



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

MEASURING THE ACTIVITIES OF DAILY LIVING AMONG THE ELDERLY:

A Guide to National Surveys

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This report was prepared for the Forum on Aging-Related Statistics by the Committee on Estimates of Activities of Daily Living in National Surveys. For additional information, you may visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the Office of Disability, Aging and Long-Term Care Policy, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, SW, Washington, DC 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The DALTCP Project Officer was Robert Clark.

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Joshua M. Wiener
Raymond J. Hanley

The Brookings Institution

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FORUM ON AGING-RELATED STATISTICS

Committee on Estimates of Activities of Daily Living in National Surveys

CO-CHAIRS

Joan F. Van Nostrand, National Center for Health Statistics

Robert Clark, Office of the Assistant Secretary for Planning and Evaluation

MEMBERS

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Health Care Financing Administration

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Robyn Stone
National Center for Health Services Research

Joan Turek-Brezina
Office of the Assistant Secretary for Planning and Evaluation

Joshua Wiener
Brookings Institution

EXECUTIVE SUMMARY

The "activities of daily living" or ADLs are the basic tasks of everyday life, such as eating, bathing, dressing, toileting and transferring (i.e., getting in and out of a bed or chair). Although persons of all ages may have problems performing the ADLs, disability prevalence rates are much higher for the elderly than for the nonelderly. Within the elderly population, disability rates rise steeply with advancing age and are especially high for persons aged 85 and over.

To the casual observer, estimates of the size of the elderly population with activity of daily living disabilities differ substantially across national surveys. There are a number of reasons for this variation, but differences in which ADL items are being measured and in what constitutes a disability account for much of the variation. Other likely explanations are differences in sample design, sample size, survey methodology and age structure of the population at the time the surveys were conducted.

When an effort is made to standardize ADL items for comparison, estimates for the community-based population vary by no more than 3.1 percentage points and for the institutionalized population, with the exception of toileting, by no more than 3.2 percentage points. As small as these differences are in absolute terms, they can be large in percent differences across surveys. For example, the National Medical Expenditure Survey estimates that there are 60 percent more elderly with ADL problems than does the Supplement on Aging.

The main conclusion is that ADL estimates will differ for good reasons and that there is no one "right" estimate. Researchers and policy analysts alike need to be aware that ADL disability rates are simply much "softer" measures than, say, mortality rates. From wording decisions made by persons who design the survey questionnaire, to the analysts who choose a particular ADL question or set of questions to analyze and report, to the programmers who must actually handle multiple question recodes and deal with missing and inconsistent data, each step will influence the final results. Thus, even an extremely large sample could not provide a definitive estimate.

What should policymakers and others make of these differences across surveys? Cost estimates for home care programs or insurance benefits based on one set of ADL prevalences will be substantially different from cost estimates based on a different set of ADL prevalences. This inconsistency will clearly be unsettling to those who must pay the bills. From a research perspective, however, the estimates are remarkably alike. If the policy interest was on the nondisabled, nobody would give the inconsistency of the estimates a second thought. The fact is that, even among the elderly, ADL limitations are relatively rare and some variation in the estimates is inevitable.

INTRODUCTION

The "activities of daily living" or ADLs are the basic tasks of everyday life, such as eating, bathing, dressing, toileting, and transferring (i.e., getting in and out of a bed or chair). When people are unable to perform these activities, they need help in order to cope, either from other human beings or mechanical devices or both. Problems performing the activities of daily living cut across diagnoses, but are especially prevalent among persons with arthritis, osteoporosis and stroke. Although persons of all ages may have problems performing the ADLs, prevalence rates are much higher for the elderly than for the nonelderly.¹ Within the elderly population, disability rates rise steeply with advancing age and are especially high for persons aged 85 and over.

Measurement of the activities of daily living is critical because they have been found to be significant predictors of admission to a nursing home,² use of home care,³ use of hospital services,⁴ living arrangements,⁵ overall Medicare expenditures,⁶ insurance coverage,⁷ and mortality.⁸ For research on the elderly, the ability to perform the ADLs has become a standard variable to include in analyses, like age, sex, marital status and income.

Estimates of the number and characteristics of people with problems performing ADLs are also important because of the increasing number of private long-term care insurance policies and proposed public long-term care insurance programs that rely on ADL dependency measures to determine whether an individual qualifies for benefits. For example, private insurance policies sold by John Hancock, Aetna, Travelers, Metropolitan Life and CNA rely on ADL measures as triggers for benefits.⁹ All of the

¹ In this paper, the term elderly refers to persons age 65 and older.

² Raymond Hanley, Lisa Alexchik, Joshua Wiener and David Kennell, "Predicting Elderly Nursing Home Admissions: Results From the 1982-84 National Long-Term Care Survey," Washington, D.C.: The Brookings Institution, August 1, 1989; Teresa A. Coughlin, Timothy D. McBride, and Korbin Liu, "Determinants of Transitory and Permanent Nursing Home Admissions," Working Paper 3726-03, Washington, D.C., Urban Institute, January 1989.

³ Sandra Newman, Raymond Struyk, Paul Wright, and Michelle Rice, "Overwhelming Odds: Caregiving and the Risk of Institutionalization," (U.I. Report 3691-01, Washington, D.C., The Urban Institute, November 1988). [<http://aspe.hhs.gov/daltcp/reports/ovrwhles.htm>]

⁴ Korbin Liu and Kenneth Manton, "Effects of Medicare's Hospital Prospective Payment System (PPS) on Disabled Medicare Beneficiaries," Final Report to the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Washington, D.C., The Urban Institute, February 1988. [<http://aspe.hhs.gov/daltcp/reports/pps.htm>]

⁵ Christine Bishop, "Living Arrangement Choices of Elderly Singles," *Health Care Financing Review*, Vol.7, Number 3, Spring 1986, pp.65-73.

⁶ Leonard Gruenberg and Christopher P. Tompkins, "Including Disability Status in the AAPCC," Waltham, Massachusetts, Health Policy Center, Brandeis University, 1986.

⁷ Burton Dunlop, James Wells and Gail Wilensky, "The Influence of Source of Insurance Coverage on the Health Care Utilization Patterns of the Elderly," *Journal of Health and Human Resources Administration*, Vol.II, Number 3, Winter 1989, Table 3.

⁸ Kenneth G. Manton, "A Longitudinal Study of Functional Change and Mortality in the United States," *Journal of Gerontology*, vol.43, Number 5, September 1988, pp.S153-S161.

⁹ Susan Van Gelder, Health Insurance Association of America, Washington, D.C., personal communication, May 26, 1989.

developed public insurance plans, including those proposed by Senators Mitchell and Kennedy and by Representatives Waxman, Stark and Pepper, do the same. Obviously, the amount of long-term care benefits paid out by such private and public plans will largely depend on the number of persons who meet the various ADL eligibility criteria.

Since 1982, a number of national surveys have been conducted which measure the ability of the elderly to perform the activities of daily living. A legitimate question is whether these diverse surveys produce consistent estimates. A cursory glance at some recent studies suggest that this is not the case. For example, one analysis using the 1984 National Long-Term Care Survey reported that there were 3.0 million elderly with impairments in one or more ADLs; while another study using the 1984 Supplement on Aging found 6.0 million impaired elderly; and, yet another study using the 1984 Survey of Income and Program Participation identified only 1.5 million elderly with "personal care needs," a concept roughly comparable to requiring help with the ADLs.¹⁰ The very wide differences in the cost estimates for Rep. Claude Pepper's long-term home care bill, H.R. 3436, between the U.S. Congressional Budget Office and the U.S. Department of Health and Human Services served to focus attention on the consistency of the estimates.

