

Reports on the Meetings of the Federal Interagency Subcommittee on Disability Statistics

The following reports were revised by the DSQ Editor removing or condensing material presented elsewhere, not appropriate (like job and personal announcements), or with past deadlines.

Report of February 10, 1999 Meeting

1. Janice Miller (email: millerj@who.ch), Co-Chair of the ICIDH-2 International Task Force on Environmental Factors in Functioning and Disability, reported on the discussion and deliberation of the first meeting of the Task Force that was held in February. She explained the multiple purposes of this WHO/CDC Joint Project. The Task Force was created to 1) advance scientific understanding of the role of Environment in the disablement process; 2) examine the role of Environmental Factors (EF) as an essential component of ICIDH-2 for all ages; 3) contribute to the current ICIDH-2 revision process, including field testing; 4) provide WHO with recommendations on a two level classification of EF; 5) participate in the development of an international literature review and policy papers on EF.

The Task Force is structured to have representatives from all six WHO regions. The body as a whole will consist of between 30-40 members. It has an Executive Committee with Chair Rachel Hurst (European region) and Co-Chair Janice Miller (Pan-American Region). The other members of the Executive Committee include Serge Ebersold (European region), Rhonda Gaibally (Western Pacific Region), David Gray (Pan-American Region), Sebenzile Matsabula (African Region), DM Naidu (South East Asian Region), and Satoshi Ueda (Western Pacific Region). The larger Advisory Group also brings representation from the 6 regions, including the EMRO region. Recruitment of members is underway. Technical advisors and consultants will also be recruited to support the Task Force in specific areas of expertise. A Steering Committee comprised of WHO and CDC members has been created. Additionally, Senda Benaissa, formerly of NCHS, has been appointed the Project Coordinator and is based at WHO headquarters.

The Environmental Task Force (ETF) is responsible for reviewing the role of environmental factors in the disablement process from several viewpoints: 1) over the lifespan; 2) across different regions of the world; 3) from as many different languages as possible. It will review classifications and instruments relevant to Environmental factors and will recommend strategies related to needs and practices. The Task Force will also review terms and definitions and suggest operationalization of environmental factors relevant to disablement. It will integrate environmental factors into the overall scheme of the ICIDH-2. It will develop a research agenda and assessment strategies.

The Task Force will develop several products. It will produce a working paper related to the role of environmental factors and their assessment. It will also create a draft revision of Environmental Factors. A review of Beta 1 testing results has been conducted and another review will focus on Beta 2 results. It will produce a policy paper on Environmental Factors and a strategic plan regarding the role of Environmental Factors.

Review of Beta-1 Input on Environmental Factors indicated a number of issues including the role of EF in the ICIDH model, and the use of EF as a qualifier of Participation. A number of gaps were identified and suggestions for revision of specific terms were made. There was some support for a classification of EF as well as support to maintain it as a list.

A preliminary review of the first version of Beta-2 (Feb. '99) identified additional gaps, and suggestions that the NIDRR and European Classifications be examined. Some overlaps or duplications were noted including: 1) the personal assistance and support chapter covered in other health categories (informal social structures, social assistance, and other health services), and 2) the potential overlap of housing and residential buildings.

An examination of what elements should be listed in different levels will take place. For example, e100 has products and drugs both at a second level, and e120 - Assistive Technology, may

have too many categories at the 3rd level. The Task Force may recommend adding a 4th level. Chapter 2 may change to separate the physical personal assistance from the psychological support of family, creating two chapters. And, the Task Force may consider two chapters for Assistive Technology and Modified Devices.

The Task Force may use Blocks in ways similar to dimensioning. It may recommend: 1) Physical (natural, built, products), Personal (support types), Social (attitudes, culture, etc.) OR 2) Physical Environment, Attitudinal (or social) Environment, Policy (organizational, government) Environment.

Input regarding infants and children has also been received, particularly with regards to the unique aspects of primary caregivers, caregiving environment, instructional and social nature of school environments (with universal applicability for children), and attitudes of medical and health professionals. The Task Force will work collaboratively with the Children's Task Force to ensure consistency and adequate coverage of relevant categories.

The Task Force will review the role of EF including its impacts on Participation only, its impacts on all dimensions, and whether to keep Participation as a list or develop it as a taxonomy/classification. It will consider whether items in Activity should be in Participation because the focus appears to be on the society level and not the person level. Examples shared included moving around in traffic situations as a pedestrian, managing at work and school, and managing in different climactic conditions.

Specific terms will be reviewed to standardize the approach. For e315, services will be put on all third level terms used. For e120, assistive will be used on all 3rd level terms. For e630, Climatic Conditions will be suggested as a 2nd level.

One of the recommendations of the Task Force Executive Committee was to consider Environmental Factors in terms of different levels, i.e. individual services and systems levels of environment (also commonly referred to as micro, meso and macro levels). In sum, the Environmental Task Force recommendations cover the role of EF, second levels, qualifiers (barriers, facilitators) and a matrix approach to environment.

Janice Miller reminded the group of the principles underpinning the development of Environmental Factors and ICDH-2 in general. The classification system must be universal in approach, focus on functioning as well as disability, cover the lifespan, have broad cultural applicability, convey parity, and use neutral language. Taxonomic requirements call for a strong hierarchical structure that is logical, coherent, ensures mutual exclusivity of standards, and can stand alone. The classification and coding conventions must be feasible and easy to use.

Timelines and Deliverables were presented:

Planning Meeting	January 1999
Executive Committee Meeting	February 1999
ETF Recruitment	Ongoing
Consultation with Advisory Committee	March 1999
Children's Task Force Meeting	April 1999
Preliminary Literature Review	April 1999
Redraft of EF for Beta-2	April 1999
Beta-2 Protocols for EF	April 1999
Beta-2 analysis	May 2000
Annotated bibliography	September 2000
Policy papers	September 2000
Strategic plan	September 2000

Cille Kennedy suggested that the representation of many different perspectives (including mental health, legislative) is implicit in the consideration of EF, specifically on Activity and Participation. She felt it as important for the ETF to coordinate with other Task Forces or Collaborating Centers. Janice Miller agreed and noted that the ETF plans to circulate its proposals broadly. It will also

present a profile of the group working on these issues.

Bob Wasserman asked about the matrix approach. He wondered how two dimensions differ in the conceptualization. Janice Miller replied that there is concern regarding overlap, redundancies, or inconsistencies in the matrix. Alternative solutions may be proposed.

Mitch LaPlante sought information on how the coding scheme will be used and whether it will be part of the ICIDH or a supplementary classification. Ustun commented that WHO is considering coding EF for body functions. That will mean an increase in codes. The Task Force will work to identify how the Environment interacts with functioning. On the issue of positive or negative qualifiers, instead of using a decimal point, there is consideration of using a + or - sign, which may be considered an unconventional approach.

