

## **Executive Summary**

**June 20, 2005 ICF Tutorial**

**And**

**June 21-24, 2005 11<sup>th</sup> Annual NACC Conference held at Mayo Clinic in  
Rochester, Minnesota**

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#### **Meeting Theme: Mapping the Clinical World to the ICF**

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## **Tuesday, June 21, 2005 – Tutorial**

The objectives of the tutorial were to:

- o Describe the ICF conceptual structure and content;
- o Apply National Library of Medicine experiences in mapping clinical classification systems;
- o Examine select experiences in mapping clinical assessments to the ICF;
- o Examine select experiences in ICF based clinical measurement development and analysis.

Up to six Continuing Education credits were offered for the all-day tutorial. Marjorie Greenberg spoke first on “Improving the Population’s Health Through Standards: The Case of the ICF”. She reviewed the case for data standards and on the implementation of ICF in North America and internationally. More specifically, she focused on:

- Data standards, which are the essential building blocks of information systems (ICF, ICD, core data sets, etc.) needed for an effective health care system;

- The structure and activities of the international network of WHO Collaborating Centres for the Family of International Classifications;
- The history and development of ICIDH (The International Classification of Impairments, Disabilities and Handicaps) by WHO;
- The old ICIDH paradigm vs. the new ICF paradigm in comparison;
- The strengths of the ICF as an international standard;
- The structure of the ICF and all its domains, including the four options for delineation of A and P; and
- The ICF for Children and Youth, available for review in 2005.

Ms. Greenberg gave these challenges for ICF implementation:

- To crosswalk assessment tools to ICF;
- To develop new ICF-based assessment tools;
- To improve ICF as a classification;
- To determine who should report on functional status (FS);
- To decide whether FS should be measured with or without assistive technology; and
- To neatly distinguish between capacity and performance (see slides).

The second presenter in the tutorial was Olivier Bodenreider with “Mapping New Vocabularies to the UMLS: Experience with ICF”. The UMLS has three components: the metathesaurus; the semantic network; and the lexical resources. The metathesaurus contains 1.2 million concepts, 4.2 million terms, and 5.5 million atoms. The example of Addison’s disease was given to show its various perspectives within UMLS. Starting with 1,495 terms in the ICF, Dr. Bodenreider filtered out 478 terms and worked with 1,017 terms. Of these, 717 were mapped with an exact map or a normalized match. He used the ICF illustrations of “pain in back” (ICFb – 28013) and impulse control (b1304) to illustrate the nuances of mapping. He concluded that the ICF could be integrated into the UMLS, it is relatively small, and many ICF concepts are already present in the UMLS. The challenges are unspecified terms and other ambiguities. The benefit of this integration for the UMLS is that it would add new perspective. The benefit for the ICF is that it would link ICF to other vocabularies. Expert consultation must be combined with automated algorithms in order to map successfully. Discussion arose around these points: that WHO would be very interested in his work; that ambiguity in the terms will impair mapping; that “goodness of fit” after mapping should be evident in the judgment of an expert; and that the UMLS is based on the medical model and that the ICF could enhance the UMLS due to its inclusion of terms for social participation and environment.

The third tutorial presenter was Geoffrey Reed with “Applying the ICF in Health Care Settings”. For some years, Dr. Reed and The American Psychological Association have spearheaded a multi-disciplinary group of representatives of various professional associations to prepare a guide for standardized applications of ICF by health professionals. It is scheduled for

completion in 2005 and is entitled: “Procedural Manual and Guide for a Standardized Application of the ICF”. Based on a draft of this manual, he provided an overview of the codes and standard qualifiers, and he discussed how the qualifiers work with capacity and performance. He pointed out that the ICF is not an assessment tool, but that it is compatible with a range of assessment approaches. He illustrated the application of four qualifiers (performance in the current environment, capacity without assistance, capacity with assistance, and performance without assistance) to d 4502—walking on different surfaces with the qualifiers coded as described d 4502.2189. Dr. Reed’s second example was that of Gregory Curry as described in the Washington Post, but with ICF codes applied to capture the rich detail in Curry’s life situation. Dr. Reed also pointed out the difficulty in distinguishing between certain codes such as attention functions (b 140) and focusing attention (d 160), and stated that the Manual addresses these difficulties. Finally, he addressed the concepts of normative vs. ideographic data using examples of a lawyer and a convenience store worker, both with TBI.

The fourth tutorial presenter was Nancy Mayo, who presented “Mapping Health Outcomes to the ICF”. She stated that “mapping equals cross walking”. Mayo stated that her goal is to use the ICF to measure functioning, not merely describe the presence and severity of disability. Mapping should be done now because we are in the electronic era and we have an abundance of data. However, we can’t capture function electronically unless we have a universal common language. Mapping has value in guiding the selection of instruments, in providing content validity of instruments, in giving validity to translations of instruments, in further developing the ICF, and in developing new ICF-based instruments. She discussed ICF core sets, which provide a method of standardizing the identification process of prevalent impairments, activity limitations, participation restrictions and environmental factors. She used the clinical example of stroke to describe the link between the ICF framework, ICF core sets and standardized outcome measures.