In May 1988, the Interagency Forum on Aging-Related Statistics decided to systematically examine the surveys measuring ADLs and to try to discover the reasons for the varying estimates. A Committee on Definitions of Functional Limitations, including government and nongovernment experts familiar with the different surveys, was formed to study the issue. This paper is the report of that Committee. The report focuses on the activities of daily living and does not address potential differences across surveys in the estimated number of persons with problems performing the "instrumental activities of daily living" or the number of cognitively impaired elderly. The goal of this paper is to provide a guide to policymakers and researchers on the national surveys that measure ADLs and on the issues that must be addressed in using data from these surveys.

The remainder of this report has four sections. The first section defines the activities of daily living in greater detail and reviews the history of the concept. The next section provides an overview of eleven recent national surveys that measure activities of daily living. The third section discusses some potential sources of differences among surveys. The final section presents the conclusions of the analysis.

¹⁰ Kenneth Manton, "A Longitudinal Study of Functional Change and Mortality in the United States, p.S157, Table 2; Judith D. Kasper, "Using the Long-Term Care Surveys: Longitudinal and Cross-Sectional Analyses of Disabled Older People," *Proceedings of the 1987 Public Health Conference on Records and Statistics*, DHHS Pub.No.88-1214 (Hyattsville, Maryland: National Center for Health Statistics, 1988), p.358, Table 3; U.S. Bureau of the Census, *Disability, Functional Limitation, and Health Insurance Coverage: 1984/85*, Current Population Reports, Household Economic Studies, Series P-70, No.8, (Washington, D.C.: U.S. Department of Commerce, December 1986), p.28, Table 4.

I. ACTIVITIES OF DAILY LIVING: DEFINITION AND HISTORY

General measures of health status such as diagnoses or medical conditions are limited indicators of the independence and functional capabilities of an individual. For example, diagnoses have been found to be a poor predictor of use of long-term care services.¹¹ Therefore, disability researchers have devoted considerable attention to developing measures that tap practical dimensions of everyday life as a way of measuring a person's physical functioning. The activities of daily living are increasingly being used as the way to measure disability.

The term "activities of daily living" refers to a set of common, everyday tasks, performance of which is required for personal self-care and independent living. The most often used measure of functional ability is the Katz Activities of Daily Living Scale.¹² In this scale, the set of tasks assessed are bathing, dressing, transferring, using the toilet, continence and eating.

Over the years, a number of other measures of physical dysfunction have been introduced which cover tasks similar to the Katz ADL Scale. Most of these other measures of activities of daily living include some measure of mobility, such as walking, getting around inside, and getting around outside. One newer measure, the Barthel scale, also subdivides the eating activity into two different tasks and transferring into four different activities. Another measure is the PULSES scale which focuses less on the specific task and more on the physical characteristics that make task completion difficult, thereby indicating which areas of the body require rehabilitation. Appropriately, the PULSES acronym refers to Physical condition, Upper limbs (self-care), Lower limbs (ambulation), Sensory abilities, Excretory, mental and emotional Status.¹³

Measures of the ability to perform the ADLs have become routine in surveys of the elderly, partly displacing the National Health Interview Survey disability classification of being "unable to perform your major (or usual) activity."¹⁴ ADLs are more specific and concrete than an inability to perform a "major activity," thus minimizing situational or contextual differences among survey respondents. For example, the physical requirements of the major or usual activity of a construction worker are very different than those of an accountant. Moreover, because ADLs have been defined as having at least five or more elements, they can provide more highly differentiated levels of disability. In addition, ADLs can be used to provide general information on the basic service needs of the disabled. A person unable to feed himself needs help eating; it is not clear what, if any, services a person needs who is "unable to perform his major

¹¹ Korbin Liu and Elizabeth Cornelius, "ADLs and Eligibility for Long-Term Care Services," The Commonwealth Fund Commission on Elderly People Living Alone, Background Paper Series No.14, December 1988, p.2.

¹² Sidney Katz, Amasa B. Ford, Roland W. Moskowitz, Beverly A. Jackson and Marjorie W. Jaffe, "Studies of Illness in the Aged," *Journal of the American Medical Association*, September 21, 1963, pp.94-9.

¹³ Gerda Fillenbaum, "Activities of Daily Living," in George L. Maddox (ed.), *The Encyclopedia of Aging* (New York: Springer, 1987), pp.3-4.

¹⁴ National Center for Health Statistics, "Current Estimates from the National Health Interview Survey: United States, 1979," *Vital and Health Statistics*, (Hyattsville, Md.: NCHS), Series 10, no.136, pp.59-60.

activity." Finally, as mentioned earlier, ADL status is a good predictor of a wide range of health-related behavior.

As useful as they are, ADLs do not measure the full range of activities necessary for independent living in the community. To partly fill this gap in disability classification, the "instrumental activities of daily living" or IADLs were developed.¹⁵ The IADLs capture a range of activities that are more complex than those needed for personal self-care, including handling personal finances, meal preparation, shopping, travelling, doing housework, using the telephone, and taking medications.¹⁶ Recent research suggests that there is a hierarchical relationship between some IADL items and ADL items, with IADL disabilities representing less severe dysfunctional.¹⁷

Because they seek to measure certain activities which are not universally performed by all individuals, IADLs have certain limitations. First, IADLs are difficult to use in institutional settings, where many activities, such as meal preparation and housework, are routinely performed by others. Second, some IADLs tend to emphasize tasks traditionally done by one sex or another. For example, an elderly male's inability to cook may reflect the fact that his wife always performs that task for him. Thus, his inability to prepare meals is not related to any physical or mental disability.

Another domain, related to ADLs and IADLs, is cognitive ability. Persons with Alzheimer's Disease and related dementias are prime examples of individuals with cognitive impairment. Measures of cognitive impairment are much less well developed than are ADL measures. One cognitive assessment scale that has been included in a number of national surveys is the Short Portable Mental Status Questionnaire (SPMSQ). The SPMSQ assesses mental functioning based on a ten-item test of orientation, recent memory, long-term memory, and capacity for serial calculation.¹⁸ Some example questions are: "What is the date today?", "When were you born?", and "Who is the President of the United States?".

Cognitive impairment and ADL status are correlated but are separate dimensions of functioning.¹⁹ Not all persons with substantial cognitive impairment have ADL dysfunctions. One recent study found nearly 40 percent of the elderly with moderate to severe cognitive impairment, as measured by the SPMSQ, received no active human assistance with any of five ADLs.²⁰ As a result, studies estimating the extent of need

¹⁵ M. Powell Lawton and Elaine Brody, "Assessment of Older People: Self-Maintaining and Instrumental Activities of Daily Living," *Gerontologist*, vol.9 (Autumn 1969), pp.179-86.

¹⁶ Gerda Fillenbaum, David Dellinger, George Maddox, and Eric Pfeiffer, "Assessment of Individual Functional Status In A Program Evaluation and Resource Allocation Model," in Duke University Center for the Study of Aging and Human Development's *Multidimensional Functional Assessment: The OARS Methodology*, second edition (Durham, N.C.: Duke, 1978) Appendix, p.14.

¹⁷ William Spector, Sidney Katz, John P. Fulton, "Hierarchical Relationship Between Activities of Daily Living and Instrumental Activities of Daily Living," *Journal of Chronic Diseases*, vol.40, 1987, pp.481-90.

¹⁸ Eric Pfeiffer, "A Short Portable Mental Status Questionnaire for the Assessment of Organic Brain Deficit in Elderly Patients," *Journal of the American Geriatrics Society*, vol.23, 1975, pp.433-41.

¹⁹ Fillenbaum and others, "Assessment of Individual Functional Status," table 1, p.6.

²⁰ David Kennell, Lisa Alecxih, Polly Erickson, Joshua Wiener and Raymond Hanley, "The Estimated Costs of a Proposed Home Care Program," final report to the Commonwealth Fund Commission on Elderly People Living Alone, May 22, 1989, Table 5.

for long-term care services that rely solely on ADL measures will miss a substantial proportion of the target population.

