

**Federal Activities Related to the World Health Organization's
International Classification of Functioning, Disability and Health (ICF)**

Cille Kennedy, Ph.D.

**Office of the Assistant Secretary for Planning and Evaluation
Disability, Aging and Long-Term Care Policy**

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Revision of the Office of Personnel Management's Standard Form 256, 'Self-Identification of Handicap' – The Office of Personnel Management (OPM) has been revising its form that Federal government employees use to voluntarily identify themselves as having a disability. This information is requested after the individual has already been hired and is not related to the request for, or provision of, reasonable accommodation. This Standard Form 256 (SF 256), the 'Self-Identification of Handicap,' collects information under the authority of the Rehabilitation Act as amended (P.S. 93-112) and is used to inform agency top management, the OPM, the Congress, and the public on the status of the Federal government's employment of people with disabilities. The information is published in OPM's *Federal Civilian Workforce Statistics: Demographic Profile of the Federal Workforce* and is available from the OPM's web address: <http://apps.opm.gov/publications/pages/default.htm>. The current version of SF 256 was revised in 1987. The current revision was initiated, in part, in response to comments from members of the disability community criticizing the form.

The current SF 256 puts the definition of 'handicap' of the Rehabilitation Act into operation. The form collects limited personal information, and asks: whether the employee has a handicap and, if so, to identify it from a list of impairments; whether the employee does not have a handicap; has a handicap that is not on the list; or does not wish to identify her or his handicap status. The listed impairments contain impairments of body functions (i.e., speech, hearing and vision); missing, limited functions in, or paralyzed body structures (e.g., missing hand, pain or weakness in a joint, and loss of ability to move lower half of body); and a series of mental and physical health conditions traditionally associated with disabilities. The form does not query about major life activities that must be limited by these impairments to fulfill the requirements of the statutory definition. More important perhaps, without information on affected life activities, it is not possible to understand OPM's data in view of Federal surveys that collect important policy data on disabilities in the national population.

In response to this situation, Disability, Aging and Long-Term Care Policy staff in the Office of the Assistant Secretary for Planning and Evaluation (ASPE), developed a draft Checklist of Major Activities and submitted it to the OPM for consideration as an addition to the SF 256 draft revision to identify the actual disabilities experienced by people with the disabling impairments and health conditions. The Checklist of Major Activities is drawn directly from key chapters in the ICF, contains items that appear on the ICF Checklist, crosswalks with major sections of the World Health Organization’s Disability Assessment Schedule (WHO DAS II) (see below) and responds to US Federal initiatives (e.g., the Faith and Community-based Initiative).

It is a brief checklist in keeping with reducing the burden on the respondent, and is drafted—like the ICF—in neutral terminology to avoid both stigmatization and an aversive reaction of the employee. The Checklist of Major Activities is intended to complement the OPM’s existing information as well as the input from other Federal agencies, such as the Equal Employment Opportunity Commission.

Draft Compendium of Disability Questions on Selected National Surveys Coded to the ICF – As part of a project to develop concise measures of mental health and cognitive impairments for use in Federal surveys, a review of existing measures of mental disorders and cognitive impairments in major national surveys was conducted. Eleven Federal surveys or data sets were reviewed (e.g., the National Health Interview Survey-Disability Supplement and the Survey of Income and Program Participation). In order to identify the potential for inclusion of items or questions in a concise set of measures, in addition to the diagnostic items, sections of each survey pertaining to disabilities and environmental factors that affect performance of activities or involvement in life situations—irrespective of etiology—were coded and organized using the ICF classification system.

Consultants to the project remarked on the potential utility of the resulting draft compendium. At present, no review of this project product has been conducted to assure its accuracy or feasibility of use. Additional work is also needed to assure that it is formatted for audiences of researchers, survey designers, and data and policy analysts. A methodology to develop this nascent compendium needs to be designed and a formal process undertaken toward the development of a useful and accurate product that is faithful to the intent of survey questions and the ICF item definitions.

Contact: Cille Kennedy
Office of the Assistant Secretary for Planning and Evaluation
Disability, Aging and Long-Term Care Policy
Phone: 202 260 0370
Email: cille.kennedy@hhs.gov

National Institutes of Health

NIH/WHO Joint Project – In 1996, three NIH Institutes—the National Institute of Mental Health, National Institute on Alcoholism and Alcohol Abuse, and National Institute on Drug Abuse—awarded a four-year grant of \$4.044 million to the World Health Organization (WHO) to develop a disability assessment instrument that would be compatible with (and designed in tandem with) the evolving WHO *International Classification of Functioning, Disability and Health* (ICF). The resulting research instrument is the WHO Disability Assessment Schedule II (WHO DAS II), which has been used in major US and other international surveys.

