

MAY, 2007
NORTH AMERICAN COLLABORATING CENTER
ICF NEWSLETTER

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ALL ARE WELCOME, AND REGISTRATION WILL BE FREE OF CHARGE.**

- 5) **BRIEFLY NOTED: ICF NEWS OF INTEREST**

Recently in the Literature:

- **"Preliminary Results for the PAR-PRO: A Measure of Home and Community Participation."**
 - **"Validation of the Comprehensive ICF Core Set for Rheumatoid Arthritis: The Perspective of Physical Therapists."**
 - **"Access for Persons with Neurogenic Communication Disorders: Influences of Personal and Environmental Factors of the ICF."**
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**1) ALERT! ALERTE! PLANNING TO ATTEND THE 2007 ICF CONFERENCE?
PLEASE NOTE: THE DISCOUNTED HOTEL RATE DEADLINE IS MAY 4.**

This is a Courtesy Announcement for subscribers to this ICF Newsletter: If you are planning to attend the 2007 North American Collaborating Center (NACC) Conference on the ICF, in Niagara Falls, New York between June 5 –7, please note that the negotiated, deeply discounted hotel room rate deadline is approaching fast. The deadline is Friday, May 4.

NACC commends our co-sponsoring colleagues at the Center for International Rehabilitation Research Information and Exchange (CIRRIE) at the University of Buffalo for all their hard work preparing for this year's ICF Conference. CIRRIE has also done a big favor for every prospective Registrant: they negotiated an outstanding room rate of \$119.00 US per night at the newly-renovated Crowne Plaza Niagara Falls Hotel. Taxes are additional.

This hotel presents us with an outstanding venue both outside with the dramatic Niagara Falls, and inside with newly-renovated meeting and lodging facilities. It will be nearly "high season" in this lovely setting, so we encourage you to take advantage of this outstanding room rate!

You can still register for the ICF Conference up until Saturday, May 26, but the negotiated Crowne Plaza Hotel room rate will expire on Friday, May 4. Accessible rooms are available.

Below is the website at which you can obtain your Hotel On-Line Reservation:

<http://cirrie.buffalo.edu/icf/conference/locations.html#hotel>

And below is the link to the ICF Conference On-Line Registration page:

http://www.ubevents.org/regengine/event_page.php

Welcome! *Bienvenue!* Enjoy Niagara Falls and this outstanding conference opportunity.

**2) SHARING KNOWLEDGE THROUGH THE ICF"
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JOIN US FOR THE 2007 NORTH AMERICAN COLLABORATING CENTER
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The North American Collaborating Center warmly invites members of the ICF community from all nations, but especially Canada and the United States, to the 13th Annual NACC Conference on the ICF, to be held June 5 – 7 in Niagara Falls, New York., at the Crowne Plaza Hotel.

The theme of this year's ICF Conference will be "Sharing Knowledge Through The ICF."

That theme derives from the premise that the ICF can contribute to Knowledge Translation in many fields related to disability and rehabilitation.

As mentioned in the entry above in this ICF Newsletter, we encourage you to register on-line for the ICF Conference before Saturday, May 26. This year the Registration Fee is \$220.00 for the two-day conference. The popular Pre-Conference ICF Coding Workshop, scheduled for Tuesday, June 5, does involve a separate tuition fee of \$80.00, but that fee includes the impressive and very practical course materials, a luncheon, and many of the latest strategies for learning and engaging in ICF coding directly in clinical practices and health systems.

You can learn more about the ICF Conference theme, setting, lodging and accommodations, continuing education information, the Pre-Conference Workshop, and the details of the always-popular Social Event --- this year a lovely dinner at The Top of the Falls Restaurant --- on the ICF Conference website. The home page web address is below:

<http://cirrie.buffalo.edu/icf/conference/index.html>

NACC extends sincere thanks to our co-sponsoring colleagues at CIRRIE and the University of Buffalo for their hard work preparing for the ICF Conference. We are confident you will enjoy their hospitality, and we all will benefit from their planning and commitment to scientific rigor.

NACC is also pleased to announce details of the Preliminary Program for the ICF Conference. A rendering of the "Program At A Glance" will be available on the ICF Conference website shortly, but below is an abbreviated roster of the forthcoming session titles, to illustrate the depth and breadth of this year's scientific content.