II. NATIONAL DATA BASES MEASURING ADLS

In recent years, a number of national surveys, designed for a variety of purposes, have collected information on the ADL status of the elderly. Figure 1 lists eleven of these surveys, the population each seeks to describe, the sample design, how disability was defined and which ADLs were asked about. Appendix I describes the eleven surveys in considerable detail.

A. 1982 National Long-Term Care Survey

The 1982 National Long-Term Care Survey (1982 NLTCS) is a nationally-representative survey of noninstitutionalized Medicare beneficiaries aged 65 and over with functional limitations. The survey was designed to provide data on the number and type of physical limitations affecting the elderly, the kind, amount and costs of services they receive, and their ability to pay for that care. The sample frame was 36,000 Medicare enrollees screened by phone or in-person for an ADL or health-related IADL problem that had or would endure for three months or longer. The screen netted a final sample of 6,393 disabled elderly who received detailed personal interviews. Elderly residing in hospitals, nursing homes or other institutions were excluded. This survey was sponsored by the Office of the Assistant Secretary of Planning and Evaluation/U.S. Department of Health and Human Services and the Health Care Financing Administration.

B. 1982 New Beneficiary Survey

The 1982 New Beneficiary Survey (NBS) is a nationally representative household survey of **new** Social Security beneficiaries. The survey provides detailed information on new Social Security participants to address program operation research needs. Personal interviews were conducted with 18,599 persons who had begun receiving benefits between mid-1980 and mid-1981 as retired workers, disabled workers aged 18 and older, or auxiliary benefits for wives and aged widows, and workers aged 65 and older who lost benefits because of the earnings test. Responses were later linked to Social Security administrative data on benefits and earnings, and to data from the Medicare Automated Data Retrieval System. The survey was sponsored by the Social Security Administration.

C. 1982-84 NHANES I Epidemiologic Followup Study

The 1982-84 NHANES I Epidemiologic Followup Study (NHEFS) is a longitudinal study of those persons aged 25-74 at baseline who participated in the first National Health and Nutrition Examination Study (NHANES I) which was conducted between 1971-75. The Followup was designed to investigate the relationship between risk factors measured at baseline and subsequent morbidity and mortality. Approximately 5,700 NHANES I participants were aged 55 and older at baseline; 5,500 of whom were successfully traced. Of these, 3,500 were alive at followup and had reached the aged of 65 years. An extensive battery of questions were designed to characterize general

functional ability. In addition, particular functional limitations can be related to reported symptoms, diagnosed conditions and hospital utilization. Two additional waves of followup have been conducted--one in 1986 and the second in 1987. This survey was sponsored by the National Center for Health Statistics and other agencies of the Public Health Service.

D. 1984 National Long-Term Care Survey

The 1984 National Long-Term Care Survey (1984 NLTCS) is primarily a followup survey of the sample of 36,000 elderly Medicare beneficiaries initially screened for the 1982 NLTCS. In addition, approximately 5,000 persons who turned aged 65 after 1982 were added to the 1984 sample screened for impairments, and those reporting a disability were then given a detailed interview. This provided a representative cross-section of the population aged 65 and older with functional limitations for 1984. The 1984 NLTCS provides data on elderly with a chronic impairment in 1982, elderly in institutions in 1982 and elderly screened in 1982 but not reporting a chronic limitation. The 1984 NLTCS contained an institutional and decedent component as well. This survey was sponsored by the Health Care Financing Administration and the National Center for Health Services Research.

E. 1984 National Health Interview Survey, Supplement on Aging

The 1984 National Health Interview Survey (NHIS), Supplement on Aging (SOA) is an in-person, household survey of 16,148 persons aged 55 and older. Designed to provide national estimates on middle-aged and older noninstitutionalized persons, the SOA collected information on various health-related topics such as family structure, disability and health service use. About 11,500 interviews were obtained for persons aged 65 and over. This survey was sponsored by the National Center for Health Statistics.

F. 1984-86 Longitudinal Study of Aging

The 1984-1986 Longitudinal Study of Aging (LSOA) is a prospective survey of 5,151 persons aged 70 and older who were initially interviewed in the 1984 SOA. The LSOA was designed to measure change in functional status, living arrangements, and health service use. Data were collected primarily by telephone and mail-outs. This survey was sponsored by the National Center for Health Statistics and the National Institute on Aging.

G. 1984 Survey of Income and Program Participation

The 1984 Survey of Income and Program Participation (SIPP) is designed to collect data on changes in income and participation in federal programs such as Social Security, Supplemental Security Income and Medicaid. SIPP is a longitudinal survey of about 26,000 housing units representing the noninstitutional population. Each household in the initial sample was interviewed at four-month intervals over a period of two and one-half years beginning in October 1983. The third wave supplement to the 1984 panel of SIPP contained a set of questions on disability status. Approximately

20,900 households were interviewed and about 5,900 respondents were aged 65 and older. This survey was sponsored by the Bureau of the Census.

H. 1985 National Nursing Home Survey

The 1985 National Nursing Home Survey (NNHS) provides information on current residents and discharges from nursing homes. The Current Resident Component is a nationally-representative sample of nursing home residents collected from 1,079 nursing and related care homes. Through interviews with nursing staff, information was collected on a sample of residents on the nursing home's roster the night before the survey. There are 4,650 elderly in this sample. The Discharges Component of NNHS contains a sample of 5,329 elderly nursing home discharges over a 12-month period. This survey was sponsored by the National Center for Health Statistics.

I. 1986 National Mortality Followback Survey

The 1986 National Mortality Followback Survey (NMFS) provides nationally-representative estimates of all decedents in 1986 aged 25 and older. Data was collected by mail-out, telephone and personal interviews with next-of-kin for 18,500 persons who died in that year; 10,154 decedents were aged 65 and older. The National Mortality Followback Survey was designed to provide data on socioeconomic differentials in mortality, the association between risk factors and mortality, care in the last year of life and the reliability of certain death certificate data. This survey was sponsored by the National Center for Health Statistics.

J. 1987 National Medical Expenditure Survey

The 1987 National Medical Expenditure Survey (NMES) provides nationally-representative data on health services use and expenditures among both noninstitutionalized and institutionalized individuals. The NMES Household Component consists of a longitudinal sample of 14,000 households. About 5,750 sample members were aged 65 and older. Data were collected at four points in time in 1987 using an in-person interview with each household member or, when unavailable, a proxy. The NMES Institutional Component is a longitudinal survey of 2,800 current residents and 2,800 new admissions from 815 nursing homes and personal care facilities. About 2,550 current residents were aged 65 and over. Data were collected over one year by personal interviews with nursing staff for the Baseline Questionnaire and from a primary informal caregiver for the Personal History Questionnaire. This survey was sponsored by the National Center for Health Services Research.

III. COMPARING ESTIMATES FROM DIFFERENT SURVEYS

Public policymakers and insurance actuaries typically want to know the answer to what seem to be simple questions: How many persons aged 65 and older have ADL problems? How many have ADL problems by each type of activity? How many elderly have more than a threshold number of ADL problems? Unfortunately, researchers designing and analyzing surveys quickly find that answering those questions are complicated tasks requiring decisions for which there is not an obvious choice.²¹ Differences in lists of ADLs, what constitutes an ADL problem or limitation, and varying technical survey techniques accounts for many, but not all, of the differences in ADL estimates across surveys.

A. Which ADLs Are Included?

Not all surveys or analysts use the same list of ADLs. Most surveys include eating, toileting, transferring, dressing, and bathing. However, because of considerations of time and respondent burden, sometimes not all of these are asked about or may not be asked about separately. For example, the 1984 Survey of Income and Program Participation asks one combined question about "dressing, eating and personal hygiene." Other surveys and analysts may or may not include as ADLs such additional activities as walking, getting around inside, getting around outside and controlling bowels or urine.

