Report of the Twelfth Annual North American Collaborating Center Conference on ICF

June 5–7, 2006

Canadian Institute for Health Information

Institut canadien d'information sur la santé

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Overview

The North American Collaborating Center (NACC) for the World Health Organization Family of International Classifications (WHO-FIC) conducted its 12th Annual Conference on the International Classification of Functioning, Disability and Health (ICF) in Vancouver, British Columbia, June 5–7, 2006. The NACC Conference included 110 attendees. An additional 39 RehabNet members attended the ICF conference. Fifty ICF papers and posters were accepted for presentation and three workshops were delivered.

The Conference sponsors were: The Canadian Institute for Health Information (CIHI); Statistics Canada; the National Center for Health Statistics (NCHS, CDC); and Human Resources Social Development Canada.

The conference theme was "Living in Our Environment: The Promise of ICF." One of the two concurrent session tracks during the conference was dedicated to this theme. This was the first ICF NACC conference devoted to the Environmental Factors domain within ICF. The NACC Conference opened on Monday, June 5, with a Welcome Reception. On June 7, the NACC invited RehabNet, an association of Canadian rehabilitation facility administrators, to share the day and present a third track of their specific concurrent sessions. This was a very successful partnership.

The opening and closing plenary speakers were Sam Sullivan, the Mayor of Vancouver, and Michael Harcourt, the former Premier of British Columbia and former Mayor of Vancouver, respectively.

June 6—Opening Plenary

The opening keynote speaker, Sam Sullivan, Mayor of Vancouver is a person with quadriplegia with an inspiring array of accomplishments. His participation in life, especially recreation and work, is what has motivated him. He provided a number of examples of what helps him to participate. What are needed are environments that provide assistive devices and people willing to lend a hand. He is the founder of: the Disabled Sailing Association in British Columbia; the Vancouver Adapted Music Society (which works with 50 disabled musicians annually); the Tetra Society (in which engineers develop projects to assist persons with disabilities); and the B.C. Mobility Opportunities Society (which uses trailrider devices to allow a hiking experience for persons with disability). Mayor Sullivan expressed optimism that the 2010 Winter Olympic Games and Paralympic Games, to be hosted in Vancouver, would yield not only new buildings and physical environmental changes in Vancouver, but also attitudinal changes about the capabilities represented by our populations with disabilities.

Mayor Sullivan's challenge to participants is to use the ICF to help make the world more accessible.

June 6—Welcoming Remarks

Caroline Heick of CIHI thanked Mayor Sullivan for sharing his vision of an accessible Vancouver with us. She went on to describe CIHI's mandate of health information for health policy and several Canadian ICF initiatives such as "The Ontario Round Table: Return to Function, Return to Work," and providing three Canadian experts for the WHO-FIC Functioning and Disability Reference Group.

Susan Stobert of Statistics Canada gave an overview of the 2006 Canadian "PALS" (Participation and Activity Limitation Survey) that used the ICF as a reference point.

Marjorie Greenberg, head of the NACC, noted that this was the third ICF NACC conference with tutorials, concurrent sessions, and poster sessions, the second with ICF coding training sessions, and the first with a focus on the environment. She also noted a focus on ICF applications in Federal government by the New Freedom Initiative ICF Subcommittee, a special issue of *Rehabilitation Education* with ten articles on the ICF, and ICF endorsements by the National Council on Disability and The American Therapeutic Recreation Association. She challenged participants to consider a role for ICF as a conceptual model and classification for application in "hot topics" areas such as: in health information policy; electronic health records; health data standards; clinical terminology, and eliminating health disparities.

Discussion: After Ms. Greenberg's presentation, John Stone and Paul Placek were invited to describe the new ICF Community of Practice. There are now several ICF websites plus a "one stop shopping for all ICF needs." Another attendee pointed out a "disconnect" between the annual ICF meetings and the annual Society for Disability Studies meetings, and suggested that this gap be bridged. Patrick Fougeyrollas stated that in August 2008, he was hosting the meeting of the 21st World Congress of Rehabilitation International in Québec City.

June 6—10:30 a.m.–12:00 p.m.
Concurrent Session: "Environmental Factors"

G. Scott Danford: "Universal Design and the ICF" (co-author Edward Steinfeld). This paper proposed a way to blend the principles of universal design with the ICF. The "Seven Principles of Universal Design" were developed ten years ago to help design practitioners implement universal design concepts and make the everyday environment more effective for people with various abilities. Both the ICF and the Principles recognize the physical environment as a major influence on human experience, and both recognize that people without impairments also experience limitations due to the influence of non-supportive environments.

Harry Feliciano: "Public Health Policy as Continuing Medical Education." This presentation described Palmetto GBA's incorporation of the ICF into public health policy statements known as Local Coverage Determinations (LCDs). LCDs are Medicare public policy statements specifying under what clinical circumstances a service is considered to be "reasonable and necessary." The LCD uses the ICF to help Medicare providers understand Medicare coverage of "teaching and training" home health services for caregivers of beneficiaries with Alzheimer's disease and behavioral disturbances.

Jon A. Sanford: "The Physical Environment as an Independent Measure: A Framework for Understanding the Role of Environmental Attributes in Activity and Performance Outcomes (co-author, Carrie Bruce). The authors proposed a hierarchical model for understanding and measuring the attributes (i.e., spaces, products, and interfaces) of environmental elements. A conceptual framework for applying this model within the home was described using examples of 20′ vs. 30′ ramps of differing slopes.

