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

Publicly-Financed Home Care for the Disabled Elderly:

Who Would Be Eligible?

December 1990

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.

ASPE develops or reviews issues from the viewpoint of the Secretary, providing a perspective that is broader in scope than the specific focus of the various operating agencies. ASPE also works closely with the HHS operating divisions. It assists these agencies in developing policies, and planning policy research, evaluation and data collection within broad HHS and administration initiatives. ASPE often serves a coordinating role for crosscutting policy and administrative activities.

ASPE plans and conducts evaluations and research--both in-house and through support of projects by external researchers--of current and proposed programs and topics of particular interest to the Secretary, the Administration and the Congress.

Office of Disability, Aging and Long-Term Care Policy

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 report was prepared under contract #HHS-100-88-0041 between HHS's Office of Social Services Policy (now DALTCP) and SysteMetrics. For additional information about this subject, you can visit the DALTCP home page at 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. The Project Officer was Robert Clark.

PUBLICLY-FINANCED HOME CARE FOR THE DISABLED ELDERLY:
Who Would Be Eligible?

Mary E. Jackson, Ph.D.
Brian O. Burwell

SysteMetrics/McGraw-Hill

December 1990

Prepared for
Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services
Contract #HHS-100-88-0041

TABLE OF CONTENTS

LIST OF TABLES

INTRODUCTION

At present, there is no uniform Federal policy for financing home care services for elderly persons in need of long-term care. Although in 1989, the Federal government financed over $4 billion in home care services for the disabled elderly, these resources were divided between multiple funding sources, including Medicare, Medicaid, the Social Services Block Grant, Department of Veterans Affairs' programs, Older Americans Act programs, and other funding mechanisms. Eligibility criteria which determine who is eligible to receive publicly-financed home care services varies considerably from funding source to funding source. To a large extent, these criteria are established at the State level, since States have primary responsibility for resource allocation decisions under many of these funding mechanisms, particularly Medicaid.

In recent years, there have been numerous proposals for establishing a uniform Federal benefit for home care services for disabled elderly persons. Proposals have included financing expanded home care benefits under Medicare, mandating expanded home care coverage under Medicaid; and even the establishment of entirely new Federal programs for financing home care. For example, the U.S. Bipartisan Commission on Comprehensive Health Care, also known as The Pepper Commission, has recommended the establishment of a new social insurance program for providing home and community-based services to the disabled elderly, which although financed entirely with Federal dollars, would be administered under contracts with State governments (The Pepper Commission, 1990). However, the Pepper Commission proposal is but one of a multitude of proposals that have been advanced recently for expanding the public sector's role in providing home care services to disabled elderly persons.

All of these proposals have had to address a fundamental policy issue: which elderly persons with disabilities are to be eligible for publicly-financed home care and which are not? Among the elderly population, an extremely wide spectrum of disability is evident, from extremely mild forms of impairment associated with the aging process to very severe disabilities which prevent individuals from living in the community without daily assistance from caregivers. Thus, virtually all of the proposals specify eligibility criteria for home care benefits based upon some standardized assessment of an applicant's disability status. Physical disability is always included as a criteria and is typically indicated by the inability of the person to perform daily self-maintenance activities--commonly referred to as Activities of Daily Living or ADLs. In addition, most proposals also specify criteria that would include persons who require human supervision due to cognitive impairment problems, most notably Alzheimer's disease, which could result in behavior harmful to the disabled person or to others.

While nearly all proposals have been specific about the number of ADL disabilities necessary to qualify a person as eligible for services, only a few go so far as to define how disability in a specific ADL--bathing, toileting, dressing, eating, or transferring--would be measured. For example, does impairment mean that the

individual is totally incapable of performing the activity without human assistance, or does it include those who can usually perform the activity but need someone nearby in case help is needed? What about people who may be impaired in a specific ADL but who have adapted to their impairment by using mechanical aids, such as walkers, raised toilets, special shower facilities, grab bars, and so on? Should they also be eligible for services?

Without such specificity in defining disability in ADLs, it is difficult to make accurate estimates of the number of persons who might be eligible under a proposed program. Equally important, without standardized definitions, it is extremely difficult, if not impossible, to insure equitable access to services among program applicants.

As non-specific as some of the ADL eligibility criteria are in the expansion proposals, they are vastly more specific than language pertaining to criteria that would establish eligibility for services based on cognitive impairments. This lack of specificity regarding cognitive criteria is not simply a deficiency in policy development, but also reflects the state of the art in measuring, and screening for, cognitive impairment in the elderly population.

Proposals for establishing a uniform Federal benefic for home care have stimulated research to estimate the number of disabled elderly persons who would be eligible for services under alternative proposals. This research demonstrates that estimates of program eligibles are very sensitive to alternative definitions of disability. For example, Stone and Murtaugh (1990), using the 1984 National Long-Term Care Survey, showed that disability estimates vary considerably depending upon whether an ADL disability is defined as reliance on hands-on assistance only, or whether the definition includes stand-by assistance as well. They estimated that 5.9% of the elderly were disabled in one or more ADLs when the definition of hands-on assistance was invoked, but that 7.8% were disabled when stand-by criteria were included in the definition, thereby increasing the size of the "eligible" population by about a third.

