



Canadian Institute
for Health Information
Institut canadien
d'information sur la santé

8th North American Collaborating Centre Conference on ICF

June 2–4, 2002
Toronto, Ontario, Canada

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June 2–4, 2002**

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Introduction

The 8th North American Collaborating Center Conference on ICF was hosted by the Canadian Institute for Health Information (CIHI) and the National Center for Health Statistics—Center for Disease Control and Prevention (NCHS-CDC) and sponsored by the World Health Organization Collaborating Center for the Family of International Classifications (WHO-FIC)—North American Collaborating Center (NACC). It was held June 2–4, 2002 in Toronto, Canada.

This was the first NACC conference since the official publication in May 2001 of the International Classification of Functioning, Disability and Health (ICF) in six languages. It offered an open forum to present and discuss the implementation of ICF in the United States and Canada as well as other parts of the world. It provided a valuable opportunity for sharing knowledge and networking with the policy makers, scientists, researchers and clinicians.

The conference was launched with a welcoming reception for all participants on Sunday, June 2, 2002. It brought together 74 participants involved with ICF from academia, health and health related fields not only from the North American countries but also Germany, Netherlands, Switzerland, Denmark and Brazil. Preparation for the 8th NACC Conference began in January with a solicitation for papers and participation via e-mail. This planning activity resulted in 32 individual presentations and one panel with four presentations. Since 1995, NCHS has taken the lead in developing ICIDH/ICF training tools. The web-based Code ICF, being developed in collaboration with Western University and WHO, was demonstrated during the breaks on Monday, June 3, 2002. One of four Educational Videos being developed by Debbie Farmer, in collaboration with the National Center for Health Statistics–CDC and WHO was also available for preview on Tuesday, June 4, 2002.

Marjorie Greenberg, Head, WHO Collaborating Centre for the Family of International Classifications for North America gave the welcoming remarks followed by opening remarks from Richard Alvarez, CEO and President, CIHI. The keynote speaker was Dr. Michael Wolfson, Assistant Chief Statistician, Statistics Canada.

Diane Caulfeild, BSc, MBA served as chair for the first day and Paul Placek, PhD chaired the second day. The presentations and papers reflected six themes: Strategies for ICF; ICF Conceptual and Issue Areas; ICF Surveys; ICF for Clinical Practice; Capturing and Coding Functional Status Information; and Basic ICF Research. Three of the six themes were addressed on Monday, June 3, 2002 and the other three on Tuesday, June 4, 2002.

Each presentation is summarized below. The web link to the PowerPoint presentation and the paper, if available, are provided. Not all presentations have a paper to accompany it. A summary of the open discussion held at the conclusion of each theme is provided.

Marjorie Greenberg—Opening Remarks and NACC Activities

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_1_e.pdf

The theme of Marjorie Greenberg’s opening remarks, “Where have we been, and where are we going,” touched upon recent events and their significance for ICF implementation. She expressed appreciation to the Canadian Institute for Health Information for hosting the meeting and to the planning committee.

The NACC participated in the WHO meeting in Madrid, November 2000 and contributed to the final version of ICF. A “mini” NACC meeting was held in conjunction with the UN International Seminar on Measuring Disability in June 2001. An NACC study coordinated by CIHI on “Development of Mutually Exclusive Lists for Activities and Participation” was considered. The NACC leaders met to plan for the 2001 WHO-FIC Center Heads meeting.

The NACC also hosted the first joint ICD/ICF meeting of WHO Collaborating Centers for the Family of International Classifications in Bethesda, MD, October 2001. The North American “launch” of Family and ICF sessions were held on coding guidelines, implementation issues, training, outreach and dissemination, adaptations, measurement of ICD and ICF together as well as the maintenance and update the process.

A workshop on Disability Models and Disability Statistics was held in Canada, November 2001. The purpose was to improve functional status information in administrative data, to add participation items to Canadian Community Health Survey and increase disability content in General Social Survey Strategic research initiative from CIHR.

Members of the NACC participated in the WHO Conference on Health and Disability in Trieste, Italy in April 2002. More than 70 countries were represented in sessions that addressed: health and wealth of nations; disabled and health; what’s wrong with disability statistics; ICF and health information systems; and ICF in surveys and clinical practice. Dr. Gro Harlem Brundtland, Director-General of the WHO, challenged countries to make their health information systems consistent with ICF.

The DISTAB Group thrives and there is an international effort to compare and standardize disability questions and back-code to ICDH-2/ICF. The group including U.S., Canada, France, Netherlands, South Africa and Australia was established in 1999, meets annually and holds monthly conference calls. They have “inspired” a UN Seminar and the Washington City Group. A report authored by DISTAB on methodology has been accepted for publication. A report on DISTAB tables is in progress. DISTAB is currently conducting an inventory of participation and environment questions.

In the area of clinical and administrative records, several projects are ongoing. The American Psychological Association (APA) is creating a Procedural Manual and Guide for health care professionals. A strategy for operationalizing ICF is being studied by Seltser and Hendershot. The U.S. National Committee on Vital and Health Statistics (NCVHS)

Report on Classifying and Reporting Functional Status has been completed. There will be a special Spring 2003 issue of the Health Care Financing Review that will include ICF information on recording and classifying functional status for payment and quality purposes.

An NACC ICF Clearinghouse is being created. Potential uses for the clearinghouse include dissemination of a monthly e-mail summary of ICF activities, passive versus active outreach for ICF involvement, marketing through presentations and exhibits and training and technical assistance. Available resources will determine the final scope of the clearinghouse.

Marjorie Greenberg noted that the agenda of this conference reflects the wide variety of ICF-related activities in U.S. and Canada, and the need for regular information exchange, coordination and technical assistance.

Richard C. Alvarez—President and CEO, Canadian Institution for Health Information

Mr. Alvarez welcomed all participants on behalf of CIHI to the conference. He explained CIHI's role of providing national health information for Canada and collaboration with other organizations such as Statistics Canada, Health Canada and the NCHS. The importance of data for managing health care was described as the basis for needing to measure health status. Mr. Alvarez noted that CIHI has been involved extensively in the ICDH-2/ICF revision process including translation, beta testing and task forces.

Michael Wolfson—The Future of ICF-Based Disability Information

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_2_e.pdf

Dr. Wolfson's presentation provided a brief review of where we've come to date on this important classification system, outlined the major problems he sees in the current situation, illustrated a number of problems and opportunities for the ICF in Canada, and concluded with suggestions for next steps for both Canadian and international collaborative work.

While ICF is a significant improvement over ICDH-2, it is still a work in progress. Still pending is a well-grounded short form or summary description of individual functioning. This would create the means for characterizing communities, in terms of "participation gaps". There is a continued need for conceptual/methods development. Applied development should include instruments such as surveys (short form) and a clinical profile. International partnerships with WHO will strengthen international comparability.

Major improvements include less stigmatizing language, a framework which is no longer premised on simplistic causal pathways and the explicit recognition of external physical and social environments.

Dr. Wolfson reviewed the definitions of health, domains of health/functioning, domains of industry, the WHO items, and questionnaire items. He then reviewed ICF as a framework and a vocabulary to describe health, disability and functioning as a means to identify participation gaps.

He reviewed the extensive ICF and health information developments in Canada. These include broad national work and developments at CIHI and Statistics Canada. CIHI provided extensive effort and leadership in the ICIDH/ICF revision process. The CIHI National Rehabilitation Reporting System and the Continuing Care Reporting System are ICF related. A CIHI minimum data set that is under development for Home Care has been “inspired” by ICF.

ICF related developments at Statistics Canada include: Participation and Activity Limitation Survey (PALS, formerly HALS); National Population Health Survey (NPHS); Person-Oriented Information (POI); Canadian Community Health Survey (CCHS); Canada—U.S. Joint Health Survey; and Canadian “Burden of Disease” Study.

A 2001 census survey of persons with disabilities included a short disability indicator on the census long form (May 2001) and a 40,000 sub-sample (Fall 2001). This was preceded by two major post-census “health and activity limitation” surveys (HALS), in 1986 and 1991.

A Health Survey was jointly sponsored by Statistics Canada and NCHS with additional funding from the Canadian Institute for Health Research (CIHR) and the Robert Wood Johnson Foundation. For this study included a sample of 3,000 in Canada and 5,000 in U.S. The study used PALS disability indicator, the McMaster HUI and the U.S. “limitation” and “vocational restriction” questions.

Canada’s priorities for health and disability data include a “global” measure in surveys (census / health / disability surveys) with international comparisons (mainly with a sub-set of OECD countries), a short form for health care encounters, a longer version for specialized care and a method for measuring participation gaps. The data must be suitable for “Global Burden” analyses.

Dr. Wolfson stated that on the international front, we may need to become more explicit about carrying on developmental work along two separate, but parallel tracks. Many OECD countries like Canada already have substantial investments in our health info-structures—both administrative data systems and population survey programs. This is unlike the situation in many developing countries. As well, the prevalence of different kinds of health problems among our populations and the variety of environmental barriers and facilitators are sometimes quite different. He noted, that comparison to all the world’s countries is not essential. Finally, there is a range of important and creative work underway in both international agencies like WHO and the UN’s Washington City Group (WCG), as well as in a number of countries.

Somnath Chatterji—Trieste and Beyond

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_3_e.pdf

Dr. Chatterji began by providing background and contextual information for the need to place disability within the overall framework of health. ICF is the common international framework for describing and measuring health at both the individual and population levels. The ICF is a framework to understand the interaction between health and other factors such as education, income, etc. As such, it provides the framework for measuring health outcomes and assess the effectiveness of health interventions.

