

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:

COMPARISONS ACROSS NATIONAL SURVEYS

Office of the Assistant Secretary for Planning and Evaluation

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MEASURING THE ACTIVITIES OF DAILY LIVING: Comparisons Across National Surveys

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The "activities of daily living," or ADLs, are the basic tasks of everyday life, such as eating, bathing, dressing, toileting, and transferring. Reported estimates of the size of the elderly population with ADL disabilities differ substantially across national surveys. 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 to which the sample refers. When essentially equivalent ADL measures are compared, estimates for the community-based population vary by up to 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 people with ADL problems than does the Supplement on Aging.

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The term "activities of daily living," or ADLs, refers to the basic tasks of everyday life, such as eating, bathing, dressing, toileting, and transferring. 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. Although persons of all ages may have problems performing the ADLs, prevalence rates are much higher for the elderly than for the nonelderly. Within the elderly population, ADL prevalence rates rise steeply with advancing age and are especially high for persons aged 85 and over (Rivlin and Wiener, 1988).

Measurement of the activities of daily living is critical because they have been found to be significant predictors of admission to a nursing home (Branch and Jette, 1982); use of paid home care (Garber, 1989; Soldo and Manton, 1985); use of hospital services (Branch, Jette, and Evashwick, 1981; Wan and Odell, 1981); living arrangements (Bishop, 1986); use of physician services (Wan and Odell, 1981); insurance coverage (Dunlop, Wells, and Wilensky, 1989); and mortality (Manton, 1988). For research on the elderly, the ability to perform the ADLs has become a standard variable to include in analyses, just 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 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 a trigger for benefits (Van Gelder and Johnson, 1989). All of the proposed public insurance plans, including those introduced by Senators George Mitchell and Edward Kennedy and by Representatives Henry Waxman, Fortney "Pete" Stark, and Claude 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.

A number of national surveys which measure the ability of elderly people to perform the ADLs have been conducted. A legitimate question is whether these diverse surveys produce consistent estimates. A cursory glance at some recent studies suggests 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 (Manton, 1988); while another study using the Supplement on Aging found 6.0 million impaired elderly (Kasper, 1988). 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 (U.S. Bureau of the Census, 1986). 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 inconsistency of the ADL estimates across surveys.

In May 1988, the federal 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 Estimates of Activities of Daily Living in National Surveys, including government and nongovernment experts familiar with the different surveys, was formed to study the issue. This article is based on the report of that committee.

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 (Fillenbaum, 1984; Kane and Kane, 1981). Therefore, researchers have devoted considerable attention to developing measures that tap practical dimensions of everyday life as a way of measuring a person's functional status. The ADLs are increasingly being used to measure disability. They are key elements in efforts to measure quality of life and functional status (Spitzer, 1987).

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 (Katz et al., 1963; Katx, 1983). In this scale, the set of tasks assessed are bathing, dressing, transferring, using the toilet, continence, and eating. A theoretical basis for selecting these functions is that they represent milestones in the sociobiological development of self-care independence in children (Katz and Akpom, 1976). Its original purpose was to differentiate physical functional abilities among rehabilitation and recuperating patients.

Over the years, a number of other measures of physical dysfunction which cover tasks similar to the Katz ADL Scale have been introduced (Kane and Kane, 1981; McDowell and Newell, 1987). There are more than 43 different published indexes that assess ADLs in both patients and populations (Feinstein, Josephy, and Wells, 1986).

Most of these other measures of ADLs add some measure of mobility, such as walking, getting around inside, and getting around outside (Fillenbaum, 1987). In general, these indexes of functional disability have not been well evaluated for their validity or reliability (Feinstein, Josephy, and Wells, 1986; McDowell and Newell, 1987).