Other research has demonstrated that estimates of disability are also influenced by the specific measures used to assess disability. Wiener and Hanley, in work conducted for the Inter-Agency Forum on Aging-Related Statistics, highlighted differences in estimates chat result when alternate wording is used in designing disability-related survey questions, Even when ADL items were "standardized" for comparability, estimates still differed considerably across the data sets. Other factors identified as possible causes of discrepancies in estimates were: 1) age composition of the elderly population in the survey year; 2) sample frame; 3) methods used to collect the data; and 4) chance sampling variability (Weiner & Hanley, 1990).

Spector (forthcoming) has further contributed to this body of research by showing how estimates of the number of elderly persons with cognitive impairments are also highly sensitive to alternative definitions of impairment. Spector also developed estimates of the number of elderly who might require home care services due to

disruptive behaviors such as wandering, pathological stealing, or frequent temper tantrums.

This paper extends the work of these researchers by providing a series of estimates of the long-term care population using differing definitions of disability, including both functional and cognitive criteria. Definitions of disability and cut-off points for developing estimates used, in this paper were selected on the basis of eligibility criteria invoked in many recent legislative proposals. Since nearly all of the proposed legislation has focused on the more severely disabled, i.e., those with ADL disabilities or cognitive impairments, the estimates derived for this paper focus on this same population. We have excluded from our working definition of the long-term care population persons with disabilities in the Instrumental Activities of Daily Living (IADL) only, such as laundry, meal preparation, grocery shopping, housework, chores, etc. Although such individuals may legitimately be included in the long-term care population, we have excluded them here since our estimates are intended to enumerate those with more severe limitations.

The purpose of this paper is to demonstrate the variability in estimates of disability in the U.S. elderly population as a function of differing definitions of physical disability and cognitive impairment. Differing cut-off points along the disability continuum are employed, in conjunction with the varied definitions of disability, in order to demonstrate their effect on the number and types of persons eligible under a uniform Federal home care benefit.

METHODS

Data

Data from the 1984 National Long-Term Care Survey (NLTCS) were used to generate estimates of disability. As part of the NLTCS, indepth interviews were conducted of a sample of Medicare beneficiaries aged 65 and older on April 1, 1984 who were found to have either an ADL or IADL limitation (Manton, 1988). The NLTCS was designed so that national estimates of the elderly physically disabled population could be developed on a number of factors, and differs from other surveys in that reliable estimates of relatively rare disability events, even among the elderly, could be obtained. Information required to develop the estimates in this paper draw upon ADL and IADL questions in the survey as well as information on sample members' performance an a cognitive impairment screening instrument, data on diagnoses, and information on behavior problems.

The estimates presented are based on the community resident (non-institutionalized) sample of the NLTCS. Estimates have been subjected to a weighting procedure whereby cross-sectional weights were applied in order to adjust for non-response and the complexities of the sampling design. Application of weights results in nationally representative estimates of the aged 65+ community-dwelling population. All estimates presented in this paper meet precision standards of relative standard errors of 30% or less, and are based on unweighted cell sizes of 400 or larger.

Because the estimates derived from the survey reflect the number of persons disabled in 1984, we have adjusted 1984 estimates to be consistent with 1990 population estimates for the aged 65+ population. Adjustments were made by multiplying the percent of persons in each of five age groups (65-69: 70-74; 75-79; 80-84; 85+) in 1984 who were found to be disabled (according to the differing criteria) by the estimated community population in each age group in 1990, subtracting out the estimated 1990 nursing home population.[1]

Functional Disability Measures

Estimates of disability were developed from specific questions posed to NLTCS respondents or their proxies regarding the types of help the respondent received in five

[1] The 1990 nursing home population was estimated by multiplying the percent of the elderly population in nursing homes in 1985 in each age group by the projected total population in each age group in 1990. We thus assumed no change in age-adjusted nursing home utilization rates between 1985 and 1990. The estimated nursing home population by age group was then subtracted from 1990 population estimates. Data from the 1985 National Nursing Home Survey (National Center for Health Statistics, 1989) were used to derive the percent of the population in each age group residing in nursing homes. The 1990 population estimates were taken from projections by the Bureau of the Census (Bureau of the Census, 1989).

core ADLs: bathing, dressing, toileting,[2] transferring and eating. Receipt of services is used in these analyses as a proxy for disability, with the acknowledgment that there may well have been individuals who did not receive services but who were in need of them, and who, if an in-depth assessment were conducted, might have been determined disabled. The opposite may also be true, i.e. that some survey members were receiving assistance but really did not need them, although this seems a remote possibility with respect to the basic body maintenance activities associated with ADLs.