The fifth tutorial presenter was Craig Velozo, (no slides) who discussed “Developing Measures Using the ICF”. Dr. Velozo showed the use of ICF to create a measure, discussed a measurement model, created an ICF-based measure, administered the measure, and described output of the measure. His ICF-based measure is on the web at [www.ICFmeasure.com](http://www.ICFmeasure.com). Velozo used the Rasch model, which is an IRT (Item Response Theory) model. The person’s ability and item (task) difficulty are central to the IRT model. He developed item banks with a hierarchy of difficulty in functional tasks, had the item banks reviewed by experts, evaluated with cognitive interviewing, and checked with empirical testing. To construct a computerized adaptive testing algorithm, eight steps are involved:

- 1) Begin with initial score estimates;
- 2) Select and present optimal scale items;
- 3) Score the responses;

- 4) Estimate the confidence intervals;
- 5) Determine if the “stopping rule” is satisfied;
- 6) End scale assessment;
- 7) End the battery, and
- 8) Administer the next construct, etc.

The “take home message” was that outcome measures are likely to replace mere scores for assessing outcomes in health care. These measures have the potential to reduce respondent burden, improve outcomes measurement precision, and have the added benefit that the outputs produced by these measures will be immediate.

The sixth and final tutorial presentation was made by Nenad Kostansjek in “ICF Concept, Content and Implementation Strategy”. He pointed out that the “information paradox” is that the least disability information is available for developing countries where the need is greatest and many life years are lost due to higher rates of disability. A major WHO/UNESCAP project on health and disability has begun to develop and test ICF-based disability question sets for use in censuses and surveys. The value of ICF in clinical practice and management is to measure disability in different health care settings, use a common language, and use ICF as a “Rosetta Stone” for linking different outcome measures. WHO has a CDC-funded project to crosswalk a variety of assessment tools to ICF. WHO will map from those instruments to the ICF. A number of countries (Switzerland, Greece, Turkey, Romania, Hungary, Georgia, Italy, and Armenia) now have ICF embedded in disability certification, social security, and labor law.

**Wednesday, June 22, 2005**

### **ICF Meeting: Mapping the Clinical World to the ICF**

On June 22-24, 2005 the National Center for Health Statistics (NCHS) and the Mayo Clinic on behalf of the World Health Organization (WHO) Collaborating Center for the Family of International Classification for North America, held the 11<sup>th</sup> Annual North American Collaborating Center (NACC) Conference on the International Classification of Functioning, Disability and Health (ICF) at Mayo Clinic in Rochester, Minnesota. Clinical applications of the ICF were emphasized in the plenary sessions. The science of mapping and uses of “mapped” clinical data for research and policy received emphasis. Up to 15 Continuing Education Credits were available for participation in the conference. The conference objectives were to:

- Analyze implications for future extensions of the ICF in relation to clinical concept representation in electronic and web-based environments;

- Describe approaches to both mapping questionnaires, clinical data, and coding systems to the ICF;
- Describe approaches to developing questionnaires, clinical data, and coding systems based on the ICF;
- Examine the ICF in relation to clinical practice, education, and research efforts;
- Review progress on the APA training manual for use of the ICF;
- Compare the ICF to the ICF version for Children and Youth; and
- Apply the ICF in simulated clinical encounters.

Jeffrey R. Basford, MD and Michael Rock, MD welcomed the 99 registered participants to the conference and to the Mayo Clinic. The Mayo Clinic is a charitable, not-for-profit organization based in Rochester, Minnesota (a 1,626-physician group practice), Scottsdale, Arizona (a 332-physician group practice), and Jacksonville, Florida (a 316-physician group practice). The Mayo Clinic evolved from the frontier practice of William Worrall Mayo, M.D., and his two sons, William J. Mayo, M.D. and Charles H. Mayo, M.D. Twenty years before both brothers died in 1939; they turned over the Mayo Clinic name and assets, and their life savings, to a not-for-profit, charitable organization now known as the Mayo Foundation. Mayo Clinic staff now treats complex medical problems in every specialty. The Mayo School of Graduate Medical Education has trained more than 16,000 alumni since 1915. About 12,000 allied health staffers (clinic and hospital) are part of the Mayo Health System. The Mayo School of Continuing Medical Education formally became a school in 1996.

Marjorie Greenberg then presented an “Activities of the NACC”. After welcoming attendees and thanking the Planning Committee, she pointed out that this was the first NACC ICF meeting with a focus on clinical practice, the first with an ICF coding training session and the first to offer continuing education credits. It was only the second of 11 NACC meetings to have a pre-conference tutorial, concurrent sessions, and poster sessions. She stated that at the 10<sup>th</sup> Annual Meeting in Halifax, participants assigned the highest priorities to these activities:

- 1) Crosswalks of assessment tools and terminologies to ICF;
- 2) Development of ICF-based assessment tools;
- 3) Delineation of activities and participation;
- 4) National and international comparisons;
- 5) Empirical applications in clinical practice; and
- 6) Research on environmental factors.