Measures of the ability to perform the ADLs have become routine in surveys of older people, partly displacing the National Health Interview Survey disability classification of being "unable to perform your major (or usual) activity" (National Center for Health Statistics, 1979). ADLs are more specific and concrete than an inability to perform a "major activity," thus avoiding situational or contextual differences among survey respondents. This is particularly an issue among those elderly persons for whom their "major activity" is ill-defined (Branch and Meyers, 1987). Another advantage of ADLs is that they can be used to provide general information on the basic service needs of the disabled. A person unable to feed himself needs help eating; if is not clear what, if any, services a person needs who is "unable to perform his major activity." Finally, as discussed above, 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 (Lawson and Brody, 1969). The IADLs capture a range of activities that are more complex than those needed for the ADLs, including handling personal finances, meal preparation, shopping, traveling, doing housework, using the telephone, and taking medications (Fillenbaum et al., 1978). Recent research suggests that there is a hierarchical relationship between some IADL items and ADL items, with IADL disabilities representing less severe dysfunction (Spector, Katz, and Fullton, 1987).

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. Cognitive impairment and ADL status are correlated but are separate dimensions of functioning (Fillenbaum et al., 1978). Not all persons with substantial cognitive impairment have ADL dysfunctions.

Because ADLs do not cover all domains of disability, estimates of the need for long-term care services that rely solely on ADL measures will miss a substantial proportion of the disabled population. Nonetheless, there is a great deal more uniformity and consensus on measurement of ADLs than on IADLs or on cognitive impairment.

NATIONAL DATA BASES MEASURING ADLS

In recent years, 11 national surveys, designed for a variety of purposes, have collected information on the ADL status of elderly persons. Chart 1 summarizes pertinent information about the surveys.

1982 National Long-Term Care Survey. -- The 1982 National Long-Term Care Survey (1982 NLTCS) is a nationally representative survey of 6,393 noninstitutionalized Medicare beneficiaries age 65 and over with health-related ADL or IADL functional limitations that have or would endure for three months or longer. 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. This survey was sponsored by the Office of the Assistant Secretary for Planning and Evaluation/U.S. Department of Health and Human Services and the Health Care Financing Administration.

1982 New Beneficiary Survey. -- The 1982 New Beneficiary Survey (NBS) is a nationally representative household survey of new Social Security beneficiaries. Personal interviews were conducted with 18,599 persons who started receiving benefits between mid-1980 and mid-1981 as retired workers, disabled workers age 18 and older, or auxiliary benefits for wives and aged widows, and workers age 65 and older who lost benefits because of the earnings test. This survey was sponsored by the Social Security Administration.

1982-84 NHANES I Epidemiologic Followup Study. -- The 1982-84 NHANES I Epidemiologic Followup Study (NHEFS) is a longitudinal study of those persons age 25-74 at baseline who participated in NHANES I, which was conducted between 1971-1975. The Epidemiologic Followup Study was designed to investigate the relationship between risk factors measured at baseline and subsequent morbidity and mortality. Of approximately 5,700 NHANES I participants aged 55 and older at baseline, 5,500 were successfully traced. Of these, 3,500 were alive at followup and were age 65 or older. This survey was sponsored by the National Center for Health Statistics.

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 to determine if they were disabled. In addition, approximately 5,000 persons who turned age 65 after 1982 were added to the 1984 sample screened for impairments, and those reporting a disability were then given a detailed interview. This survey was sponsored by the Health Care Financing Administration and the National Center for Health Services Research.

1984 National Health Interview Survey, Supplement on Aging. -- The 1984 National Health Interview Survey, Supplement on Aging (SOA) is an in-person, household survey of 16,148 persons age 55 and older. Designed to provide national estimates on middle-aged and older non-institutionalized 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 age 65 and over. This survey was sponsored by the National Center for Health Statistics.

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. The third wave supplement to the 1984 panel of SIPP contained a set of questions on disability status. Approximately 20,900 households were interviewed; about 5,900 respondents were age 65 and older. This survey was sponsored by the Bureau of the Census.

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 is designed to measure change in functional status, living arrangements, and health service use. Data were collected primarily by telephone and mailouts. This survey was sponsored by the National Center for Health Statistics and the National Institute on Aging.

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; there are 4,650 elderly persons in this sample. The Discharge component of the 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.

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 were collected by mailout, telephone, and personal interviews with next-of-kin for 18,500 persons who died in that year; 10,154 decedents were age 65 and older. This survey was sponsored by the National Center for Health Statistics.

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. 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. This survey was sponsored by the National Center for Health Services Research.

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 age 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 about which there is not an obvious choice. Differences in lists of ADLs, what constitutes an ADL problem or limitation, and varying survey techniques account for many, but not all, of the differences in ADL estimates across surveys.