Good health is both intrinsically and instrumentally valuable for the health and wealth of Nations. Improving health will release scarce resources from promotion, prevention, treatment and rehabilitation to use elsewhere.

WHO is committed to de-stigmatize the notion of ill-health by incorporating functioning into the concept of health state profiles. Health is a separate concept from well-being and is comprised of multiple domains of functioning and is an attribute of the individual.

Statistics on disability, internationally, have been hampered by the lack of an agreed international conceptual framework. The challenge has been identifying the most appropriate methodology for measuring the threshold across surveys, clinical practice and social policy needs. ICF should serve as the unifying framework.

The ICF framework provides the multiple dimensions to describe the many aspects of how individuals function in their environment as a requisite characterization of their health. ICF needs to have linkages with a risk factors framework to characterize future risks to health. There is a need to find ways to summarize the complex ICF framework to enable data collection on population health using surveys and similar data drawn from administrative records. In developing countries, the challenge is to integrate ICF in the existing health information systems, and create a culture of information conducive to a wide use of ICF.

The need is to make ICF more user friendly, tailored to specific user needs, clinically relevant, easier to use, and cross-validated to established instruments. It is valuable to develop minimum data sets of functional domains to best characterize health outcomes.

There is a strong focus on use of activity limitation with growing concern and interest in using participation and environment codes. Examples of different ways of using the framework include collecting data on all levels of functioning/disability, and combining ICD and ICF; collecting environmental factors data which is limited in scope to technical aids and personal assistance; and back-coding/cross-walking existing surveys to the ICF framework.

ICF must be used as the framework for examining the relationship between health and development in order to influence health and social policy. There is a need to look at the gap between the experiences of disabled people compared to non-disabled and move away from just asking disability survey questions to disabled people. It is important to link disability and health surveys more directly to implementation strategies.

Implementation strategies by the WHO are extensive, including using the ICF framework in health and disability surveys such as the World Health Survey (WHS), an ongoing data collection platform in 75 countries. ICF should be incorporated into Health Information Systems and electronic patient records. The development of training materials and curricula will continue and include work on a standardized application manual for implementation strategies and testing generic and specific core sets of functioning domains to be used in minimum data sets for a range of purposes. Assessment instruments will be linked to the ICF framework. The child and youth version of ICF is currently being developed and primary care versions are considered for the future. The ICF is expected to be a working document; it will change as the needs of the users change.

Open Discussion

Discussion on the keynote presentation by Dr. Wolfson included the aggregation or disaggregation of data at the community level. If aggregating, which group will be considered? Dr. Wolfson responded that since the work is in such early stages, this decision has not yet been determined. When more extensive data has been collected, it will be analyzed for trends and meaningful reporting tables as well as necessary changes for the future collection of data. Dr. Wolfson estimated that the data would be available in Spring 2003 and is not expected to be available on the website at that time but would be available to researchers through the university system and research data centers.

Discussion surrounding Dr. Chatterji's presentation included the availability of the revised World Health Survey instrument and preliminary data for researchers. He responded that the data will be presented first to the country collecting it and then will be made available to the researchers via the web, estimating its publication by the end of 2002.

Dr. Chatterji responded to an inquiry that the ICF checklist has been updated to match the current printed version (as opposed to the beta version) and is available on the WHO website. The training materials, including the interview structure and set of guided questions, have also been updated and are available as well.

In response to a question about a primary care version, Dr. Chatterji stated that all items may not be needed for primary care and that a smaller version might facilitate training of primary care providers. Primary care providers participating in the conference indicated that the entire version could be used in their work.

Theme: Strategies for ICF

Gerry Hendershot – A Strategy for Operationalizing the ICF for Use in Clinical and Administrative Records

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_4_e.pdf

Perhaps the greatest challenge to implementing the ICF is found in clinical settings. Clinicians in many medical specialties do not routinely record any information on functional status in patient records. The United States system pays providers based on diagnoses (derived from the ICD) and treatment (derived from the Current Procedural Terminology (CPT)). This basis for payment biases care toward the medical treatment of diseases, not toward improving the positive health and quality of life of persons. ICF, which defines health broadly, and more explicitly includes personal activity, social participation, and environmental factors would direct the system toward patient needs and positive health.

A strategy for reaching that goal must have several features: it must involve the medical specialty professions in deciding what ICF domains are relevant to their needs; substantial funds must be provided to research and develop clinical measures of levels of functioning in the relevant domains; students and practitioners must be trained on the assessment tools which must be integrated with the CPT as part of the payment system; and placeholders must be introduced on all forms for recording enrollment, encounters, and payments.

A preliminary list of tasks to accomplish the operationalization of the ICF includes medical research, surveillance research, quality of care research, health care financing research, training research and welfare research. Research is the lever that will enable the medical care system in the US to move away from the treatment of disease and toward improving the positive health and quality of life. The key agencies expected to undertake these tasks include the National Institutes of Health, the Centers for Disease Control and Prevention, the Agency for Healthcare Research and Quality, the Center for Medical Services, the Health Resources and Services Administration, and the Social Security Administration.

Further steps include increasing public awareness of the changes the ICF could bring about and enticing the academic research community to actively participate in the research and development needed to operationalize the ICF. A series of papers and several model Request for Proposals (RFP) have been drafted for instrumentation, curriculum development, clinical record systems, and medical research. One paper, "ICF and Terrorism" has been accepted for publication. The ICF provides a more realistic definition of disability that recognizes social participation and environmental factors as central to the experience of disability. A health and welfare system that is focused on activity, participation, and environment would increase personal control over decisions about care and benefits.

Jerome Bickenbach—Functional Assessment and ICF in Canada, Proposals and Aims

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_5_e.pdf

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_papers_1_e.pdf

Like many countries, in Canada central obstacles to evidence-based health care quality assessment and health system performance assessment are reliable data based on health encounter and episodes of care. The Federal and Provincial agencies responsible for Canada's health care delivery systems have recently signed a Health Accord. This Accord, including initiatives at the Canadian Institute of Health Information (CIHI), proposes to enhance health and functional status data collection and standardize functional status information for administrative records across the full continuum of care.

These initiatives are in recognition of the need to track and monitor health encounters across episodes of care, and in particular to bridge the gap between acute, in-patient rehabilitation and community-based care. Functional status information is precisely the data needed to bridge these gaps, in as much as alterations in functional status creates the continuity that links all episodes of care and health service utilization. Functional status, in the case of chronic disabilities, links the health care system with the other health and social services that may be called up by the individual.

The Health Accord also created an agency to develop electronic health records for ease of data collection. Overall, the prospects for a coherent, across-the-system, data collection mechanism are made more likely given Canada's universal, single-payer, health financing structure. But, in order for these goals to be realized, a standardized functional status classification is needed on which minimal functional data sets and standardized assessment tools can be based. For this purpose, the International Classification of Functioning, Disability and Health (ICF) is the most likely tool.

Among the aims and challenges of such an endeavor includes convincing stakeholders that functional status information is feasible to collect and includes health information and health care outcome information that is distinct from diagnostic data. Issues include the many sources of health related data and the lack of standardized information. To improve the standardization process, there needs to be a common core set of elements, standards for coding, comparable data from diagnostic tests and comparable data across the continuum of care.

Yerker Anderssen—Strategies for ICF Implementation

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_6_e.pdf

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_papers_2_e.pdf

The new adoption of both the social and medical models of disability by International Classification of Functioning, Disability and Health, abbreviated as ICF, may imply that health professionals, behavioral scientists, researchers, and others will be expected to become familiar with a greater diversity among the viewpoints of people with disabilities than before. Even though disability groups share the same goal, namely accessibility,

individuals with sensory, physical and mental disabilities have quite different needs and experiences. In order to develop a working knowledge of their perspectives on disabilities, these occupational groups will likely have to consider new ways to involve experts with different disabilities in their implementation of ICF. Because of time restraints, my discussion will necessarily be limited to three selected strategies.

First, the involvement of scientists or researchers with disabilities in surveys, now called Participatory Action Research, abbreviated as PAR, has already been discussed at length in the 1998 issue of Canadian Journal of Rehabilitation and some other professional journals. This sharing process of individuals with disabilities trained in various health and welfare fields will certainly enhance the quality and objectivity of health surveys. A recommendation was made for future health surveys to focus on the diversity of both body functions, instead of disabilities, and daily activities and participation for health purposes.

Organizations of people with disabilities have expressed their strong opposition to the use of terms for labeling or categorizing purposes, such as the deaf and hard of hearing people rejecting “hearing impaired” while both “blind” and “visually impaired” still are acceptable. Consultation with disability organizations and also universities with services for students with disabilities should be considered as a possible strategy to reduce a possible confusion among new terms in different languages. The recent involvement of disability organizations in the process of making policies or laws has increased cooperation between consumers and policymakers at both the national and international levels which, no doubt, is an ideal way of standardization.

It was recommended that, in addition to dissemination of information about the applicability of ICF and their health survey results, the possibility of assisting organizations of consumers with disabilities in interpreting health survey results be considered. Such interpretation of survey results would certainly give consumer organizations an impetus to increase their cooperation with researchers. Cooperation among health professionals, regardless of what physical, sensory, and mental limitations they may have, should not be forgotten as the most important strategy for the implementation of ICF.