Corinne Kirchner: "Assistive Mobility Technologies in Urban Neighborhood Environments: Research to Use and Improve ICF's Environmental and Activity/Participation Domains" (co-authors, Brooke Smith, Elaine Gerber). The authors reported research underpinned by ICF concepts regarding environmental barriers to physical activity in urban neighborhoods. They compared four types of assistive mobility technology (AMT): manual vs. motorized wheelchairs used by persons with motor impairments, and guide dogs vs. long canes used by persons with visual impairments.

Discussion: In response to a question, Mr. Danford stated his five-year grant was just beginning, and that he was interested in universal design for homes, neighborhoods, and public accommodations. He also suggested that universal design is for all people and therefore very palatable as a "carrot," whereas the ADA takes a "stick" approach which often generates antagonism from building owners.

June 6—10:30 a.m.–12:00 p.m.
Concurrent Session: "ICF in Surveys"

S. Antonio Ruiz-Quintanilla: "Using the ICF to Assess and Categorize Survey Questions" (co-authors Robert Weathers and Andrew Houtenville). The authors showed how current survey questions on disability map to ICF concepts. The survey instruments used were the American Community Survey (ACS), the decennial Census long form, the CPS (Current Population Survey), the National Health Interview Survey (NHIS), and the Survey of Income and Program Participation (SIPP).

Andrew MacKenzie: "Testing the Social Model of Disability with the 2001 Participation Activity Limitation Survey (PALS)" (co-author Pat Newcombe-Welch). The authors tested the social model of disability using the 2001 Participation Activity Limitation Survey (PALS) by examining the relationship between people reporting activity limitations and their environments. The definition of environment included physical environments (including housing, transportation and buildings), social environments (including care received, social contacts, leisure activities and living arrangements), and political environments (including employment characteristics, income levels, and sources of income).

Patrick Fougeyrollas: "Subjective Measurement of Participation and Environmental Barriers and Facilitators in Population Surveys: Use of Standardized Tools with a Sub-sample of the Quebec Activity Limitations Survey (QALS)" (co-authors Julie Tremblay, Luc Noreau, Myreille St-Onge, and Serge Dumont). Dr. Fougeyrollas stated that participation situations and their environmental determinants are new domains to be measured and require new tools. He provided a brief overview of the characteristics of the Life-H (a measurement of social participation) and of MQE (Measurement of Quality of Environment). Results of recent research were presented from the Quebec Activity Limitations Survey (QALS) in which Life-H and MQE short versions were used.

Valerie Bizier: "The Participation and Activity Limitation Survey: Methodology and Construction of a Disability Index" (co-authors Danielle Laroche and Dany Faucher). Statistics Canada has collected information on people with disabilities since 1983. In 1986, two general questions, to identify people with activity limitations and long term disability (referred to as disability filter questions), were added to the Census of Population questionnaire. This addition allowed the conduct of the first postcensal survey on activity limitation, the Health and Activity Limitation Survey (HALS). Except for 1996, a postcensal survey on activity limitation has been conducted after each Census. This survey uses the Census as a sampling frame to identify its target population. In 2001, HALS was renamed the Participation and Activity Limitation Survey (PALS). The PALS methodology and screening questions were presented.

Discussion: In response to several questions, Mr. MacKenzie fielded questions related to PALS in reference to income, variances, odds ratios, sample sizes, weights, stepwise regression, and whether he was satisfied that 2006 PALS had adequate coverage of the participation domain. Dr. Fougeyrollas addressed the need to have social data for policy purposes and to have good measurement tools for micro and macro environmental data. There was also a brief discussion of whether there is a need for a "theory of disability" to use with the ICF model.

June 6—1:30–2:15 p.m.
Plenary Session: David Gray and Patrick Fougeyrollas

David Gray: "Conceptual Evolution of Classifying and Measuring Participation and the Environment." He clarified the components of the interactive model and provided comments on two conceptualizations: the ICF and the Disability Creation Process (DCP). Dr. Gray pointed out that the key to clarifying the components of models is to recognize that the types of questions asked are fundamentally different for activities and participations. He addressed the following topics: measures to inform national policy and intervention effectiveness; which codes are amenable to use by health care professionals; possibilities for further development of E codes in the ICF, and the linkage of participation to environmental influences in a manner that makes participation an essential component to interventions.

Patrick Fougeyrollas: "Convergences and Differences Between ICF and DCP: The Issue of Environmental Factors' Influences in the Construction of Human Functioning and Disability." The Quebec Classification—Disability Creation Process (DCP)—grew out of a disability social movement three decades ago. Human rights and the social environment issues were central in discussions during the revision process of ICIDH. ICF and DCP were both the result of international work for improving ICIDH. They had mutual concerns in their development and have similarities and differences related to their scope, concepts, segmentation, operationalization and status of domains.

Discussion: It was acknowledged that both Dr. Gray and Dr. Fougeyrollas played a major role in developing the participation and environment parts of the ICF. Dr. Gray has developed assessment tools for the ICF, and Dr. Fougeyrollas has developed assessment tools for the Quebec DCP. One comment was that "these presentations gave us the makings of ICF-2." There were opposing viewpoints from the audience on whether the term "standard environment" is useful and practical. There was also discussion of the four A & P options, with one of them defining activity as capacity and participation as performance.

June 6—2:30–4:00 p.m.
Concurrent Session: "Looking Ahead"

Elizabeth Badley: "More than Facilitators and Barriers: Fitting the Full Range of Environmental and Personal Contextual Factors into the ICF Model." Dr. Badley stated that the ICF model shows contextual factors as being associated with the other components, but little guidance is given as to the nature of these associations. The classification of environmental factors likewise gives little guidance as to how it should be used. She presented a conceptual analysis that suggested there are different relationships of various types of environmental factors with parts of the ICF model. She asserted that environmental factors could act as independent, mediating or moderating variables in the disability models.