The NLTCS asked multiple questions about functioning in each of the five ADLs. From the myriad of questions asked, we classified NLTCS sample members into one of the following four categories:

- No Disability
- Uses assistive device but receives no human help
- Receives stand-by assistance, but no active hands-on help (may or may not also use an assistive device)
- Receives active hands-on assistance (may or may not also receive stand-by assistance and/or use an assistive device).

Besides persons who received active human assistance, two other groups of individuals were treated as if they received hands-on assistance: (1) persons not performing a given ADL at all; and (2) those who reported no hands-on assistance and who also did not use any assistive devices in the performance of a given ADL, but who said they needed help.

Each ADL was further classified with regard to the duration of the ADL problem. If the problem had lasted, or was expected to last, for at least three months at the time of the survey interview, we considered the ADL problem to be a chronic ADL problem. only chronic disabilities are considered in the estimates, as the purpose of the study was to estimate the elderly population with chronic or long-term care needs.

Cognitive Impairment

The NLTCS was not specifically designed to estimate the number of elders with cognitive problems, and thus we were only able to derive cognitive impairment estimates for persons who met the functional disability screen for the NLTCS sampling frame. However, the NLTCS sampling frame for identifying disabled community elders was quite liberal in its definition of disability. Any type of assistance, human or mechanical, for any ADL (bathing, dressing, toileting transferring, bladder or bowel incontinence, indoor mobility, outdoor mobility) or for any IADL (meal preparation, Laundry, light housework, grocery shopping, money management, medication management, telephoning) which had lasted, or was expected to last for a minimum of

[2] Persons who reported not receiving assistance in toileting, but who reported receiving help getting around inside were treated as if they received help in toileting since the definition of toileting includes getting to/from the bathroom.

90 days was included in the definition. Given the wide net that the NLTCS cast in its sampling frame of the elderly disabled, as well as the fact that most cognitively impaired elders can expect to have at least some limitation in functioning (IADL or ADL), we are fairly confident that elders with cognitive impairments are sufficiently represented in the estimates. We do acknowledge, however, that estimates based on cognitive impairment criteria in this paper run the risk of underestimating the numbers of all elders with cognitive impairment, specifically those who have such slight cognitive deficits that they do not experience any limitations in any ADLs or IADLs.

Three definitions of cognitive impairment were used to develop estimates. The first definition of cognitive impairment includes persons with an error score of 4 or more on a modified Short Portable Mental Status Questionnaire (SPMSQ), designated as "CI" in the tables below. The SPMSQ is a ten-item screening instrument designed to identify elderly persons with probable cognitive impairment. The instrument's content includes orientation to surroundings, short-term and long-term memory, and mathematical thinking (Pfeiffer, 1975). A score of 4 or higher was used to indicate cognitive impairment, rather than the customary approach of 5 or higher, because one of the SPMSQ questions was altered in the NLTCS, resulting in fewer errors than the original item typically elicits. The cut-off point indicating cognitive impairment was adjusted downward to accommodate this modification.

There are a number of community respondents in the NLTCS for whom the SPMSQ is missing. SPMSQ data is missing for those sample members who were not capable of responding to the questionnaire themselves and whose information was provided by a proxy respondents in order to identify sample members with missing SPMSQ information who were cognitively impaired, alternative criteria were developed as indicators of cognitive impairment. If a person with missing SPMSQ information was judged to be senile by the respondent's proxy, she/he was considered to be cognitively impaired. Also, any person without SPMSQ information for whom it was reported that she/he had a disability that was caused by disorders classified as mental retardation or senile psychotic conditions was also classified as cognitively impaired on the CI variable. This first approach for defining cognitive impairment replicates the measure used by Spector in his estimates of the cognitively impaired disabled elderly (forthcoming).

The second approach to defining cognitive impairment, which seeks to operationalize eligibility language from some legislative proposals, includes evidence of behavior problems, along with the CI criteria, in the definition of cognitive impairment. Some argue for the use of behavior problems in determining the need for long-term care services because behavior problems are considered to be conditions which require supervision and oversight to insure the health and safety of the afflicted person.

Wandering, frequent temper tantrums and compulsive stealing are the behavior problems on which the NLTCS collected information, and are therefore represented in our behavior problems measure, designated by the acronym "BP". Because the NLTCS did not collect information on other types of behavior problems besides these three, our

results may underestimate the prevalence of behavior problems among the elderly. One behavior problem which is notably absent from the NLTCS is the "inability to avoid simple dangers".

The third cognitive impairment measure employed in our estimates is more stringent than the other two. Under the "CI+" measure, a person must not only meet the CI criteria but must also either demonstrate disability in at least one ADL (where ADL disability is defined as receiving active or stand-by assistance for three months or longer) or one of the cognitively-oriented IADLs (money management, medication management, telephoning) or exhibit a behavior problem (BP). This particular cognitive impairment measure requires that there be evidence of the need for oversight or some type of service need before the individual is determined to meet the definition of cognitive impairment. The CI+ criteria attempts to operationalize language in proposed legislation which stipulates that a person with Alzheimer's disease or other cognitive impairments must demonstrate needs similar to persons meeting ADL criteria in order to be deemed eligible. The CI+ criteria operationalizes such criteria by requiring some evidence for the need for care beyond a diagnosis or a score on a cognitive impairment screen, neither of which may reflect an impairment severe or progressed enough to require home care services.

