code ICF, contact Nenad Kostanjsek at Kostanjsek@who.int.

3. ICF VIDEOS AVAILABLE SOON

In the Fall of 2001, just after ICF was approved by the World Health Assembly, 23 ICF experts were videotaped and interviewed by Deborah Farmer on four aspects of ICF. Six hours of interviews were edited into four 20 minute videos: Environment and Participation, Clinical Applications, Statistics and Surveys, and Consumer Issues. The experts interviewed were: Mounkaila Abdou, Yerker Andersson, Jerome Bickenbach, Ching Choi, Tora Dahl, Marjorie Greenberg, Willem Hirs, Marijke de Kleijn, Jayne Lux, Richard Madden, Margaret Mbogoni, Jane Millar, Janice Miller, Vladimir Ocharov, Paul Placek, Bjorn Smedby, Edward Sondik, William Raub, Catherine Sykes, Bedirhan Ustun, Satoshi Ueda, and Jose Luis Vazquez-Barquero. In early 2005, we plan to have DVD videos available free, for those who will contact NCHS and provide a couple of sentences on the teaching or training application of your proposed use. All four videos are on one DVD. To get on the waiting list for this free item, please email your complete shipping information including phone number to Marjorie Greenberg at MSG1@cdc.gov.

4. JANUARY 18 DEADLINE FOR OPPORTUNITY FOR PUBLIC COMMENT ON ICF, DISABILITY AND REHABILITATION SERVICE ISSUES IN HEALTH INFORMATION TECHNOLOGY AND ELECTRONIC HEALTH RECORDS

The April, 2004 Executive Order 13335 (available at <http://www.hhs.gov/healthit/executiveorder.html>) called for the majority of Americans to have interoperable electronic health records (EHRs) within a decade. To assist in this process, the U.S. Department of Health and Human Service's Office of the National Coordinator for Health Information Technology (ONCHIT), has released a Request for Information (RFI) that seeks public comment regarding how widespread interoperability of health information technologies (HIT) and health information exchange can be achieved through a National Health Information Network (NHIN). Interoperability is the ability to exchange patient health information among clinicians and other authorized entities in real time and under stringent security, privacy, and other protections. Through the RFI, ONCHIT seeks information from health information technology organizations, healthcare providers, industry associations, and other stakeholders regarding options to deploy, operate, and sustain health information exchange. The RFI is available through ONCHIT's website: <http://www.hhs.gov/healthit/rfi.html>, and can be found as officially published in the *Federal Register* at: http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=2004_register&docid=DOCID:fr15no04-78. Comments from the public at large also are invited. The public comment period expires on January 18, 2005. Individuals with an interest in disability issues may wish to review the RFI and comment regarding: availability of EHRs in alternative formats; inclusion of persons with disabilities in the development, planning, implementation, and evaluation of EHRs; or disability and rehabilitation services issues related to EHRs and HIT. Additional information about HIT is in the attached document.

HITattachment.12.27.04.doc

5. DISABILITY STUDIES QUARTERLY ARTICLE ON ICF

Check out Disability Studies Quarterly, Fall 2004, Volume 24, No. 4, www.dsqsds.org, Copyright 2004 by the Society for Disability Studies. In an article entitled "Redefining Disability to Promote Equality: The Role of Disability Studies in Educating Occupational Therapists", author Beth Ann Wright, J.D., OTR/L bwright@email.unc.edu points out that preeminent scholars in the field of OT endorse the development of the WHO's ICF instrument. Second, allied Health Professions, such as OT, who embrace the use of the ICF instrument help preserve, rather than destroy the fundamental framework of disability studies as well as the medical model. Third, both OT and DS can examine external environmental factors, such as the law, as relevant contextual factors to improve the health status of individuals with disabilities under the WHO's ICF instrument.