She stated that reasons for holding the 11<sup>th</sup> ICF conference at Mayo include taking advantage of unique expertise and experience of Mayo Clinic hosts in clinical practice and research, terminology development, clinical concept representation, and mapping. Since last year’s meeting in Halifax there have been a number of ICF accomplishments:

- 1) Monthly or bi-monthly ICF Clearinghouse messages published at <http://www.cdc.gov/nchs/about/otheract/icd9/icfhome.htm> have continued (albeit with a gap due to Paul Placek's retirement, then rehiring as a CDC contractor);
- 2) NACC presented the draft research agenda from the Halifax meeting at the WHO-FIC (Family of International Classifications) Network meeting held October 2004 in Reykjavik, Iceland;
- 3) Margaret Giannini, M.D., Director of the Office on Disability/DHHS continued support for the ICF Subcommittee of the U.S. New Freedom Initiative and encouraged ICF awareness and training in Federal agencies;
- 4) An interactive, web-based training tool developed by NCHS called "Code ICF" was completed and sent to WHO for installation on their website;
- 5) Several significant research awards with ICF components were noted;
- 6) NACC applauds progress on the Procedural Manual and Guide for Standardized Application of the ICF: A Manual for Health Professionals;
- 7) NACC also notes the review version of the ICF for Children and Youth;
- 8) The National Institute on Disability and Rehabilitation Research has funded a Rehabilitation and Research Training Center at Cornell University;
- 9) The NACC Head conducted ICF training in Thailand in partnership with Sirindhorn National Medical Rehabilitation Center and other members of the WHO-FIC Network.

Carolyn Heick of the Canadian Institute for Health Information (CIHI) gave a welcome from Canada and an overview of Canada's past year ICF accomplishments. CIHI works on various disease and intervention classifications, grouping methodologies, and clinical data standards. A variety of ICF activities in Canada are completed or underway. CIHI hosts and sponsors the annual NACC conference, and helped launch the NACC Clearinghouse listserv in 2002. CIHI undertook a study exploring the development of mutually exclusive lists for activities and participation, and coordinated the Canadian French translation of ICF. Statistics Canada was involved in DISTAB and in the United Nations Washington City Group on Disability Statistics. ICF is included in the curriculum of all Schools of Rehabilitation in Canadian universities from the baccalaureate to the Ph.D. level. The Vancouver Coastal Region Health Authority is exploring using the ICF framework in strategic review of rehabilitation services.

Canada's national health interview survey, the Participation and Activity Limitation Survey (PALS), is based on the ICF framework. CIHI has been instrumental in The Round Table Project of Ontario embracing the ICF

framework. The Human Resources Social Development Department in the Federal Government has launched discussions with CIHI to investigate using ICF in their Disability Income Replacement programs. Finally, as a member state of the WHO, CIHI contributes to the WHO-FIC and Collaborating Center meetings through participation and presentations.

Bedirhan Üstun of WHO presented “The WHO Report” on the “Added Value of ICF within the WHO Family of Classifications”.

Üstun stated that the WHO constitution mandates the production of international classifications on health so that there is a consensual, meaningful and useful framework which governments, providers and consumers can use as a common language. The WHO Family of International Classifications is comprised of reference classifications, derived classifications, and related classifications. Reference classifications are ICF, ICD (The International Classification of Diseases), and ICHI (The International Classification of Health Interventions). Derived classifications are the International Classification of Diseases for Oncology, Third Edition – ICD-0-3; the ICD-10 Classification of Mental and Behavioral Disorders; the Application of the International Classification of Diseases to Dentistry and Stomatology, Third Edition—ICD-DA; and the Application of the International Classification of Diseases to Neurology—ICD-10-NA. Related classifications are those that partially refer to reference classifications, and include ICPC (the International Classification of Primary Care), ICECI ((International Classification of External Causes of Injury), ATC (The Anatomical, Therapeutic, Chemical Classification System with Daily Defined Doses), and ISO 9999 Technical Aids for Persons with Disabilities. He provided an example of how ICF captures the disability experience with an African boy with HIV, “before”, and nine months after treatment. He agreed with President George Bush’s January 20, 2004 statement on the need to computerize health records, and proposed that ICF’s use in e-records would assist in matching of concepts, coding, and technical representation. He described “SHOW ME” projects (such as those incorporating ICF into e-health records) and “U-2” projects (such as on item banking and terminology links). Finally, he referred interested persons to the ICF website <http://www.who.int/classification/icf>.