Rune Simeonsson asked about assistive technology and whether it fits into the framework of environmental dimensions. Assistive Technology sits at a 2nd level in Chapter 1 (items of personal use).

2) Denny Vaughan (email: DRVAUGHAN@aol.com), and Bernard Wixon (email: Bernard.J.Wixon@ssa.gov) reported on their structural model of the Social Security Disability Determination Process. They sought to answer the following question: how can one use self-reports on work and activity limitations and relevant socio-economic characteristics to represent SSA's definition of disability?

The question led them to pursue three lines of inquiry where they considered the sequential disability determination process: 1) They used self reports and other relevant socio-economic information to model the outcome of SSA's sequential disability determination process for a set of actual applicants. 2) They estimated the prevalence of disability according to SSA's definition for persons in the general population who have never applied for disability benefits. 3) They modeled the factors which yield the decision to apply for benefits.

They got involved in this inquiry by modeling eligibility for Supplemental Security Income (SSI), the principle means-tested cash assistance program for indigent aged and disabled persons, using the Survey of Income and Program Participation (SIPP). They found that participation rates for persons with disabilities were grossly sensitive to the way in which self reports of work and activity limitations were employed to identify persons to be considered eligible based on disability.

Since the SSI program was becoming more and more a program serving persons with disabilities, they felt they needed to directly confront the issues of those disabled according to SSA's definition. Their basic approach was to model the relationship between survey self reports of health status, functional and activity limitations and work limitations and relevant socio-economic characteristics on the one hand, and the outcome of the application for disability benefits on the other. An exact match between the survey sample and SSA's disability applicant record system provided well-differentiated information on outcome of the application for benefits.

Vaughan noted that the application process involves five steps: 1) An earning screen - earnings above \$500 per month are taken as presumptive ability to work. 2) A severity screening step - persons found to have a severe impairment are passed along for further evaluation; those not meeting the severity test are denied. 3) A determination of whether a severely impaired individual has a condition that meets or equals one of a hundred or so "medical listings" presumed to preclude the ability to work with a positive finding yielding an award and a negative finding resulting in further evaluation. 4) A review of the individual's ability to perform past work a positive finding resulting in denial and a negative finding resulting in further evaluation. 5) A review of the individual's ability to perform any job available in the national economy with a positive finding resulting in denial and a negative finding resulting in an award.

Administrative data from the match allowed the researchers to identify and model separately the outcomes for steps 2-5. They used standard logit techniques creating four separate models, one for each step in the sequential evaluation process.

The estimated models yield a set of coefficients which nominally translate self-reports and

socio-economic characteristics into a probabilistic representation of SSA's disability criteria for applicants in the SIPP sample. Given that the survey provides a common set of information for applicants and nonapplicants, the researchers were able to use the coefficients associated with the applicant characteristics to infer (simulate) SSA Disability Status for those who have never applied for benefits.

However, employing this approach involves a major methodological problem since the relationship the researchers observed between self-reports and SSA disability status for applicants is likely to differ systematically from the relationship between self-reports and SSA disability status for sample members who have not come into contact with the program and applied for disability benefits. Technically this sort of problem is known as one of "selectivity" or "endogeneity."

As a result, a straight forward simulation of eligibility status based on coefficients from the applicant model would be likely to yield seriously biased estimates of the number of nonapplicant eligibles.

The researchers dealt with this problem by modeling the outcome of the agency's decision regarding the applicants' disability status simultaneously with the probability of application. They could respecify the estimates of the relationship between self-reports and the Agency's characterization of disability status based on the probability that an individual with given characteristics (basically self-reports on health and disability status and their financial circumstances) would apply for benefits.

The researchers found that the selectivity corrected estimates of the prevalence of disability in the general population with respect to SSA's criteria were much lower than naive estimates based solely on the relationships estimated from the applicant model. After introduction of preliminary selectivity corrections, prevalence estimates are on the order of 5-8% for non-institutionalized persons aged 18-64.

These prevalence levels compare to estimates developed by the Bureau of the Census from the same data set using conventional Bureau definitions employed in the SIPP context of 18% of adults aged 18-64 with some level of disability and 8% with a severe disability for the late 1991/early 1992 time period. Based on estimates from the survey, 3-4% of this age group were receiving cash benefits from one or both of the agency's principal disability programs at this point in time.

Further work is called for to refine the selectivity adjustments by developing a more fully specified model of the application decision, which leads to the third principal phase of the group's work which is just getting underway.

The boundary between the agency's disability programs and the general population is defined by the agency's assessment of applicant disability status (and the financial dimensions of eligibility such as insured status and means testing) and by the disabled individual's decision to apply for benefits. As noted, modeling the application decision is required to deal with the selectivity issue when making general population estimates of the prevalence of disability according to SSA criteria. Also, since the decision to apply necessarily precedes entrance on the rolls, even for those fully eligible, understanding the decision to apply is critical to understanding the sources of program growth per se. This model of the disability determination process will emphasize household events leading to the decision to apply. Particular emphasis will be placed on family labor supply, health insurance coverage and its relationship to family labor supply, and the availability of cash and noncash transfers and family assets as substitutes for family earnings.

The work these researchers have undertaken in this set of projects complements and will be coordinated with SSA's upcoming Disability Evaluation Study (DES). In particular, the DES will obtain assessments of disability status according to SSA criteria on the basis of actual medical and functional assessments for a probability sample of the general population. Thus DES findings will permit introduction of adjustments to the researchers' modeled estimates of the disability status of the nonapplicant population that would be required to deal with remaining selectivity problems stemming from the dependence of the group's work on information drawn principally from applicants. In addition, to the extent that the DES identifies more valid approaches to obtaining self-reports of disability status, it may be possible to introduce improved self-reported measures in surveys such as the SIPP.

The group has written two reports and a third report is nearing completion: Kajal Lahiri, Denton R. Vaughan and Bernard Wixon, "Modeling SSA's Sequential Disability Determination Process Using Matched SIPP Data," Social Security Bulletin, vol. 58, no. 4, (Winter 1995), pp. 3-42; Jianting Hu, Kajal Lahiri, Denton R. Vaughan and Bernard Wixon, "A Structural Model of Social Security's Disability Determination Process," ORES Working Paper Series, No. 72, Social Security Administration, Office of Research, Evaluation and Statistics, (August 1997).

A third piece, describing the methods and results of their attempt to estimate the prevalence of disability in the general population according to SSA criteria, is in preparation.