- "PROMIS and the ICF: Using the ICF to Interpret Patient-Reported Outcomes"
[PROMIS is the acronym for the NIH-funded Patient-Reported Outcomes Measurement Information System]
- "The Future of Disability in America: Dialogue About the ICF in the IOM Report"
- "Implementing the ICF in Health Promotion and Health Education"
- "Teaching the ICF" and "Going Beyond Diagnosis"
- "Biomedical Ontologies"
- "Activities & Participation, Environmental Factors, and Universal Design"
- "Mapping to Functional Assessment Instruments" and a "Mapping Workshop"
- "ICF Implementation Activities Within PAHO Member States"
- "Current ICF Research: Surveys, Rehabilitation Classification, and Qualitative Research"
- "Assistive Technologies and ICF"
- "ICF-CY Developments and Children's Classification"

Even this short roster of topics exhibits the breadth of interests currently associated with the ICF around the world. There is plenty of Knowledge to be Shared!

This year's ICF Conference will also benefit from another outstanding array of Poster Session presentations. The Poster Session is always popular, and another wonderful opportunity for networking. This year we're planning a lunch-time Poster Session with two dozen posters.

Please join us in Niagara Falls, June 5-7 for this annual North American event!

3) **THE FUTURE OF DISABILITY IN AMERICA: NEWLY-RELEASED REPORT FROM THE INSTITUTE OF MEDICINE RECOMMENDS BROADENED ICF UTILIZATION, AND PROPOSES CLARIFICATIONS AND ADDITIONS.**

<http://www.iom.edu/CMS/3740/25335/42494.aspx>

In late April, the Institute of Medicine (IOM), one of the associated organizations of the National Academy of Sciences, released its much anticipated successor to the famous 1991 IOM report entitled Disability in America, and the 1997 report, Enabling America. The 2007 report is entitled The Future of Disability in America, prepared by the IOM's Committee on Disability in America. Professor Alan Jette from the Boston University School of Public Health served as the Committee's chairman, and Marilyn Field from the IOM served as the Study Director.

The IOM is a private, non-governmental organization. Studies undertaken for the U.S. government by the Academy of Sciences are usually funded out of appropriations made available to U.S. government agencies. Most of the studies carried out by the Academy of Sciences are at the request of federal agencies. In this case, the IOM received contract funding from the Centers for Disease Control and Prevention, the National Institute on Disability and Rehabilitation Research, and the National Institutes of Health.

A "prepublication copy" is now publicly available for review, free of charge, on the National Academies Press website; the NAP is another affiliated organization within the National Academy. The book is available on that website for purchase at pre-publication prices. The final published version in book form is scheduled for a summer, 2007 release. The website address above leads the reader to a description of the study. The website below leads the reader to a "page-by-page viewer," the use of which is governed by NAP's on-line license agreement.

http://books.nap.edu/openbook.php?record_id=11898&page=R1

This is an enormously important report. NACC encourages all the subscribers to this ICF Newsletter to become familiar with this report, obviously primarily in the United States, but also in other countries as well. It will substantially influence our work on the ICF for many years.

Pertinently, The Future of Disability in America incorporates many references to the ICF. Within its set of 18 formal Recommendations, the Committee has prompted much broader utilization of the ICF within American health systems, particularly in federally-supported disability monitoring initiatives, including surveys and data dissemination activities.

For example, within Chapter 2, “Definition and Monitoring of Disability,” the Committee recommended “Adopt[ing] and refin[ing] the ICF as the conceptual framework for disability monitoring and research.” Stemming from that foundation, the Committee also recommended creating a comprehensive disability monitoring system, funding a national program of broad-based disability research “that is commensurate with the need,” and increasing the visibility and coordination of federally-supported disability research.

Specifically, Recommendation 2.1 reads:

“The National Center for Health Statistics, the U.S. Census Bureau, the Bureau of Labor Statistics, and other relevant government units involved in disability monitoring should adopt the *International Classification of Functioning, Disability and Health* (ICF) as their conceptual framework and should actively promote continued refinements to improve the framework’s scope and utility for disability monitoring and research. The Interagency Subcommittee on Disability Statistics of the Interagency Committee on Disability Research should coordinate the work of these agencies to develop, test, validate, and implement new measures of disability that correspond to the components of the ICF, consistent with public policy priorities.” [Prepublication Copy, 2007, page 2-21, italics in original.]

Included within the rubric of promoting “continued refinements to improve the framework’s scope and utility,” the Committee proposed the following as priority areas:

- “Clarifying or otherwise resolving the lack of operational differentiation between the concepts of activity and participation;
- Explicitly incorporating quality of life in the framework of key concepts for understanding health and disability and conducting research;
- Developing classifications for personal factors affecting functioning and disability;
- Further developing the classification of environmental factors;
- Incorporating secondary health conditions as an ICF concept; and
- Supplementing the ICF with a dynamic model of factors that influence the movement of individuals among states of functioning or disability.” [Prepublication Copy, 2007, page 2-22, Box 2-5.]