6. MARY LAW USING ICF IN CANCHILD PROJECT

Mary Law, Associate Dean and Professor of the School of Rehabilitation Science at McMaster, reports that the conceptual model upon which the CanChild project is

based is the ICF, and that she is measuring the non-school aspects of childhood participation as defined by the ICF. The CanChild's Participation Research Project is supported by an NIH grant, and more information is available at <http://www.fhs.mcmaster.ca/canchild/>. Mary can be contacted at lawm@mcmaster.ca or phone 905-525-9140 x 27837.

7. NEW ICD and ICF PAGES AT <http://www.who.int/classifications/en/>

There is an online version of ICD-10 Second Edition incorporating the updates that came into effect through 1 January 2003. This is accessible from the home page.

Details about Collaborating Centres are shown at:

<http://www.who.int/classifications/network/collaborating/en/>

8. PAUL PLACEK RETIRES JANUARY 3, 2005

Paul has worked on ICF development and implementation for the past 12 years of his 30+ year career at the National Center for Health Statistics. He started at NCHS in August of 1974 with a Ph.D. in Medical Sociology and Biostatistics at Vanderbilt. After 18 years working on vital records followback surveys, he began working in disability classification 12 years ago. His recent responsibilities have included writing these Clearinghouse messages, developing ICF projects, helping plan the annual NACC meetings on ICF, participating in the annual WHO conferences of the Family of International Classifications, and encouraging ICF research. He hopes to continue with ICF consulting, and asks his friends and colleagues to continue contacting him with ICF news and events at:

Paul J. Placek, Ph.D.
103 Big Holly Court
Stevensville, MD 21666-3333
tel 410-643-2817
fax 410-643-0390
PJPLACEK@DMV.COM

His retirement party in Hyattsville is set for January 25th, and an announcement may be obtained by contacting Dr. Gerry Hendershot at 301-927-1120 or Ghendershot@earthlink.net. Paul hopes to have a little more time for his nine-year old son Vincent, wife of 27 years Becky, and his classic and hot rod car collection, as shown in this photo of Paul with his 1941 Ford streetrod.

File: 41ford0001.jpg

Paul wishes to thank his colleagues for very kind remarks and good wishes, and these are reproduced below with their permission. Paul says that it is really great to read such nice things about himself, especially since he did not have to be dead to have them said!

"It's been wonderful working with you on ICF matters for the past 4 1/2 years. I appreciate so much all the guidance you offered me during the initial learning curve. Our Canadian/US international border seemed to almost melt away as we worked together on NACC activities, in particular the annual conference. I'm delighted that you're staying involved with ICF. My very best wishes on this new chapter of your career." Diane Caulfeild, Canadian Institute for Health Information

"Dear Paul, Thank you so much for being such a positive moving spirit behind the field. You know retirement is never absolute--who knows maybe we can work on some joint projects in the future? Please keep in touch. All the best for a happy retirement! With gratitude, respect, and admiration, JJ"
Josefina J. Card, Ph.D., President, Sociometrics Corporation

"You deserve enormous credit for the focus and energy you've put into disability measurement, statistics, and ICF. I hope you will find some mechanism for continuing to help in this work. Peace, Don" Donald J. Lollar, Ed.D., National Center on Birth Defects and Developmental Disabilities

"Paul, I will miss you. Your intelligence, compassion, humor and perseverance will not easily be matched by anyone who may take over. However, begrudgingly, I must say you've been at our common work a long, long time. Enjoy your retirement, which sounds as if it will keep you busy. I hope that your activities bring you here one day or that we will find a common ground for future activity. Thanks, you enriched my professional life. Kate Seelman " Katherine D. Seelman, Ph.D., University of Pittsburgh

"I really wish you all the best as you turn the page and pursue new endeavors--including more time with your son. I'm sure you'll find that to be one of the most rewarding experiences. Enjoy this time to the fullest and you should be well pleased with the contributions you've made from your position there. Best wishes always,
Jayne Lux"