The group is pleased to provide copies of the first two papers on request and will forward the third when it becomes available for general circulation. If interested in obtaining copies, forward your request along with your mailing address to Bernie Wixon (email: Bernard.J.Wixon@ssa.gov)

Neal Nair asked if the SSA statutory/regulatory definition of "disabled" is the same as the one given in the Rehabilitation Act. The SSA definition goes beyond whether the person has a permanent, total disability. It reflects the nuances of the five stage process defined. Allowance of Disability Benefits may involve an impairment identified in SSA's list or a vocational grid requiring a lower threshold for eligibility. For example, those who are in their late 50's or early 60's with limited education and sporadic work history may be considered less adaptable than other people, thereby qualifying for disability benefits.

Ray Seltzer asked why people decide to apply for benefits and how their decision relates to health insurance. Wixon noted that health insurance is an important factor. The researchers hope to obtain detailed information on that.

Rick Waxweiler asked about the percentage of people receiving benefits. Vaughan replied that the preliminary model results suggest that approximately 7-8% of the population aged 18-64 meet SSA's definition of disability exclusive of the Substantial Gainful Activity (SGA) test. Of course not all such individuals would meet the financial requirements of disability, i.e., be insured for disability under Social Security and/or meet the income and asset requirements of the Supplemental Security Income (SSI) Program. This compares to survey estimates indicating that approximately 5 to 6% of persons belonging to the survey population and aged 18-64 were receiving cash benefits under one or both of the two cash benefit programs.

Cindy Jones asked about the medical listings and whether they have been updated. She noted that it is possible for a person to be severely disabled, yet with the presence or absence of assistive technology or transportation, be able to work. Wixon replied that SSA is launching research efforts to update the listings which will include technology that can influence a person's ability to work. Jones expressed concern regarding the level of \$500 as Substantial Gainful Activity (SGA) and the underground economy where people work but do not report their earnings to protect their benefits. What is a realistic amount to earn and not be considered "disabled" under the SSA definition? She also wondered about environmental factors.

Vaughan acknowledged that the earnings screen is dependent on the report of the individual. The researchers can only work from what is reported in the administrative records or in the survey. Basically, program administrators face the same limitation. Clearly, environmental factors do play a role in a disabled person's ability to work. Given the research design, to the extent that such factors are considered in the decisions rendered by the agency, they are nominally incorporated in the outcomes the researchers modeled. Assistive technology was taken into account in the study, but only in a limited way, that is, long term use of a walker, wheelchair, or cane was reported in the survey and considered in the modeling.

3) Sheryl Larson (email: larso072@tc.umn.edu) discussed the work of the Research and Training Center on Community Living in identifying people with mental retardation or developmental disabilities. Using data from the 1994 NHIS-Disability Supplement, the RTC seeks to gain further knowledge about the lives of people with mental retardation or developmental disabilities living in non-institutionalized settings. Topics of focus include prevalence of mental retardation and develop-

mental disabilities, population characteristics, use of services, devices and technologies, social and vocational experiences, access to medical care, health care and personal assistance, living arrangements, formal and informal supports needs and use.

Analyses will examine variations in these outcomes associated with age, severity of condition, racial/ethnic background, place of residence and other attributes. In-depth analyses will focus on issues such as unserved or underserved individuals waiting for services, characteristics of direct support professionals in in-home settings, and guardianship status for adults. For information about the project, access its Web site at: <www.ici.coled.umn.edu/ici/rtc/NHIS>.

In order to identify people with mental retardation in the NHIS-DS, the RTC developed a working definition of the category. People with mental retardation were identified in one or more of the following ways: 1) if they reported having mental retardation if asked directly; 2) when mental retardation was indicated as the cause of age specific activity limitations; 3) if mental retardation was identified as the primary cause of one or more specific limitations, conditions, or service needs; 4) if, through a two step process, they reported both a "learning disability" and a related condition AND they were further screened and found to have a significant functional limitation in learning.

People with developmental disabilities were identified using definitions from the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) Amendments of 1996. A multi-stage process was used for each of the seven areas of functional limitation in the federal developmental disabilities definition: 1) self-care, 2) expressive or receptive language, 3) learning, 4) mobility, 5) self-direction, 6) capacity for independent living, and 7) economic self-sufficiency. People 5 years and older were considered to have a developmental disability if they had substantial limitations as defined in three or more of the seven areas of major life activities that involved "a lot of difficulty" or that the person was totally unable to carry out and that were expected to continue at least twelve months, with a limitation in one of these areas occurring before age 22.

A separate definition was used to identify children ages 5 and younger who had developmental disabilities. They were included in the sample if they had a specific congenital or acquired condition that is consistently associated with developmental disabilities in older children or adults (such as mental retardation) or if they had substantial developmental delays in physical development, chewing, eating or toileting, receptive or expressive communication, understanding instructional materials, cognitive or mental development, participation in strenuous activity or mobility. Children ages 5 or younger who had only a hearing, vision, or speech impairment were not considered to have a developmental disability. The Project also identified people with conditions related to mental retardation.

A sample of 1667 people were identified in the 1994 NHIS Core and Phase 1 surveys who had either mental retardation or developmental disabilities or both. Preliminary prevalence estimates are that 1.52% of the non-institutionalized population have mental retardation and/or developmental disabilities. Overlaps between mental retardation and developmental disabilities are outlined in charts; findings are discussed in the RTC MR/DD Data Brief, January 1999, Vol. 1, No. 1. Inquiries about the Data Brief can be made to the Publications Office, Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive, SE, Minneapolis, MN 55455.

Rune Simeonsson asked how developmental delays or specific problems were identified in children from birth to 71 months and whether the definition took developmental milestones into account. Larson spoke of ways to operationalize a lag in development from ages 0-5. The definition used by the RTC employed developmental milestones to determine which young children were experiencing substantial developmental delays. The milestones were age specific within the 0-5 age group and were developed with consultation from early childhood disability research experts. Contact Larson if you would like more specific information about this point.

Bob Wasserman noted that children under 5 were not diagnosed as having a developmental disability but not having mental retardation. Larson explained that the DD Act identified children from birth to 71 months as having a developmental disability if they had a specific congenital or

acquired condition that was consistently associated with developmental disabilities among older children and adults in the sample, or if they had a substantial developmental delay in certain activities. By definition, any child age 5 years or younger who had mental retardation was defined as having a developmental disability.

Gerry Hendershot asked if the RTC was planning to share the codes it has developed. He also wondered whether the data briefs would be coming out according to a schedule. Larson replied that the codes are still in the development process, but welcomed inquiries about them via phone or Internet. A series of Data Briefs are planned but a specific schedule has not been outlined. Data Briefs will be available on the RTC web site as they are developed.

