### DECEMBER 2003 NACC CLEARINGHOUSE ON ICF MESSAGES

This newsletter is also available for viewing and downloading at http://www.cdc.gov/nchs/about/otheract/icd9/icfactivities.htm

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1. JUNE 1-4, 2004 NACC MEETING ON ICF IN HALIFAX, NOVA SCOTIA...JANUARY CALL FOR PAPERS WILL HAVE MARCH 31 ABSTRACT DEADLINE

In January we will send all subscribers to this listsery information about the June 1-4, 2004 North American Collaborating Center (NACC) Meeting on ICF in Halifax. A "postcard" announcement is attached and we encourage you to forward this to your colleagues. There is no registration fee to attend the June 1-4 meeting--the Monday evening reception, continental breakfasts and breaks, and conference materials will be provided at no charge. There will be a June 1 evening registration and welcoming event, two and one-half days of meetings to advance the ICF research agenda, and ending Friday June 4 at noon. The theme will be "Advancing a Research Agenda for ICF". Look for an optional June 1 all-day tutorial on ICF conducted by six ICF experts at a cost of \$100 Canadian. An optional gala evening is planned for Tuesday, June 2 at Pier 21 Museum and Exposition at a cost of \$70 Canadian. The venue is the Westin Nova Scotia, 1181 Hollis Street, Halifax, Nova Scotia at 1-877-9WESTIN and 902-496-8585, and the rate is \$159 Canadian for single or double occupancy if you reference CIHI. You must book your own room. Check out Halifax information at http://www.halifaxinfo.com -- the city offers a world-class cosmopolitan environment, cobblestone streets, and nearby small costal villages and country charm. If you wish to discuss your abstract before submission, contact Paul J. Placek, PhD, of the National

Center for Health Statistics (tel 301-458-4437 and pjp2@cdc.gov) or Diane Caulfeild, Consultant, Canadian Institute for Health Information (613-241-7860 and dcaulfeild@cihi.ca).

### 2. DAVID PFEIFFER DECEASED

It is with regret that we announce the passing of David Pfeiffer in December 2003. He was a disability scholar and an advocate. During his last few months, David very enthusiastically began work as Editor of a new journal, the <u>Review of Disability Studies</u> (RDS). The first issue of RDS will be dedicated to David and will include the last article that he wrote, reflecting on the history of disability studies, especially for the launching of the journal. The issue is due out in mid-January 2004, and the first issue will be available free on the web at <a href="www.rds.hawaii.edu">www.rds.hawaii.edu</a>. The November 2003 NACC Clearinghouse on ICF message had information about this journal under the headline "NEW DISABILITY JOURNAL WELCOMES ICF SUBMISSIONS".

# 3. AMERICAN PSYCHOLOGICAL ASSOCIATION (APA) HOLDS CONSENSUS CONFERENCE ON ICF

On December 11, the APA held a Workshop and Consensus Conference for Health Professions Leaders on the World Health Organization's International Classification of Functioning, Disability and Health. The meeting was held at the American Psychological Association offices located at 750 First Street, NE, Washington, DC. APA has been spearheading an effort—in collaboration with WHO—to develop a manual to facilitate use of the ICF by health care professionals in clinical settings. To date, psychology, speech-language pathology, occupational therapy, social work, and physical therapy have been the clinical disciplines most involved in the development of the content of the manual. The meeting was hosted by Geoffrey M. Reed, Ph.D. and Lynn F. Bufka. Ph.D., gmreed@apa.org or (202) 336-5968 and lbufka@apa.org or (202) 336-5869. Presenters and discussants also included: Diane Brandt, MS, PT, Saint Louis University, Travis Threats, PhD, Saint Louis University, Trish Welch Saleeby, MSSA, Washington University, Susy Stark, PhD, OTR/L, Washington University, Marjorie Greenberg, MA, Head, North American Collaborating Center for the World Health Organization Family of International Classifications, and Paul Placek, National Center for Health Statistics, CDC.

### 4. TWO AMERICAN PSYCHOLOGIST ARTICLES COVER ICF MODEL

The April 2003 issue (Vol. 58, no. 4) of the <u>American Psychologist</u> featured two articles which discussed the ICF conceptual model. "Discourse on Disability and Rehabilitation Issues: Opportunities for Psychology" by Constance Pledger (pp. 279-284) and "An Integrative Conceptual Framework of Disability: New Directions for Research" by Denise G. Tate and Constance Pledger (pp. 289-295). Pledger is from the National

Institute on Disability and Rehabilitation Research <u>connie.pledger@ed.gov</u> and Tate is with the University of Michigan at Ann Arbor.