Lynn Bufka: "Operationalizing the Environment: Applying the ICF in Clinical Settings" (co-authors: Christine Trask, Geoffrey Reed, Lori Ann Nicholson, David Gray, and Patricia Welch Salleeby). The American Psychological Association has been working with WHO and a number of national health professional organizations (representing audiology, occupational therapy, physical therapy, psychology, social work, speech language therapy, and therapeutic recreation) for years on the development of a *Procedural Manual and Guide for a Standardized Application of the ICF* intended for use by multidisciplinary health professionals. The Manual is intended to provide a standard approach to classification using the ICF for health service applications by including standard interpretations of concepts, operational and case examples of individual codes, and additional information relevant to each code. Recent work on the operationalization of the environment codes for the Manual was described. The Manual identifies overlapping codes (e.g., "e" codes which overlap with other "e" codes; "e" codes which overlap with "d" codes") and provides specific guidance for selecting those codes. The presenter also noted that the availability of particular products or technology is a feature of the environment, but an individual's ability to access such items might be reflective of functioning as described in Activities and Participation. Three options for coding e factors were discussed (e.g., code "e" alone; code "e" for every component; code "e" for capacity and performance qualifiers in A & P), and advantages/disadvantages of each approach were given. Guidance in the Manual includes suggestions for cross-coding items.

Gale Whiteneck: "A Critique of the ICF with Recommendations for Environmental Factors." Dr. Whiteneck's critique of the ICF identified the addition of environmental factors (including a full taxonomy) as the major step forward in conceptualizing disability. However, seven improvements are needed in ICF-2: (1) distinguish activity and participation; (2) add subjective quality of life; (3) provide more specificity about environmental factors; (4) categorize personal factors; (5) refine the model; (6) improve measurement of the domains of disability and test the model, and (7) validate the model by testing interventions.

David Gray: "Participation and the Influence of Personal Assistance and Environment." Dr. Gray developed an ICF-based measure of participation restriction for people with mobility impairments, called "PARTS/M." The ICF "d code" areas covered include: self-care, mobility, domestic life, interpersonal interactions, major life areas, community and civic life, and environmental factors in the natural, lived environments. A total of 604 persons were in the study. The PARTS/M question sequence was described. Items from six participation questions for five self-care activities (30 items) and seven participation questions for 15 other activities (105 items) provide a total of 135 scores for PARTS/M.

Discussion: During all four presentations, there was considerable discussion of the flaws in ICF and improvements needed in ICF-2. An extended comment from the floor highlighted the four major attempts which had been made in North America to distinguish between activities and participation, and that the A & P options were a political rather than scientific compromise. Without that compromise, ICF would not have been approved. It was suggested that "don't let the perfect get in the way of the good." That is, the ICF is good, and should be used now, even though it is not perfect. Dr. Gray commented that data are needed to test and improve ICF, and that critiques are needed to point out flaws to be studied.

June 6—2:30–4:00 p.m.
Concurrent Panel: "Oral Health and Communication Difficulties—Promising Applications in the ICF Environmental Factors Domain" John Hough Tami Howe, Linda Worrall, Michael MacEntee, Clive Friedman, and Oscar Raul Suarez-Sanchez

Tami Howe: "'I Know It Can Change for People with What I've Had': Environmental Factors and People with the Language Disorder of Aphasia" (co-authors L. Worrall, Louise Hickson). Tami Howe summarized the results from two qualitative studies that investigated the environmental factors that hinder or support the community participation of adults with aphasia, a language disorder often caused by stroke. Qualitative content analysis identified 181 barriers and 238 facilitators, and 36 subtypes of environmental factors. The research suggests that key areas such as the time available for communication and other people's awareness of an individual's health condition are not adequately addressed in the current ICF Environmental Factor component.

John Hough: "Oral Health and Communication Disorders: Promising Applications in the ICF Environmental Factors Domain." This presentation focused on applications of the ICF for assessing Environmental Factors (EF) in two broad clinical areas: oral health among individuals and populations with disabilities, and communication disorders, for example aphasia. Research in both areas suggests that the overall set of EF codes needs expansion in order to capture the interacting complexity of environmental characteristics and secondary conditions.

Clive Friedman: "Clinical Practitioners View Point." Dr. Friedman described the politics of disability variously seen as deviance, deficit, tragedy, and/or diversity (where the ICF fits). The limitations of ICF were discussed: complexity, ease of use; cross-trainer reliability, limited buy-in by government agencies, lack of clarity over who performs the assessment, and relevance to oral health issues. Dr. Friedman raised this question: "Can a social justice issue be helped by a classification system?"

Michael MacEntee: "Oral Health and Communication Disorders: Promising Applications in the ICF Environmental Factors Domain." Dr. MacEntee reviewed various views of health, socio-dental indicators and dental psychometrics, models of oral health, the transition from ICIDH to ICF, and new models. The basis of 17 instruments used to collect data on dental health was reviewed, and it was seen that seven (7) used ICIDH for conceptual structure. Assessment questions with positive and negative connotations were reviewed.

Raul Suarez-Sanchez: "Changing the World One Word at the Time: ICF." This presentation reviewed rehabilitation in dentistry, and related the field to the ICF. Dr. Suarez-Sanchez provided an ICF framework for tissue engineering, biomaterials, implants, and prosthetic devices. Edentulism (lack of teeth) was given as an example of the WHO definition for impairment and disability, with dental implants characterized as "failure mode." He also suggested both simple and comprehensive studies to develop research diagnostic criteria in the field of dentistry.

