



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

# **THE ACTIVITIES OF DAILY LIVING, NATIONAL SURVEYS AND LONG-TERM CARE COST ESTIMATES:**

## **TWO CURRENT INITIATIVES**

November 1989

## **Office of the Assistant Secretary for Planning and Evaluation**

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of the Department of Health and Human Services (HHS) on policy development issues, and is responsible for major activities in the areas of legislative and budget development, strategic planning, policy research and evaluation, and economic analysis.

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The Office of Disability, Aging and Long-Term Care Policy (DALTCP), within ASPE, is responsible for the development, coordination, analysis, research and evaluation of HHS policies and programs which support the independence, health and long-term care of persons with disabilities--children, working aging adults, and older persons. DALTCP is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

In particular, DALTCP addresses policies concerning: nursing home and community-based services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, children's disability, and linkages between employment and health policies. These activities are carried out through policy planning, policy and program analysis, regulatory reviews, formulation of legislative proposals, policy research, evaluation and data planning.

This paper was prepared for the **42nd Annual Meeting of the Gerontological Society of America** (November 17-21, 1989) by the HHS's Office of Social Services Policy (now DALTCP), under a contract with the Brookings Institution. For additional information about this subject, you can visit the DALTCP home page at [http://aspe.hhs.gov/\\_/office\\_specific/daltcp.cfm](http://aspe.hhs.gov/_/office_specific/daltcp.cfm) or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The e-mail address is: [webmaster.DALTCP@hhs.gov](mailto:webmaster.DALTCP@hhs.gov). The Project Officer was Robert Clark.

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SURVEYS AND LONG-TERM CARE  
COST ESTIMATES:  
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U.S. Department of Health and Human Services

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The opinions and views expressed in this report are those of the author. They do not necessarily reflect the views of the Department of Health and Human Services.

# BACKGROUND

As developed by Sidney Katz and his colleagues (1963), the Activities of Daily Living (ADL)-eating, continence, transferring in and out of bed, toileting, dressing and bathing--have made it possible to analyze "detailed observations of many basic activities of patients with chronic conditions" (Katz, S. and Akpom, C.A., 1976, p. 117). The Guttman-scaling (or hierarchical) properties of the Katz ADL scale have made it easier to track the rehabilitative progress of impaired persons.

In part because of their success in clinical settings, ADLs have also come to play a major role in large national surveys covering the long term care population. They serve as a "handle" with which researchers count the number of elderly persons who are functionally disabled, identify the types and severity of those disabilities and assess the adequacy of long term care settings and services (e.g. Liu, K., Manton, K.G., and Liu, B.M., 1982; Manton, K.M., 1988; Stone, R.I. and Murtaugh, C.M., 1989).

With increasing frequency, ADL limitations have been written into a number of congressional bills as criteria for determining the eligibility of Medicare beneficiaries for proposed long term care benefits. Before his death, Representative Claude Pepper initiated this trend.

Under H.R. 3436 (the Pepper Bill), introduced into the 100th Congress, a chronically ill individual eligible for service meant in part one certified as "being unable to perform (without substantial assistance from another individual) at least two activities of daily living..."

For the first session of the 101st Congress, the chief sponsors of long term care bills that incorporate ADLS include Senators Kennedy, Bradley, and Rockefeller as well as Representatives Wyden and Waxman. The costs of the proposed benefits depend in part on the number of persons made eligible for them by the ADL eligibility criteria.

# EASY QUESTIONS, NOT SO EASY ANSWERS

For survey research and policy analysis, it thus seems reasonable to employ ADLs in addressing the following questions.

1. What is the number of functionally disabled elderly persons nationally?
2. What is the number of elderly persons made eligible under various long term care benefit proposals?

The answers to these questions are by no means as straightforward as one might think. Estimating the extent of functional disabilities with ADLs is possible, but not easy. (Of course, estimating without an ADL-like framework might not be feasible at all.) There are in fact considerable differences in the published estimates of functionally disabled elderly based on national survey data where information on ADLs is collected.

For example, one study using the 1984 Survey of Income and Program Participation (SIPP) found 1.5 million persons with "personal care needs"; another using the 1982 National Long Term Care Survey identified 3.0 million persons disabled in one or more ADLs; and a third, using the 1984 Health Interview Survey/Supplement on Aging found 6.0 million impaired elderly (Wiener, 1989, p.2).

These in turn have contributed to wide discrepancies in estimating the costs of various long term care benefit proposals.

If we imagine that all these persons were eligible for a public long term care benefit, whose average annual per capita cost was \$1000, the cost estimates nationally would range from \$1.5 billion to \$6.0 billion a year, depending on which study undergirded the estimate.

The rest of this paper focuses on several problems associated with making estimates using ADLs and highlights some of the methodological work carried out or sponsored by the Department of Health and Human Services to overcome these problems.

