

The ICF: Potential Influence on Disability and
Rehabilitation in Federal Agencies

December 5, 2002

**Holiday Inn Capitol
Washington, DC**

BACKGROUND

The Interagency Committee on Disability Research (ICDR) hosted a one-day Symposium on the International Classification of Functioning, Disability and Health (ICF): Potential Influence on Disability and Rehabilitation in Federal Agencies on December 5, 2001 in Washington, D.C. This meeting was an annual “summit” meeting of the Interagency Subcommittee on Disability Statistics (ISDS) under the sponsorship of the statutory Interagency Committee on Disability Research (ICDR). The Chair of the ICDR is Steven Tingus, Director of the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education (NIDRR) and the Co-Chairs of the ISDS are Dr. Paul Placek of the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC) and David Keer of NIDRR. Participants received copies of both the long and short versions of the ICF, published by the World Health Organization (WHO), 2001, as well as copies of all of the presentation materials. . (These materials may be requested from Barbara Rosen at Cherry Engineering Support Services Inc.(CESSI), contractor to NIDRR, who facilitated and recorded the meeting: (703) 448-6155, Ext. 224 or brosen@cessi.net.)

The meeting was held in the Holiday Inn Capitol in Washington, DC. Inclement weather prevented many registered participants from attending, including Mr. Tingus who reported to the conference by a telephone hookup. All conference materials will be mailed to the Federal personnel who could not attend.

THE SPEAKERS

Steven Tingus, M.S., C. Phil, Director, National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education : **Welcome**

Mr. Tingus, welcomed the participants. He acknowledged the presence of Dr. Roy Grizzard, Director of Disability Policy for the Department of Labor (DOL), and thanked him for participating.

He then discussed the role of the Interagency Committee on Disability Research, which he, by statute, chairs. It is the role of the ICDR to keep all Federal agencies informed. Thus the role of the ISDS, as a subcommittee of the ICDR is particularly important: this subcommittee is active in keeping policy makers, consumers and others who use

disability statistics informed about developments and needs in the field. The ISDS reaches out to the Federal community to get input wherever and whenever possible.

NIDRR's role in disability statistics, as in disability research, is governed by its (also statutory) Long Range Plan. NIDRR and the ICF are now operating in the third year of the 1999 Long-Range Plan. A new plan is being written that Tingus hopes to have completed by the end of 2003. Whatever the plan, however, the group is assured that NIDRR will continue to play a significant role in helping Federal agencies evaluate the utility of ICF as a measure of demographics and research. Working with the National Council on Disability, NIDRR hopes to identify the disability community and offer it useful research services, including the ICF. President Bush's New Freedom Initiative also offers an excellent tool, of which this conference is a result.

Questions:

How will demographics and the ICF fit into Federal Policy of work and functioning? Tingus stated that NIDRR and other agencies were working out strategies at the present time. Decisions from his and other research agencies cannot yet be announced. He asked Dr. Grizzard from DOL to comment.

Dr. Grizzard stated that DOL found the ICF presentation intellectually stimulating and in accordance with his concerns. DOL would welcome measuring functional characteristics rather than disabilities. Also, the field needed more objective terms for disability than are traditionally used. DOL would like to form research and measurement partnerships with other agencies, including DOL's Bureau of Labor Statistics, to determine useful labor statistics.

Mr. Tingus promised to be available for further discussions of the ICF in disability and rehabilitation research.

Somnath Chatterji, M.D., Scientist, Classification Assessment Surveys and Terminology, World Health Organization, **ICF: A New Classification, A New World Standard**

Dr. Chatterji gave an overview and a history of the ICF. He traced its history from the International Classification of Impairments, Disabilities and Handicaps to its much different current form. Unlike its predecessors, the new International Classification of Functioning, Disability and Health, known as the ICF, embraces many new classification and philosophical concepts:

It is possible to measure the health of an individual rather than his or her illness or deviance from normalcy measures;

Human function is measured, not merely disability;

The measures are integrative and holistic;

Any condition has parity with another condition, not a hierarchy;

Measures include all cultures, not just Western cultures;

The measures are operational, not theory driven alone;

The model of measurement is universal, not minority; and
It covers a life span approach, not just an adult-driven model.

