

September-October, 2003 NACC Clearinghouse on ICF Messages

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## 1. HOUTENVILLE TEAM WINS DISABILITY DEMOGRAPHICS AND STATISTICS RRTC; \$3.75M FIVE YEAR PROJECT HAS ICF COMPONENT

Funded just days ago after a major competition, the third of five major requirements of the new NIDRR RRTC is to "identify, develop as necessary, and evaluate instruments, data sources, administrative records, or other sources that allow Federal policymakers to use the ICF classification system for evidence-based decision making" (US Department of Education, National Institute on Disability and Rehabilitation Research). That which follows is a brief abstract of their new project: *Rehabilitation Research and Training Center on Disability Demographics and Statistics*, CFDA 84.133B-1, Submitted by Cornell University, Office of Sponsored Programs on behalf of the Program on Employment and Disability, School of Industrial and Labor Relations-Extension Division and the Department of Policy Analysis and Management College of Human Ecology and the Cornell Center for Policy Research in Washington, DC. The Co-Principal Investigators are: *Susanne M. Bruyère*, Ph.D., C.R.C.; *Richard Burkhauser*, Ph.D.; *Andrew Houtenville*, Ph.D., Project Director; and *David Stapleton*, Ph.D. ABSTRACT  
*Importance of the Problem.* The quality of existing disability-related data and statistics is inadequate to support the needs of policymakers, service providers, researchers, educators, the media, and people with disabilities and their families. Furthermore, access to current data and statistics and related documentation is currently provided in an unsystematic manner, leading to a potential for misinformation, uncertainty, ineffective policymaking, inappropriate resource allocation, and the misrepresentation of people with disabilities. *Mission.* The proposed RRTC on Demographics and Statistics (Cornell StatsRRTC) will bridge the *divide* between the *sources* of disability data and the *users* of disability statistics. On one hand, we will conduct research exploring (1) the reliability of existing data sources and collection methods, and (2) study the potential to improve current and future data collection efforts. On the other hand, we will (a) utilize existing data sources to provide a comprehensive and reliable set of statistics, (b) increase access to and understanding of how statistics can be effectively used to support decision making, and (c) work with key organizations to determine their needs and help them maximize the use of disability statistics in their ongoing efforts to improve the lives of people with disabilities and their families. *Staff.* To fulfill this mission, we have assembled a highly capable team with expertise that spans the areas of research, dissemination, policy formation, and advocacy. This team includes individuals that are often relegated to an external advisory capacity or sought after for voluntary assistance in reaching out to key audiences. As members of the Cornell Stats RRTC, the American Association of People with Disabilities (AAPD), the Centers for an Accessible Society and InfoUse will provide vital expertise and resources needed to reach the *users* of disability data and statistics. In particular, AAPD brings people with disabilities into the StatsRRTC in more than just an advisory capacity. The StatsRRTC will include researchers from Cornell University, Mathematica Policy Research, the Urban Institute, and the Institute for Matching People and Technology, and consultant, Gerry Hendershot, all of which bring extensive expertise in working with *and* creating sources of disability data. *Activities and Outputs.* This team will conduct a comprehensive and coherent set of research and outreach (training,