Announcements (February 10 meeting)

1. WEST VIRGINIA COMMISSION ON MENTAL HYGIENE REFORM Debbie Farmer, who has worked with various ICIDH task forces since 1994, is now working for the West Virginia Supreme Court of Appeals in Charleston, WV. Debbie has requested that anyone who has information concerning current trends in social policy, legislative orders or changes in the field of Mental Health in regard to Mental Hygiene (involuntary hospitalization) proceedings, please contact her. Chief Justice Larry V. Starcher of the Supreme Court of Appeals announced on February 10, 1999, that the Court will appoint a Commission on Mental Hygiene Reform. The formation of a commission on mental hygiene was one of the recommendations proposed by the Commission on the Future of the West Virginia Judiciary in its December 1, 1998, report to the Supreme Court. The Futures Commission received public comment on West Virginia's mental hygiene system. The Commission found that there have been significant changes in the understanding and treatment of mental illnesses, disorders, and conditions, since West Virginia's mental hygiene laws were enacted over 30 years ago. "There is widespread support of the Mental Hygiene Commission's task among patients, families, advocates, medical and social service professionals, law enforcement, and the court system," Chief Justice Starcher said.

The staff involved in this project is seeking information concerning funding for support of information gathering which includes meetings, expert presentation of information, statewide surveys and focus groups.

The staff is also seeking potential candidates to speak or present expert information to the Commission during the process. If you feel that you or someone from your Agency may be of assistance to the Commission, you can contact Debbie at: Debbie Farmer, WV Supreme Court of Appeals, Administrative Office - Mercer County, 130 Scott Street, 2nd Floor, Princeton, WV 24740, 304-487-0197, 304-540-3790 (pager), e-mail <farmed@wvnm.wvnet.edu>.

2. Cindy Jones announced the creation of the Accessible Society Action Project (ASAP!), established to disseminate information developed by NIDRR-funded research to promote independent living by people with disabilities. Funded by a grant from NIDRR, the mission of ASAP! is to focus the attention of the mainstream media on disability and independent living issues. ASAP! For more information, contact Cindy Jones at: email: <cyndijones@aol.com>.

3. APRIL 28 REHABILITATION SCIENCE CONFERENCE The Ph.D. Program in Rehabilitation Science at the University at Buffalo is planning a conference April 28 on "Rehabilitation Science, Issues in Graduate Education and Research." Among the featured speakers are Dr. Kate Seelman, Director of National Institute on Disability and Rehabilitation Research, and Dr. Marcus Fuhrer, Former Director of National Center on Medical Rehabilitation Research. This conference will bring together faculty and other leaders in Rehabilitation Science to share the designs of their graduate programs and research.

The poster, registration form, and poster presenter form can be found on the web site <wings.buffalo.edu/ot/conference/>. For further information please call 1-800-628-2281, or e-mail <swilson@buffalo.edu>. Please pass this on to others who may be interested in this emerging field.

4. NEW BEOC GUIDANCE ON THE ADA On March 2, 1999, the Equal Employment

Opportunity Commission released guidance titled "Reasonable Accommodation and Undue Hardship under the Americans with Disabilities Act." The guidance and a fact sheet for small employers are available from the EEOC web site at <www.eeoc.gov>. 5. FCSM RESEARCH CONFERENCE The Federal Committee on Statistical Methodology (FCSM) Research Conference will be held on November 15-17, 1999, at the Key Bridge Marriott in Arlington, VA. Topics including the use of administrative data, small area estimation, meta data and data warehousing, statistical data analysis, improvements and alternatives to census-taking, cognitive research methods, estimation and editing, impact of the American Community Survey, matching and record linkage, confidentiality, response issues, new technologies, seasonal adjustment, data collection, statistical software, and display, dissemination and integration of statistical information. Contact Ruth Detlefsen, Bureau of the Census Bureau, Room 2641-3, Washington, D.C. 20233; Phone: 301-457-2665, E-mail: <fcsm@ccmail.census.gov> or see the web site <<http://www.bts.gov/fcsm>>.

6. CDC CONFERENCE The "Promoting the Health and Wellness of Women with Disabilities" conference will be held in San Antonio August 2-5, 1999. For registration information contact Visions, USA at 404-880-0002. For conference information contact JoAnn Thierry at CDC, tel 770-488-7097 or <jxt4@cdc.gov>. Website info at <<http://www.cdc.gov/nceh/programs/disabil/home.htm>>.

7. GAO DOCUMENTS The following items were added to GAO's World Wide Web site in Portable Document (PDF) format. SSA Disability Redesign: Actions Needed To Enhance Future Progress, HEHS-99-25, 70 pp. plus 5 appendices (26 pp.), March 12, 1999, <<http://www.gao.gov/new.items/he99025.pdf>>. This database can be searched from the World Wide Web from the search page at: <http://www.access.gpo.gov/su_docs/aces/aces160.shtml>. If you are using speech synthesizer equipment or lack World Wide Web access you may search this database with GPO's public swais client by telnetting to <swais.access.gpo.gov>. Any individual report may be retrieved directly from that archive in text and PDF formats with the following URL: <<http://www.gao.gov/cgi-bin/getrpt?RPTNO>> replacing RPTNO with the report number (e.g., GAO/OCG-98-1).

9. NATIONAL REHABILITATION AWARENESS CELEBRATION National Rehabilitation Awareness Celebration is September 12-18, 1999, sponsored by the National Rehabilitation Awareness Foundation. For posters and ways to make the week special in your organization or community, contact the National Rehabilitation Awareness Foundation, 475 Morgan Highway, P.O. Box 71, Scranton, PA 18501-0071, tel 1-800-943-6723.

10. DISABILITY AWARENESS MONTH Disability Awareness Month occurs in October in the Department of Health and Human Services. If your group has an activity which you wish to publicize, the Interagency Subcommittee on Disability Statistics would be happy to announce your event in the monthly minutes.

11. NCD AIR CARRIER ACCESS ACT REPORT The National Council on Disability (NCD) has just released a groundbreaking report documenting ineffective enforcement of the Air Carrier Access Act (ACAA) since the law's passage in 1986. NCD's report, Enforcing the Civil Rights of Air Travelers with Disabilities, contains recommendations on how to improve the enforcement of civil rights of air travelers with disabilities, including changes to the law and improvements for the Department of Transportation. The report is available at NCD's Web site (<http://www.ncd.gov>), and will have serious implications for ACAA, the Federal Aviation Act, and passenger bill of rights legislation sponsored by the President and Congress. It is the first in NCD's "Unequal Protection Under Law" series of independent analyses of federal civil rights enforcement for Americans with disabilities.