June 6—4:00–5:00 P.M.
Plenary: "Italian Advances in ICF Education, Social Policy and the European Union"

Matilde Leonardi provided an overview of a number of activities of the Headnet Public Health, Disability and ICF Research Group, of which she is the Scientific Coordinator. The Headnet Research Group of the Italian Neurological Institute "Carlo Besta" (www.headnetgroup.it) is engaged in ICF research. Headnet has ongoing collaborations with the European Union, WHO, International Research Institutions, the Italian Ministry of Health, the Italian Ministry of Welfare, and other groups: among them the most important is the EU-MHADIE project (Measuring Health and Disability in Europe: supporting policy development), a three-year project that includes 16 European Centers and 10 different countries. The goal is to develop evidence-based policies using the ICF model and guidelines.

Dr. Leonardi presented the review on the burden of disease in Europe and on disability statistical data as well as highlights from data on disability surveys and on education in children in 35 countries, reported from OECD survey to MHADIE meeting.

Dr. Leonardi also pointed out that as in national surveys also in education systems there is no coherent conceptualization of disability and in education, definitions vary from being impairment-based ("the blind"), activity-based ("attention deficit disorder"), to participation-based ("learning disabilities"). Environmental factors such as education professionals, financing of special education, policy decision, and school organization likely have impacts as well.

She presented a comparative analysis of definitions of disability in 15 countries, the Brunel University report prepared for EU, that found there was a lack of a Common EU definition of disability and this constituted an obstacle for data collection and analysis.

To help resolve this, Measuring Health and Disability in Europe (MHADIE), sponsored a one-day meeting in Prague on June 2, 2006 entitled "Measuring Health and Disability in Europe: Supporting Policy Development." Differences in disability prevalence rates were highlighted. The standard definitions within the ICF were stressed.

Dr. Matilde Leonardi: "Measuring Health and Disability in Europe: Supporting Policy Development-MHADIE" (co-authors C. Pisoni, D. Ajovalasit, G. Cattoni and A. Raggi). MHADIE is a research project financed by the EU Commission for the years 2005–2007. A large clinical data collection on 1,100 patients is ongoing, in a multi-center and cross-

sectional study. The protocol contains disease-specific assessment matched to ICF categories. Six MHADIE partners for patients with neurological, psychiatric, cardiovascular and musculoskeletal diseases are collecting data.

One of MHADIE's partners, Regione Friuli Venezia Giulia, has been mapping survey questions to ICF codes with the view that standardization of survey definitions using the ICF will improve measurement.

Dr. Leonardi discussed the Basic ICF-DIN and Advanced ICF-DIN training. The ICF checklist, WHO-DAS II, and the Supports Intensity Scales were used with 1,800 Italians age 0–64 with a disability pension.

She also pointed out that the ICF is the basic framework for a Master's course as "Case Manager" for graduate students in Medicine, Psychology, Pedagogy, Sociology, and Social Work done with the Catholic University in Milan.

Finally, Dr. Leonardi described some of the "Ethics and Public Health" efforts of Headnet. In collaboration with the Bioethics Center of the Catholic University of Milan, a course was developed for "Opera Femminile Don Guanella," a non-profit religious rehabilitation institution with 35 centers in Italy and 150 centers worldwide. In this context, Headnet trained more than 1,000 social and health workers.

Dr. Matilde Leonardi: "Population Survey on Invalidity Pension in Italy: Defining Needs of PWD with ICF Model" (co-authors G. Cattoni, D. Ajovalasit, C. Pisoni, A. Raggi). The project, in collaboration with FISH (Italian Federation against Handicap) and FIAN (Italian Federation of Neurological Associations) representing more than 60 national associations of Persons With Disability (PWD) and their families, sent over 50 of their delegates to a dedicated ICF training. Training included ICF research protocols, ICF checklist, WHO-DAS II and Supports Intensity Scales (SIS).

Dr. Matilde Leonardi: "Education and Training on ICF in Italy" (co-authors A. Raggi, D. Ajovalasit, G. Cattoni, C Pisoni). The Disability Italian Network (DIN) has provided extensive and comprehensive ICF training throughout Italy. ICF-DIN courses are structured in three steps: (1) A basic course: 8 hours mainly focusing on the non-clinical issue of ICF; (2) An exercise in using the ICF through case-vignette codification and role-playing in administering the ICF Checklist and the WHO-DAS II, and (3) Distance Learning training is provided via internet: one case per week is posted from the 15 cases on DIN's website. To date, more than 6,000 people have been trained with ICF-DIN methodology in Italy.

Discussion: Dr. Leonardi clarified that "DIN" refers to "Disability Italian Network. A comment from the floor was that there is a misconception that, because ICF has flaws, it's not ready for prime time. This commenter stated that Dr. Leonardi's presentation refuted that misconception because the Italians and Europeans have gone quite far with their applications. Dr. Leonardi then added that the extensive discussions of ICF flaws did not occur in Italy…rather, the lively disagreements were on applications. She illustrated how parents, educators, therapists, and administrators point the finger at

each other when children have disabilities, and that the ICF can be a guide in getting agreement on an approach. She closed with the rhetorical question: "Without the ICF, what do we have...ICIDH-1980?"

June 6—6–10 p.m.
Tuesday Evening Social

A dinner with live jazz music was held at the Dockside Restaurant on Granville Island. Accessible transportation was available. This activity provided an excellent venue for further networking.

June 7—8:00–9:00 a.m.
Plenary/Workshop: "An Introduction to the ICF" Susan Stark, Lynn Bufka, Andrew Mackenzie, and John Hough.

