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Office of Disability, Aging and Long-Term Care Policy



OPPORTUNITIES TO IMPROVE SURVEY MEASURES OF LATE-LIFE DISABILITY:

PART I--WORKSHOP OVERVIEW

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OPPORTUNITIES TO IMPROVE SURVEY MEASURES OF LATE-LIFE DISABILITY: Part I--Workshop Overview

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INTRODUCTION

Measurement of late-life disability is of interest to policy makers and researchers alike. Valid and reliable measures are necessary to track programmatic eligibility for public health insurance programs such as Medicare and Medicaid and income security programs such as Social Security and Supplemental Security Income. Disability measures are also crucial to accurately projecting the demand for long-term care, to produce actuarial estimates for long-term care insurance, and to understand who is afforded protection under the American with Disabilities Act. Such measures also allow researchers to evaluate the quality of life of older individuals, to understand the causes and consequences of disability in late-life, and to understand the broader public health and policy implications of population aging.

Current measures of late-life disability vary across national surveys. At the same time, most surveys include some version of activities of daily living (ADLs) (Katz 1965, 1970), instrumental activities of daily living (IADLs) (Lawton and Brody 1969), and functional limitations (Nagi 1965, 1991). These measures were initially developed for various clinical purposes during the 1960s and 1970s, and became widely adopted as self-reported items in national surveys during the 1980s and 1990s. Surveys that have maintained identical question wording from year to year have been able to provide two decades worth of evidence on trends in the prevalence of late-life disability (Manton and Gu 2001; Schoeni et al. *in press*). In addition, panel surveys have provided important insights into disability trajectories, including recovery and decline, and hierarchical patterns (Crimmins and Saito 1993; Dunlop et al. 1997; Mor et al. 1994).

Recent advances in conceptual thinking and measurement of disability provide new opportunities for national surveys to expand upon the array of scientific and policy questions that may be answered with survey data. For example, the addition of vignettes could facilitate comparisons of disability measures across groups and countries with different conceptual understandings of disability (Kapteyn et al. 2004). Moreover, the addition of measures of physical functioning (including performance measures), of assistive technology and the environment, and in time use and participation by older adults would allow analysts to more fully understand the reasons for population-level changes in disability prevalence. Currently, it remains unclear, for example, to what extent changes in disability that occurred during the 1990s reflect changes in underlying functioning, changes in the physical environment of older adults, or shifts in the use of assistive technology (Freedman et al. 2003). Similarly, it remains unclear if declines in IADLs reflect changes in underlying functioning, the physical environment, or changes in the nature of the tasks as a result of technological conveniences (Spillman 2004). Improved measures of the components of disability would also further understanding at the individual level of the physiology of functional loss and recovery (Guralnik et al. 1989), the accommodation process (including use of assistive technologies, personal care and behavioral changes; see Agree 1999), and interventions to enhance independence and participation (Freedman et al. 2005).

Although measurement of work disability has recently been explored by a Committee of the Institute of Medicine (Mathiowetz and Wunderlich 2003), recent advances in the measurement of late-life disability have not been systematically reviewed. To address this gap, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the Department of Health and Human Services (HHS) convened a workshop in May 2005 to bring together disability measurement and policy experts to re-think measurement issues around late-life disability in light of national survey efforts. Specifically, the meeting will seek to address two questions:

- Are our current measures of late-life disability meeting the needs of researchers and policy makers?
- How can we improve measures of late-life disability within our current surveys?

This issue brief provides background information on issues that will be raised at the workshop. We include a brief review of disability measurement issues and offer a framework for thinking about disability measurement that will shape the workshop panels and presentations.

EXISTING DISABILITY MEASURES

National surveys most often include variations in three sets of disability measures: ADLs, IADLs, and functional limitations. Each of these measures was developed for clinical purposes and originally intended to be filled out by a professional evaluating an older person's capabilities. For example, Katz (1963, 1970) developed the original ADL index to assess the rehabilitation potential of hospitalized geriatric patients. The index was to be assessed by means of a series of questions and observations of the patient's ADL status during the previous two weeks. The observer determined whether another person assisted the patient (through supervision, direction, or personal assistance) or whether the patient functioned alone. The original IADL scale, developed by Lawton and Brody (1969), was intended to facilitate communication about clients' everyday functional competence among different personnel and agencies involved in treatment plans. They proposed "representative" activities for consideration: women were to be evaluated by their ability to shop, cook, and do laundry whereas men were to be evaluated by their performance in transportation and handling money. The original functional limitation items developed by Nagi (1965) were used to identify social security disability applicants who had the potential for rehabilitation. The instructions directed a team of medical evaluators to assess and the applicant to self-assess his or her maximum capacity and the physical requirements for the applicant's job (both using a numeric scale from 0 for "No Ability" to 7 for "No Restriction").

The extent of variation across national surveys in ADL and IADL items has been previously noted (Cornman et al. *in press*; Freedman et al. 2004; Gregory 2004; Rodgers and Miller 1997; Wiener et al. 1990). Here we illustrate the point in Table 1 with a summary of ADL and IADL questions, respectively, for 9 current national surveys (see detailed questions provided in Appendix Table 1 and Table 2).

For ADLs, some surveys ask about difficulty and the use of help and assistive devices; others ask only a subset of these concepts. Most surveys ask about difficulty (or in one case a "problem") with daily activities, but only three surveys explicitly refer to difficulty *without help or equipment*. Most surveys ask about help, but one asks about needing help, another about help in the last week, and another about help in the last month. Two surveys ask about both hands-on help and supervision. Questions about the use of equipment also vary widely, with some surveys asking about equipment use in the series of ADL questions and other surveys asking about it separately. The number of ADL activities mentioned in the surveys varies from three to nine.

With respect to IADL activities, similar variation is evident. Five of the nine surveys ask about both difficulty and help with IADLs; however, language around the reason for the difficulty/need for help varies (e.g., because of a health or memory problem; because of a health or physical problem; because of a physical or mental health condition) as does the number of activities mentioned (ranging from two to ten).

A similar kind of variation is evident across national surveys in functional limitation items. These questions generally taking one of two forms, described elsewhere as “neutral” and “leading” (Freedman, Aykan, and Kleban 2003): does the older person have *any* difficulty carrying out basic body movements and *how much* difficulty does the older person have carrying out basic body movements? Physical tasks vary but generally include both upper (reaching up, reaching out, grasping) and lower (bending, lifting and carrying, climbing stairs) body movements.