Harlan Hahn—The ICF and the ICFIDH, Privacy, Paradigms, and Definitions

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_papers_3A_e.pdf

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_papers_3B_e.pdf

Harlan Hahn discussed concerns for persons with disabilities and the ICF. His presentation covered several areas. They included the involvement of persons with disabilities during the development of ICF, definitions of disability, priorities for persons with disabilities, privacy issues, data collection and dissemination. He expressed that while some persons with disability were involved with the revision process, many more should have been included. He provided some background information on the United States passage of the Americans with Disabilities Act (ADA) and the Health Insurance Portability and Accounting Act (HIPAA). He brought to the forefront the issue of the use of “implied consent” to protect

physicians from civil and criminal penalties for egregious medical practices. He expressed the fear that personal, identifiable data would be collected, disseminated and ultimately used to determine which services will or will not be provided, describing this as a type of “medical rationing”. He discussed the potential for automated data to “fall into the wrong hands”. He provided a historical view of various definitions of disability and handicap, indicating situations where the person with the disability was not allowed participation because of the definition. He also raised the issue of quality of life, mentioning that quality of life should be based on the individual’s perception and when incorporated into “functional, global” statistics may be misrepresented. He presented information regarding environmental barriers and made the argument that persons with disabilities have indicated the environmental barriers are the area of most importance to them.

He proposed a project that could lead to the use of detailed regulations by government agencies to implement laws requiring the creation of accessible environments. These data could be correlated with aggregate measures of the prevalence of physical and mental impairments in the same regions. This information could be used to explore numerous crucial hypotheses. Among them are whether the environmental barriers to health care or the bodily (including mental) impairments are the impediment to utilization of health care and the effects environmental barriers and bodily impairments have on other forms of activity and participation by disabled people. This could potentially answer whether the environment or the impairment is the principal source of disability.

He closed his presentation with the suggestion that WHO administrators of the ICF projects must include more persons with disabilities in future discussion and plans.

Open Discussion

Discussion surrounding Harlan Hahn’s presentation centered around the need for confidentiality of individual identifiable collected data. It was pointed out that such information is already being collected and proves valuable in identifying trends in health care and availability of services as well as a necessary component of improving the situation. In addition, current data does not present sufficient information for determining if the intervention or treatment is effective. This can only be accomplished by collecting individual data. It was suggested that automated data may, perhaps, improve the confidentiality of individualized data by eliminating the “ready access” of patient charts (such as in hospitals and physician offices where they are often placed just outside the patient room or nurses station). It was agreed that this concern should remain a consideration for future work. It was pointed out that health care is already being rationed and that we must come to grips with the fact that resources are limited and that as costs continue to rise, this is an ongoing, increasing problem.

Dr. Chatterji responded that WHO will always honor the confidentiality of the individual. He reminded the group that ICF, in principal, is to reflect the universal experience of health and disability. It is not intended to drive or affect policy for any single group of people; it is for everyone. He also supported the idea that an issue we cannot run away from is the fact that resources are never going to be infinite and will always be limited. Therefore, setting a threshold is something we cannot pretend doesn’t exist. However, the threshold has to be

set in a manner that is empirical, fair and ethical. To say we that we don't need a threshold is like saying we live in a world that doesn't exist. In acknowledging that up front, we should strive to set a threshold that is equal.

Theme: ICF Conceptual and Issue Areas

This theme was introduced by the chair, Paul Placek, who indicated these presentations, along with others from this meeting, will be featured in a special issue of the journal (Health Care Financing Review) for the Center for Medicare/Medicaid Services (HCFA). The journal's Spring 2003 issue will feature research on functional status. In addition to the presentations today, commentaries and reports from WHO will be included.

Alan Jette—Are the ICF Activity and Participation Dimensions Distinct?

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_7_e.pdf

The presentation began with some background factors including the ICF conceptual framework and definitions of Activity Limitations and Participation Restrictions. The challenge posed in this project was to construct scales that try to distinguish between Activity and Participation domains of the ICF for late life function and disability. The scales were to be designed for self or proxy report and are psychometrically adequate for research, quality monitoring, and outcomes management. They should be sensitive to meaningful levels of change. The result is called the Late-Life Function and Disability Instrument.

The design included writing 48 self-reported questionnaire items that asked about an individual's difficulty in completing daily physical tasks or actions and commonly performed life tasks. The items were based on a review of existing instruments, national experts and focus groups. The questionnaires were administered to 150 cognitively intact, community-dwelling, ethnically diverse adults in Greater Boston, Massachusetts who were 60 years of age and older who had a range of limitations in their physical functioning.

A series of factor analyses were used to identify interpretable factors that could be responsible for the co-variation in the data. The principal axis method used a 48-item scale for the initial factor extraction. Orthogonal rotation was used to evaluate factor loadings. Eigenvalues and scree plots, the proportion of the variance accounted for by each factor, the factor loadings, and the interpretability of the factors were all used to determine the final number of factors to retain. Items with high loadings of 0.45 or greater were retained. Cronbach's alpha was used to confirm that the item-composition of each retained factors were correlated (i.e. measure the same conceptual domain or construct). Promax (oblique) rotation was used to determine inter-factor correlations.

A one-factor model was tested to assess whether the 48-item scale could be used as one construct. A maximum likelihood chi-square test showed that one factor was not sufficient to adequately explain the data. Two items from the original 48-item scale were eliminated because they were not interpretable.

Consistent with the ICF classification, factor analyses of 48 questionnaire items administered to adults 60 years and older revealed distinct Activity and Participation outcome domains. Items within the two Activity domains focus on the individual's perceived difficulty in executing a specific physical task or action, a clear indication of their

underlying capacity. In contrast, Participation items predominantly address the individual's limitation in performance of life tasks within his/her current environment. Future research will include the application of item response theory methods to construct quantitative scales of each dimension, test sensitivity to change and disseminate instruments to the research community. Further information is available at www.bu.edu/roybal.

Emile Tompa—The Challenges of Operationalizing a Theory of Disablement in the Context of Secondary Data Sources

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_8_e.pdf

There are a growing number of health and labour market survey databases that contain a wealth of information on health and health-related characteristics of different populations. To date, many of these databases have not been extensively used for the purposes of studying disablement. We undertook to develop the foundations of an applied population health research program on work disability based on secondary data sources from these health and labour market surveys. This paper is a presentation of some of the issues and insights that have emerged from our efforts.

There is extensive theoretical literature on disablement, largely centered on two conceptual frameworks: that of Nagi, and that of the World Health Organization (WHO). A number of researchers have developed, advanced and critiqued these models, but less work has been done on bridging the gap between theory and applied research. An essential first step in developing an applied research program is establishing a link between theory and measurement. We address this first step by attempting to map concepts in the theoretical literature onto questions and tools in existing health and labour-market surveys. Specifically, we coded health and health-related questions in a number of Canadian and international surveys that pertained to the various stages of disablement using the ICF (Beta 2 Draft).

The coding process resulted in far more than simply an inventory of the coverage of disablement concepts in the various surveys. Because the population-based surveys employed in the exercise were not expressly designed with a specific conceptual framework of disablement in mind, we found that the measures of health and health-related characteristics in the surveys were often difficult to align with the WHO conceptual framework and ICF classification system. The approach taken was iterative, moving between survey questions and theoretical literature in order to better understand the reasons for misalignments and incongruities. Consequently, we found that the exercise resulted in a strong understanding of the strengths and weaknesses of the WHO and Nagi frameworks and the ICF classification system, as well as the fit and quality of the survey questions.

The methodology included selecting several cross-sectional and longitudinal health and labour-market surveys for coding (HALS, NPHS, OHS, GSS6, SLID, PSID). These were independently coded by two reviewers using the ICIDH-2 who met regularly to develop consensus versions. The reviewers coded all questions pertaining to body, activity and

participation if response options indicated a negative aspect in these domains (impairment, limitation, or restriction). They identified whether questions inquired about severity and/or duration and assessed the extent of 1 and 3 digit chapter coverage of each survey.

Results:

Participation and Activities

The reviewers struggled with distinction between participation and activities. In the review, they coded as participation: 1) overall involvement in a role, 2) provision of resources to make involvement possible, 3) overall assessment of limitations in the activities of a role and coded subcomponents of roles as activities.

Activities Nested within Activities

Nesting within activities code posed some problems where complex activities can be described by their component parts using simpler activities.

Simple Activities and Impairments

The distinction between some impairments and simple activities was not always clear. The criterion of purposiveness was difficult to operationalize. In general, there was difficulty placing cognitive and emotional functions.

Impairments and Health Conditions

It was difficult to distinguish between health conditions that are impairments and those that are not. The ICIDH-2 criterion of impairments as “detectable by observation or inference from observation” can be subject to interpretation. Questions arose such as “does detectable include clinical evaluation or every day observation?” Not all health conditions inquired about in surveys were necessarily detectable as defined by ICIDH-2 (e.g. some cancers).

Coverage of Surveys

Coverage of ICIDH-2 dimensions and chapters within dimensions varied across surveys according to survey focus. The population health surveys (OHS, GSS6, and NPHS) had the best coverage of body dimension in several areas.

- all surveys had at least one question on work disability
- few surveys linked questions across dimensions
- most survey questions solicited binary responses
- limited coverage of duration and severity of conditions
- some survey questions distinguished between abilities with and without assistive devices, but formulation of questions varied in terms of the dimension at which assistive devices inquired about
- when technical vs. personal assistance was inquired about
- capacity and performance concepts difficult to operationalize
- most questions referred to lived experience (performance)

The key issues encountered in the coding exercise can be classified into three broad categories, namely 1) the conceptual distinction between activities and participation, 2) boundary issues between the three dimensions of the ICF (Beta-2 Draft), and 3) the appropriate place for person-level functions. The Final Draft of the ICF has resolved the first and part of the second issues by collapsing the codes for activities and participation into one set though the body dimension codes have remained essentially unchanged between the Beta-2 and Final Drafts. Other changes in the Final Draft include the introduction of the concepts of capacity and performance for the measurement of activities and participation, and the removal of qualifiers for personal assistance and assistive devices for the coding of activities. The concepts of capacity, performance and assistance are important to the study of disablement, but will require some work to determine how best to integrate them into the framework, classification system, and the measurement process.