This session began with an overview of the development of ICF. Activities to crosswalk ICF with assessment tools and develop new assessment tools were described. Challenges to ICF were reviewed, such as: who should report functional status and the cost of collection. The need for clinical ICF applications was described in a few areas for example: describe function rather than disease and the benefits of common language. The case examples of "Elizabeth Smith," "Jennifer Smith," "Gregory," and "Sandy" were used to encourage practitioners to move away from treating problems (impairments) and towards treating people in the lived experience. Coding guidelines were given and the four qualifiers were described. ICF codes were juxtaposed with the PTSD Scale, DASH, FIM, COPM, and RNLI. The presenters ventured to identify some of the "hot topics" at this year's ICF conference: adequacy of E factors, A&P delineation, use with ICD and other WHO classifications, the forthcoming second edition of "Disability in America," and the U.N. Declaration on the Rights of Persons with Disabilities.

Discussion: One person commented that the case examples were too "impairment oriented," and did not reflect the elements embedded in the disability rights movement. Another person asked how codes can be used for outcomes assessment at the system level, and the response was that "code sets" were designed for this purpose, and noted that items outside the code set can still be coded.

June 7—9:00–10:00 a.m.
Plenary "Rights, Rehabilitation and Disability"
Don Lollar and Rune Simeonsson

Dr. Lollar stated that United Nations documents, conventions, and actions are needed because people with disabilities are often marginalized. For example, d940 describes "Human rights—enjoying all nationally and internationally recognized rights accorded to people by nature of their humanity alone." Dr. Lollar stated that the ICF embodies these rights because the ICF respects the person; espouses empowerment rather than charity and creates a common language and framework. Dr. Lollar also suggested that the ICF

meshes well with U.N. Standard Rules 1–12, which target areas such as employment, sport, and income maintenance for equal participation. Dr. Lollar asserted that our task is to use ICF as a common language, and it should be a second language for all.

Dr. Simeonsson then referred to various articles in the U.N. Convention on the Rights of the Child and pointed out how they mesh with elements of the ICF such as family environment, education, etc. Contemporary Russia was given as a case example, where at age four, a diagnostic decision was made which led to lifetime institutionalization. Various articles in the U.N. Convention on the Rights of the Child refer to elements of the ICF such as family environment and education. Dr. Simeonsson closed with an overview of how the ICF e codes mesh with the U.N. goals and so our task is to use the ICF to document environmental constraints.

June 7—10:30 a.m.–12:00 p.m. Plenary—"ICF Children and Youth Workshop" Don Lollar and Rune Simeonsson

Rune J. Simeonsson & Don Lollar: "Assessing childhood disability: developmental core sets." The presenters began with an overview of the ICF-CY, which is completed and awaiting final WHO approval. They pointed out that a CY adaptation was needed because functioning in children is often age-specific and different from that of adults. The structure of the main ICF volume is maintained, but new content was added for ICF-CY codes, and inclusion/exclusion criteria were expanded. Central concepts from theory and research guided ICF-CY development, including transactional models, ecological systems theory, and developmental delay findings. The ICF-CY has 237 new codes, including 33 in body function, seven (7) in body structure, 168 in activities and participation, and 29 in environment. Seven classification applications of ICF-CY were suggested, and ten general steps in ICF-CY coding were given. Recognition was given to the National Institute of Special Education of Japan for publishing the "Manual for Use of ICF for Children and Youth with Disabilities." The presenters highlighted the U.S. Department of Education's Early Intervention Data Handbook that uses the ICF and sample d codes, and is available electronically at http://www.ideadata.org/. Further work will include mapping existing instruments to the ICF-CY, development of ICF-CY based screening instruments, development of assessment measures compatible with ICF-CY and introduction of ICF-CY codes into surveys and information systems.

Discussion: This was an interactive session with discussion of codes and coding issues throughout. The ICF-CY Checklist and case examples were distributed and discussed and clarified. One issue was whether to obtain d and e items from the family or the clinician, and the recommendation was to use the one that benefits the child the most. There was discussion of the desirability of using ICD and DSM-IV with ICF. Other points made were that ICF-CY is not an assessment tool, and outcomes should not be confused with activities. Finally, the point was made that ICF differentiates well between children with the same diagnosis.

June 7—1:30–4:30 p.m.
Work Shop—"Using the ICF in Clinical Practice"
Geoffrey Reed and Lynn Bufka

The presenters provided an overview of the ICF and its potential for use in clinical practice. Guidance on determining the scope of coding included "develop a code set that reflects the individual's or clinic's area of practice," "use disease-specific code sets," and "use discipline based code sets." The capacity and performance concepts and qualifiers associated with A & P codes were illustrated with clinical examples. The group practiced coding case examples that included Gregory (a person with diabetes and a leg amputation), Nina (who suffered a head injury in a car crash), and a female attorney and convenience store clerk who had experienced similar head injuries but had different functional outcomes. Capacity qualifiers are based on standardized assessments (which might include tests), and performance qualifiers are based on an individual's particular life context and subjective experience.

Discussion: This was an interactive session in which clinical coding was explained using many case examples and clarified through practice, discussion and responses to many questions. For example, to code only the first and fourth modifiers for A & P codes, place an "8" or "9" in the second and third qualifier placeholders. A question was raised regarding whether the clinician needs to know how to code. Dr. Reed stated that it is preferable for the clinician to know how to code or at least to understand how the ICF is structured. He went on to say that, at a minimum, clinicians need to document clearly and provide sufficient information for those persons who are appropriately trained (clinicians or professional coders) so that they can translate the professional record into ICF codes. There was discussion of why numbers and letters are more useful than just natural language. The coding of "e" barriers and facilitators was elaborated.

June 7—1:30–2:30 p.m.
Concurrent Session—"ICF in Italy" Matilde Leonardi

Dr. Matilde Leonardi presented several papers on behalf of Headnet Research Group, and her collaborators of the Italian National Neurological Institute.

