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Prevalence and Correlates of Unmet Need Among the Elderly with ADL Disabilities

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PREVALENCE AND CORRELATES OF UNMET NEED AMONG THE ELDERLY WITH ADL DISABILITIES

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INTRODUCTION

Numerous attempts have been made over the last few years to estimate the number of elderly who are disabled.[1,2,3,4,5,6] Fewer estimates, however, have been generated to gauge the extent to which those who are disabled go without the assistance they need. Most recently, estimates have been published by Ken Manton of Duke University.[7] These estimates indicated that almost 35 percent (34.6%) of the disabled elderly experienced unmet need in one or more of the basic activities of daily living (ADL). The implication of this finding is that over one-third of the disabled are not getting some very basic needs met, and that both the informal and formal systems of care, in tandem, are overlooking these frail elderly individuals.

Long-term care policy-makers, however, are becoming increasingly aware of how sensitive estimates can be to definitions of the phenomenon being estimated. For example, recent research shows that the definition of disability invoked can substantially affect the numbers of people estimated to be disabled.[8,9,10,11] Just as there can be alternative ways of defining an ADL disability, there can also be varied approaches to defining unmet needs. In order to explore the potential variability in estimates due to definitional variation, a series of unmet need estimates for the disabled elderly were generated by altering the definition of unmet need. The construction and presentation of these estimates is the focus of this report.

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[1] Weiner, J.M., Hanley R.J., Clark, R. Van Nostrand, F.F. Measuring the Activities of Daily Living: Comparisons Across National Surveys, Journal of Gerontology, *45*, (6): S229-237, 1990. [http://aspe.hhs.gov/daltcp/reports/meacmpes.htm]

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

[3] Manton, K. Epidemiological, Demographic, and Social Correlates of Disability Among the Elderly. Milbank Quarterly, *67*, Supplement 2, Part 1, pp. 13-58, 1989. [http://aspe.hhs.gov/daltcp/reports/epdemes.htm]

[4] Jackson, M.E. & Burwell B.O. Publicly-Financed Home Care for the Disabled Elderly: Who Would Be Eligible? SysteMetrics/McGraw-Hill, 1990. Prepared for the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation under Contract No. HHS-100-98-0041. [http://aspe.hhs.gov/daltcp/reports/pubfines.htm]

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

[6] Rowland, D. Measuring the Elderly's Need for Home Care. Health Affairs, *8* (4): 39-51.

[7] Manton, 1989, op.cit.

[8] Weiner et al., 1990, op. cit.

[9] Stone & Murtaugh, 1990, op. cit.

[10] Jackson & Burwell, 1990, op. cit.

[11] Spector, forthcoming, op. cit.

In generating alternative estimates, we first replicated Dr. Manton's work using a slightly different version of the same data source that he employed. Besides presenting alternative estimates of the prevalence of unmet need, the correlates--or characteristics of persons-associated with unmet ADL need were also analyzed. In light of our findings we discuss policy implications, as well as the need for further research in this area. Before reviewing the estimates, we outline the parameters of how unmet need has been conceptualized and operationalized in this study.

CONCEPTUALIZING UNMET NEED

Persons with impairments sufficiently severe that they require some form of assistance in the basic activities of daily living (ADLs)--such as bathing, dressing, using the bathroom, transferring, moving about, and eating--are typically considered disabled. They may be totally dependent on another person to perform one or more of these tasks, or they may only require some hands-on assistance from another human being. Alternatively, they may need someone to stand-by In the event that they require help. Those suffering from Alzheimer's disease or a related condition may need supervision in initiating and/or carrying out tasks. Others may have an impairment in an ADL, but overcome their disability with the use of an assistive device such as a walker or grab bars. All of these individuals have, to a greater or lesser degree, <u>needs</u> in ADLs.

In conceptualizing "unmet need" among this population, one must distinguish between a need not being addressed at all versus a need that is receiving some, but not sufficient, attention. In the former case, the individual is not able to care for him/herself and there is no one to help fill this need; the person's need goes <u>unmet</u>. In the latter case, the person has a need which is being addressed, but insufficiently, this person's needs are <u>under-met</u>. Both types of unmet needs are usually considered under the broad umbrella of unmet needs, however.

OPERATIONALIZING UNMET NEED

Ideally, policy makers would like to know how many elders experience lack of assistance in any kind of need, be they unmet or undermet. To estimate the prevalence of unmet and undermet needs, however, researchers must rely upon existing data sources, and are thus constrained by the information available.

In this particular study, we employed data from the 1984 National Long-Term Care Survey (NLTCS) to generate estimates. The 1984 NLTCS was chosen for analysis because it was intentionally designed so that national estimates of the physically disabled elderly population could be developed on a number of factors. Yet, while the NLTCS provides a fairly comprehensive set of questions about the kinds of help an individual receives in specific ADLs, the coverage of unmet needs was somewhat

limited. More specifically, the NLTCS collected some data on unmet needs, but none on undermet needs.