"Dear Paul: For quite some time I have been thinking what to write in celebration of your retirement. There is so much to say! There are so many memories! I have known you for about 15 years. Over the years you have become a role model and great friend for me. I admire the many contributions you have made in the field of disability and I want to compliment you for all the work you have done. First, you have been instrumental in supporting, promoting and moving forward the APHA Disability Forum. Your enthusiasm and creative ideas were invaluable. And above all, your sense of humor has left many marks. Even this year at the annual APHA conference, while sitting in the APHA Disability Forum booth, we were talking about re-instating the wrapping of crackers with papers with the printed Disability Forum sponsored sessions on it. But the number of sessions is growing so fast that the paper may not fit the crackers any more..! Second, your vision and commitment in promoting the ICIDH/ICF has been most influential. In my opinion, the ICF has

received the national attention and the interest of scholars, policy makers and many others thanks to your support and effortless work in promoting the ICF. You have been a team player, a cheerleader and a perfect coach in coordinating the ICIDH revision, and now the ICF activities. I know that this has been, and still is, of significant interest to you, not only professionally but also personally. I remember how, in one of your ICIDH training presentations, about 9 years ago, you showed a slide of the cover page of the ICIDH book. "This is my baby" you said, "and here is my other baby" (a beautiful baby picture of your son). Both have grown, and both still need your help in their further growth and development! Furthermore, Paul, you are an excellent writer. I always enjoy reading your reports and papers. Your writing is succinct, persuasive and convincing. In 1996 you wrote me a reference letter when I applied for a job at Wayne State University. That was one of the best reference letters I ever received! I keep a copy of that letter in a special file. I hope, Paul, that you will continue to make many contributions, share your expertise, share your sense of humor, musical talents and stories about your two grown-up babies, and old cars, for many more years to come! Have a great retirement party. Very best wishes, Els" Els R. Nieuwenhuijsen, PhD, University of Michigan

"Hi Paul, Just got back from holidays and read the Clearinghouse letter.... and saw the news about your retirement! My first reaction is how happy I am for you... good for you! I know you enjoy some down time to spend time with your family and pursue your hobbies (I have my collector car proudly displayed in my family room). But I am sad that we won't be working on the 2006 ICF conference together. Its been a pleasure working with you and I do hope our paths cross again in the future." Kathey Cauley, Canadian Institute for Health Information

"Congratulations Paul. Wishing you full participation in retirement" Gale Whiteneck, Craig Hospital

"Hi Paul, I've just learned of your upcoming retirement from the November 2004 Messages - NACC Clearinghouse on ICF. You seem to have the after-NCHS-life all well-planned. I just want to wish you good life in your retirement and to let you know that it was a pleasure for me to have been part of the DISTAB group. Regards, Margaret" Margaret Mbogoni, United Nations Statistics Division

"Paul, Congratulations on your career and your decision to begin a new phase of life! Sometimes we don't always know how we affect events, organizations or individuals. I have been admiring your work from afar because our work assignments are not as closely aligned as before. I have been personally challenged by your example, and your willingness and ability to explore the unexplored. There are now and will be thousands more people with disabilities whose lives will be happier and more productive because of your efforts. That is an accomplishment few can match! I wish you the best in your new life. Thanks, Dan" Dan Young, National Institutes of Health

"Paul, Congratulations on your impending retirement. I hope you will continue to find fulfilling projects, paid or unpaid, that advance the causes most dear to your heart, or that you will just find the time to stop and smell the roses. Whatever! In any case, thanks for your assistance with my contacts with the ISDS. Aloha! Bob" Robert M. Schacht, Ph.D, University of Hawaii

9. SEND ICF CLEARINGHOUSE INFORMATION TO MARJORIE GREENBERG

In the future, send your ICF information for these Clearinghouse messages to Paul's supervisor:

Marjorie S. Greenberg

Head, WHO Collaborating Center for the Family of International

Classifications for North America

National Center for Health Statistics

Centers for Disease Control and Prevention

3311 Toledo Road, Room 2413

Hyattsville, MD 20782 USA

301-458-4245 (phone)

301-458-4022 (fax)

msg1@cdc.gov

She hopes to keep the Clearinghouse messages coming to you in the future. She also agrees with all of the above messages that Paul has received and will miss him very, very much! She currently is looking for a Jackie-O wig to wear to his retirement party, which will be a "Blast from the Past - Toast and Roast"!

