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**Title: Report of the Ninth Annual North American
Collaborating Center Conference on ICF**

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**WHO Collaborating Center for the Family of International
Classifications for North America**

Purpose: For information

Recommendations:

Abstract: (no more than 200 words)

This presentation elaborates on the proceedings and content of the conference and takes a look at future activities within the NACC.

The Ninth Annual North American Collaborating Center (NACC) Conference on ICF was held in St. Louis, Missouri, USA June 16 – 19, 2003. It brought together more than 78 participants working in ICF from academia, health and health related fields not only from the North American countries – Canada and the United States – but also Egypt, Australia, Finland, France and the Netherlands.

The conference opened with a visit to the Enabling Mobility Center (EMC) at Washington University and a keynote address by Dr. Margaret Gianinni, Head of the new U.S. Department of Health and Human Services Office of Disability.

There were 53 presentations over the course of two and a half days. The main themes were in the areas of: the clinical application of ICF; academia; environment; related and derived classifications; delineation of Activities and Participation; surveys and censuses, and ICF activity updates given by a number of the participants from countries outside North America.

This conference afforded an excellent opportunity for collaboration, networking and discussion of ICF work with other professionals engaged in related work.

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

Introduction

The ninth North American Collaborating Center (NACC) conference on ICF was held in St. Louis, Missouri June 16 – 19, 2003. The National Center for Health Statistics (NCHS), which houses the WHO Collaborating Center for the Family of International Classifications for North America sponsored the conference together with the Canadian Institute for Health Information (CIHI). These organizations collaborated throughout the planning with Dr. David Gray and Patricia Welch Saleeby of Washington University who hosted the conference, made all the on-site arrangements and managed the logistics.

There were 78 registered participants with 20 additional participants (faculty and students) from Washington University. Over 53 presentations addressed ICF issues including: ICF and the Environment, ICF and Participation, ICF Conceptual Issues, ICF Use in Surveys, ICF in Clinical Practice, ICF and Teaching, ICF and Children, ICF Use in Administrative Records, and International Updates.

The conference started Monday afternoon (June 16) with a visit to the Enabling Mobility Center (EMC). The EMC is a facility jointly run by Paraquad and Washington University as part of a federal grant from the National Institute on Disability Research and Rehabilitation (NIDRR) entitled “Assistive Technology in the Community”. The EMC provides assistive technology resources and demonstrations to persons with disabilities. Several international researchers and leaders of the disability community were in attendance as well as representatives from local vendors, Paraquad, Washington University, local disability advocates and research participants.

The North American Collaborating Center was especially pleased that Dr. Margaret Giannini, Director, Office of Disability, Department of Health and Human Services (DHHS) provided the opening remarks entitled: "How the Federal Government is Working to Tear Down Barriers for Persons with Disabilities, and How Can we Use the ICF to Ensure Maximum Impact?" Dr. Giannini's Office was created in October 2002 and is dedicated to oversee the coordinated development and implementation of policies, programs and special initiatives within DHHS that impact persons with disabilities. Her challenge to the participants of the meeting was: "I think the ICF is a remarkable, astounding accomplishment, yet we still need more research to find out if its going to work or not. We need to ‘actualize’ its potential. Since it is recognized by the World Health Organization, health providers and government agencies might be able to attend to factors other than the person's structural and functional impairments. But you have to show us how." The entire text of Dr. Giannini’s speech is at <http://www.cdc.gov/nchs/about/otheract/icd9/icfactivities.htm> in the July 2003 NACC Clearinghouse on ICF message. The full St. Louis report will be included in a future Clearinghouse message.