Instead of gathering information on the extent to which disability needs were met, the NLTCS collected data only on needs for which persons received no assistance, but for which they said they needed help. In other words, data exists which describes needs that were completely unmet only. Sample respondents had to first report receiving neither human assistance nor using an assistive device before they were asked by the interviewer whether or not they needed any help. Consequently, our estimates of unmet need in this report include only those persons who do not have any of their needs (per ADL) met. In general, however, none of these respondents said they did not do (or were unable to do) a given ADL task at all, and thus presumably they were performing the task themselves at some level, or at least sporadically.

PREVALENCE OF UNMET NEED

Estimates were generated for unmet need in six common ADLs: bathing, dressing, toileting, transferring, indoor mobility, and eating. Before estimating persons with unmet needs in each ADL, we first defined what constituted a disability in each ADL; from this denominator we then estimated the proportion of those disabled who had unmet need. Several alternative definitions of disability and unmet need were employed in generating the estimates; each are described in detail below.

Disability Definitions. Settling on a definition of disability is less than clear-cut. Good arguments can be made for using alternatively stringent or liberal definitions of disability (and unmet need). In this report we take four separate approaches to defining ADL disability. Each of these approaches is summarized at the bottom of the tables in which the estimates appear (Table 1, Table 2, Table 3 and Table 4).

First, we replicated the definition of disability used by Ken Manton in his Milbank Quarterly publication.[12] Criteria used by Dr. Manton were:

- *Does not perform the ADL at all*
- *Receives active human assistance (stand-by assistance not included)*
- *Uses an assistive device*
- *Does not receive human assistance, does not use assistive device, but reports needing help*

The above criteria were employed in generating the estimates in Table 1, and in the "DUKE-1" column of Table 5 and Table 6. These are relatively liberal criteria because they do not require that an ADL disability be chronic in order to be considered a

[12] Manton, 1989, op.cit.

disability.[13] Most current estimates of the disabled elderly do not consider transient disability that is likely to resolve within a few months or less. Another factor consistent with Dr. Manton's liberal definition of disability is the inclusion of persons whose only indicator of disability is the use of special equipment. Yet he does invoke relatively restrictive criteria by excluding from the disabled group those who require stand-by assistance.

Dr. Manton included incontinence as evidence of disability in toileting. Typically, however, disability in toileting is reserved for persons unable or needing help to get to the toilet and/or In using the toilet. Thus, to provide estimates consistent with the traditional definition of toileting dependency, we devised a second approach to the definition of disability which is the same as Dr. Manton's except that it excludes incontinence from the disability criteria for toileting. Estimates based on these criteria are found in Table 2, and in the "DUKE 2" columns of Table 5 and Table 6.

Our third approach was to redefine disability so that only chronic disabilities--those lasting or expected to last for three months or longer--are included in the estimate. Besides chronicity, other criteria include:

- *Does not perform the ADL at all*
- *Receives active human assistance*
- *Receives stand-by assistance*
- *Does not receive human assistance, does not use assistive device, but reports needing help*

Estimates based on this third definition of disability may be found in Table 3, as well as in the "SMI-1" columns of Table 5 and Table 6. In contrast to the first two approaches, this definition of disability is somewhat more stringent. Even though it includes stand-by assistance, at the same time it excludes the use of special equipment from the criteria used to establish disability. We consider as disabled anyone receiving any kind of human assistance, but treat those whose dependency is restricted to special equipment as non-disabled. For example, someone needing a steady hand while walking across a room would be labeled as disabled by this definition, but a person using a walker or cane, with no other assistance, would not be considered disabled. We acknowledge, however, that the use of an assistive device as insufficient evidence for an ADL disability is debateable. On the one hand, using special equipment implies some level of disability; that is, without the use of the device the performance of the ADL would be difficult at best. On the other hand, the use of the device often renders a person independent of the assistance of another, and therefore enabled, rather than disabled.

Acknowledging the differences of opinion in the long-term care community about whether or not to include the use of assistive devices in definitions of disability, we also developed a fourth approach which incorporates the use of special equipment into the

[13] While nearly all 1984 NLTCS respondents had a least one chronic ADL or IADL disability, a given individual may not have had any chronic disability in the basic ADLs used in these and Dr. Manton's estimates.

definition of disability. This particular criteria of disability was used to construct the estimates presented in Table 4, and in the "SMI-2" columns of Table 5 and Table 6. The only difference between the disability definitions in Table 3 and Table 4 is that Table 3 excludes, and Table 4 includes, use of special equipment as evidence of disability.

Unmet Need Definitions. Just as there is divergence of opinion on how best to define disability, differences also exists with regard to defining unmet need. In this paper we present estimates based on three alternative definitions of unmet need. The first corresponds, once again, to criteria used by Ken Manton in his Milbank Quarterly article.[14] In that study, an unmet need was defined to exist if a person met one of the following criteria:

- *Does not perform the activity at all*
- *Receives no human assistance, does not use an assistive device, but reports needing help*

and two additional criteria that are ADL-specific:

- *Persons who are incontinent (of bowel or bladder) are considered to have an unmet need.*
- *Those who report (initially) that they do not bathe at all, but later in the interview state that they take a bed/basin/sink bath are not considered as having an unmet need in bathing.*

This last criterion is actually an exception to the first criteria, and is exclusionary rather than inclusionary. These unmet need criteria are reflected in the estimates appearing in Table 1 and in the DUKE-1 columns of Table 5 and Table 6.