The first of two plenary presentations was by Christopher Chute: “The Spectrum of Clinical Data Representation: A Context for Functional Status”. He admittedly gave what he called a “fun overview” of clinical data representation, and pointed out that “compassionate resource management” is a euphemism for “saving money”. He suggested that the computer is the bicycle of the mind, because even if you read ten journal articles per day, you are still 800 years behind in your reading. He discussed frame language, descriptive logic, attributive logic, and computational complexity. He gave the example of prostate cancer in SNOMED-CT. He asserted that ICF is relevant to “descriptive logic (DL) because DL is transforming our understanding of what defines a concept and DL tooling is transforming our ability to craft, edit, and maintain coherent and

cogent vocabularies. He discussed digital biology, digital medicine, bio-computing, ontologies, Ogden's Semiotic Triangle, modern health vocabularies, aggregation logic, and abstraction layers. In discussion after his presentation, he asserted that computers won't do all the work, and that the human/computer interface is still needed to make judgment calls.

The second plenary presentation of the day was by Julie Richards of Canada Health Infoway: "Strategies for Terminology and Implementation: The Canadian Perspective". She provided an overview of the Canadian Health Care System, which recognizes the need for electronic health records (EHR's). The goal for Canada is EHR's in place for 50% of the population by 2009 and 100% by the year 2020. The EHR is: a private lifetime record; clinically relevant; includes all encounters; and is structured, integrated and semantically consistent. Canada Health Infoway <http://knowledge.infoway-inforoute.ca> will guide the transition. Infoway is developing a portfolio of clinical terminologies to cover all of the programs. ICF is being considered in this context, but the ICF community must push policymakers to include ICF or it may not become part of the portfolio.

The third and final plenary of the day was presented just after lunch by Elizabeth Badley: "An Integrated Model of Disablement for Research and Clinical and Rehabilitation Practice".

She presented her own model, which integrates the ICF with the other tripartite classifications of disablement (ICIDH, Nagi model, Quebec model). Her "Integrated Model of Disability" has five components:

- 1) body function and structure;
- 2) actions;
- 3) tasks;
- 4) societal participation; and
- 5) social involvement.

These five are distinguished by a number of specified criteria.

She asserted that her model is fully-specified, accounts for all distinct aspects of disablement, and has potential for increasing understanding for clinical treatment and rehabilitation.

**Wednesday, 2:00-3:30 p.m.**

**Concurrent Session 1: Mapping Questionnaires and Surveys to the ICF:  
Tools and Resources for Mapping**

Roger Smith with Kathy Rust presented “Matching Assistive Technology Interventions to the ICF”. Smith developed a prototype computerized assessment instrument (called “ICF-FACT”) which allows matching and scoring ICF categories to assistive technology device outcomes. ICF FACT uses the ICF taxonomy as its branching question set and continues the application of memo fields (originally developed in OT-FACT, with AOTA) to track assistive technology device use.

The second paper in Concurrent Session 1 was “Analysis of ICF-Compatible Items on Support Needs in a National Administrative Dataset” presented by Philip Anderson. Australia’s Commonwealth State/Territory Disability Agreement National Minimum Data Set is an administrative data collection which covers all users of government-funded disability in Australia. The items on assistance were designed to be compatible with the Activities and Participation part of the ICF, and with the Australian National Survey of Disability, Ageing and Carers. This paper demonstrates the operationalization of ICF in both surveys and administrative data. For more information: [www.aihw.gov.au](http://www.aihw.gov.au).

The third of these papers in Concurrent Session 1 was “Use of ICF in Health Information Systems and Surveys”, by Richard Madden et. al. The authors suggested that clarity of purpose for different uses of ICF is essential, including: purposes of information collection; the selection of components and domains “fit for purpose”; operationalization of qualifiers including the “constructs” of capacity and performance; and relationship to existing applications and data sources.

**Wednesday, 2:00-3:30 p.m.**

**Concurrent Session 1: Mapping Questionnaires and Surveys to the ICF:  
Clinical and Administrative Mappings to the ICF**

Michelle Dougherty, Susan Fenton, and Kathy Giannangelo authored “Creating a Business Case for ICF”, and the paper was presented by Sue Bowman. The American Health Information and Management Association (AHIMA) considers the ICF as key to ensure the collection of complete and accurate health care data, but first a “business case” must be made to

stakeholders. Needed steps are: to review the relationship of ICF to traditional coding systems; to evaluate how ICF and other coding systems can be used together; to discuss how ICF can be used in the electronic health record; to investigate training requirements; and to explain the uses of mappings. A goal is to present this paper to the U.S. National Committee on Vital and Health Statistics Workgroup on Quality should they decide to hold hearings on this subject.

Marcia Scherer (with co-authors Quintanilla and Houtenville) presented “Barriers to Data Integration among Various U.S. Rehabilitation Agencies”. U.S. agencies are inconsistent in how they define disability and collect relevant data, which presents barriers to establishing the ICF as the basis for inter-agency communication, data collection, and sharing. The Rehabilitation Research Training Center on Demographics and Statistics at Cornell University is a five-year project funded by the U.S. Department of Education. It will focus on the ICF as providing a common language for administrative data and disability determination.

Carolina Gonzalez Schlenker presented the “ICF as a Tool for Community-Based Participatory Research”. Twenty five key informants in Kenosha, Wisconsin were interviewed about physical and psychosocial health data of Latino Children (birth to teenage) to develop a consensus on the state of health of area children and develop a plan of action. The themes searched were the categories of the ICF, and statements were coded to the ICF. Therefore, the ICF can be the framework for community-based participation research and can be used to create consensus on health policy.