Which and how many activities are included can make a big difference in the number of people counted as having disabilities, especially if the analyst is "counting" the number of ADL problems. Obviously, the more ADLs that are included, the larger will be the number of people with ADL disabilities. For example, one study using the 1984 Supplement on Aging found that there were 3.7 million elderly with limitations in one of the five ADLs but 6.0 million elderly with limitations in one of seven ADLs.²²

²¹ Even carefully specified ADL estimates obtained from the same data source may vary between analysts. For example, to assist with this report, both the Center for Demographic Studies at Duke University and the National Center for Health Services Research furnished the Committee with estimates obtained from the 1982 and 1984 National Long-Term Care Surveys on the number of elderly receiving help with bathing, dressing, transferring, toileting, eating, and with any one of these activities. Even though the two sets of results were close, no pair matched exactly. The average difference for a given ADL was about 55,000 elderly (range 1,000 - 103,000), but neither source was consistently high or low. The reasons for the different estimates involve dissimilar handling of missing data, minor differences in programming the questionnaire skip patterns, and varying definitions of "receives help with" based upon whether the helper provide "active" or "stand-by" assistance. Personal communication, Frances Pendergrass, Duke University, June 27, 1989.

²² Diane Rowland, Barbara Lyons, Patricia Newman, Aliva Salganicoff and Lydia Taghavi, "Defining the Functionally Impaired Elderly Population," (#8808, Washington, D.C.: American Association of Retired Persons, November 1988), p.24, Figure 4. The five ADLs are bathing, dressing, transferring, toileting and eating. The seven ADLs are the original five plus getting around outside and walking.

Recently, a number of legislative proposals have surfaced that focus on five ADLs--eating, toileting, transferring, dressing, and bathing.²³ These are the ADL items which have been proposed for use in determining eligibility for benefits in several proposed public insurance programs. Private insurance plans are more varied in which ADLs they use to determine eligibility for benefits.²⁴

B. How Are ADLs Measured?

Although there is some consensus across surveys as to which activities of daily living should be included, there is a great deal of variation in the way surveys ask about ADL functioning. The surveys differ in measuring what type of assistance was received, the degree of difficulty in performing each ADL, and the duration of the disability. Differences in question wording can also produce subtle variation. Even within a single survey, the inclusion of multiple questions for a given ADL item can produce different estimates depending on which questions are chosen to measure a limitation. Some of the important variations in the type of information collected on ADL items by each survey are summarized on Figure 2 .

A critical definitional issue concerns whether to count as disabled only persons "receiving active human assistance" or whether to include persons who rely on "special equipment or mechanical aids" and persons requiring only "supervision or stand-by assistance." Mechanical assistance can include such devices as grab bars on special beds to facilitate transferring. Arguably, some people would need human assistance if the special equipment were not available. Stand-by assistance is often needed by persons with cognitive impairment whose motor abilities may actually be quite good, but who are not always sure what they are supposed to do.

Whether or not to limit ADL dependencies to persons receiving active human assistance can have a major impact on the estimates. One study using the 1982 National Long-Term Care Survey found that if only people receiving active human assistance were classified as having a disability, there were 1.0 million people with problems performing two of five ADLs; when a more inclusive definition was used, 1.7 million people were identified with two of five ADLs.²⁵ Another study using the 1984 National Long-Term Care Survey found that among the 1.7 million elderly with a bathing limitation who were not using mechanical help, 60 percent had active human help, 27 percent required only stand-by help, another 11 percent reportedly did not bathe, and 3 percent reported an unmet need for bathing help.²⁶

²³ This included bills introduced in the 100th Congress by Representatives Pepper (H.R.2762), Waxman (H.R.5320), Senators Kennedy (S.2681), Mitchell (S.2305) and Melcher (S.2671).

²⁴ Susan Van Gelder, "Long-Term Care Insurance: Market Trends," (Washington, D.C.: Health Insurance Association of America, March 1989), p.25, Table 2.

²⁵ David Kennell and others, "The Estimated Costs of a Proposed Home Care Program," prepared for the Commonwealth Fund Commission on Elderly People Living Alone, May 22, 1989. Estimates shown in the report were based on 1982 prevalence which was aged up to 1989 population totals.

²⁶ Robyn Stone and Christopher Murtaugh, "The Elderly Population with Chronic Functional Limitations: Implications for Home Care Eligibility," paper presented at the annual meeting of the American Public Health Association, Boston, MA, November 13-18, 1988, (Rockville, Md: National Center for Health Services Research).

Some surveys, such as the 1984 Supplement on Aging and the 1986 Longitudinal Study of Aging, asked each respondent to classify his or her ADL limitation by the level of difficulty in performing them--some, a lot, unable. For example, among the estimated 2.0 million persons aged 70 and older who reported a bathing difficulty in the 1984 Longitudinal Study of Aging, 40 percent had "some" difficulty, 22 percent had at least "a lot" of difficulty, and 38 percent were "unable" to bathe.²⁷ Other surveys do not ask for such gradations. Where level of difficulty measures exist on the survey, the analyst has the option of only considering the respondent to be disabled if she has "a lot" of difficulty or is "unable" to perform the activity.

A third definitional issue relates to the duration of the disability. When screening persons for inclusion in the detailed surveys, the 1982 and 1984 National Long-Term Care Surveys asked whether respondents had at least one ADL or health-related IADL problem "which had lasted, or was expected to last, 90 days or longer." In contrast, most other surveys asked about disability on the day of the survey. Thus, compared to the 1982 and 1984 National Long-Term Care Survey, other surveys may include more short-term disability. A recent study using the 1987 National Medical Expenditure Survey, for example, found the number of elderly with a bathing limitation that had lasted over 90 days was 10.4 percent lower than the same estimate for the day of the survey.²⁸

Differences in each survey's wording of ADL questions may also introduce subtle variation in survey response. To illustrate, compare the wording of the initial question on bathing limitations from three of the surveys:

The 1987 NMES:

"Because of a mental or physical health problem, do you (or anyone in the family) have any difficulty bathing or showering without help?"

The 1984 NLTCS:

"Since last (insert day one week ago), did any person help (sample person) bathe, or was (sample person) unable to bathe at all?"

The 1984 SOA:

"Because of a health or physical problem, do you have any difficulty bathing or showering?"

Among the three, note that only the National Long-Term Care Survey omits "showering" from the question and gives the respondent a one week reference period. Another difference is the mention of a "physical health problem" in the Supplement on Aging and the National Medical Expenditure Survey questions which is not found in the

²⁷ Estimates tabulated by the Brookings Institution, 1988 (unpublished).

²⁸ Joel Leon and Tamra Lair, "Functional Status of the Elderly: Estimates of ADL and IADL Difficulties," National Medical Expenditure Survey Research Findings 4 (Rockville, MD: National Center for Health Services Research and Health Care Technology Assessment) August 31, 1989 draft, Table 1.

National Long-Term Care Survey. Moreover, only National Medical Expenditure Survey mentions "mental health" as a potential source for a bathing problem. Finally, both National Medical Expenditure Survey and the National Long-Term Care Survey start off the bathing questions by asking about "help". The Supplement on Aging asks about bathing "help" in a completely separate question. To the extent that questions vary, so will the responses.

Differences in how questions are asked and who is counted as being disabled are often the result of answering different research questions. For example, an epidemiologist studying the relationship between a disease and its symptoms may be most interested in whether there is any physical problem and the exact nature of that dysfunction (e.g., does the bathing problem reflect difficulty controlling the faucet or does it reflect getting in and out of the tub?) The epidemiologist may be less interested in knowing whether a person receives human assistance in performing their ADLs. In contrast, an actuary estimating the potential demand for a new home care insurance benefit is probably less interested in the underlying biological problems than in whether the person could, for example, bathe independently with grab bars or whether he or she needs human help.

