MEASURING THE ELDERLY'S NEED FOR HOME CARE

by Diane Rowland

Prologue: *Among the nation's thirty-one million people age sixty-five and over, nearly four million live at home, despite physical limitations that make it difficult to carry out activities of everyday life. Most of these elderly people live in the community, with family and friends or on their own. As the nation's elderly population continues to grow, an emerging federal funding priority revolves around financing long-term home care for impaired elderly people. While Medicare pays for the medical care these people receive in institutions, a gap remains in funding for home care. Increasingly, policymakers and payers are using the activities of daily living (ADL) scale developed by Sidney Katz in the 1960s to measure elderly people's ability to function—and thus their eligibility for home assistance. Impairment in these activities—eating, dressing, bathing, transferring from bed to chair, and using the toilet—can be strongly predictive of an elderly person's need to receive assistance. This article by Diane Rowland profiles the population of elderly most likely to benefit from a home care proposal such as the one put forward by the late Rep. Claude Pepper (D-FL). Rowland, who received her doctorate in health policy and management from The Johns Hopkins School of Hygiene and Public Health, is an assistant professor in that institution's Department of Health Policy and Management. She is associate director of The Commonwealth Fund Commission On Elderly People Living Alone, an $8 million initiative that since 1985 has been addressing the unique needs of this elderly population. The commission's May 1989 report,* Help at Home: Long-Term Care Assistance for Impaired Elderly People, *proposes a modest expansion of Medicare benefits to provide home care services for the two million most severely impaired elderly, which would help alleviate the burden placed on these elderly and those who care for them.*

Inadequate financing for long-term care services remains the major gap in health care coverage of the elderly. Home care as an alternative to institutional care has increased in prominence on the federal health policy agenda and promises to be a major contender for legislative action. The recent legislative proposal to expand Medicare coverage of home care to severely impaired children and adults, championed by the late Rep. Claude Pepper (D-FL), served to heighten growing recognition of the importance of long-term care assistance in the community for the functionally impaired population.[1]

One key issue shaping the policy debate and legislative proposals is the criteria for establishing eligibility for long-term care services within the Medicare population. Increasingly, legislators and policy analysts rely on impairments in activities of daily living (ADL) to define the elderly population living in the community and needing long-term personal care. Difficulty in performing two or more ADLs has become a common benchmark for expanded benefits under various policy proposals.[2]

This article examines the extent of ADL impairment among the elderly and the characteristics of the impaired elderly who would be covered for long-term care benefits using ADL-based eligibility criteria. The long-term care population with two or more ADL restrictions is compared to the general elderly population in terms of socioeconomic characteristics, health status, use of medical care, and assistance with long-term care needs. Estimates of the size and characteristics of elderly Americans are based on the Supplement on Aging to the 1984 Health Interview Survey.[3] Conducted by the National Center for Health Statistics, the Supplement on Aging is a comprehensive household interview survey with a nationally representative sample of 11,497 people age sixty-five and older, living in the community. Elderly nursing home residents and disabled Medicare beneficiaries under age sixty-five are omitted from this analysis because they are not included in the survey sample.

Criteria For Home Care Benefits

Long-term home care encompasses personal care and supportive services that a person needs to compensate for losses in independent functioning as a result of physical or cognitive impairment. Such services entail broad-scale assistance with daily functions, such as eating or dressing, rather than specific procedures for curing medical conditions or treating chronic disease. The eligibility standards for long-term care assistance thus should be based on the functional disability that underlies the need for long-term care, not the medical condition that may have contributed to the disability.[4]

The most widely employed approach to assessing disability among individuals living in the community is based on difficulty these persons have in performing five basic self-care tasks, referred to as ADLs. The ADL scale, originally developed by Sidney Katz, measures functional impairment by examining degree of difficulty in eating, bathing, using the toilet, dressing, and transferring from a bed or chair.[5] These ADL limitations reflect the types of deficits that long-term care services, most notably homemaker and personal care services, are designed to fill. The use of this standard assessment tool has gained acceptability because it uses well-defined criteria, is sensitive to changes in functional status, and is more predictive of future need than either physical or mental measures alone.[6] As a result, ADLs are increasingly used by researchers and analysts to assess the functionally impaired, long-term care population.[7]