The ICF has taken seven years to develop and has been field tested in 61 countries, in 27 languages, and through 2000 live case evaluations. It can thus be used for both domestic and international comparisons.

The ICF has three components, which are explained in detail in the ICF manual:
Body Functions and Structures;
Activities and Participation, which has components of capacity and performance, and
Environmental Factors with measurements of barriers and facilitators.

Two documents are available and important to the Clinician and the Researcher using the ICF: The ICF Checklist, which is particularly useful in disability management, and the Disability Assessment Schedule II (WHO-DAS-II) which has domains of understanding the world around you, getting around, self-care, getting along with people, life activities and participation in society. Both documents can be obtained from WHO.

Dr. Chatterji explained how the ICF can be used in research, health information systems and in clinical practice. He also explained that the ICF, in medical research and clinical practice, is enhanced by using it along with its companion document, the International Statistical Classification of Diseases and Related Health Problems –10th Revision (ICD-10), which takes a more medical model of physical disability.

Extensive material can be found on the WHO website: www.who.int/classification/icf. He encouraged all Federal agencies to consider using the ICF to enrich their data collection and to make it comparable to international populations. Classifications are not good unless used extensively.

Marjorie Greenberg, M.A., Chief, Data Policy and Standards, NCHS/CDC,
Head, WHO Collaborating Center for the Family of International Classifications for
North America, **Disseminating and Implementing ICF in the United States**

Ms. Greenberg is the Head of the North American Collaborating Center (NACC), one of the major collaborating centers established to work with WHO on international classifications. This Center, along with others, worked on the revision of the ICIDH (now ICF) from 1993 to 2000. The centers have combined two separate centers for work on developing and maintaining ICD and ICF to single centers called the Centers for the Family of International Classifications (WHO-FIC). They meet annually to address their joint work plan, responding to their mission to “develop, disseminate, implement and update the WHO Family of International Classifications to support national and international health information system, statistics and evidence.” More information about the NACC can be obtained at the website: .

As part of the efforts of the NACC, five U.S. Dissemination Projects have been awarded:

“Code ICF” offers interactive, Web-based training in the ICF; will include 15-second video clips from expert interviews, as well as winners of the WHOICF photo contest; and will enable translations into other languages. It will be delivered to WHO in early 2003. “ICF Videos” will provide videos on ICF use by consumers, ICF applications in surveys and clinical areas, historical development, and conceptual /issues areas. It will be available free to Federal agencies in the Spring of 2003.

“ICF Curriculum in North American Colleges and Universities” will deliver model curricula, and track use of ICF in curricula for public health, physical therapy, occupational therapy, special education, maternal and infant health, rehabilitation sciences, environmental health, health care finance, health promotion, biostatistics and disability studies

“North American ICF Clearinghouse”

(www.cdc.gov/nchs/about/otheract/icd9/icfhome.htm and, for Canada, www.cihi.com) is tracking ICF activities in North America, but anyone can participate and submit information. Agencies are encouraged to invite others to join the list. Participants receive monthly, one-way information of use to users or potential users of ICF and can unsubscribe at any time.

“Health Care Financing Review,” a special issue will be published by the Centers for Medicare and Medicaid Services in Spring 2003 with a focus on capturing functional status in administrative records for payment and quality. It has 10 articles now in review; edited by Drs. Gerry Hendershot and Paul Placek.

2002 has been an important year for ICF-based meetings. Many developmental, educational and consensus meetings have taken place in Washington, DC; Trieste, Italy; Toronto, Canada; Brisbane, Australia, and now, this meeting. The first of these meetings was hosted by NCHS and participants were named the “Washington City Group.” They are a collection of experts from around the world who are working to develop international consensus on comparable general disability indicators, based on the ICF. These indicators will be for use in censuses and surveys.