12. ADA DISCRIMINATION COMPLAINTS Complaints of discrimination under Title II or Title III of the Americans with Disabilities Act (or Section 504 of the Rehabilitation Act), may be filed with U.S. Dept. of Justice, Civil Rights Division, Disability Rights Section, P.O. Box 66738, Washington, D.C. 20035-6738. Complaints must include the following information: (1) name, address, and phone(s) of complainant or of person discriminated against (if other than complainant); (2)

name, address, and phone(s) of business, organization, or governmental entity that complainant believes discriminated; (3) description of discriminatory acts/omissions alleged, date(s) of discrimination, and names of individuals who complainant believes discriminated (if known); (4) efforts made to resolve matter informally (e.g., filing grievance, mediation, etc.) (if any); (5) list of courts and/or other agencies, including contact person(s), address(es) and phone number(s), with which complaint was filed or will be filed (if any); (6) signature of complainant and date signed.

13. GAO REPORTS & TESTIMONY To obtain copies of GAO reports or testimony, Email <documents@gao.gov> or call GAO's Document Distribution Center, 202-512-6000. To receive facsimile copies of any of the daily listings of GAO documents released during the past 30 days, call 202-512-6000 using a touchtone phone. A recorded menu will provide information on how to obtain these listings.

REPORTS: (1) Nursing Homes: Complaint Investigation Processes Often Inadequate to Protect Residents GAO/HEHS-99-80, March 22; (2) Nursing Homes: Additional Steps Needed to Strengthen Enforcement of Federal Quality Standards GAO/HEHS-99-46, March 18; (3) Gulf War Illnesses: Procedural and Reporting Improvements Are Needed in DOD's Investigative Processes GAO/NSIAD-99-59, February 26.

TESTIMONY: (1) Nursing Homes: Stronger Complaint and Enforcement Practices Needed to Better Assure Adequate Care, by William J. Scanlon, Director of Health Financing and Public Health Issues, before the Senate Special Committee on Aging, GAO/T-HEHS-99-89, March 22.

14. NCD ANNUAL REPORT The National Council on Disability released its Annual Report to the President and Congress for Fiscal Year 1998. The report, which chronicles NCD's activities and accomplishments, is now available online at <<http://www.ncd.gov/publications/fy98report.html>>.

Report of April 14 Meeting:

1) Bedirhan Ustun (email: ustunt@who.ch) provided an update on the ICIDH-2 Revision and Plans for London Meeting. He presented alone, explaining that the ICIDH Children's Task Force meeting was going on. He announced that the ICIDH-2 Annual Revision Conference would take place April 22-24, 1999, in London. More than 75 participants are expected from 30 countries. The North American Collaborating Center (NACC) is sending 12 participants - 2 representatives, 2 observers, as well as U.S. Task Force members, and chairs.

On Tuesday, April 13, 1999 the WHO Cabinet, the governing body of the World Health Organization, approved the ICIDH-2 Revision process. It gave the ICIDH-2 a positive review and welcomed the initiative. It confirmed use of the concepts of Functioning and Disability, consideration of Body Functions and Structure, Activities, and Participation and examination of the Environment as a component. The WHO cabinet agreed to send specific letters of ICIDH-2 Revision support to Ministries of Health as well as to contact organizations such as the ILO, UNICEF, and UNESCO to promote common sharing of the ICIDH.

At the London meeting, Centers have been asked to provide concise presentations on salient points raised. There will be a review of the vision and conceptual basis of the revision process, followed by an examination of Environmental factors, Participation, Activities, Body Functions/Structure. There will be a structured presentation of the ICIDH Beta 2 and possible tests. Discussions of the general introduction, qualifiers, user guides, and the Beta 2 test will take place. After lunch, there will be a post-mortem of the meeting.

Bedirhan Ustun discussed ICIDH-2 improvements and highlights. A short version of the ICIDH-2, totaling 90 pages, now exists with 100 categories maximum per class. The categories exist at the two-digit level, making the document user friendly. The Beta 2 draft has uniform general qualifiers (which are the same throughout) for Impairment, Body Function, Participation, Activity and Environment. Additionally, blocks, interim categories, have been identified.

There are other issues for ICIDH to address. For instance, what will be second qualifiers?

How will the coding of cases take place, particularly when multiple cases may apply to the same person? Bedirhan Ustun welcomes suggestions on these topics.

The ICIDH introduction has been shortened. Originally 45 pages, it is now 18. Details are given. The problem of unwanted terminology has been addressed. ICIDH has moved away from use of the term consequences to functional states. It has also moved from use of the term disablement, using disability as an umbrella term.

The term function is always used at the body level. This is to reduce miscoding. There is a constant debate regarding body function. For example, is planning, talking, speaking or understanding a body function or an activity? The ICIDH tries to clarify differences by operational rules. Any functioning, including that of the body, participation, and activity, has multiple components.

The floor was opened to discussion. Paul Placek posed several questions: What parts of the Beta 2 document can be shared? Will the London meeting will provide a forum for changes in the document? Will there be another document after these deliberations? He also asked how other countries can join in the revision process and suggested that it might be useful to have the ILO present at an upcoming ISDS meeting. He wanted more information about the uniform general qualifier.

Ustun explained that the documents can be shared with colleagues and constituents with the understanding that it is in draft form and comments on it are sought. He expected there would be minor changes to the document. He did not envision a major overhaul, rather, that final touches would be put on it.

There is evidence that the classification is being well-received globally. As to the uniform qualifier, there is discussion about using + and - signs instead of decimal points. Centers will be asked to weigh in on this issue.

Frederica Barrow asked whether training will be provided at the end of the ICIDH Revision process. Ustun replied that training is taking place now and will also occur once the document is finalized. A major thrust of the Beta 2 Field Trials will focus on coding.

Ustun noted that ICIDH will have its fundraising meeting in the fall instead of June, when, it turns out, the WHO Cabinet will do fundraising. Twelve ICIDH Project Proposals have been developed and fundraising efforts will be discussed with the Collaborating Centers.

Gerry Hendershot wondered whether the document presented to the Cabinet could be shared and used for other purposes. The Cabinet documents are internal. When they are published, they will be placed on the Internet.

David Wasserman asked whether rules for the complex functions exist in the document. Information on Activity, Participation, and Body Functions exist in the document introduction

Mitch LaPlante suggested that disability refers to negative aspects of functioning. He wondered whether another way exists to describe that. Otherwise, he felt the conceptual scheme was appealing and exciting. Ustun explained that an umbrella term was needed. Ultimately, terms cannot be sanitized. Those with negative connotations remain. But, disability does not only connote negatives.

Ustun discussed the Universal Model of Disability - everyone may be disabled in some form or other. ICIDH is a functional state classification; it does not identify people with disabilities alone.

At the next ISDS meeting, Ustun will report on the London meeting.