Other common items included in national surveys to assess late-life disability include measures of work disability (for details see Mathiowetz and Wunderlich 2003), sensory impairments (e.g., difficulty with vision or hearing), and self-reports or tests of cognition (Herzog and Rodgers 1999). More recently surveys have begun to ask about difficulty with valued activities. For example, the National Health and Nutrition Examination Survey (NHANES) and National Health Interview Survey (NHIS) ask about the amount of difficulty with leisure activities such as: going out to things like shopping, movies, or sporting events; participating in social activities [visiting friends, attending clubs or meetings or going to parties]; and doing things to relax at home or for leisure [reading, watching TV, sewing, listening to music].

TABLE 1. Measures of Activities of Daily Living in Selected Nursing Surveys							
Survey	ADL Items				IADL Items		
	Difficulty	Help	Equipment	Number of ADLs Mentioned	Difficulty	Help	Number of IADLs Mentioned
American Community Survey (ACS); 1999 and later	X			3	X ⁹		2
Health and Retirement Study (HRS); 1995 and later	X	X (if difficulty)	X ⁷	6	X ¹⁰	X (if difficulty)	7
Medicare Current Beneficiary Survey (MCBS); 1992 and later (Community sample)	X ¹	X (if difficulty) ³	X (if difficulty)	6	X ¹¹	X (if difficulty)	6
Medical Expenditure Panel Survey (MEPS-Long Term Care Supplement); 1997 and later		X ^{3,4}	X ⁸	5		X ^{3,12}	7
National Health and Nutrition Examination Survey (NHANES); 1999-2000	X ¹		X ⁸	5	X ⁹		3
National Health Interview Survey (NHIS); 1997 and later		X ⁵	X ⁸	6		X ^{5,9}	4
National Long Term Care Survey (NLTC); 1982 and later (Community sample)	X ²			9	X ¹³		
Screener:							7
Community interview:		X ^{3,6,14}	X ⁶	6		X ¹⁴	10
Survey of Income and Program Participation (SIPP); 1991 and later	X ¹⁶	X (if difficulty) ⁵	X ⁸	8	X ¹⁵	X (if difficulty) ⁵	4
Supplement on Aging (SOA); 1995	X ¹	X	X	7	X ¹¹	X	8

1. Difficulty by oneself and without special equipment.
2. Problem without help lasting three or more months.
3. Help or supervision.
4. In past month.
5. Needs help.
6. In last week.
7. Walking and transferring only.
8. Equipment asked separately from disability items.
9. Because of physical, mental or emotional condition/problem/illness.
10. Because of a health or memory problem.
11. Because of health or physical problem.
12. Because of an impairment or physical or mental health problem.
13. Because of a disability or health problem unable for three or more months.
14. Gets or needs help.
15. Because of a physical or mental health condition.
16. Difficulty by oneself and with an aid if used.

OPPORTUNITIES TO IMPROVE EXISTING DISABILITY MEASURES

Recent advances in disability theory and measurement provide new opportunities for surveys to improve upon existing disability measures. To facilitate discussion and set the stage for workshop presentations on innovations in measurement, here we provide background in three areas: advances in conceptual thinking about disability; efforts to standardize disability measures across groups and countries; and efforts to understand and improve measures of the underlying components of disability--physical functioning, technological accommodations, the environment, and the specific tasks in which older people engage.

Advancements in the Conceptual Understanding of Disability

Over the last several decades, several overarching perspectives have emerged that guide efforts to enumerate the extent of disability in the United States population. Over time these perspectives have evolved from a strictly medical model to one that recognizes the social and environmental context of disability (Fujiura and Rutkowski-Kmitta 2001). The traditional medical model emphasizes the individual's medical condition or organ impairment underlying the disability. In contrast, Nagi's functional limitation model (Nagi 1965, 1991; Verbrugge and Jette 1994) and the original International Classification of Impairments, Disabilities, and Handicaps (ICIDH) make explicit the social context of disability.

Nagi's functional limitation model emphasizes four stages, first, *pathology*, or compromised organ function due to chronic or acute conditions or injury; second, *impairment*, or the loss of system function; third, *functional limitations*, defined as limitations in physical or mental actions due to the loss in system function; and finally, *disability*, or the inability to carry out socially defined roles or activities. In this paradigm, disability exists if the functional loss is sufficient to restrict an individual from performance of a socially defined role. Similarly, the ICIDH depicted a four-stage sequence of *disorder, impairment, disability, and handicap*. In this approach, disability is defined as a limitation in activity, whereas handicap refers to a disadvantage relative to others that is caused by an activity limitation.

The concepts embedded in these models are evident in many of the disability measures that are in national surveys today. For example, concepts embedded in the classic medical model are evident in questions in the NHIS and the Survey of Income and Program Participation, which allow adults with limitations in activities to be classified according to conditions. Similarly, the most recent Census asks about "the presence of a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying." Nagi's influence is readily seen in the adoption of functional limitation items on most national surveys.

More recently, the International Classification of Functioning, Disability and Health (ICF) has linked health conditions to participation in society through the influence of body functions and structure, activities, the environment, and personal factors (World Health Organization 1999). Unlike earlier frameworks, the ICF explicitly links health dimensions to participation in society and makes explicit contextual factors--the individual's health condition, the environment, and other personal factors--that may influence and interact with the process by which body functions and structures relate to participation.

Several recent measurement-development projects build on these conceptual frameworks. Based on Nagi's disablement model, for example, Jette and colleagues (2002a, 2002b) developed questionnaire items that assess late-life function and disability. Similarly, Gill et al. (1998) and Jette (1994) have demonstrated the distinct but complementary nature of measures of "difficulty" (difficulty with task) and "dependence" (need for help with task). Freedman and Agree (2005) highlight the role of assistive technology in the disablement process by making explicit the concepts of the environment and accommodations (i.e., the use of help, assistive technology, or changes in behavior). And, drawing upon the conceptual elements of the ICF model of disability, The Washington Group has proposed the development of internationally comparable census measures of disability to assess equalization of opportunity (Madans et al. 2004).

Efforts to Standardize Measures Across Surveys and Countries

The Federal Government has long recognized the value in attempting to introduce some level of standardization of disability measures into national survey efforts. For example, in 1988 the Forum on Aging-Related Statistics systematically examined surveys measuring ADLs to identify reasons for variation in estimates (Wiener et al. 1990). Most recently, the Federal Interagency Forum on Aging-Related Statistics has recommended that surveys that have ADL, IADL, and other measures of physical functioning use consistent wording and response categories whenever possible. Standardization of disability questions across countries has also received attention, as illustrated in a recent draft position paper by the Washington Group (Madans et al. 2004). The authors make the important point that measures may need to vary to suit different purposes, but they also argue for the need to standardize disability questions across countries as much as possible.