Lists of ADLs. -- Not all surveys or analysts use the same list of ADLs. Most surveys include a list of eating, toileting, transferring, dressing, and bathing activities. 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, SIPP 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 major difference in the number of people included 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.

Recently, public policy has focused on five ADLs -- eating, toileting, transferring, dressing, and bathing. These are also the ADL items that have been proposed for use in determining eligibility for benefits in several proposed public insurance programs. Private insurance plans vary more in which ADLs they use to determine eligibility for benefits (Van Gelder and Johnson, 1989).

How ADLs are 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. Since self-report instruments do not incorporate strict definitions for the activity being assessed or the possible response categories, estimates may vary simply because respondents interpret the questions differently (Guralnik et al., 1989). Culture, language, and education can also affect how individuals assess disability (Linn, Hunter, and Linn, 1980). The surveys differ in whether they assess the degree of difficulty in performing each ADL, what type of assistance was received, and the duration of the disability.

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." Persons requiring active human assistance are persons who are clearly dependent on others. Mechanical assistance can include such devices as grab bars or special beds to facilitate transferring. Persons who can function with aids are more independent than those requiring active human assistance (Feinstein, Josephy, and Wells, 1986). 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 or when they are supposed to do it.

Whether or not to limit ADL dependent to persons receiving active human assistance can have a major impact on the estimates. One analysis using the 1982 NLTCS 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 (tabulations by the authors).

Some surveys, such as the SOA and the LSOA, asked each respondent to classify their ADL limitation by the level of difficulty in performing them -- some, a lot, or unable. For example, among the 2.0 million persons age 70 and older who reported a bathing difficulty in the LSOA, 40 percent had "some" difficulty, 22 percent had "a lot" of difficulty, and 38 percent were "unable" to bathe (tabulations by the authors). Without precise guidelines by which to assess level of disability, it may be problematic for subjects to report whether they have a little, some, or a lot of difficulty with a particular activity (Guralnik et al., 1989). Moreover, 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 NLTCS 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 NLTCS, other surveys may include more short-term disability.

Differences in how questions are asked and who is counted as being disabled are often the result of trying to answer 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 she needs human help.

Other factors. -- Differences in ADL estimates may also derive from a combination of technical factors, although the effect of these factors is often 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 composition of the elderly population could result in different prevalence estimates. For example, between 1982 and 1987, the number of people age 65-74 increased 9.1 percent, while the number age 75-84 increased 13.7 percent and that number age 85 and older grew by 17.3 percent (U.S. Bureau of the Census, 1988).

Another possible explanation for varying estimates involves differences in sampling frame. To estimate ADL status in the community, the 1982 and 1984 NLTCS sampled elderly 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 SOA, SIPP, and NMES were based on a subsampling of all household members aged 65 and over from a representative sample of all U.S. households.

Still another source of variation among surveys was the way in which data were collected. The SOA obtained face-to-face information from elderly sample persons, but close to 30 percent of disabled respondent data came from proxy respondents (National Center for Health Statistics, 1987). The LSOA interviews were conducted by telephone and mail. In many cases, SIPP and NMES 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 (Branch and Meyers, 1987). More information is needed on the potential biases created by proxy respondents. Even more fundamentally, none of the surveys verified answers by actually asking elderly respondents to perform the indicated ADLs (Branch and Meyers, 1987; Guralnik et al., 1989).

Yet another potential explanation of divergence in ADL estimates is that similar ADL information may be contained in more than one place on the same survey. For example, the 1982 NLTCS screened about 36,000 elderly Medicare beneficiaries to develop the sample used to collect detailed information from 6,393 disabled elderly. When surveyors came to conduct the detailed survey, nearly 9 percent reported that they were no longer disabled (Liu, Manton, and Liu, 1985; Macken, 1986). This two-step process resulted in at least two separate sets of ADL prevalence estimates from the NLTCS -- one from the screen interview, and one from the detailed survey.

Estimates after standardization. -- 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 try to control for these differences. In order to develop more comparable estimates, a closely specified set of ADL data on the elderly population was collected from each survey. Weighted and unweighted data were developed for all persons age 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 in at least one of these activities. Of course, differences in wording, lead-in items, format, and other factors remain and could not be eliminated.