The scientific portion of the conference took place on the days following the opening ceremony –Tuesday to Thursday morning. The presentations on these two and half days covered such topics as ICF in the clinical setting, in academia and the environmental component of ICF. Presentations were made by many North Americans who are involved with ICF as well as by some of the international participants who recounted the extent of ICF activities within their countries. These presentations were from Australia, Finland, France, Italy and the Netherlands. At the end of the day on Tuesday, videos taken in Bethesda, Maryland in 2001 and edited by Debbie Farmer about the development and purposes of ICF were shown. Wednesday at noon there was a very interesting panel presentation – Dr. Scott Brown, Dr. David Gray, Dr. Joel Kahn and Dr. Margaret Stineman - on the Potential Value of the ICF to People with Disability (PWD). On Wednesday evening, a majority of the participants enjoyed a picturesque riverboat ride and dinner on the Missouri River. Two students from Washington University very capably performed the duties of the rapporteurs for all the conference proceedings.

Dr. Bedirhan Üstün launched the presentations with a stimulating address Tuesday morning. He was speaking to the assembly via teleconference from Geneva, Switzerland while his PowerPoint presentation was on in St. Louis, Missouri. He challenged us to build networks globally to expedite the implementation of ICF at the country level. Countries like Canada and the U.S. can do certain things on their own but others need support from WHO. WHO would like to have ICF at a similar status as ICD with every country using ICD also considering using ICF in a similar manner. Beyond mortality and morbidity, information on functional status is needed. Implementation should basically address this paradigm shift from regional measures of mortality. Dr. Ustun advocated that we need to go beyond health measures to measure functional outcomes and to answer the question, “How healthy are the people?”

Scientific Presentations

The following presentations dealt with some of the clinical activities in ICF:

- **ICF and Medical Rehabilitation Research**

Dr. Michael Weinrich proposed that in the ICD, there is classification; in the ICF, there is quantification. The ICF is a set of measurements. Everything in the ICF is a measurement in order to determine someone’s functional level. Another critical issue is contextual sensitivity between ICF and ICD. Again, one either has a myocardial infarction or one does not. How one functions and how one participates depend a tremendous amount on context.

- **Disambiguation of the ICF Ontology**

Dr. Alexander Ruggieri’s presentation focused on the importance of ontology for the viability of ICF as a major health classification. He introduced the notion of an ontology and why it’s important to explicate ontologies for health care terminologies and classifications, particularly ones which we might expect to help serve us in electronic environments.

- **ICF and Participation**

Dr. Yerker Andersson focused on the World Federation of the Deaf and his experiences at the Regional Secretariat in Asia/Pacific, where he provided a presentation on ICF.

- Development of a Measure of Upper Extremity Function Based on ICF

Leigh Lehman presented a study that is looking at ICF to develop a measurement system based on a large item bank. The purpose of their study was to examine the quality of items in a large item bank for quality, unidimensionality, the number of constructs present, and the match of the items to the sample. The large item bank will eventually be used in a computer-adapted version of the test.

- Development of a Computerized Adaptive Measure of Disability Based on the ICF
- Dr. Craig Velozo's presentation focused on the prototype computerized version of the previous study.

- Incorporating the ICF Perspective in the Development of Rehabilitation Outcomes Measures: Applied Cognition

Dr. Wendy Coster focused on how to use the ICF as a guide for developing better outcome measures in rehabilitation; specifically measures that more comprehensively reflect the most important aspects of health and function to the recipients of services and that are based on a clear, conceptual model.

- Developing ICF Codes for OASIS

Dr. Gerry Hendershot discussed why is it important to link administrative data to the ICF; what is the Outcome & Assessment Information Set (OASIS) and how it is used in the United States to measure the health and functional outcomes of health care provided in patients' homes; and some illustrations of attempts to link domains of OASIS to ICF domains.

- Integration of the ICF into Electronic Health Records (e-records) to Create a Standard, Coded List of Functional Status Indicators for Use in Administrative Databases

The objective of Lisa Poissant's project is to develop an automated computerized method of translating routinely collected clinical information on an optimal e-chart into standardized coded functional status indicators that would populate administrative databases and facilitate population and health services research. Funding for the project is being sought in Canada.