For survey research, the problems associated with ADLs can be summarized as follows.

1. *There is no standard set of ADLs across national surveys.*

Most surveys include a set of five "core" ADLs--eating (or feeding), getting in and out of bed, toileting, dressing and bathing. Other ADLs found in many surveys include: (a) urinary and bowel continence--sometimes separated, sometimes combined; (b) getting in and out of chairs; (c) getting around inside; and (d) walking.

In the 1982 and 1984 National Long Term Care Surveys (NLTCS) . for examples, nine ADLs are used in the screener, while six are covered in the detailed interview. The 1984 National Health Interview Survey/Supplement on Aging (HIS/SOA) also uses nine ADLs in its screening questions (though not exactly the same nine as in the NLTCS) and seven in the more detailed questions. The 1987 National Medical Expenditure Survey/Household Component uses seven screener ADLs and six for detailed questions.

2. *The questions aimed at identifying ADL limitations vary within and across surveys.*

How survey respondents are determined to be or not be ADL-impaired depends on (a) the kinds of questions asked and (b) the selection among those questions made by analysts for making their determinations. For screening purposes, the NLTCS made a respondent eligible for the detailed interview if he or she indicated an ADL problem that lasted or was expected to last at least three months. In contrast, the 1984 HIS/SOA screening questions ask about current difficulty with ADLs.

The detailed questions include factors like: (a) ability to perform ADLs versus actual performance; (b) degree of difficulty in performing ADLs; (c) whether or not human assistance was provided and whether the assistance was active or standby; and (d) use of mechanical aids in performing ADLs. Not all these types of questions are included on every survey. Even when the same types of questions are included on two separate surveys, the different ways that questions are worded can affect response rates.

Even when the data are available, analysts may use different criteria to determine the presence of functional disability. Some, for example, use human assistance alone as a measure while others incorporate use of mechanical aids as well. Even within human assistance, some draw a distinction between active and standby (or supervisory) assistance.

3. *Survey design factors can affect the estimates of ADL-impaired elderly.*

These factors can include: (a) the year in which the survey was administered; (b) the sampling frame used to generate the survey sample; and (c) data collection procedures. Since persons age 85 and over, who are more likely to be disabled, are an increasingly higher percentage of the total elderly population, more recent surveys can be expected to show higher rates of disability.

The sampling frame for national surveys can account for some variation among response rates. The NLTCS sample frame was a file of Medicare enrollees, the HIS relies on a sample of the civilian non-institutionalized population and the NMES was a year-long panel of a Census sample of 14,000 households.

Differences in data collection procedures include: (a) face-to-face versus telephone interviews; (b) rate of proxy respondents; (c) skip patterns in the progression of questions; and (d) time intervals (e.g. administering a screener at a different time from the detailed interview questions).

All these factors have some probable--though as yet unmeasured--effect on differences in the rates of functional disability generated by these surveys.

I now want to turn to two initiatives, one completed and one in progress, designed to make more effective use of ADLs in analyses of the functionally disabled elderly population.

# THE FORUM ON AGING-RELATED STATISTICS

The first initiative addresses the first question raised above--namely, the number of functionally disabled persons nationally. The second addresses the second question --the number of persons eligible for various long term care benefits where ADLs serve as eligibility criteria.

In May, 1988, the federal Interagency Forum on Aging Related Statistics established a committee to compare the results of national surveys that use ADLs to measure functional disability. The Forum, whose co-chairs are the Directors, respectively, of the Census Bureau, the National Institute on Aging and the National Center for Health Statistics, sought to account for differences across these surveys, which in turn have affected cost estimates of proposed long term care legislation.

The Committee on Estimates of ADLs in National Surveys identified eleven national surveys that used ADLs. Among the factors that account for differences across surveys and that, for comparative purposes, could be standardized was the number of ADLs in the surveys and the wording of questions about them.

Thus, all the surveys included the five core ADLs, namely, eating, toileting, transferring in and out of bed, dressing and bathing. The question applied commonly across all surveys was whether or not the respondent received the help of another person with one or more of the core ADLs.

Table 1, which is reproduced from the report of the committee to the Forum, shows how the results vary for five of the national surveys that focused on the noninstitutionalized elderly population.

As you can see, the number of persons (and percent of the total elderly population) receiving the help of another person with one or more ADLS was:

- 2,250,000 (8.1%) from the 1987 NMES
- 2,062,000 (7.8%) from the 1984 NLTCS
- 1,992,000 (7.8%) from the 1982 NLTCS
- 1,538,000 (5.8%) from the 1984 SIPP and
- 1,318,000 (5.0%) from the 1984 HIS/SOA

The numbers range from 2.25 million or 8.1% of the elderly population down to 1.32 million or 5.0% of the elderly population. How significant these differences are may lie in the eye of the beholder. The difference between the highest and lowest estimates of the percent of the population with ADL impairments is 3.1%. However, looked at from another angle, we see that the highest number is 60% greater than the lowest.