The fourth and final paper in the “Clinical and Administrative Mappings to the ICF” Concurrent Session was presented by Nathalie Veillette et. al.: “Identifying Content Areas for the Assessment of Functional Status for Frail Elderly in the Emergency Department”. The authors conclude that the ICF conceptual framework would be helpful for developing a tool for assessing functional status of the frail elderly visiting emergency departments. This conclusion was based on reviews of content domains from inventories of functional status and from 18 instruments in use in Canada. None of the inventories or instruments covered all ICF domains, so the ICF was judged to be the most comprehensive framework for assessing functional status.

**Wednesday, 4:00-5:30 p.m.**

**Concurrent Session 2: Developing Questionnaires and Surveys from ICF: Comparisons between Clinical Observations and Structured Questionnaires**

Anthony Lequerica (co-author, Els Nieuwenhuijsen) presented “Mapping a Dataset Examining Older Post-Polio Survivors to the ICF: A Confirmatory Factor Analysis Approach”. Data from 1,135 polio survivors in Michigan were back coded to ICF dimensions of Body Structure and Function, Activity, and Participation. Confirmatory factor analysis and goodness-of-fit indices were compared to determine the best fitting model. Results supported the ICF model, with distinctions between Activity and Participation, but also with two distinct components within the Activity dimension.

Carolina Moriello et. al. presented “Activity and Participation among Elderly: Using the ICF to Identify CAN DO before it becomes CAN’T DO.” All 41 items on the CHAMPS (Community Health Activities Model Program for Seniors) were coded to the ICF by consensus of three raters. A set of activity indicators was qualified to monthly frequency and change from before to after surgery is planned. The ICF captures much of the “can do” but lacked specificity for some exercise-related activities.

Marcia Scherer (co-author, Caren Sax) presented “Cross Mapping the ICF to a Measure of Assistive Technology (AT) Predisposition and Use”. Ninety-nine items on the Assistive Technology Device Predisposition Assessment (ATD PA) were successfully cross-mapped to the ICF. ICF “matches” were even found for many ATD PA items on subjective health, well-being, and quality of life. More information is available at: <http://members.aol.com/IMPT97/MPT.html>. There is rarely a one-to-one correspondence between survey items and ICF codes; multiple ICF codes may underlie a particular survey response; and many ICF codes consist of more than one type of behavior or response.

**Wednesday, 4:00-5:30 p.m.**

**Concurrent Session 2: Developing Questionnaires and Surveys from the ICF: Developing New assessment Tools Based on the ICF.**

Caryn Nash et. al. presented “Identifying Frailty Using the ICF: Proof of Concept”. Frailty is a concept for understanding aging and has disability at its core. Using Hogan et. al.,’s 2003 paper on “Models Definition and Criteria of Frailty”, 97 frailty indicators were indicated and mapped to ICF by three experts. Overall, 83% of these indicators could be mapped to the ICF. Several commonly-

used terms in the frailty literature (vulnerability, pre-death, poor self-rated health, eligible for institutionalization) could not be coded and the use of such terminology should be discouraged.

Jiro Okochi presented “Development of Communication Scale for the Elders Based on the ICF and its Qualifiers”. Data were from 788 Japanese elders age 65 and over. The 27 ICF items in the Activity and Participation and Body Function (related to communication) domains were measured using the ICF qualifier. Rasch analysis was performed. As a result, seven ICF items were selected as candidates for a scale to measure communication performance and function among elders.

Seija Talo et. al, presented “The ICF-based documentation of the Quantified Biopsychosocial Functional Status for Administrative Purposes in the Finnish Client Work”. Talo presented an ICF-based scheme to quantify the biopsychosocial functional status profiles of administrative client work at Tampere University Hospital. Baseline and outcome functional status were assessed in clients sent by social- and Labour Offices or Service centers and Central Hospital Mental health units. The ICF was successfully demonstrated for use in: 1) assessment; 2) documentation; and 3) intervention plans.

Satoshi Ueda (co-author, Yayoi Okawa) presented “A Project Named Comprehensive Collaborative Functioning--Promoting Initiative and ICF-based Population Survey in a City near Tokyo”. Near Tokyo, a survey of 5,938 persons age 65 or over were surveyed. They included people without disabilities and those with disabilities (recipients of National Personal Assistance Insurance). An 86-item questionnaire based on the ICF was administered with response rates over 90%. This survey yielded many interesting results on objective and subjective functioning. These subjective factors should be incorporated in the ICF when it is updated.

**Wednesday, June 22, 2005**

### **AFTERNOON POSTER SESSION**

Seven papers were presented in poster sessions on Wednesday afternoon.

Carolina Schlenker presented “Solidarity as an Organizing Principle for the ICF”. This was a position paper which challenged the decision by ICF writers of leaving out of the ICF circumstances brought about by socio-economic factors. Solidarity is used as understood by Durkheim in his sociology and in his theory of stress. The solidarity model has been used in studies of Latino health and is essential for understanding the social determinants of health.