Related to this notion of standardization is the challenge of identical words not providing a shared meaning for all groups. For example, the term 'disability' or even "difficulty" may not carry the same meaning across countries or across cultures within a country. The use of anchoring vignettes has received recent attention as a means of improving comparisons across groups or countries of survey-based measures of health (Salomon et al. 2004; King et al. 2004) and disability (Banks et al. 2004; Kapteyn et al. 2004; Tourangeau et al. 2005). The approach involves including in surveys a self-

assessment of respondent's health (or disability) and an assessment of several hypothetical persons' health, as described in short vignettes. The anchoring vignettes for measuring self-care in the World Health Study, for example, are shown in Table 2. Because the vignettes measure the variation in concepts for a set of specific circumstances, they answers may be used to standardize or "anchor" differences in perceptions across groups or countries (see King et al. 2004 for a description of methodological approaches).

Advances in Measuring the Underlying Components of Disability

Disability is defined at the intersection of several key concepts: an individual's capacity to physically and cognitively function, the physical and social environment, the tasks that individuals choose to carry out, and the accommodations they make to carry them out (e.g., use of assistive devices, use of personal care from another person, or changes in their behavior). Advances in the understanding and measurement of each of these components have taken place over the last decade.

Physical functioning. There are two basic approaches to measuring physical functioning--that is the ability to function without help or the use of assistive devices. Subjective, self-reported measures of functioning and objective, performance-based measures appear to measure different, although related, constructs (Reuben et al. 1995); however, when combined they appear to provide more precise predictors of mortality and future hospital costs (Reuben et al. 2004a, 2004b).

Physical performance measures involve an individual performing a movement or task according to a standardized protocol and a trained observer rating the performance using objective, predetermined criteria (Guralnik et al. 1989, 1996; Halter and Reuben 2000). Batteries have been developed to measure the basic components of functioning (e.g., strength, balance, coordination, flexibility, endurance) as well as physical movements (e.g., walking) and goal-oriented functions (e.g., ADLs and IADLs). NHANES, for example, includes performance measures of balance and strength in its mobile exam center protocol. Further work is needed to promote standardization of performance measures in research settings (Guralnik and Ferrucci 2003).

Self-reports of functioning include Nagi's functional limitations items and other self-assessments of the ability to function without assistance. More recently, Sayers et al. (2004) report high correlations between performance-based measures and new self-reported measures of functioning from the Late-Life Function and Disability Instrument (LLFDI) (Haley et al. 2002). The LLFDI subscale asks about difficulty without help or special devices (none, a little, some, quite a lot, cannot do) with 32 functions (including, for example, unscrewing the lid off a previously unopened jar without using any devices; running half a mile or more; making a bed). They conclude that the functioning component of the LLFDI is an acceptable substitute for performance-based measures when self-report is a preferred mode of data collection format.

There are a number of challenges in incorporating measures of physical functioning into national surveys. In December 2003, the National Institute on Aging sponsored a meeting on physical functioning to review existing protocols and discuss issues related to their use in population-based studies (Suthers and Seeman 2004). Methodological challenges were outlined for both self-reports and performance-based measures. For example, both types of measures would benefit from enhanced discriminatory capability of measures. Other issues raised specifically about performance measures related to the feasibility of administering tests in the home, the need for systematic training of observers, and need to consider possible bias associated with differential refusal rates.

Measures of time use and participation. Although ADLs and IADLs have been used widely in research and policy making activities and have advanced our understanding of functioning in late-life, it is unclear the extent to which these measures--and IADLs in particular--reflect meaningful activities to older Americans today.

Information on time use can help identify how older Americans are spending their time. Time use information is typically collected either using “stylized” questions about time (e.g., last week how many hours did you spend _____) or using time use diaries (e.g., At 5 AM what were you doing? For how long?). The Bureau of Labor Statistics has recently revised the American Time Use Survey (Horrigan and Herz 2004), which takes advantage of computer-assisted telephone interviewing technology and time use diaries.

The reliability and validity of various strategies for collecting time use data has been explored. Juster et al. (2003), for example, find that similar estimates of labor market work hours and of historical trends are produced by diaries and stylized questions. Most often information on time use is reported in broad categories (e.g., unpaid work, paid work, self-care, active and passive leisure activities). For example, research in Canada suggests that older adults are active and engaged (Fast and Frederick 2004) and cross-national comparisons find similarities in the age patterns of activities (Gauthier and Smeeding 2003).

Measures of the environment and technological accommodations. Over the last decade awareness has grown that disability cannot be assessed outside of the physical and social environment and the accommodations individuals make to carry out purposeful tasks and roles (Brandt and Pope 1997; Satariano 1997). Current measures of disability rarely acknowledge the environment in which tasks take place. For example, questions about difficulty bathing generally do not address whether an individual bathes in a stall shower or a bathtub or whether they hold on to a grab bar or use a shower stool.

A recent project funded by ASPE in HHS seeks to begin to remedy this gap by developing and evaluating new measures of assistive technology use and the home environment (Freedman and Agree 2005). The purpose of this project was to develop,

pilot, and disseminate an instrument to be used in national surveys to collect information on assistive technology and environmental modifications used in both the home and workplace. The instrument has been extensively cognitively tested and then pilot tested under the direction of the National Center for Health Statistics by telephone with 360 older adults (ages 50 and older) living in the community. The final instrument consists of brief modules that may be adopted in whole or in part by national surveys. Concepts that have been measured include the use of assistive technology, intensity of use, the home environment, difficulty with ADLs residual to technology use, and the effectiveness of assistive devices on several quality of life dimensions.

Other instruments have been developed to assess barriers in the community that may impede mobility. For example, Shumway-Cook et al. (2003) have developed an instrument to measure environmentally specific mobility disability. Their approach involves self-reports of frequency of encounter and avoidance of 24 features of the physical environment, grouped into eight dimensions: distance, temporal, ambient, terrain, load, postural transitions, attention, and density. Initial evaluations of validity and reliability with a small sample suggest that the approach appears promising (Shumway-Cook et al. 2005).

TABLE 2. Anchoring Vignettes to Measure Self-Care: 2002 World Health Study*	
Vignettes	
1.	[Helena] pays a lot of attention to the way she looks. She requires no assistance with cleanliness, dressing and eating.
2.	[Anne] takes twice as long as others to put on and take off clothes, but needs no help with this. Although it requires an effort, she is able to bathe and groom herself, though less frequently than before. She does not require help with feeding.
3.	[Victor] usually requires no assistance with cleanliness, dressing and eating. He occasionally suffers from back pain and when this happens he needs help with bathing and dressing.
4.	[Sandra] lives on her own and has no relatives or friends nearby. Because of her arthritis, she is house-bound. She often stays all day in the same clothes that she has slept in as changing clothes is too painful. A neighbor helps her wash herself.
5.	[Sue] is quadriplegic and must be washed, groomed, dressed and fed by somebody else.
Questions	
1.	Overall in the last 30 days, how much difficulty did [name of person/you] have with self-care, such as washing or dressing [yourself/himself/herself]?
2.	In the last 30 days, how much difficulty did [name of person/you] have in taking care of and maintaining [your/his/her] general appearance (e.g., grooming, looking neat and tidy, etc.)
Response Categories	
1.	None
2.	Mild
3.	Moderate
4.	Severe
5.	Extreme/Cannot Do
* A list of vignettes, including those listed here, can be found at http://gking.harvard.edu/vign/ .	