These are the results when one attempts to standardize the number of ADLs covered and the types of questions asked. The differences can be expected to be larger when analysts use different sets of ADLs and different questions.

It seems reasonable to ask that, in reporting their results, analysts provide information on how they defined ADL disability and which data elements were used. Survey designers need to be cognizant of different research foci. From a policy perspective, receipt of assistance and unmet needs are key issues. From an epidemiological perspective, information is needed on the underlying causes of ADL disabilities and the exact nature of the dysfunction.

To facilitate comparisons with other research findings, analysts should provide a standard set of tabulations using the approach of the Forum's ADL committee--namely, the number of persons receiving help with the five core ADLs.

# REAL WORLD APPLICATIONS

The second initiative concerns ongoing work being sponsored by the DHHS' Office of the Assistant Secretary for Planning and Evaluation through a contract with Systemetrics, Inc.

Systemetrics, Inc. is in the process of carrying out three major tasks under this contract:

1. *Reviewing the eligibility provisions of existing and proposed long term care benefit proposals.*

This entails identifying policy options and congressional bills where functional disability as indicated by ADL limitations is used to determine eligibility for benefits. The contractor is also looking at how eligibility is determined under existing long term care vehicles like Medicare, Medicaid, state-funded community care programs and private long term care insurance.

2. *Examining existing national data sets for their utility in estimating eligibility for and costs of expanded long term care benefits.*

The study carried out for the Interagency Forum on Aging Related Statistics provides an excellent starting point for this activity. However, that study was primarily methodological. The numbers it generated were used for purposes of comparison across surveys, not for yielding actual prevalence estimates. Systemetrics will endeavor to produce defensible prevalence estimates both of the entire long term care population and for groups eligible for various proposed long term care benefits.

This work involves developing alternative operational definitions of functional disability that address such factors as: (a) the inclusion of Instrumental Activities of Daily Living (IADL) and cognitive impairments as well as ADLs; (b) the role of mechanical aids along with human assistance in carrying out daily activities; (c) whether to emphasize capacity to perform or actual performance of activities; (d) the extent to which unmet or undermet needs can be covered; and (e) the ability of surveys to discriminate within functional disabilities by level of severity.

3. *Developing estimates of persons eligible for long term care benefits under current legislative proposals.*

The contractor will make population estimates of the number of persons covered under various long term care bills, using alternative definitions of functional disability. Additionally, the contractor will generate cost estimates for these bills, based on assumptions concerning: (a) participation rates; (b) unit costs of covered services; (c) frequency of service use; and (d) intensity of service use.

Already this contract has yielded a report on the extent to which functional criteria are used in existing programs and current legislative proposals, plus the policy implications of using ADLs to allocate long term care benefits (Jackson, M.E. and Burwell, B.O., 1989).

# CONCLUSION

The two initiatives outlined in this paper--the study of ADLs across national surveys sponsored by the Forum on Aging Related Statistics and the estimates of covered populations and costs under various long term care bills being prepared by Systemetrics--will strengthen our ability to assess the strengths and weaknesses of alternative long term care initiatives. They will also provide guidance on how best to use national survey data and ADLs in making these estimates.

While our understanding of how to measure functional disability using ADLs has improved, additional work is needed. For example, it is not clear that ADL limitations in non-institutional settings mean the same thing as ADL limitations in institutional settings. The applicability of ADLs to the non-elderly requiring long term care needs study. The kind of methodological work done on ADLs needs to be carried forward to IADLs, and, more critically, to cognitive impairments, which are often proposed along with ADLs as eligibility criteria for long term care benefits.

Finally, we need to examine more closely the relationship between measures of disability and the allocation of resources. Persons with the same ADL disabilities have very different needs depending on the availability of informal caregivers, technological aids, and environmental modifications in housing and in the community. The challenge in policy development is how to use disability criteria in association with other factors to distribute resources, control costs and meet long term care needs.

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<b>TABLE 1: Activity of Daily Living Disabilities Among the Noninstitutionalized Elderly Age 65 and Over, by Survey and Type of Activity (in thousands)</b>					
	<b>1982 National Long-Term Care Survey</b>	<b>1984 National Long-Term Care Survey</b>	<b>1984 Supplement on Aging</b>	<b>1984 Survey on Income and Program Participation</b>	<b>1987 National Medical Expenditure Survey</b>
<b>Total Noninstitutionalized Elderly Population/% Age 65 and Over (unweighted n)</b>					
	25,440/100.0%	26,481/100.0%	26,268/100.0%	26,422/100.0%	27,909/100.0%
	(17,658)	(19,720)	(11,425)	(5,900)	(5,751)
<b>Receives Help of Another Person With...</b>					
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% <sup>a</sup> (381)	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% <sup>a</sup> (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	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.					