2) Hugh Berry (email: hugh_berry@ed.gov) presented findings on the Supplemental Security Income Program and Employment for Young Adults with Disabilities from his analysis of the National Health Interview Survey on Disability (NHIS-D). He prefaced his remarks by noting the increasing numbers of individuals joining the SSI rolls and the importance of examining the employment outcomes of young people with disabilities.

Berry discussed the National Longitudinal Transition Survey (NLTS) on school to work issues. NLTS data were generated about 10 years ago, so its information is somewhat dated. He conducted his study as he recognized that not a lot is known at present about youth with disabilities

who participate in the SSI program. He turned to the 1994-1995 NHIS-D survey to describe SSI program participation and non-participation, to identify individual and environmental factors associated with employment outcomes, and to identify self-reported barriers and facilitators to employment.

For his study, the responses of SSI participants and non-participants with disabilities, aged 18-29 years, were examined. Non-participants were identified if they met any of the following criteria: 1) difficulty with one or more functional activities or ADLs, 2) used a wheelchair, 3) used a cane, crutches, or walker, 4) had a disabling mental or emotional condition, 5) reported a limitation in kind or amount of work or housework he or she could do, or 6) received SSDI or was covered by Medicare. This definition was adapted from one used by McNeil (1993) and later by Kruse (1997). Berry sought to compare young people with disabilities who were on SSI to those with disabilities who did not receive SSI benefits.

Variables included sociodemographic, disability, health, education, program participation, and employment characteristics. Analyzed health data consisted of self-reported health status, and short term hospital stays during the year. Level of education attained was reported. Program participation in such areas as SSI, SSDI, VR and food stamps was noted. Employment status, i.e., if the person had worked within the last two weeks or if they had worked within the last 12 months, was recorded. Barriers and facilitators to work were also identified.

Berry discussed highlights of his findings. Those with limited ADLs and IADLs were less likely to work. Additionally, self-reported health status appeared to be positively associated with employment status. Education played a critical role in employment outcomes for both SSI and non-SSI beneficiaries. The odds of achieving employment appeared to be greater for those who remained in school. SSI participants were less likely to complete school and were less likely to work than the non-participants.

The median income of SSI recipients was \$500 a month which happened to equal the level of substantial gainful activity (SGA). Non-SSI beneficiaries who were working had a median income of \$800 a month, substantially higher than their SSI counterparts.

For those SSI recipients who received vocational rehabilitation services, participation in the vocational rehabilitation system did not appear to have significant impact on their employment outcomes. Berry noted that this finding should be considered in the context of other research regarding the VR program and that there is a clear need for additional research in this area.

Berry spoke of employment barriers and facilitators. This descriptive information needs to be approached with caution. He noted the limited sample size of both SSI and non-SSI participants and the number of barriers reported. Participants identified several barriers to employment including: the lack of appropriate jobs (which may be interpreted in many different ways), the lack of transportation, family responsibilities, and potential loss of benefits. Facilitators identified included: personal assistance services, reduced work hours, and accommodations. The findings and conclusions of the study raised issues related to health, education, and disability policy.

Berry fielded questions. He was asked about the availability of the report. For those seeking the full report, it will be available within the next month. Contact Berry directly at: hugh_berry@ed.gov to receive a copy. A shorter publication will be released as well.

Richard Home asked whether the study addressed special education under the Individuals with Disabilities Education Act (IDEA). NHIS-D focused on a transition aged population, those 18-21, which resulted in a very small sample size. Research Triangle Institute (RTI) is examining the special education population via a VR longitudinal study. One interim report addressing special education and VR was already released and there are tentative plans for another report that should focus on transitioning youth.

Judy Holt mentioned that a second National Longitudinal Transition Survey will be conducted in the near future. The Office of Special Education Programs (OSEP) will welcome input on this effort.

Aaron Prero asked if sheltered employment was an outcome considered. Berry explained

that the NHIS-D included information regarding sheltered employment, but these data were not analyzed within his study. Within the logistic regression model, the dichotomous dependent variable was whether the person had worked in the last two weeks.

David Wasserman asked about the facilitators. He wondered whether there was any discussion of the ADA, reasonable accommodations, or anti-discrimination legislation. Issues considered included if people needed: technical devices to go to work, Braille, large print, readers or interpreters, job coaches, PAS, special pens, pencils, chairs, job redesign, reduced work hours, reduced or part time work hours, or other arrangements.

Barbara Wenger sought comparative data, including information on the age that individuals acquired their disabilities. Berry replied that this was beyond the scope of his work. The NHIS-D, however, does address such issues.

Don Lollar asked if these findings have been shared with RSA. Berry replied that the findings were discussed with RSA staff. Using NHIS-D, RSA is also looking at what services may be most effective and areas of unmet need. Berry noted that in his study, a single question on VR is not enough to evaluate the effectiveness of the entire program. He commented that other sources of data (e.g., the RSA 911 Database) are available on specific VR services and outcomes. Study findings must be considered in this context.

3) Don Lollar (email: dcl5@cdc.gov) discussed the status of "Healthy People 2010" and efforts to include health promotion objectives for persons with disabilities both within a specific chapter and throughout the report. NIDRR has been involved in this process and in particular he noted David Keer's assistance. HHS will have an opportunity to comment on the draft document; Dr. Satcher will add final touches. The document is scheduled to go to the printer in July. The report will be unveiled in January 2000.

The HP 2010 draft document ensures that objectives on general health cover persons with disabilities as a select population. Other objectives, in such areas as Cancer and Health Education will specifically address the needs of persons with disabilities. Lisa Sinclair has worked on HP 2010. For a draft copy of the report, contact either Lollar (email: dcl5@cdc.gov) or her (email: lvs4@cdc.gov).

The Chapter which focuses specifically on persons with disabilities may go through more revisions. It recommends that all data sets objectively identify persons with disabilities in all surveillance tools identified throughout the report. It addresses emotional support of children and adults, partnership in social activities, the inclusion of special education, parity of employment rates for persons with disabilities, and the elimination of health disparities. It promotes the social model of disability, recommends that health and other programs comply with the ADA, discusses assistive technology use by self report and addresses environmental barriers. Public health and disability programs are promoted in all 50 states for persons with disabilities and their caregivers. This represents a 5 to 10 year agenda. Lollar suggested that a conference may be held to focus on the importance of these issues.

Paul Placek asked about the recommendation on identifying persons with disabilities in all surveillance tools. He wondered if the HHS Data Council is implementing this, or if it will start implementation after the objectives are approved. Lollar noted that these issues would be brought to the Data Council's attention. He was uncertain where the Data Council would fit in. If 2010 Objectives are accepted, future data activities would be required.

Gerry Hendershot inquired as to how many of the 13 disability related objectives were supported by data systems. Lollar replied that 10 of the 13 Objectives are data driven. The other three, covering the ADA, the Environment, and Assistive Technology, are developmental in nature.

