Call for Manuscripts

The guest editors of the DSQ Spring 1999 issue on Disability Identity are now inviting submissions. The deadline for manuscripts is December 15, 1998. Suggestions for topics include: the intersection of disability identity with other dimensions, such as gender, sexuality; race, class, and ethnicity; identity formation vis-à-vis various cross-sections of disability, such as different or under-represented disability types, different ages of acquiring disability, and visibility of disability; and individual disability identity development vs. group or community disability identity development. Theoretical, experiential, and conceptual pieces are invited, as well as empirical work. Innovative topics and wide-ranging perspectives are welcome; however, all submissions should focus on disability identity and emphasize a disability studies approach. Further information, including guidelines for contributors, is available from the guest editors, Carol Gill (tel: 312-355-0550, cg16@uic.edu) and Miriam Hertz (tel: 312-996-2091, mhertz@uic.edu).

Announcements

Research in Social Science and Disability is a new annual volume to be published by JAI Press. It will focus on linkages between disability and the social and cultural environment. It is based upon the premise that disability is not purely a medical phenomena, but rather is based on the interaction between the social and physical environment and a person's physical or mental state. It will consider aspects of disabilities as viewed through the lens of social science disciplines including history, economics, geography, political science, psychology, anthropology, sociology, demography, or closely related fields. It will consider all forms of disability, including mental and physical.

Submissions could include theoretical and critical papers, analyses based on qualitative as well as quantitative research methodologies, methodological or conceptual papers, and comprehensive reviews of the literature. Examples of submissions could include topics such as cultural aspects of blindness, the history of institutionalization for mental illness, the demography of mental retardation, the social structure of deaf communities, measuring disability for research purposes, or changing attitudes towards persons with disabilities. Research in Social Science and Disability will not consider medical or clinical aspects of disability, case studies, practice descriptions, or program evaluations. All articles will be peer-reviewed by reviewers from the same disciplinary background.

The editors, Barbara M. Altman and Sharon N. Barnartt, are soliciting original, unpublished manuscripts for Volumes 2 and 3. Papers should not exceed 40 pages double spaced. Four copies should be submitted to Sharon Barnartt, Department of Sociology, Gallaudet University, Washington, DC 20002, by June 1, 1999, for Volume 2, and June 1, 2000, for Volume 3. Instructions for authors available on request.

The University of Illinois at Chicago is pleased to announce the creation of a new academic department of the University. The Department of Disability and Human Development (DHD) offers interdisciplinary academic training providing graduate level education
focused on the intersection of disability and human development. The Department offers the Master of Science degree in Disability and Human Development with an opportunity for students to concentrate their major study in three key areas of specialization: disability policy and organization, disability studies, and rehabilitation technology. A Doctor of Philosophy degree in Disability Studies is also offered. This Ph.D. is an interdisciplinary degree program offered jointly by the Department of Disability and Human Development in collaboration with the Department of Occupational Therapy and the Department of Physical Therapy.

Admissions: The MS in Disability and Human Development admits students to begin in either the Fall or Spring Semesters. The Ph.D. in Disability Studies admits students to begin only for Fall Semester. Admission is open to qualified persons who hold undergraduate or graduate degrees from accredited colleges and universities. Persons from minority backgrounds, including persons with disabilities, are encouraged to apply. Please indicate whether you are interested in the M.S. or Ph.D. program when inquiring. Application materials may be obtained by writing to: Graduate Admissions, Department of Disability and Human Development, College of Associated Health Professions, University of Illinois at Chicago, 1640 W. Roosevelt Road, Chicago, IL 60608-6904.

Further information may also be obtained by writing to the above address or using any of the following: voice (312) 413-1647; fax (312) 413-1630; tdd (312) 413-0453; e-mail: <DHD@uic.edu>.