During the annual meeting of Collaborating Centres in Brisbane, Australia, an ICF Subcommittee was created within the WHO-FIC Implementation Committee. Related groups are working on training and credentialing and electronic tools.

The Eighth Annual NACC meeting was held in Toronto, Canada; papers can be found on the NACC web site under “meetings”. The next NAAC meeting will be the “Ninth Annual North American Collaborating Center Meeting on ICF and will be held June 16-19, 2003 in St. Louis, Missouri. The call for papers is currently published in the ICF Clearinghouse. The WHO Subcommittee on ICF Implementation, will hold its first official meeting following the NACC meeting on June 19-20, 2003. Everyone is invited to the NACC meeting, particularly participants of today’s meeting. It is up to the participants today to begin the implementation of the ICF in their agency’s data collection and analysis.

Dr. Placek then introduced Dr. Cille Kennedy, an Operations Research Analyst in Disability, Aging and Long-Term Care Policy in the Office of the Assistant Secretary for Planning and Evaluation(ASPE), in the Department of Health and Human Services.

Dr. Kennedy briefly referred to her paper, *Federal Activities Related to the World Health Organization's ICF*, included in the program book available to participants. In the paper, all the Federal projects that could be identified in the Departments of Health and Human Services, Education and Labor, are listed, as are their contacts, their collaborators, Websites, and their purposes. Federal agencies not included are invited to give Dr. Kennedy information so that she can update the report. Material in the report is available on the ICF Clearinghouse website.

Mary Chamie, Ph.D., M.P.H., Branch Chief, Demographic and Social Statistics, Statistics Division, United Nations: **ICF: Basis for United Nations Disability Statistics Program**

Dr. Chamie stated that talking about the ICF is like offering the audience desert before the main course. It follows the more substantial part of the meal, is more universally liked, and is always delicious.

In her metaphor, the substantial part of the “statistics meal” is the effort and tradition that has gone into developing something as appealing as the ICF. The effort at classification started in the 1700’s when people labeled visible infirmities with often discriminatory language and applied to this language deterministic viewpoints, e.g., unable to work, needs institutionalization, etc. These concepts lasted until the 1950s.

In the 1960s to the present, new methods of classification were proposed. Self-reported disabilities became more common. The ICD classifications were emphasized as being for “identification purposes” only. Medically verified organ dysfunction was emphasized and there was some focus on activity limitations, reduction of function and consideration of the classification scheme of the ICIDH. In 1993, work began on the revision of the latter classification that resulted in the ICF.

What are the next statistical steps for the UN?

To implement the statistical concepts and classifications based on ICF
Agree on data collection methods, statistical guidelines and standards
Identify the minimal dataset for national/subnational profiles

The United Nations Statistical Commission has worked diligently with government agencies on classification systems. It worked on ICF adoption by the UN in 2001. It worked with the survey standards and measurement deliberation of the Washington City Group in 2002. The Commission is now proposing the integration of disability into the regular United Nations international data collection program, the “Demographic Yearbook,” in 2003.

Dr. Chamie made comparisons between the ICF and the ISIC (measures of Economic Activity and Production). While there are interesting overlaps, data from both complement studies of all individuals with disabilities and their societies.

She ended by displaying future projections of age demographics in several countries, indicating how future changes will require governments to have more and better data to understand these populations and their needs. The ICF offers this better data and understanding.

Geoffrey Reed, Ph.D., Assistant Executive Director for Professional Development, American Psychological Association: **Procedural Manual and Guide for a Standardized Application of the ICF, a Collaboration of Eight U.S. Professional Associations**

The American Psychological Association (APA) is the world's largest scientific and professional association of psychologists, including over 159,000 researchers, educators, clinicians, consultants and students. They publish 41 scientific journals, 425 book titles and the major interactive research databases in social science. Involved actively in ICF efforts since 1995, they have their own work group and have been a member of the Mental Health Task Force, They are presently involved with the NACC, were an active collaborator in ICF field trials, and offer sustained educational and advocacy efforts within psychology. The APA is now involved in the development of a procedural manual and guide for the standardized application of the ICF.