### 5. OFFICE ON DISABILITY STAFF DISCUSSES ICF

On December 2, 2003, the Office on Disability, DHHS, held a staff meeting at which Paul Placek of NCHS and David Gray of Washington University gave a one-hour seminar entitled "OD Briefing on Disability Definitions and Statistics". This presentation was at the invitation of Eileen Elias, Deputy Director, OD/DHHS (tel 202-205-1104, tty 202-205-8280, eileen.elias@hhs.gov). They covered the following points:

- 1. Federal definitions of disability
- 2. Different definitions yield different statistics
- 3. How ICF makes disability statistics comparable
- 4. How does ICF relate to other definitions?
- 5. What did the World Health Assembly approve?
- 6. What did the U. S. National Committee on Vital and Health Statistics Recommend to the Secretary of DHHS?
- 7. Who is studying ICF?
- 8. What research is needed now? Should OD take a position on ICF definitions, or other definitions?

Handouts to address each point were given out. Margaret Giannini, MD, Director, OD/DHHS, decided to set up an ICF study group made up of Federal representatives, and directed Paul to develop a mission statement and proposed list of members for her review. For more information, contact David B. Gray, Ph.D., Associate Professor of Neurology and Associate Professor of Occupational Therapy, Program in Occupational Therapy, Washington University School of Medicine, Campus Box 8505, 4444 Forest Park, St. Louis, MO 63108, tel 314 286-1658, FAX 314 286-1601, grayda@wustl.edu or Paul Placek, PhD, Senior Statistician, CPHDSS, Office of the Center Director, National Center for Health Statistics, CDC, 3311 Toledo Road - Metro IV - Suite 2414, Hyattsville, MD 20782 tel 301-458-4437 fax 301-458-4022, pjp2@cdc.gov.

# 6. 20 COUNTRIES JOIN WORKING GROUP ON ICF AND POLICY/LEGISLATION

As of December 2003, 29 persons from 20 countries have joined a group just begun in October 2003 on "ICF and Policy/Legislation". The group is sponsored by the Rehabilitation International (RI) Social Commission. An objective is to collect and disseminate information on this topic from different countries in the next few months. The plan is to present a report in June 2004 in Oslo to the RI Congress and then post the information on the RI home page. All countries are welcome. For more information contact Hisao Sato <a href="mailto:hisao.sato@jcsw.ac.jp">hisao.sato@jcsw.ac.jp</a>. As of December 2003, the members are as follows:

Cameroon	Ondoua Abah Gabriel	facaph2002@yahoo.fr
Denmark	Per Tretow-Loof	ptl@handicap.dk
Denmark	Kirsten Piltoft	kp@marselisborgcentret.dk
Finland	Ms. Anu Muuri	Anu.Muuri@stakes.fi

France	Catherine Barral	c.barral@ctnerhi.com.fr
Germany	Michael Schuntermann	michael.schuntermann@vdr.de
Ghana	Charles Aappiagyei	charlesappiagyei@yahoo.co.uk
Ghana	Grant Anim	grantanim@yahoo.com
Ghana	Mr. Thomas Brewu-Asiedu	brewuasiedu@yahoo.com
Hong Kong SAR	Joseph Kwok	SSJK@cityu.edu.hk
Hong Kong SAR	Karen Ngai	SCNGAI@cityu.edu.hk
Hungary	Dr. Géza Bálint	balintg@mail.datanet.hu
Japan	Hisao Sato	hisao.sato@jcsw.ac.jp
Japan	Oho Mari	oho-mari@mtg.biglobe.ne.jp
Ireland	Mr. Donal McAnaney	donalmcananey@rehab.ie
Israel	Rena Feigin	feigin@post.tau.ac.il
Korea	Ms. Jung Hee Whang	samyook@hanafos.com
Korea	Won sok Lee	rikorea@hanmail.net
Korea	Ick Seop Lee (Korea)	yis93@yonsei.ac.kr
Netherlands	Mineke Hardeman	m.hardemanrhenen@planet.nl
South Africa	Mr. Mark Webber	NA
South Africa	Dorothy-Anne Howitson	elohim@mweb.co.za
Sweden	Sonja Calais van Stokkom	sonja.calais_van_stokkom@soc.uu.se
Swiss	Judith Hollenweger	judith.hollenweger@phzh.ch
Thailand	Dr. Ubonwan Wathanadilokul	wonwat64@hotmail.com
Thailand	Pattariya Jarutat	pattriya@health.moph.go.th
Uganda	(Uganda National Action on Physical Disability)	unapd98@yahoo.com
USA	Patricia Welch	welchp@gwbssw.wustl.edu
USA	Ruth Hughes	ruthhughes@iapsrs.org

### 7. HURST: "ICF WILL CHANGE THINKING"

"The greatest hopes for the future are that the ICF will significantly change people's thinking to disability as a rights issue; that policy makers will use the environmental factors as a basis for assessing appropriate services...and move away from the negative assumptions that lie within DALYS and similar tools." Check out Rachel Hurst, "The International Disability Movement and the ICF", <u>Disability and Rehabilitation</u>, June 2003, Vol. 25, No. 11-12, 572-576. Hurst is with Disabled Peoples International and lives in London.