Our second approach to defining unmet need again replicates the criteria used by Dr. Manton, with one change. Incontinence is dropped as an indicator of unmet need. In Dr. Manton's analysis, incontinence was treated as both a need and an unmet need under the toileting ADL. While incontinence may require attention from a caregiver, and its management can legitimately be considered a long-term care need, the NLTCS does not solicit information from respondents on unmet need in the management of incontinence, and thus it may not be appropriate to count It as an unmet need. Therefore, in the second approach to unmet need definition, we drop incontinence as evidence of unmet need in toileting. These definitions are reflected in the estimates which appear in Table 2 and in the "DUKE-2" columns of Table 5 and Table 6.

Our third and last approach to defining unmet need breaks with Dr. Manton's definition. First, we mainly consider an unmet need to exist only if a person:

- *Receives no human assistance, does not use an assistive device, but reports needing help.*

[14] Manton, 1989, op.cit.

In contrast to Dr. Manton's approach, this third approach excludes from the unmet need criteria most persons who do not perform an ADL task at all. However, unmet need in three ADLs--bathing, dressing and toileting--was defined to exist for a subset of individuals who did not do the ADL at all. Persons with the following characteristics were defined as having unmet need:

- *Bathing: Unable to bathe, did not wash in a sink/basin, and did not have a bed bath within the prior week*
- *Dressing: Does not dress at all and no one helped the person change bed clothes in the prior week*
- *Toileting: Does not use the toilet at all, and did not take care of toileting needs by using any special equipment (e.g., bed pan, portable toilet, commode, special underwear), and did not use a urinary catheter or colostomy bag.*

Unlike Dr. Manton's approach, persons who reported not doing any of the other three ADLs--Mobility, Transferring and Eating--are not considered to have unmet need. Persons not getting around inside at all may have unmet need in mobility, but they may just as well be bed-bound or chair-bound and not have the ability to get around inside even if help were available. Likewise, persons who are bedbound would not be considered to have unmet need in transferring if they did not have the ability to transfer, even with help. The NLTCS does not allow us to distinguish between these two states. And with respect to the eating ADL, those not eating are unlikely to have unmet need in this area, but rather do not sat because they are receiving nutrition intravenously or through a feeding tube. The NLTCS does not provide information on alternative sources of nutrition, and thus we cannot identify those who don't eat and have authentic unmet need in eating. Therefore, because we cannot identity with any certainty those with unmet needs in these three ADL's who do not do the activity at all, we chose to consider them as not having unmet need in this last definition.

A summary of the alternative definitions of unmet need used in the estimates that follow may be found at the bottom of Tables 1-4, where estimates based on these definitions are presented.

Estimates. Four sets of estimates were generated. Each set contains estimates for 1984 as well as for 1990. The 1984 estimates are those derived from the 1984 NLTCS, and those for 1990 are based on the 1984 estimates but have been adjusted to the

projected elderly population in 1990.[15] The 1984 estimates appear in Tables 1-4, and are summarized in Table 5. Estimates for 1990 are summarized in Table 6.

All estimates were based on the community resident (non-institutionalized) sample of the 1984 NLTCS, and were 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.

We could have presented the updated 1990 adjusted estimates only, but chose to present the 1984 estimates, found in Tables 1-5, as well. We did this for two reasons. First, it was on the 1984 estimates that we could legitimately apply precision criteria. An estimate is considered reliable if its unweighted cell size is 75 or larger and if its relative standard error is .30 or smaller.

In reviewing Tables 1-4, it is noteworthy that although all disability estimates meet the precision criteria, many of the unmet needs estimates do not. This is especially true for estimates of the number of elders with unmet need in specific ADLs. Relatively few ADL-specific unmet need estimates are reliable because their corresponding unweighted cell sizes are very small. Small cell sizes also contribute to the higher relative standard errors attached to these estimates. Use of the ADL-specific unmet needs estimates should therefore be interpreted judiciously. One should refrain from using these estimates per se; however, they do provide us with a sense for which individual ADL needs are more or less likely to be met.

Our second reason for presenting the 1984 estimates is to provide direct comparison to Dr. Manton's published estimates which are reported in 1984 figures. In this regard, our replication of Dr. Manton's criteria yield slightly different results from his published estimates, which are reproduced in Exhibit A. Table 1 presents our replication of Exhibit A. Comparing these two tables, we find somewhat higher estimates of overall disability and unmet need in our replication (DUKE-1). That is, Dr. Manton's initial estimate for the total number of disabled elderly is 3,499,000 whereas our replication effort yielded an estimate of 3,705,000, a difference of 5.6 percent. Also, Dr. Manton's estimates indicate a slightly larger proportion of elders with severe disability (5-6 ADL

[15] 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 and had unmet needs by the estimated community population in each age group in 1990, subtracting out the estimated 1990 nursing home population.