Some surveys ask about different aspects of the same ADL problem. The detailed 1982 and 1984 National Long-Term Care Survey interviews asked about eight or nine separate questions about each activity. For example, some of the eight separate, consecutively asked questions designed to get at different aspects of eating limitations were: "Did you use special utensils or special dishes to help you eat?"; "Did someone usually stand by just in case you needed help?"; "Did someone feed you?"; and, "Did someone help you cut your meat or butter your bread?" The additional detail afforded by asking about specific aspects of a person's eating limitation may generate divergent estimates simply because the analyst chooses to analyze one rather than another question from the same survey.

Further complicating matters, the National Long-Term Care Surveys had a section referred to as the "control card" in 1982 and the "flap" in 1984, which required the interviewer to recap whether the respondent had reported a particular ADL limitation. Some analysts choose to report estimates based on this constructed measure rather than on the detailed questions.²⁹

C. What Effect Do Year of Survey, Sample Frame, and Survey Techniques Have on ADL Estimates?

Differences in ADL estimates may also derive from a combination of technical factors, although the effect of these factors is not clear in terms of direction and magnitude. These differences include the year the survey was conducted, sample frame, use of proxy respondents, and survey instrument design.

One clear difference among surveys is in the year the interviews were conducted. Given the strong association between age and ADL status, a change in the age

²⁹ Korbin Liu, Kenneth G. Manton and Barbara Marzetta Liu, "Home Care Expenses for the Disabled Elderly," *Health Care Financing Review*, vol.7 (Winter 1985), p.52; Kenneth Manton, "A Longitudinal Study of Functional Change and Mortality in the United States," p.S156, table 1.

composition of the elderly population could result in different prevalence estimates.³⁰ For example, between 1982 and 1987, the number of elderly aged 65-74 increased only 9.1 percent, while the number aged 75-84 increased 13.7 percent and the number aged 85 and older grew by 17.3 percent.³¹

Another possible explanation for varying estimates involves differences in sampling frame. To estimate elderly ADL status in the community, the 1982 and 1984 National Long-Term Care Surveys sampled individuals, not households, and only Medicare-enrolled individuals--a very close approximation but still an incomplete set of all U.S. elderly. Estimates from the 1984 Supplement on Aging, the 1984 Survey of Income and Program Participation and the 1987 National Medical Expenditure Survey were based on a subsampling of all household members aged 65 and over from a representative sample of all U.S. households. Similarly, for the institutionalized population, the 1985 National Nursing Home Survey used a sampling frame of 20,479 nursing and related care facilities contained in the National Master Facility Inventory.³² On the other hand, the 1987 National Medical Expenditure Survey used a much larger sampling frame called the Inventory of Long-Term Care Places which contained 38,930 facilities and included board and care facilities that are excluded from the National Master Facility Inventory.

Still another source of variation among surveys was the way in which data were collected. The 1982 National Long-Term Care Survey relied primarily on face-to-face interviews with disabled beneficiaries, except in 24 percent of the cases where the interview was conducted with a proxy respondent. A proxy was used when a sample person was absent, physically or mentally unable to participate, did not speak English, or had speech or hearing problems.³³ The 1984 Supplement on Aging also obtained face-to-face information from elderly sample persons, with close to 30 percent of disabled respondent data coming from proxies.³⁴ In many cases, the 1984 Survey of Income and Program Participation and the 1987 National Medical Expenditure Survey interviewed only one person in each household who was asked about all other household members. Proxy respondents may answer questions differently than the sample person would if asked in-person. Even more fundamentally, none of the surveys actually asked respondents to perform the indicated ADLs. Preliminary research being conducted at the National Institute on Aging and the National Center for Health Statistics suggest that there may be discrepancies between survey responses and actual physical capabilities.³⁵

³⁰ Timothy D. McBride, "Measuring the Disability of the Elderly: Empirical Analysis and Projections into the 21st Century," paper presented at the Population Association of America Meeting, Baltimore, Md, March 31, 1989 (Washington, D.C.: The Urban Institute).

³¹ U.S. Bureau of the Census, "United States Population Estimates, by Age, Sex, and Race: 1980 to 1987," *Current Population Reports*, Series P-25, no.1022, (Washington, D.C.: Department of Commerce, 1988) Table 1.

³² Esther Hing, "Use of Nursing Homes by the Elderly: Preliminary Data From the 1985 National Nursing Home Survey," *Advance Data* (Hyattsville, Md: National Center for Health Statistics), No.135, May 14, 1987, p.1.

³³ Candace L. Macken, "A Profile of Functionally Impaired Elderly Persons Living in the Community," *Health Care Financing Review*, vol.7 (Summer 1986), p.35.

³⁴ National Center for Health Statistics, "The Supplement on Aging to the 1984 National Health Interview Survey," *Vital and Health Statistics*, series 1, no.21, (Hyattsville, Md: NCHS, June 1987) p.22, Table F.

³⁵ Jack Guralnik, National Institute on Aging and Tamara Harris, National Center for Health Statistics, personal communication, June 14, 1989.

Yet another potential explanation of divergence in ADL estimates is that similar ADL information may be collected at more than one time in the same survey. For example, the 1982 National Long-Term Care Survey screened about 36,000 elderly Medicare beneficiaries to develop the sample used to collect detailed information from 6,393 disabled elderly. When interviewers came to conduct the detailed survey, nearly 9 percent reported that they were no longer disabled.³⁶ This two-step process resulted in two separate sets of ADL prevalence estimates from the 1982 National Long-Term Care Survey--one from the screen interview, and one from the detailed survey.³⁷

D. What Happens to the Estimates When Standardized for List of ADLS and Definition of Having a Problem?

Given the apparent variability of estimates based upon differences in lists of ADLs and in definitions, the only meaningful way to compare ADL estimates across surveys is to control for these differences. The Committee on Definitions of Functional Limitations collected a closely-specified set of ADL data on the elderly population from each survey. Weighted and unweighted data were developed for all persons aged 65 and older, with separate estimates for persons receiving help with bathing, dressing, transferring, toileting, and eating, along with an overall estimate of the elderly receiving help at least one of these activities. The data were not, however, age-adjusted.

Comparable estimates of the prevalence of functional limitations for the elderly were assembled for eight of the eleven national surveys identified as collecting information on ADLs.³⁸ Estimates for the five comparable surveys covering the noninstitutionalized elderly are shown in Table 1.

Standardizing reduces but does not eliminate the differences across surveys. The estimates show that the proportion of all elderly in the community receiving help with at least one ADL limitation ranges from a low of 5.0 percent in the 1984 Supplement on Aging to 8.1 percent in the 1987 National Medical Expenditure Survey Household Survey--a difference of about 750,000 to 850,000 elderly depending on the year of the survey. For each ADL item asked, the 1984 Supplement on Aging consistently produced the lowest estimate of elderly functional limitations. No one survey was consistently high over the range of ADLs. Taken together, the five surveys suggest that between 4.6 and 6.9 percent of the noninstitutionalized persons aged 65 and older

³⁶ This is the difference between the number of persons screened into the detailed interview sample (5.1 million) versus those persons who reported a functional limitation on the control card of the detailed interview (4.65 million). For an example of the first see, Candace L. Macken, "A Profile of Functionally Impaired Elderly Persons Living in the Community," p.37, table 1. For the smaller estimate see Korbin Liu and others, "Home Care Expenses for the Disabled Elderly," p.52.

³⁷ In general, the estimates from the detailed 1982 interview are lower than the 1982 screen estimates because of remission from disability which occurred in the interim between the interviews. Nondisabled screen respondents were not rescreened to qualify for a detailed interview until the follow-up survey conducted in 1984.

³⁸ Four of the surveys were not designed to provide prevalence estimates for a nationally-representative sample of the elderly in the community or in institutions. The 1982 New Beneficiary Survey covered only new (not all) Social Security beneficiaries. The 1982-84 NHANES I Epidemiologic Followup did not have enough persons who had reached age 85 to produce estimates for the entire elderly population. The 1984-86 Longitudinal Study on Aging did not interview any elderly under age 70, and the 1986 National Mortality Followback Survey can represent only that subset of elderly who died during the year.

require personal help bathing, between 2.9 and 4.4 percent need similar help dressing, between 2.6 and 4.2 percent need help transferring, between 2.4 to 3.4 percent need help with toileting, and between 0.7 to 2.5 percent need help eating.