The CAR Study - Preliminary to the development of the disability assessment was an international study on:

- Concepts and cultural relevance of disability; and
- The structure and content (domains (i.e., chapters), and individual items and sub-items) into which disability is organized.

The CAR Study (Cross-Cultural Applicability Research Study) also provided the conceptual and organizational foundation for the ICF. The methodology included linguistic analyses, concept mapping, key informant interviews, pile sorting, and focus groups. CAR Study participants included people with disabilities; caretakers and health care professionals; and key figures for policy making and health care program development.

Contact: Richard Pine

National Institute of Mental Health

Phone: 301 443 3703

Email: rpine@nih.gov

Cille Kennedy

Office of the Assistant Secretary for Planning and Evaluation
Disability, Aging and Long-Term Care Policy

Phone: 202 260 0370

Email: cille.kennedy@hhs.gov

The National Comorbidity Surveys – A set of nationally representative surveys of the prevalence of mental and substance abuse disorders, their associated disabilities, and health care service utilization are currently funded by five-year grants totaling \$16.877 million from the National Institute of Mental Health and the National Institute of Drug Abuse to Harvard University. The disability assessment instrument used in these surveys is a version of the WHO DAS II noted above, an instrument developed to be conceptually linked to the ICF.

Contact: Lisa Colpe

National Institute of Mental Health

Phone: 301 443 3944

Email: lcolpe@mail.nih.gov

Richard Pine
National Institute of Mental Health
Phone: 301 443 3703
Email: rpine@nih.gov

The International Mental Health Task Force – was originally convened by WHO to assume overarching responsibility to assure that the disabilities associated with mental disorders were accurately and comprehensively represented in the ICF. In fact, a preliminary mental health work group predated the formal ICF revision process. Early in the revision, staff of the National Institute of Mental Health assumed the Chair of the Task Force.

The International Mental Health Task Force participated in all compulsory and mandatory field trials that were part of the development of the ICF. Among these field trials were tests of the reliability (including test-retest and inter-rater reliability) of using the then-named ICIDH-2 Checklist (now entitled the ICF Checklist) on both case vignettes and in-person evaluations. The Task Force conducted these field trials internationally and across a diverse population within the U.S. Data were sent directly to WHO for analysis.

When the International Mental Health Task Force data were combined with data from other international participating sources, the data included 1,884 live case evaluations. Kappa values for separate sections of the Checklist were calculated:

- The Kappa values for Body Functions ranged from 0.79 to 0.95;
- For Body Structure the range was 0.66 to 1.00;
- Activities ranged from 0.78 to 0.95;
- Participation (then a separate section) ranged from 0.69 to 0.97; and
- Environmental Factors from 0.60 to 0.97.

The Task Force sun-setted with the formal adoption of the ICF by the World Health Assembly in May 2001. (Toward the end of the revision, the revision process, the NIMH staff member moved to the Office of the Assistant Secretary for Planning and Evaluation (ASPE), Office of Disability and Long-Term Care Policy, and the Chair-ship transferred to ASPE.)

Contact: Cille Kennedy
Office of the Assistant Secretary for Planning and Evaluation
Disability, Aging and Long-Term Care Policy
Phone: 202 260 0370
Email: cille.kennedy@hhs.gov

National Committee on Vital and Health Statistics

Report to the Secretary on Classifying and Reporting Functional Status – On July 17, 2001, the National Committee on Vital and Health Statistics (NCVHS) submitted its report to Secretary Thompson. The report had two major purposes:

- 1) To put functional status solidly on the radar screens of those responsible for health information policy, and
- 2) To begin laying the groundwork for greater use of this information beyond its current applications in clinical settings.

The report surveyed current and potential uses of functional status information and described the ICF. The committee commended the ICF as a promising approach to coding functional status information and endorsed that the ICF be studied for use as a reporting tool for functional status.

Contact: Marjorie Greenberg
National Center for Health Statistics
Centers for Disease Control and Prevention
Phone: 301 458 4245
Email: msg1@cdc.gov
Jim Scanlon
Office of the Assistant Secretary for Planning and Evaluation
Office of Science and Data Policy
Phone: 202 690 7100
Email: jim.scanlon@hhs.gov

Centers for Medicare and Medicaid Services

Health Care Financing Review – In planning for future issues of the *Health Care Financing Review*, the Centers for Medicare and Medicaid Services (CMS) deliberated on the NCVHS report on Classifying and Reporting Functional Status, described above. CMS approached the National Center for Health Statistics, Centers for Disease Control and Prevention (NCHS/CDC) with the idea of developing a special issue on functional status for payment and quality that would include a focus on the ICF. The special issue is actively making progress and its publication is anticipated as the Spring 2003 issue.

