Unmet Need for Personal Assistance Services: Estimating the Shortfall in Hours of Help and Adverse Consequences

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Objectives. Perceived unmet need for personal assistance services (PAS) in activities of daily living (ADLs) and instrumental ADLs and its association with reduced hours of help received and with adverse consequences due to lack of help are examined for adults aged 18 and older using data from the 1994–1997 National Health Interview Survey on Disability.

Methods. A two-part multivariate regression model of the probability of PAS use and hours of help received was developed to control for need level, living arrangements, and other characteristics that may differ between persons with met and unmet needs and to determine the shortfall in hours associated with unmet need.

Results. Individuals with unmet need for personal assistance with two or more of the five basic ADLs have a shortfall of 16.6 hours of help per week compared with those whose needs are met. The relative shortfall is twice as great for persons who live alone as for those who live with others. People who live alone and have unmet needs fare worse than people with unmet needs who live with others, and both groups are more likely than those whose needs are met to experience adverse consequences, including discomfort, weight loss, dehydration, falls, burns, and dissatisfaction with the help received.

Discussion. Overall, just 6.6% of needed hours are unmet among the 3.3 million people needing help in two or more ADLs. We estimate the annual cost of eliminating unmet need among persons with incomes under 300% of the Supplemental Security Income level between \$1.2 and \$2.7 billion for those living alone and from \$2.2 to \$7.1 billion for those living with others.

OMMUNITY-RESIDING adults of all ages with needs for personal assistance services (PAS) in daily activities are at risk of all or some of their needs being unmet, which can reduce their quality of life, compromise safety, and increase risks of a number of adverse consequences (Allen & Mor, 1997; Desai, Lentzner, & Weeks, 2001; Lima & Allen, 2001). These include injuries from falls, burns, weight loss, dehydration, discomfort, and other problems that can further worsen health and disability and increase risks of institutionalization and death. Minimizing unmet need is the primary goal underlying long-term care policy.

PAS refers to human help provided to individuals in specific activities that are generally obligatory for bodily maintenance and for living in the community, comprising the activities of daily living (ADLs; bathing, dressing, transferring from a bed or chair, toileting, and eating) and the instrumental activities of daily living (IADLs; such as taking medications and shopping for groceries). PAS include all help, whether hands-on, standby, or supervisory, whether paid or unpaid. Unmet need occurs when assistance from others is needed but not provided or inadequate.

There are many causes of unmet need. Over 85% of all of the hours of assistance people receive with ADLs and IADLs are provided by family and friends (LaPlante, Harrington, & Kang, 2002). Informal helpers, who may have to balance other responsibilities, including work and child care, are often limited in the amount of help they can provide. People with low informal resources, such as those who live alone, are especially

likely to have unmet needs and depend largely on formal assistance, if affordable and available. Public PAS remain biased toward institutional rather than community living (Harrington et al., 2000), and people who live in states that do not provide enough home- and community-based services may be at greater risk of unmet need (LeBlanc, Tonner, & Harrington, 2000, 2001; Muramatsu & Campbell, 2002).

To address the magnitude of the problem of unmet need for PAS, it is useful to know what the national prevalence of unmet need is, what populations are most at risk, and how much of their needs are lacking. Surveys of individuals are convenient for measuring unmet need because obtaining professional judgments on a large scale is prohibitively expensive (Williams, Lyons, & Rowland, 1997). The prevalence of survey-discovered unmet need lies between one fifth and one third of elderly people with PAS needs (Desai et al., 2001; Kennedy, 2001; Lima & Allen, 2001; Manton, 1989; U.S. General Accounting Office, 1988; Williams et al., 1997).

The need for PAS spans a continuum, measured often by the number and type of ADLs a person requires human help with. The ADLs define a hierarchy of needs (Katz & Akpom, 1976), with dependence in eating defining the most severe need. The IADLs define a lesser degree of need for PAS. An important measurement issue concerns *who* determines need. Bradshaw (1972) outlined several distinctions in operationally defining need: *normative need*, which is assessed by experts; *felt need*, the level of help the individual feels he or she needs; *expressed need*, the amount of help received or demanded by the

individual; and *comparative need*, disparities in help received. Conflict arises between normative and felt need, as when a professional feels that institutional placement is warranted but the individual may not want it or when the individual wants help that a professional will not give. Differences are known to exist between professional and self-assessments of need. In one study, self-rated ADL disability was greater than that observed by professionals (Kelly-Hayes, Jette, Wolf, D'Agostino, & Odel, 1992). Professionals assess need differently than individuals, but neither is necessarily better than the other (Verbrugge & Sevak, 2002).