Table 2 adds the NHANES I Epidemiologic Followup Study to the list and focuses the comparison on the noninstitutionalized elderly aged 65-74. The pattern of results is very similar to Table 1. The main difference is that the percentage point spread between the highest and lowest estimates for each ADL narrows, reflecting the overall lower prevalence rate for this age group. In addition, the 1984 Supplement on Aging no longer consistently produces the lowest estimates.

Two of the eleven surveys can be used to compare functional limitations among the institutionalized elderly population. Table 3 presents these estimates for the resident population. The National Nursing Home Survey and the National Medical Expenditure Survey Institutional Component surveys found just over 91 percent of the institutionalized elderly received help with at least one of the five ADLs and both found just over 90 percent of residents received help with bathing. Estimates for dressing, transferring and eating were slightly higher for the 1987 National Medical Expenditure Survey than for the 1985 National Nursing Home Survey. The largest difference between the two surveys of the institutionalized elderly was for toileting which ranged from 51 percent in the National Nursing Home Survey to 67 percent in the National Medical Expenditure Survey. However, since only about 5 percent of the elderly are institutionalized on a given day, the absolute difference of this discrepancy is only about 200,000 elderly.

Because the estimates obtained from each of these surveys are based on a sample, the data for any survey will differ somewhat from what would be obtained if a complete census were taken. Variations which could occur by chance because only a sample of the population is surveyed are measured by the relative standard error of the estimate. Sample size and the number of observations of a particular trait greatly affect the size of the standard error. When sample size is increased, the standard error declines. As shown on Table 1, there is great variability across surveys in the number of actual observations for each ADL. At the extreme, for eating disabilities, the range in the actual number of cases varies from 650 for the 1984 National Long-Term Care Survey to 76 for the Supplement on Aging.

If the confidence interval of the ADL limitations resulted in overlapping estimates between these surveys, then chance variation could account for the observed differences. To illustrate the potential range in estimates, we calculated confidence intervals for the number of elderly receiving help with one or more ADLs and for those receiving help eating, which is the least frequent ADL problem. Table 4 presents the 68 percent, 95 percent, and 99 percent confidence ranges for the 1984 Supplement on Aging, the 1984 National Long-Term Care Survey and the 1987 National Medical Expenditure Survey. For example, the 1984 Supplement on Aging estimate of 183,000 persons aged 65 and older requiring help to eat has a relative standard error of 13

percent.³⁹ The 1984 National Long-Term Care Survey estimate of 618,000 elderly having a comparable eating limitation has a relative standard error of 4 percent.⁴⁰

Calculating these confidence intervals also reduces but does not eliminate differences across surveys. The estimates for eating disabilities between the 1984 Supplement on Aging and the 1984 National Long-Term Care Survey are still 314,000 apart even at the upper and lower ranges of the 99 percent confidence interval. Sampling variability among estimates of elderly receiving help with one or more ADLs shows substantial overlap between the 1984 National Long-Term Care Survey and the 1987 National Medical Expenditure Survey beginning at the 95 percent confidence interval. However, like estimates for eating limitations, the 1984 Supplement on Aging estimate is still over 500,000 lower than either of the other two surveys even at the high and low end of the 99 percent confidence interval.

³⁹ National Center for Health Statistics, "Current Estimates from the National Health Interview Survey of the United States, 1984, *Vital and Health Statistics*, Series 10, no.156, July 1986, Figure VII, p.139.

⁴⁰ Duke University Center for Demographic Studies, "Overview and Use of the Public Use Data Files of the 1982 and 1984 National Long-Term Care Surveys," documentation for the public use tapes, January 6, 1988, table 5B, p.21.

IV. CONCLUSIONS

To the casual observer, estimates of the prevalence of activity of daily living disabilities for the elderly population differ substantially across national surveys. Sources of the variation in national survey-based estimates of the elderly with ADL problems includes potential differences in:

- Which ADLs are included (especially when counting the number of ADLs).
- How ADLs are classified by:
 - level of difficulty;
 - type of assistance;
 - duration of problem.
- Exact wording of questions.
- Age composition of the elderly population in the survey year.
- Sample frame used to select respondents.
- Methods used to collect data.
- That similar ADL information may be contained in more than one place in the same survey.
- That multiple questions are often asked on each ADL item in a single survey.
- Chance sampling variability.

When an effort is made to standardize ADL items for comparison, estimates for the community-based population vary by no more than 3.1 percentage points for the noninstitutionalized population; and for the institutionalized population, with the exception of toileting, by no more than 3.2 percentage points. As small as these differences are in absolute terms, they can be large in percent differences across surveys. For example, the National Medical Expenditure Survey estimates that there are 60 percent more elderly receiving help with ADL problems than does the Supplement on Aging.

Our main conclusion is that there is no one "right" estimate of ADL prevalences. Researchers and policy analysts alike need to be aware that ADL disability rates are simply much "softer" measures than, say, mortality rates. From wording decisions made by persons who design the survey questionnaire, to the analysts who choose a particular ADL question or set of questions to analyze and report, to the programmers who must actually handle multiple question recodes and deal with missing or inconsistent data, each step will affect the results. Given a lack of consensus on exactly how to measure ADLs, even an extremely large sample could not provide a definitive estimate.

Notwithstanding these differences, the estimates are remarkably alike. This is especially true if we focus on the percentage of persons without an ADL limitation. At one extreme, the Supplement on Aging estimates that 95 elderly out of 100 do not receive help with any of five ADLs. At the other extreme, the National Medical Expenditure Survey puts the number of comparably nondisabled elderly at 92 persons out of a 100. If the policy interest was on the nondisabled, no one would give these differences in estimates a second thought. Indeed, most observers would be commenting on the consistency of the estimates across surveys. The fact is that, even among the elderly, ADL limitations are relatively rare and some variation in the estimates is inevitable.

Moreover, it should be remembered that conducting survey research is different than running a public or private program that pays for long-term care services. Actual participation rates for benefits which use ADL status as an eligibility trigger may be quite different than what is estimated by a survey. Even aside from the technical design and analysis issues, the incentives for the respondent are very different when applying for Medicare or insurance benefits than they are when answering a research survey. Policy analysts and actuaries will need to make their cost estimates consistent with how tightly the program will be administered, how they believe the elderly will respond to the availability of financing, and how important it is that costs not be under- or overestimated.

In sum, much of the variation in ADL estimates across national surveys can be explained by legitimate differences in survey and analytic methodologies. Once this is done, estimates for the noninstitutionalized and institutionalized elderly population are consistent within a few percentage points. However, since there is no one "right" methodology, estimates can legitimately vary a great deal in percentage terms, especially for relatively rare ADL problems such as eating. Thus, in choosing which survey to examine and which survey items to use, policy analysts and researchers will need to think carefully about what questions they are trying to answer. In addition, to avoid confusion, in reporting their results, they need to specify in greater detail than they might otherwise how they defined ADL disabilities and which data elements they used.

