

April NACC CLEARINGHOUSE ON ICF

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. ST. LOUIS UPDATE.

The 9th Annual NACC meeting on ICF to be held in St. Louis June 16-19, 2003 will include over 40 scientific papers plus other major presentations and events. Look for complimentary 5 star dinner and lunches, a Mississippi riverboat cruise, a live demo of Code ICF, a peek at ICF videos, and unveiling of the new ICF desktop display. Registration is free and the optional riverboat ride is \$25. You just have until May 16 to receive the discounted Chase Park Plaza hotel rate of \$135 (call 314-633-3000). Earlier NACC Clearinghouse on ICF messages on this website have more conference information.

2. DEDICATION

Patrick Fougeyrollas of Quebec sends regrets that he will miss his first NACC meeting on ICF after attending eight in a row. He will be in the field as a social anthropologist working in a research study on Handicap International humanitarian action with people with disabilities in Salvador de Bahia, Brasil. On the other hand, our "Spotlight" featured ICF'er for this month is Jerome Bickenbach, who plans to be in St. Louis and has not missed one yet!

3. ON PLANNING A GREAT MEETING

The Robert Wood Johnson Foundation has updated its "Planning a Great Meeting" guidelines to include information related to disability access and accommodating participants with disabilities. Here is the link: <http://www.rwjf.org/publications/publicationsPdfs/grMeetingPlanning.pdf>. Trish Welch Saleeby, of NACC Clearinghouse on ICF fame, had a major hand in the update. We all know that you cannot "plan a great meeting" without addressing the needs of participants with disabilities.

4. MEDICAL REHAB SUBCOMMITTEE OF ICDR GETS ICF REPORT

On April 15, Paul Placek, Gerry Hendershot (as NCHS Consultant), and Marjorie Greenberg made ICF presentations to the Medical Rehabilitation Subcommittee of the Interagency Committee on Disability Research. This Subcommittee meets four times per year and over a dozen persons attended this meeting in Rockville, which was chaired by Dr. Michael Weinrich, Director of the National Center for Medical Rehabilitation Research/NIH. Marjorie spoke on "Medical Rehabilitation Research: The Promise of ICF". She suggested that rehabilitation routinely assesses functional status and is a good starting place for testing the ICF. She pointed out that challenges for coding functional status involve cross-walking assessment tools to ICF, identifying gaps, and standardizing assessment tools in relation to ICF codes for clinical specialties.

Paul described the American Psychological Association project to develop a procedural manual and guide for a standardized application of ICF, spearheaded by Dr. Geoffrey Reed, Geoffrey <mailto:gmreed@apa.org> at APA. Realizing a user guide was needed, APA made an agreement with WHO to develop this manual, which is a clinical application. The goals of the manual are to provide a standard approach to the classification that is clinically grounded; and to provide consistent interpretation of concepts and terms. The audience for the manual are professionals that have been trained to independently assess clients 18 years of age and older. The APA has joined with representatives from nine professional disciplines to draft different parts of the manual. The advantage of the system is that it doesn't constrain professionals to use a specific array of assessments, but lends itself to varied assessment approaches (e.g., psychometric measures, clinical interviews, direct observation). APA's next steps in producing the manual include seeking greater participation from health professionals in the U.S. and internationally (2003), convening an expanded drafting team (2003), completing a final draft of all chapters (2004), comment and review (2004) and publishing version 1.0 in 2005.