WORKSHOP RATIONALE AND GOALS

Advances in conceptual thinking since the development of ADL and IADL items provide new opportunities to expand the range of questions that might be answered with survey data. Standardization of disability measures, for example, may promote comparisons across surveys, groups, and countries. Distinguishing physiological, environmental, and social components of disability, for example, may help policy makers better target resources at interventions likely to have high impact on population disability rates. Moreover, such distinction can help researchers track and understand shifts in population-level disability trends. Widespread use of these new measures could also improve our understanding at the individual level of the physiology of functional loss and recovery, the accommodation process, and the effectiveness of interventions to enhance independence and participation. Many of the advances discussed here are quite recent and have not been routinely incorporated into most national surveys that address late-life disability.

The workshop on Improving Survey Measures of Late-Life Disability will review advances in our understanding and measurement of late-life disability with the aim of answering two fundamental questions:

- Are our current measures of late-life disability meeting the needs of researchers and policy makers?
- How can we improve measures of late-life disability within current surveys?

The meeting will involve three sessions. The first session will be a panel discussion to flesh out the opportunities that new measures of disability might provide to policy makers and researchers. The second session will include six speakers, each focusing on an innovation in disability measurement. Presentations will address efforts to standardize measures and underlying components of disability (physical functioning; the environment and assistive technology; and time use and participation). The final session will involve a panel discussion about the practical considerations in implementing new measurement techniques with the aim of identifying the most promising strategies. The complete workshop agenda and biographies of participants are included in the Appendix.

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APPENDIX A. ADDITIONAL TABLES

TABLE A-1. Measures of Activities of Daily Living in Select National Surveys		
Survey	Question	Activities
American Community Survey (ACS); 1999 and later	Does this person have any of the following long-lasting conditions: A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?	Not applicable.
	Because of a physical, mental, or emotional condition lasting six months or more, does this person have any difficulty in doing any of the following activities (fill in activity).	Dressing, bathing, or getting around inside the home
Health and Retirement Study (HRS); 1995 and later	<p><i>Respondents who report one or more functional limitations are asked:</i> Because of a health or memory problem, do you have any difficulty (fill in activity)?</p> <p><i>For transferring and walking (all respondents asked regardless of difficulty):</i> Do you ever use equipment or devices such as a cane, walker or railing when (walking/ transferring)?</p> <p><i>Respondents who report difficulty:</i> Does anyone ever help you (fill in activity)?</p>	Bathing or showing Dressing including putting on socks and shoes Eating such as cutting up your food Getting in or out of bed Using the toilet including getting up and down Walking across a room
Medicare Current Beneficiary Survey (MCBS); 1992 and later (Community sample)	<p>Now I'll ask about some other everyday activities. I'd like to know whether (you have/sampled person has) any difficulty doing each one by (yourself/himself/herself) and without special equipment. Because of a health or physical problem, do you have any difficulty (fill in activity)?</p> <p><i>If doesn't do activity:</i> Is this because of a health or physical problem?</p> <p><i>For those who report difficulty, ask:</i> You said (your/sampled person's) health makes (fill in activity) difficult. You said that (fill in activity) is something (you don't/sampled person doesn't do) do. (Do you/Does sampled person) receive help from another person with (fill in activity)?</p> <p><i>If respondent does not receive help ask:</i> Does someone usually stay nearby just in case (you need/ sampled person needs) help with (fill in activity). That is, does someone usually stay or come into the room to check on (you/him/her)?</p> <p><i>For those who report difficulty, ask:</i> (Do you/Does sampled person) use special equipment or aids to help (you/him/her) with (fill in activity)?</p>	Bathing or showering Dressing Eating Getting in or out of bed or chairs Using the toilet Walking
Medical Expenditure Panel Survey (MEPS); 1996/ 1997 and later	<p><u>Household Component Survey</u> Does anyone in the family receive help or supervision with personal care such as bathing, dressing, or getting around the house?</p>	Not applicable
	<p><u>Long-Term Care Supplement</u> We have some questions about everyday activities such as bathing and eating. We are interested in the kinds of help people receive, not just hands-on help but instructing or prompting or being there just in case help is needed. Because of an impairment or physical or mental health problem, did (reference person) receive help (fill in activity) in the past month?</p> <p><i>If received help:</i> Look at this card and tell me which types of help (reference person) received. (1. Hands-on; 2. Instruction or prompting; 3. Staying in room in case help is needed.)</p>	Bathing or showering (including getting to the bath or shower and turning on the water) Dressing (that is getting clothes and putting them on) Getting to the toilet or using the toilet Getting out of bed or chair Eating (not including meal preparation)

TABLE A-1 (continued)

Survey	Question	Activities
National Health and Nutrition Examination Survey (NHANES); 1999-2000	The next questions ask about difficulties (you/sampled person) may have doing certain activities because of a health problem. By health problem we mean any long-term physical, mental or emotional problem or illness (not including pregnancy). By (yourself/himself/herself) and without using any special equipment, how much difficulty (do you/does sampled person) have (fill in activity). (1. No difficulty; 2. Some difficulty; 3. Much difficulty; 4. Unable to do.)	Walking ¼ mile Walking from one room to another on same level Getting in or out of bed Eating, like holding a fork, cutting food or drinking from a glass Dressing (yourself/himself/herself) including tying shoes, working zippers and doing buttons
National Health Interview Survey (NHIS); 1997 and later ¹	Because of a physical, mental, or emotional problem, (do you/does anyone in the family) need the help of other persons with personal care needs, such as eating, bathing, dressing, or getting around inside this home? Who is this? (Anyone else?) (If yes, ask for each person identified: (Do you/Does reference person) need the help of other persons with (fill in activity)?)	Bathing or showering Dressing Eating Getting in or out of bed or chair Using the toilet, including getting to the toilet Getting around inside the home
National Long Term Care Survey (NLTCS); 1982 and later (Community sample)	<p><u> Screener </u> I'd like to ask about (sampled person's) ability to do everyday activities without help. By help I mean either the help of a person, including people who live with (sampled person), or the help of equipment. Does (sampled person) have any problem (fill in activity) without help?</p> <p>You said that (sampled person) has a problem (<i>Read ADLs marked "Yes"</i>). Have you had (this problem/any of these problems) for three months or longer? <i>If no</i>: Do you expect that (this problem/any of these problems) will last for the next three months or longer? <i>If no</i>: Altogether, from beginning to end, will (this problem/any of these problems) have lasted three months as longer?</p> <p><u> Main Questionnaire </u> (<i>Asked to those who reported an ADL and IADL problem that lasted longer than three months in the screener.</i>) During the past week (since last (day)), did any person help (sampled person) (fill in activity) or did (sampled person) not (fill in activity)?</p> <p>Did (sampled person) use special equipment like (name special equipment) to (fill in activity)?</p> <p>Did someone usually stay nearby just in case (sampled person) might need help?</p> <p>About how long has (sampled person) had help or used (special equipment)/been unable to (fill in activity)?</p> <p><i>If no help received</i>: Does (sampled person) need help with (fill in activity)?</p>	Eating Getting in and out of bed Getting in and out of chair Walking around inside Going outside Dressing Bathing Getting to the bathroom or using the toilet Controlling bowel movements or urination or ever having accidents
Survey of Income and Program Participation (SIPP); 1991 and later	Because of a physical or mental health condition, does (reference person) have difficulty doing any of the following by him/herself (exclude the effects of temporary conditions)? Exclude the effects of temporary conditions--If an aid is used, ask whether the person has difficulty even when using the aid. <i>If difficulty with activity is reported in difficulty question, respondents are asked: Does (reference person) need the help of another person with (fill in activity)? Mark yes if person sometimes or usually needs help.</i>	Getting around inside Going outside home Getting in/out of bed/chair Taking a bath or shower Dressing Walking Eating Using or getting to the toilet