Certainly, if need is a continuum, then unmet need is also a continuum. Some people may lack help entirely, whereas others may need just a little more help. A professional may judge that a person needs a lot of help when he or she receives only a little. Few studies exist comparing self-reports and professional assessments of unmet need. One study suggests that self-ratings of unmet need may be conservative compared with professional ratings of unmet need (Morrow-Howell, Proctor, & Rozario, 2001).

To advance the understanding of unmet need beyond mere prevalence, it is useful to know how much help is lacking and what the cost might be to address it. Quantifying unmet need for PAS in terms of the shortfall in hours of help is an important step in that direction. This analysis builds on a prior national study estimating hours of PAS received among adults of all ages (LaPlante et al., 2002) to examine the relationship of hours with unmet need. We define unmet need as the gap between felt need and expressed need. We use a large nationally representative survey to estimate the shortfall in hours associated with unmet need by comparing the hours of help received by people who report that their needs are met with those whose needs are unmet, after controlling for population differences in need levels and demographics (comparative need). We then estimate the cost of eliminating the unmet-need shortfall in hours and demonstrate that unmet need is associated with a variety of adverse consequences.

METHODS

Sample

Data are from supplements to the National Health Interview Survey (NHIS), a large nationally representative survey of households in the United States conducted annually by the Census Bureau for the U.S. National Center for Health Statistics (U.S. NCHS). Respondents to the 1994 and 1995 NHIS (94% core response rate) were given a supplemental screening questionnaire, known as Phase I of the National Health Interview Survey on Disability (NHIS-D; U.S. NCHS, 1998a, 1998b). The 202,560 respondents of all ages (93% Phase I response rate) were screened for disability, using an extensive set of criteria including functional limitation, specific disabling diagnoses, perception of disability, and use of disability-related services. A sample of 32,788 individuals was reinterviewed in Phase II (89% Phase II response rate), also known as the Disability Followback Survey. Data collection began in September 1994 and concluded in April 1997, with reinterviews taking place between 7 and 26 months after the Phase I interview (normally distributed about the mean of 14 months). Phase I excluded individuals in nursing homes, prisons, and large residential facilities. About 3.1% of the eligible adult sample died before follow-up, 3.4% refused, 3.0% could not be located, and 1.4% were not interviewed for unknown reasons. A small number of respondents moved into institutions and, although interviewed, were excluded from this analysis (n = 335). The sample for this analysis is restricted to adults with met or unmet need for help in any IADL/ADL (n = 9,646).

Measures

Data from Phase II of the NHIS-D are used to estimate met and unmet need for assistance with ADLs/IADLs and to estimate hours of paid and unpaid help received. Individuals were asked if they were helped in any of 5 ADL and 10 IADL activities, including hands-on help, supervision, or stand-by help, and whether they needed help or more help (activities a person does not do for reasons other than health are excluded). Individuals who lacked help or needed more help in one or more ADL/IADL activities are defined as having unmet need. For each of up to four helpers, the respondent was asked (a) how many days the helper helped during the last 2 weeks and (b) how many hours per day the helper provided help. The two measures were multiplied for each helper, summed over helpers, and divided by 2, to yield the total hours received per week.

The survey contains a number of demographic variables that are used in this analysis. Age and living arrangement were measured in Phase II; gender, race, and individual income were measured in the initial interview. A measure of the presence of cognitive symptoms (Phase I) was constructed by combining affirmative responses on having "a lot of trouble concentrating long enough to complete everyday tasks," being "frequently confused, disoriented, or forgetful," or having "Alzheimer's disease or another type of senile disorder." A second variable indicating cognitive impairment was whether the respondent had a proxy interview in Phase II because of poor memory, senility, confusion, Alzheimer disease, or other mental condition.

Several additional questions were asked about experiencing discomfort and other problems when individuals could not do activities as frequently as they needed to (Phase II). Additional questions were asked about falls, bedsores, contractures, dissatisfaction with the person's primary helper, and problems of being left alone. In some cases, respondents were asked if the problem was caused by a lack of help, thus attributing causality to unmet need. This battery yielded 53 measures that we used for this study. We expected that people with unmet need would be more likely to experience these problems and be more likely to be dissatisfied.