The functional approach to assessing disability has gained acceptance over more medically oriented approaches based on diagnosis and presence of chronic disease. Disability measures, such as the ADL scale, have been found to be strong predictors of the use of long-term care resources, such as both risk of institutionalization and use of nursing staff time after admission.[8] In the community, use of nursing care, home health aides, and home therapy correlates with ADL dependency.[9] General health indicators, such as the presence of specific chronic or acute disease, have limited value in indicating the need for long-term care.

Using the ADL scale as a criterion for receiving personal home care helps to distinguish these benefits from the medically related home health services covered by Medicare and some private "Medigap" plans. Home health services are part of the continuum of medical care and are closely related to acute episodes of illness. Medicare home health benefits are usually provided for fewer than twenty-one days and are covered only when the individual is certified by a physician as needing skilled care or active therapy. By way of contrast, the services provided under a home care benefit to ADL-impaired individuals would focus on less medically oriented personal care.

Congress established a precedent for using ADL limitations as eligibility criteria in the respite care benefit included in the Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360). Key legislative proposals cited in Notes 1 and 2 rely on disability-based criteria using ADL limitations as the screening mechanism for establishing eligibility for home and community-based long-term care benefits.

Other public and private long-term care plans also have begun to employ ADL restrictions in assessing eligibility. Most state long-term care and Medicaid programs use ADL impairment as one of the criteria for receipt of home and community-based long-term care services.[10] As

private long-term care insurance plans have moved toward coverage of home care, they too have begun to use ADL limitations instead of medical criteria.[11]

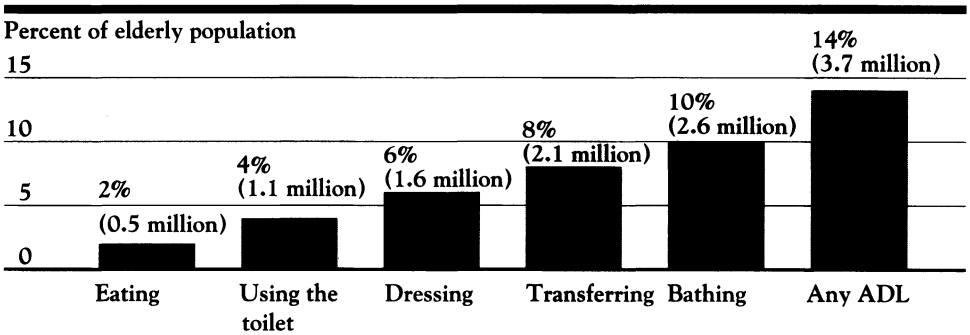
Although measurement-related and administrative issues would have to be resolved before ADL impairment could be broadly applied to determine long-term care eligibility, using limitations in two or more ADLs has become the standard for discussion purposes. This standard, however, excludes those whose long-term care needs stem from cognitive rather than physical limitations. Extending coverage to the cognitively impaired, including those with Alzheimer's and related diseases, is a policy priority, but it requires additional work to establish eligibility criteria.[12] Although instruments such as the Short Portable Mental Status Questionnaire can be used to estimate cognitive impairment, a more comprehensive assessment would need to be performed to actually determine benefit eligibility.

Defining The Long-Term Care Population In The Community

In 1984, 3.7 million people among the 26.4 million people age sixty-five and older living in the community reported some limitation in their ability to eat, use the toilet, dress, bathe, or transfer from a bed or a chair (Exhibit 1). This 14 percent of the elderly population is potentially eligible for long-term care assistance on the basis of their impairments in these ADLs.