Yuichiro Haruna presented “Disabilities in Working Life for Persons with Various Intractable Diseases Influenced by Workplace Environments—Results of Mail Survey Based on ICF Framework in Japan”. He used Activity and Participation domain questions in a mail survey of 3,691 (of 9,901 contacted) patient groups age 18 to 65 with various intractable diseases. He found that workplace and environmental modifications ameliorated many activity and participation limitations.

Elias Mpofu presented “Developing a Measure of Patient Values for Community Participation”. This paper proposes the use of concept mapping procedures to identify patient values for the measure construction. In this approach, concept mapping is defined as an inductive, qualitative method for describing social reality from the viewpoint of the participants. Outcomes from this mapping are then used to construct items for a patient values scale, and then item response theory techniques are used to scale the items.

Jiro Okochi presented “Do Three Digit ICF Items Really Represent Four Digit Items?” This was a cross-sectional study of 788 Japanese elders age 65 and over in which analysis was performed on mental function of language-related items in the Body Function domains. One conclusion was that precedent 3<sup>rd</sup> digits do not always connote the 4<sup>th</sup> digit in ICF items, when measurement is carried out.

Prvu Bettger and co-authors presented “Home and Community Participation Outcomes Post Acute Care: The Role of the Environment”. This was a cohort study of 365 older adults followed up at one and six months after discharge from acute and rehabilitation facilities. Six environmental factors (home and community mobility barriers, social support, transportation facilitators, and communication and mobility assistive technologies) were found to influence participation, at least in the early post-acute care stage.

Kassem Sara presented “Arabic-English Version of ICD and ICF Module”. The authors represented the Regional Office for the Eastern Mediterranean (WHO/EMRO) which consists of 23 member states. Arabic is the official language of 18 of them. The author was disseminating the CD-ROMs for both ICD-10 and ICF in Arabic.

Kris Pizur-Barnekow (with co-authors) presented “Missing in Action: Products and Technology for Medical Services”. The authors point out that while the ICF recognizes health services (e580) and technology (e110-e199), products and technology for medical services are neglected. This ICF omission is identified using information from the Medical Equipment Device—Accessibility and Universal Design Information Project.

After the meeting adjourned on Wednesday, there was an optional tour of the Mayo Historical Suite, history of Mayo presentation, tour of a Mayo museum, and reception.

**Thursday, June 23, 2005**

## **Plenary 1 – The ICF and Clinical Practice**

Geoffrey Reed presented “Utility of the ICF for Health Professional”. Reed described an activity supported by the American Psychological Association—the development of the Procedural Manual and Guide for a Standardized Application of the ICF. This effort has been a multi-disciplinary endeavor with support from representatives of these professions: audiology, medicine, nursing, occupational therapy, physical therapy, psychology, social work, speech-language pathology, therapeutic recreation, and vocational rehabilitation. He discussed results of consensus conferences of health professionals and envisioned a final product in fall of 2005.

Diane Brandt presented “Physical Therapy and ICF: Functional Stepping Stones to the Future”. Brandt is the American Physical Therapy liaison for Chapter 4 (Mobility) of the ICF Clinical Manual. She pointed out how the ICF translates to physical therapy terminology. The PT guide examination categories related to specific ICF codes were: aerobic capacity/endurance; anthropometric characteristics; arousal, attention, and cognition; assistive and adaptive devices; circulation; and cranial/peripheral nerve integrity.

Marie Di Cowden presented “The Impact of ICF Coding in Practice”. She described the Biscayne Institute of Health and Living in Miami as a model for community-based, integrative care that employs the ICF to track progress in patients over the long term and uses ICF—based data to influence reimbursement and regulatory health care policy. She described the case of Joseph, for which she is using the ICF in a current legal challenge with the Florida Division of Workers’ Compensation. Finally, D. Cowder has cross walked the ICF with the Functional Independence Measure and Functional Assessment Measure in analyzing patient progress.

The third plenary presenter was Amy Coenen: “Mapping ICF to the International Classification for Nursing Practice (ICNP)”. The International Council of Nurses released the ICNP Version 1 in May 2005. It was developed in Web Ontology Language (OWL) with Protégé Software, enabling electronic patient record systems and corsets. Mapping the ICF to ICNP was proposed. More information is at: [www.icn.ch](http://www.icn.ch).

**Thursday, June 23, 2005**

## **Plenary 2 – ICF: Issues Related to Children and Youth**

Don Lollar presented “Aligning ICF with Childhood Assessments”. He described the work of the WHO International Child and Youth Task Force in developing ICF-CY. ICF-CY was designed for use with infants through youths up to age 18. The work of the Task Force was completed in 2005, and soon the ICF-CY will be on the WHO ICF website for a six-month review and comment period. The ICF codes structure is retained with the majority of the original 1,495 ICF codes unchanged. There are over 200 new “CY” codes, almost 100 expansions, and about 200 modifications.