Less than 3% of responses are missing for the ADL need for help items and <6% for the IADL items. Cognitive symptoms were missing in <1% of records. As item nonresponse is generally low on these measures, we assume, when it occurs, that the individual does not have the characteristic in question. Reason for proxy interview was not ascertained for about 20% of those with proxy interviews; in these cases, we assume that a proxy response was needed for reasons other than cognitive ones.

The data set includes imputation for individual income based on a detailed hot deck imputation procedure carried out by the University of Michigan Survey Research Center (U.S. NCHS, 1998a, 1998b). In the sample with a need for help in IADLs/ADLs, 33.3% had some income components imputed, the most frequent being earnings and interest income.

The hours data used for the dependent variable included data we imputed previously for 19.5% of persons who said they were helped in the last 2 weeks but had missing data for the number of days or hours per day. We used multiple imputation, an iterative approach generally considered the most appropriate method when dependent variable data are missing (Crawford, Tennstedt, & McKinlay, 1995; Rubin, 1987). Indeed, missing hours were not random: Those with missing data were actually somewhat less disabled. The imputation involved estimating three separate regression models for hours received from paid helpers, a primary informal helper, and secondary informal helpers. Independent variables included demographics, living arrangement, income, Medicare and Medicaid coverage, supply of helpers, and IADL and ADL activities the helpers helped with. The imputation introduces a random component to the regression parameters, based on their estimated variances, and the prediction is replicated 10 times to yield a distribution of values, which were then averaged and summed over the three models to yield imputed total hours (LaPlante et al., 2002).

The 53 adverse consequence items had low nonresponse, generally under 8%, with the exception being three questions regarding needing help eating (about 16%) and several satisfaction questions (8–15%).

Analysis Methods

We employed statistical methods to estimate the shortfall in hours associated with unmet need. The hours data are nonnormal in two ways: There are some cases with 0 hours and some with a high number of hours. Using multivariate regression methods, we estimated a two-part model of PAS utilization (Duan, Manning, Morris, & Newhouse, 1983), which takes into account both types of skewness: The first step predicts whether or not any hours of help are received by weighted logistic regression, and the second step predicts the hours of help among recipients by weighted least-squares (WLS) regression, using survey sampling weights in both. In the latter, we use the logarithm of hours as the dependent variable to eliminate right skewness. Each person's level of need is measured by 15 dummy variables for the specific IADLs/ADLs they need help with. The log-transformed dependent variable in the WLS regression makes the contributions of the activities multiplicative rather than additive. That is, the logarithm of the total hours received does not equal the sum of the logarithms of the hours received for each activity. We include a count of multiple activities to correct for this effect, an integer equal to the number of activities minus 2, if help is needed in two or more activities, or 0 otherwise.

Four dummy variables measure cognitive difficulties: having cognitive symptoms, being unable to manage money, being unable to manage medications, and having a proxy interview because of a cognitive condition. Living arrangements are measured using two dummy variables: living alone and living with a spouse, the comparison group being those who live with others. To identify individuals with low incomes based on Supplemental Security Income (SSI) eligibility criteria, two additional dummy variables are included classifying personal

income at or below 100% of SSI federal benefit rate (\$446 per month in 1994 and \$458 per month in 1995 if living alone; \$669 per month in 1994 and \$687 per month in 1995 if living with a spouse) and from 101% to 300% of the SSI federal benefit rate level, the comparison group being those with incomes >300% of the federal benefit rate. Although individuals on Medicaid may retain \$2,000 in tangible assets, the survey questions were not detailed enough to make further distinctions on assets. The unadjusted data suggest that unmet need has a larger impact among people with two or more ADLs (as discussed herein; Table 1), so we wished to test that. We further wished to distinguish unmet-need effects by whether people live alone or with others. Four dummy variables measure the effects of unmet need for four population groups of interest: people living alone or living with others and having fewer than two or two or more ADL needs. These groups are compared with those who have no unmet need. We developed the models first introducing unmet need and living arrangements, then level of need, and finally, age, race, gender, and income. We deleted variables not significant in either model. In the WLS model, we ascertained that the model residuals were normally distributed.

A concern may arise over a potential circularity between the measures of unmet need and hours of help received, in that unmet need is determined in large part by a perceived shortfall in hours. However, the presence of unmet need (needing more help in any one activity) does not determine the total hours of help received. If there were circularity, hours of help and unmet need would be correlated, but they are not (Pearson r = .002, p = .79).