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 the 1990 population estimates. Data from the 1985 National Nursing Home Survey (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) were used to derive the percent of the population in each age group residing in nursing homes. The 1990 population estimates went taken from projections by the Bureau of the Census (Bureau of the Census, Vital and Health Statistics, Series 13, No. 97, January 1989).

limitations) than does our replication. Dr. Manton's estimate of the number with unmet needs is 1,212,000 and ours is 1,563,000, a difference of 29 percent. Overall 34.6% of the disabled in Dr. Manton's estimates have unmet needs whereas our replication shows 42.2% to have unmet needs. Both sets of estimates indicated that persons with 5-6 limitations have the highest prevalence of unmet need, i.e., over half of those with 5-6 limitations in both sets of estimates have unmet needs.

Obviously, our replication of Dr. Manton's estimates yielded some substantial differences--a 5 percent difference in the overall disability estimate and nearly a 29 percent difference in the unmet need estimate. These differences may be attributed to a number of factors, the first of which may be error in replicating Dr. Manton's operationalization of disability and unmet need. His exact coding scheme was not available to us for direct translation, and we thus had to rely on conversations with his staff at the Duke University Center for Demographic Studies. Second, Dr. Manton used the public use tape to generate estimates, and we relied on a version of the 1984 NLTCS edited by staff at the Agency for Health Care Policy and Research (AHCPR). We know that the AHCPR version includes edit changes on ADL items for about 12 percent of the sample. These changes probably account for some of the discrepancy in the total count of those with disability, as well as for the differing proportions of persons within each of the three limitation categories (i.e., 1-2, 3-4, 5-6 limitations). And finally, differing weighting variables were used in the estimates. Dr. Manton's estimates were generated using the weighting variable included on the public use tape, and our replication effort relied upon a more recent weighting variable developed by staff at AHCPR for the 1984 cross-sectional analyses.[16] Taken together, these factors may explain the differences in the two estimates, but it is difficult to ascertain which element is responsible for what proportion of the discrepancy.

We now turn to our second set of estimates (DUKE-2) which again replicates Dr. Manton's criteria--with one major exception. In these estimates incontinence is excluded both as a criterion for disability, as well as for unmet need, in toileting. As shown in Table 2, when incontinence is excluded 1.35 million *fewer* persons are identified as having unmet needs (compared to Table 1 estimates). This change translates into fewer disabled elderly (3,249,000 versus 3,705,000), as well as a drastically reduced proportion with any unmet need (8.9% versus 42.2%).

As noted above, our final two sets of estimates (SMI-1, SMI-2) provide alternatives to Dr. Manton's conceptualization of disability and unmet need. In these estimates, we restrict disability to those with a chronic disability in at least one of the six ADLs under consideration. Other major differences include excluding incontinence as evidence for either disability or unmet need in toileting, and excluding from the unmet need category certain persons who do not/cannot perform a given ADL task. Also, receipt of stand-by assistance is considered grounds for disability in both sets of estimates. The use of an assistive device is not considered evidence of disability in the SMI-1 estimates, but is included in the disability definition in the SMI-2 estimates.

[16] Brenda Spillman, AHCPR, "Construction of New Sample Weights for Live Population"; memo to Ase Sewell, Social and Scientific Systems, 6-12-89, revised 6-26-89.

Focusing on the SMI-1 results (Table 3), we see a decrease in the number of persons defined as disabled (N=2,064,000) by approximately 79 percent and 37 percent when compared to the DUKE-1 and DUKE-2 estimates, respectively. This is due to excluding those without chronic disability from the disability pool, as well as those whose only evidence of disability is the use of an assistive device. Findings from Table 3 also demonstrate that by employing refined definitions of unmet need, both the actual number and proportion of disabled elders estimated to have unmet need drops from 1,563,000 (42.2%) in the DUKE-1 and 288,000 (8.9%) in the DUKE-2 estimates, to 168,000 (8.1%) in the SMI-1 estimate.

Turning to results from Table 4 (SMI-2), we note a substantial increase in the number disabled, as compared to Table 3 (SMI-1). This increase is attributable to the inclusion of the use of an assistive device in the disability criteria. This addition inflates the number of disabled elderly by approximately 1.1 million. Note that Table 4's estimate of overall unmet need is unchanged from Table 3 (N=168,000). This is because the definition of unmet need is the same in both tables. But the proportion of elderly disabled with unmet needs decreases from Table 3 to Table 4 (from 8.1% to 5.2%) simply as a function of the larger denominator in Table 4.

Interestingly, even when disability and unmet need definitions are modified, as presented in Table 3 and Table 4, persons with the greatest disability (5-6 limitations) are still found to have an inordinate proportion of unmet needs compared to persons with fewer disabilities. While this pattern is upheld, regardless of definitions employed, the pattern is not as strong in the SMI-1 estimates where those with only 1-2 limitations experience nearly as much unmet need as do those with 5-6 limitations (i.e., 8.4% of those with 1-2 limitations and 9.0% of those with 5-6 limitations have unmet needs).

