

JUNE 2003 NACC CLEARINGHOUSE ON ICF MESSAGES

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1. [JUNE 16-19 NINTH ANNUAL NACC MEETING ON ICF A SUCCESS](#)
2. [SPOTLIGHT ON DR. GIANNINI: "I THINK THE ICF IS A REMARKABLE, ASTOUNDING ACCOMPLISHMENT..."](#) (text of speech, photo)
3. [JUNE 2 BRIEFING ON ICF TO SSA OFFICE OF DISABILITY POLICY STAFF](#)
4. [ICDR STAKEHOLDER'S MEETING](#)
5. [THIRD WCG MEETING POSTPONED TO DECEMBER](#)
6. [HEADS OF ICD/ICF TO MEET IN COLOGNE THIS OCTOBER](#)
7. [THE ICF IN ITALY](#)
8. [LARRY BURT RETIRES](#)
9. [ANDERSSON TO GIVE ICF WORKSHOP TO XIV WORLD CONGRESS OF THE WORLD FEDERATION OF THE DEAF](#)
10. [SPOTLIGHT ON YERKER JOHAN OLOF ANDERSSON](#)

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1. [JUNE 16-19 NINTH ANNUAL NACC MEETING ON ICF A SUCCESS](#)

The June 16-19, 2003 North American Collaborating Center's Ninth Annual Meeting on ICF was hosted by Dr. David Gray and (soon to be Dr.) Patricia Welch Saleeby of Washington University. There were over 53 presentations and about 80 participants. The 50 or so papers covered: ICF Use in Surveys; ICF in Clinical Practice; ICF Use in Administrative Records; Using ICF as a Code Set to Record Functional Status for Payment and Quality Purposes; Coding with ICF; Preparing ICF Codebooks and Procedures Manuals; ICF Conceptual and Issue Areas; Strategies for ICF Implementation; ICF Assessment Tools Crosswalked with Other Assessment Tools; Basic ICF Research; ICF Training Tools; ICF and Teaching; ICF and Environmental

Assessments; and International Updates. We were especially pleased that Dr. Margaret Giannini, Director, DHHS' Office of Disability gave opening remarks entitled: "How the Federal Government is Working to Tear Down Barriers for Persons with Disabilities, and How Can we Use the ICF to Ensure Maximum Impact?" Dr. Giannini's Office was created in October 2002 and is dedicated to oversee the coordinated development and implementation of policies, programs and special initiatives within HHS that impact persons with disabilities. Her challenge to the meeting participants, and we quote verbatim: "I think the ICF is a remarkable, astounding accomplishment, yet we still need more research to find out if its going to work or not. We need to "actualize" its potential. Since it is recognized by the World Health Organization, health providers and government agencies might be able to attend to factors other than the person's structural and function impairments. But you have to show us how." Closing remarks were made by Dr. Don Lollar of NCBDDD/CDC. He made the following ICF recommendations: 1) The need for a research agenda; 2) The need to operationalize clinical coding protocols; 3) The desirability for a U.S. user guide, somewhat like the Australian user guide; 4) The need for Federal agency information on if and how ICF is informing what they are doing in disability; and 5) The need for measurement research keyed to ICF. A full meeting report will be available in a few weeks.

2. SPOTLIGHT ON DR. GIANNINI: "I THINK THE ICF IS A REMARKABLE, ASTOUNDING ACCOMPLISHMENT..."

On June 16, at the opening of the NACC Meeting on ICF in St. Louis, Dr. Margaret Giannini, Director, DHHS' Office of Disability gave a powerful speech entitled: "How the Federal Government is Working to Tear Down Barriers for Persons with Disabilities, and How Can We Use the ICF to Ensure Maximum Impact?" The entire text of her speech is reproduced here. Her photo shows her with the new NACC Clearinghouse on ICF brochure with the new NACC Clearinghouse on ICF table top exhibit in the background.

3. JUNE 2 BRIEFING ON ICF TO SSA OFFICE OF DISABILITY POLICY STAFF

Paul Placek, Gerry Hendershot (Disability Consultant, retired from NCHS two years ago) and Marjorie Greenberg gave a briefing on ICF to the SSA Office of Disability Policy Staff in Baltimore on June 2nd. Marjorie talked about how ICF fits in to data standards, while Paul and Gerry talked about the NCVHS report on ICF and clinical coding projects. The invitation came indirectly as a result of Dr. Salan of SSA attending an ICF talk which they gave several months ago to the Interagency Committee on Disability Research's Medical Rehabilitation Subcommittee meeting in Rockville. The invitation came directly from Susan Roecker, SSA's Deputy Commissioner for Disability Policy. About eight SSA staffers attended.