Contact: Dan Waldo
Centers for Medicare and Medicaid Services
Phone: 410 786 7932
Email: DWaldo@cms.hhs.gov

Centers for Disease Control and Prevention: National Center for Health Statistics

North American Collaborating Center (NACC) - The National Center for Health Statistics (NCHS) houses the WHO Collaborating Center for the Family of International Classifications (FIC) for North America, otherwise known as the North American Collaborating Center (NACC). The NACC had responsibility for the revision of the ICF in the United States and Canada and is responsible for the maintenance and promotion of the classification in both countries. The NACC also represents North America in the network of WHO-FIC collaborating centres and annually sponsors a meeting on ICF,

alternating between venues in Canada and the United States. The Ninth Annual NACC Meeting on ICF will be held in St. Louis, Missouri on June 17-19, 2003. This meeting is likely to provide an opportunity for the new ICF Subcommittee of the WHO-FIC Implementation Committee to convene. Current information on NCHS ICF activities can be found at <http://www.cdc.gov/nchs/about/otheract/icd9/icfhome.htm>. The Canadian Institute for Health Information (CIHI) assumed responsibility for Canadian activities for NACC. The activities listed below are currently ongoing or planned by NCHS, many of which include CIHI:

DISTAB - Since 1999, five countries (U.S., Canada, South Africa, Netherlands, France) have been actively involved in developing methodologies to and statistical tables that back code disability data from their five national disability surveys to the ICF. An article on this methodology has been accepted for publication, and another paper with comparative tables is in preparation. The DISTAB group is currently working closely with the United Nations Statistics Division, which is also using the ICF in its statistical program to back code surveys and censuses.

International Seminar on the Measurement of Disability Statistics – This seminar, held in June 2001, was stimulated by DISTAB’s work. A brief description of this meeting is included under the CDC National Center on Birth Defects and Developmental Disabilities below.

CODE ICF - CODE ICF is web-based training on ICF. Feedback on this interactive tool was widely solicited in international ICF meetings in Trieste and Toronto. CODE ICF is scheduled for completion late in 2002 with installation on the WHO website shortly thereafter.

NACC ICF Clearinghouse - The clearinghouse activity begins with NCHS staff in fall 2002, with a monthly informational announcement to a primarily U.S. and Canadian email group. It also includes a new 2002 contract with four components:

- 1) Identification and Typology of ICF Users in North America;
- 2) Marketing;
- 3) Training and Technical Assistance; and
- 4) ICF Conference Support.

ICF Videos Project – This project is producing four instructional videos from interviews with experts on ICF, which were videotaped in October 2001 at the Heads of ICD/ICF Meeting in Bethesda October 2001. Additional selected clips appear in CODE ICF. The topics covered by the four videos are:

- 1) ICF use by consumers;
- 2) ICF applications in surveys and clinical areas;
- 3) Historical development; and
- 4) Conceptual/issue areas.

ICF Curricula in North American Colleges and Universities – This project is:

- 1) Assembling model U.S. and Canadian college and university curricula which use ICF for the fall 2002 semester;
- 2) Testing a model curriculum with ICF, and
- 3) Preparing a report for the June 17-19, 2003, ICF NACC meeting in St. Louis.

Washington City Group – An outcome of the International Seminar on the Measurement of Disability Statistics was the recognition that statistical and methodological work was needed at an international level in order to facilitate the comparison of data on disability cross-nationally. Consequently, the United Nations Statistical Division authorized the formation of a City Group to address some of the issues identified in the International Seminar and invited the National Center for Health Statistics, the official health statistics agency of the United States, to host the first meeting of the group.

The purpose of the first Washington City Group meeting, convened in February 2002, was to guide the development of comparable global or general measures of disability for use in censuses and large national surveys and to develop the agenda and objectives for subsequent meetings. Representatives of national statistical agencies and international organizations of people with disabilities participated in three days of sessions directed toward developing agreement on the nature of a general measure of disability to be recommended for use in censuses and surveys in the world community. The ICF model will be used as a framework for developing the measures. It was agreed that an initial focus for an internationally comparable general indicator should be the activity dimension of the ICF. In its first meeting, the group also sought to develop an agenda for future meetings by prioritizing the most pressing issues in disability measurement and data collection. Two or three more meetings of the group are anticipated. The next meeting will be held in January 2003 in Ottawa, Canada. Additional information about the Washington City Group can be found at <http://www.cdc.gov/nchs/citygroup.htm>