TABLE A-1 (continued)

Survey	Question	Activities
<p>Supplement on Aging (SOA); 1995</p>	<p>These questions are about some other activities and how well you are able to do them by yourself and without using special equipment.</p> <p>Because of a health or physical problem, do you have ANY difficulty (fill in activity)?</p> <p><i>Ask if doesn't do:</i> Is this because of a health or physical problem? <i>If yes, mark box 1; if no, mark box 3.</i></p> <p>By yourself and without using special equipment, how much difficulty do you have (fill in activity), some, a lot, or are you unable to do it?</p> <p>Do you use any special equipment or aids in (fill in activity)?</p> <p>Do you receive help from another person in (fill in activity)? Is this hands-on help?</p> <p>How often do you have hands-on help with (fill in activity)? Would you say always, sometimes, or rarely?</p> <p>Do you need (more) hands-on help with (fill in activity)?</p>	<p>Bathing or showering Dressing Eating Getting in or out of bed or chairs Using the toilet, including getting to the toilet Walking Getting outside</p>
<p>1. The NHIS also asks whether because of a health problem the reference person has any difficulty walking without using any special equipment.</p>		

TABLE A-2. Measures of Instrumental Activities of Daily Living in Select National Surveys		
Survey	Question	Activities
American Community Survey (ACS); 1999 and later	Because of a physical, mental, or emotional condition lasting six months or more, does this person have any difficulty in doing any of the following activities (fill in activity).	Going outside the home alone to shop or visit a doctor's office
Health and Retirement Study (HRS); 1995 and later ¹	<p>Please tell me whether you have any difficulty with each activity I name. If you don't do the activity at all, just tell me so. Exclude any difficulties that you expect to last less than three months. Because of a health or memory problem, do you have any difficulty (<u>activity</u>)?</p> <p><i>If can't do or don't do:</i> Is that because of a health or memory problem?</p> <p><i>If yes, don't know or refused and for those that can't or don't do because of a problem:</i> Does anyone help you (fill in activity)?</p> <p>(Besides any help you have told me about) Do you get any help with (<u>activity</u>) because of your health problems?</p>	<p>Using a map to figure out how to get around a strange place</p> <p>Preparing a hot meal</p> <p>Shopping for groceries</p> <p>Making phone calls</p> <p>Taking medication</p> <p>Managing money, such as paying your bills and keeping track of expenses</p> <p>Work around the house or yard²</p>
Medicare Current Beneficiary Survey (MCBS); 1992 and later (Community sample)	<p>Now I'm going to ask about some everyday activities and whether (you have/sampled person has) any difficulty doing them by (yourself/himself/herself). Because of a health or physical problem, do you have any difficulty (fill in activity)?</p> <p><i>If don't do activity:</i> Is this because of a health or physical problem?</p> <p>You said that (fill in activity) is something that (you have difficulty/you don't do/sampled person has difficulty doing/sampled person doesn't do). (Do you/does sampled person) receive help from another person with (fill in activity)?</p>	<p>Using the telephone</p> <p>Doing light housework (like washing dishes, straightening up, or light cleaning)</p> <p>Doing heavy housework (like scrubbing floors or washing windows)</p> <p>Preparing own meals</p> <p>Shopping for personal items (such as toilet items or medicines)</p> <p>Managing money (like keeping track of expenses or paying bills)</p>
Medical Expenditure Panel Survey (MEPS); 1996/1997 and later	<p><u>Household Component Survey</u></p> <p>The next few questions are about difficulties people may have with everyday activities such as getting around, bathing or taking medications. We are interested in difficulties due to an impairment or a physical or mental health problem.</p> <p>Does anyone in the family receive help or supervision using the telephone, paying bills, taking medications, preparing light meals, doing laundry, or going shopping?</p> <p><u>Long-Term Care Supplement</u></p> <p>Now I would like to ask about a few (more) daily activities which some people have difficulty with.</p> <p>(Do/Does) (reference person) receive help or supervision (fill in activity) because of an impairment or a physical or mental health problem?</p>	<p>Not applicable</p> <p>Shopping for groceries. Please do not include help in getting to or from the store</p> <p>Getting around the community outside of walking distance</p> <p>Preparing meals</p> <p>Taking medication</p> <p>Managing money, such as keeping track of expenses or paying bills</p> <p>Doing laundry</p> <p>Doing light housework, such as straightening up, putting things away or washing dishes</p>