4. ICDR STAKEHOLDER'S MEETING

On June 26 there was a "Stakeholder's Meeting" of the Interagency Committee on Disability Research. About 50 disability consumers and representatives of disability organizations attended. The purpose was to prioritize research needs for the National Institute on Disability and Rehabilitation Research in the area of assistive technology and universally-designed products across disability groups. One of the recommendations by RESNA was as follows: "Develop measures of health outcomes that take function, community participation, and other key quality of life variables into account. Evaluate the implications on treatment patterns, costs, benefits, outcomes of supplementing or replacing definitions of "disability" with the ICF (International Classification of Function) codes." RESNA stands for the Rehabilitation Engineering Society of North America. Contact Nell Bailey: nbailey@resna.org

5. THIRD WCG MEETING POSTPONED TO DECEMBER

The third Washington City Group meeting on the measurement of disability statistics has been postponed, tentatively to Dec. 9-10, 2003 in Brussels. It was to have met October 14-15 in Brussels. For further information, contact Marleen Desmedt: Marleen.Desmedt@cec.eu.int

6. HEADS OF ICD/ICF TO MEET IN COLOGNE THIS OCTOBER

The annual WHO Meeting of Heads of the Family of International Classifications (ICD/ICF) will be October 20-25 in Cologne, Germany. Last year's meeting was in Brisbane, Australia and about 100 papers were accepted, including 35 on the ICF. This meeting is by invitation only. For more information, contact: Dr. med. Michael Schopen Tel. +49 221 4724 325, Deutsches Institut fuer Fax. +49 221 4724 444, Medizinische Dokumentation, und Information DIMDI <http://www.dimdi.de>, Waisenhausgasse 36-38a, D-50676 Koeln s#chopen@dimdi.de.

7. THE ICF IN ITALY

From Matilde Leonardi we have learned that the Disability Italian Network, DIN, the scientific group that is implementing ICF use and WHO-FIC in Italy, has developed the Italian implementation strategy in collaboration with Ministry of Welfare, and some of the Regional authorities. She states: "Since the Italian ICF translation (April 2002) we have been overwhelmed by requests from all the Country and WHO has been constantly updated about the incredible success of this classification in the Italian setting. We have a national training plan and we are preparing a national inventory of ICF use, as well as needs for its use, in different settings. Some sectors in Italy will start a sistematic ICF, ICF checklist and WHO-DAS 2 use: mainly rehabilitation and work and we have a working group at the Ministry of Health that is discussing about our invalid pension system and legislation and how this will have to change introducing ICF. A group of architects in Milan has developed a project and build some apartments basing all the technological applications on ICF, so we have an "ICF based" building. We have been

collecting all the publications done in Italian journals and all the articles that are related to it. They are in Italian. The Agenzia Regionale Friuli Venezia Giulia, which organized the World Conference on Health and Disability in Trieste last year, is developing a national ICF web site that will have all these information as well as all the Italian legislation related to disability and links to all WHO, WHO-CC, European Union related sites and other international ICF and WHO-FIC's worksites. You might also be interested to know that in these weeks it is under discussion at the Italian Parliament a new law on long term care for people with special needs based on ICF and that this law will use WHO-FIC as conceptual framework. Hope this information can be added to your discussion." For more information: Dr. Matilde Leonardi, neurologist, paediatrician, Coordinator, International Scientific Research and Disability Project, DIN coordinator and WHO liaison, Scientific Direction, Italian National Neurological Institute C. Besta, Via Celoria 11, 20133 Milan, Italy, Tel: +39 02 2394 511/ 498, Fax: +39 02 2363973, leonardi@istituto-besta.it