While the reliability of unmet need estimates for specific ADLs is questionable, as discussed above, these estimates do provide us with some information about in which ADLs the elderly are most likely to report unmet need. In all four sets of estimates unmet need in toileting is most prevalent. Due to varying definitions of both disability and unmet need, the percent of the disabled elderly with unmet need in toileting ranges from 2.6 percent (SMI-2) to 39.8 percent (DUKE-1). Unlike most of the ADL specific estimates these do meet precision criteria and thus we have confidence that they are reliable estimates. Interestingly, this varies from what the General Accounting Office (GAO) reported in their results using the 1982 NLTCS where indoor mobility was found to be the most prevalent unmet ADL.[17] It is difficult to isolate the reasons for this difference as the GAO report did not specify operational definitions. In contrast it is worth noting that indoor mobility ("Getting Around") is one of the two least prevalent unmet ADLs in all of our estimates, along with eating Dr. Manton's original estimates as published are consistent with our findings in this regard (see Exhibit A).

[17] U.S. General Accounting Office. "Elderly Who Lack Long-Term Care Assistance," in Medicare Home Health Care, GAO/HRD-87-9, 1987.

Table 5 provides a summary of the four alternative estimates for the 1984 population. In Table 6, the 1984 estimates have been adjusted to reflect the 1990 population. Trends described above remain essentially unchanged for the 1990 adjustments. Of course, both the number of disabled, as well as the number with unmet need increases between 1984 and 1990 due to the growth of the elderly population during these years. For example, the total number of disabled using the SMI-1 definitions is approximately 2.4 million, up from 2.0 million in 1984. The comparable increase in unmet need is about 31,000 for a total of 199,000, up from approximately 168,000 in 1984.

CORRELATES OF UNMET NEEDS

The majority of persons reporting unmet need as defined in the SMI-1 and SMI-2 estimates above have only one unmet need. That is, nearly 84 percent (83.9%) of those with any unmet need report not getting help in just one ADL (data not shown). As shown in Table 7, the oldest-old (age 85+) are slightly more likely to have an unmet need as compared to their younger counterparts (9.2% for 85+ versus 8.1% and 7.8% for the 65-74 and 75-84 age groups, respectively). In contrast to what was reported by an earlier study by the General Accounting Office,[18] our results suggest that disabled males are slightly more likely to have unmet needs (8.6%) than are disabled females (7.9%). Also, whites and those with impaired cognitive status were more likely to report unmet need. None of these differences are very substantial, as the overall prevalence of unmet need for the disabled population was 8.1 percent, using the SMI-1 definitions of disability and unmet need.

More striking, however, is the finding that a full 16.5 percent of the disabled elderly who live alone have unmet need. This contrasts to 5.1 percent of those living with a spouse, 4.9 percent of those residing with a spouse and another household member(s), and 7.1 percent of those who live with a non-spouse household member(s). The marital status finding, while not as marked, indicates that the non-married disabled elderly are also at greater risk of experiencing unmet need. Both results suggest the importance of informal supports in meeting the needs of the disabled elderly.

DISCUSSION

How many disabled elderly are at risk because they do not receive the assistance that they need in basic self-maintenance activities? This question, as is its answer, is reminiscent of the question: How many disabled elderly are there? As demonstrated by prior research, the answer to the latter question is not at all straight-forward, and has been shown to be dependent on how one defines disability. Likewise, the results presented in this report indicate that estimates of the number of elderly with

[18] General Accounting Office, 1987, op. cit.

unmet need are sensitive to how one chooses to define "unmet need". Depending upon the specific definition invoked, estimates range between approximately 199,000 and 1.8 million in 1990. This translates to between 5.3 and 42.0 percent of the disabled elderly population.[19]

These estimates, regardless of their definitional origins, should be considered underestimates of the true prevalence of unmet need in ADLs. Not counted in these estimates are needs which receive some, but not sufficient, attention. Undermet, or residual unmet, needs conceivably place the elderly at risk of further functional decline, morbidity, or even perhaps institutionalization and death. But we were unable to estimate the number of disabled older persons with undermet needs due to limitations in the data provided by the NLTCS. Nevertheless, these estimates do provide an indication of the magnitude of the most serious type of unmet needs, i.e., those that are remaining completely unaddressed.

Clearly, one way of meeting unmet needs is to supply formal services in the form of home or institutional cars, or to rally the support of family and friends so that they may provide care for the vulnerable elderly person. In many instances, there are obstacles--financial as well as social--to one or both of these solutions. But that discussion is beyond the scope of this paper.

There may be, however, an alternate method for meeting at least some of the needs that are going unmet. Some impaired individuals may be able to compensate for a disability by using an assistive device that currently exists or which may be developed in the future. Use of such equipment may enable some to overcome disability altogether, or at the very least may relieve some of the burden assumed by caregivers. More extensive use of assistive devices may, in selected cases, be instrumental in addressing the unmet needs of those who live alone, a group identified by our analyses as having the highest rate of unmet need of any group of disabled elders.