dissemination, technical assistance and utilization) projects that directly address the topic and requirements set forth in the *Priority*. These projects will produce a comprehensive set of knowledge, deliverables, resources and services: (a) tests of key hypotheses regarding the demographics of disability, (b) *Best Practices Guide for Surveying People with Disabilities*, (c) a set of *User Guides* to existing data sources, (d) design options for existing data sources and a plan for a future *National Disability Survey*, (e) a comprehensive set of disability statistics, (f) *Annual Disability Report Cards*, (g) comprehensive disability and demographic statistics which will be accessible through [www.disabilitystatistics.org](http://www.disabilitystatistics.org), (h), on-line user-directed *Disability Statistics Templates*, (i) a *Disability Statistics Syllabus*, reflecting an extensive training curriculum on the use of disability data and statistics, (j) an *On-Call Technical Assistance Service* and a targeted *On-Call Disability Statistics Estimation Service*, (k) a set of trainings targeted on key audiences, as well as, (l) a *State-of-the-Science Disability Statistics Conference in Year 3* with a follow up *Year-Four Edited Volume. Outcome and Impact*. Our ultimate goal is to create a NIDRR-led National Disability Statistics System (NDSS) that will be the premier source of disability data and statistics and provide technical assistance on how to *collect* and *use* disability data and statistics nationwide. The NDSS would bridge the *divide* between the *sources* of disability data and the *users* of disability statistics. This project will start December 2003. For more information, contact: Andrew J. Houtenville, Ph.D., Senior Research Associate, Program on Employment and Disability, School of Industrial & Labor Relations, Cornell University, Rm 331, Ives Hall, Ithaca, New York 14853-3901 USA, Telephone: (607) 255-5702, Fax: (607) 255-2763, TTY/TDD: (607) 255-2891, e-mail: [ajh29@cornell.edu](mailto:ajh29@cornell.edu), <http://www.ilr.cornell.edu/RRTC/>

## 2. BODINE TEAM FROM COLORADO WINS \$450,000 THREE-YEAR AWARD FOR ICF RESEARCH

This new grant recipient is Cathy Bodine, University of Colorado Health Sciences Center <mailto:cathy.bodine@uchsc.edu> at 303-315-1281 for "Utilization of the ICF to Develop a Longitudinal Assistive Technology Outcomes Measurement System". The award was made just prior to October 1, 2003, and follows on the heels of her earlier, smaller NICHD/NIH award using ICIDH-2 award which ended in August 2003. This study looks at technology impact on people with disabilities. It is a longitudinal study and uses the ICF Checklist. Hand-held PDA's are used to enter data. Her abstract for Field Initiated Development Project #84.133G2 "Development of an Assistive Technology Outcomes Measurement System Utilizing the International Classification of Functioning (ICIDH-2/ICF)" follows. ABSTRACT: The purpose of this Field Initiated Development project is to further the development of a secure, HIPAA (Health Insurance Privacy and Accountability Act of 1996) compliant, multi-site, web-based assistive technology (AT) outcomes system designed to capture data that will enable the measurement of the impact of assistive technology devices and services for children and adults with disabilities. The project will result in the design and development of a working prototype complete with instructional support for users. The project will be designed for easy addition of data

fields to support the ever-evolving schema for outcomes assessment in assistive technology. The two key elements in the organization and design of this project is the use of the International Classification of Functioning, Disability and Health (ICIDH-2/ICF) as the framework for development and builds on initial pilot work already completed by faculty of Assistive Technology Partners, University of Colorado Health Sciences Center, and collaboration with two NIDRR funded national projects focused on AT outcomes development (ATOMS/CATOR). Information gained will lead to maximizing the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities, especially individuals with the most severe disabilities; and will lead to improved information and research on the effectiveness of assistive technology devices and evidence-based practices.

### 3. OSERS, NIDRR INVITE FY 2004 APPLICATIONS FOR ICF RESEARCH; \$450,000 OVER THREE YEARS

The following information is from the Federal Register: September 25, 2003 (Volume 68, Number 186)

"Deadlines: Letter of intent, November 10; Proposal, December 9

Maximum grant: \$150,000 per year for three years

DEPARTMENT OF EDUCATION

[CFDA Nos.: 84.133G and 84.133P]

Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR); Notice Inviting Applications for New Awards for Fiscal Year (FY) 2004

**SUMMARY:** We invite applications for new FY 2004 grant awards under the Field-Initiated (FI) Projects (84.133G) and Advanced Rehabilitation Research Training (ARRT) Projects (84.133P) of NIDRR's Disability and Rehabilitation Research Project and Centers Program. We take this action to focus attention on an area of national need in the rehabilitation field.