The University Affiliated Program (UAP) at the University of Hawai‘i announces that it has created an umbrella Center on Disability Studies (CDS) which incorporates the UAP and another 25 programs associated with it including a new NIDRR funded National Center for the Study of Postsecondary Educational Supports. The mission of the Center is to support the quality of life, community integration, and self-determination of all persons accomplished through training, service, research, demonstration, evaluation, and dissemination activities in Hawai‘i, the Pacific Region, and the U.S. mainland. The Center provides a structure and process to support and maintain internal professional development, collegiality, and cooperation, reflecting an organizational commitment to excellence. Center activities reflect a commitment to best practice and interdisciplinary cooperation within an academic, community, and family context. Activities are culturally sensitive and demonstrate honor and respect for individual differences in behavior, attitudes, beliefs, and interpersonal styles.

The Center on Disability Studies also announces a new program, Pacific Partnerships in Disability and Diversity Studies. Stipends are available to students accepted into post-master's, doctoral, and post-doctoral programs at the University. The stipends range from $3000 to $5000 annually for up to four years or completion of the program requirements, which ever comes first. Students must be actively enrolled in disability studies courses in order to receive funding completing a minimum of fifteen semester credits in core curriculum classes, specialty courses, and research/internship experiences.

The purpose of the program is to educate students in a number of disciplines to be leaders and/or researchers in areas serving children and youth with disabilities, to infuse cultural competence in systems and services for children and youth with disabilities, and to
institutionalize disability and diversity studies at the graduate level at the University of Hawai‘i in cooperation with collaborating graduate programs.

Funding priority is targeted for students of under-represented ethnic minority groups including Hawaiian/Part-Hawaiian, Filipino, and Pacific Islanders. Students are required to provide two years of service in or research on programs funded under IDEA for each year of financial support, upon graduation.

For more information contact Norma Jean Stodden, Ph.D., at 808-956-4454 (V), 808-956-3162 (FAX), or nhemphil@hawaii.edu via email.

Communications

Now Available

Makas, Elaine, Haller, Beth, & Doe, Tanis (Eds.). Accessing the Issues: Current Research in Disability Studies. Lewiston, ME: The Society for Disability Studies & The Edmund S. Muskie Institute of Public Affairs, 1998, 343 pages, $25.00 SDS members, $30.00 non-members. (For all non-U.S./Canada orders only, add $4.00 per book surface mail or $14.00 per book airmail.)

Note: This book is also available on 3.5 microdisk in Wordperfect 5.1 at the same per copy cost. Clearly indicate disk version if ordering this alternative format.

Available from the Society for Disability Studies, c/o Professor Carol Gill, Department of Disability and Human Development, University of Illinois at Chicago (MC 626), 1640 Roosevelt Road #236, Chicago, IL 60608-6904. All orders must be prepaid.

Accessing the Issues, the latest in a series of publications by the Society for Disability Studies, includes summaries of presentations given at the June 1995 annual meeting of the Society for Disability Studies, and the April 1995 annual meeting of the Chronic Illness, Impairment, and Disability Section of the Western Social Science Association, both held in Oakland, California. The book's 53 chapters represent the latest in disability-related research and theory from experts in a broad array of disciplines: sociology, political science, anthropology, psychology, women's studies, literature, history, education, and many other social science/humanities perspectives. The book includes complete, up-to-date contact information on all contributing authors, and extensive reference listings for more in-depth investigations of the issues presented.

The book is divided into fourteen sections, each organized around a unifying theme. Connections within sections and between sections are highlighted by introductions at the beginning of each unit.

Accessing the Issues is a highly useful and timely text for multidisciplinary Disability Studies courses and a valuable resource for individuals, academic institutions, and organizations involved in disability-related research/policy.

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Interagency Subcommittee on Disability Statistics

In order to provide information about disability studies and the meetings of the...
Report of the April 8 meeting of the Interagency Subcommittee on Disability Statistics (edited by the editor of DSQ).

1. Mitch LaPlante (Mitch_LaPlante@quickmail.ucsf.edu) reported that the Fifth National Disability Statistics and Policy Forum was scheduled for Monday, July 27, 1998. Entitled "Status of Americans with Disabilities, the forum concentrated on the current status of Americans with disabilities and definitions of disability. The agenda will included Disability Watch, the 1994-95 NHIS-D data, and the 1998 Harris poll. A report on the definitions and prevalence of disability was ready in time for the July forum.