Fairly comparable estimates of the prevalence of functional limitations for the elderly were assembled for 8 of the 11 national surveys identified as collecting information on ADLs. Estimates for the five comparable surveys covering the noninstitutionalized elderly are shown in Table 1. The 1982 and 1984 NLTCS are weighted so that the total sample (including the nondisabled) represents the noninstitutionalized elderly Medicare-eligible population. The SOA, SIPP, and NMES are weighted so that the total sample represents U.S. Bureau of Census estimates of the total noninstitutionalized elderly population.

Standardizing reduces but does not eliminate the differences across surveys. The estimates in Table 1 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 SOA to 8.1 percent in the NMES 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 SOA 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 age 65 and older 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 and 3.4 percent need help with toileting, and between 0.7 and 2.5 percent need help eating.

Table 2 compares the surveys for the noninstitutionalized elderly age 65-74, adding the NHEFS (which lacks data on the age 85 and older population). 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 SOA 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 NNHS and the NMES Institutional Component 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 NMES than for the NNHS. The largest difference between the two surveys of the institutionalized elderly was for toileting, which ranged from 51 percent in the NNHS to 67 percent in the NMES. However, as only about 5 percent of the elderly are institutionalized on a given day, the absolute difference of this discrepancy is only about 200,000 individuals.

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 that 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 in Table 1, there is great variability across surveys in the number of actual observations for each ADL. At the extreme, for eating disability, the range in the actual number of cases varies from 650 for the 1984 NLTCS to 76 for the SOA.

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 SOA, the 1984 NLTCS, and NMES.

Calculating confidence intervals also reduces but does not eliminate differences across surveys. The estimates for eating disabilities between the 1984 SOA and the 1984 NLTCS 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 NLTCS and the 1987 NMES at the 95 percent confidence interval. However, like estimates for eating limitations, the SOA 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.

CONCLUSIONS

To the casual observer, estimates of the prevalence of ADL 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 include 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;
- Age composition of the elderly population in the survey year;
- Sample frame used to select respondents;
- Methods used to collect data;
- Chance sampling variability.

When essentially equivalent ADL measures are compared, estimates for the community-based population vary by up to 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, NMES estimates that there are 60 percent more elderly with ADL problems than does the SOA.

Notwithstanding these differences, from a statistical perspective, the estimates are reasonably alike. This is especially true if we focus on the percentage of persons without an ADL limitation. At one extreme, the SOA estimates that 95 percent of the elderly do not receive help with any of five ADLs. At the other extreme, NMES puts the number of comparably nondisabled elderly at 92 percent. If the policy interest was on the nondisabled rather than the disabled, few observers would find these differences worth noting. The fact is that, even among the elderly, ADL limitations are relatively rare, and some variation in the estimates is inevitable.

Researchers and policy analysts alike need to be aware that ADL disability rates are simply much "softer" measures than 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 handle multiple question recodes and deal with missing or inconsistent data, each step will influence the results. Given a lack of consensus on exactly how to measure ADLs, even an extremely large sample could not provide a definitive estimate. This lack of consensus is a major impediment to standardization of ADL measures.

What should policymakers and others make of these differences across surveys? Cost estimates for home care programs or insurance benefits based on one survey will be substantially different from cost estimates based on a different survey. Obviously, this inconsistency is very unsettling to those who must pay the bills.

It should be remembered, however, that conducting survey research is different from 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 from what is estimated by even the best survey. Even aside from the technical design and analysis issues, the respondent incentives are very different when applying for Medicare or private insurance benefits than 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 elderly people will respond to the availability of financing, and how important it is that costs not be under- or overestimated.

In sum, when choosing which survey to examine and which items to use, policy analysts and researchers 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 have previously how they defined ADL disabilities and which data elements they used.

