

Minutes of the Interagency Subcommittee on Disability Statistics

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Report of June 9, 1999 Meeting:

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1) Gooloo Wunderlich (email: GWUNDERL@NAS.EDU) reported on the Institute of Medicine (IOM), National Academy of Sciences' (NAS) Workshop on Measurement of Work Disability: Challenges for Survey Design and Method, held May 27-28, 1999. The National Academy of Sciences' Committee to Review the Social Security Administration's (SSA) Disability Decision Process Research invited a number of experts to convene this workshop. Its purpose was to provide a focused exchange between disability researchers and survey methodologists for identifying unanswered questions relating to measurement of work disability and to provide a framework for a research agenda in this area.

The workshop objectives were 1) to better understand the conceptual issues that relate to the existing measures of work disability as well as to provide answers to questions about measurement errors, and the essential survey conditions which impact the measurement of disability; 2) to aid the committee in advising SSA on methods for measuring work disability in the Disability Evaluation Study (DES), and on ways to facilitate cross-walks between the DES and data collected in other federal household surveys to monitor the size of the pool of persons eligible for benefits under SSA's programs; 3) to develop a research agenda for SSA with respect to survey design and measurement of work disability.

The workshop was open to the public. Two background papers were commissioned: one on conceptual measures and issues, written by Elizabeth Badley and Alan Jette; the other on survey measures by Nancy Mathiowetz. An interactive panel approach was adopted with discussion leaders and discussants.

The opening session provided an overview of the background papers. Session II covered the implications of different concepts for survey measurement problems. Session III focused on sampling, accessing, and measuring people with disabilities. Session IV examined questionnaire development issues for measures of work disability. Session V considered the role of environment in survey measurement of disability; the final session involved defining a research agenda.

Conference proceedings will be published in the next few months and will include the background papers. In response to a question, she stated that copies of the draft background papers can be read or obtained at the NAS Public Access Records Office at (202) 334-3543.

Gooloo Wunderlich responded to questions regarding next steps after the conference, the possible development of new definitions of disability and their relationship to current statutory requirements outlined in laws such as the Rehabilitation Act, and opportunities for collaboration (by organizations such as WHO and those involved in the ICIDH-2 revision process) on this initiative. She explained that the workshop was a single effort with the goal of providing the Committee to Review the Social Security Administration's (SSA) Disability Decision Process Research with broad perspectives. As to possible new statutory definitions, this is beyond the scope of the NAS contract. The NAS is mandated to focus on research related to the SSA's redesign of the disability decision process and the development of the disability survey. She also noted that several individuals involved in the ICIDH-2 revision process were presenters or participants in the meeting.

2) Diane Wagener (email: DKW1@CDC.GOV) presented on summary measures of population health: construction, problems and prospects. She explained that in the goals that are being outlined in the Surgeon General's report, "Healthy People 2010," there is an emphasis on increasing

the quality and years of healthy life for all people. It is therefore important to look at a range of summary measures.

When considering summary measures and which ones to use, a number of factors need to be taken into account. Several questions must be addressed: 1) What questions does one want to answer? 2) What data are available or can be developed? 3) How does one plan to change the population's health? 4) Will the summary measures change? Why?

NCHS's approach has consisted of evaluating the behavior of a set of measures over the past twenty years, determining data needs, developing data collection mechanisms, and evaluating behavior over several years.

Wagener explained that summary measures integrate mortality or morbidity data. They may be general or specific. Such measures tend to be preferred in populations with low mortality and high morbidity rates, such as in the United States.

Summary measures are used for a variety of purposes. They monitor the health of a population over time. They summarize group differences and evaluate the use of resources. Such measures track the process of health change and can measure performance. Diseases, conditions, impairments, functioning loss, disability, and death are the potential health changes for the individual that can be measured.

Two broad types of summary measures exist: 1) health expectancy; 2) potential health loss (disability adjusted life years - DALYs). They differ in several ways. Health expectancy is not dependent on population composition whereas potential health loss generally, though not necessarily, is. The data collection burden is less for health expectancy than for potential health loss. It is unclear whether health expectancy is responsive to rapid change while it appears that potential health loss probably is. When adding multiple states or multiple conditions, potential health loss tends to be additive while health expectancy tends to be complex. In terms of public comprehension, health expectancy is stated in terms of years per individual, whereas potential health loss is stated in terms of total years for a population. The public may respond more personally to the former measure.