Additional evidence provided by the 1984 NLTCS indicates that there are needs that might be ameliorated if assistive devices were used with more frequency. That is, we found that 36 percent of those with ADL disabilities (SMI-1 definition) said that they didn't use a specific device (e.g., hand rails, grab bars, ramps, elevators/stair lifts, extra wide doors/hallways, push bars on doors, a raised toilet seat, or a more convenient toilet room/portable toilet), but that such equipment would make things easier or more comfortable for them. More specifically, for example, about 16 percent of those with unmet needs in toileting (SMI-1 definition) said that they didn't have hand rails or grab bars in their homes, but could use them if they had them. Also, 16 percent of those with an unmet need in toileting reported that they didn't have access to a raised toilet seat, but if they did life would be easier. Moreover, nearly 13 percent of those with toileting unmet need also said that they didn't have easy access to a bathroom or portable toilet at night, and 16 percent didn't have adequate access during the daytime. While it's difficult to estimate how much unmet need in toileting, and other ADLs, could be

[19] Percentages also reflect the definition of disability used in calculating the denominator of the proportion.

alleviated by introducing special equipment, undeniably it would have some impact on reducing unmet need.

Persons responsible for designing future surveys of the disabled should consider including questions crafted to elicit information on the extent of unmet need. This might be done by employing a skip pattern in the survey whereby persons identified as disabled in a given functional task (i.e., needing or receiving human assistance, or using an assistive device) would be asked an additional question about unmet need in that task. The question might be worded:

> *How often do you go without the help that you need, because no one is available to help you?*
>
> - *Always, or almost always*
> - *Sometimes*
> - *Almost never, or never*

A question worded in this manner would elicit information on both unmet as well as undermet need in a given ADL (or IADL). If the survey budget prohibits the addition one unmet need question per functional task, then clustering a few functional items within one unmet need question might be a reasonable alternative. One might also consider a second unmet need follow-up question that solicits information about the respondent's potential use of special equipment which might render him/her both more independent and perhaps diminish unmet need. That question might have wording similar to the following:

> *(How much) would special equipment, such as … help you to be less dependent on the help of others in (task)?*

In sum, one current survey of the elderly (NLTCS) does furnish us with some information on the number of elderly with unmet needs. But this information is limited, and at best affords an underestimate of those whose needs are being neglected. There is still a major gap in our knowledge, and it is an important gap to fill. In the current fiscal environment, legislators and policymakers contemplating expanding long-term care coverage will no doubt be faced with having to justify the need for expansions, and this type of information could prove valuable when eligibility and coverage issues are debated.

EXHIBIT A: From Manton, K. Epidemiological, Demographic, and Social Correlates of Disability Among the Elderly. *Milbank Quarterly*, Vol.67, Supplement 2, Part 1, pp.13-58, 1989.

TABLE 7: Number and Percentage of Community-Based Disabled Elderly Population with ADL Limitation Unmet Needs, by Disability Level and Type of ADL Unmet Need, and Number of Elderly with Selected IADL Limitation (number in thousands)

Disability Level	Total Disabled Persons	Number of Persons Reporting ADL Unmet Needs	ADL Limitation Unmet Need					
			Eating	Getting Up	Getting Around	Dressing	Bathing	Toileting
1-2 limitations	1,826	459 (25.2)	7 (0.4)	10 (0.6)	8 (0.4)	17 (0.9)	130 (7.1)	358 (19.6)
3-4 ADL limitations	836	312 (37.3)	6 (0.7)	11 (1.3)	8 (1.0)	26 (3.1)	107 (12.8)	238 (28.5)
5-6 ADL limitations	837	441 (52.7)	36 (4.3)	64 (7.7)	53 (6.3)	38 (4.5)	81 (9.7)	379 (45.3)
Total	3,499	1,212 (34.6)	49 (1.4)	85 (2.4)	69 (2.0)	81 (2.3)	318 (9.1)	976 (27.9)

SOURCE: 1984 National Long-Term Care Survey.
Number in parentheses are percentage of persons at disability level with specific unmet need. Total may not sum due to rounding error.

TABLE 1: DUKE-1--Number and Percentage of Community-Based Disabled Elderly Population with ADL Limitation Unmet Needs, by Disability Level and Type of ADL Unmet Need, 1984 (number in thousands)

Disability Level	Total Disabled Persons	Number of Persons Reporting ADL Unmet Needs	ADL Limitation Unmet Need					
			Eating	Getting Up	Getting Around	Dressing	Bathing	Toileting
1-2 limitations	1,847 a	750 a (40.6)	* (**)	1 (0.1)	* (**)	10 (10.6)	21 (1.1)	731 a (39.6)
3-4 ADL limitations	1,232 a	409 a (33.2)	3 (0.2)	10 (0.8)	4 (0.3)	22 (1.8)	20 (1.7)	384 a (31.2)
5-6 ADL limitations	625 a	404 a (64.6)	13 (2.1)	42 (6.7)	33 (5.3)	110 a (17.6)	7 (1.2)	360 a (57.6)
Total	3,705 a	1,563 a (42.2)	17 (0.3)	52 (0.9)	38 (0.6)	142 a (2.4)	49 (1.3)	1,476 a (39.8)