Scott Campbell Brown presented “Operationalizing the ICF for Evaluation of Infants and Toddlers in Early Intervention Using the Bayley Short Form Research Edition”. He reviewed efforts to synthesize the ICF with the Bayley Short Form, The Early Childhood Longitudinal Study Birth Cohort survey, and the National Early Intervention Longitudinal Study. Data were extracted on the basis of the ability to be back coded to the ICF. Most childhood development measures from these data sets and assessment tools could be captured in the ICF, and the author concluded that the ICF could be used to describe results in a nationally-representative survey that employs clinical-type assessments. As a result of this study, the Office of Special Education Programs Early Intervention Data Handbook Version 1.1 includes 14 ICF codes. More information is available at: [www.ideadata.org/](http://www.ideadata.org/).

The third Plenary 2 presentation was by Rune Simeonsson: “Clinical Documentation with the ICF in Child Services”. Simeonsson pointed to the ICF-CY as the basis for a common language for documenting functional characteristics of health of children with chronic conditions and disabilities. The ICF-CY provides both a model for framing the focus of services and also a set of codes to document health states. The ICF-CY can contribute to clinical practice in four applications: 1) a profile of functional characteristics can complement medical conditions diagnosed with ICD; 2) repeated assessments overtime can track changes in functioning; 3) documentation of functional status is a basis for intervention and treatment plans; and 4) the ICF model can frame domains of outcomes, and intervention effects can be documented.

**Thursday, June 23, 2005**

**Concurrent Session 3: “The ICF Life-Cycle Change Management: Revisions, Updates, Code Enhancements**

Anita Scarborough (co-author, Rune Simeonsson) presented “Defining Environment Factors of Young Children in Early Intervention”. Data were from the National Early Intervention Longitudinal Study (NEILS) [www.sri.com/neils](http://www.sri.com/neils) in which primary caregivers were interviewed when their child was between 36 and 40 months of age (N=2,584). ICF codes were assigned to child factors (disability indicators) and environment (products, housing, transportation, economic, etc.). Child disability indicators and the use of a medical device were found to be significant predictors of child participation. Social support and transportation were associated with family participation. This study showed that the ICF can document the need for environmental accommodations and supports.

Koji Tanaka presented “Evaluation of the Environmental Factor of the Elderly People with the ICF”. He studied 690 persons age 65 and over in Japan with a questionnaire based on all three-digit ICF items and 20 four digit items of the environmental factor with the ICF facilitator qualifier. He found that some ICF items were difficult to evaluate due to some ambiguities of terminology in ICF environmental factors.

Aiko Takunaga et. al. presented “Use of the ICF-CY to Develop a Comprehensive Intervention Program for a Child with Autism: A Case Study from Japan”. The ICF Checklist 2.1a was used with an ICF-CY questionnaire and an individual education plan was developed after discussing ICF-based information with teacher and parents. A core set of ICF-CY checklist items should be developed for autistic children. A manual in Japanese is now available from the National Institute of Special Education Japan and approved by WHO: “The Applied Use of ICF: Focus on Support for Children with Disabilities”.

**Thursday, June 23, 2005**

**Concurrent Session 3: The ICF Life Cycle—Information Technology Considerations**

Michael Bales et. al. presented “Human and Automated Coding of Rehabilitation Discharge Summaries According to the International Classification of Functioning, Disability and Health”. The authors used a form of natural language processing—MedLEE—to code 75 rehabilitation discharge summaries

to ICF codes. MedLEE's lexicon and coding table were modified to allow for five selected ICF main codes. Expert coders were found to perform significantly better than novice coders, who performed slightly better than the MedLEE system. Facets of human and automated ICF coding were discussed.

Cyril Gryfe presented "Navigating from Engel to Weed Using an ICF Map". A cumulative patient profile (problem) list; as promoted by Lawrence Weed was integrated with a conceptual model of the initial patient-physician encounter based on G. L. Engel's biopsychosocial model, using ICF as a guide. Implications for an interactive computerized cumulative patient profile were discussed.

G. Savova et. al. presented "Frame Representation of ICF". This study explored the applicability of FrameNet (FN) methods to the ICF, towards the eventual goal of ICF semantic processing. FrameNet uses frame semantics and addresses natural language variability by slot-and filler templates that can be combined for text semantics. The self-care domain (d510-d599) was compared with automated FN mapping and FN mapping after validation. Ambiguities within the ICF were observed, and FN provided near complete coverage for the ICF self-care domain.

Catherine Sykes et. al. presented "A Health Outcome and Functioning Module: The Development of a Data Capture Tool for Health Information System". The authors described work which the Australian Institute of Health and Welfare has engaged in to explore the value of a module of information on functional status using ICF as the framework. Mapping existing tools to the ICF has shown that the tools vary in the domains they cover, the questions used, the response categories and measurement scales, the temporal context, the assessment environment, etc. It was judged not possible to reliably map data collected using a range of existing tools to a single data capture framework based on the ICF by "rolling up" to a "meta map". It was concluded that a new compact outcome module should draw from existing tools.