Health expectancy and potential health loss share some similarities. Both are complex. Therefore, understanding the underlying health experience of the population when a change is noted in the summary measure, and in fact when NO change is noted, can be complicated. When trying to combine states or dimensions in summary measures, a need exists to develop weights and to include evaluative judgments. Healthy People 2010 tries to look at and compare a range of measures.

The floor was opened to questions and discussion. Paul Placek noted that NCHS has looked at summary measures in response to Healthy People 2010. The agency has not embraced these measures generally. He spoke of WHO's keen interest in summary health measures. Wagener agreed with this assessment, but commented that summary measures were important statistics to understand.

John Hough remarked that intensive data collection efforts are needed for potential health loss measures. Bedirhan Ustun agreed that DALYs are heavily data driven. He felt that DALYs seem more sensitive to change. Disability has not been well studied and that gap needs to be addressed.

Neal Nair asked about the expectation of life at different ages. These issues are addressed in the "Healthy People" series of reports.

Dave Moriarty spoke of working on a health expectancy approach based on the Behavioral Risk Factors Survey System (BRFSS) where self reports are provided on perceived physical and mental health status over a 30 day period. Wagener felt that potential health loss measures and health expectancy are not strictly complementary. These summary measures are currently under development.

3) Tom Hale (email: HALE_T@BLS.GOV) presented on the Bureau of Labor Statistics (BLS) and measurement of disability. Three years ago, BLS was approached by the PCEPD and EEOC to look at the employment of people with disabilities. Based on these discussions, two questions were added to the Survey of Income and Program Participation (SIPP) to gain a summary measure on people with disabilities. The questions did a poor job of identifying people with moderate

disabilities.

On March 13, 1998, the Presidential Task Force on Employment of Adults with Disabilities was created. Its purpose is to create a coordinated and aggressive national policy to bring adults with disabilities into gainful employment at a rate that is as close as possible to that of the general adult population. That mandate required valid and reliable employment data on adults with disabilities. Such information was not available in either the SIPP or the Current Population Survey (CPS).

Under the auspices of the Presidential Task Force, an Employment Rate Methodology Work Group was formed. It has explored such issues as: 1) what definition of disability ought to be used? (Should and could the new or old paradigm of disability be used?) 2) who would be using the data and how would such numbers be used? 3) do questions exist that have been tested for reliability and validity? Information on reliability and validity testing is being collected and will be disseminated to the Work Group and other interested parties upon request.

When comparing people with moderate disabilities to their non-disabled counterparts, income differentials are obvious. Otherwise, these populations are similar. The sharpest differences appear between those with severe disabilities and those who are able-bodied.

BLS is developing an annotated bibliography on disability measures and their record of reliability and validity testing. This material will be distributed to the Methodology Work Group on July 2. The group will consider: 1) which disability measures it ought to pursue; 2) whether a summary measure will be made part of the CPS; 3) whether a supplement to the CPS is possible.

Neal Nair asked about the 1994 CPS and its disability questions. Hale explained that currently, the CPS focuses on the numbers of employed persons, the numbers of unemployed persons, and discouraged workers (those who have stopped seeking employment). Disability responses are mixed with a set of non-mutually exclusive responses for those not in the labor force.

A questioner from San Francisco asked about "ability to work" as a measure of disability. Has the work group taken pains not to use that as a measure of disability? Hale replied that using work disability as a definition of disability causes confounding problems. There are difficulties in defining disability in terms of work status and BLS feels very strongly that this should not be the definition used in a labor force survey.

Hale welcomed information on disability measures, survey information, or other relevant materials that would assist the Work Group in its task. Please email him at <Hale_T@BLS.GOV>.
ANNOUNCEMENTS (June 9, 1999 Meeting)

1. NATIONAL CONFERENCE: The 14th National Conference on Chronic Disease Prevention and Control will be held at the Adams's Mark Hotel in Dallas, Texas from November 30 - December 2, 1999. Topics include: public health advocacy, chronic disease emerging issues, training and infrastructure development, building successful partnerships, reaching diverse populations, intervention research and best practices, and using and communicating data.