Contact: Marjorie Greenberg

National Center for Health Statistics
Centers for Disease Control and Prevention
Phone: 301 458 4245
Email: msg1@cdc.gov

Jennifer Madans

National Center for Health Statistics
Centers for Disease Control and Prevention
Phone: 301 458 4500
Email: jhm4@cdc.gov

Paul Placek
National Center for Health Statistics
Centers for Disease Control and Prevention
Phone: 301 458 4437
Email: pjp2@cdc.gov

Barbara Altman
National Center for Health Statistics
Centers for Disease Control and Prevention
Phone: 301 458 4654
Email: Baltman@cdc.gov

Beth Rasch,
National Center for Health Statistics
Centers for Disease Control and Prevention
Phone: 301 458 4248
Email: Erasch@cdc.gov

Centers for Disease Control and Prevention: National Center on Birth Defects and Developmental Disabilities

International Seminar on the Measurement of Disability Statistics – This international seminar—co-sponsored by the CDC National Center for Birth Defects and Developmental Disabilities (NCBDDD), the United Nations Statistics Division, the United Nations Children’s Fund, and the Statistical Office of the European Communities—was convened to:

- 1) Review and assess current methods used in population-based data collection activities to measure disability in national statistical systems, with particular attention to questionnaire design;
- 2) Develop recommendations and priorities to advance work on measurement of disability, and;
- 3) Contribute to building a network of institutions and experts, including producers and users of disability statistics, to implement the developments in the field.

Seminar papers from this meeting are available at the United Nations website, <http://www.un.org/Depts/unsd/disability/methods/index.html>

“731” Extramural Research Grants – During the development of the ICF, NCBDDD awarded grants to develop measures of the environment affecting disability/functional status and that are consonant with ICF concepts and items. The projects have continued to receive funding. The descriptions below are taken from the NCBDDD’s website (<http://www.cdc.gov/ncbddd/dh/scres.htm>):

- 1) Developing a community health environment checklist. Investigators at Washington University and the Paraquod Independent Living Center aim to develop a set of objective, reliable, and valid measures of the physical, social, and cultural environments that are relevant to the participation of people with disabilities in everyday community life, particularly those with mobility

limitations. The measures will provide a Community Health Environment Checklist that can be used by people with disabilities, health professionals, employers, recreational site planners, telecommunication operators, transportation providers, and commercial establishment owners to assess the barriers to, and facilitators of, participating in everyday community life. This research will help guide the "next steps" towards reducing community inaccessibility, a risk factor for poor health and well-being. Dr. David Gray of Washington University is the Principal Investigator for this research.

- 2) Craig Hospital Inventory of Environmental Factors (CHIEF). CHIEF is a measurement of community environmental barriers in Colorado. Investigators at Craig Hospital recently developed and validated a survey instrument designed to assess the frequency and magnitude of perceived physical, attitudinal, and policy barriers that keep people with disabilities from doing what they want or need to do. This instrument has been used to demonstrate frequent and problematic environmental barriers that people with disabilities encounter. Moreover, CHIEF has demonstrated that the type and severity of the disability is associated with the impact of barriers encountered in the environment. The investigators are furthering their work using three distinct tools: a community characteristics checklist of physical/structural aspects of the environment, a survey of attitudes toward disability expressed by community members, and a service use and outcomes discrepancy analysis comparing service use and outcome achievement data between people with and without disability in a community. Dr. Gale Whiteneck of Craig Hospital in Colorado is the Principal Investigator of this research.
- 3) Measuring the environment of children and youth with disabilities. Investigators from University of North Carolina, Gallaudet University, and the Center for Discovery in New York are developing a measurement instrument to assess environmental factors affecting children and youth with disabilities in their communities. The conceptual and taxonomic framework of the International Classification of Functioning, Disability and Health (ICF), serves as the basis for defining and documenting environmental factors that affect functioning and secondary conditions of children and youth with disabilities. The study will yield a set of sound and efficient measures of the environment that will be disseminated widely for use in public health monitoring, intervention, and evaluation efforts. The Principal Investigator of this project is Dr. Rune Simeonsson of the University of North Carolina at Chapel Hill.

Potential Extramural Research Topics (PERTs) related to ICF – CDC/NCBDDD has awarded extramural grants designed to explore how environmental supports affect treatment. NCBDDD requires that grantees utilize the ICF as a classification in looking at how environmental supports affect accessibility as an outcome of treatment.

- 1) Automated ICF Coding Using Medical Language Processing – An extramural research grant was awarded to the Mailman School of Public Health, Columbia University.
- 2) Compatibility of ICF and American Association on Mental Retardation 1992 and 2002 Systems – An extramural research grant to the Department of Family Medicine, Boston University Medical Center.