Dr. Matilde Leonardi: Functioning and Disability in Children with Neuro-Oncological Disease: The ICF framework to define cure and care (co-authors Ajovalasit D., Cattoni G., Pisoni C., A. Raggi) This is the first application of ICF-CY and its related questionnaire. Medical and health researchers will undergo intensive training on ICF, on its applications to children, and on its instruments (a 4–day course followed by 10 weeks Distance Learning via internet).

Dr. Matilde Leonardi: "ICF and Mental Health: Inclusion in the Labour Sectors of People with Psychiatric Disorders" (co-authors: A. Raggi, D. Ajovalasit; G. Cattoni, C. Pisoni). Headnet developed a project to identify the needs of 35 persons with psychiatric disease in three relevant areas: work, housing, and socialization. These persons all have severe

psychiatric disease (psychosis, schizophrenia and persons with a co morbidity of drug or alcohol addiction), and will be followed for three years by a multidisciplinary team made up of psychiatrists, psychologists, nurses and social workers. All the professionals have undergone the same ICF training.

Dr. Matilde Leonardi: "Accessible Tourism and ICF" (co-authors P. Cornelio, D. Ajovalasit, G. Cattoni, C. Pisoni, A. Raggi). Headnet Research Group is doing applied research to evaluate use of the ICF in the tourism sector, particularly regarding Environmental Barriers or Facilitators. Statistical reports indicate that, just in Italy, 3.5 million persons can belong to this category of potential clients with special needs for the tourism sector. The group developed seven practical "Rules for Tourism Operators."

Dr. Matilde Leonardi: "ICF in Neurology" project: the Italian National Neurological Institute C. Besta database on functioning and disability in Neurology" (co-authors Raggi A., Ajovalasit D., Cattoni G., C. Pisoni) Data collection was completed on a large sample of patients with Myasthenia Gravis—it is progress with patients with Migraine and Parkinson's Disease and soon to start with children with brain tumours and their families seen at the Besta Institute. The common feature gathered so far in their functional profiles is their invisibility, since symptoms may not show themselves when the patients take medications regularly. In more severe cases of myasthenics or migraine, patients may have difficulties in articulating words and sentences and these affect social activities. Disability is often due to barriers in attitudes (e4) and system services and policies (e5).

Discussion: There was discussion on the paralympic paper, extensive Chinese training for paralympics, wheelchair rugby, and children with disabilities in sports. There was also discussion around the point on whether people with disabilities have more prerogatives to speak on the topic of disability, and the point was made that "ICF helps open up the debate."

June 7—3:30–4:30 p.m.
Plenary: "ICF Through the Stages of Life"

Rune Simeonsson and Don Lollar: "Assessing Childhood Disability: Developmental Core Sets." This project involved preparing "developmental core sets" for children focusing ICF-CY on indicators of disability defined by critical child-environment interactions at key ages. Indicators of "developmental core sets" were identified for four age groups of children: <3, 3–6, 7–12 and 13–18 years, emphasizing Body Functions, Activities and Participation, and Environmental Factors domains of the ICF-CY.

Discussion: Dr. Simeonsson pointed out that the work is being carried out in three rounds using a Delphi procedure (consensus by reviewers). The core sets will be available at no cost.

Janet Prvu Bettger: "Post-acute Care Support and Health Service Environmental Factors Associated with Change in Personal Care and Instrumental Functional Activity Performance (co-authors W.J. Coster, J.J. Keysor, and N.K. Latham). The purpose of the Rehabilitation Outcomes Survey (ROS) study was to examine the association of support and health

services with change in personal care and instrumental functional activity performance (PCI) over a 12-month period following acute rehabilitation. It was a prospective cohort study of 516 people who received acute rehabilitation for a neurological, lower extremity musculoskeletal, or medically complex condition.

Discussion: Dr. Bettger responded to a question to indicate that no further improvement was noted after 24 or 36 months of rehabilitation, and that social supports seemed not to be related to the outcome of mortality.

Stephen Haley: "Blending Activity and Participation: Evidence for Five Major Factors Underlying Disability and Function" (co-authors Alan Jette and Wei Tao).
Item banks were developed, The Activity Measure (AM-PAC) and Participation Measure for Post-acute Care (PM-PAC)—to assess a broad range of human functioning during recovery through an episode of post-acute care for 272 patients across inpatient and community rehabilitation settings. The analyses suggested that clear distinctions in ICF activity and participation are not supported in certain functional areas, such as mobility, personal care, domestic life and tasks that require higher cognitive functions.

Discussion: Mr. Haley was thanked for shedding light on the delineation of A & P, and one attendee suggested that orthogonal research be undertaken in this project. The methodological issue of why factor analysis was used was explored. Mr. Haley suggested that factor analysis helps to identify which domains hang together in order to build scales and then construct instruments.

Randall Phelps: "Planning for Success: ICF-Based Toolkit to Facilitate Transition to Adulthood" (co-authors Edith Cook, Jenn Baldwin, Elizabeth Masten, Sundie Goulding McGarry, Danielle Blum, Angela Logsdon, Diego Chaves-Gnecco, and Heidi Feldman). At the UCLID Center (the program for Leadership Education in Neurodevelopmental Disabilities (LEND), University of Pittsburgh, the authors brought together an interdisciplinary team to create a comprehensive, function-oriented, family-centered transition planning tool based on the ICF-CY.

Discussion: It was noted that the tool will be soon available to download free of charge from the UCLID website, and the list of resources will be organized by ICF domain. It was suggested that the tool would be useful for health promotion, particularly if families would use it to structure discussions with their adolescents.