The term 'disablement' refers collectively to the multiple and interrelated concepts associated with the consequence of a health condition. Our intention is to use the term without suggesting a particular school of thought, though the term has been associated with the ICIDH (Wood, 1980). The term 'disablement process' was coined by (Verbrugge and Jette, 1994) and is generally associated with the Nagi framework.

The recommendations of this research is, for survey developers and managers to better study disablement, survey questions need to:

1. be based on a particular theoretical framework;
2. linked across the different dimensions of the framework;
3. inquire about the degree of limitation/restriction; and
4. distinguish between limitations with and without assistance.

Rune Simeonsson—Developing an Adaptation of the International Classification of Functioning, Disability and Health for Children

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_9_e.pdf

Preventing disease, injury and disability, and promoting health and well-being are complementary goals for children around the world. With growing concerns regarding childhood morbidity, particularly in the developing world, the development of a universal tool to document health conditions and their consequences is an important priority. The publication of the WHO-ICF in 2001 makes available an international taxonomy that can be adapted to encompass the functional characteristics and environments that uniquely describe the developing child. This presentation described the process of preparing an adapted version of the ICF to classify functional characteristics, disability and environmental factors of children that can be used in conjunction with the ICD-10 to document their health status across service sectors.

This presentation provided a report of the first meeting of a small WHO work group held in Trieste in April 2002. The rationale for the ICF version for children is based on developmental and demographic issues. Among issues discussed were the crucial need for identification of disability and risk factors in early childhood for prevention and early intervention efforts as well as trends that reflect an increase in childhood disability and disablement. Children in developing nations have a disproportionately high rate of disability. The importance of an ICF version for children is necessary to:

- Facilitate continuity of classification in transitions from child to adult services
- Support U.N. Conference on Children (2002) and UN Convention on the Rights of the Child
- Complement existing childhood classifications in related areas:
- DSM IV-PC (Child and Adolescent Version)
- Multiaxial Classification of Child and Adolescent Psychiatric Disorder (ICD-10)
- Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood

The development of an adaptation of the ICF for children and youth will be based directly on the organizational framework and structure of the 2001 ICF main volume (Body Functions/Structures, Activities and Participation, Environmental Factors). The hierarchical structure of chapters, blocks and categories of the version for children will be completely complementary with the ICF main volume. The version will retain content applicable for children. New information that needs to be added will take the following form: (a) expanding or modifying existing descriptions; (b) assigning new content to unused codes; (c) expanding or modifying inclusion/exclusion criteria; (d) use of 2nd, 3rd or 4th qualifiers as appropriate. Examples of additional content drafted by the work group were shared.

The work group will convene over a two-year period (2002–2004) with major activities focused on: (a) developing drafts of an adapted version of the ICF for children; (b) testing of draft versions; (c) identifying existing and needed tools for measurement; and (d) preparing a final, print-ready version for publication in 2004. The next meeting will be in Sweden in August 2002. Next steps include synthesizing findings of reviews, identification of new content, securing stakeholder participation and planning the development and evaluation of the first draft.

Marijke de Kleijn de Vrankrijker—Classification of Technical Aids for Persons with Disabilities—ISO 9999

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_10_e.pdf

Ten years ago the International Organization for Standardization (ISO) published the first edition of the international standard “Technical aids for disabled persons-Classification” (ISO 9999–1992). It took almost ten years of preparation and international cooperation to reach this result. Because of the need for improvement the classification has been revised twice since its first edition. At the moment the second revision (third edition) of the standard is subject to international voting procedures following the rules of the ISO as ISO/FDIS 9999–2001.

The classification includes technical aids used by individuals and does not include those used by health care professionals. In the set of definitions, use is made of ICIDH terminology; in the next version, ICF terminology will be included in the definitions and other consequences of the ICF will be envisaged. The ICF will be used to indicate the intended use of ISO9999.

Technical aids are being classified according to their function and the Environment as in the ICF. The classification consists of three hierarchical levels and the codes consist of three groups of two digits each. The current version includes eleven chapters (first level):

- aids for personal medical treatment;
- aids for training skills;
- orthoses and prostheses;
- aids for personal care and protection;
- aids for personal mobility;
- aids for housekeeping;
- furnishings and adaptations to homes and other premises;
- aids for communication, information and signaling;
- handling products and goods;
- aids and equipment for environmental improvement, tools and machines; and
- aids for recreation.

It was agreed to maintain the classification as a living and dynamic document and to consider the time intervals for revisions after the next (third) revision.

ISO 9999 is currently being used in countries around the world as a national standard and in medical practices. Multiple translations are available. More countries are invited to participate in this work. Future discussions will include consideration of the ISO9999 becoming an official member of the World Health Organization—Family of International Classifications (WHO-FIC).

Open Discussion

Dr. Simeonsson responded to an inquiry that the version for children would be fully compatible in structure, hierarchy and qualifiers with the current version. Data should be able to “follow” a child into adolescence and adulthood. Yerker Anderson commented that care should be taken to ensure all four aspects of ICF be considered due to potential cultural differences. He gave an example of clumsiness, indicating that clumsiness may not be a problem in a developing country; however, in the US, clumsiness could affect one’s opportunities to participate in computer related activities.

There was much discussion for the presentation by Dr. Jette. Dr. Jette indicated that this research focused on basic tasks as activities and complex tasks for performance were considered as participation. Although some of the problems in ICIDH2 have been resolved, the consensus of the group was that the empirical research should continue and that existing research should be cross-walked, if necessary, to the current ICF version. It was agreed that these and future findings should be considered in future revisions of ICF.

Marjorie Greenberg commented that this would be an appropriate topic for the Clearinghouse.

Theme: ICF Surveys

Janette McDougall – Measuring Chronic Health Condition and Disability

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_11_e.pdf

Population-based estimates of the prevalence of chronic health conditions and disabilities are needed to assess the numbers of people who may have distinct service requirements. To ensure accurate estimates, national surveys are required to validly measure the concepts of chronic health condition and disability. Recent emphasis has been placed on assessing outcomes such as social participation and quality of life for persons with chronic health conditions and disabilities. To ensure a comprehensive assessment of health, national surveys are needed that accurately measure such outcomes as well as the personal and environmental factors that are related to them (Canadian Institute of Child Health (CIH), 2000; World Health Organization, 2001). In particular, the need for national surveys that validly assess the prevalence of chronic health conditions and disabilities and associated social outcomes for children and youth has recently been recognized (CanChild, 2001; CIH, 2000).

Estimates of the numbers of children with disabilities have been shown to have dramatically increased over time in the United States and indirect evidence suggests that a broadening of the range of questions that tap activity limitations explains a portion of this trend (Newacheck, Budetti, and McManus, 1984). In Canada, estimates have fluctuated, and may, in part, be due to how disability has been defined and measured. For instance, the 1991 Health and Activity Limitations Survey (HALS) measured childhood disability using a combination of items that captured the presence of chronic condition, difficulty in hearing, seeing, or speaking, use of technical aids, general limitation in activity due to physical or mental health, and attendance at a special school or classes (Furrie, 1995). The total percent of children with a disability aged 5 to 9 was 7.4% (Statistics Canada, 1995). The 1994/95 National Longitudinal Survey for Children and Youth (NLSCY) measured disability using a single question about general activity limitations in major life areas due to a chronic health condition or health problem. This operational definition has been taken to indicate presence of disability in many surveys and in disability legislation (Druss, et al, 2000). Using this method of measurement, the total percentage of children aged 4 to 11 years with a disability was 4.4% (Statistics Canada, 2002).

The valid measurement of childhood chronic health condition and disability is vital for ensuring that national and regional policy makers and planners know where to make policy changes and where to best direct funds and provide services. This presentation was concerned with the adequacy of health measurement in Canadian national surveys of school-aged children (i.e. children aged 5 to 14). A major concern is that chronic health condition and disability are often mistakenly viewed as indistinguishable concepts. Due to this definitional ambiguity, the two concepts have been identified incorrectly in survey research. This presentation:

1. Pointed out the merits of developing national survey measures of chronic health condition and disability for school-aged children using the WHO International Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) and the International Classification of Functioning, Disability, and Health (ICF).
2. Identified and described Canadian national surveys that are available for assessing childhood chronic health condition and disability.
3. Described the types of health measures (single indicators, indexes, etc.) that exist, their advantages and disadvantages, and which of these measures are available in each survey.
4. Provided a review of the coverage in each survey of chronic health conditions and the domains of disability as they are laid out in the ICD-10 and the ICF, respectively.
5. Made recommendations for future survey use and construction.

Recommendations for Measuring Disability:

- Impairments be measured distinctly from chronic health conditions and activity limitations using a standard approach based on the ICF;
- A standard “global disability item” (Verbrugge et al., 1999) and a profile measure based on the sub-domains of the activity limitations/participation restrictions dimension of the ICF should be developed for survey use; and
- Measures of ICF environmental factors excluded in surveys should be developed for use

Recommendations for Measuring Chronic Health Conditions:

- A standard list of specific relevance for school-aged children based on the ICD-10 should be developed and used in Canadian health and disability surveys; and
- The use of condition lists based on the ICD-10 over a “non-categorical approach” for identifying children with chronic health conditions.

The ultimate aim of this presentation was to encourage facilitation for the development of population survey measures of childhood chronic health condition and disability that are based on distinct definitions for each concept provided by the ICD-10 and the ICF, respectively. Such an approach to population survey design is consistent with a biopsychosocial perspective of disability that acknowledges the dynamic, nonlinear interaction among the dimensions of disability, chronic health conditions, as well as personal and environmental factors. It would facilitate the collection of data on these constructs independently and, consequently, the analysis of the associations among them.