**Thursday, June 23, 2005**

### **Hands-on Coding Workshop**

The hour-and-a-half Hands-on Coding Workshop was primarily managed by Nancy Mayo and Lynn Bufka, with assistance by Marcelline Harris and Geoffrey Reed. Nancy Mayo presented a case example of Mr. WHM, an 81-year-old gentleman who had suffered a stroke eight weeks earlier. On the handout, persons were encouraged to highlight the key functional status terms. These were then shown on the screen, with correct ICF codes juxtaposed. Nancy Mayo also used another handout on Mr. WHM entitled "The Preference-Based Stroke

Index—A Stroke-Specific Preference-Based Index Measure to Accompany the EQ-5D”, developed by Lise Poissant, Nancy Mayo, Sharon-Wood-Dauphinee, and Ann Clarke (Health and Quality of Life Outcomes 2003, 1:43). Fifteen ICF domain areas for Mr. WHM were listed, and participants were asked to assign a severity level.

Lynn Bufka presented the case example of a 78-year-old man with advanced Alzheimer’s disease living in a nursing home. Attendees were asked to highlight key phrases in the narrative and suggest ICF codes. She also distributed the “Adult Functional Adaptive Behavior Scale” authored by Philip S. Pierce, which lists 14 functional conditions from D.S.M. IV. These conditions were then related to ICF codes. Finally, a case study of Mrs. B., who was admitted to a nursing facility from a hospital following a fall in her home, was distributed. There was insufficient time to discuss it, but the exercise can be found at: <http://son.uth.tmc.edu/coa>.

After the session ended, an optional dinner at the Plummer House was held.

**Friday, June 24, 2005**

### **Plenary - Policy and Consumer Issues**

Joel Kahn presented “The National Council of Disability Perspective on Statistics”. NCD is an independent federal agency chartered to advise the President and Congress on matters affecting people with disabilities. Dr. Kahn is one of 15 NCD members appointed by the President and confirmed by the U.S. Senate. He is also an Engineer at Procter and Gamble in Cincinnati, Ohio. His voice was soft due to multiple sclerosis, so his assistant Ian Grumbine made part of the presentation. The NCD position on improving federal disability data is specified in two reports at [www.ncd.gov](http://www.ncd.gov): “Reorienting Disability Research” (1998), and “Improving Federal Disability Data” (2004). Look for a Fall 2005 report soon.

“I believe that using the ICF would improve Federal disability data”, Dr. Kahn stated “ICF should be the common core of data for Americans with disabilities”, he continued. Dr. Kahn pointed to the same advances in the field, such as 2000 Census data on disability and the Americans with Disabilities Act. He also pointed to a policy need for ICF because it moves from a disease model to a functional limitation model. Dr Kahn pointed out that data affects policy decisions, and he emphasized the types of data needs by private industry and legislatures. He stated that future data needs include: back coding of surveys to improve comparability; more comparisons of international disability data; the use of ICF-CY; the implementation of ICF into surveys; the use of ICF longitudinally;

the use of ICF in government programs with career and job training emphasis; and the use of ICF for long-term support services and benefit determination. Afterwards, there was discussion on how the NCD as an organization might take a more active role in ICF implementation.

Next, Marcelline Harris summarized the meeting from her own perspective in a presentation entitled: “Mapping—Can We Get There from Here?” She felt that the meeting had met many of its objectives: examining the ICF in relation to practice, education and research; describing the potential of health information systems to shape future ICF developments; analyzing motivations and methods for mappings of various types; investigating challenges in mapping between ICF and other coding systems; applying the ICF in simulated clinical situations; discussing the role of the ICF in setting priorities; and mapping the clinical world to the ICF (or, mapping the ICF to the clinical world?). Harris reported that there were papers on “what is mapping?” and pointed to variety in mapping “to”, “from”, and “across”. She highlighted research presented on typologies, taxonomies, and ontologies. Harris pointed out papers presented in “mapping methods” (roles for obtaining consensus, validity in clinical studies, statistical methods, and computational methods emphasizing semantics). Harris raised definitional issues on “What is the ICF?” Some regard it as a conceptual framework for guiding assessments, while others regard it as a tool for measurement, a diagnostic tool, or an ontology for organizing domain language.

After Harris’ presentation, there was discussion around these issues: the need for operational definitions of all kinds which are ICF-based; the need for ICF items banks and a proposed hiatus on other scales; the need to map ICF to the UMLS and the entire terminological world; and the need for ICF to be implemented into the electronic era. Several participants issued cautions: “We are at ICF-1, not ICF-10, so let’s give ourselves a break”; “Be aware of relevant political issues, and recognize the political aspects of ICF implementations;” “Be realistic that the ICF may not do well all the things which some say it will;” “Be cautious about the reliability issue, a weak link”.

Finally, brief international updates were given, and ceremonial gifts were exchanged to thank planners and hosts. Diane Caulfeild of the Canadian Institute for Health Information announced that the 12<sup>th</sup> Annual NACC Meeting on ICF will take place in Canada in June 2006.