2. Gretchen Swanson (SwanCo_Inc@msn.com) and LeeAnne Carrothers of the Western University of Health Sciences reported on their new grant entitled "ICIDH-2 Assessment Tool Development for Physical Therapy." The Functional Risk Assessment Research Unit was founded in 1998 with funds from a Western University of Health Sciences intramural grant. The overall mission of the research unit is to create a risk assessment tool that utilizes the nomenclature and philosophy of the ICIDH-2, specifically examining the relationships that exist between context, participation and secondary impairments.

Information gleaned from the instrument would:

-- Provide payors with the ability to estimate risk for a given population and thus determine potential utilization in a given risk pool;

-- Provide pertinent information to clinicians wishing to educate their patients regarding risk prevention or reduction;

-- Provide communities with information necessary to determine which prevention-oriented programs would best serve their communities;

-- Utilize a common functional language for all users;

-- Assist in the creation of criteria for application of functional data for clinicians and purchasers.

As a foundation for the development of this tool, the Functional Risk Assessment Research Unit is currently engaged in three projects which reflect its goals for 1998, and which it believes are integral to the overall project mission. Each individual project will attempt to survey a distinct sub-group of the targeted population. Data collected will be used to develop needs-based standards for functional risk and assist in the development of the overall composite risk assessment tool. For each of the individual sub-projects, the Unit anticipates presentable and publishable results, targeted to each specific group and the ICIDH-2 community in general.

FRARU 1998 Projects:

Verify payor standards for functional risk. Recent findings of an ICIDH-2 Payor Consensus Panel indicate that there are systematic needs of the payor community, and a stated appreciation for the insight a functional data classification system provides. At present, how-
ever, there is no way for the payors to utilize the data in a meaningful fashion (ICIDH-2 Payor Consensus Panel, 1997).

In November 1997, Western University of Health Sciences hosted an ICIDH-2 consensus conference for the payor community, which was sponsored by Swanson & Company. The payors at this conference represented several different perspectives, including health maintenance, indemnity, 24 hour coverage, worker's compensation and medical review. Included in this conference were a general introduction to functional outcomes, a discussion of the utility of the ICIDH-2, and a discussion of which information would be most useful to them as payors. (See the Report on the ISDS Dec. 10, 1997 meeting for further information).

The FRARU has a collaborative relationship with Swanson & Company, and is in the process of reviewing the data collected in that conference in order to determine which ICIDH-2 information best represents the needs and opinions of the payor community.

Define Health Perception in terms of the ICIDH-2 functional taxonomy. Several scholars describe the relationship between health and function. In particular, Patrick, et al., (1970) defines health as current and future function. From the consumer's perspective, there are tools that assess health perception, but none that classify future health. The SF-36 is a well-validated and reliable instrument used to assess health perception. It includes measures of activities of daily living, pain, mental health, and health in general. FRARU plans to crosswalk the SF-36 to ICIDH-2 to evaluate its utility in risk assessment. To accomplish the overall task, three stages have been identified as necessary to the process:

-- Crosswalk ICIDH-2 to an SF-36 standardized dataset;
-- Acquire sanitized payor SF-36 and utilization data set(s);
-- Transform and analyze payor data to ICIDH-2 classifications.

To date, FRARU is in the process of investigating the "crosswalk" process, and examining the WHO/ICIDH-2 assessment tool as a potential means of comparison with the SF-36.

Model Interdisciplinary orientation to functional risk assessment. Empirical and anecdotal evidence suggests that, with the exception of programs in the Health Sciences i.e., Physical Therapy and Occupational Therapy, functional models are not being taught in most health professional education programs, and the issues surrounding disability tend to be ignored completely.

A 12-hour elective on "Documenting Functional Outcomes" is scheduled in the Western U physical therapy curriculum. In this course, the FRARU will:

-- Introduce the concept of Functional Outcome classification using ICIDH-2;
-- Use a case-study approach to practice classification and determine the need for referral to other health care practitioners;
-- Assess student skill at correctly classifying cases;
-- Determine the utility of an ICIDH-2 classification schema to entry-level physical therapy practitioners.

Although this first course is directed towards physical therapists (the student elective occurs at the very end of the curriculum), it is FRARU's intention to survey clinicians in a variety of health professions.