Diane Shinberg—Report on the Meeting of the Washington City Group on Disability Statistics

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_12_e.pdf

This presentation summarized the first meeting of the Washington City Group on Disability Statistics, an independent advisory group to the United Nations Statistical Commission. The meeting was hosted by the National Center for Health Statistics, United States, February 18–20, 2002 in Washington, DC. The presentation began with an explanation of

what a City Group is and why one was needed for Disability Statistics. The Washington City Group was formed to address unresolved issues raised at the June 2001 UN International Seminar on Measurement of Disability. It will serve as a mechanism to foster discussion and generate international consensus with an ultimate goal for measuring disability in a general and internationally comparable way.

The meeting was planned with members from Australia, Eurostat, Mexico, Uganda and U.S. The agenda was set by email with occasional conference calls. Session chairs prepared written discussion questions and guided the discussions.

In addition to the host country, thirty-one countries (from developed and developing countries, from all regions) sent at least one representative to the City Group. In total, approximately 64 persons participated in the three-day meeting. Sessions included paper presentations supplemented by structured discussion questions to guide the Group toward recognizing areas of agreement or consensus.

Formal objectives of the Group are:

- To guide the development of small set(s) of general disability measures suitable for use in censuses, sample-based national surveys and other statistical formats;
- To recommend one or more extended sets of survey items to measure disability (or principles for their design) to be used as components of population or specialty surveys
 - Such measures will be culturally comparable.
 - The ICF model will be used as a framework to develop such measures; and
- To address the methodological issues associated with the measurement of disability.

Areas of Agreement include:

- The crafting of internationally comparable general disability indicators is important and possible;
- The development of multiple measures is relevant for multiple specific purposes;
- A clear linkage of the purpose of measurement to operationalization of the indicator(s);
- Short and long sets of measures should be developed with longer sets cross-walked to short set;
- There is a need for clear, specific definitions of the aspect of disability to be measured;
- There is a need for flexibility in translating agreed-upon reference documents;
- There should be specification of limitations of such measures;
- There should be specification of how personal assistance and device use is treated in relation to measures;
- The activity dimension of the ICF should be initial focus of such measures;
- Census and survey questions should avoid words with negative connotations, such as "disability";
- Persons with disabilities should be included in the development of indicators;
- The City Group should provide technical support for the development of internationally comparable general disability measures, including a research and testing program; and

- Working networks should be developed among participants, including a process of technical assistance from higher resource to lower resource countries.

The report, agenda, and presentations can be found at:
<http://www.cdc.gov/nchs/citygroup.htm>.

John Hough—ICF and the U.S. Health Agenda

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_13_e.pdf

If the ICF is to be of utility over time, it must be effective in aiding a variety of disability-related activities. The United States has recently entered its third decade of agenda setting to improve the health of its citizens. The publication is called Healthy People 2010. The 28 chapters include some 460 objectives. For the first time a chapter has been devoted to the health promotion and reduction of secondary conditions among people with disabilities. The conceptual framework of the ICF provides grounding for the Healthy People 2010 section on disability.

The first national health targets were in 1979. These included four age-related mortality reduction goals and one goal to increase elder independence. While 3 of the 4 mortality reduction goals were met, there was no data to track older adult independence.

In 2000, since there was no data, there was still no focus on disability although sixteen objectives referenced disability. Nine of those objectives related to health issues for people with disabilities in the areas of leisure activity, overweight, stress, mental health treatment, and clinical preventive services.

In Healthy People 2010, for the first time, there is an emphasis on disability. The process included over 250 individuals from 75 advocacy, professional, university, and governmental entities. Chapter 6 and demographic variables offer opportunities for data collection on disability.

The goal for Chapter 6: Disability and Secondary Conditions is to “Promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the United States population”. The core issues uncouple two false equations: disability = illness and health = medical; and develops a standard survey definition of disability and highlights the role of environment and uses ICF as the framework for the objectives. Chapter 6 has 13 objectives; 10 are data driven and 3 are developmental with no data yet (expected 2003).

“Disability” is included as a descriptive/demographic variable in over 100 objectives in 27 Health Chapters (e.g. oral health, physical activity, nutrition, injury, smoking, violence).

Specific objectives in Healthy People 2010 are linked to ICF in the areas of Body Functions, Activities, Participation and Environment.

Open Discussion

Discussion centered on the relationship of the work in these presentations to that of DISTAB and the Washington City Group. In the US, this included the requirement of Objective 6.1 in the Healthy People 2010. Several participants provided supporting information that data collection endeavors in the US and Canada are using consistently worded screening questions. From these data collection efforts, using the consistent set of screeners, comparable information should be available in the very near future. This work is being performed in conjunction with work of DISTAB and the Washington City Group. DISTAB has begun work to identify national surveys that include environment and participation items.

Theme: ICF for Clinical Practice

Jayne Lux and Geoffrey M. Reed—Clinical Implementation of the International Classification of Functioning, Disability and Health

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_14_e.pdf

As implementation efforts related to the ICF begin, it is critically important that users adopt consistent solutions to aspects of the classification that remain unclear or unresolved.

The American Psychological Association, in collaboration with WHO, has convened an interdisciplinary team to draft a Procedural Manual and Guide for a Standardized Application of the ICF for health care professionals. The goal of the procedural manual includes providing a standard approach to the classification that is clinically grounded, provides consistent interpretation of concepts and operational terms, and is clinically useful, reliable and valid. The intended audience for the manual is multidisciplinary health care professionals who work with individuals 18 years of age and older. These professionals should possess the skills necessary to independently assess clients and make a diagnosis. The project is a multidisciplinary endeavor including audiology, medicine, nursing, occupational therapy, physical therapy, psychology, social work, speech language pathology, therapeutic recreation and vocational rehabilitation.

Based on this work, a number of important implementation issues have emerged and clinically based solutions have been proposed. Clinical practice provides a tool for the description of human functioning as multi-faceted; detailing more than the biological perspective on health. It allows for a description of functioning in clinical and everyday environments. It supports clinical judgment related to the evaluation of a particular client in a particular context, guides treatment planning and is useful in monitoring treatment outcomes. Examples were presented including needs assessment, assessment methodologies and looking at implementation of the codes and qualifiers for a variety of disciplines.

Successful implementation of the ICF can result in a consistent and reliable means for coding functional status providing meaningful and detailed information. However, it must be easy to use; connecting ICF codes and concepts with clinical practice activities must be easy. Electronic tools to enable easy navigation of the ICF system to locate relevant codes for individual clients will be necessary.

Obstacles to ICF in the U.S. include low level of awareness among health professionals, a variety of other systems are available and no immediate interface is available. There is general agreement that it is unlikely that functional classification will be incorporated in reimbursement mechanisms in the near future. Such implementation will require an expansion of the current champions in the health policy arena.

Differentiating Codes

In some cases, ICF item labels and definitions for select codes within and across domains cannot be distinguished clinically (e.g., certain body function coded and the assessment of capacity for a corresponding d code). This raises the question of whether to disallow the use of duplicative codes or to develop other coding conventions for these items. In other cases, some codes appear redundant, but can be differentiated if operational examples are provided.

Qualifiers

In order to implement the qualifiers, clinically based definitions of “capacity” and “performance” need to be developed and endorsed. Likewise, to understand the assessment of an individual’s capacity with and without assistance, it is important to describe what is meant at the clinical level. Is it possible to conduct a meaningful clinical evaluation when all assistance has been removed? If it were possible, how meaningful and useful is the information that would be obtained? How can the capacity qualifiers be meaningfully translated into a clinical context?

In the case of the performance qualifiers, performance is often variable across the different current environments encountered by individuals. Should performance be coded to best or typical performance? Is it possible to derive an “average” performance rating and if so, how useful is that for purposes of treatment planning? Should performance be rated in light of the reasons for seeking treatment?

Standard Environment and Current Environment

Definitions for standard and current environments need to be developed if these concepts are to be implemented consistently. However, even with definitions, implementation issues arise. Is a standard environment always the best one to use for determining an individual’s capacity (highest probable level of functioning)? If an individual’s current environment is temporary, such as inpatient drug rehab facility, should that be considered the current environment? How is the coding completed in one current environment distinguished from the coding conducted in a different current environment?

Assessment Methodologies

Many ICF codes do not represent unitary aspects of human functioning. That is, a single code frequently includes many facets of functioning.

Therefore, it is not realistic to assume that one-to-one mapping is possible between standardization tests and most ICF codes. Rather, what is more likely is that multi-modal approaches (e.g. psychometric measures, clinical interviews, direct observation, key informant interviews) will best serve as a basis for communicating assessment results through the ICF system.

Other clinical assessment issues include the aggregation of 3rd and 4th level codes to 2nd level codes and the implementation of codes with multiple sub-parts.

A comprehensive work plan would be to use computer applications to facilitate coding and to implement the development of assessment instruments, including electronic versions. The ICF advocacy efforts are with governmental, private and accrediting agencies in the development of professional education programs.

Alarcos Cieza—The Development of ICF Core-Sets

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_15_e.pdf

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_papers_4_e.pdf

Rehabilitation medicine is dedicated to optimize patients' functioning and health. Models of functioning and health are the basis for clinical practice, teaching and research. The new ICF model of functioning, disability and health is scientifically based and has been developed in a comprehensive consensus process over the last years. It is thus likely to become the generally accepted model in rehabilitation.