The APA endorses the ICF because:

It provides a tool for the description of human functioning as multi-faceted;

Functional status is often a better indicator of treatment needs and outcomes than a diagnosis alone;

ICF allows for a description of functioning in clinical and everyday environments;

It conveys "best" and "typical" functioning;

Using it allows health professionals to convey results of specialized professional assessments in universally understandable terms;

It supports clinical judgment related to the evaluation of a particular client in a particular context;

Data can guide treatment planning; and

The ICF concepts and data are useful in monitoring treatment outcomes.

Despite many obstacles to using the new ICF, the APA is committed to developing a guide for standard applications of the ICF that can be used by many psychology and psychology-related disciplines, i.e., audiology, medicine, nursing, occupational therapy, physical therapy, social work, speech-language pathology, therapeutic recreation and vocational rehabilitation. WHO agrees on this need and encourages APA to take the lead. The APA is currently working diligently on this manual, both in its written form and in its Web/interactive form. It will be written for those who serve clients over 18 years of age. The schedule for completions is as follows:

APA completed the drafting and the testing of the first four chapters of the manual and the introduction in the Fall of 2002.

APA now seeks participation of health professional from the US and abroad and expects to complete input early in 2003.

An expanded drafting team will be convened early in 2003.

Final drafts of all chapters are to be completed by early 2004.

Comment and review will be sought in mid 2004.

Version 1.0 will be published in 2005.

Some possible applications for the Federal government are speculated on by the APA, including the standardization of “medical evidence” required by Social Security, standardized assessment for Medicare claims, and the standards for eligibility reviews for disabled persons seeking education through the mandates and programs of the Department of Education.

The APA continues to seek partnerships with both government and non-governmental organizations, and with representatives of all relevant disciplines for input.

Gerry Hendershot, Ph.D., Consultant on disability statistics, NCHS, and Ray Seltser, M.D., M.P.H., Dean Emeritus, University of Pittsburgh Graduate School of Public Health, Consultant, NCHS: **A Strategy for Operationalizing the ICF for Use in Clinical and Administrative Records**

Dr. Hendershot presented. The presentation is part of a journal article that will soon be published in the “Health Care Financing Review” (mentioned in the presentation by Ms. Greenberg).

The ICF presents a new and valuable tool to researchers and practitioners working with disability populations. What is now needed is a proactive strategy that will implement the ICF. The speakers visualize a fully operationalized ICF in the health care system where providers will be paid under ICD, ICF and CPT standards, and function and quality of life will be central to decisions and interventions.

The speakers propose that the government develop strategies that include the following features:

Professionals from many disciplines will select relevant ICF codes.

Major funding for research and development will be available from public and private sources, with contingencies for the use of the ICF.

A Manual on “Level of Functioning Assessment Tools and Techniques” (LOFATT) will be developed by contract to a Federal agency.

Placeholders on forms for ICF codes will be developed and universalized.

Funding for training and education of both professionals and consumers will be made available.

Public awareness will be raised.

The speakers identified key research and the key actors of such research who would immediately benefit from this strategy and demonstrated the value of ICF to these actors.

Finally, the speakers presented a series of conceptual RFA's that will be circulated to various agencies to consider as funding priorities. These five RFA's would orchestrate the strategy recommendations. (Federal agency representatives may obtain these RFAs from Dr. Paul Placek.)

Acceptance of the ICF will benefit the disability community by offering more realistic and functional definitions of disability, by creating standards for benefits, by providing more data for care decisions, by universalizing disability, and by offering new paradigms on which to base universal designs.