Gerry Hendershot asked about the objectives in other chapters that relate to disability: how many data systems would be affected? Lollar explained that there are thirty-one datasets where ODPHP would like to involve persons with disabilities on surveillance activities. Hendershot wanted to know if there was a strategy for the implementation of disability data systems. Lollar replied that his office was forwarding these suggestions gently, assuming that other offices will comply unless they say

something to the contrary.

Announcements (April 14 Meeting)

1. IOM WORKSHOP On May 27-28, there will be an IOM Workshop on Measurement of Work Disability: Challenges for Survey Design and Method at 2001 Wisconsin Ave, NW, Wash, DC for further information contact Gooloo Wunderlich <gwunderl@nas.edu>.

2. NATIONAL INFORMATION CENTER ON PHYSICAL ACTIVITY The Centers for Disease Control and Prevention announced the April 1, 1999, \$750,000 award for the National Information Center on Physical Activity for Persons with Disabilities to the University of Illinois at Chicago. The National Information Center is charged with providing best practices data on physical activities for this target population. For more information on the new Center, contact: Dr. Jim Rimmer (email: jrimmer@uic.edu), telephone: 312-413-9651.

3. ACCESS ISDS MINUTES ON THE WEB For minutes of past ISDS meetings, turn to the NIDRR-funded National Center on the Dissemination of Disability Research (NCDRR) Web site: <<http://www.nccdr.org/icdr/isds>>.

Report of May 12 Meeting:

1. Bedirhan Ustun (email: USTUNT@WHO.CH) reported on the April 22-24, 1999, London meeting on the ICIDH-2 revision process. It was hosted by the National Health Service Centre for Coding and Classification of the United Kingdom. Those in attendance included representatives from the seven WHO Collaborating Centers (North America, Australia, France, Japan, the Netherlands, the Nordic Center, and United Kingdom), the three Task Forces (Mental Health, Children, Youth and Disabilities, and Environmental), UN agencies, countries from all WHO Regions, Non-Governmental Organizations, the newly formed Spanish-speaking network, the WHO secretariat and observers. Eighty people participated; the meeting chairs were Ann Harding and Marijke de Kleijn.

Ustun described the goal of the London meeting as a means for creating a common language on classification. The ICIDH-2 is now identified as the International Classification of Functioning and Disability. It recognizes the interaction of such concepts as health condition with such domains as Body Function, Activities, and Participation. Environmental and Personal Factors are included in this schema.

Ustun discussed the changes that have taken place between ICIDH-1 and ICIDH-2. A conceptual transformation has taken place in this process. ICIDH-2 meets user needs, takes advocacy and applies it to science needs. ICIDH-2 will be used in a summary health measure to help inform policy in evidence-based practice. The ICIDH-2 views causality as a multilinear web, allowing users to explore functioning and disability in different ways.

Issues that could contribute to polarization were discussed at the London meeting. Instead of distinguishing between a medical or a social model, there were attempts to synthesize these models. There was recognition that global, international classifications may not fit all local needs. Cultural applicability needs to be respected. Debate took place on the universal model, the idea that functioning and disability involve everyone. The meeting also addressed the issue of how to classify and differentiate between activities and participation.

The domains of body functions and structures were generally found to be acceptable to the assembled group. A suggestion was forwarded that more weight be given to Impairments and medical conditions with more precise formulations.

The definition of Activity was explored. The original definition was: activity is the nature and extent of performance of a function at the person level. Suggested changes included: delete "function," add task or action, delete "nature and extent." Activities cover changes to terms and conditions. Activities include such things as acquiring a place to live, acquiring daily necessities, caring for possessions, and assisting others.

The concept of Participation, its definition and terms, were considered satisfactory by the

group. Suggestions were provided on the interpretation of the concept "involvement in."

The London meeting addressed Environmental Factors, viewing them as integral components in the classification system. Two level categories were accepted. Discussion took place about organizing categories.

Functioning and Disability are seen as a Spectrum in ICDH-2. Or, the system may be seen as a multidimensional construct. Activity and Participation may be viewed in either positive or negative terms. When negative, it is possible to learn from examples, identify facilitators, create awareness and implement research and development. Functioning and content include the interaction between the person and the environment on societal, individual, and body levels.

The London meeting presented coding cases to assist participants in using the classification. The Uniform Qualifier, using + and decimal points (for negative values), was accepted. Its feasibility of use in different setting will be tested. Efforts will be made to identify any possible gaps or alternate ways of classifying specific sections. Testing the reliability of coding in different settings will occur. Questions related to validity will be addressed.

Recommended Beta 2 Field Trial Tests will include: translation and linguistic evaluation, basic questions on feasibility and reliability in evaluation, feasibility and reliability in case summary (using vignettes and popular movies such as "Forrest Gump" and "My Left Foot") and coding with questions. Optional Beta 2 Field Trials will include: application in record reviews, in surveys and in predictive validity. Other possibilities consist of utility for intervention planning and option tests for comparison with national classifications.

Field Trial development of protocols involve what questions need to be answered and what ought to be done with the answer. Methodological concerns cover how the question is to be addressed: is it scientifically robust or feasible to carry out? Implementation will take place internationally. Resources that need to be taken into account include the required human resources, time and cost effectiveness. Ustun concluded his formal presentation by citing the development of the short revision of the Beta 2 document with its less than 99 specific categories per dimension.

Paul Placek, who attended the meeting as an NACC representative, noted that the revision process is on track. He mentioned Rachel Hurst's recommendation that people with disabilities or their organizations should be involved in the process. That occurred at the London meeting. He wanted more discussion of Field Trials, especially the coding of Census and Survey data. He explained that the NACC is working with the United Nations DISTAT.

He sought information on ICDH fundraising projects. Ustun mentioned that a Fall fundraising meeting will take place. Fundraising will occur as a network activity. Researchers will develop proposals which will be marketed as part of the international network. Twelve to fourteen proposals are being floated at present, a number of them look promising.

Neal Nair asked about indicators for rehabilitation potential, recognizing the complex dynamics of rehabilitation. Ustun replied that the ICDH can be used for intervention matching.

John Hough wondered about universality and how these changes have been implemented. The concept of universality is firmly entrenched in ICDH-2. Disability is a universal human experience. It is a continuous, not a categorical variable. WHO has rejected the minority model.

Andrew Houtenville questioned whether rehabilitation, particularly access to services, would be considered in a medical or social context. Ustun indicated that the ICDH can be used to identify the context when considering access to services.