## 8. MEDICAL REHAB SUBCOMMITTEE RECOMMENDS INVENTORY OF FEDERAL ICF RESEARCH

On October 9, 2003, the Interagency Subcommittee on Medical Rehabilitation (a Subcommittee of the Interagency Committee on Disability Research) sponsored a workshop entitled: "ICF: Development of Clinical Measurement Tools". The participants developed these five recommendations: (1) To have the ICDR contractor do an inventory of the research carried out by federal agencies in the various domains of the ICF to get an estimate of the order of magnitude; (2) Conceptual models of disability are useful in guiding measurement research and federal agencies should encourage

investigators who are developing measurement tools to be explicit about and reference the conceptual models they are using as well as define their variables; (3) There is relatively little current research in measuring participation and environment, and researchers should be encouraged to submit applications in those areas; (4) There is a need for continuing dialogue about the progress being made in measurement, what tools might be shared, as well as the controversies that still exist. Federal agencies should hold a meeting on measurement and disability at a frequency no greater than once a year; and (5) To make sure the measurements are meaningful for people with disabilities by including the people the research is on in establishing the validity of the instruments being used. This meeting was chaired by Dr. Michael Weinrich, MD, Director, National Center for Medical Rehabilitation and Research, and he is available at <a href="weinricm@mail.nih.gov">weinricm@mail.nih.gov</a> and Phone 301-402-4201. Conference results should be available soon in alternative formats from CESSI: Attn: Barbara Rosen, tel 703-448-6155 x224, TTY 703-448-3079 or Fax 703-442-9015.

#### 9. NCMRR GRANTEES PUBLISH ICIDH-2 WORK

Kevin Smith at the New England Research Institutes has published a paper entitled "Developing a Response Measure of Change for Pediatric Brain Injury in Patient Rehabilitation in <u>Brain Injury</u>, 2002, Vol 16, No.8 pp.659-671 using the ICIDH-2 model from his grant with NCMRR HD36569-01. The second NCMRR-supported paper is "Participation Readiness at Discharge from Inpatient Rehabilitation in Children and Adolescents with Acquired Brain Injuries" by Bedell, et al. in <u>Pediatric Rehabilitation</u>, 2002 vol. 5, no.2, pp. 107-116, also supported by grant HD36569-01. This information is courtesy of Dr. Louis Quatrano, Deputy Director, National Center for Medical Rehabilitation and Research/NICHD/NIH.

#### 10. SPOTLIGHT ON GEOFF REED

Each month we try to feature a North American who is prominent in ICF work. This month the spotlight is on Geoff Reed.

Geoffrey M. Reed, Ph.D. is Assistant Executive Director for Professional Development at the American Psychological Association (APA). He is a clinical and health psychologist whose clinical work and research has focused on responses to life-threatening illnesses, including AIDS and breast cancer. He has published numerous scientific and policy articles in such journals as *American Psychologist*, *American Journal of Cardiology*, *Health Psychology*, *Professional Psychology*: *Research and Practice* and the *Journal of Social Issues*. From 1990 to 1995, he was a member of the research faculty of the Department of Psychiatry and Biobehavioral Sciences at UCLA School of Medicine, where he was named one of the 50 Most Innovative AIDS Researchers in the US. At APA, Dr. Reed is responsible for the development and implementation of collaborative projects focused on improving health care outcomes and patient care. He has recently been responsible for the design and implementation of PracticeNet<sup>TM</sup>, APA's new

Internet-based infrastructure for the collection of information regarding psychological practice. He was the lead inventor for the PracticeNet's unique electronic network based Real Time Behavior Sampling methodology, which is currently being patented by APA. Since the mid/late-1990's, he has worked extensively with the World Health Organization (WHO) on the implementation of the ICF. He is currently leading a multi-organizational, multidisciplinary team in the development of a manual for the ICF intended to facilitate use of the ICF in health care settings. He has attended a number of WHO and NACCsponsored ICF meetings to make presentations on the new ICF operations manual. He is a native Californian (second generation) and found adjustment to the East Coast to be a fairly long and difficult process. Now that he has been in DC for 8 years, he is used to the fact that cab drivers ask you about pending legislation, not to mention the occasional snow. He is in the process of learning Spanish, as it has become the second language of the US and is spoken in so much of the rest of the world. He is planning to spend the month of February in Peru, participating in an intensive Spanish language program. Besides tirelessly promoting the ICF in clinical practice, one of his hobbies is cooking, and he has been learning to cook Peruvian food in preparation for his trip. The attached photo was taken in Cologne, Germany, where Geoff presented on the APA manual at the WHO Heads of the Family of International Classifications in October 2003.