Lisa Iezzoni, M.D., M.Sc., Professor of Medicine, Beth Israel Deaconess Medical Center, Harvard Medical School: **Capturing Functional Status Information through Administrative Databases**

The question: "Why should we capture ICF data routinely?" is answered by a look at the national health expenditures. In 2002, that sum was \$1.5 trillion. We need to know what we are buying for those dollars as well as what we want, societally and personally for these dollars, and how we can better manage our health care systems to achieve our goals. The ICF is one instrument that can help us with these tasks.

The governmental impetus for functional data gathering was given a push by the report of the National Committee on Vital and Health Statistics titled "Classifying and Reporting Functional Status" published in June, 2001 (www.ncvhs.hhs.gov/010617rp.pdf). In this report the Committee noted that there are many signs that agreement is emerging on the importance of functional status information for the optimal carrying out of clinical care, public health practice, policy and administration. The obstacles remaining are how to secure this information, particularly in administrative databases.

Dr. Iezzoni named potential administrative databases that could contain ICF data:
Administrative data that oversees public and private health insurance;
Plan enrollment, paying claims, reporting encounters;
Classifications currently used in these databases tell us about diseases, disorders, services and costs, but little about the health and functioning of the American public.

Even though the current documentation practices are poor and varied, the routine collection of functional status data could be merged into the administrative data bases:
Measurements of functional status during clinical encounters (difficult now because clinicians do not often have a chance to observe function outside of examining rooms);
Documenting functional assessment in medical records;
Coding functional status information using consistent classification scheme; and
Capturing information in routine, electronic, administrative transactions.

Adding ICF to administrative transactions would require decisions from ANSI Accredited Standards Committee (ASC) X12N. The full support of the health care industry would also be required, thus arguing a “business case” for the inclusion of ICF data.

That business case has been made by the NCVHS (2001) report for use of functional measurements to improve health care management, quality, public health, setting priorities for scarce resources and research. Demographic factors, e.g., “Baby Boomers” and their inevitable challenges to health care system outcomes is one of the most powerful “business case” arguments for ICF measures in administrative databases.

The bottom line conclusions are that: 1) adding functional status information to administrative transactions will require careful study and testing, and 2) policymakers, payers and providers will need to be convinced that the value of collecting functional status information outweighs costs.

Yerker Andersson, Ph.D., L.L.D., Professor Emeritus, Gallaudet University
Judi Chamberlin, Director of Education and Training, National Empowerment Center:
Consumer Comment on ICF and Disability Research

Dr. Andersson has been a member of the National Council on Disability (NCD) for a number of years and has worked on many of their committees dealing with terminology and issues of data. At the present time, he sits on the DISTAB, a committee that meets monthly and discusses Federal agencies’ disability surveys and research.. NCD has a Website, (www.ncd.gov) which has many publications of relevance to the standardization of terminology across government research. It has, in past publications, recommended functional measurement.

He noted inconsistencies in current language:

Hearing impairment is sometimes called “hard of hearing,” sometimes “deaf”. He prefers “deaf” because it signifies a culture. He does not like the term “hearing impairment.” On the other hand, people with blindness prefer “visually impaired”. It is a matter of choice, not logic.

A new word “diffable” is appearing, and he favors it as a generic term, finding it less emotional than “disability.”

Several adjectival phrases are now being used: “single disability,” “cross-disability” and “trans-disability.” He feels that “trans-disability” is more appropriate than “cross-disability”, especially internationally.

In a recent ICF presentation in Japan, he noted that hearing was described as a body function, but listening was an activity. He feels that hearing needs to be within the continuum of activity and should be related to environmental factors; for instance loops, hearing aids, sign language assist hearing.

He objected to the ICF manual referring to a “formal” sign language, since “formal” has different meanings, not only in this and other cultures, but in other languages.

He hopes that Disabled Peoples International will be asked to comment on future modifications of the ICF; this will insure cross-cultural input from consumers. He is grateful that the ICF works on a health model. It is the holistic concept that is needed.