TABLE A-2 (continued)		
Survey	Question	Activities
National Health and Nutrition Examination Survey (NHANES); 1999-2000 ³	<p>The next questions ask about difficulties (you/sampled person) may have doing certain activities because of a health problem. By health problem we mean any long-term care physical, mental or emotional problem or illness (not including pregnancy).</p> <p>By (yourself/himself/herself) and without using any special equipment, how much difficulty (do you/does sampled person) have (fill in activity)? [1. No difficulty; 2. Some difficulty; 3. Much difficulty; 4. Unable to do.]</p>	<p>Managing money</p> <p>Doing chores around the house (vacuuming, sweeping, dusting, etc.)</p> <p>Preparing (your/his/her) own meals</p>
National Health Interview Survey (NHIS); 1997 and later ³	Because of a physical, mental, or emotional problem, (do/does) (you/anyone in the family) need the help of other persons in handling ROUTINE NEEDS, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?	Not applicable
National Long Term Care Survey (NLTC); 1982 and later (Community sample)	<p><u>Screeners</u> (<i>INSTRUCTION--If a person does not do, but is able to do, an activity listed below, mark "Yes" for the activity.</i>)</p> <p>Are you able to (fill in activity)?</p> <p>Does a disability or a health problem keep (sampled person) from (read activity marked "No" in item above)?</p> <p>Which of these activities is (sampled person) unable to do because of a disability or health problem (read IADLs marked "No" above)? Mark (1) all that apply.</p> <p>You said that (sampled person) has a problem (Read IADLs marked "Yes"). Have you had (this problem/any of these problems) for three months or longer?</p> <p><i>If no:</i> Do you expect that (this problem/any of these problems) will last for the next three months or longer?</p> <p><i>If no:</i> Altogether, from beginning to end, will (this problem/any of these problems) have lasted three months or longer?</p>	<p>Prepare meals without help</p> <p>Do laundry without help</p> <p>Do light housework such as washing dishes</p> <p>Shop for groceries without help</p> <p>Manage money such as keeping track of bills and handling cash</p> <p>Take medicine without help</p> <p>Make phone calls without help</p>
	<p><u>Main Questionnaire</u></p> <p>Does (sampled person) usually do (fill in activity)?</p> <p><i>If no, ask:</i> If (sampled person) had to (fill in activity), could...do it?</p> <p><i>If had to do activity, but couldn't, ask:</i> What is the reason (sampled person) cannot do (fill in activity)--is that because of disability or health problem, or is there some other reason? (1. Disability or health problem; 2. Other reason.)</p> <p>Does someone usually help (sampled person) with (fill in activity) or do it for (sampled person)?</p> <p>Does (sampled person) need any help (fill in activity)?</p>	<p>Heavy work around the house</p> <p>Light work around the house such as straightening up, putting things away, or washing dishes</p> <p>Own laundry</p> <p>Prepare own meals</p> <p>Shop for groceries</p> <p>Get around outside</p> <p>Go places outside of walking distance</p> <p>Manage money</p> <p>Take medicine</p> <p>Make telephone calls</p>
Survey of Income and Program Participation (SIPP); 1991 and later	<p>Because of a physical or mental health condition, does (sampled person) have difficulty doing any of the following by himself/herself)?</p> <p>Exclude the effects of temporary conditions--If an aid is used, ask whether the person has difficulty even when using the aid.</p> <p><i>If difficulty with activity is reported in difficulty question, respondents are asked:</i> Does (sampled person) need the help of another person with (fill in activity)? Mark yes if person sometimes or usually needs help.</p>	<p>Keeping track of money and bills</p> <p>Preparing meals</p> <p>Doing light housework such as washing dishes or sweeping a floor</p> <p>Taking the right amount of prescribed medicine at the right time</p>

TABLE A-2 (continued)

Survey	Question	Activities
<p>Supplement on Aging (SOA); 1995</p>	<p>These questions are about some other activities. Please tell me about doing them by yourself.</p> <p>Because of a health or physical problem, do you have any difficulty (fill in activity)?</p> <p><i>Ask if doesn't do:</i> Is this because of a health or physical problem? <i>If yes mark box 1 if no mark box 3.</i></p> <p><i>If doesn't do for other reason, ask:</i> Does someone else regularly do this for you?</p> <p><i>Ask the following for each activity marked "yes":</i></p> <p>By yourself, how much difficulty do you have (fill in activity)? (1. Some; 2. A lot; 3. Unable.)</p> <p>Do you receive help from another person in (fill in activity)?</p> <p>Is this hands-on help?</p> <p>How often do you have hands-on help with (fill in activity)? Would you say always, sometimes, or rarely.</p> <p>Do you need (more) hands-on help with (fill in activity)?</p>	<p>Preparing own meals</p> <p>Shopping for personal items (such as toilet items or medicines)</p> <p>Managing your money (such as keeping track of expenses or paying bills)</p> <p>Using the telephone</p> <p>Doing heavy housework (like scrubbing floors or washing windows)</p> <p>Doing light housework (like doing dishes, straightening up, or light cleaning)</p> <p>Getting to places outside of walking distance</p> <p>Managing your medication</p>
<p>1. The 1994 HRS and 1993 AHEAD also included items but wording differed.</p> <p>2. Difficulty question not asked for work around the house or yard.</p> <p>3. The NHANES and NHIS also ask about the amount of difficulty with leisure activities such as: Going out to things like shopping, movies, or sporting events; Participating in social activities (visiting friends, attending clubs or meetings or going to parties); and Doing things to relax at home or for leisure (reading, watching TV, sewing, listening to music).</p>		

APPENDIX B. WORKSHOP AGENDA

Workshop on Improving Survey Measures of Late-Life Disability

Funded by
Office of the Assistant Secretary for Planning and Evaluation

AGENDA

Urban Institute
May 17, 2005

- 9:00 - 9:15 **Introductions and Opening Remarks**
- 9:15 - 10:15 **Panel Discussion:** *Opportunities for new measures of late-life disability*
- Moderator:** Brenda Spillman, Ph.D.
Urban Institute
- Panel Participants:** Susan Allen, Ph.D.
Brown University
- Howard Iams, Ph.D.
Social Security Administration
- Lisa Iezzoni, M.D.
Harvard University
- Robert Schoeni, Ph.D.
University of Michigan
- 10:15 - 10:30 **Break**
- Presentations:** *Innovations in measurement*
- Moderator:** Vicki Freedman, Ph.D.
Polisher Research Institute
- 10:30 - 11:00 Jennifer Madans, Ph.D.
National Center for Health Statistics
Standardizing Disability Measures I: Concepts and Initial Measures from the Washington Group
- 11:00 - 11:30 James Smith, Ph.D.
RAND
Standardizing Disability Measures II: The Use of Vignettes

- 11:30 - 12:00 Thomas Gill, M.D.
Yale University
Measures of Physical Functioning in Late-Life
- 12:00 - 1:00 **Lunch**
- Presentations:** ***Innovations in measurement*** (cont'd)
- 1:00 - 1:30 Janet Fast, Ph.D.
University of Alberta
Measures of Engagement and Participation in Later Life
- 1:30 - 2:00 Emily Agree, Ph.D.
Johns Hopkins University
Linking Measures of Assistive Technology and Disability
- 2:00 - 2:30 Anne Shumway-Cook, Ph.D.
University of Washington
Measures of Environmentally-Determined Mobility Disability
- 2:30 - 2:45 **Break**
- 2:45 - 3:45 **Panel Discussion:** ***Considerations from the Field***
- Moderator:** Timothy Waidmann, Ph.D.
Urban Institute
- Panel Participants:** David Weir, Ph.D.
University of Michigan
- Kenneth Manton, Ph.D.
Duke University
- DEB Potter, M.A.
Agency for Healthcare Research and Quality
- Julie Weeks, Ph.D.
National Center for Health Statistics
- 3:45 - 4:00 **Closing Remarks**