8. LARRY BURT RETIRES

Robert L. "Larry" Burt, who served as Acting Deputy Director, Division of Human Development and Disability at the National Center on Birth Defects and Developmental Disabilities (NCBDDD) retired from CDC effective June 30, 2003 after more than 38 years of dedicated service to the Federal Government. Larry began his career with the (at the time Venereal Disease Control) - now STD Program in 1965 in Baltimore, MD. His career advanced to two field assignments in the North Carolina STD program, and then to a senior program position with the Chicago Department of Public Health. Larry then served as the CDC senior state STD representative in both Kansas and Mississippi before being assigned to the National Center for Environmental Health (NCEH) in 1985. In that position, Larry was a key member of the Emergency Response Team and was instrumental in such activities as the tracking of the Soviet space station "Cosmos" and in training and response situations related to actual and potential health threats. Larry became the program manager for the new Disabilities Prevention Program (now Disability and Health Team) shortly after its establishment at NCEH in 1988. He guided the program through a vast and complex agenda of extramural programs, federal collaborations, and partnership building among CDC's CIOs. When the program was shifted to NCDDDD in 2001, Larry became the Acting Deputy Division Director for one of its two new Divisions. Larry has been recognized for his dedication and career efforts through many awards for Workforce Development, Contributions to Disability and Health, and Special Olympics. In each of these roles, Larry has overseen all aspects of program performance and received the highest levels of respect and renown among key colleagues, constituents, and from within the disability community. Please join us in congratulating Larry in his retirement. We wish him, wife Lynn, and sons Brad and Bob all the happiness as they begin this new chapter in their lives. The next move will include a transition to Kansas to build their retirement home and settle in for the long term. We will all miss his enthusiasm, candor, sincerity, and dedication.

9. ANDERSSON TO GIVE ICF WORKSHOP TO XIV WORLD CONGRESS OF THE WORLD FEDERATION OF THE DEAF

Dr. Yerker Andersson will give a two hour workshop on the ICF to members of the General Assembly of the World Federation of the Deaf at their 14th annual meeting to be held in Montreal July 18-26, 2003. About 120 countries are members of the WFD and about 50-75 countries send representatives. This invitation was extended by Carol-lee Aquiline, General Secretary, WFD, Finland. Dr. Andersson plans to use the new ICF brochure, exhibit, and video (he is in the movie!) in his presentation. More information on the meeting and organization is at www.wfdnews.org.

10. SPOTLIGHT ON YERKER JOHAN OLOF ANDERSSON

Yerker has lived in the USA since 1955. However, he was born in 1929 (not a typo) in Sweden, where he attended Manillaskolan Elementary School for the Deaf in Stockholm from 1937 to 1945. He agreed to be in the ICF Spotlight because he wants to encourage young individuals with disabilities to make a career in health sciences. We are all envious of Yerker because he is holding up so well for his tender age of 74. Longevity runs in his family...his maternal grandmother lived to 99, his father lived to 94, and his father's sister lived to 96. This is excellent news for the ICF, since Yerker still has another 25 years left to get the ICF message out! Yerker reports that neither he nor his younger brother has children. In Sweden, he estimates that one million people have the last name of Andersson. Yerker's brother is also deaf and still lives in Sweden. Yerker reports that his parents were surprised that he and his brother were deaf at birth and could not recall that there was any deaf relative in their family history. His father was a superintendent of four public schools his mother was also a teacher. He is the fourth generation teacher. His brother speaks in Swedish Sign Language and his wife speaks in American Sign Language, so Yerker has to interpret for both when they get together. Yerker's wife Ann Marie is a New Jersey native who graduated with BA in Art from Gallaudet College (now University) in 1958--this is where they met. Yerker's hobbies are stamp collecting (Swedish stamps and deafness-related stamps); woodworking; reading, and cooking. His professional background is as interesting as his personal history.

Yerker earned an M.A. degree in Rehabilitation Counseling from Columbia University in 1962 and a Ph.D. in Sociology from the University of Maryland in 1981. He had a distinguished career with Gallaudet University from 1964 to 1996, when he retired as Chairperson of the Deaf Studies Department. Since retiring seven years ago, he has: chaired the Nippon World Deaf Leadership Committee; served on the Institutional Review Board of Gallaudet University; been selected by President Clinton to serve on the National Council on Disability; served on the International Advisory Editorial Board for the Encyclopedia of Disability by Sage Publications; and participated actively in the DISTAB group of the National Center for Health Statistics. Dr. Andersson can read six languages (English, Swedish, Danish, Norwegian, French, and German) and his is fluent in American Sign Language, Swedish Sign Language, and Gestuno (International Sign

Language). Dr. Andersson also knows the "ICF language" quite well, which makes an even ten languages in which he is fluent.