- Extending the Usability of ICF for Fine Grained Clinical Representation of Functional Status Using Semantic Frames

Dr. Alexander Ruggieri proposed that the notion of granularity is very important to grasp in terms of understanding where ICF fits in the terminology continuum and what's going to be needed in order to make ICF work within this continuum.

- Use of the ICF for Development of an Early Intervention Data Handbook

Dr. Scott Brown presented how ICF could be used in the development of an early intervention handbook. ICF recognizes both health and health-related circumstances. It would establish a common language, provide an organized coding scheme, and provide the basis for collecting consistent data.

- Developing the ICF Version for Children and Youth: Status Report

Dr. Rune Simeonsson reported the progress to date of a work group developing a version of the ICF pertaining to children and adding content that relates to the issues of childhood, and also to develop assessment instruments.

- Overview of the APA Clinical Manual

Dr. Geoffrey Reed of the American Psychological Association (APA) provided an overview of the plans for clinician field trials of the prototype procedural manual and

guide for health care professionals. Clinical field trials are being organized with five disciplines. There are two versions of this feasibility study - individualized version and the consensus conference. There are two levels - coding of cases by clinicians and more general questions about the framework. Professionals will be asked about how they would apply the environmental codes and which ones are most relevant to their scope of practice.

- Overview of the APA Clinical Manual

Dr. Travis Threats indicated that for the ICF to be used widely, a clinical guide is needed. The APA, who has worked from the beginning to make sure all professions were involved, has spearheaded the development of the Procedural Manual and Guide for a Standardized Application of the ICF. Even with such a guide, a major educational effort will be required to enable health care professionals to use ICF.

- The Use of the ICF in the Field of Speech Language pathology

Dr. Travis Threats spoke to how the scope of practice in speech-language pathology encompasses all components and factors identified in the ICF framework.

- Use of the ICF by Occupational Therapy: A Critique and Future Directions

Dr. Susan Stark presented this paper as the representative from the American Occupational Therapy Association (AOTA) describing the experiences of the revision to ICIDH during beta-2 field trials and the current applications of ICF by occupational therapists. Occupational therapists are using it as part of assessment development.

- The Uses of the ICF in the Professional Field of Social Work

Patricia Welch Saleeby has been promoting the ICF in the field of social work. There are mechanisms to link the ICF and social work. A key framework used in social work is the “person-in-environment” (PIE) approach. PIE recognizes that individuals are affected by factors in the environment and that this is a dynamic process.

- The ICF: Implications for Physical Therapy and the Broader Role for Empowerment and Policy

Diane Brandt, as a physical therapist and a doctoral student, looked at ICF through a gestalt perspective. Through a therapist’s eyes: how can ICF be used on a clinical daily basis. From a student perspective: looking at a unified framework of disability and the potential implications ICF might bring to bear on policy issues.

- Interdisciplinary Clinical Use of the ICF in an Inpatient Rehabilitation Unit

Heather Hancock is a speech pathologist, who as the head of rehab at her facility, was given the charge of revamping the rehab, and she has chosen the ICF framework. This is an example of how clinicians actually put the ICF in use.

The following presentations covered some of the academic activities in ICF:

- Teaching with ICF

Dr. Kristine Mulhorn reported on work funded by NCHS to identify how ICF is being integrated into university courses in the U.S. and Canada. Placek covers this topic more fully in a separate paper.

- ICF as a Foundation for Curriculum Design

- Utilizing the ICF as a Framework in an Undergraduate and Post-Baccalaureate Occupation Based Curriculum

- Face Validity and Content Validity of a Curriculum Design for Physical Therapist Education Using ICF, ICD-10 and the APTA Guide

The following presentations included some of the activities in the environmental component of ICF:

- **Developmental Measurement of School Environments**

Dr. Simeonsson's work has been to define and measure aspects of school environments of students with disabilities. He is also looking at children's home and community environments. This is a two-stage study. One part applies the Delphi procedure to develop items for the instrument, and the second part is the utilization of those items in a national teacher survey.