Ms. Chamberlin believes it is important not to avoid disability terminology. Persons with disabilities are not necessarily viewed negatively in modern world. What are needed by advocates and consumers are definitions of stigma. She challenged whether the ICF can measure whether people cannot participate actively in society because of societal structures, e.g., institutions, laws, etc. She also questioned whether the ICF could measure temporary obstacles and barriers, e.g., a person groggy because of medication. There is a large communication gap between consumers and professionals that is not bridged by the ICF.

Following luncheon, the participants met in breakout groups to discuss the potential utility of the ICF to their agencies.

Breakouts: Due to the weather and reduced attendance, only two break-out groups were held. Each group met for approximately one and one-half hours, with a recorder taking notes, and a facilitator leading the discussion. The recorders reported on the discussions following the breakout sessions.

Breakout Group I-II:

Leaders: Dr. Paul Placek, NCHS, David Keer NIDRR (one-half the session)

Recorder: Paul Ackerman, Consultant, Disability and Leadership, (CESSI)

Participants: Dr. Mary Chamie, United Nations, NY; Dr. Robert Jaeger, NIDRR; Dr. Scott Brown, Office of Special Education Programs, U.S. DoED; Judi Chamberlin, National Empowerment Center, MS (one-half the session); Lois Thibault, U.S. Access Board; Dr. Karen Schwab, Defense and Veterans Brain Injury Center, Walter Reed Army Medical Center; Dr. Cille Kennedy, ASPE/HHS; Dr. Harold Kay, Rehabilitation Services Administration (RSA); Dr. Mary Naifeh, RSA; Dr. Marin Allen, Nation Institute on Deafness and Other Communication Disorders, NIH.

Initial questions revolved around what the ICF could do, what it could measure, what problems it could solve. Each agency represented in the breakout session had different needs; they wanted to know if those who had experience with it thought the ICF could meet their data needs for:

Setting human factors' standards

Ergonomic design (such as for the Access Board)

Determine capacity

Cut across disability areas

Mine already existing data

Measure attitudes towards disability and consequent barriers.

Those that were experienced with the ICF stated that, indeed, the ICF could be used to collect data on all those issues, with the exception of the attitude parameter. (Attitudes

are a concept, thus they are an interpretation of data that include several measures fitting a contextual definition of attitudes.)

One of the participants with the most experience stated that the major rule in using the ICF is planning. If you plan what you need and you know the ICF, you can answer most questions. The ICF is relevant to the activities, functions, and environments you want to measure, but the validity of your conclusions is the result of the detailed planning of the parameters measured and how the data will answer your research questions. Because the ICF uses parameters and measures not traditionally used in research, it offers alternative ways of defining research subjects and interventions; thus it can easily be used to cross traditional disability definitions, measure new outcomes, and better explain the effects of research interventions.

Many of the agencies are interested in using ICF but are not sure how to plan for it or to initiate it through an inexperienced research constituency. The agency representatives compared notes about the activities that were now going on in their agencies to initiate the ICF as a viable tool in their data collection:

Some agencies were developing study groups to look over existing research and see how to mine it further, or to introduce ICF to their research communities.

Other agencies are developing working groups, either within their units, or across units to study large or common problems that might be solved with ICF data and/or collaboration. Contractors for developing ICF measures or for providing technical assistance are being considered. Dr. Paul Placek of NCHS is considered to be an excellent resource for activities of this nature and, indeed, provides some of that technical assistance through his and his agency's own efforts and contracts.

Many agencies just starting will be seeking further guidance from the ICDR and the ISDS subcommittee; they will keep track of other agencies' activities through this medium and also know where to get agency- to- agency assistance and collaboration.

Some of the agencies reporting were already starting in ICF activities. The following is a list of what activities are occurring, mostly on an informal level:

Backcoding of extant studies with ICF measures will give agency research decision makers a sense of reliability and validity. Some agencies are getting ready to initiate sample studies of this nature.

Agency decision makers are looking at extant studies to back-code for the purpose of getting richer data.

Agencies are looking at their overall program goals and trying to determine if such goals can be put into researchable problems using the ICF. Such research might be the functional measurement of projected outcomes for focused disabled groups.