While the ICF provides the model for the classification of patients' functioning and health, practical, reliable and valid applications for rehabilitation practice, teaching and research need to be developed. ICF applications for rehabilitation need to be linked to the distinct although related concept of disease according to the ICD-10. While there is no casual link between health conditions and health states, there is an association of specific health conditions and commonly involved health states. It is thus possible to define core-sets of a limited number of commonly involved health states or ICF categories for specific conditions.

The aim is to develop empirically and consensus-based condition-specific ICF core-sets for clinical practice, teaching and research and test them for feasibility, reliability, validity and sensitivity. Different musculoskeletal, internal medicine, neurological and mental conditions have thereby been selected. The main goal is to define what should be measured, (not how to measure) and to make the ICF feasible for use in clinical practice, clinical and epidemiological studies, health reporting and monitoring of functioning and health. Once accomplished, the project will link the ICF to the ICD and to existing health status measures.

The project has two phases to develop core-sets for specific health conditions:

Phase I aims to select the ICF categories to be included in the different condition specific core-sets. Within this phase the results of preliminary studies using empirical data from patients (frequency of categories when applying the ICF-checklist), international Delphi surveys (categories nominated by experts) and systematic reviews (use of categories in clinical studies) are presented to a panel of international experts. International consensus conferences are thereby organized in collaboration with the WHO. On the basis of a nominal group process within the conference, the ICF categories to be included in the ICF-core-sets are defined. The first consensus conference on musculoskeletal conditions (low back pain, osteoarthritis, osteoporosis and rheumatoid arthritis) took place in Spring 2002. Results were presented and are detailed in the powerpoint presentation. The consensus for neurological conditions and internal medicine will take place January 31–February 2003 and June 2003 respectively.

Phase II aims to test the feasibility, reliability, validity, and sensitivity of the condition specific ICF core-sets developed during Phase I. To accomplish this objective, a multi-center prospective cohort study will be performed.

Empirically and through a methodologically sound consensus process, core-sets may help to address the challenges when using the ICF in clinical practice and strengthen the patient perspective and the multidisciplinary management of functioning and health.

Patricia Welch—Exploring the Past, Present and Potential Applications of the ICF in the Social Work Field

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_16_e.pdf

ICF is designed for multiple uses across sectors and disciplines, including social work education. Little work has been completed in applying the ICF and ICIDH to social work. Related fields like psychology have been actively involved in the ICIDH revision process but social work has been absent. Hence, further probing was needed to assess the status and extent of ICF and ICIDH.

A recent study (2000) surveying social work schools for disability content in their curricula noted that the ICIDH was rarely mentioned. A curriculum resource, "Integrating disability content in social work education," includes only one model syllabus that describes ICIDH terms and only one reference in its annotated bibliography regarding the ICIDH and ICF.

A literature review of major social work journals found minimal articles regarding ICIDH and ICF. Of these references many were in cross-discipline journals (e.g. Social Science and Medicine). Most ICIDH and ICF articles were published in medical and rehabilitation journals as well as disability-related journals (e.g. Disability and Society, Disability and Rehabilitation).

Since the ICF differs from the ICIDH, the changes enhance the feasibility of applying the ICF to the social work field. One critical change is the recognition of the social aspects of disability and the use of the "bio-psychosocial" approach in the ICF. Social workers frequently deal with the social construct of disability in theory and in practice. Another important change is the inclusion of social and physical factors in the ICF. Since social work embraces a person-in-the-environment framework, it is anticipated that the ICF framework would be more accepted than its predecessor, the ICIDH. Due to parallels between the ICF and social work there is a greater likelihood of social workers using the ICF than the ICIDH.

Steps need to be taken to increase ICF awareness and promote its application among social work educators and students as well as professionals and practitioners. Involvement of social workers and their input in ICF-related activities would facilitate ICF recognition and potential usage. Inclusion of "how to," examples using the ICF in social work would be helpful to practitioners. Publications in key social work journals and association newsletters will increase knowledge of the ICF among social workers.

Debra Stewart— Opportunities and Challenges Facing Canadian Occupational Therapists

Using the ICF http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_17_e.pdf

The new ICF provides a common language and framework for the description of human functioning and disability, and many health and rehabilitation professions are exploring ways to incorporate its use into practice. The Canadian Association of Occupational Therapists (CATO) has demonstrated an interest in the ICF by identifying a representative to promote the implementation of the new classification system by occupational therapists in Canadian.

This presentation outlines some of the opportunities and challenges that a group of occupational therapists have identified about the “fit” between the ICF and occupational therapy practice. These therapists have been involved in the revision process of the ICDH-2 and the ICF, and they are presenting a workshop on the ICF at the World Federation of Occupational Therapists (WFOT) Congress in Stockholm, Sweden in late June 2002. This presentation is a brief synopsis of the WFOT Congress workshop.

First, the conceptual fit between the ICF framework and current practice models in occupational therapy was explored. The Canadian model of Occupational Performance (CMOP) and the Person-Environment-Occupational Model are two well-known practice models in Canada that acknowledge the importance of the interaction between person and environment in health, which is similar to the conceptualization of functioning and disability in the ICF. Some issues have been raised by occupational therapists that are familiar with the ICF about the Activity and participation dimensions in the ICF, and these issues are discussed.

The potential uses of the ICF in occupational therapy practice were also explored, including, mapping the ICF with current assessments of occupational performance, in particular, the Canadian Occupational Performance Measure (COPM). The new assessment measures under development fit well with the ICF framework. The benefit of using the ICF is to promote interdisciplinary team communication. A good fit is with occupation-based interventions. The increase focus in the occupational therapy profession is on using environments to enable occupational performance.

A specific example was shared for the study of transition from adolescence to adulthood for youth with disabilities and the participation of children with disabilities. This example showed the “occupation” of attending class at school.

John Hough—Coding Information of Health Promotion Applications Using a Hand-Held Personal Digital Assistant Device and the ICF Feasibility and approach to developing hand-held device for coding with ICF

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_18_e.pdf

The objectives of this study were to: inquire about a research agenda representing functional status data in computable formats—algorithmic versus syntactic or semantic and medical language processing via batch entry; describe the basic research needed to develop the programming code or algorithms that would make such a device practical and potentially profitable; and propose a “Public Health Informatics” research agenda that would incorporate ICF codes within data derived from clinical practice.

The need to utilize ICF coding via an automated Personal Digital Assistant (PDA) software for health outcomes research or evaluation in clinical and health promotional settings was discussed. Broad acceptance and generic applicability of ICF coding will transpire only when the ICF becomes computerized, easy to use in clinical practice, associated reimbursement, less cumbersome to new users and a topic of entrepreneurial interest. It must reliably generate an ICF code in fewer than 6-8 strokes or fulfilled machine oriented queries.

Two approaches were considered for extracting ICF relevant information—algorithmic (decisions based on responses to questions on the ICF checklist) and syntactic (phrases and sentences). The tradeoff for the practical PDA approach using the checklist is the capacity to keep the process simple. The limitation is the “controlled vocabulary” of the ICF itself.

The pros of the algorithmic approach included ease of programming at the two level classification, direct observation of problem followed by a qualifier and the opportunity for wireless transmission of data. The cons included difficulty at the four level classification for health promotion, poor inter-rater reliability at the four level codes and the extremely high potential (12,816) of coding for only one outcome code per case.

Consideration for future applications includes determining the need for hand-held versus batch processing, rehabilitation or environmental interventions and the benefits of wireless transmission.

Future research will include a need for access to a large computerized database of anonymized patient records from general or rehabilitation practice, using algorithms to generate ICF codes and compare results to those of a panel of experts. Also required is string matching vs. structural matching to adapt an existing “medical language processing” system to generate structured output for terms associated with ICF codes, rather than the codes own prose strings within text. Linking adjective strings like “severe” in medical records to the context of a Qualifier depicting magnitude would be necessary.

Questions were presented for discussion in the areas of funding priorities, whether the product should be proprietary versus public domain and if the tool could take advantage of strengths of the taxonomy's semantic structure in some areas but "build around" weaknesses.

Open Discussion

This discussion session centered around the scientific requirements of automation of data. Representatives from the Mayo Clinic provided input based on their work using Unified Modeling Language which is syntactically precise as opposed to freehand notation. They offered their support to this endeavor. It was widely agreed that extensive support is necessary for this empirical work. Concern was expressed whether the existing document is sufficient for automation. Consensus exists for the need for funding for further work on the terminological knowledge and application manuals (such as the work by APA). There was some discussion concerning funding that might place research on this fundamental infrastructure in the private sector which could compromise the public good. Some participants agreed that a "dual track" of research could be beneficial.

Panel Theme: Capturing and Coding Functional Status Information

Alan Jette—A Comparison of Outcome Assessments Used in Post-Acute Care

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The background factors in a public policy mandate exist in the US to monitor the quality of post-acute care. The functional status is one important quality indicator for post-acute care. Functional outcome data are needed across diagnoses, across time, and across post-acute care settings.

Activity limitations are difficulties that the individual may have in executing tasks or actions. The challenge is to construct scales to assess the activity domain of ICF for use across post-acute care settings with a comprehensive range of coverage, item content, and spacing then compare the results with existing instruments used in Post-Acute Care settings.

The Activity Measure for Post-Acute Care (AM-PAC) is an item bank that includes items from existing instruments and allows new items to be added to fill in important content gaps. Activity items are based on ICF content and core items in the prototype AM-PAC. Comparison with existing instruments shows the augmented item bank improves the content coverage over any single instrument used in post-acute care or the range of coverage.

The conclusions are that ICF can provide a framework for measuring functional activity in post-acute care. Instruments designed for one setting are not adequate for quality monitoring across post-acute care settings. Combining items from existing instruments with new items extends the range of content needed for comprehensive assessment.