**Invitational Priorities:** The Secretary is particularly interested in applications that address one of the following invitational priorities. However, under 34 CFR 75.105(c)(1), an application that meets an invitational priority does not receive competitive or absolute preference over other applications. The invitational priorities are:

- (a) Projects that improve the exit of individuals with disabilities from buildings, vehicles, and other settings in emergencies;
- (b) projects that study use of the new "International Classification of Functioning, Disability and Health" (ICFDH-2) systems in promoting the independence and quality of life of persons with disabilities;
- (c) projects that collaborate with international assistive technology and rehabilitation engineering projects including, but not limited to, those that could be carried out under Science and Technology Agreements between the U.S. and other countries;
- (d) projects that enhance the functioning of people with chronic fatigue (CF);
- (e) projects that study chronic pain and pain management strategies to enhance the functioning of individuals with disabilities; and

(f) projects that study mental health interventions related to traumatic stress of individuals with disabilities."

For the full announcement, go to

<http://www.ed.gov/legislation/FedRegister/announcements/2003-3/092503b.html>

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*(Note: sent in by Gerry E. Hendershot, PH.D., Consultant on Disability and Health Statistics, 4437 Wells Parkway, University Park MD 20782, Voice: 301-927-1120, Fax: 301-927-1120, [ghendershot@earthlink.net](mailto:ghendershot@earthlink.net))*

#### 4. NIH ROADMAP HAS \$138M AVAILABLE IN FY04, MORE OVER NEXT FIVE YEARS

In an October 9 presentation to an interagency group, Deborah Ader of NIH described a new NIH funding mechanism that might offer opportunities for ICF research. The Web site for this initiative reveals that there is a section possibly relevant to ICF, per this excerpt: "Many of the most debilitating chronic illnesses gradually erode patients' quality of life because of the associated fatigue, pain and mood changes. Currently, these critical symptoms cannot be objectively measured in the same way, for example, as blood sugar levels or blood cell counts. More sensitive, well-validated tools need to be developed to improve measurements of these types of symptoms. Technologies, such as a computerized adaptive health assessment, could revolutionize how symptoms and treatment outcomes are assessed. Scientists will be better equipped to understand how patients perceive changes in their health status resulting from new interventions, thereby directing research to therapies that would be most highly valued by patients." (From <http://www.nihroadmap.nih.gov/clinicalresearch/index.asp>)

Ader stated that there will be RFA's and RFP's. Some specifications have yet to be issued. For more information, contact Deborah N. Ader, PhD., Director, Behavioral and Prevention Research Program, National Institute of Arthritis and Musculoskeletal and Skin Diseases, NIH, tel 301-594-5032 and <mailto:da132c@nih.gov>.

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*(Note: sent in by Gerry E. Hendershot, PH.D., Consultant on Disability and Health Statistics, 4437 Wells Parkway, University Park MD 20782, Voice: 301-927-1120, Fax: 301-927-1120, [ghendershot@earthlink.net](mailto:ghendershot@earthlink.net))*

#### 5. DISABLED PEOPLES' INTERNATIONAL SELECTS ICF AS PREFERRED DEFINITION OF DISABILITY

Disabled Peoples' International (DPI) is a network of national organizations or assemblies of disabled people established to promote human rights of disabled people through full participation, equalization of opportunity and development <http://www.dpi.org>. For many years, DPI had not adopted a definition of disability due to the many different definitions used, the fact that most definitions in use were medical definitions, problems with translations, etc. Frank Mulcahy, Secretary, DPI, states on the DPI website: "...within the new ICF the definition of disability that is used, can, I propose be utilized for our purposes."