ESTIMATES

Estimates of the Elderly with ADL Impairments

Impairments in Activities of Daily Living (ADLs) are designated eligibility criteria in almost all legislative proposals for expanded Federal support of home care. The majority of proposals require that applicants be disabled in two or more ADLs to qualify for home care services. The Pepper Commission proposal goes one step further by limiting eligibility for home care services to persons impaired in three or more ADLs. In doing so, the Pepper Commission stated its intent that new Federal resources be targeted to those persons with the most severe disabilities (The Pepper Commission, 1990).

Table 1 presents estimates of the number of elders in 1990 who would be eligible for home care services if criteria were established at 1 or more AOL impairments (1+), two or more (2+), or three or more (3+). Estimates are also provided for three different options for defining disability in a specific ADL. The first option corresponds to the most narrow definition of an ADL disability, whereby a person must rely on hands-on (active) human assistance in the performance of an ADL for him/her to be considered disabled in that ADL. The second definition of ADL disability is somewhat broader than the first in that it includes persons who require stand-by assistance only. The third, the most broad definition, adds those who use an assistive device but require no human assistance to perform an ADL.

While the receipt or need for active or stand-by help in an ADL almost unquestionably signifies the need for assistance, the use of an assistive device as sufficient evidence of an ADL disability, as previously discussed, is debateable. On the one hand, it could be argued that using an assistive device implies some level of disability; without the use of the device the performance of the ADL would be difficult at best. On the other hand, it could be argued that the use of the device renders the person independent of the assistance of another, and therefore not in need of formal home care services.

As shown in Table 1, estimates of the number of elderly disabled are very sensitive to the number of ADLs considered as well as to the relative restrictiveness of the ADL disability definitions. Under the broadest definition of disability (in need of active or stand-by assistance or use of an assistive device in at least one ADL) over 12 percent of the community-dwelling elderly in 1990 would be considered disabled, about 3.3 million individuals. Using the same definition of ADL disability (active, stand-by or use of an assistive device), estimates of disability (or program eligibles) drop to 8.2 percent if 2+ ADL criteria are used, and to 5.2 percent if 3+ ADL criteria are invoked. In brief, each additional ADL criteria. reduces the estimated disabled population by about 35 percent.

When the most circumscribed definition of disability in a specific ADL is used (requires active human assistance), estimates of the disabled population are significantly lower, as also shown in Table 1. For example, the number of persons requiring active assistance in 1+ ADL is only about half of those who require assistance under the broadest definition. At the 2+ and 3+ cut-off points, the differences are even greater. The number of persons requiring active assistance in 3+ ADLs is only about 40 percent of the number of who require assistance in 3+ ADLs under the broadest definition. Under the most stringent definition of disability (active human assistance required in 3+ ADLs) only about 630,000 elderly meet the definition, only about one-sixth the number who meet the broadest definition with the 1+ cut-off presented in Table 1.

Estimates by Number of Chronic Heavier Care ADL Disabilities

Recent legislative proposals to establish a uniform Federal home Care benefit show more sensitivity to the effects of alternative definitions of disability. For example, bills sponsored during the 101st Congress by Representative Roybal (H.R. 4093) and Oakar (H.R. 4253) in the House and Senator Kennedy (S.2163) in the Senate make the distinction between total and partial dependence in ADLs. Under the provisions of these bills, Medicare beneficiaries aged 65 and older would have to be either completely dependent in one ADL (out of the core five) or partially dependent in two or more ADLs in order to be eligible for publicly-financed benefits. In the language of these bills, complete dependence generally refers to an individual who does not participate at all in the performance of an ADL, and partial dependence to the inability to perform the activity without some kind of human assistance or supervision.

Even more stringent criteria appear in bills sponsored by Senator Rockefeller and Representative Wyden (S. 1942 & H.R. 3933) in which Medicaid recipients aged 65 and older, to be eligible for services, would have to be unable to perform, without “substantial assistance” from another individual, at least two of the three ADLs of toileting, transferring or eating. In this case disability in bathing and/or dressing would not be considered at all in the eligibility process. Since research has shown that persons tend to lose functioning in the ADLs in an hierarchical, step-wise fashion with loss of functioning first occurring in bathing followed by dressing, toileting, transferring and eating (Katz et. al, 1963), being disabled in toileting, transferring or eating is approximately equivalent to being disabled in at least three or more of the core five ADLs. Thus, disability criteria which reduce the number and type of ADLs in which a person must be impaired usually reflects a more stringent eligibility decision rule.

Consequently, Table 2 presents estimates of the number of elderly who would meet more stringent eligibility criteria based on a reduced list of ADL impairments, as discussed above. Again, we also use alternative definitions of ADL disability, from those that include only persons who require active assistance to those which include individuals who use assistive devices.