Cille Kennedy addressed the Spanish language network which included members from Central, South America, and Spain. The network has developed a universal Spanish translation of Beta 2 and conducted outreach to PAHO database users. Spain has offered to host the next ICDH-2 Meeting. Ustun mentioned that Australia has also offered to host the meeting at the Paralympics. No decision has been reached yet on where it will be held.

A questioner requested information on how to obtain manuals and their cost. Ustun explained that the ICDH manuals are being updated and will be available by May 30. WHO's informa-

tion on the ICIDH is located at this Website address: <<http://www.who.int/msa/mnh/ems/icidh/index.htm>>. An earlier version of the document is available for thirty Swiss Francs.

Don Lollar, who attended the London meeting, felt that the ICIDH revision process has come a long way. Environmental Factors have become a stable and important addition. Questions raised in the meeting involved conceptual models and need to be addressed.

David Gray discussed some of the issues raised in the London Meeting. He believed it is difficult to separate activity from participation. He also wondered about how to add the Environment to the classification scheme. The Australian Center is testing participation. The Japanese are measuring satisfaction with participation. WHO is entertaining the subjective approach on satisfaction/quality of life issues raised by the Japanese Center.

David Gray worried that Participation was described in the London meeting as being couched in terms of the inability to participate (by using a negative scale of Participation). Ustun disagreed with this assessment. Participation restrictions are defined as external hindrances, barriers. The ICIDH language was selected in a specific way. Ustun explained there are controversies among different centers and testing will occur in light of these differences.

2. Cyndi Jones (cjones@accessiblesociety.org) reported on the Accessible Society Action Project (ASAP!), a plan to help get disability and independent living research results more widely known. NIDRR has funded ASAP! to place such information in the mass media. The New York Times, the Wall Street Journal, major TV media and national news outlets, viewed as the agenda setting media are the audience that ASAP! wants to reach.

Jones noted that most people obtain information from the popular mass media. ASAP! analyzed disability issues and recognized that NIDRR funded research needs to be placed on the national radar screen. It was found that in the last four years, NIDRR was mentioned seven times in the national agenda setting media. Six out of the seven times the University Affiliated Programs (UAPs) were identified. That may mean that the UAPs are a good mechanism through which to approach the media.

ASAP! seeks to shift focus to the new paradigm of disability. The paradigm recognizes that disability is a product of the interaction between the persons and the environment. It seeks to enhance understanding of independent living and disability research.

ASAP! will act as a contact or conduit to the media on NIDRR-funded and related research. It is pulling together experts in the field who can act as spokespersons to the media. When reporters need authoritative sources, they go to those whom they can find. ASAP! seeks to provide the media with a cadre of informed advocates and researchers who can speak to national regional or local issues in a timely fashion. Media training to prepare spokespersons is planned.

ASAP! will work towards the active placement of stories in the media. It will also respond to stories generated in the media through letters to the editor and Op Ed pieces.

ASAP! will conduct editorial board meetings on the East Coast. Its staff, which includes Bill Stothers, Mary Johnson, and Cyndi Jones, have long established roots in the disability world and in the media.

Jones noted that many disability stories that appear in the popular press lack context. ASAP! will work to create context for stories on disability and independent living research.

ASAP! has a Website <www.accessiblesociety.org>. It is designed for use by the working press and is intended to present disability research in a helpful forum. The Web site is developing links to useful, well-organized, up to date sites. ASAP! wants its Web site to be easy to navigate for its audience. Each year ASAP! will focus on different issues. This year, the emphasis is on PAS and Employment Issues (in part due to the Presidential Task Force on Employment of Persons with Disabilities). The project is making an effort not to be spread too thin. For additional information, contact Cyndi Jones at email: cjones@accessiblesociety.org or by telephone: 619-232-2727, ext. 111).

Paul Placek wondered if the ICIDH is too technical a story for the popular press to cover. Jones explained that perhaps everyone does not need to know how the ICIDH system works, but

rather they need to know its implications.

Don Lollar commended ASAP! for its work. He has looked at the Website and suggested that the definition of disability used is somewhat confused. It is possible that use of the ICIDH construct would assist in clarifying the definition. He looked forward to a time when the Web site would allow for interactive comments. Jones noted that it would be possible to include information on ICIDH-2 in the ASAP! Website. The Website, now up and running, will be interactive in the future with chat rooms.

Gerry Hendershot asked whether it was typical in the agenda setting media for one reporter to be assigned to cover stories on disability. Jones replied that no beat reporters cover disability. Generally, it is inexperienced staff who write the disability stories. Disability issues need a critical mass of reporters who write stories and become moved to address related issues. ASAP! seeks to work with economic, education, sports, etc. beat reporters to cover disability broadly.

Paul Placek noted that David Gray and Patricia Welsh have written a paper on Consumer vs. Professional Perspectives on the ICIDH. It might be a useful resource to ASAP. Jones said she would be in touch with them on their work. He asked whether ASAP! would list correct terminology to use when discussing disability on its Web site, since the media often uses improper language. ASAP! is not turning to its Web site as this kind of resource. Rather, it is modeling appropriate language. If media people use improper terminology, they are corrected through interactions with ASAP! staff or spokespersons.

David Keer asked about outreach to national organizations that are often resources used by the national media and outreach to free lancers. ASAP! is conducting initial outreach to staff reporters. Later on, outreach to free lancers will take place.

Neal Nair requested additional information on the methods ASAP! is using to impart information to the media. They include the web site, press releases, meetings, and follow up phone calls as well as promotion of articles on disability related issues.

Don Lollar asked about workshops for researchers that could help make ASAPs! job easier. Jones agreed that the need exists to make researchers more responsive to the media. He also offered to provide information on Healthy People 2010 Objectives as a source of information for the media. Health and Wellness is on the ASAP agenda in the future.

David Gray asked if events at the Society on Disability Studies would be newsworthy. Jones felt something like that was hard to predict prior to an event. She emphasized the importance that initial contacts with the media need to be successful. He felt that input by persons with disabilities on policy issues such as funding would be worthwhile.

Gerry Hendershot wondered if the project is working with schools of journalism. Jones replied that ASAP! is working with the Society for Professional Journalists as well as working with educators of future journalists. She also wants to see internships in the mass media for students with disabilities seeking journalism careers. Such young people could be ambassadors in the future.

Announcements (May 12 Meeting)

1. **DISABILITY GRAPHICS** Here is a site where you can copy all kinds of graphics on disability: <<http://www.visi.com/~pjlareau/disgraph.html>>.

2. For copies of past ISDS minutes, corrections, or revisions to the ISDS mailing list: Carolyn Ward at Conwal Incorporated, 6858 Old Dominion Drive, Suite 200, McLean, VA 22101, tel: 703-448-2300, tt: 703-448-3079, fax: 703-448-3087, Email: <CWARDCON@AOL.COM>.