## 6. HEBLER OF SRI INTERNATIONAL CODING CHILDREN'S DATA TO ICF

Scott Brown reports that OSEP has awarded a small supplement (\$15,500) to SRI International to code early childhood developmental domains to the ICF. Kathy Hebler of SRI is directing this effort. Hebler has worked with Rune Simeonsson in the past on coding the NEILS to ICF. Where past coding has looked at the reason for entry and has tended to focus more on ICD and impairment variables, this effort will examine developmental delay and the actual functional results of the program related to the domains and early learning. For more information, contact: Scott Brown, PhD, Office of Special Education Programs, Office of Special Education and Rehabilitation Services, United States Department of Education, Mary E. Switzer Building, Room 3522, Washington, D. C. 20202-2641, Telephone: 202 205-8117, FAX: 202 205-8105, email: [Scott.Brown@ed.gov](mailto:Scott.Brown@ed.gov).

## 7. ICF DISSERTATION BY VALLUZZI

Jan Valluzzi, a Doctor of Public Health Candidate at The George Washington University, is working on back-coding the ICF with variables from the Medical Expenditure Panel Survey (MEPS) to examine health care utilization and expenditures for persons with disabilities in the U.S. non-institutionalized population. She is seeking information about the validity of the ICF for dissertation efforts. Did you include any validity measurement when doing your Beta-2 testing? Do you have some unpublished or soon to be published findings regarding face, content, or construct validity that you are willing to share on a limited basis to her and her committee members? Please forward information to her: Jan Valluzzi, Service Fellow, Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, Phone: (301) 427-1646, FAX: (301) 427-1276, [jvalluzz@ahrq.gov](mailto:jvalluzz@ahrq.gov) and [valluzzi@gwu.edu](mailto:valluzzi@gwu.edu).

## 8. ICDR MEDICAL SUBCOMMITTEE HELD ICF MEASUREMENT TOOLS MEETING ON OCTOBER 9

The Interagency Committee on Disability Research's Subcommittee on Medical Rehabilitation held a meeting entitled "ICF Workshop: Development of Clinical Measurement Tools" at the Holiday Inn Capitol in Washington, D.C. on October 9th.

Michael Weinrich, Co-chair, Interagency Subcommittee on Medical Rehabilitation, and Director, National Center for Medical Rehabilitation Research opened the meeting along with his ICDR Co-Chair, Theresa San Agustin of NIDRR. About 40 persons attended. Geoffrey Reed, Assistant Executive Director for Professional Development Practice Directorate, American Psychological Association, discussed "Standardized Application of the ICF in Clinical Settings". He described a coalition of professional groups' development of a procedure manual to use the ICF, and summarized progress in the ongoing testing. Gale Whiteneck, Director of Research at Craig Hospital, gave "A Critique of the ICF". Whiteneck's wish list for future ICF enhancements included delineation of A and P, development of quality of life and subjective satisfaction, elaboration of environmental factors, and development of personal factors. Dr. Whiteneck also gave his own rationale for criteria to delineate A and P. Claudia Moy of NIH described "Quality of Life Across Neurological Disorders". She stated that there are few measures in the

areas of participation and environment, and recognized that the ICF model, because it includes participation and environment, will stimulate the development of P and E measures. Craig A. Velozo, Associate Professor, Associate Chair and Graduate Coordinator, Department of Occupational Therapy, University of Florida, presented "Developing Measures Based on the ICF". He related ICF to the Rasch Model, which is measurement theory. Velozo is funded by NIDRR to develop "Procedures for Building ICF-Based Measures". He has used focus groups, cognitive interviews, and field tests to develop validated, short measures of activity. His measures are on the web at [www.ICFmeasure.com](http://www.ICFmeasure.com). Deborah Ader of NIH described a new NIH funding mechanism that might offer opportunities for ICF research over the next five years, starting with \$138M in funding in FY04. The research to be funded through a mix of RFA's and RFP's is described at <http://www.nihroadmap.nih.gov/clinicalresearch/index.asp>. Ader is at [<da132c@nih.gov>](mailto:da132c@nih.gov).