FIGURE 1 . Comparison of ADL Questions on National Surveys

Survey	Population	Sample Design	Screener			Detailed		
			Separate Instrument	Questions	ADLs	Questions	ADLs	Comments
National Long-Term Care Survey (1982)	Functionally impaired elderly, age 65+ (sample N=6,393).	1982 Medicare HISKEW file; 36,000 cases screened, 6,393 eligible; 6,088 interviewed.	Yes	1. Any problems with ...[ADL]? 2. Duration is or will be 3 months or longer?	1. Eating. 2. Getting in/out of bed. 3. Getting in/out of chairs. 4. Walking inside. 5. Going outside. 6. Dressing. 7. Bathing. 8. Using bathroom. 9. Controlling bowels/urination.	If "any problem"-- 1. Any person help with [ADL]? 2. Special equipment? 3. Someone stand by? 4. How often help received/ equipment used? 5. How long help received/ equipment used? 6. How long unable to do [ADL]? 7. Need help? 8. Who helps most?	1. Eating. 2. Getting in/out of bed. 3. Getting around inside. 4. Dressing. 5. Bathing. 6. Using bathroom.	A. Has unmet need. B. Has cognitive impairment (SPMSQ).
New Beneficiary Survey (1982)	New Social Security beneficiaries (between mid-1980 and mid-1981).	National probability sample of 17,150 new Social Security beneficiaries (retired, disabled, spouses) plus 1,444 Medicare beneficiaries eligible for Social Security but not receiving it.	No	N/A	N/A	1. Have to stay in bed? chair? wheelchair? 2. How often need help with personal needs (dressing, eating, hygiene combined)? 3. Can get out of bed and wash and dress? 4. Usually able to get out of doors? use public transportation?	1. See QUESTIONS.	A. Level of difficulty questions. B. Focus on ability/ inability to perform work.
NHANES I Epidemiologic Follow-up Study (1982-84)	Persons aged 25-74 examined in the first National Health and Nutrition Examination Survey (1971-75).	14,407 participants who were age 25-74 during NHANES I (1971-1975). Includes persons aged 65+ at time of 1982-1984 follow-up.	No	Now I am going to read a list of activities with which people have difficulty. Please tell me if: you have no difficulty, some difficulty, much difficulty or are unable to do these activities at all when you are by yourself and without the use of aids.	1. Dressing. 2. Transferring; in/out of bed/chair. 3. Eating: lifting full cup or cutting meat. 4. Bathing; wash and dry entire body. 5. Toileting. 6. Walking.	You said that (you have much difficulty/are unable to do) (ACTIVITY) by yourself. Do you have help from: 1. Another person? 2. A mechanical aid or device?	1. Dressing. 2. Transferring; in/out of bed/chair. 3. Eating: lifting full cup or cutting meat. 4. Bathing; wash and dry entire body. 5. Toileting. 6. Walking.	A. These ADLs are part of larger 26 item battery. B. Upper age limit.

Survey	Population	Sample Design	Screener			Detailed		
			Separate Instrument	Questions	ADLs	Questions	ADLs	Comments
National Long-Term Care Survey (1984)	Functionally impaired elderly, age 65+	Four groups: a. All persons alive in 1984 with functional limitations and previously interviewed in 1982 (N=25,010). b. All persons alive in 1984 and in institutions in 1982 (N=1,182). c. Subsample of persons alive in 1984 who had been screened but found not disabled in 1982 (N=11,130). d. Sample of persons alive in 1984 who had 65th birthday since 1982 survey.	Yes	1. Any problem with... [ADL]? 2. Duration is or will be 3 months or longer?	1. Eating. 2. Getting in/out of bed. 3. Getting in/out of chair. 4. Walking inside. 5. Going outside. 6. Dressing. 7. Bathing. 8. Using bathroom. 9. Controlling bowels/urination.	If "any problem"-- 1. Any persons help with [ADL]? 2. Special equipment? 3. Someone stand by? 4. How often help received/equipment used? 5. How long help received/equipment used? 6. How long unable to do [ADL]? 7. Need help? 8. Who helps most?	1. Eating. 2. Getting in/out of bed. 3. Getting around outside. 4. Dressing. 5. Bathing. 6. Using bathroom.	A. Has unmet needs. B. Has cognitive impairment (SPMSQ).
National Health Interview Survey Supplement on Aging (1984)	Elderly persons, age 55+ (Sample N=16,148)	Sample of civilian noninstitutionalized population (40,000 households; including elderly).	No	1. Because of a health or physical condition, do you have any difficulty with [ADL]? (1-7). 2. Do you have difficulty...? (8-9).	1. Bathing. 2. Dressing. 3. Eating. 4. Getting in/out of bed/chairs (transferring). 5. Walking. 6. Getting outside. 7. Using toilet. 8. Controlling bowels? 9. Controlling urination?	If "any difficulty"-- 1. [ADL difficulty] because of health/ physical problem. 2. How much difficulty with [ADL]? 3. Help from another person. 4. Who gives help? 5. Special equipment.	1. Bathing. 2. Dressing. 3. Eating. 4. Getting in/out of bed/chairs. 5. Walking. 6. Getting outside. 7. Using toilet.	A. Has level of difficulty.
Survey of Income and Program Participation -- Disability Module (1984)	Civilian noninstitutionalized U.S. population.	Complex design involving panels, four subsamples ("rotating groups") and quarterly "waves" of interviews over 2½ for each panel. Panels consist of approximately 15,000 - 17,000 households. Wave 3 interviews (May - August 1984) included health and disability module.	No	Any difficulty with [ADL]?	1. Getting around outside. 2. Getting around inside. 3. Getting in/out of bed. 4. Personal needs (dressing, eating, personal hygiene combined).	For "any difficulty" 1. Need help of another person? 2. Who helps?	1. Getting around outside. 2. Getting around inside. 3. Getting in/out of bed. 4. Personal needs (dressing, eating, personal hygiene combined).	A. Health and disability module included because of relationship to work, earnings, income sources and public program participation.
Longitudinal Study of Aging	Persons aged 70+ in 1984--5,151 (1986); 7,064 (1988).	Persons age 70+ who participated in 1984 NHIS/SOA.	No	1. Because of a health or physical condition, do you have any difficulty with [ADL]? (1-7) 2. Do you have difficulty...? (8-9)	1. Bathing. 2. Dressing. 3. Eating. 4. Getting in/out of bed/chairs (transferring). 5. Walking. 6. Getting outside. 7. Using toilet. 8. Controlling bowels. 9. Controlling urination.	If "any difficulty". 1. [ADL difficulty] because of health/ physical problem? 2. How much difficulty with [ADL]? 3. Help from another person? 4. Who gives help? 5. Special equipment?	1. Bathing. 2. Dressing. 3. Eating. 4. Getting in/out of bed/chairs? 5. Walking. 6. Getting outside. 7. Using toilet.	Has level of difficulty.

Survey	Population	Sample Design	Screener			Detailed		
			Separate Instrument	Questions	ADLs	Questions	ADLs	Comments
National Nursing Home Survey (1985)	Current residents.	Fixed sample of 5 or fewer residents per sampled nursing or related care home. 1,220 homes selected for 1985 survey.	No	Require any assistance with [ADL]?	1. Bathing/shower. 2. Dressing. 3. Eating. 4. Transferring in/out of bed/chair. 5. Controlling bladder. 6. Using toilet room.	If "any assistance". 1. Does respondent do [ADL] with help of: a. special equipment? b. another person? 2. How frequent does respondent have difficulty with bowels/bladder only?	1. Bathing/shower. 2. Dressing. 3. Eating. 4. Transferring in/out of bed/chair. 5. Controlling bladder. 6. Using toilet room.	
National Mortality Followback Survey (1986)	Persons aged 25 and over who died in 1986.	One percent sample of decedents from death certificates; questionnaire mailed to next-of-kin. Data mainly on last year of life, 18,500 deceased, including 10,154 age 65+.	N/A	N/A	N/A	1. Help from others or special equipment for [ADL]? 2. How long unable to perform [ADL] or receive help or use special equipment?	1. Walking. 2. Eating. 3. Bathing. 4. Dressing. 5. Using toilet.	Covers: A. Last year of life. B. Entire life.
National Medical Expenditure Survey -- Household (1987)	Civilian, noninstitutional U.S. population.	Year long panel (baseline, 3 follow-up interviews) of Census sample of 14,000 households includes oversample of elderly (4,400 households with 7,700 persons 65+).	Yes	1. Any difficulty with [ADL]? 2. Receive help?	1. Bathing. 2. Feeding. 3. Dressing. 4. Transferring. 5. Shopping. 6. Walking. 7. Getting around community?	1. Any difficulty with [ADL]? 2. Problem for more than 3 months? 3. Unable to do [ADL] at all (NOTE: not asked for bathing and dressing). 4. Receive help from another person? 5. Someone supervise, instruct or stay nearby? 6. Who gives help? 7. Special equipment or aids?	1. Bathing. 2. Dressing. 3. Toileting. 4. Transfer. 5. Feeding. 6. Walking.	Contains information on continence.
National Medical Expenditure Survey -- Institutional (1987)	Persons in nursing homes and personal care facilities.	38,930 facilities drawn from 1986 Inventory of LTC Places. Interviews with nursing staff and informal caregiver, 2,800 current residents; 2,800 new admittees (in 1987).	No	N/A	N/A	1. Any difficulty with [ADL]? 2. Problem for more than 3 months? 3. Unable to do [ADL] at all (NOTE: not asked for ing and dressing). 4. Receive help from another person. 5. Someone supervise, instruct or stay nearby? 6. Special equipment or aids?	1. Bathing. 2. Dressing. 3. Toileting. 4. Transfer. 5. Feeding. 6. Walking.	Contains information on continence.