Gerry Hendershot described a European project on core sets and linking tools to the ICF. Gerry spoke on "Research Needs to Operationalize the ICF in Clinical, Administrative and Survey Records". He described ICF research in Germany, which began with four different specialty areas and asked the question: "What are the aspects of the ICF that would be useful to know?" They brought in specialists in those key areas for a consensus conference and developed core-sets for selected conditions. The next step is a multi-center prospective cohort study to test feasibility, reliability, validity and sensitivity of core-sets. They have also been learning about the general problem of linking rules to the ICF and have developed rules to solve these linking problems and are involved in inter-rater reliability as part of that work

5. FRENCH DISCUSSION OF ICF REVISION PROCESS AS HORSERACE

Check out http://www.disabilityworld.org/01-03_03/resources/newwho.shtml for an interesting article by M. Miles entitled "French Experts' Cool Gaze at New WHO Disability Classification". The author comments on the latest double issue of the French academic journal *Handicap - Revue de Sciences Humaines et Sociales*, which examines the process of revision of ICIDH-2 and the 'compromise version' of ICF. The journal is

published by France's Centre Technique National d'Études et de Recherches sur les Handicap et les Inadaptations, in Paris, one of eight WHO Collaborating Centres to engage in the revision. And we now quote the Miles article: "Here, the chief editor of *Handicap*, Catherine Barral, gives a frank account of the revision process (pp. 1-23), with a fascinating racecourse commentary. Starting around 1992, some Collaborating Centre horses galloped off in more or less the same direction with the goal of improving ICIDH. By 1995 we hear of more horses joining the race, which is now being run on several different routes simultaneously, while bookies are taking side bets on some unexplained features that the original runners are never told about. By 1997 the horses are being randomly tested for deviant thinking, and they have been joined by a troupe of bears juggling statistics, and some elephants on bicycles. The stewards set the finish at 1999, but as the runners near this line it is suddenly hoisted onto a lorry, which speeds off into the distance. Finally, as the weary creatures jump the last fence and turn into the finishing straight, their course is blocked by a brace of camels balancing on their humps and waving their legs in the air. To the consternation of all, a third camel appears on the far side of the obstruction and canters away to pass the finishing post and lift the prize amidst public acclaim." Somehow, a stuffed parrot enters the analogy. If your head goes buzzy reading ICF codes, this piece could brighten your day.

6. CHILD AND YOUTH VERSION OF ICF

At the April 9 meeting of the Interagency Subcommittee on Disability Statistics, Rune Simeonsson described progress on the ICF for Children and Youth. He stated that the conjoint use of health information and documentation and the functional characteristics of the ICF, particularly for early childhood, can be effectively used to answer key questions about a child's health status, body/mind function, ability to perform daily life activities, and the environmental context. The goal of the children and youth version of the ICF is to provide the additional detail needed to capture aspects of the environment unique to phases of development. This will promote uniform concepts across health education and related sectors for universal use. Simeonsson has established a work group, in conjunction with WHO, to further develop the ICF version for children and youth and ready it for publication in 2004. They are retaining content of ICF applicable to children in reference to the three major domains and will add content to encompass aspects of infancy, early/middle childhood and adolescence. The work group will also identify and develop assessment instruments that are compatible with the children's version of the ICF. There are guidelines built into the ICF in Appendix 8 and identical structures will be put in place, along with an identical hierarchical format of chapters, blocks and categories. In terms of structural considerations, descriptions of items will be modified or expanded to encompass the extent or magnitude of the problem of a development nature. New content will be assigned to unused codes and inclusion/exclusion criteria modified and/or expanded. In reference to capturing development, Simeonsson's group has a well-conceived strategy, which will be further evaluated during field trials. Section 4.1 of the ICF Introduction defines impairments as problems in body function or structure, as a significant deviation or loss. These are generally deviations from population standards. The criteria are defined as (a) loss or lack, (b) reduction, (c) addition or excess, or (d) deviation. Building on these definitions, they are framing the qualifier for body functions and structures in a manner similar to