#### 9. MCDOUGALL ARTICLE ON ICD-10 AND ICF

We are pleased to note an ICF article published in Disability and Rehabilitation, Vol. 25, Number 16, 922-939, August 2003, "Measuring chronic health condition and disability as distinct concepts in national surveys of school-aged children in Canada: A comprehensive review with recommendations based on the ICD-10 and ICF" written by Janette McDougall and L. Miller. For reprints, contact Janette McDougall, Research Program, Thames Valley Children's Centre, 779 Base Line Road East, London, Ontario, Canada, N6C 5Y6, Tel: 519-438-3740, [janettem@tvcc.on.ca](mailto:janettem@tvcc.on.ca).

#### 10. NATIONAL FREEDOM INITIATIVE STAFF LEARNS MORE ABOUT ICF

Dr. Margaret Giannini, Director, Office on Disability, HHS invited Marjorie Greenberg and Paul Placek of NCHS/CDC and David Keer of NIDRR to make presentations on ICF at the monthly staff meeting of the New Freedom Initiative (NFI) on September 4. The NFI focuses on integrating people with disabilities into the workforce, community-based services and supports, housing and home ownership, respite care for caregivers, transportation, access to community life, and health. Keer spoke on various Federal agency projects on ICF and noted that NIDRR would soon make a 3.75 million dollar award for a new Rehabilitation and Research Training Center on Disability Demographics and Statistics that would use the ICF for evidence-based decision making. Placek spoke on the relationship of the ICF to the NFI, the research agenda for the 10th NACC Meeting on ICF, and six ICF projects at NCHS. Greenberg spoke on the need for functional status information, the case for data standards, the ICF, and needed ICF research and demonstration projects. The new Office on Disability has been established to monitor what federal agencies are doing related to the ADA, the President's New Freedom Initiative (see <http://www.whitehouse.gov/news/freedominitiative/freedominitiative.html>), and implement Olmstead. Olmstead is the Supreme Court decision on integrating people with disabilities into the community. Paul Placek is now detailed to the HHS Office on Disability (OD) one day per week. This grew out of Dr. Margaret Giannini's participation in the North American

Collaborating Center meeting on ICF in St. Louis, MO in June of this year. Dr. Giannini is intrigued by ICF and is interested in exploring how it might be used to monitor NFI, ADA and Olmstead. Paul is there as an ICF and survey expert resource person.

#### 11. BARROW TALKS ON ICF TO INTERNATIONAL SOCIAL WORK EDUCATORS

Frederica H. Barrow, Ph.D, LCSW-C, gave a paper entitled "The International Classification of Functioning, Disability and Health, A New Tool for Social Workers" at the 6th Biennial Conference of Caribbean and International Social Work Educators in Bridgetown, Barbados in July-August 2003. The objective of the paper was to acquaint Caribbean Social Workers with the ICF and to identify resources that are readily available to them for further investigation, training and use. Two applications were discussed: a policy application and an individual case application. At the University of South Florida, Dr. Barrow teaches three courses in which she includes the ICF: (1) Social Welfare Policy and Programs in the Undergraduate Social Work Program (2) Foundations of Human Behavior and (3) Individual Treatment in the Graduate Program. For more information, contact: Frederica H. Barrow, Ph.D, Assistant Professor, The School of Social Work, The University of South Florida (USF) Telephone: 813-974-1276, [e-mail- fbarrow@chuma1.cas.usf.edu](mailto:fbarrow@chuma1.cas.usf.edu)

#### 12. WELCH SALEEBY TALKS ON ICF AT WASHINGTON UNIVERSITY DISABILITY MONTH EVENT

Trish Welch Saleeby spoke on the ICF at Washington University's School of Social Work at its Disability Awareness Week events held October 13-17, 2003. For more information, contact her: Patricia Welch Saleeby, MSSA, Research Associate, Washington University, Campus Box 8505, 4444 Forest Park Avenue, St. Louis, MO 63108, tel 314-286-1612, fax 509-351-3280, [[welchp@gwbssw.wustl.edu](mailto:welchp@gwbssw.wustl.edu)].