FIGURE 2 . Type of Information on ADL Items in National Surveys										
Survey	Specified Duration		Special Equipment		Needs Assistance		Receives Assistance		Perceived Level of Difficulty	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
1982/1984 NLTCs	X		X		X		X			X
1982 NBS		X		X		X	X		X	
1982-84 NHANES I NEFS		X	X			X	X		X	
1984 SOA/ 1984-86 LSOA		X	X			X	X		X	
1984 SIPP		X		X	X		X			X
1985 NNHS		X	X			X	X			X
1986 NMFS		X	X			X	X			X
1987 NMES/ INST.		X	X			X	X			X
1987 NMES/ HOUSEHOLD	X		X			X	X			X

TABLE 1 . Activity of Daily Living Disabilities Among the Noninstitutionalized Elderly Aged 65 and Over, by Survey and Type of Activity (in thousands)

	1982 National Long-Term Care Survey	1984 National Long-Term Care Survey	1984 Supplement on Aging	1984 Survey on Income and Program Participation	1987 National Medical Expenditure Survey
Total Noninstitutionalized Elderly Population/% Aged 65 and Over (Unweighted n)	25,400/100.0% (17,658)	26,481/100.0% (19,720)	26,268/100.0% (11,425)	26,422/100.0% (5,900)	27,909/100.0% (5,751)
RECEIVES HELP OF ANOTHER PERSON WITH...					
One or More ADLs	1,992/7.8% (2,388)	2,062/7.8% (2,123)	1,318/5.0% (574)	1,538/5.8% ^a (351)	2,250/8.1% (546)
Bathing	1,609/6.3% (1,925)	1,660/6.3% (1,718)	1,211/4.6% (527)	1,459/5.5% ^b (332)	1,926/6.9% (472)
Dressing	1,072/4.2% (1,286)	1,063/4.0% (1,102)	771/2.9% (337)	^b	1,228/4.4% (305)
Transferring	1,072/4.2% (1,286)	1,072/4.0% (1,121)	675/2.6% (295)	699/2.6% (161)	977/3.5% (247)
Toileting	857/3.4% (1,030)	880/3.3% (919)	619/2.4% (269)	n.a.	670/2.4% (247)
Eating	624/2.5% (744)	618/2.3% (650)	183/0.7% (76)	^b	^c

n.a. not asked.

a. Excludes toileting.

b. Combines bathing, dressing, eating and personal hygiene in one question.

c. Cell size too small for reliable estimate.

TABLE 2 . Activity of Daily Living Disabilities Among the Noninstitutionalized Elderly Aged 65-74, by Survey and Type of Activity (in thousands)

	1982 National Long-Term Care Survey	1984 National Long-Term Care Survey	1982-84 NHANES I Epidemiologic Followup Study ^a	1984 Supplement on Aging	1984 Survey on Income and Program Participation	1987 National Medical Expenditure Survey
Total Noninstitutionalized Elderly Population/% Aged 65-74 (Unweighted n)	15,859/100.0% (10,439)	16,682/100.0% (12,687)	14,302/100.0% (980)	16,288/100.0% (7,054)	16,306/100.0% (3,648)	16,886/100.0% (3,489)
RECEIVES HELP OF ANOTHER PERSON WITH...						
One or More ADLs	801/5.1% (939)	813/4.9% (806)	502/3.5% (39)	457/2.8% (199)	471/2.9% ^b (108)	739/4.4% (180)
Bathing	634/4.0% (742)	639/3.8% (642)	303/2.1% (21)	404/2.5% (175)	432/2.6% ^c (99)	625/3.7% (150)
Dressing	430/2.7% (505)	436/2.6% (434)	272/1.9% (23)	288/1.8% (127)	c	456/2.7% (112)
Transferring	443/2.8% (515)	404/2.4% (405)	302/2.1% (23)	242/1.5% (104)	204/1.3% (47)	d
Toileting	343/2.2% (403)	328/2.0% (319)	101/0.7% (8)	209/1.3% (89)	n.a.	d
Eating	225/1.4% (260)	209/1.3% (200)	170/1.2% (17)	63/0.4% (27)	c	d
<p>n.a. not asked.</p> <p>a. Due to weighting considerations, estimates are not based upon data from the entire sample. See appendix for a discussion of sample weights.</p> <p>b. Excludes toileting.</p> <p>c. Combines bathing, dressing, eating and personal hygiene in one question.</p> <p>d. Cell size too small for reliable estimate.</p>						

TABLE 3 . Activity of Daily Living Disabilities Among the Institutionalized Elderly Aged 65 and Over, by Survey and Type of Activity (in thousands)		
	1985 National Nursing Home Survey^a	1987 National Medical Expenditure Survey^a
Total Institutionalized Elderly Population/% Aged 65 and Over (Unweighted n)	1,318/100.0% (4,650)	1,209/100.0% (2,449)
RECEIVES HELP OF ANOTHER PERSON WITH...		
One or More ADLs	1,207/91.6% (4,310)	1,104/91.3% (2,235)
Bathing	1,191/90.4% (4,254)	1,088/90.0% (2,204)
Dressing	1,002/76.0% (3,593)	952/78.7% (1,929)
Transferring	815/61.8% (2,907)	780/64.5% (1,581)
Toileting	666/50.5% (2,362)	807/66.7% (1,634)
Eating	502/38.1% (1,808)	422/34.9% (858)
a. Current resident survey.		

TABLE 4 . Sampling Variability for "Receives Help of Another Person" With Eating and With One or More ADLs for the Noninstitutionalized Elderly Population Aged 65 and Over (in thousands)					
Surveys	Prevalence Estimate	Standard Error	Confidence Interval		
			68%	95%	99%
1987 NMES (Household)					
One or more ADLs	2,250	4.7%	2,144-2,356	2,039-2,462	1,986-2,514
Eating	a	a	a	a	a
1984 NLTCS					
One or more ADLs	2,062	2.2%	2,017-2,107	1,971-2,153	1,949-
Eating	618	4.0%	593-643	569-667	556-
1984 SOA					
One or more ADLs	1,318	3.5%	1,272-1,364	1,226-1,410	1,203-1,430
Eating	183	13.0%	159-207	135-231	124-242
a. Sample size too small for reliable estimate.					
SOURCES: Prevalence estimates from Table 1, standard error for 1987 NMES, Joel Leon, National Center for Health Services Research, personal communication; 1984 NLTCS, "Overview and Use of the Public Use Data Files of the 1982 and 1984 National Long-Term Care Surveys," p.21, table 5B; 1984 SOA, <i>Vital and Health Statistics</i> , series 10, no.156, figure VII, p.139.					