As a research team, FRARU is excited about the potential that its project has to
provide meaningful data on a number of levels. FRARU believes that creating a tool that provides pertinent standardized information to end-users (specifically patients or purchasers) will fill a previously unmet need in the market/community. Ideally, once risk is accurately and meaningfully assessed, preventive measures can be taken to reduce identified risk as able.

The results are not proprietary to the project. The project has been funded for 1998 and expects to have results ready this fall. The investigators are looking for sanitized datasets and invited ISDS participants to call Gretchen Swanson at 800-984-8489 with suggestions. Dr. Ustun suggested devoting an entire ISDS meeting to look at ICIDH-2 assessment tools.

3. Carol Cohen (Carol_Cohen@ed.gov) of NIDRR introduced the issue of data collection and assistive technology (AT) by stating that systems change is central to the Technology-Related Assistance for Individuals with Disabilities Act of 1988, as amended (known as the Tech Act). Under the Tech Act, funds are to be used to increase access to assistive technology by persons with disabilities. Systems change includes revised or new laws and regulations designed to make AT more accessible to persons who need it. Currently, 56 entities are funded under the Tech Act, the 50 states, District of Columbia, Puerto Rico, and the four island territories. Rob Sheehan, consultant to RESNA, described current data collection by RESNA to evaluate impact of the Tech Act on accessibility of AT. The immediate need is for data to show whether systems change has occurred. If it has, then data are needed to determine whether access has increased. Data are then needed to determine whether independence, productivity, and social integration have increased as a result of increased access to AT. In 1997, 47 of the 56 funded entities reported systems change. However, most of the laws were lemon laws that protect consumers against faulty AT, predominantly wheelchairs. Also, 55 of the 56 entities have revised their regulations or policies to be more responsive to persons who need financial assistance to purchase AT, including leveraging resources through loan programs. Other issues to be investigated using data from projects are: whether providing information leads to increase access (146,000 persons received information in 1997); whether training increases access; whether the ability to borrow and try out devices increases access; and the impact of the Tech Act on modification of insurance reimbursement. The increased willingness to fund equipment is trackable, and Sheehan is looking for data that will measure it. Preliminary results show that there has been an increase in communications devices and less growth in mobility AT. Performance indicators are available at the RESNA Web site: <www.resna.org>.

4. Bedirhan Ustun (ustunt@who.ch) reported on the March 23-26 ICIDH-2 revision meeting held in Tokyo. There were 56 participants who reviewed the beta-1 field trials; discussed ways to implement beta-2; initiated new informational networks; and reviewed progress and timetables. There are now 9 collaborating centers and 2 task forces. Outcomes of the meeting were: (1) accepted general direction; (2) feasibility and utility of field trials; (3) valuable input; data to come; (4) useful feedback to come; (5) identified political/ideological issues; and (6) organizational suggestions. Several themes emerged: (1) need to use simple and plain English; (2) use of umbrella terms (disability vs. disablement); (3) inclusion of environment; (4) separate personal factors such as life experience, family support, resources; (5) classification issues; and (6) ethical issues. Future events include: (1) September and October 1998 meetings of the Collaborating Centers and Task Forces; (2) No-
November 1998 fundraising meeting; and (3) April 24-26, 1998 meeting in Mexico City to discuss ICIDH-2 field trials in 9 Spanish-speaking countries.

ANNOUNCEMENTS

CPS DISABILITY QUESTIONS. The Bureau of Labor Statistics is developing and testing questions about disability to be added to the Current Population Survey. The goal is to include questions that provide reasonable counts of the numbers of persons with any disability and the number with severe disability. The intent is to have enough information within the CPS so that disability status can be considered against the many employment indicators within the survey. BLS hopes to capture the information it needs in two questions. If you know of surveys where BLS can add its test questions for comparison against other disability indicators within the survey, please contact David Keer (Email: DAVID_KEER@ED.GOV) to discuss options.