#### 13. CALL FOR ABSTRACTS APRIL 19-20, 2004 MEETING ON "BEST PRACTICES FOR SURVEYING PEOPLE WITH DISABILITIES"

This meeting has an ICF component in the call for research in five areas:

1. Current surveys and their inclusion of persons with disabilities
2. The role of persons with disabilities in all phases of survey research.
3. Innovations in survey data collection and design, including the use of technology, and the impact on inclusion of people with specific impairments.
4. The role of the International Classification of Functioning, Disabilities, and Health (ICF) and measures of the environment in improving data comparability across surveys.
5. Standards and best practices for assuring maximum participation by people with disabilities in surveys.



The meeting will be held at the Capital Hill Holiday Inn in Washington, D.C. and travel expenses are available for non-Federal presenters. The meeting is sponsored by the Interagency Committee on Disability Research's (ICDR) Subcommittee on Disability Statistics. There is a January 16, 2004 deadline to submit hard copy and electronic copy to Barbara Rosen at CESSIat [brosen@cessi.net](mailto:brosen@cessi.net). The required information is in the attachment entitled "Best Practices Call for Abstracts".

#### 14. ICF AUSTRALIAN USER GUIDE VERSION 1.0 JUST RELEASED

The ICF Australian User Guide Version 1.0 was released today. To view this publication on-line, please copy and paste the following link into your web browser:

<http://www.aihw.gov.au/publications/index.cfm?type=detail&id=9329> For more information, contact Tim Beard [tim.beard@aihw.gov.au](mailto:tim.beard@aihw.gov.au), Functioning and Disability Unit, Australian Institute of Health & Welfare, Phone:(02) 6244 1270, Fax: (02) 6244 1199.

#### 15. "SPOTLIGHT" ON DON LOLLAR

Each month we try to feature an ICF professional who has had a significant impact in the disability field. This month we are pleased to highlight Don Lollar. Don Lollar, Ed.D. is a Senior Research Scientist, Division for Human Development and Disability, National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention in Atlanta. Prior to coming to CDC, Dr. Lollar practiced rehabilitation psychology for 25 years, providing assessment and therapy services to children, adults, and families across the lifespan. His advanced degrees are from Indiana University, and his most recent writings include co-editing an *Archives of Physical Medicine and Rehabilitation* supplement on the Science of Disability Outcomes, and articles for the 2003 *Annual Review of Public Health* and 2002 *Public Health Reports*, outlining public health strategies to improve the health and well-being of people with disabilities. He has spent the past seven years developing public health science and programs to increase participation in society among people with disabilities by promoting health and preventing secondary conditions. He currently serves as the co-lead of the *HEALTHY PEOPLE 2010* workgroup on Disability and Secondary Conditions (Chapter 6 of HP 2010), and is CDC representative to the advisory committee for the Child and Adolescent Measurement of Health Initiative and the Surgeon General's Task Force on Children's Mental Health. Dr. Lollar is an initiator and member of the World Health Organization task force to adapt the international classification (ICF) for children and youth with disabilities. On a personal note, Don enjoys Atlanta Braves baseball, baroque music, travel (usually) and watching his children find their way. He loves spending relaxing time with his partner of 35 years, Miriam. Don says that major pivotal factors in his life are growing up in the south, playing basketball much of his life, meeting Miriam, raising their two children, singing in a madrigal group for 10 years, and leaving private practice to join CDC. When Don opens the redbook, he calls attention to the red ribbon book mark, and says: "I come from the South, and where I come from, if a book has this red ribbon in it, that means it's reeeal important." It is hard to imagine how ICF development would have occurred without the dedicated efforts of Don Lollar.