Other agencies are looking at their traditional disability grouping programs to see if they can redefine these groups through ICF measures.

Agencies that have centers of research and training to determine if these centers can be charged to assess the relevance of ICF measures to their focused populations and issues. Multi-disciplinary research and training efforts are being looked at to see if ICF measures could make the training more universal and the research more comparable between disciplines.

Agencies who know that they may have to break down traditional “cultural” stereotypes of individuals with disabilities are investigating how the “new culture” of ICF might be developed.

Some of the issues that arose are open-ended and relative to each agency or each effort. A discussion of intellectual property rights of the ICF revealed that even though the material of the ICF is in the public domain, it is owned by the WHO, who would like to exercise some control over its use. It is expected that every agency that reprints it, or includes it in applications, keeps the WHO informed and shares data with them.

Technical assistance will always be a problem, not only for the Federal agencies, but for the many researchers and research firms who are not yet on board with ICF measures. The agency representatives gratefully acknowledged the technical assistance efforts of the NCHS and its contracts, but realized that they, too, needed to mount efforts with their constituent researchers in order to affect meaningful change.

Substantial monies will be needed to mount a successful ICF “revolution”. The perpetual question of where this money is to come from was again floated. It is hoped that the ICDR may help to spur collaborations in ICF data gathering that will not put an undue fiscal burden on any one agency.

A successful strategy for implementation, such as that articulated by Drs. Hendershot and Seltser, was again mentioned. Copies of the RFAs generated by their project were circulated to the agency representatives.

The participants felt that the meeting had been successful in helping them to see new uses for the ICF, giving them resources for further study, and providing an ongoing forum for information and action.

Breakout Group III-IV:

Leaders: Marjorie Greenberg, NCHS; David Keer, NIDRR (one-half the session)
Recorder: Dr. Gerry Hendershot, Consultant on Disability Statistics and Health Statistics
Participants: Dr. Don Lollar, National Center on Birth Defects and Developmental Disabilities, CDC; Dr. Somnath Chatterji, WHO, Dr. Yerker Andersson, Gallaudet University; Dr. Lynn Bufka, American Psychological Association; Dr. Arlene Bierman, Agency for Healthcare Research and Quality, HHS; Dr. Geoffrey Reed, American Psychological Association; Dr. William Reynolds, School of Social Welfare, Center for Excellence in Aging Services, University of Albany, NY; Dr. Raymond Seltser, Consultant, NCHS.

In this breakout group, there was a far-ranging and spirited discussion of the relationship of the ICF to the disability community. The discussion was prompted by comments made by the mental health disability advocate in the morning’s plenary session that she saw little of value in the ICF for the disability community. “This community”, she stated,

“regards ‘disability’ as the result of socially imposed environmental barriers, including discrimination, whereas professionals such as those represented at this conference seem to regard disability as something inherent in the individual. The disability community is more interested in what people with disability can do, whereas the ICF seems more interested in what they cannot do.”

Breakout group members made a number of points in response to these comments:

The criticism is not justified because the ICF does, in fact, give full recognition to the effect of environment, including discrimination, on disability;

If the comments quoted do accurately represent the views of the disability community, WHO and other promoters of the ICF have failed in their communication with the disability community;

The primary audience for the conference was professionals in Federal agencies whose work and orientation naturally incline them to emphasize impairments and activity limitations rather than environmental barriers.

In psychiatric disorders, the issues raised are perhaps more pronounced than in any other segments of the disability community.

The underlying philosophical viewpoint of the ICF is that disability is a universal experience that is not limited to a minority population; this created something of a tension between ICF and disability groups that identify themselves as minority groups for purposes of pursuing their particular agendas.

Even if the ICF were correctly understood as giving appropriate recognition to environmental factors and positive features of disability, it might still be in political interests of disability groups to criticize the shortcomings of the ICF.

ICF advocates must be sensitive to the need for educating the disability community on the “disability-friendliness” aspect of the ICF.