NHIS-D CD-ROM "ROLL-OUT" ON JULY 28. Gerry Hendershot of NCHS/CDC has set Tuesday, July 28, 1998 as a tentative target date for a public event at NCHS to announce the availability of all of the NHIS-D public use files on CD-ROM. That's almost exactly two years after the first such event, which was very successful, and it is one day after Mitch LaPlante's disability data meeting in DC that will attract many other persons interested in disability data. For further information contact: Gerry E. Hendershot, Ph.D., Assistant for Data Analysis and Dissemination, Division of Health Interview Statistics, National Center for Health Statistics, Room 850, 6525 Belcrest Road, Hyattsville MD 20782, Tel: 301-436-7089 ext. 136, Fax: 301-436-3484, Net: geh2@cdc.gov Web: http://www.cdc.gov/nchs www CDC DISABILITY AWARD. The 1998 CDC Honor Award in the category of Contributions to Disability Awareness "for providing leadership in promoting employment, accessibility, and awareness to the CDC family and our partners regarding the contributions to persons with disabilities", citing last October's Disability Awareness Envision, was jointly received by NCHS employees Paul Placek, Linda Adams, Patricia Ragwar, Linda Tompkins, and Nichola Travers.

Minutes of the Interagency Subcommittee on Disability Statistics for June 10, 1998, MEETING:

1. Don Lollar (email: dcl5@cdc.gov), with assistance from Bedirhan Ustun (email: ustunt@who.ch), Somnath Chatterji (email: chatterjis@who.ch) and Jerome Bickenbach (bickenbachj@who.ch) reported on the ICIDH International Task Force on the Environment. Dr. Lollar focused on CDC's interest in placing Environmental factors and their impact on the health and well-being of persons with disabilities on the public health agenda. CDC and WHO are developing a collaborative proposal on this issue, which is close to being finalized. It will include a Chair and Co-Chair, WHO and CDC Project Officers and up to 10 members representing major WHO regions.

As part of the ICIDH-2 Revision Process, the need for a strong, empirical and inclusive classification system and framework that includes Environmental factors has become evident. Under the leadership of Gerry Hendershot and Paul Placek, The ICIDH's North American Collaborating Center (NAAC), has been actively examining Environment-
tal issues. The CDC is currently funding three projects (in Colorado, Missouri, and North Carolina) that are developing measures of participation and environment as key factors.

Somnath Chatterji provided an overview on the International Task Force on Environmental Factors and the experience of disablement. He explained that the goals of the task force are to: 1) Examine the role of Environmental factors; 2) Carry out ICIDH-2 field testing protocols; 3) produce a simple and practical two digit code for Environmental factors. Its tasks include: 1) reviewing the role of environmental factors; 2) reviewing classification and instruments; 3) recommending strategies; 4) reviewing terms and definitions; 5) integrating environmental factors into the overall scheme of the ICIDH; 6) reviewing the research agenda and developing assessment strategies.

The Task Force is expected to generate several products. These will consist of a working paper on Environmental factors and assessment, a draft revision of Environmental factors, Beta 1 and 2 testing, a Policy Paper and a Strategic Plan. As part of the project, there will be a person employed by WHO to work as coordinator during the two years of the project.

Jerry Bickenbach explained that this was the beginning of a process to examine Environmental factors and the Environmental Task Force will generate a research agenda.

Bedirhan Ustun highlighted the importance of Environmental factors and ways in which the issue has been brought to the forefront. He cited NIDRR's meeting last July on the ICIDH Revision Process, and changes within WHO (i.e., the appointment of a new Director General whose interest involves bringing scientific and political aspects of the Environment into the organization).

It is expected that it will take two years to complete the work. The CDC projects are designed to coincide with the ICIDH timetable. Specific products such as the two digit classification system, will not be ready by the time of the Oct. 5-6 ICIDH Revision Meeting in Vail, CO.

2. Dr. Gerry Hendershot (email: geh2@cdc.gov) along with Paul Buckley (email:paulbuckley@abtassoc.com) and Elena Andresen (email:andresen@wpogate.slu.edu) discussed "Methodological Research Needed in Disability Surveys." At the May meeting of the Interagency Committee on Disability Research (ICDR) where Dr. Hendershot also presented, three new demands for disability survey data were highlighted. On March 13, President Clinton signed an Executive Order, "Increasing Employment of Adults with Disabilities." The Order calls on the federal government to develop reliable measurements for employment of persons with disabilities by the year 2000. Additionally, Healthy People 2010, the document outlining the nation's future health objectives, seeks data to track outcomes. Such measurements would include the success of people with disabilities in meeting these objectives. And, the Office on Disability and Health in the CDC seeks to enlarge and enhance its nationwide surveillance system.