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CHART 1. Type of Information on ADL Items in National Surveys								
Surveys	Population	Number of ADLs ^a	Minimum Duration of Disability	Needs Assistance	Receives Human Assistance	Uses Special Equipment	Receives Stand-by Help	Level of Difficulty
National Long-Term Care Survey (1982)	Noninstitutionalized, functionally impaired elderly	9	Yes	Yes	Yes	Yes	Yes	No
New Beneficiary Survey (1982)	New Social Security beneficiaries (between mid-1980 and mid-1981	4	No	No	Yes	No	No	Yes
National Health and Nutrition Examination Survey I Followup (1982-84)	Persons aged 25-74 (between 1971-1974 and 1974-1975) examined in NHANES I	6	No	No	Yes	Yes	No	Yes
National Long-Term Care Survey (1984)	Functionally impaired elderly, age 65+	9	Yes	Yes	Yes	Yes	Yes	No
National Health Interview Survey Supplement on Aging (1984)	Elderly persons, age 55+	9	No	No	Yes	Yes	No	Yes
Survey of Income and Program Participation Disability Module (1984)	Noninstitutionalized population	4	No	Yes	Yes	No	No	No
Longitudinal Study of Aging (1984-86)	Noninstitutionalized persons aged 70+ in 1984	9	No	No	Yes	Yes	No	Yes
National Nursing Home Survey (1985)	Current residents of nursing homes	6	No	No	Yes	Yes	No	No
National Mortality Followback Survey (1986)	Persons aged 25 and over who died in 1986	5	No	No	Yes	Yes	No	No
National Medical Expenditure Survey Household (1987)	Noninstitutionalized population	7	Yes	No	Yes	Yes	No	No
National Medical Expenditure Survey Institutional (1987)	Persons in nursing homes and personal care facilities	6	No	No	Yes	Yes	No	No

a. Some surveys have a different number of ADLs on the instrument that screens for disability than on the detailed survey. Where that occurs, the larger of the two numbers is reported.

TABLE 1. Activity of Daily Living Disabilities Among Noninstitutionalized Persons							
Aged 65 and Over, by Survey and Type of Activity (in thousands)							
Total Noninstitutionalized Elderly Population / % Aged 65 and Over (Unweighted n)	25,440 / 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 Pe	erson 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% (1,278)	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% (167)		
Eating	624 / 2.5% (744)	618 / 2.3% (650)	183 / 0.7% (76)	b	С		

	1982 National Long-Term Care Survey	1984 National Long-Term Care Survey	1982-84 NHANES I Epidemiologic	1984 Supplement on Aging	1984 Survey on Income and Program	1987 National Medical Expenditure
			Followup Study ^a		Participation	Survey
Total Noninstitutionalized Elderly Population / % Aged 65-74 (Unweighted n)	15,859/100.0% (939)	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 And	other 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%° (99)	625 / 3.7% (150)
Dressing	430 / 2.7% (505)	436 / 2.6% (434)	272 / 1.9% (23)	288 / 1.8% (127)	С	456 / 2.7% (112)
Transferring	443 / 2.8% (515)	404 / 2.4% (405)	302 / 2.1% (22)	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)	С	d
n.a. = not asked.	, ,	, ,	, ,	, ,		
a. Due to weightingb. Excludes toileting		timates are not ba	sed upon data fron	n the entire sample	9.	

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 3. Activity of Daily Living Disabilities Among Institutionalized Persons 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 Noninstitutionalized Elderly Population / % Aged 65 and Over (Unweighted <i>n</i>)	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 Population Aged 65 and Over (in thousands)							
Surveys	Prevalence	Standard	Confidence Interval				
	Estimate	Error	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	а	а	а	а	a		
1984 NLTCS							
One or more ADLs	2,062	2.2%	2,017 - 2,107	1,971 - 2,153	1,949 - 2,175		
Eating	618	4.0%	593 - 643	569 - 667	556 - 680		
1984 SOA							
One or more ADLs	1,318	3.5%	1,272 - 1,364	1,226 - 1,410	1,203 - 1,433		
Eating	183	13.0%	159 - 207	135 - 231	124 - 242		

SOURCES: Prevalence estimates from Table 1. Standard error estimates for: 1987 NMES, Joel Leon, Agency for Health Care Policy and Research, personal communication; 1984 NLTCS, Duke University Center for Demographic Studies (1988), Table 5B, p.21; 1984 SOA, derived from National Center for Health Statistics (1986), Figure VII, p.139.

a. Sample size too small for reliable estimate.

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