2. 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.ncddr.org/icdr/isds>>.

3. GAO REPORTS: The General Accounting Office (GAO) just released the following reports: Food Stamp Program: Relatively Few Improper Benefits Provided to Individuals in Long-Term Care Facilities GAO/RCED-99-151, June 4; Adults With Severe Disabilities: Federal and State Approaches for Personal Care and Other Services GAO/HEHS-99-101, May 14; Year 2000 Computing Crisis: Actions Needed to Ensure Continued Delivery of Veterans Benefits and Health Care Services GAO/AIMD-99-190R, June 11; Equal Employment Opportunity: Data Shortcomings Hinder Assessment of Conflicts in the Federal Workplace. GGD-99-75, May 4, 1999; Medicare Home Health Agencies: Closures Continue, With Little Evidence Beneficiary Access Is Impaired. HEHS-99-120, May 26, 1999; SSI Children: Multiple Factors Affect Families' Costs for Disability-Related Services. HEHS-99-99, June 28, 1999; Supplemental Security Income: Progress Made in Implementing Welfare Reform Changes; More Action Needed. HEHS-99-103, June 28, 1999. The 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>. GAO's Document Distribution Center, 202-512-6000.

4. FALL '99 VVALEO INITIATIVE MEETING: The VValeo Initiative is a national effort to conceive and implement an organization capable of providing all individuals with access to the information, services and resources necessary for them to achieve optimal health. It will be equitably and collaboratively conceived, owned, and governed by all health-related stakeholders, including individuals, health care providers, insurers, purchasers, employers, and other relevant groups.

VValeo is taken from the Latin "valeo," which roughly translated means "to obtain a state of wellness." (The double "V" spelling is being used until trademark issues are resolved.) The Initiative's intent is to help every individual achieve this state of optimal health.

A Fall meeting will introduce VValeo to a broader group of potential participants (including consumers) and will engage them in the process of creating a transcendent, trusted organization. The agenda will initiate the process of creating a clear statement of purpose, developing shared principles, and planning for the next phases of organizational development.

For additional Information, contact Rob Kolodner (email: robkolodner@hq.med.va.gov).

5. AGING CONFERENCE: PROMOTING INDEPENDENCE AND QUALITY OF LIFE FOR OLDER PERSONS, An International Conference on Aging, December 2 - 4, 1999, Hyatt Regency Crystal City, Arlington, VA; Sponsored by: Rehabilitation Engineering Research Center on Aging; American Society on Aging; RESNA (Rehabilitation Engineering and Assistive Technology Society of North America).

CONFERENCE PARTICIPANTS WILL: Hear recent research on issues related to aging and independence, including assistive technology, aging with a disability, housing and home modifications, tele-rehabilitation, employment, transportation, injury prevention, and aging with mental retardation. Analyze and discuss current problems with service provision and information dissemination for older persons with disabilities and their caregivers. Provide input in the drafting of policy statements relative to service provision and information dissemination for older persons and their caregivers. FOR FURTHER INFORMATION: Shari A. Wilson, Conference Coordinator, RERC on Aging, State University of N Y at Buffalo, 3435 Main Street, 515 Kimball Tower, Buffalo, NY 14214; email <swilson@buffalo.edu>; (800) 628-2281.

7. HEALTH STATISTICS CONFERENCE: There were two sessions on Disability at the National Conference on Health Statistics at the Omni Shoreham Hotel in Washington, DC: "Measuring Dimensions of Disablement" and it includes presentations by Allen Meyers, Susan Kinne, Eleanor Locklin, John Hough, Matthew Janicki, and David Keer; and "Improving Disability Data: ICIDH-2 Revision Activities in North America" and it includes presentations by Paul Placek, Holly Fedeyko, Rune Simeonsson, Janey Sturtz McMillen, Patricia Welch, and Ana Maria Murgueytio.