- **Measurements of Community Environments**

Dr. Gale Whiteneck spoke about the three major areas involved in this project. The first is a General Population Attitude Survey. The second is a follow-up questionnaire on earlier work on the Craig Hospital Inventory of Environmental Factors (CHIEF), and the Community Checklist is the last.

- **Measurements of Environmental Receptivity**

Dr. David Gray presented this study that has looked at what environments enhance participation for people with mobility impairments or limitations. His presentation provided preliminary evidence and empirical evidence of codes that could be considered for a third or fourth level in the environment portion of the ICF. They found that many barriers and facilitators considered important are not included in the coding structure.

- **Measuring Community Accessibility: CDC Research on Disability and Environment**

Dr. Susan Kinne explained that the objective of the project was to produce and test reproducible and valid community indicators. The study was broadened to people with mobility, hearing and vision impairments since the criteria for accessibility and usability in the community are very different for these groups. Measuring barriers and facilitators and not "accessibility" was decided since every individual's environment is different and how they assess their environment is different.

- **Accessibility Instruments Measuring Fitness and Recreation Environments (AIMFREE)**

Dr. James Rimmer explained his slightly different approach in developing a measurement instrument in that his focus was on environments of physical activity. The goal was to develop an instrument to make some social change in recreational facilities due to the importance of physical activity for overall health and well-being. People with disabilities are significantly less active than people in the overall population. The purpose was to develop a measure that was complex and dynamic.

- **A Spherical Model of Internal and External Life Space Functioning**

Dr. Margaret Stineman proposed that if the ICF is to expand concepts of health and well-being, these concepts must be actualized. The challenge is to get physicians to understand ICF since their training is so reductionistic. A conceptual model has been developed called the health environmental integration (HEI). This can be used to understand the relationships between the ICF context and various dimensions.

- **Home and Community Assessment: Development of a New Measure**

Julie Keysor explained that this work is based conceptually on the ICF framework. Environmental factors are contextual elements that are important in looking at impact of participation. The objectives of the study were to determine if people are capable of characterizing their home and community environments and if this can be done reliably.

She found that people were most capable of characterizing home and external local communities and less capable of characterizing buildings and government programs and services.

- Disability in the Occupational Therapy Clinic and Clients' Homes

Dr. Joan Rogers and Dr. Margo Holm examined the influence of environment on activity performance. Specifically, they studied the influence of the occupational therapy clinic and the client's home environment on performance of daily living activities in older women with knee osteoarthritis.

- The Impact of Environment on the Health Related Quality of Life of Persons with Spinal Cord Injuries

Dr. Karen Barney presented a component of her dissertation research, which was an Internet survey of people with spinal cord injury. Most spinal cord injury studies have not addressed the full scope of adjustment to spinal cord injury. Few have used generic standardized measures limiting comparability. No studies have used the Internet to access this population so this study was rather unique. The focus was on the person's impairment factors, orientation to life, and environmental factors, and how these contributed to the respondent's health related quality of life. The research question was to determine the nature of the individual contextual, impairment, and participation factors that affect overall quality of life.

- The Round Table Project in Canada: A Unique Opportunity for ICF

Diane Caulfeild presented a project that is taking place in Ontario that is trying to facilitate the Return to Function/Return to Work (RTF/RTW) for persons with disabilities (PWD). Processes that are currently in place are generally dysfunctional because of a lack of communication throughout the system. It was demonstrated how ICF can facilitate communication at all levels throughout the system. A separate paper by Caulfeild describes this activity in greater detail.

The following presentations involved other related work in ICF:

- Health Behavior Change and the ICF: A Proposal for Discussion

Dr. Els Nieuwenhuijsen discussed three points: behavior change as a priority for people with disabilities; interactive health behavior change model; and a few examples of health behavior change theories and application of the ICF. She posed the question - can the ICF provide a scientific basis for understanding and studying health behavior change? Her recommendation was that there needs to be a closer look at the theories related to health behavior change.