The predicted probability of receiving any help is calculated using the exponentiated model parameters from the logistic model. To retransform the predictions of the WLS regression (predicted logarithm of hours) into a linear scale (predicted hours), we exponentiate the model prediction and multiply by a retransformation or "smearing" factor (Duan, 1983; Duan et al., 1983), obtained by averaging the exponentiated residuals. Heteroscedasticity across populations requires separate smearing factors (Manning, 1998). We observe smaller mean squared residuals for people living alone (versus living with others) or having two or more ADLs (versus less than two) and calculate separate smearing factors for the four populations thus defined. We then multiply the predicted probabilities of use by the predicted hours of use. Finally, we estimate the predicted hours of PAS for those with unmet need, along with their expected hours if their unmet need were to be eliminated, by setting the relevant unmet need dummy variable to zero. The difference in expected hours represents an estimate of the shortfall in hours, the hours that would be required to fulfill the person's needs.

The weekly shortfall is multiplied by 52 weeks to obtain an annual estimate (which is allowable because the survey is conducted continuously). PAS costs are assumed to be \$10 per hour on average, based on average state Medicaid reimbursement data for PAS collected from a survey of state officials in 1998–1999 (LeBlanc et al., 2000, 2001). Finally, we use a bootstrap procedure (resampling with replacement) to calculate 95% confidence intervals around the estimated cost.

We hypothesized that the percentage of people experiencing adverse consequences would be greater on every measure for those with unmet versus met need, which we tested using a one-tailed t test. Because the estimates are based on a sample of the

Table 1. Adults Needing Help in IADLs or ADLs and Hours of Help Received per Week, by Perceived Unmet Need for Help and Number of ADLs. United States, 1994—1997

			Total					With Unmet Nee	Need					With Met Need	Veed			Difference in	nce in
No. of ADLs	Sample Size		Median Hours	Mean Mean Hours SE	Mean SE	Sample Size	Persons (1,000s)	% of Total Persons	Median Hours	Mean Hours	Mean SE	Sample Size	Persons (1,000s)	% of Total Persons	Median Hours	Mean Hours	Mean SE	Median Hours	Mean Hours
0	6,153	9,650	5	12.8	0.43	1,137	1,768	18.3	2	11.9	1.62	5,016	7,883	81.7	9	13.0	0.43	4-	-1.1
1	1,358	2,127	13	25.6	1.23	335	503	23.6	11	24.1	2.67	1,023	1,624	76.4	13	26.1	1.4 4.	-2	-1.9
2	718	1,109	21	40.7	2.40	204	303	27.3	14	28.5	2.94	514	908	72.7	25	45.3	3.06	-11	-16.8**
3	486	746	33	55.2	3.16	150	213	28.6	21	40.3	5.69	336	533	71.4	40	61.2	3.91	-19	-20.9**
4	447	684	53	76.2	3.77	162	237	34.6	42	70.0	95.9	285	447	65.4	26	9.62	4.67	-14	9.6-
5	484	750	104	112.0	3.78	131	194	25.9	84	8.66	8.01	353	556	74.1	108	116.2	4.27	-24	-16.5*
0 or 1	7,511	11,777	9	15.1	0.47	1,472	2,270	19.3	3	14.6	1.55	6,039	9,507	80.7	7	15.3	0.48	4-	9.0-
>2	2,135	3,289	4	9.79	1.90	647	949	28.9	28	56.2	2.93	1,488	2,341	71.2	48	72.3	2.20	-20	-16.1**
Total	9,646	15,066	∞	26.6	0.70	2,119	3,219	21.4	7	26.9	1.56	7,527	11,848	78.6	∞	26.5	99.0	-	0.3

Notes: IADL = instrumental activity of daily living; ADL = activity of daily living. Data source: 1994–1997 National Health Interview Survey on Disability < .05, **p < .01, based on one-tailed t test. population, they are subject to sampling error. All estimates are calculated using sampling weights, and sampling errors have been calculated directly using STATA survey data commands (Stata Corp., 2003), which take into account the geographic clustering of the sample design by Taylor series approximation.

RESULTS

About 15.1 million community-residing adults need help in ≥ 1 of the 15 IADLs and ADLs, 21.4% of whom have unmet need (Table 1). The percentage with unmet need is lowest for those who need help only in IADLs (18.3%) and generally increases with higher numbers of ADLs, from 23.6% with one ADL need to 34.6% at four ADLs, but declines to 25.9% at five ADLs. Most people with unmet need get some help but do not get all the help they need. We find that only 545,000 adults of the 3.2 million with unmet need receive no help at all, a population with a low level of disability, mostly needing help in IADLs only, and in particular the single activity of heavy housework (not shown). For most people with unmet need, the issue is not whether they get help, but how much help they get.