Although these new data demands exist, researchers are not far along in making state of the art surveys inclusive of people with disabilities. At the May 1998 annual meeting of the American Association for Public Opinion Research (AAPOR), the draft document, "Standard Definitions: Final Disposition Codes and Outcome Rates For RDD Telephone Surveys and In-Person Household Surveys" that covers details on how to establish standards and code structures for surveys, was made available. The document can be found at the AAPOR Website: www.aapor.org. The standards provide no way of identifying whether or not the survey attempted to accommodate persons with disabilities. The document in
cludes no incentives to make special efforts to interview people with disabilities.

Dr. Hendershot also cited a recently published and otherwise excellent book on Non-response in Household Surveys, by Robert Groves and Mick Couper, which barely addresses disability. Gerry Hendershot juxtaposed the new demand for data on persons with disabilities with the inadequate state of development of household surveys. He made the case that research on survey methodology is needed and lists of specific research topics exist. It is critical to find the best modes of collection to encourage accurate responses from persons with disabilities. The ISDS has been charged to come up with action steps to respond to this issue.

Gerry Hendershot covered total survey error, the difference between true population statistics and sample-based estimated numbers. Total survey error is composed of sampling error and non-sampling error. Non-sampling errors include: 1) coverage error (where the frame of the sample fails to include all relevant parties); 2) non-response error (where not everyone was contacted, or where respondents were non-cooperative, meaning that they differ from those who cooperate); 3) measurement error (where it may be that the survey fails to pose the right questions) and 4) processing error. He then turned to Paul Buckley and Elena Andresen to illustrate problems in survey research for people with disabilities.

Paul Buckley explained that traditionally, there has been little or no interest in disability surveys within survey organizations or their clients, which include the federal government. In 1989, there was a survey in Pennsylvania that made a concerted effort to find those who use a TTY. Out of 150,000 households, the surveyors ended up making contact with only 3 households whereas an estimated 1600 households used TTYs.

Those in the survey community do not feel they are missing something significant in failing to identify persons with disabilities. Actually survey researchers do not want to classify the "non-interviewed." Such numbers count against them. Instead, they prefer to conclude that someone is not eligible. Presently, TTYs are lumped in with fax machines and data lines allowing for persons who use them to be deemed ineligible. Direct measurement is needed of populations that use TTYs and other "non-standard" equipment or who may require use of proxies.

Interviewing persons with disabilities for household surveys can pose a number of different problems. It is more difficult to make contact with persons with disabilities. Due to privacy issues, accurate lists of persons with disabilities are unavailable. Obtaining the cooperation of respondents can be problematic, particularly if they do not feel that a survey serves their community or interests directly. Even when persons with disabilities decide to cooperate, they may not be trained respondents. Some persons may have a tendency to ramble when they answer questions, introducing a mode effect. This type of measurement problem makes the data incomparable to that of individuals who have more experience being interviewed.

Other issues arise when surveying persons with disabilities. For those who are deaf or hard of hearing and use American Sign Language (ASL), interpretation is not always direct. The potential exists for measurement errors. Technology can be a barrier to survey research. TTYs are not well designed for conducting surveys. Only two lines of text can be displayed at a time. So, survey instruments need to be written specifically for this
technology. Finally, the cost of data conversion can be substantial. It is therefore possible to develop other forms of survey errors. So, errors can be compounded.

Elena Andresen presented on Surveillance Issues: Performance of the Behavioral Risk Factor Surveillance System (BRFSS), a CDC funded study. Its objectives are to evaluate the performance of four generic Health Related Quality of Life instruments covering respondent burden, respondent acceptability, floor and ceiling efforts, and discrimination among specific impairment groups. The goal is to test and retest the BRFSS to examine the reliability of this instrument.