Two other formal Recommendations explicitly refer to further work with the ICF, including Recommendation 6.1 within Chapter 6, “The Environmental Context of Disability: The Case of Health Care Facilities” and referring broadly to Environmental Barriers. It reads:

“Given the limited research on the effects of environmental factors on disability, the National Institute on Disability and Rehabilitation Research, the National Institutes of Health, the Veterans Health Administration, the Centers for Disease

Control and Prevention, and other relevant agencies should collaborate to develop a program of research in this area. As part of developing such a program, these agencies should

- Organize a symposium to engage people with disabilities, relevant government agencies, researchers, methodologists, and other interested parties in a collaborative process to recommend priorities for research on environmental factors, as defined in the *International Classification of Functioning, Disability and Health*;
- Apply those priorities in a plan for outcomes research to investigate the relative effects of different aspects of the environment on disability; and
- Intensify current efforts to improve epidemiological, observational, and experimental measures and methods to assess the effects of specific environmental features on independence, participation, and quality of life over the short term and long term for people with disabilities.” [Prepublication Copy, 2007, page 6-14.]

Continuing, within Chapter 10, “Organization and Support of Disability Research,” Recommendation 10.3, the final recommendation in the book, reads as follow:

“To facilitate cross-agency strategic planning and priority setting around disability research and to expand efforts to reduce duplication across agencies engaged in disability research, the U.S. Congress should authorize and fund the Interagency Committee on Disability Research to

- Undertake a government-wide inventory of disability research activities using the *International Classification of Functioning, Disability and Health*;
- Identify underemphasized or duplicative areas of research
- Develop priorities for research that would benefit from multi-agency collaboration;
- Collaborate with individual agencies to review, fund, and administer this research portfolio; and
- Appoint a public-private advisory committee that actively involves people with disabilities and other relevant stakeholders to provide advice on the activities described above.” [Prepublication Copy, 2007, page 10-25.]

With these formal Recommendations, you can perceive that this IOM Report, The Future of Disability in America, will be considered an important milestone in the advancement of disability research and the expanded utilization of the ICF.

Subscribers are invited to participate in several ICF Conference activities related to The Future of Disability in America during the 13th Annual NACC meeting in Niagara Falls. A Plenary Session has been planned to address the new IOM Report, and specifically these Recommendations and their importance for ICF research in the future.

NACC commends the funding sources, the IOM Committee members, consultants, reviewers, and the IOM staff including Marilyn Field and her colleagues, for their commitment to generating this outstanding report, during this collaborative effort requiring two years of work.

4) “NEW FEDERAL APPLICATIONS OF THE ICF” --- A STATE-OF-THE-SCIENCE CONFERENCE, JULY 10-11, 2007 IN CRYSTAL CITY, VIRGINIA. ALL ARE WELCOME, AND REGISTRATION WILL BE FREE OF CHARGE.

The Interagency Subcommittee on Disability Statistics (ISDS), together with its counterpart Interagency Subcommittee on the New Freedom Initiative (ISNFI), are pleased to announce that their “State-of-the-Science Conference” for 2007 will focus on the ICF. These two groups are components of the Interagency Committee on Disability Research (ICDR).

This year’s conference will be entitled “New Federal Applications of the ICF.”

The conference is scheduled for Tuesday and Wednesday, July 10 and 11, 2007, at the Sheraton Crystal City Hotel in Crystal City, Virginia, just outside of Washington, D.C. This hotel is served by the adjacent Metro Yellow and Blue Lines, and a block of guest rooms will also be available for our out-of-town guests.

As part of the ICDR’s “State-of-the-Science Conference” series, there is no registration charge to attend the “New Federal Applications” conference. We do ask that prospective attendees register in advance, as there will not be on-site registration available, but registration will be free. The conference also will not be soliciting abstracts for paper presentations.

Another characteristic of the State-of-the-Science Conference series is their inclusion of recommendation-oriented Breakout Groups as part of the regular format. Therefore registrants need not bring any registration money, but they must bring their Thinking Caps!

Also, you don’t have to be an employee of or otherwise affiliated with the U.S. federal government to attend. This conference is open to all. Non-federal participants are encouraged to attend, so that dialogue with the federal participants attending can be enriched for everyone.

The purpose of the “New Federal Applications” conference will be to demonstrate the capability of the ICF to serve as the “Classification backbone” of many of our health data systems that involve functional status information.