Lisa Iezzoni—The Case for Capturing Functional Status Information

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_20_e.pdf

Rising health expenditures prompt a variety of questions at the individual and societal levels. What are we buying with health care dollars? What do we want for our money? How can we better manage the health care system and expenditures to get what we want?

The US National goals for health care include: the President's Advisory Commission on Consumer Protection and Quality to reduce the impact and burden of illness, injury and disability and improve health and functioning; and the Institute of Medicine's goal of safe, effective, patient-centered health care and respect for patient preferences.

The National Committee on Vital and Health Statistics (NCVHS) reports that achieving optimal health and well being for Americans requires an understanding across the life span of the effects of people's health conditions on their ability to do basic activities and participate in life situations—in other words, their functional status. The reality is that we pay bills and collect information on diagnoses services and expenditures. There is a gap between national health care system goals and the data routinely available to measure performance and manage resources. The NCVHS Report on Functional Status recognized significant value of functional status information in clinical and administrative records and identified the International Classification of Functioning, Disability and Health (ICF) as the only viable candidate for a code set to classify functional status.

The findings indicate that health care and health policy must go beyond a narrow disease-based focus. ICF is a promising approach to coding functional status and deserves careful study. A coding system that specifies the elements of functioning is a reasonable place to start to measure and interpret functional status. Functional status information is integral to understanding health and should be included in patient records and reported at appropriate intervals in standardized data sets.

Work is needed before recommendations are made about widespread implementation of ICF. The requirements are for measuring functional status during clinical encounters, documentation of measurement in medical records, coding information in a consistent fashion across settings of care, using a comprehensive classification system and ability to capture coded information in routine, electronic and administrative transactions. The most important requirement is to use the information.

The NCVHS Report recommends research, analysis, testing and demonstration projects to examine a variety of issues. Gaps in availability of instruments for assessing functional status should be identified and addressed. The department is encouraged to take the lead in pursuing recommendations and to provide resources within the Department and to WHO to support work on ICF.

Christopher Chute—Functional Status Concepts, Data Capture, and Classification

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_21_e.pdf

Health care is an information intensive industry. Control of health care costs, improved quality of care, improved outcomes, appropriate use of health technology and compassionate resource management depend upon information collected, such as patient data. The heritage of continuous improvement in the central role of technology determines the description of medical concepts, events, observations, and interventions. The language and codes by which this information is presented is critical. All of these information needs are based on clinical data and will require the availability of machine processable clinical data.

The consistent and comparable coding of concepts shows great promise in realizing the potential of computer based clinical systems to meet diverse needs for information.

Sources of functional status data are nursing notes, assessment instruments and clinical patient records. Among the requirements for such computer based concept systems are: a structured terminology that provides information about the attributes of the concepts that encode domain knowledge; an ontology that specifies domain concepts, axioms, and relationships that can be shared across application systems; an explicit logic on which inference rules are based; computer based programs by which to implement applications; and an information model the structure by which different types off information are related to each other in electronic messages within or across applications and information systems. Well coordinated, terminologies and ontology provide the semantics or meaning of concepts whose instances are stored in the information model and made available across applications through a technical infrastructure that is based on the underlying logic.

The development of a concept based system for functioning and disability is particularly challenging because of the conceptual ambiguities that have characterized this subject field. The International Classification of Functioning, Disability, and Health (ICF) was developed specifically to provide consistent and comparable coded data related to functioning and disability. As such, the ICF provides a critical conceptualization of functioning and disability within health and health-related domains on which a formal concept based systems could be developed. The presentation provided an overview of key standards influencing the development of clinical information systems and proposed a research agenda whereby the ICF could be extended to meet the requirements of formal concept-based systems. The Harris Criteria for Computer Based Concept Systems, including structured terminology, ontology, explicit logic and information model, was explained.

The challenge presented was that of human navigation and computer interface. The ICF as a consistent high-level aggregation of terminology and patient data, including functional status should be integrated into clinical systems.

Gretchen Swanson—Change Requirements When Using Functioning Status for Payment and Quality

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_22_e.pdf

Data related to functioning alters decision-making in payment and review in many ways. A brief background was presented, followed by a perspective of barriers, change, and use. Definitions were shared and the Health Care Financing Administration (HCFA-700) Form was explained. The HCFA-700 Form is the written report used by physical therapists, occupational therapists, and speech pathologists when justifying treatment for Medicare beneficiaries. The form, and the regulatory language that explains it, offer the chance to use a numeric functioning code and narrative to explain the relationships between the person's health condition and current and future functioning status.

The major payment methods require a medical diagnosis to justify treatment procedures. Using potential functional outcomes could alter funding trends. Target groups would fear cutback of relevant but not yet proven clinical programs. From a broader view, the system

and those that pay for it, might no longer ignore primary and secondary prevention, early intervention, on-going care for chronic conditions, and at-risk programming. Moving from an illness model to a health model remains the obstacle.

Perspectives of barriers, change and use were then discussed. It is difficult to broadly and uniformly change to a health or chronic care model in the US health care system due to obstacles in getting critical information. Mandates and tools to transition the US health care system to a health and function model would be needed. There would need to be a careful evaluation of medical necessity and the relationship to functioning.

A broad and collaborative plan to use ICF widely in the US health care system would be needed. To avoid pitfalls and potential negative consequences transition from illness to health model would require a structured implementation of ICF. Functional status information, based on terms and rules, would need to be integrated into clinical systems. ICF would form the basis for a high-level, consistent aggregation of data. A successful implementation approach combines a "change perspective" with a "use perspective" to achieve desired results for payment and quality.

Open Discussion

Dr. Jette explained that the mapping to activity domains was done by simultaneous fielding the instruments and making a direct comparisons of the scores from each with scores from AM-PAC. They attempted to incorporate some items of the other instruments into the item bank of the AM-PAC prototype.

Discussion included the interaction of environmental factors and the problem of fiduciary responsibility. Dr. Jette developed a measure by revising Whiteneck's work on the environment which directly measures the domains and dimension interaction. This is being incorporated into the study.

Dr. Lezzoni indicated that for ICF to be used as rubric for reimbursement there might have difficulties in general care practice. Work is going on now that may clarify the issue in the next five years. Dr. Jette indicated that reimbursement in Post Acute Care already is being based on function. The use of ICF holds promise. Gretchen Swanson indicated that if reimbursement begins to be based on expected functional outcome, many groups would be unhappy with it.

Theme: Basic ICF

Patrick Fougeyrollas—The Next Challenge of International Standardization, the Issue of Validation of Measurement

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A method for validating measurement with ordinal scales in the five level qualifiers as proposed in the ICF is needed. The challenge with ICF is to make the bridge between specific, disciplinary, clinical judgement or assessment tools, which are generally not designed on the basis of ICF concepts, to an aggregate measurement with a five-level ordinal scale that has not been validated.

A validation study of ordinal scales was undertaken in the Quebec Traumatic Brain Injury (TBI) monitoring system. The research team designed a validation study of rating with ordinal scales that would be reliable, reproducible and sensitive to change, and related to motor, psychological, behavioral capabilities, life habits (participation) and environment (family). It was noted in the study that detailed guidelines could influence which level of severity was selected on the ordinal scale and improve the reliability of the data. It was also noted that motor disabilities or simple participation were more easily assessed than cognitive or psychological capacity.

The study concluded that guidelines are required for each ICF domain and subcategory with precise criteria for existing validated assessment tools—specifically for variables that are more difficult to assess. For ICF to be a reliable tool for aggregate data, a coordinated action plan for validation research in different fields and the development of user-friendly guidelines is required. This would lead to the development of knowledge on the measurement of functioning and disability and enhance the scientific credibility of ICF.

Craig Velozo—Use of Focus Groups in the Development of and ICF Activity Measure

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_24_e.pdf

The purpose of the study was to incorporate input from individuals with disabilities concerning the clarity and relevance of questions through the use of focus groups in the development of an ICF Activity Measure. The goal was to clarify questions, delete or remove irrelevant questions and add questions that are meaningful to persons with disabilities.

Ten Focus Group participants completed three tasks concerning ICF Activity measure domains of movement, moving around and self care. Each domain included a subset of activities. They commented on the clarity of questions and wording on the ICF Activity Measure, identified questions or activities that were irrelevant, misleading, or difficult to comprehend and suggested additional activities not on the ICF Activity Measure that were considered important components in their daily lives.

Based on the information provided in focus groups, 117 improvements were suggested for the ICF Activity Measure. The rationale for three major categories of improvements to ICF included: clarification of questions due to terminology or questions difficult to understand; deletion of questions due to the activities being too challenging, not commonly performed, not specific enough, or gender-biased; and questions added that were felt to have been overlooked.

It was concluded that the focus groups appear to be a beneficial research methodology in survey development. By incorporating input from the “experts” or individuals with disabilities, the ICF Activity Measure is likely to be more relevant to respondents.

P. Peter Wang—Modeling the Impact of Contextual Factors Associated with Labour Force Participation in People with Disability in Canada

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_25_e.pdf

People with activity limitations are associated with reduced labor force participation. For people with activity limitation (disability), being employed is associated with increased life-expectance and enhanced quality of life. Prior research indicates that lower employment rates of persons with activity limitations is, in part, due to contextual factors. The purpose of this study was to examine how workplace barriers affect labor force participation in people with activity limitations. The source for the data was the 1991 Canadian Health and Activity Limitation Survey (HALS), a household post-census survey that includes participants aged 15 years or older with at least one activity limitation. The outcome variable was the labor force participation. Variable definitions included Activity limitation, workplace barriers and socioeconomic status including age, sex, education and occupation.