Difficulty with bathing is the most common ADL limitation, afflicting one in ten elderly people. Less than 5 percent of the elderly report difficulties in eating and using the toilet, making these limitations the

Exhibit 1
Percentage Of Elderly Living In The Community With ADL Limitations, By Type Of Limitation, 1984



Source: Author's estimates based on 1984 Supplement on Aging, National Health Interview Survey.
Note: ADL is activities of daily living. Percentages are based on an elderly population of 26.4 million.

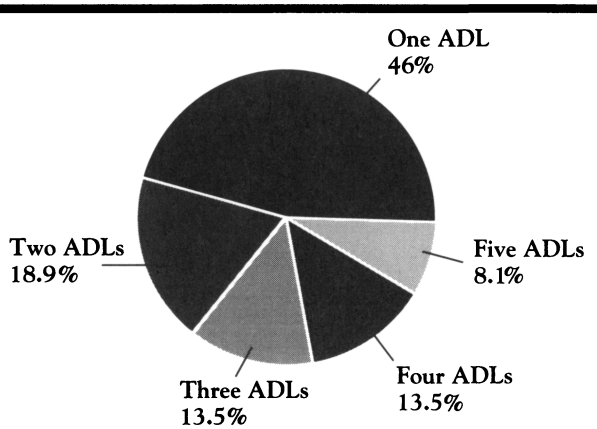
least prevalent. ADL impairments tend to be hierarchical; elderly persons with problems related to eating or using the toilet are generally limited in most other ADLs as well.[13]

The extent of disability varies widely among elderly people with one or more ADL limitations (Exhibit 2). Almost half of the impaired population (46 percent) is limited in a single ADL and would be ineligible under most long-term care plans because coverage is limited to those restricted in at least two ADLs (two million elderly). Within this population, 1.2 million people have two or three limitations, and the remainder are impaired in four or five activities.

The severity of disability is not uniform within the ADL-impaired population. Among the two million people with two or more ADL limitations, 1.1 million report some difficulty and 0.9 million report a lot of difficulty or inability to perform at least two ADLs. Only 30 percent of elderly with a single ADL restriction reported a lot of difficulty or inability to perform that activity.

The size of the potential long-term care population thus is determined both by the number of ADL limitations and the degree of impairment required for coverage. Two million people are covered if eligibility is limited to those with two or more ADL limitations. Pending legislative proposals further restrict coverage to the nearly one million elderly who have great difficulty or are unable to perform two or more ADLs. However, it may be difficult to distinguish between those with moderate and those with severe difficulty in ADL performance. Thus, for the

Exhibit 2
Distribution Of ADLs Among Elderly Population Having One Or More ADL Limitations, 1984



Source: Author's estimates based on 1984 Supplement on Aging, National Health Interview Survey.
Note: N = 3.7 million. ADL is activities of daily living.

purposes of this analysis, the two million elderly people with two or more ADL impairments, whether moderate or severe, are considered the potential long-term care population.

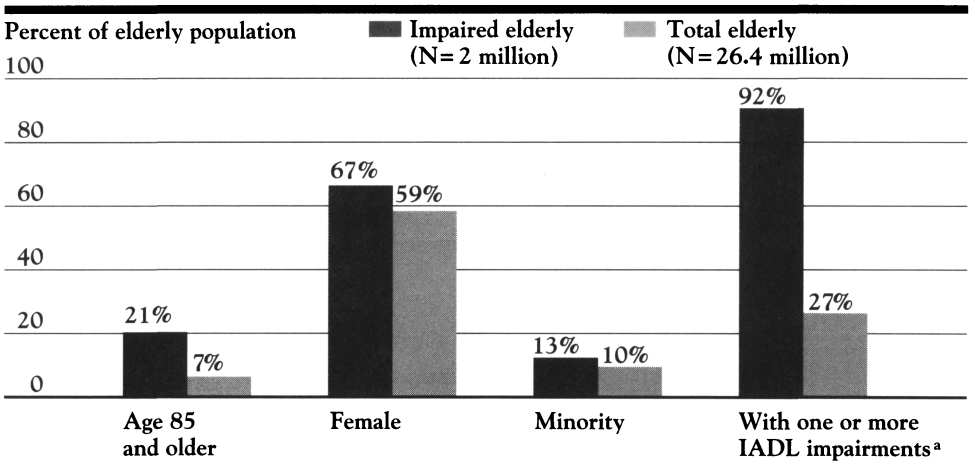
Profile Of The Long-Term Care Population