June 7—4:30–5:30 p.m.
"In Search of Healthy Cities"

The closing plenary was delivered by The Honorable Michael Harcourt, former Premier of British Columbia and former Mayor of Vancouver. He is a spinal-cord injury survivor. This experience has given him a firsthand exposure to inaccessible environments and led him to encouraging the criterion of "health" for supporting local community policies. Mr. Harcourt stated that "the ICF classification is an important tool that can inform policy decisions." Mr. Harcourt provides leadership to "CitiesPlus." This organization is affiliated with the

University of British Columbia and focuses on urban economic, social and environmental priorities to yield sustainable metropolitan areas with healthy environments. Vancouver and British Columbia are among North America's most accessible environments. Applying the ICF could enhance that degree of accessibility, perhaps even in tandem with the oncoming 2010 Winter Games and Paralympics.

Poster Presentations

Carl Granger, MD: "Using the LIFEware System to Map to ICF Categories While Tracking the Functional Status of Patients Through the Continuum of Care" (co-author Michael Gilewski, Ph.D.). The authors describe creating a continuum of care that describes functional status and outcomes that uses the UDS-PROi™ product for inpatients, the LIFEwareSM system for outpatients, and the 18-item FIM™ instrument. Accounting for item responses within multi-item measures allows mapping the functional status of patients to ICF categories.

Satoshi Ueda: "Impact of a Natural Disaster on the Functioning of Elderly People: A Japanese Experience" (co-author Yayoi Okawa). A great earthquake occurred a northern part of Japan in October 2004. The authors conducted a survey with an ICF-based questionnaire on the elderly population (65 years+) in March 2005. It revealed a high percentage of activity limitation occurring without any trauma. For example, gait difficulty occurred in 66.0% of 159 elderly people who had had previous activity limitation(s) and in 30.6% of 1,626 "healthy" elderly people. It had not returned in 40.3% of the former and in 11.0% of the latter group five months after the earthquake. The most important risk factor predictive of activity limitation and poor recovery in "healthy" elderly people was the state of "limited independence" of gait and other activities before the earthquake. The authors consider these activity limitations were caused by disuse syndrome because of externally imposed inactivity due to the great environmental changes.

Marlene Wiens: "Environmental Factors Affecting People with Disabilities in a Remote Mexican Village" (co-authors Chantal Camden, Francine Dumas, Jacques Girard, and Helene Moffet). Environmental factors and their relationships to the condition of health and participation of people with disabilities were examined in a remote indigenous Mexican village. Five semi-structured interviews were done with families followed by content analysis.

David Howard: "The Significance of Environmental Factors for Older Men Diagnosed with Prostate Cancer." This study concerns the impact of prostate cancer and treatment on older men's quality of life, personal attitudes, and behavior modification using qualitative methodology based conceptually on the ICF. Men's stories included poignant examples of importance of E factors found within the ICF.

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William Mortenson: "Using the ICF to Classify Activity and Participation Outcome Measures for Wheelchair Users" (co-author William Miller). A critical review of 18 activity and participation outcome measures for wheelchair users using the ICF as a framework was conducted in order to understand and compare the theoretical foundation of each instrument. These instruments were plotted on a three dimensional grid; position along the x-axis indicated the degree to which the instrument measured activity or participation; position on the y-axis indicated whether the instrument measured performance or capacity; position on the z-axis indicated whether the instrument measured personal assistance or assistive technology use.

Koji Tanaka: "Evaluation of the Environmental Factors of the Elderly People Using the International Classification of Functioning, Disability and Health" (co-author Jiro Okochi). The authors investigated the degree of influence of each ICF environmental factor on the activities of daily living of 690 elderly citizens using services of long-term nursing care insurance in Japan. They also applied the ICF qualifiers to assess the environmental factors with the strongest influence.

Carolina Moriello: "What do Generic Quality of Life Measures Tell Us About Function and the Environment?" (co-author Nancy Mayo). A standard mapping protocol was used to map the 75 items of the EQ-5D, HUI, SF-36, SF-12, and WHO-QUOL Bref to the ICF. A total of 15 persons coded. Efficiency was determined by the number of single, unique, functional status indicators (FSI) obtainable from the items and the spectrum of function and environmental content.

Naoko Yura Yasui: "Disability Rights Philosophy in Service Delivery: Independent Living, Consumerism, Empowerment, and Self-Determination." This poster was a review of how disability philosophy has historically directed disability-related policy in the United States. It examined four concepts: independent living, consumerism, empowerment, and self-determination.

Jiro Okochi: "Effect of Environmental Factors in Disability Development" (co-author Tai Takahashi). The authors have been annually following two cohorts of over one thousand elders age 65 and over in two Japanese towns since 1999. The Typology of the Aged with Illustrations measurement scale was cross-validated to the relevant items of the ICF.

Matilde Leonardi: "Mental Retardation, Competitive Sports Activities and ICF" (co-authors D. Ajovalasit, G. Cattoni, and C. Pisoni). Upon request of the Italian Paralympic Committee, in preparation of future Paralympic Games of Beijing 2008, Headnet undertook a study on mental retardation (MR), ICF and competitive sports. The main objective of this research is to explore whether ICF and its framework can help to solve the situation of exclusion of Italian athletes with MR from Paralympic Games. A dedicated ICF checklist for athletes with MR has been developed to capture the activities related to sport competition and the functions that are essential to be able to practice sport and execute some tasks and environmental factors that can be facilitators or barriers.