Additionally, this conference will emphasize the role of the ICF in federal Health Information Technology initiatives that pertain to the transmission of large volumes of data involving functional status information. Specifically, and as reported in the November-December, 2006 edition of this ICF Newsletter, the federal Consolidated Health Informatics (CHI) initiative recommended to the Secretary of Health and Human Services that the ICF be considered a “CHI-

endorsed vocabulary” for this purpose, and that the ICF should become a component of the National Library of Medicine’s Unified Medical Language System. Such a step would enable “mapping” research using the ICF to expand beyond the laboratory and begin generating useful tools, such as software products. In a previous report on the ICF, the National Committee on Vital and Health Statistics, which concurred with the CHI recommendations, also referred to the ICF as “the only existing classification system that could be used to code functional status across the age span” (2001).

Moreover, because the ICF can be used to classify activity and participation limitations associated with difficulties obtaining services in health care, education, transportation, housing, employment, or leisure or civic activities, the role of the ICF as a tool for achieving success in the President’s New Freedom Initiative can’t be underestimated. In light of those interests, our colleagues from the ISNFI will ensure that this State-of-the-Science Conference remains firmly planted on earth for practical applications, both within and outside of the federal government.

The conference website is currently under construction, but an announcement will be forthcoming about that website address, where you will be able to register for the conference and begin the process of making on-line hotel reservations, if necessary.

Please plan to attend! July 10-11, 2007, at the Sheraton Crystal City Hotel.

5) **BRIEFLY NOTED: ICF NEWS OF INTEREST**

Recently In The Literature

- **"Preliminary Results for the PAR-PRO: A Measure of Home and Community Participation."**

This important article reports on the reliability testing and validation of a newly-developed measure of home and community participation, derived explicitly from the ICF. The instrument is called the PAR-PRO, a product of the Uniform Data System for Medical Rehabilitation (UDSMR). A rendering of the copyrighted instrument’s Assessment Form is included in the article as Appendix 1; use of the instrument is governed by UDSMR. The 20-item PAR-PRO is designed to reflect a patient’s “Participation Profile” retrospectively, namely at the time of or before admission, and prospectively, namely the post-discharge goals reflecting what the patient would like to do in the future, as part of longer-term rehabilitation. There is also a concurrent assessment of what the patient can actually perform or do at the time of assessment. In this study, the authors described the instrument’s favorable psychometric properties.

Citation: Ostir GV, Granger CV, Black T, *et al.* Preliminary results for the PAR-PRO: A measure of home and community participation. *Archives of Physical Medicine and Rehabilitation* 2006 (August); 87:1043-1051.

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- **“Validation of the Comprehensive ICF Core Set for Rheumatoid Arthritis: The Perspective of Physical Therapists.”**

This useful article builds on the firm foundation of this research team’s investigations of “ICF Core Sets,” which are validated, parsimonious subsets of the ICF directly relevant to a particular medical specialty or clinical practice caseload. These authors, from the ICF Research Branch at the WHO German Collaborating Center for the Family of International Classifications in Munich, had previously published results from their validation studies of Core Sets for rheumatoid arthritis (RA), as well as similar Core Sets for other endocrine disease categories. In this article, the authors have advanced this brand of research by not only continuing to validate the precision of the existing Core Set for RA in medical practice, but also by having that validation demonstrated among another set of clinicians, Physical Therapists, in physical therapeutic practice. Because physicians and Physical Therapists must work together in treating cases (and caseloads) of RA, their combined ability to use the *same* ICF Core Set is a very desirable characteristic. Moreover the Core Set’s capacity to represent nearly 100 percent of the ICF-coded RA cases in a given group practice or a clinic’s caseload is also quite desirable for accuracy in case-counting and outcomes measurement.

Citation: Kirchberger I, Glaessel A, Stucki G, Cieza A. Validation of the comprehensive *International Classification of Functioning, Disability and Health* core set for rheumatoid arthritis: The perspective of physical therapists. *Physical Therapy* 2007 (April); 87:368-384.

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- **“Access for Persons with Neurogenic Communication Disorders: Influences of Personal and Environmental Factors of the ICF.”**

In this article, Professor Travis Threats from Saint Louis University engages in a very thorough investigation of Personal Factors, which theoretically would have enormous relevance in clinically addressing speech or other communication disorders, especially in populations. However, Personal Factors are “under-studied.” Clinicians in many disciplines are consistently expressing demand for more clarification and explication of the Personal Factors, which currently are only the subject of research. Personal Factors currently are not assigned discrete codes in the ICF. A competitive argument could be expressed that, without fully explicating coded Personal Factors, the ICF might be considered incomplete, at least for some clinical practice environments, notably in this

case for aphasia patients, among whom the putative influence of Personal Factors could be profound. The author also encouraged clinicians to recognize that “un-coded” Personal Factors and coded Environmental Factors often interact

Citation: Threats T. Access for persons with neurogenic communication disorders: Influences of personal and environmental factors of the ICF. *Aphasiology* 2007 (January); 21(1):67-80.

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