This potential long-term care population is a vulnerable group. Along with their greater degree of functional impairment, they are more likely to be quite old and to suffer from poor health and low economic status. Thus their need for medical care and personal assistance is great, but they possess fewer resources to finance such care.

Age and personal characteristics. Functional impairment reflects the diminished ability to care for oneself as one grows older and more frail. The proportion of impaired elderly who are age eighty-five or older is three times higher than that of the general elderly population (Exhibit 3). One-fifth (21 percent) of the impaired population is age eighty-five or older, in contrast to 7 percent of all elderly people. Reflecting the predominance of women among the oldest old, 67 percent of impaired elderly people are female, compared to 59 percent of the general elderly population. Also, minorities account for a larger proportion of the impaired elderly population (13 percent) than their share of the general elderly population (10 percent).

Among the functionally impaired population, inability to manage a

Exhibit 3
Characteristics Of Impaired Elderly And Total Elderly Populations, 1984



Source: Author's estimates based on 1984 Supplement on Aging, National Health Interview Survey.
[a] Instrumental activities of daily living (IADL) include housekeeping, taking medication, shopping, and preparing meals.

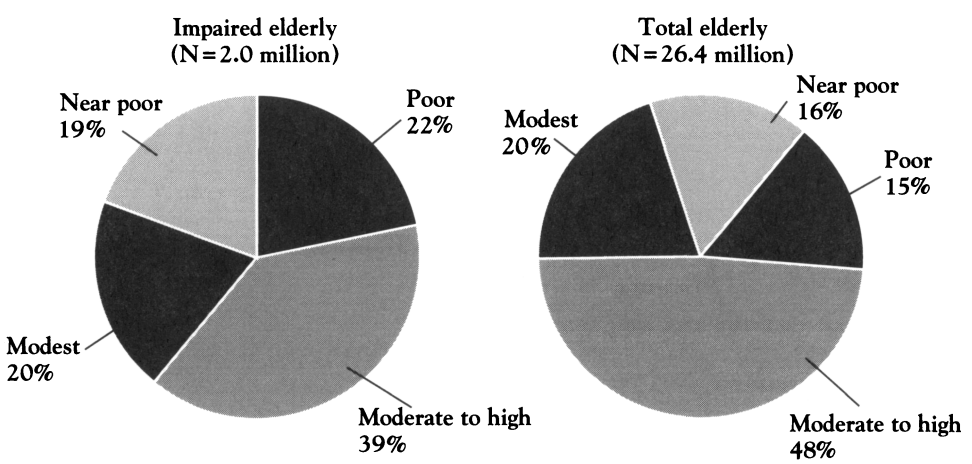
household compounds actual physical limitations. Ninety-two percent of impaired elderly people report difficulty in at least one instrumental activity of daily living (IADL), compared to 27 percent of the general elderly population. IADL limitations measure difficulty in activities such as shopping, preparing meals, housekeeping, and taking medication. Presence of multiple IADL limitations can be an indicator of cognitive as well as physical impairment.

Income and insurance. Elderly people with multiple ADL impairments are likely to be economically strapped. Forty-one percent of impaired elderly people have incomes below 150 percent of poverty, compared to 31 percent of all elderly people (Exhibit 4). Nearly a quarter (22 percent) of impaired elderly people are below the federal poverty level. Given this income distribution, coverage of the long-term care population therefore would target the low-income population.