*: <1,000
**: <0.1%
a. Meets precision criteria
Definition of Disability:
- Active assistance; does not do; uses assistive devices; no human assistance or assistive device but needs help
- Incontinence included in the toileting variable

Definition of Unmet Need:
- Does not do at all; no human assistance or assistive device but needs help
- Exception: Persons who do not bathe at all, but take a bed/basin/sink bath are not considered to have an unmet need
- Incontinence considered an unmet need in toileting

SOURCE: 1984 National Long-Term Care Survey, AHCPR-edited version.
Number in parentheses are percentage of persons at disability level with specific unmet need. Total may not sum due to rounding error.

TABLE 2: DUKE-2--Number and Percentage of Community-Based Disabled Elderly Population with ADL Limitation Unmet Needs, by Disability Level and Type of ADL Unmet Need, 1984 (number in thousands)

Disability Level	Total Disabled Persons	Number of Persons Reporting ADL Unmet Needs	ADL Limitation Unmet Need					
			Eating	Getting Up	Getting Around	Dressing	Bathing	Toileting
1-2 limitations	1,446 a	42 (2.9)	* (**)	4 (0.3)	* (0.1)	11 (0.8)	21 (1.5)	8 (0.6)
3-4 ADL limitations	1,196 a	56 (4.7)	3 (0.3)	7 (0.6)	4 (0.3)	24 (2.0)	20 (1.7)	16 (1.3)
5-6 ADL limitations	607 a	190 a (31.3)	13 (2.2)	42 (6.9)	33 (5.5)	107 a (17.7)	7 (1.2)	102 a (16.9)
Total	3,249 a	288 a (8.9)	17 (0.5)	52 (1.6)	38 (1.2)	142 a (4.4)	49 (1.5)	126 a (3.9)

*: <1,000
**: <0.1%
a. Meets precision criteria

Definition of Disability:

- Active assistance; does not do; uses assistive devices; no human assistance or assistive device but needs help
- Incontinence not included in the toileting variable

Definition of Unmet Need:

- Does not do at all; no human assistance or assistive device but needs help
- Exception: Persons who do not bathe at all, but take a bed/basin/sink bath are not considered to have an unmet need
- Incontinence not considered an unmet need in toileting

SOURCE: 1984 National Long-Term Care Survey, AHCPR-edited version.
Number in parentheses are percentage of persons at disability level with specific unmet need. Total may not sum due to rounding error.

TABLE 3: SMI-1--Number and Percentage of Community-Based Disabled Elderly Population with ADL Limitation Unmet Needs, by Level and Type of ADL Unmet Need, 1984 (number in thousands)

Disability Level	Total Disabled Persons	Number of Persons Reporting ADL Unmet Needs	ADL Limitation Unmet Need					
			Eating	Getting Up	Getting Around	Dressing	Bathing	Toileting
1-2 limitations	936 a	79 (8.45)	1 (0.1)	8 (0.8)	1 (0.1)	26 (2.8)	36 (3.8)	17 (1.8)
3-4 ADL limitations	425 a	25 (5.93)	5 (1.1)	4 (0.9)	3 (0.7)	11 (2.6)	8 (1.9)	15 (3.6)
5-6 ADL limitations	703 a	63 (9.00)	7 (1.1)	5 (0.8)	* (**)	8 (1.2)	5 (0.7)	51 (7.2)
Total	2,064 a	168 a (8.12)	13 (0.6)	17 (0.8)	4 (0.2)	45 (2.2)	49 (2.4)	83 a (4.0)

*: <1,000
**: <0.1%

a. Meets precision criteria

Definition of Disability:

- Active assistance; does not do; no human assistance or assistive device but needs help
- Three month duration criteria for each ADL
- Incontinence not considered

Definition of Unmet Need:

- Persons with no human assistance in an ADL who use no assistive device but report needing help

SOURCE: 1984 National Long-Term Care Survey, AHCPR-edited version.
Number in parentheses are percentage of persons at disability level with specific unmet need. Total may not sum due to rounding error.

TABLE 4: SMI-2--Number and Percentage of Community-Based Disabled Elderly Population with ADL Limitation Unmet Needs, by Level and Type of ADL Unmet Need, 1984 (number in thousands)

Disability Level	Total Disabled Persons	Number of Persons Reporting ADL Unmet Needs	ADL Limitation Unmet Need					
			Eating	Getting Up	Getting Around	Dressing	Bathing	Toileting
1-2 limitations	1,338 a	43 (3.2)	* (**)	4 (0.3)	* (0.1)	9 (0.7)	21 (1.6)	11 (0.8)
3-4 ADL limitations	1,085 a	50 (4.6)	2 (0.2)	7 (0.7)	3 (0.3)	17 (1.6)	20 (1.9)	17 (1.6)
5-6 ADL limitations	797 a	75 (9.4)	10 (1.3)	6 (0.7)	* (**)	19 (2.3)	7 (0.9)	55 (7.0)
Total	3,221 a	168 a (5.2)	13 (0.4)	17 (0.5)	4 (1.1)	45 (1.4)	49 (1.5)	83 a (2.6)