The first two rows of estimates in Table 2 require that an individual have at least one or two ADL disabilities of the four "heavier care" ADLs of dressing, toileting, transferring and eating (DTTE). When compared to estimates presented in Table 1, the number of persons disabled in one or more of the heavier care ADLs is significantly reduced. This is simply due to the fact that many elderly persons require assistance only in the ADL of bathing, and are able to perform other ADLs independently. In comparison to Table 1, it can also be seen that employing a more restrictive definition of disability in specific ADLs has a more severe effect on reducing estimates of disability than when all five ADLs are included. For example, for persons with 2+ ADL limitations of DTTE, the number who require active assistance is only about one-third of those who require assistance under the broadest definition.

Confining estimates of the elderly disabled to those with impairments in toileting, transferring and eating (TTE), as presented in the third and fourth rows of Table 2, further reduces the eligible population. The 2+ ADL of TTE criteria operationalizes eligibility criteria specified in the bills sponsored by Congressman Wyden and Senator Rockefeller described previously. Depending upon the definition of disability employed, only between 472,000 and approximately 1.7 million individuals would meet the disability criteria specified in these bills.[3]

The final two rows of estimates in Table 2 distinguish between ADLs in which the person receives extensive human assistance (totally dependent) and where some help is received but the person participates at least somewhat in his/her care (partially dependent). We call the former Extensive Assistance ADLs (EXT ADL) and the latter Limited Assistance ADLs (LIM ADL). These definitions differ slightly from the definitions of active or stand-by assistance discussed previously. In general, an ADL is defined as an EXT ADL when the person either does not do the activity at all, or when it is completely done by another person. A LIM ADL is defined as receiving some assistance with the activity--either active or stand-by help (or even use of an assistive device when devices are included in the definition of disability), but not being totally dependent on another person for the performance of the activity.

The criteria of 1+ EXT ADL or 2+ LIM ADL operationalizes the disability criteria specified in recent legislation by Senator Kennedy and Representatives Okar and Roybal. Interestingly, this set of criteria yields slightly more persons eligible than does the 2+ ADL/5 criteria. Between approximately 1.7 and 2.5 million elders are estimated to meet these criteria, compared to 1.6 to 2.4 million under the 2+ ADL/5 criteria. If the “1+ EXT ADL or 3+ LIM ADL” criteria were invoked, somewhat fewer persons than under the 2+ ADL/5 criteria would meet the requirements, between about 1.5 million and 1.8 million persons.

[3] The Rockefeller and Wyden bills target services to Medicaid clients. The financial criteria associated with Medicaid eligibility would reduce the estimates presented in Table 2 even further. The content of these bills was enacted as part of the Omnibus Budget Reconciliation Act of 1990.

Estimates that Include Cognitive Impairment in Eligibility Criteria

Eligibility rules which rely exclusively on physical disability criteria have been criticized for excluding persons who have the physical capacity to perform ADLs, but not the ability to remember when to initiate a task and/or those who need supervision or cuing in order to complete a task (Advisory Panel on Alzheimer's Disease, 1989). These are typically individuals with Alzheimer's disease or a related disorder who are cognitively impaired. Most legislative proposals for expanding Federal financing for home care now include criteria intended to capture the cognitively impaired in the population targeted for services. In Table 3, we present a series of estimates using different indicators from the NLTCS as proxies for cognitive impairment criteria.

Table 3 presents estimates which include cognitive as well as ADL criteria in eligibility decision rules. The table is divided into three sections (A, B & C), where the definition of an ADL disability distinguishes the difference among sections. This format is similar to the previous two tables in that an ADL disability in section A is defined as receiving active hands-on assistance only, in section B as active or stand-by assistance, and in section C as either active assistance, stand-by assistance, or the use of an assistive device. There are three sets of estimates in each section which correspond to one of the three cognitive impairment measures used in the estimation procedure.

For example, in section A there are three different estimates (columns) corresponding to the “2+ADL/5" criteria. The first column estimates the number of elders who would be eligible for services if the criteria were 2+ ADL/5 or CI or BP. This decision rule targets individuals with either: two or more ADL disabilities (active assistance only) or those who are cognitively impaired (according to a score of 4+ on the SPMSQ or who have a cognitive impairment-related diagnosis) or those who exhibit one or more behavior problems (wandering, frequent temper tantrums, compulsive stealing). The rationale for considering those with behavior problems within the cognitive impairment group is that behavior problems are considered a proxy for cognitive impairment, and that those with behavior problems are thought to need oversight and supervision in order to insure their health and safety.

Slightly more than 2 million elders would meet the "2+ ADL/5 (active only) or CI or BP" criteria in 1990. Approximately an additional one million persons (or 3.5 percent more of the elderly population) would be eligible for services if these criteria were used as compared to comparable criteria which exclude the cognitively impaired from consideration. Even using the most conservative ADL definition criteria, 2+ ADL/5 (active) **or** CI **or** BP, over an additional one million persons are added to the estimate when this particular cognitive impairment criterion is employed.