For poor, impaired elderly people, Medicaid coverage can provide important assistance by paying premiums and cost sharing under Medicare as well as providing additional medical and long-term care benefits. However, Medicaid coverage to supplement Medicare reaches only 16 percent of the impaired elderly population (Exhibit 5). Nearly a quarter of impaired elderly people rely solely on Medicare for health care protection.

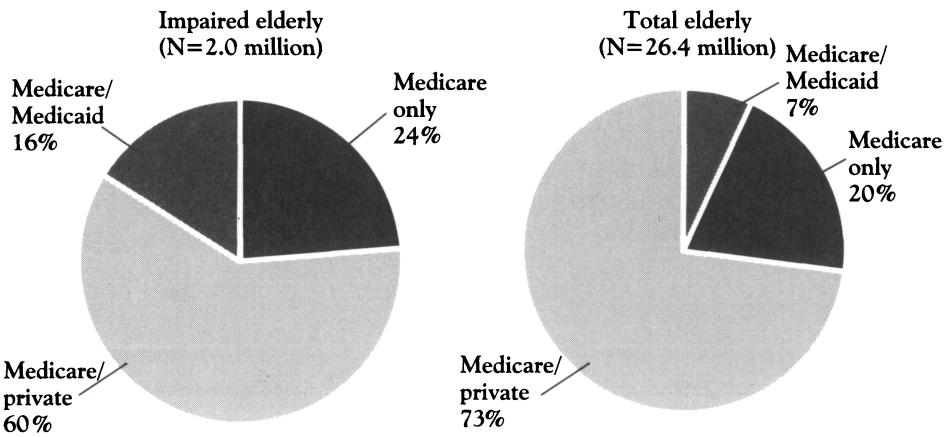
The Medicare Catastrophic Coverage Act of 1988 provided for Medicaid coverage of Medicare premiums and cost sharing for those with

Exhibit 4
Income Distribution Of The Impaired And Total Elderly Populations, 1984



Source: Author's estimates based on 1984 Supplement on Aging, National Health Interview Survey.
Note: Poor is less than 100 percent of the federal poverty level; near poor, 100–149 percent; modest, 150–199 percent; and moderate to high, 200 percent or more.

Exhibit 5
Distribution Of Health Insurance Coverage For Impaired And Total Elderly Populations, 1984



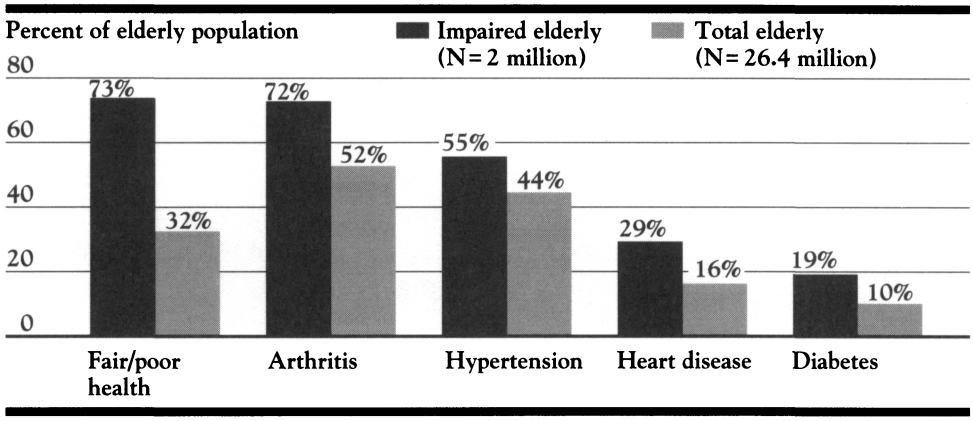
Source: Author's estimates based on 1984 Supplement on Aging, National Health Interview Survey.

incomes below the poverty level. Although this provision survived the late 1989 revisions to the catastrophic law, it still does not help the near-poor. Extending Medicaid to elderly people with incomes up to 150 percent of poverty would help to pay the health care costs of two of every five impaired people.