John Stone: "ICF Community of Practice" (co-authors Paul Placek and Marcia Damen). The Center for International Rehabilitation Research Information and Exchange (CIRRIE) created the ICF Community of Practice (COP) (http://cirrie.buffalo.edu). CIRRIE is dedicated to fostering ICF dissemination and utilization. The main components of the ICF COP are: (1) ICF Forum (an interactive venue dedicated to fostering online threaded discussions); (2) ICF Bulletin Board (posting messages); and (3) ICF presence at Interagency Subcommittee on Disability Statistics teleconferences.

Caryn Nash: "Measuring Frailty Using the ICF" (co-author Nancy Mayo). The Functional Autonomy Measurement System (SMAF) is an instrument developed based on the ICF to measure functional performance in the frail elderly which has been adopted in Quebec's public sector to determine needs and allocate support services. The SMAF was found to be a good functional performance measure. The efficiency of using the ICF as a framework for instrument development was confirmed.

Margaret Grant: "Turning Environmental Barriers into Facilitators in the Design and Clinical Practice of a Rehabilitation Centre" (co-author Gerrit Groeneweg). The Brain Injury Rehabilitation Centre (BIRC) provides an applied example of how the ICF can be used in rehabilitation to guide assessment of the environment and to address environmental barriers. While prospective program attendees are on BIRC's wait list, the centre ensures that the necessities are met, in terms of food, housing, income supports and transportation. The centre places an emphasis on changing access to the physical environment, sustaining relationships, developing new contacts, community building, and negotiating systems and services.

Steven Pruett: "Contact as Environmental Influence on Participation with a Disability" (co-author Elias Mpofu). The authors investigated contact experiences of human service students who self-reported on their community experiences with persons with disabilities to determine the perceived functional aspects of the contacts and their attitudinal valences using the Contact with Disabled Persons Scale. They used Rasch analysis and found that higher ability to interact with the disability population appear to be from greater actual contact with people with disabilities.

Susan Stobert: "The 2006 Participation and Activity Limitation Survey Programme (PALS) (co-author Eleanor Shaughnessy). This poster indicated that a primary objective of PALS 2006 is to track progress that has occurred on key issues since the 2001 survey. The presentation discussed analytical work planned for the 2006 PALS analysis program at Statistics Canada.

Susan Stark: "Used of the International Classification of Functioning, Disability, and Health in an Occupational Therapy Clinical Setting." Retrospective ICF coding of clinical encounters was performed on 67 subjects who received an occupational therapy intervention. Items from the assessment battery within nine standardized assessment tools were cross-walked to ICF codes based on the ICF Clinical Manual and linking rules (Cizera, et.al., 2002) were determined a priori. The study confirmed the utility of ICF activity and participation dimension in assigning codes, but the environmental codes did not have sufficient detail.

Patricia Welch Saleeby: "A Comparison of the ICF and the Person-in-Environment (PIE) Systems." The lack of use of ICF in social work may be due to the existence of a popular alternative classification known as the PIE system. PIE includes social roles in relationship to others, social environment, mental health, and physical health. Unlike the PIE, the ICF includes components of all aspects of functioning and is more comprehensive.

Ruth Farber: "The Mother's Interpersonal Environment: The Relationship of Social Support, Role Participation and Maternal Role Satisfaction of Mothers with Multiple Sclerosis (MS)." Conceptually based on the ICF, this study explored the relationship of a social environmental factor (availability of social support) and role participation. Although women with MS (as a group) demonstrated less social support, a significant relationship was found between social support, role participation and maternal role satisfaction. The study confirms the importance of the ICF environmental factor "support and relationship" for improved functioning and satisfaction for people with disabilities.

Hannah Friesen: "Facilitators and Barriers in Community Sites for Individuals with Mobility Impairments (co-authors Jacqueline Webel, Kerri Morgan, Holly Hollingsworth, and David Gray). Two expert raters assessed eighteen tourist destinations in St. Louis, Missouri for accessibility using the ICF-based Community Health Environment Checklist (CHEC). The CHEC, an objective assessment, was used to determine the accessibility of a building or site (e.g. entering the building, using the building, restrooms, amenities, and usability of area of rescue assistance). Data from the Facilitators and Barriers Survey (FABS), completed by160 individuals with lower limb mobility impairments, was analyzed. Similar constructs from the two assessments were compared to determine the relationship between the objective environmental assessment and subjective reports. The facilitators included flat terrain, elevators, automatic doors, paved surfaces, ramps, curb cuts and escalators, and barriers included crowds, gravel, winter weather, noise, rain, and summer weather.

June 7—5:30–6:00 p.m.
Closing Remarks

On behalf of the NACC, Marjorie Greenberg presented a conference wrap-up entitled "Challenges of ICF." Among these challenges were the following: (1) Promoting the ICF framework as a conceptual organizer for projects and policies related to disability; (2) "Using ICF to enter the debate" (quoting Dr. Leonardi); (3) Using ICF as a framework for research on health-related quality of life; (4) Using ICF as a rubric for constructing and evaluating survey questions; (5) The need to operationalize the Environmental Factors chapters more thoroughly and transparently; (6) The need to delineate better the (A&P) domains; (7) The desirability of developing a common ICF information portal; (8) The need to continue "mapping" efforts that map existing functional assessment instruments to the ICF, and (9) The need to finalize the ICF-CY during the coming year. Ms. Greenberg stressed the importance of working with the WHO-FIC Implementation and Education Committees on an enhanced "ICF Educational Plan," and she encouraged all conference attendees to contribute to the development and eventual operation of the international information portal.

NACC Conference on ICF, 2007

John Stone announced that the 13th Annual NACC Conference on ICF would be held June 5–7, 2007 in Niagara Falls, New York. More information about the meeting can be found on the CIRRIE-2 website, http://cirrie.buffalo.edu/icf/icfconference.html. The tentative theme for the conference is "Educating on the ICF."

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