- Delineation of Activities and participation in ICF: What Options Should be Adopted in the U.S?

In this paper by Dr. William Reynolds, it was found that ambiguity remains regarding the use of the domains of activities and participation. Although it was hypothesized that increased utilization of the ICF might result if the U.S. chose one of the four options provided by WHO to resolve any ambiguity, an expected finding of Dr. Reynolds' investigation was that a majority of researchers consulted felt that this would be premature.

- The International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities: What Role Can ICF Play in its Design?

Dr. Scott Brown described potential elements for a human rights disability taxonomy. It included environmental structures, environmental function, environmental characteristics, person/environment access dimensions, person/environment inclusion/exclusion, and environmental human rights legal expressions.

The following presentations covered some of the international work in ICF in Surveys:

- DISTAB update

Dr. Paul Placek provided a summary of the DISTAB group, based on work with national disability survey experts representing U.S., Canadian, South African, French, Dutch and Australian surveys. The Group published a technical paper on the methods of back coding in Disability and Rehabilitation; statistical tables have been completed for all countries in the group; “quality profiles” or standardized descriptions of surveys were prepared for all surveys; and an inventory of environment and participation items in six surveys is underway.

- Washington City Group on Disability Statistics

Dr. Marijke de Kleijn de Vrankrijker presented an update on the Washington City Group. Objectives for the group include developing a small set of general disability measures for censuses/sample-based surveys/other statistical activities, one or more extended sets of survey items to measure disability, and methodological issues. A draft matrix to provide a link between the purpose of disability measurement and the instrument was prepared by NCHS, including the distinction between purpose at the individual and population levels. The ICF dimensions (environment, participation, activity, body function/structure) were included as well as the characteristics of possible questions (degree of severity, duration, etc).

- International Updates – France

Dr. Catherine Barral provided information on the activities of the French Collaborating Center for ICF, which is housed at the National Center for Research and Disability in France, a center supported by the Ministry of Social Affairs since 1989. There are increasing numbers of national, regional and local initiatives using ICF in various domains. These include ICF training and the use in surveys, studies, assessment and measurement instruments. Additionally, there is the use of the ICF systemic model for current reform of legislation towards persons with disabilities. The main focuses include participation, the rights of the person, and the environment.

- International Updates – Finland

Seija Talo provided information on the activities in Finland. The Classification Center in STAKES is responsible for implementation and dissemination of ICF in Finland. The main mission is knowledge management in classifications for social affairs and health. ICF offers a valuable tool for this kind of knowledge management. But implementing ICF, STAKES will use the biopsychosocial approach, and therefore the multi-professional teams will have important roles to take messages to those in administrative power to communities, acts, regulation, and laws.

- International Updates – Netherlands

Dr. Marijke de Kleijn de Vrankrijker presented information regarding the ICF implementation strategy in the Netherlands. There is a focus on key issues including Dutch translation, web site and informational exchange.

- Implementing the ICF in Australia

Nicole Fortune reported the Australian Collaborating Center is pushing forward with ICF implementation activities. The Center promotes ICF by giving presentations in various forums and through the AIHW web site and the Australian ICF user guide. A disability advisory group provides a way of consulting broadly on implementation of ICF.

Summary

Dr. Don Lollar of NCBDDD/CDC concluded with the following ICF recommendations:

- The need for a research agenda;
- The need to operationalize clinical coding protocols;
- The desirability for a U.S. user guide, somewhat like the Australian user guide;
- The need for Federal agency information on if and how ICF is informing what they are doing in disability; and
- The need for measurement research keyed to ICF.

Marjorie Greenberg in her closing remarks challenged the group to not only define the problems but also identify the solutions. Each year progress is being made to actualizing the ICF conceptual model.

The 10th Annual NACC Conference on ICF is planned for June 1-4, 2004 in Halifax, Nova Scotia, Canada.