Health status and medical care. The functional limitations of impaired elders are further complicated by poor health status and the struggle to cope with medical problems. Functional disability is associated with the increased presence of debilitating chronic conditions and increased reliance on medical care. The impaired elderly population is at great risk of substantial out-of-pocket outlays for medical expenses as well as long-term care costs. Improved long-term care coverage would reduce the financial hardships such individuals bear.

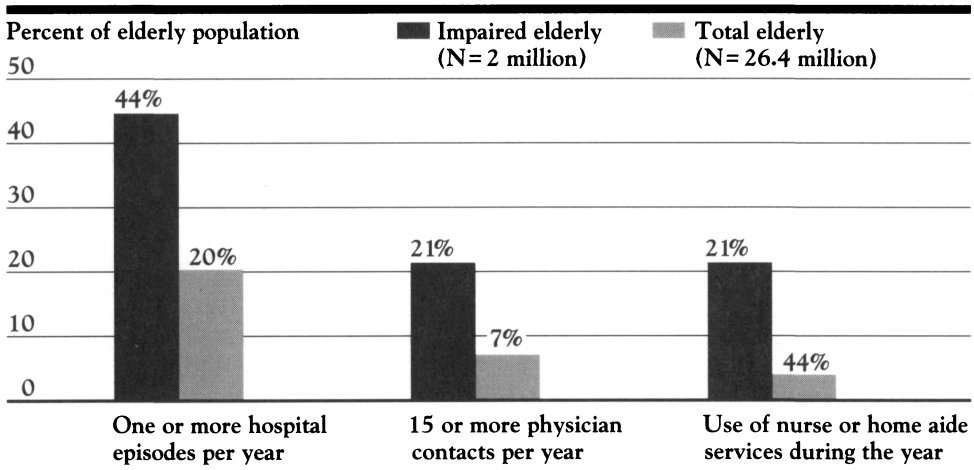
Nearly three-quarters (73 percent) of impaired elderly people are in fair or poor health, compared to less than a third (32 percent) of the general elderly population (Exhibit 6). These elders suffer from chronic health problems such as diabetes, heart disease, arthritis, and hypertension more widely than is true for the general elderly population. This poorer health status translates into higher use of medical care. Impaired elderly people are much more likely to have received physician or home care services or to have been hospitalized within the past year than are other elderly people (Exhibit 7). During a given year, 44 percent of impaired elderly people are hospitalized, a rate double that of all elderly

Exhibit 6
Selected Health And Medical Conditions Of Impaired Elderly And Total Elderly Populations, 1984



Source: Author's estimates based on 1984 Supplement on Aging, National Health Interview Survey.

Exhibit 7
Use Of Medical Care By Impaired And Total Elderly Populations, 1984



Source: Author's estimates based on 1984 Supplement on Aging, National Health Interview Survey.

people. High levels of physician use are also more common among the impaired elderly. Twenty-one percent of impaired elderly people, compared to 7 percent of all elderly people, experience fifteen or more physician contacts during the year. Similarly, the impaired population is five times as likely to use home health or in-home nursing services as the general elderly population.

Living arrangements and social support. Long-term care services to assist impaired elderly people are generally provided informally by family and friends.[14] Most impaired elderly people live with someone who can