Relationship of Unmet Need to Hours of Help

We expect that people with unmet need would have fewer hours of help than those whose needs are met. We find only a small difference in the mean hours of help received between those with unmet versus met need among people who need help with just IADLs or only one ADL (<2 hours per week) but large and highly significant differences for those needing help in two or more ADLs. This group amounts to 949,000 people almost a million-with perceived unmet need, who average 16.1 fewer hours per week than those whose needs are met (see Table 1). Persons with unmet needs have fewer hours for each number of ADLs above one that they need help with, and the differences in mean hours are statistically significant for those needing help in two, three, or five ADLs. If we combine those with two or more ADLs, there is a large significant difference in mean hours for those with unmet needs, but not for those with fewer than two ADLs.

These differences in mean hours received, however, might be due to differences between the met-need and unmet-need populations with respect to level of need and other individual characteristics that influence the amount of help received. We use multivariate methods to control for such differences to estimate the true shortfall among people with unmet need for PAS.

Estimating the Unmet-Need Shortfall in Hours

The sample means and standard deviations are shown in Table 2 for variables tested in the regressions, contrasting those with and without unmet need. Adults with unmet need are less likely to get help but receive about the same average hours when they do get help. They are more likely than those with no unmet need to be non-White, to be female, and to live alone. They are less likely to live with a spouse, have a greater number of ADLs and IADLs, are more likely to have cognitive symptoms but less likely to have a proxy interview for cognitive or other reasons, and are slightly more likely to have incomes below 100% of the SSI level.

Results from the regression models are shown in Table 3. Both models are highly significant. All the specific IADLs/ADLs that individuals need help with are associated with

Table 2. Weighted Means and Standard Deviations for Selected Variables Among Persons Needing Assistance in IADLs or ADLs

	To $(N = 1)$		With M $(n = 1)$	let Need 7 527)	With Unme $(n = 2,1)$	
Variable	<u> </u>	SD		SD	$\frac{(n-2,1)}{M}$	SD
Receives any hours of help $= 1$	0.82	0.39	0.84	0.36	0.73	0.44
Hours (range 0–504)	26.60	60.44	26.54	59.14	26.86	64.84
Natural log of hours (for hours > 0 , range $-0.69-6.2$)	2.55	1.77	2.52	1.77	2.68	1.75
Non-White = 1	0.17	0.47	0.16	0.46	0.21	0.50
Female = 1	0.64	0.60	0.63	0.61	0.70	0.56
Age (range 18–99 years)	61.40	23.14	61.67	23.36	60.41	22.31
Living with spouse = 1	0.44	0.62	0.46	0.63	0.36	0.59
Living alone = 1	0.25	0.54	0.22	0.52	0.35	0.59
Needs more help	0.21	0.51	0.00	0.00	1.00	0.00
<2 ADLs and lives with others = 1	0.09	0.36	0.00	0.00	0.43	0.61
<2 ADLs and lives alone = 1	0.06	0.30	0.00	0.00	0.28	0.55
>2 ADLs and lives with others = 1	0.05	0.27	0.00	0.00	0.23	0.51
≥2 ADLs and lives alone = 1	0.01	0.15	0.00	0.00	0.07	0.31
Needs help with specific activities						
Bathing or showering = 1	0.29	0.57	0.27	0.56	0.36	0.59
Dressing = 1	0.22	0.51	0.20	0.50	0.28	0.55
Transferring (from bed or chair) = 1	0.18	0.48	0.16	0.45	0.26	0.54
Toileting (using or getting to the toilet) = 1	0.11	0.39	0.10	0.37	0.15	0.44
Eating = 1	0.08	0.33	0.07	0.32	0.10	0.37
Walking = 1	0.23	0.52	0.20	0.50	0.32	0.57
Getting outside = 1	0.25	0.54	0.23	0.53	0.32	0.57
Preparing meals = 1	0.31	0.58	0.29	0.57	0.38	0.60
Shopping for groceries = 1	0.48	0.62	0.47	0.63	0.54	0.61
Managing money = 1	0.19	0.49	0.19	0.49	0.21	0.50
Using the phone = 1	0.10	0.37	0.09	0.36	0.11	0.38
Doing light housework = 1	0.31	0.58	0.28	0.56	0.43	0.61
Getting to places outside the home = 1	0.45	0.62	0.42	0.62	0.53	0.62
Managing medications = 1	0.18	0.48	0.17	0.48	0.19	0.48
Doing heavy housework = 1	0.70	0.57	0.68	0.59	0.79	0.50
Multiple activities (range 0–13)	2.38	4.23	2.17	4.11	3.18	4.49
Cognitive symptoms $= 1$	0.20	0.50	0.20	0.50	0.24	0.53
Cannot manage medications = 1	0.10	0.37	0.10	0.38	0.09	0.34
Cannot manage money = 1	0.08	0.33	0.08	0.34	0.07	0.31
Proxy or assisted interview due to cognitive condition = 1	0.13	0.42	0.14	0.43	0.10	0.37
Proxy interview for other reason $= 1$	0.08	0.33	0.08	0.35	0.05	0.27
Individual income below 100% SSI level = 1	0.25	0.54	0.24	0.53	0.29	0.56
Individual income above 100% and below 300% SSI level = 1	0.46	0.62	0.46	0.63	0.46	0.61
Individual income below 300% SSI level = 1	0.71	0.57	0.70	0.58	0.75	0.53