The “CI or BP” criteria is the most liberal of the three cognitive impairment criteria included in the estimates. Examination of Table 3 indicates that it clearly yields the highest estimates of the measures. However, these particular criteria may result in an overestimate of the cognitively impaired population because of how the behavior problem factor figures into the criteria. For example, under the "2+ ADL/5 or CI or BP"

rule a person without any ADL disabilities, who is not considered cognitively impaired by the “CI” criteria, but who compulsively steals would be deemed eligible. A person with this particular profile may not be an appropriate candidate for home care services, and including such persons in an eligibility pool may results in misspecifying the targeted population, even under very liberal targeting policies.

A more conservative approach would be to define cognitive impairment solely in terms of evidence of cognitive impairment, for example as operationalized by the "CI" criteria. Using this criteria, fewer individuals would fall into the eligibility pool. While using the "CI" criteria instead of the "CI or BP" criteria does lower the estimates, the decrease is only on the order of 0.2 to 0.5 percent, or 60,000 to 150,000 fewer eligible persons nationwide, depending upon the exact ADL criteria invoked and the definition of disability used.

This approach, though more conservative, is still subject to criticism. A score on a cognitive impairment test, or even a diagnosis of Alzheimer's disease, does not necessarily correspond to a need for home care. The target population for home care services should probably not include persons for whom organicity has not yet impeded independent functioning of ADLs or presents no threat to the safety of the individual. This criticism has led to the suggestion that eligibility for home care services for persons with cognitive impairment be linked to more specific evidence of the need for care. The "CI+" criteria responds to this suggestion by requiring that eligibility for services be evidenced by an SPMSQ score indicating cognitive impairment (or a cognitive impairment related diagnosis) and some evidence of the need for care or oversight as indicated by either: (1) one or more ADL disabilities; or (2) a disability in one of the three cognitively-oriented IADLs of money management, medication management, or telephoning; or display of behavior problems.

The "CI+" criteria are undoubtedly the most restrictive of the three cognitive impairment criteria. For example, 6.8 percent of elderly would be service eligible under the 2+ ADL/5 (active) or CI or BP criteria, 6.5 percent under 2+ ADL/5 or CI criteria, but only 4.8 percent under the 2+ ADL/5 or CI+ criteria. Yet this 4.8 percent estimate is substantially higher than the same criteria without the cognitive impairment component added. This translates into an additional 450,000 eligible persons under the 2+ ADL or CI+ criteria who are eligible on cognitive impairment criteria component alone.

DISCUSSION

If legislation were enacted at the Federal level which established uniform entitlement to home care services for the elderly based on standardized measures of disability, who would be made eligible? In this study, we have demonstrated how various eligibility criteria can be operationalized for deriving estimates of the disabled elderly population living in the community and how these various criteria affect the size of the population that would be made eligible for benefits under alternative definitions of disability. The objective of the study is to provide guidance to the policy process in the consideration of alternative Federal proposals for expanding home care services to the disabled elderly.

However, there are some limitations to using these estimates in projecting the number of elders who would become eligible for services if a home care entitlement program was enacted and implemented. First, it must be recognized that these estimates are derived from survey data where incentives for respondents to overstate their disabilities are minimal. Unlike a program application process, there was no potential benefit available if they did. In fact, there is some evidence that survey respondents may underestimate their disability levels (Ford et al., 1989). Thus, we would expect some increase in self-reported disability if persons were applying for services and knew that service-receipt was contingent upon a disability measure.

Second, these estimates are not a true representation of persons <u>needing</u> assistance in the various functional activities. The NLTCS did not conduct a clinical assessment of sample members, but rather relied on self-reports regarding the type of assistance <u>received</u>. In brief, the survey did not include efforts to measure unmet need. Even though some survey items did allow for measuring some unmet need, the measures were circumscribed in that they did not take into account the conceptualization of undermet need. The NLTCS does allow us to identify persons not receiving <u>any</u> help (human or mechanical) and who say they need help. But the questionnaire did not inquire or assess whether adequate assistance was being received. This bias in survey methods may have resulted in underestimates of disability as presented in this paper.

Third, the number of persons enumerated under the cognitive impairment criteria may be slightly underestimated as well. Because the NLTCS was designed to provide estimates of the functionally disabled elderly, we were able to derive estimates only of the number of cognitively impaired elderly who had some kind of functional disability. However, the definition of disability employed in the NLTCS sampling frame was inclusive of persons receiving any kind of assistance (human or mechanical) in seven IADL or eight ADL items. The chances are slim, therefore, that many cognitively impaired elders needing home care services were not accounted for in the estimates.