10. SPOTLIGHT ON NANCY MAYO

Each month we put the "spotlight" on a professional who is "making a difference with the ICF". Nancy Mayo is a James McGill Professor in the Department of Medicine and the School of Physical and Occupational Therapy, McGill University (Division of Geriatrics and Division of Clinical Epidemiology). She is also Research Scientist at the McGill University Hospital Center Research Institute where she is the head of the Health Outcomes Axis. Dr. Mayo is a Physical Therapist by training as well as an Epidemiologist and, thus, has a natural relationship with the ICF both as a model for rehabilitation and also as a method for classification of health outcomes relevant for health services and population health research. Her research program has focused on the evaluation of rehabilitation interventions targeted towards reducing impairment post-stroke, and improving activity, participation and quality of life. While her main interest is in stroke, including surveillance and health services optimization, she is also involved in projects involving women with breast cancer and in evaluating interventions to improve surgical outcomes in high risk groups, persons with cancer, the morbidly obese and the elderly. Methodologically Dr. Mayo's expertise lies in the conduct and analysis of clinical trails, longitudinal studies, and measurement studies. Dr. Mayo uses the ICF framework extensively in teaching and research on outcomes. Through her research activities around design and implementation of electronic health records, Dr. Mayo identified the ICF coding system as a feasible method of obtaining information on functional status indicators that could be used to

monitor the health of clinical populations through clinical and administrative databases. However, to be feasible the ICF needs to be linked to clinical tests and measures that are routinely used rather than as a parallel system. She has published a “proof of concept” paper on mapping the SF-12 to the ICF in order to create functional status indicators which can be used to identify service needs for persons with stroke. She also has used the same procedure to illustrate how these functional status indicators can improve prediction of hospitalization, institutionalization and death in a cohort of elderly persons managed in the primary care setting, over and above standard case-mix adjustment variables of co-morbidity and medical visits. Dr. Mayo has been funded to carry out mapping of other outcome measures used in stroke, respiratory conditions, cardio-vascular disease and orthopaedics. The need to develop a standard way of doing this mapping or “cross-walking” between standard outcome measures and the ICF was highlighted recently at the NACC Conference on ICF in Halifax, in June 2004. Arising from this meeting was the development of a standard protocol applying mapping rules already developed by the Munich group of G Stucki, A Cieza et al. Dr. Mayo hopes to implement this protocol internationally to get as many outcome measures as possible mapped to the ICF. Originally from Ottawa, Dr. Mayo is a graduate of Queen's University in Physical Therapy and McGill University with a Master's degree in Rehabilitation Science and a PhD in Epidemiology and Biostatistics. Dr. Mayo has 13 years of clinical experience in cities across Canada and has been involved with many aspects of rehabilitation including a specialization in the treatment of children with cerebral palsy and other types of neurological conditions. She has supervised 30 students in Rehabilitation Science and Epidemiology and has over 75 life-time publications and more than 100 scientific presentations in Canada, North America and Europe. When not at work or at the hockey arena with her two children, aged 17 and 14, and her epidemiologist/hockey coach partner, Dr. Mark Goldberg, Dr Mayo can be found with her family on the golf course where her main goal is directed to reducing her “handicap”. Dr. Mayo is speaking on "Standardizing Clinical Assessments to ICF" at the Mayo Clinic in the June 21, 2005 ICF Tutorial at the 11th Annual NACC Meeting on ICF in Rochester, Minnesota. Check out her latest ICF article at: Mayo NE, Poissant L, Finch L, Jaglal S, Salbach N, Ahmed S, Soicher J. Incorporating the international classification of functioning, disability and health (ICF) into an electronic health record to create indicators of function: Proof-of-concept using the SF-12. JAMIA, Aug 2004 (Pre-Publication). Contact her at nancy.mayo@mcgill.ca or tel 514-842-1231.