Study methods include the use of computer assisted interviews. Random instrument order is employed; the time of each instrument and the time of the entire interview are recorded. The acceptability of the questions is also considered.

The BRFSS core questions, used in all 50 states, cover a variety of disability-related measures, such as 1) Self-Rated General Health; 2) "Not Good" Physical Health Days; 3) "Not Good" Mental Health Days; 4) Limited Activity due to Mental or Physical Health Problems. Severe work disability is also covered. The BRFSS also has a 10 question module that covers such issues as limitation, major impairment of health problem, length of limitation, personal care needs, routine needs and days that pain limits usual activities.

Five hundred thirteen people were interviewed. Fifty-seven percent of those were interviewed in person; 43% were interviewed by telephone. The mean age of respondents was 62.2 years of age, and persons aged 18 - 101 were interviewed. Fifty-eight percent were women. 26.1% receive Social Security benefits and 32.4% receive veterans benefits. The study identified the numbers and percentages of people with specific disabilities who indicated they were limited in any way on any activity.

BRFSS Kappa Values were computed to measure the test-retest reliability of disability measures. Fifty-two people were retested within a week of the initial survey. The kappa value for personal care needs was .70, for routine care needs .75, and limitations of any kind, .61. Kappa values of this magnitude indicate a relatively high level of reliability in the measures. Results will be ready for publication in the next month.

Questions: Mitch LaPlante asked, what is the more efficient mode for surveying persons with disabilities, telephone or household surveys? Elena Andresen commented that it is important to test reliability and whether it differs according to disability. Such work has not yet taken place, but it is a good suggestion. Paul Buckley thought in person interviews are better, since language specialists skilled in ASL could be used for people who are deaf or hard of hearing. He also felt that the Web may be a possible mechanism for future use. Oftentimes, telephone interviews are dependent on the skill of the interviewer. The issue is one of writing questions that actually get at the answers surveyors are seeking.

Don Lollar suggested the creation of a federal contract requirement that would report attempts to involve persons with disabilities in survey research. Paul Buckley explained that RFPs are currently silent on this issue. Since involving persons with disabilities increases cost, generally the industry does not pursue this target population. If there was a standard disposition code and federal contracts required reporting, there would be the potential for viewing significant impacts.

Elena Andresen pointed out that some people with disabilities do not perceive themselves as having limitations. So, respondents may not perceive questions similarly.
Paul Placek raised the issue of surveys in terms of the ADA. He recommended that the HHS Data Council develop a standard set of protocols on access that should be embedded in all federal contracts. Ray Seltser commented that the survey research industry is not taking the ADA seriously if it denies access to survey participation by persons with disabilities. People with disabilities are part of the general population. Excluding this segment of the population who is covered by antidiscriminatory legislation has serious ramifications.

The 5th National Disability Statistics and Policy Forum on "The Status of Americans with Disabilities," took place on Monday, July 27 at the Holiday Inn Capitol, 550 C Street S.W., Washington, DC. The Forum is sponsored by the National Institute on Disability and Rehabilitation Research. The conference was being held on the 8th anniversary of the passage of the Americans with Disabilities Act.

The purpose of the Forum is to bring leading policymakers, disability advocates, and researchers (both producers and users of statistics) together to present the evidence and discuss its significance. The Forum will help to develop specific recommendations for improving statistical monitoring of how well people with disabilities are faring in society.

The Society for Disability Studies

The Society for Disability Studies is a nonprofit scientific and educational organization. It is a multidisciplinary and international organization composed of social scientists, scholars in the humanities, and disability rights advocates concerned with the problems of disabled people in society. The purpose of the Society is to bring together people from diverse backgrounds to share ideas and to engage in dialogues that cut across disciplinary backgrounds and substantive concerns. The Society is committed to developing theoretical and practical knowledge about disability and to promoting the full and equal participation of persons with disabilities in society.

Further information on membership and the annual meeting can be obtained by contacting the national office. The mailing address is: Society for Disability Studies, c/o Professor Carol Gill, Department of Disability and Human Development, University of Illinois at Chicago (MC 626), 1640 Roosevelt Road #236, Chicago, IL 60608-6904.

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