activities and participation, with a focus on problems of deviation or delay, as defined previously. A generic qualifier with the negative scale is used to indicate the extent or magnitude of a problem, deviation or delay, whether permanent or temporary. New content will be assigned to unused codes in body structures and body functions. Under activities, descriptions were expanded, or modified to include more interactive data for children. The work group has had a series of regional meetings in Italy, Sweden and Washington, DC. Additional meetings are planned in Africa, Europe, Asia and Latin America, followed by a meeting with CDC in July, 2004 before convening a meeting with WHO in Geneva at the end of the process in the fall of 2004. A first draft report will be completed shortly, with field trials in the summer. A second draft is expected in the fall, with field trials in the winter, 2004. A final draft revision is due by summer, 2004, followed by submission to WHO in the fall. In field trials they will build on Geneva's experience with alpha and beta versions of ICIDH-2, the development of checklists, content validation and clinical utility. Content validation will focus on a review by consumers, providers, policy makers, and researchers from representative countries of WHO regions. Clinical utility will highlight application of the taxonomy in health, education and related sectors on children and youth covering a wide range of age, conditions and severity levels. This work provides an excellent document for recognizing the rights of children and contributing to advancing those rights under Article 23 of the UN Convention, the UN Standard Rules for the Equalization of Opportunities, and national acts on rights for health education for children and youth with disabilities. Potential applications of the ICF for children and youth include a framework for policies and initiatives for child health and development by international organizations (e.g. UNICEF, World Bank, Funding agencies, Foundations, NGO's); the development of screening and assessment tools compatible with ICF; the development of composite indices for population surveillance of childhood disability and use of common indicators for eligibility across agencies and systems. For more information, contact Rune at <simeonsr@mail.fpg.unc.edu>.

7. ICF A MODEL OF BEST PRACTICES

ICF collaborations will be the topic for the closing morning of the July 23-24, 2003 invitational meeting on *International Collaboration in Rehabilitation Research: Models and Best Practices*. This meeting is sponsored by the Center for International Rehabilitation Research Information and Exchange (CIRRIE), which you can check out at <http://cirrie.buffalo.edu> and get more information from John Stone, the organizer <jstone@buffalo.edu>. The ICF topics and speakers are:

(1) *DISTAB: Overview of ICF and Disability Tabulations from the U.S., Canada, South Africa, Australia, France, and the Netherlands and Backcoding to the ICF: A Four-Year Collaborative Effort* by Dr. Gerry E. Hendershot, Disability Consultant; (2) *How the Canadian Institute for Health Information relates to the Provinces, the World Health Organization, and the North American Collaborating Center* by Diane Caulfeild, Canadian Institute for Health Information; (3) *Adoption of the ICF in Italy and Relation of ICF to European Year of People with Disability* by Matilde Leonardi, MD, of the Italian National Neurological Institute and WHO Medical Officer; and (4) *International Collaboration Mechanisms Leading to the ICF for Children and Youth*.

8. SPOTLIGHT ON "JERRY B"

This month's "Spotlight" starts with a quiz. Who is a total science fiction fanatic, is devoted to a 15 year old daughter named Morgan, has a Labrador dog named Jessie, holds dual Canadian and U.S citizenship, is a lawyer by trade, tends to be long-winded and pondersome when on the podium, wrote a book on the ICIDH, and travels so much that one never knows where he will turn up? Give up? The answer is Jerome E. Bickenbach, Ph.D, LL.B. He is often called "Jerry B" so he is not confused with the Gerry Hendershot, who is usually just called "Gerry". Dr. Bickenbach is a full professor in the Department of Philosophy and Faculties of Law and Medicine at Queen's University, and holder of the Queen's Research Chair. As a lawyer, Dr. Bickenbach was a human rights litigator, specializing in anti-discrimination for persons with intellectual impairments and mental illness. He is the author of *Physical Disability and Social Policy* (1993) and the co-editor of *Introduction to Disability* (1998), *Disability and Culture: Universalism and Diversity* (2000), *A Seat at the Table: Persons with Disabilities and Policy Making* (2001), *Quality of Life and Human Difference* (2003), and numerous articles and chapters in disability studies, focusing on the nature of disability and disability law and policy. He is a content editor for Sage Publication's 5 volume *Encyclopedia of Disability*. Since 1995 he has been a frequent consultant to WHO and is one of the writers of ICF. Despite these impressive credentials, Jerry B always enjoys a good lawyer joke! So send him one at <bickenba@post.queensu.ca>.

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