APPENDIX C. BIOGRAPHIES OF WORKSHOP PARTICIPANTS AND ORGANIZERS

Workshop on Improving Survey Measures of Late-Life Disability

Funded by

Office of the Assistant Secretary for Planning and Evaluation

BIOGRAPHIES OF WORKSHOP PARTICIPANTS AND ORGANIZERS

Emily Agree, Ph.D. (Johns Hopkins University)

Dr. Emily Agree is an Associate Professor in both the Population and Health Sciences and Sociology departments at Johns Hopkins University. She is currently involved in research on the social consequences of chronic illness among older persons in the United States. Dr. Agree has studied the role of assistive technology in long-term care among older persons in the United States, including how older disabled persons choose technology and/or personal care to meet their long-term care needs and the effectiveness of technology and personal care arrangements in alleviating disability, relieving the burden on informal caregivers, and reducing health care costs. She is currently collaborating on a project to develop and evaluate measures of assistive technology and the environment.

Susan Allen, Ph.D. (Brown University)

Dr. Allen is an Associate Professor in the Departments of Community Health and Sociology at Brown University. She is also Acting Director of the Center for Gerontology and Health Care Research at Brown. Dr. Allen has a long history of studying home care issues among people with chronic conditions and impairments. Her research has focused on both formal and family home care, and on the implications of unmet need for help at home for the quality of life and patterns of service use among people with disability who live in the community. Recently Dr. Allen has extended her interest in home supports from formal and informal human assistance to technological assistance. Dr. Allen has served as Principal Investigator on grants funded by the National Institute on Aging, the National Cancer Institute, the Robert Wood Johnson Foundation and the Milbank Memorial Fund.

Janet Fast, Ph.D. (University of Alberta)

Dr. Fast researches family and consumer policy issues. A major theme is the paid and unpaid work of family members. She currently co-leads a large international, multidisciplinary team investigating the juxtaposition of costs and contributions of adults with chronic illness and disability. On the cost side, the team is examining the consequences of recent health and social policy reform for family and friends who care for frail seniors or other adults with chronic illness and disability. On the contributions side, they are exploring the productive activities of older adults and adults with chronic illness and disability. Dr. Fast also conducts research on workplace policy as it relates to family members' ability to balance paid work and family demands.

Vicki A. Freedman, Ph.D. (Polisher Research Institute)

Dr. Freedman is a Senior Research Scientist and at Polisher Research Institute, a private, non-profit gerontological research organization affiliated with the Abramson Center for Jewish Life (formerly, Philadelphia Geriatric Center). From 2002-2005 she served as the Institute's director. Dr. Freedman has published extensively on the topics of population aging, disability, and long-term care, including several widely publicized articles on trends in late-life functioning. Her current portfolio of research projects focuses on disparities and causes of late-life health trends; policy interventions to promote late-life disability decline; the development of measures of assistive technology use and the home environment; barriers to the use of technology in residential long-term care settings, and the role of neighborhoods in late-life health.

Thomas Gill, M.D. (Yale University)

Dr. Gill is Associate Professor of Medicine with Tenure at the Yale University School of Medicine. He is a graduate of the Pritzker School of Medicine at the University of Chicago, and he completed his residency training in internal medicine at the University of Washington. Dr. Gill received his research training in clinical epidemiology as a Robert Wood Johnson Clinical Scholar at Yale, and he joined the Yale faculty in 1994 after completing an additional year as a geriatrics fellow. Dr. Gill is a leading authority on the epidemiology and prevention of disability and functional decline among older persons. His findings have been published in high impact biomedical and epidemiology journals, including the New England Journal of Medicine, JAMA, Annals of Internal Medicine, and American Journal of Epidemiology. Dr. Gill is the recipient of numerous awards, including the 2001 Outstanding Scientific Achievement for Clinical Investigation Award from the American Geriatrics Society. In April 2005, he was elected to the American Society of Clinical Investigation (ASCI), one of the nation's oldest and most respected medical honor societies. Dr. Gill's research and mentoring program in disability and disabling disorders is currently supported by an NIA Midcareer Investigator Award in Patient-Oriented Research (K24) and two NIA-funded R01s.

Howard Iams, Ph.D. (SSA)

Dr. Iams is the Director of the Division of Policy Evaluation in the Social Security Administration's research office. Since coming to SSA in 1978, Dr. Iams has worked on a variety of research and evaluation activities. He worked on evaluation demonstrations in the AFDC program specializing in the subjects of performance measurement and work demonstrations. Using the 1982 New Beneficiary Survey data system, he conducted analyses of mortality and of employment patterns of newly disabled and retired beneficiaries. Dr. Iams also managed the 1991 re-interviews to the New Beneficiary Survey. Since 1986 he Iams has been conducting policy evaluations with survey data from the Census Bureau's Survey of Income and Program Participation (SIPP) matched to SSA administrative records of earnings and benefits. In collaboration with Steve Sandell, he designed and developed the Modeling Income in the Near Term (MINT) data system with matched SIPP data. SSA uses MINT to estimate the distributional impact of Social Security reform proposals and to project the baby boom and other future retirees in the 21st Century.

Lisa Iezzoni, M.D., M.Sc. (Harvard University)

Lisa I. Iezzoni is Professor of Medicine at Harvard Medical School and Co-Director of Research in the Division of General Medicine and Primary Care, Department of Medicine, at Beth Israel Deaconess Medical Center in Boston. She received her degrees in medicine and health policy and management from Harvard University. Dr. Iezzoni has conducted numerous studies for the Agency for Healthcare Research and Quality, the Medicare agency, and private foundations on a variety of topics, including evaluating methods for predicting costs, clinical outcomes, and substandard quality of care. She has published and spoken widely on risk adjustment and has edited a textbook, now in its third edition (2003), on risk adjustment for measuring health care outcomes. A 1996 recipient of the Investigator Award in Health Policy Research from The Robert Wood Johnson Foundation, she is studying health policy issues relating to persons with disabilities. Dr. Iezzoni is a member of the Institute of Medicine in the National Academy of Sciences, serves on the editorial boards of major medical and health services research journals, and is on the Board of Directors of the National Quality Forum. Her book *When Walking Fails* was published in the spring 2003.

Jennifer Madans, Ph.D. (CDC/NCHS)

Dr. Madans has been the Associate Director for Science, National Center for Health Statistics, since May 1996 and is responsible for the overall plan and development of NCHS's data collection and analysis programs. Since Dr. Madans joined the Center, she has concentrated her research efforts on data collection methodology, aging, health services research and chronic disease epidemiology. She has directed two national longitudinal studies (NHANES I Epidemiologic Followup Study and the National Nursing Home Followup Study) as well as the redesign of the National Health Interview Survey questionnaire. She was one of the designers of the DHHS Survey Integration Plan and of the State and Local Area Integrated Telephone System. Dr. Madans is a Fellow of the American Statistical Association.