Nonetheless, the estimates presented in this paper demonstrate how substantially different estimates of the disabled elderly population are generated by

employing varying definitions of disability. Alternatively relying on more stringent or more liberal eligibility criteria for home care services will have dramatic effects on the number of elders who would qualify for services. The most obvious implication is that the specific eligibility criteria employed in legislation to expand Federally- financed home care services for the disabled elderly will be major factors in determining the ultimate costs of such an expansion. A second implication is that unless the eligibility criteria designated in the legislation are specific in their definitions of disability, the number of persons who will actually qualify for benefits will depend largely upon how the general language of the legislation is interpreted in regulatory and administrative procedures during program implementation. This could lead to considerable discrepancy between the intent of the legislation and its actual implementation.

Definitions of disability using measures of ADL impairment have become popular mechanisms for allocating home care resources under proposed Federal legislation. However, the need for publicly- financed home care depends upon a variety of factors, not just one's level of disability. Financial need is an obvious factor, and one that is also built into many legislative initiatives. However, it is also true that the elderly adjust to their disabilities through a multitude of adaptive behaviors, just as non-elderly persons with disabilities do. In addition, the elderly have access to a wide spectrum of social support systems which can serve to augment the formal provision of services. Given the variety of factors which contribute to the "need" for home care, should a Federal entitlement program for home care services based solely on standardized measures of disability be implemented?

In any case, it is apparent that the establishment of criteria to determine which elderly persons with disabilities should be eligible for publicly-funded home care, and which should not, is not a simple matter. In this context the question must be raised whether it is possible to enact Federal legislation which would ensure that benefits are allocated in an equitable manner according to true need. Unlike access to publicly-financed acute care services which is determined primarily by physicians, access to expanded Federal home care benefits will require policymakers to establish relatively specific decision rules about who is eligible for benefits, and who is not.

REFERENCES

Advisory Panel on Alzheimer's Disease, Report on the Advisory Panel on Alzheimer's Disease, DHHS Pub.No.(ADM)89-1644, Washington, D.C., 1989.

Bureau of the Census, Vital and Health Statistics, Series 13, No.97, January 1989.

Ford, A., Folmar, S.J., Salmon, R.B., Medalie, J.H., Roy, A.W., & Galazka, S.S., Health and Function in the Old and Very Old, Journal of the American Geriatrics Society, 36:187-197, 1988.

Katz, S., Ford, A., Moskowitz, R., Jackson, B., & Jaffe, M., Studies in the Illness in the Aged: The Index of ADL: A Standardized Measure of Biological and Psychosocial Function, Journal of the American Medical Association, 185(12): 914-919, 1963.

Manton, K.G., A Longitudinal Study of Functional Change and Mortality in the United States, Journal of Gerontology, 43(5): S153-161, 1988.

National Center for Health Statistics, The National Nursing Home Survey: 1985 Summary for the United States, U.S. Department of Health and Human Services, Public Health Service, Center for Disease Control, Hyattsville, DHHS Publication No.(PHS)89-1758, January 1989.

Pfeiffer, E., A Short Portable Mental Status Questionnaire for the Assessment of Organic Brain Deficit in Elderly Patients, Journal of the American Geriatrics Society, 23(10): 433-441.

Spector, W.D., Cognitive Impairment and Disruptive Behavior Among Elderly Persons Living in the Community: Implications for Targeting Long-Term Care, The Gerontologist, forthcoming.

Stone, R. & Murtaugh, C., The Elderly Population with Chronic Functional Disability: Implication for Home Care Eligibility, The Gerontologist, 30(4): 491-496, 1990.

The Pepper Commission (U.S. Bipartisan Commission on Comprehensive Health Care), A Call For Action, U.S. Government Printing Office, Washington, D.C., 1990.

Weiner, J.M., Hanley, R.J., Clark, R., Van Nostrand, J.F., Measuring the Activities of Daily Living: Comparisons Across National Surveys, Journal of Gerontology, 45(6): S229-237. [Available at http://aspe.hhs.gov/daltcp/reports/meacmpes.htm]

TABLES

TABLE 1. Number of Community Elderly (in 000's) Aged 65+ by Alternative Chronic ADL Disability Criteria, 1990

Number of ADL Disabilities	ADL Disability Definition		
	Active Assistance	Active or Stand-By Assistance	Active Assistance or Stand-by Assistance or Assistive Device
1+ ADL/5[a]	1,837 (6.1)	2,417 (8.0)	3,770 (12.5)
2+ ADL/5	1,007 (3.3)	1,578 (5.2)	2,455 (8.2)
3+ ADL/5	630 (2.1)	1,157 (3.8)	1,561 (5.2)

a. Five Core ADL: Bathing, Dressing, Toileting, Transferring, Eating.