*: <1,000
**: <0.1%
a. Meets precision criteria
Definition of Disability:

- Active assistance; does not do; uses assistive device; no human assistance or assistive device but needs help
- Three month duration criteria for each ADL
- Incontinence not considered

Definition of Unmet Need:

- Persons with no human assistance in an ADL who use no assistive device but report needing help

SOURCE: 1984 National Long-Term Care Survey, AHCPR-edited version.
Number in parentheses are percentage of persons at disability level with specific unmet need. Total may not sum due to rounding error.

TABLE 5: Alternative Estimates of ADL Disability and Need Among the Community-Dwelling Disabled Elderly, 1984 (number in thousands)

Disability Level	DUKE-1 a		DUKE-2 b		SMI-1 c		SMI-2 d	
	Number Disabled	Number Unmet Needs	Number Disabled	Number Unmet Needs	Number Disabled	Number Unmet Needs	Number Disabled	Number Unmet Needs
1-2 limitations	1,847 e	750 e (40.6)	1,446 e	42 (2.9)	936 e	79 e (8.4)	1,338 e	43 (3.2)
3-4 ADL limitations	1,232 e	409 e (33.2)	1,196 e	56 (4.7)	425 e	25 (5.9)	1,085 e	50 (4.6)
5-6 ADL limitations	625 e	404 e (64.6)	607 e	190 e (31.3)	703 e	63 (9.0)	797 e	75 (9.4)
Total	3,705 e	1,563 e (42.2)	3,249 e	288 e (8.9)	2,064 e	168 e (8.1)	3,221 e	168 e (5.2)

a. For definitions of disability and unmet need, see Table 1.
b. For definitions of disability and unmet need, see Table 2.
c. For definitions of disability and unmet need, see Table 3.
d. For definitions of disability and unmet need, see Table 4.
e. For definitions of disability and unmet need, see Table 5.

SOURCE: 1984 National Long-Term Care Survey, AHCPR-edited version.
Number in parentheses are percentage of persons at disability level with specific unmet need. Total may not sum due to rounding error.

TABLE 6: Alternative Estimates of ADL Disability and Need Among the Community-Dwelling Disabled Elderly, Adjusted to 1990 (number in thousands)

Disability Level	DUKE-1 a		DUKE-2 b		SMI-1 c		SMI-2 d	
	Number Disabled	Number Unmet Needs	Number Disabled	Number Unmet Needs	Number Disabled	Number Unmet Needs	Number Disabled	Number Unmet Needs
1-2 limitations	2,160	868 (40.2)	1,698	50 (2.9)	1,099	92 (8.4)	1,575	51 (3.2)
3-4 ADL limitations	1,445	479 (33.1)	1,404	65 (4.6)	499	31 (6.3)	1,274	59 (4.6)
5-6 ADL limitations	734	474 (64.6)	711	225 (31.6)	823	75 (9.1)	932	88 (9.5)
Total	4,339	1,821 (42.0)	3,813	340 (8.9)	2,421	199 (8.2)	3,782	199 (5.3)

a. For definitions of disability and unmet need, see Table 1.
b. For definitions of disability and unmet need, see Table 2.
c. For definitions of disability and unmet need, see Table 3.
d. For definitions of disability and unmet need, see Table 4.

SOURCE: 1984 National Long-Term Care Survey, AHCPR-edited version, adjusted to 1990.
Number in parentheses are percentage of persons at disability level with specific unmet need. Total may not sum due to rounding error.

TABLE 7: Percentage of the Elderly Disabled a Population with Unmet Need b by Various Characteristics, 1984	
Age	
65-74	8.1%
75-84	7.8%
85+	9.2%
Sex	
Male	8.6%
Female	7.9%
Race	
White	8.2%
Non-White	7.6%
Cognitive Status c	
Not Impaired	7.8%
Impaired	9.2%
Living Arrangements	
Alone	16.5%
With Spouse	5.1%
With Spouse & Others	4.9%
With Others (no spouse)	7.1%
Marital Status	
Married	5.3%
Not Married	11.7%

a. Definition of Disability:
- Active assistance; does not do; no human assistance or assistive device but needs help
- Three month duration criteria for each ADL
- Incontinence not considered

b. Definition of Unmet Need:
- Persons with no human assistance who use no assistive device, but report needing help.

c. Operational definition of Cognitive Impairment:
- A score of 5 or greater (errors) on the Short-Portable Mental Status Questionnaire or a Cognitive Impairment-Related Diagnosis

PLUS

- At Least One of the Following:
  - A Behavior Problem (wandering, frequent temper tantrum, compulsive stealing)
  - One or more ADL disabilities
  - Disability in money management, telephoning or medication management

SOURCE: 1984 National Long-Term Care Survey, AHCPR-edited version.