Ken Manton, Ph.D. (Duke University)

Dr. Manton is Scientific Director of the Center for Demographic Studies at Duke University and a Research Professor in Duke's Department of Sociology, as well as a Medical Research Professor in the Department of Community and Family Medicine at the Duke University Medical Center. He is currently Principal Investigator on a number of grants and cooperative agreements, among them the National Long Term Care Survey and a program project grant focusing on health forecasting and Medicare utilization funded by NIA. Dr. Manton's primary expertise is in the areas of mathematically sophisticated analytic procedures and biologically-based population level models of health and mortality, particularly of aged populations. He has published over four hundred monographs and articles and received in 2000 the first M. Irene Ferrer Award for Outstanding Original Research in Gender-Specific Medicine from The Partnership for Women's Health at Columbia University. He was the 1990 recipient of the Mindel C. Sheps Award in Mathematical Demography and Demographic Methodology.

DEB Potter, M.S. (AHRQ)

Ms. Potter is Senior Survey Statistician at the Agency for Healthcare Research and Quality. She has a wide range of experience in the design and collection of government health and long-term care surveys. She is project manager for the Medical Expenditure Panel Survey (MEPS) Nursing Home Component (NHC). She is co-leader of AHRQ's Long-Term Care Research and Data Development Group. Her research interests include the design and implementation of an integrated data system to support long-term care health services research for the Department of Health and Human Services (HHS).

Robert Schoeni, Ph.D. (University of Michigan)

Dr. Schoeni is Associate Research Professor at the Institute for Social Research and Associate Professor of Economics and Public Policy at the University of Michigan. He studies labor economics, the family, aging, and welfare policy. Recent studies include the investigation of changes in old-age health status and disability, the effects of welfare reform on various outcomes, the economic consequences of workplace injuries, and poverty among older women. Dr. Schoeni also serves as Associate Director of the Panel Study of Income Dynamics.

Anne Shumway-Cook (University of Washington)

Dr. Shumway-Cook is an Associate Professor and Physical Therapist in the Department of Rehabilitation Medicine at the University of Washington. Her research interests include mechanisms underlying imbalance in the aging adult and clinical methods for assessing and treating imbalance. She has recently published several articles on the role of environmental demands and community mobility in older adults.

James P. Smith, Ph.D. (RAND Corporation)

Dr. Smith holds the RAND Chair in Labor Markets and Demographic Studies and was the Director of RAND's Labor and Population Studies Program from 1977-1994. He has led numerous projects, including studies of immigration, the economics of aging, black-white wages and employment, wealth accumulation and savings behavior, and the interrelation of health and economic status. He is currently a co-Principal Investigator for The New Immigrant Survey. Dr. Smith was the Chair of the Panel on Demographic and Economic Impacts of Immigration (1995-1997), for the National Academy of Sciences. The Panel was convened to examine the interconnections of immigration, population, and the economy, and to provide evidence about the impact of immigration. Dr. Smith has served on the Population Research Committee at the National Institutes of Health. He currently serves on the NIA Data Monitoring Committee for the Health and Retirement Survey (HRS) and was chair of the National Science Foundation Advisory Committee for the Panel Study of Income Dynamics. Dr. Smith was the public representative appointed by the Governor on the California OSHA Board. He has received the National Institutes of Health MERIT Award, the most distinguished honor NIH grants to a researcher.

Brenda Spillman, Ph.D. (Urban Institute)

Dr. Spillman, a health economist, joined the Urban Institute as a Senior Research Associate in August 1998. Before that she was a research fellow at the Agency for Health Care Policy and Research (now AHRQ) for 11 years. In recent years she has specialized in research on disability and long term care use and financing, including nursing home use and financing, home care, long term care insurance and public financing, informal caregiving, and projections of service use and cost for the Medicare elderly. Dr. Spillman's earlier work focused on the nonelderly uninsured, Medicaid, Medicare, and the impact of financing on health care utilization. In addition to continuing work on long term care and disability-related projects, Dr. Spillman's current work deals with access and utilization of services by low-income adults, as part of the Assessing the New Federalism Project. Dr. Spillman has worked with a broad range of complex national surveys, Medicare, and Medicaid data and has experience in the design of questionnaires and analytic oversight of editing and imputation through her work on the Medical Expenditure Panel Survey.

Timothy Waidmann, Ph.D. (Urban Institute)

Dr. Waidmann is an economist with post-doctoral training in the demography of aging. He has worked on a series of projects dealing with the measurement of disability in surveys. Much of his research studies the potential for policy and economic factors to contaminate self-reported health and disability measures in surveys. In the areas of aging, disability and long-term care, Waidmann has designed and conducted studies of disability trends among the elderly in the U.S. and other industrialized countries; the impact of these trends on Medicare spending; the impact of potential reforms in the Medicare program; access to physician services among Medicare beneficiaries; and models of residential transition among the elderly. In the area of work-disability, Waidmann has worked on several studies of the impacts of health and government disability policy on labor force decisions using the Health and Retirement Survey, and a study of the social welfare implications of imperfect medical screening in the Social Security disability insurance program.

Julie Weeks, Ph.D. (CDC/NCHS)

Dr. Weeks has been employed at the National Center for Health Statistics since 1989, and is currently with the Office of Analysis and Epidemiology. Since she came to NCHS, she has worked on the Longitudinal Studies of Aging (LSOAs), and is currently the Project Director. Her research interests include the demography of aging, including health status and social support among the elderly, and survey methodology. She currently serves a committee member of the Interagency Forum on Aging-Related Statistics & Interagency Household Survey Nonresponse Group.

David R. Weir, Ph.D. (University of Michigan)

Dr. Weir is Associate Director of the Health and Retirement Study. His current research interests include the measurement of health-related quality of life; the use of cost-effectiveness measures in health policy and medical decision-making; the role of supplemental health insurance in the Medicare population; the effects of health, gender, and marital status on economic well-being in retirement; and the effects of early-life experience on longevity and health at older ages.

OPPORTUNITIES TO IMPROVE SURVEY MEASURES OF LATE-LIFE DISABILITY

Files Available for This Report

Part I--Workshop Overview

HTML Version <http://aspe.hhs.gov/daltcp/reports/2006/survmeasI.htm>

PDF Version <http://aspe.hhs.gov/daltcp/reports/2006/survmeasI.pdf>

Part II--Workshop Summary

HTML Version <http://aspe.hhs.gov/daltcp/reports/2006/survmeasII.htm>

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