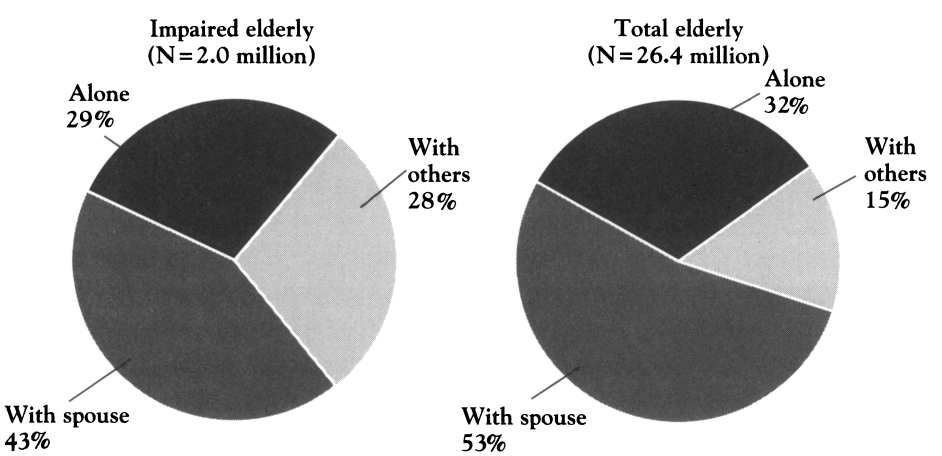
serve as an informal caregiver (Exhibit 8). For 43 percent of impaired elderly people, the spouse is potentially available as a caregiver. A quarter (28 percent) of such people live with family other than a spouse or with nonrelatives, compared to 15 percent of the general elderly population.

Yet, over a quarter (29 percent) of impaired elderly people live alone despite their disability and need for assistance. As severity of impairment increases, these elders are less able to continue to live alone, which could be a major factor causing them to move in with others or into institutions. It is still striking that more than one in four elderly people with multiple impairments live alone. For this group, the absence of a resident caregiver is likely to result in a greater need for formal home care services.[15]

Assistance with long-term care needs. Those who are severely compromised in their functional abilities depend on social support and personal assistance from family and friends or paid help to cope with their disabilities. One in five impaired elderly people report receiving no ADL assistance. Given their level of impairment, the reported lack of help is surprisingly high and may reflect impaired elders' failure to recognize informal stand-by assistance from family and friends as active help.

The extent of assistance available to the impaired population today varies widely and differs by income and living arrangement. High-income elderly are more likely to have assistance, due in part to their greater ability to purchase care when necessary. Of the poor and near-poor, 26 percent and 21 percent, respectively, do not receive help. Living arrange-

Exhibit 8
Living Arrangements Of Impaired And Total Elderly Populations, 1984



Source: Author's estimates based on 1984 Supplement on Aging, National Health Interview Survey.

ment appears to be the most important influence on receipt of help. Impaired elderly people who live alone are most at risk for being without assistance; 44 percent do not receive help from another person. In contrast, less than 10 percent of impaired elderly people living with others and 15 percent living with a spouse report that they do not receive help. The absence of informal support from family and friends for impaired elderly people living alone makes the availability of financing for home care particularly important.

In sum, although the impaired elderly population receives help from family and friends and some assistance from community service programs, gaps clearly exist in the assistance available. Those who are poor and those who live alone suffer more acutely because they have fewer financial resources and social supports to help with their activity limitations.

Policy Implications

Using ADL limitations as criteria for long-term care eligibility appears to direct home care services to a vulnerable and predominately low-income group of elderly people. The two million elderly people with two or more ADL limitations appear to be more impaired and in poorer health than the general elderly population and have fewer economic resources to cope with their disabilities. Expanding Medicare benefits to include personal care services for this population could assist those currently without help and give some relief to overburdened caregivers.

The size of the population covered under any long-term care plan will be shaped by both the eligibility criteria selected for coverage of the impaired population and the administration of the eligibility process. Under most pending legislative proposals, assessment agencies would be established and funded to conduct the initial evaluation of ADL limitations and certify individuals as eligible to receive benefits. Periodic reevaluations of ADL impairment status also would be required every three to six months to revise the scope of benefits as functional status either improves or declines.[16]

The number of elderly individuals who would actually qualify for benefits on the basis of an ADL impairment assessment performed by an independent agency is likely to be lower than the estimate of two million physically impaired people based on self-reported limitations in a household interview survey. Such agencies are also likely to operate under guidelines that restrict coverage to those who have a lot of difficulty or are unable to perform two or more ADLs. This would reduce the size of the potential population to about one million people.