TABLE 2. Number of Community Elderly (in 000's) Aged 65+ by Alternative Heavier Care Chronic ADL Disability Criteria, 1990

Number of ADL Disabilities	Active Assistance	Active or Stand-By Assistance	Active Assistance or Stand-by Assistance or Assistive Device
1+ ADL of DTTE[a]	1,281 (4.3)	1,838 (6.1)	3,080 (10.2)
2+ ADL of DTTE	683 (2.3)	1,256 (4.2)	1,876 (6.2)
1+ ADL of TTE[b]	901 (3.0)	1,628 (5.4)	2,961 (9.8)
2+ ADL of TTE	472 (1.6)	1,071 (3.6)	1,673 (5.6)
1+ EXT ADL[c] or 2+ LIM ADL[d]	NA[e]	1,748 (5.8)	2,514 (8.4)
1+ EXT ADL or 3+ LIM ADL	NA	1,487 (4.9)	1,763 (5.9)

a. Dressing, Toileting, Transferring, Eating.
b. Toileting, Transferring, Eating.
c. Extensive assistance in ADL.
d. Limited assistance in ADL.
e. Not applicable since definition of limited assistance includes stand-by and/or use of assistance device.

TABLE 3. Number of Community Elderly (in 000's) Aged 65+ by Alternative Chronic ADL Disability and Cognitive Impairment Criteria, 1990			
ADL Disabilities	**Cognitive Impairment**		
	CI or BP[a]	**CI[b]**	**CI+[c]**
A. ADL DISABILITY CRITERIA: ACTIVE ASSISTANCE ONLY			
1+ ADL/5[d]	2,701 (9.0)	2,606 (8.7)	2,114 (7.0)
2+ ADL/5	2,056 (6.8)	1,947 (6.5)	1,458 (4.8)
3+ ADL/5	1,780 (5.9)	1,657 (5.5)	1,174 (3.9)
1+ ADL or DTTE[e]	2,281 (7.6)	2,176 (7.2)	1,692 (5.6)
2+ ADL of DTTE	1,817 (6.0)	1,677 (5.6)	1,217 (4.0)
1+ ADL of TTE[f]	1,993 (6.6)	1,877 (6.2)	1,396 (4.6)
2+ ADL of TTE	1,654 (5.5)	1,518 (5.0)	1,041 (3.5)
1+ EXT ADL[g] or 2+ LIM ADL[h]	NA[i]	NA	NA
1+ EXT ADL or 3+ LIM ADL	NA	NA	NA
B. ADL DISABILITY CRITERIA: ACTIVE OR STAND-BY ASSISTANCE			
1+ ADL/5[d]	3,179 (10.6)	3,098 (10.3)	2,619 (8.7)
2+ ADL/5	2,520 (8.4)	2,425 (8.1)	1,942 (6.4)
3+ ADL/5	2,182 (7.3)	2,076 (6.9)	1,588 (5.3)
1+ ADL or DTTE[e]	2,733 (9.1)	2,642 (8.8)	2,167 (7.2)
2+ ADL of DTTE	2,263 (7.5)	2,157 (7.2)	1,669 (5.5)
1+ ADL of TTE[f]	2,566 (8.5)	2,447 (8.2)	1,997 (6.6)
2+ ADL of TTE	2,119 (7.0)	2,005 (6.7)	1,515 (5.0)
1+ EXT ADL[g] or 2+ LIM ADL[h]	2,647 (8.8)	2,551 (8.5)	2,075 (6.9)
1+ EXT ADL or 3+ LIM ADL	2,445 (8.1)	2,337 (7.8)	1,856 (6.2)

TABLE 3 (*continued*)			
ADL Disability	**CI or BP[a]**	**CI[b]**	**CI+[c]**
C. ADL DISABILITY CRITERIA: ACTIVE ASSISTANCE OR STAND-BY ASSISTANCE OR ASSISTIVE DEVICE			
1+ ADL/5[d]	4,217 (14.0)	4,164 (13.8)	3,915 (13.0)
2+ ADL/5	3,192 (10.6)	3,107 (10.3)	2,717 (9.0)
3+ ADL/5	2,490 (8.3)	2,390 (7.9)	1,946 (6.5)
1+ ADL or DTTE[e]	3,695 (12.3)	3,623 (12.0)	3,505 (11.0)
2+ ADL of DTTE	2,749 (9.1)	2,651 (8.8)	2,228 (7.4)
1+ ADL of TTE[f]	3,600 (12.0)	3,521 (11.7)	3,209 (10.7)
2+ ADL of TTE	2,584 (8.6)	2,477 (8.2)	2,050 (6.8)
1+ EXT ADL[g] or 2+ LIM ADL[h]	3,238 (10.8)	3,154 (10.5)	2,771 (9.2)
1+ EXT ADL or 3+ LIM ADL	2,658 (8.8)	2,556 (8.5)	2,105 (6.9)

a. Score of 5+ on SPMSQ or cognitive impairment-related diagnosis or behavior problem.
b. Score of 5+ on SPMSQ or cognitive impairment-related diagnosis.
c. CI plus behavior problems or CI plus either 1+ ADL or disability in money management, telephoning or medication management.
d. Five Core ADLs: bathing, dressing, toileting, transferring, eating.
e. Dressing, toileting, transferring, eating.
f. Toileting, transferring, eating.
g. Extensive assistance in ADL.
h. Limited assistance in ADL.
i. Not applicable since limited assistance includes stand-by and/or use of assistive device.