The disability community, because of its emphasis on short-run improvements, tends not to value research and classification, whose payoffs are longer term.

The disability community’s emphasis on ability *versus* disability could work to their disadvantage, because eligibility for medical and income benefits currently depends on what a person cannot do.

Although the ICF was designed to allow assessment of positive aspects of disability, its application in that manner has been researched very little.

Some way of defining and measuring disability is needed before the quality of medical care for persons with disabilities can be measurably improved.

To improve communication with the disability community, ICF advocates need long term relationships with leaders in that community.

ICF proponents should consider making greater use of public relations professionals to market their “product.”

Two Federal agencies with interests in ICF spoke about what they are doing to promote ICF into their activities:

The Agency for Healthcare Research and Quality, HHS (AHRQ) represented by Dr. Arlene Bierman. AHRQ does research on quality of medical care, outcome of medical care, and the costs and benefits of medical care. The research involves several types of

activity: (1) data collection such as MEPS and HCUP; (2) funding of extramural research; and (3) intramural research.

The MEPS staff has considerable interest in coding MEPS data to the ICF or adding questionnaire items to obtain ICF-codable data.

Much of AHRQ's research budget is targeted for research topics chosen by Congress or the Administration; funds for ICF development are more likely to be obtained if the research is related to target priorities such as work with the States.

AHRQ sponsored a conference on an agenda for research on disability that was published in the Milbank Memorial Fund Quarterly. AHRQ has not followed through by hiring an Associate Director for Special Populations, who would pursue that research agenda.

When he was the Associate Director for Special Populations at the predecessor agency of AHRQ, Ray Seltser chaired a Task Force on Improving the Medical Determination of Disability. The Task Force focused on getting functional status into the medical records used by SSA to determine eligibility for disability benefits. Work Groups on that Task Force are largely responsible for the "Model RFAs" distributed to the participants of this conference.

The Health Plan Employer Data and Information Set (HEDIS) is designed to measure the performance of health plans. It now includes some functional measures. The measures in HEDIS could be coded to ICF codes.

The DHHS Data Council provides a department-wide forum that might be useful in promoting and coordinating ICF development activities. The ICDR is another such forum.

AHRQ might find it useful to "crosswalk" items in frequently-used Health Related Quality of Life (HRQoL) measures to the ICF, although in some cases the links may be at such a gross level that utility would be limited.

It would be useful to have a seminar on the ICF at AHRQ. Marjorie Greenberg and Arlene Bierman agreed to work together to set that up.

Further recommendations of the breakout group were that other agencies should be represented that were not at this meeting. Specifically, the Quality Interagency Coordinating Council (QUICC) was mentioned. It was also noted that the 1964 Debakey report on heart, cancer and stroke generated an outpouring of research funds that attracted many research institutions into the field. A similar government-wide, well-funded research program is needed for the ICF. The PHS Task Force (mentioned above) provided guidelines for such an effort, and it should be resurrected for that purpose.

The NIDRR and the ICF. David Keer represented NIDRR during a discussion of its current and prospective ICF-related activities, and the following points were made. NIDRR is a grant-making agency, and currently a number of its grantees are working on ICF-related research; an example is Alan Jette at Boston University. NIDRR collaborated with AHRQ in funding the Consumer Assessment of Health Plans (CAHPS).

The NIDRR-funded Center for Disability Statistics at San Francisco University has a new, ICF-compatible approach to survey questions on disability that is being tested at the NCHS Questionnaire Design Research Laboratory.

NIDRR has several mechanisms for funding ICF-related research: Requests for Proposals, Field Initiated Research or Development, and Rehabilitation Research and Training Centers.

In both breakout groups, technical assistance to all Federal agencies was offered through the office of Dr. Paul Placek and Marjorie Greenberg. The participants were reminded that the growth of the ICF and better data collection was now up to them and their respective agencies. Any and all progress in this matter would be gratefully received, if not abetted by the ISDS.