Legislation to expand financing for home and community-based long-term care can also be expected to broaden the population covered to include individuals with cognitive impairments, including Alzheimer's disease. Approximately half of the population with severe cognitive impairment would fail to qualify if only physical impairments are used as an eligibility test.[17] Coverage of those with severe cognitive impairments who do not meet the two or more ADL limitations test would increase the size of the long-term care population by more than half a million.

Analysis of elderly with multiple ADL limitations provides a useful starting point for describing the long-term care population and helps to define those who would be the target for expanded Medicare benefits. Future research and policy development should focus on further refining the standards for determining physical impairment and on incorporating a measure of cognitive impairment into the criteria for long-term care eligibility.

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NOTES

1. U.S. House of Representatives, *Long Term Home Care Act of 1988*, 101st Cong., 2d sess., 1988, H.R. 2263; and U.S. House of Representatives, *Medicare Long-Term Care Catastrophic Protection Act*, 100th Cong., 24 June 1987, H.R. 2762.
2. Bills introduced in the 100th Congress, in addition to the Pepper-Roybal bill (H.R. 2263), include: U.S. House of Representatives, Energy and Commerce Subcommittee on Health and the Environment, *Elder-Care Long-Term Care Assistance Act of 1988*, 100th Cong., 16 September 1988, H.R. 5320; U.S. House of Representatives, Ways and Means Subcommittee on Health, *Chronic Care Medicare Long-Term Care Coverage Act of 1988*, 100th Cong., 27 September 1988, H.R. 5393; U.S. Senate, Finance Subcommittee on Health, *Long-Term Care Assistance Act*, 100th Cong., 21 April 1988, S. 2305; and U.S. Senate, Labor and Human Resources Subcommittee on Health, *Life-Care Long-Term Care Protection Act*, 100th Cong., 3 August 1988, S. 2681.
3. National Center for Health Statistics, *The Supplement on Aging to the 1984 National Health Interview Survey*, DHHS Pub. no. (PHS)87-1323 (Hyattsville, Md.: NCHS, 1987).
4. K. Liu and E.S. Cornelius, "ADLs and Eligibility for Long-Term Care Services," report prepared for The Commonwealth Fund Commission On Elderly People Living Alone, Background Paper Series 14 (December 1989).
5. S. Katz et al., "Studies of Illness in the Aged: The Index of ADL—A Standardized Measure of Biological and Psychosocial Function," *Journal of the American Medical Association* (23 September 1963): 914-919.
6. S. Katz et al., "Progress in the Development of the Index of ADL," *The Gerontologist*

(Spring 1970): 20–30; and W.D. Spector et al., "The Hierarchical Relationship Between Activities of Daily Living and Instrumental Activities of Daily Living," *Journal of Chronic Diseases* (Supplement 1987): 481–489.

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8. Liu and Cornelius, "ADLs and Eligibility for Long-Term Care Services."
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10. J. Luehrs and R. Ramthun, "State Experiences with ADLs," report prepared for The Commonwealth Fund Commission On Elderly People Living Alone, Background Paper Series 17 (June 1989).
11. P. Libassi, Travelers Insurance Company, Hartford, Connecticut, personal communication, 1989.
12. J.D. Kasper, "Characteristics and Functional Limitations of the Cognitively Impaired Elderly: Implications for Long-Term Care Policy," report prepared for the Public Policy Institute of the American Association of Retired Persons under grant no. 3-905-7300-000000 (1989).
13. Liu and Cornelius, "ADLs and Eligibility for Long-Term Care Services."
14. Liu et al., "Home Care Expenses for the Disabled Elderly;" and The Commonwealth Fund Commission On Elderly People Living Alone, *Help at Home* (New York: The Commonwealth Fund, 21 July 1989).
15. *Help at Home.*
16. Liu and Cornelius, "ADLs and Eligibility for Long-Term Care Services."
17. *Help at Home.*