Intramural Research – An intramural investigation by NCBDDD staff Drs. John Crews and Vincent Campbell has been accepted for publication in the *American Journal of Public Health*. The article, “Vision Impairment and Hearing Loss Among Community-Dwelling Older Americans: Implications for Health and Functioning” looks at vision impairments and hearing loss within an ICF context.

International Environmental Task Force – During the development of the ICF, CDC/NCBDDD funded a Cooperative Agreement with WHO to support the work of the International Environmental Task Force, which had responsibility for developing the classification of environmental factors that are or can be related to functioning and disability. The Task Force sunsetted when the World Health Assembly endorsed the ICF.

Adaptation of the ICF for Children – Although the International Children’s Task Force participated in the development of the ICF, further work to capture the nuances of the development in early childhood in the ICF is being done. CDC/NCBDDD staff are participating in this continuing project.

Contact: Larry Burt

National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
Phone: 770 488 7081
Email: lrb1@cdc.gov

Vincent Campbell

National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
Phone: 770 488 7684
Email: vbc6@cdc.gov

Donald Lollar

National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
Phone: 770 488 7094
Email: dcl15@cdc.gov

Department of Education

National Institute on Disability and Rehabilitation Research

Field Initiated Research Priorities Grant Announcement in Federal Register – On September 13, 2002, the National Institute on Disability and Rehabilitation Research (NIDRR) published its field initiated research priorities in the Federal Register. The deadline for application submission is November 12, 2002. NIDRR anticipates funding up to \$2.5 million for fifteen three-year grants. NIDRR announced five priority areas, one of which specifies projects that study use of the ICF in promoting the independence and quality of life of persons with disabilities. This announcement can be found at the NIDRR web-address, <http://www.ed.gov/legislation/FedRegister/announcements/2002-3/091302a.html>

ICF Forum - The Interagency Committee on Disability Research, a Congressionally-mandated committee headed by the Director of NIDRR, at the request of one of its subcommittees, the Interagency Subcommittee on Disability Statistics, announced that it is sponsoring an invitational meeting entitled *The ICF: Potential Influence on Disability and Rehabilitation in Federal Agencies*. The meeting will be held on December 5, 2002 at the Holiday Inn Capitol in Washington, DC. The meeting will provide an introduction to the ICF to Federal agencies and to identify and discuss prospects and problems, barriers, and opportunities for ICF applications in each agency.

Contact: Robert Jaeger
National Institute on Disability and Rehabilitation Research
Department of Education
Phone: 202 205 8061
Email: Robert.Jaeger@ed.gov

David Keer
National Institute on Disability and Rehabilitation Research
Department of Education
Phone: 202 205 5633
Email: DAVID.KEER@ED.GOV

Paul Placek
National Center for Health Statistics
Centers for Disease Control and Prevention
Phone: 301 458 4437
Email: pjp2@cdc.gov

Department of Labor

Bureau of Labor Statistics

Method to Measure the Employment Rate of Adults with Disabilities – To fulfill the mandate of Executive Order 13078, which is "...to design and implement a statistically reliable and accurate method to measure the employment rate of adults with disabilities..." The Bureau of Labor Statistics (BLS) formed the Employment Rate Measurement Methodology (ERMM) Workgroup. The ERMM Workgroup is chaired by Phil Rones, the Commissioner responsible for the Current Population Survey (CPS) and is composed of approximately 20 Federal agencies. The CPS is the official source of labor force data for many protected classes, and is being considered as the host survey for the disability questions that would provide the employment rate of adults with disabilities.

The definition of disability that is being put into operation to identify people with disabilities is from the first prong of the Americans with Disabilities Act, and is also provided in the Executive Order that mandated the ERMM activity: An individual with a disability is a person with a physical or mental impairment that substantially limits one or more of the major life activities of such individual.

The BLS and Department of Labor invested nearly \$1 million in order to identify questions that would elicit disabilities in a survey population. The BLS compiled a bibliography of disability survey instruments annotated with what is known about their psychometric properties, conducted analyses to identify candidate questions, and conducted cognitive tests on candidate questions. The candidate questions and a short set of questions to determine if the respondents were employed or not employed were then placed in the National Comorbidity Survey (NCS), described above, which has been in the field since February 2001. Questions are in the process of being tested and analyzed in a variety of qualitative and quantitative psychometric and other techniques.

Contact: Thomas Hale
Bureau of Labor Statistics
Phone: 202 691 5454
Email: hale_t@bls.gov