Statistical analyses included the Categorical Structural Equation Modeling (SEM) and Mplus. The impact of activity limitation on labor force participation based on the 1991 HALS was presented.

It was concluded that both lower and upper limb activity limitations increase the likelihood of being out of the labor force. Lower limb activity limitation affects labor force participation more than upper limb activity limitations. Most of the impacts of physical activity limitations on labor force participation are mediated through workplace barriers. Reducing workplace barriers can be an effective means to enhance labor force participation in people with disabilities.

James A. Lenker and Jeff Jutai—ICF, A Useful Model for AT Research and Practice

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_26_e.pdf

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_papers_6A_e.pdf

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_papers_6B_e.pdf

Design of products and environments for people with disabilities falls along a continuum of research and practice areas for clinicians and engineers who work in the field of assistive technology (AT). This continuum encompasses a range of devices and products that include: crutches, canes, walkers and wheelchairs that facilitate mobility; computer-based software that aid spoken and written communications; and relatively simple devices used for dressing, bathing, and eating. Practitioners in the AT field include occupational and physical therapists, speech-language pathologists, special educators, rehabilitation engineers, prosthetics and orthotists, and information technologies. Typical AT settings include schools, rehabilitation hospitals, community based DD centers, workplaces and university-based clinics.

A comprehensive table with examples of AT devices that could be identified on the basis of functional performances in each domain, reimbursement models and their respective funding criteria, and measurement tools that are domain-specific and domain spanning was presented.

It was suggested that by applying the ICF model appropriate AT devices could be identified on the basis of functional need within each domain, which would simultaneously place them in the context of a reimbursement model and measuring the effectiveness or outcome of the AT device.

A table was developed with this information that provides a useful taxonomic structure for AT devices and identifies areas for research and practice. The limitations of the table were noted as inadequate temporal and causal components, and the imprecise coding of device categories.

Open Discussion

Discussion began with an inquiry to participants as to the use of the ICF “Red Book” in instructional settings. Four participants indicated they use the book in their courses.

Peter Wang responded to an inquiry about the investigation of barriers, facilitators or both and indicated that the unavailability of facilitators was often quoted as a barrier and agreed that conceptually this is not a barrier but a lack of facilitators.

James Lenker confirmed the that “self pay” was one of the options for funding in the research presented.

David B. Gray and Janice Miller—Community Environmental Surveys and ICF EF Codes

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_27_e.pdf

The International Classification of Function, Disability and Health (ICF) recognizes that disability is the result of the interaction of factors internal to people and the context in which they live. Contextual factors constitute part two of the ICF, which has two components: Environmental factors (EF) and Personal factors. Environmental factors include broad categories of external influences on the activities and participation of people living in their communities, including physical, social and attitudinal factors. The inclusion of environmental factors in the ICF is essential for developing a classification system that can be used to examine the influences of differing external factors on the participation characteristics of people with similar impairments.

This presentation described progress on surveys designed to measure aspects of the community that are facilitators or barriers to full participation by people with mobility impairments and limitations in community activities. Five measures were presented for assessing the receptivity of communities. They included selection of the geographic area; Community Participation and Receptivity Survey (CPRS/ML); Community Resources Index (CRI); Community Health Environment Checklist (CHEC/ML); and Coding of environment using ICF EF. The purpose, format, method and outcome were defined for each phase.

The Community Resource Index provides information about the types of resources and services in a community that are relevant to people with mobility impairments and limitations. Another survey, the Community Health Environment Checklist, is being tested in a portion of St. Louis for the purpose of discerning the physical and attitudinal receptivity of sites that are important for people with mobility impairments and limitations.

Coding of Environment using ICF falls under three different types of data taken on sites and services as: CPRS, the self report of target community members; CRI, the description of sites from existing data sources; and CHEC, the site visited to review receptivity attributes. The intention is to identify ICF EF code profiles of different communities for a variety of groups.

Three communities have been selected to test the CRI and the CHEC for feasibility of use in small and moderately sized cities in the Midwest. Knowing the quantity, location and type of services will provide an opportunity to compare the relative density of available sites and the services and facilities in different communities. Participation differences for those with mobility impairments living in dense communities will be examined as the survey tools are tested in these communities.

Mobility limited members of the community will be asked to provide a subjective appraisal of their participation in major life activities, their access to community sites, and their perceptions of the attitudes of persons in their community towards people with disabilities.

In summary a matrix of surveys and ICF EF codes with issues arising from the mapping process was shown. It was noted that for mobility limited persons:

- A range of ICF EF Chapters and 2nd level categories are reflected in study surveys;
- ICF Environmental Factors include important/key categories for mobility limited persons although there is a lack of specificity at the second level;
- There is a potential for inconsistent reporting (e.g. Ch1 versus Ch 5); and
- It is recommended that additional guidelines are required for EF coding, e.g. self-report on surveys, different data sources.

Gale Whiteneck – Measuring Community Environments, Incorporating Environmental Factors into Research

http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_presentations_28_e.pdf

The Craig Hospital Research Department, with funding from the Centers for Disease Control and Prevention (CDC) Office of Disability and Health is in the fifth year of a six year effort to develop, test, and apply new measures of environmental barriers in disability and rehabilitation research. This presentation covered progress to date, providing an overview of a measure of participation—The Craig Hospital Inventory of Environmental Factors (CHIEF) and a measure of the environment—The Craig Handicap Assessment and Reporting Technique (CHART).

Current environmental research strategies, built on a wealth of quantitative and qualitative information from CHIEF, move from subjective perceptions to more objective measures, move from individual measurement to community measurement and move from a single methodology to multiple assessment methodologies. These include assessments of the physical environment and of community attitude surveys.

This presentation described analysis-comparing incidences reported by people with disabilities and those without disabilities highlighting similarities and differences. Attitudes toward disability that can function as either supports or barriers have been identified as key components of the environment. To develop a new assessment instrument, applicable for use in broad scale surveys, multiple existing instruments including more than 80 questions were examined. Additionally, new questions were designed. Preliminary Rasch analysis of the thirteen questions currently being tested in the Colorado Behavioral Risk Factor Surveillance Survey (BRFSS), a statewide, random-digit-dialing survey include differences in report of attitudes of self versus others, positively versus negatively worded statements and physical versus mental disabilities. Six questions were identified for the best fit for the scale (3 pairs of Physical/Mental questions). Sub-group differences on the Preliminary Attitude scale indicate a more positive attitude expressed by younger people and those with higher incomes. No significant differences appear by gender, minority status or disability status.

Results of more than 950 interviews were presented. Some of the attitudes are:

- Most employers will hire a person with a disability if he or she is qualified for the job;
- There are too many handicapped parking spaces;

- People with disabilities receive too much special treatment under the law;
- It is inappropriate for people with disabilities to have children;
- Most people would be willing to accept a person with a physical/mental disability as a close friend;
- Children with physical/mental disabilities should be integrated into regular classrooms;
- People in a restaurant are uncomfortable being seated near a person with a physical/mental disability; and
- Most people would be willing to accept a group home for people with physical/mental disabilities in their neighborhood.

Open Discussion

David Gray clarified the process of identification of “community” as used in the study by saying that a municipality in the St. Louis area was selected. They then laid the census track on it, identified zip codes for a residential mailing. This defined a proximal community. Next the distal community, the resources such as the hospitals, recreation were determined via vector analysis of the mobile people (houses around the mobility limited). Janice Miller also indicated that the project should include a report card process to apply the information to consumers. The study should show participation in activities in the community including a comparison of the perception by those persons having a mobility limitation and those who do not. Perception of specific buildings will be compared. This might relate to the identification of “activity friendly communities” mentioned by Gretchen Swanson if the term “activity” is replaced by “participation”.

A brief discussion followed concerning appropriate methods of dissemination for this type of study. It was agreed that such research must be disseminated in mainstream journals and not just disability or disease specific publications. It was suggested that such a journal be initiated. Patrick Fougeyrollas invited submissions for his journal “Human Development, Disability and Social Change”.

Closing Remarks by Marjorie Greenberg

Marjorie Greenberg summarized the findings of the conference. Classifications are the bedrock of our information systems and health care is very information intensive industry. The conceptual model of ICF is a very powerful tool to provide the functional status component of that information. Participants agree that personal knowledge needs to be supplemented with terminological knowledge. It is important to make distinctions between classifications and measurement—ICF is a classification, not a measurement tool. The challenge is to bring these together and make sure that those interested in taxonomy and those interested in measurement are talking to each other.

Functional status is not just about the disabled community; it is about all of us. We all have functional strengths and weaknesses. It is part of living and relates to our quality of life and participation in society. There should be a focus on short term things that can be done in administrative data systems while looking at things that need to be done longer term.

The idea of a functional status journal was presented with an invitation issued from Patrick Fougeyrollas for submissions to his journal. There was consensus that there is a need to get more ICF publications in the literature, not only the disability journals, but also the mainstream literature. The proposed NACC ICF Clearinghouse could begin the expansion of dissemination.

ICF work is a work in progress and the infrastructure in which to implement ICF is also a work in progress. A lot of empirical work is needed to expand on and to operationalize the conceptual model in surveys, clinical data, and in community studies, etc. The research must stay focused on not just functioning, but also the environment. Toward this end, a business plan, including financial and policy support should be developed. The business plan should also include methods to ensure dissemination of survey results to persons with disabilities.

The next meeting will be hosted by Washington University in St. Louis, Missouri, June 16–19, 2003. It will start with a session reporting on the five CDC Environmental study results. Marjorie Greenberg issued an invitation for participants to a roundtable discussion on activity and participation.