Notes: IADL = instrumental activity of daily living; ADL = activity of daily living; SSI = Supplemental Security Income. Source: 1994–1997 National Health Interview Survey on Disability.

a higher likelihood of getting help, except toileting, and all are associated with more hours of help. The count of multiple activities and its square are significantly negative in both models, making a negative adjustment to the chance of getting help and hours of help the more activities a person needs help with. Cognitive symptoms have no relation to getting help but are associated with more hours of help received. Proxy or assisted interviews because of cognitive impairment have a higher likelihood of getting help and more hours of help. Proxy interviews for reasons other than cognitive impairment have higher hours. Independent of measured need, neither being non-White nor being older is associated with the odds of getting help, but both are associated with higher hours among those who get help, as is individual income below 300% of the SSI level. Living alone has a large negative relation with getting help and with hours.

Now we consider the effects of unmet need, which is measured within four groups of interest. Among people with less than two ADLs who live with others, unmet need is associated with lower odds of getting help but has no relation to hours (see Table 3). Among people with less than two ADLs who live alone, unmet need is associated with lower odds of getting help and fewer hours of help received. Among those with two or more ADLs who live with others, unmet need is not related to getting help but is associated with fewer hours. Among those who live alone and have two or more ADLs, unmet need is associated with a lower odds of getting help and fewer hours. The combined effect of unmet need is largest among people who live alone.

In Table 4, the shortfall in hours estimated by the regression models is shown for people with two or more ADLs who have unmet need, by living arrangement and income level. As explained in Analysis Methods, the estimated shortfall is the model prediction of the difference between needed and received hours. Overall, people needing help in two or more ADLs and reporting unmet need receive 56.2 hours of help and are

Table 3. Results From Multivariate Regression Models Predicting the Probability of Receiving Help and Hours of Help Received Among Adults Needing Assistance in IADLs or ADLs

	Probability of Help (Logistic	•	Hours per l Receiving Help (V	
Independent Variable	β	SE	β	SE
Intercept	0.0464	0.171	1.0360**	0.078
Non-White $= 1$	-0.0958	0.095	0.1312**	0.041
Age (range 18–99 years)	-0.0001	0.002	0.0020*	0.001
Lives alone = 1	-0.3509**	0.087	-0.5913**	0.037
Has ≥ 2 ADLs = 1	-0.7012*	0.282	0.0224	0.072
Needs more help				
<2 ADLs and lives with others = 1	-1.0793**	0.102	-0.0826	0.058
<2 ADLs and lives alone = 1	-1.4616**	0.133	-0.3430**	0.065
>2 ADLs and lives with others = 1	0.0207	0.249	-0.2197**	0.056
\geq 2 ADLs and lives alone = 1	-0.8557*	0.344	-0.4889**	0.100
Needs help with specific activities				
Bathing or showering $= 1$	1.0589**	0.155	0.5972**	0.057
Dressing = 1	0.9555**	0.199	0.5579**	0.069
Eating = 1	0.9366**	0.245	0.8817**	0.070
Transferring (from bed or chair) = 1	0.4935**	0.171	0.4681**	0.065
Toileting (using or getting to the toilet) = 1	0.0589	0.262	0.8838**	0.068
Walking = 1	0.9181**			0.057
Getting outside = 1	0.7146**			0.060
Preparing meals = 1	0.8415**	0.140		
Shopping for groceries = 1	0.9635**	0.112	0.4509**	0.045
Managing money = 1	0.6534**	0.155	0.4202**	0.058
Using the phone = 1	0.6671**	0.193	0.6172**	0.066
Doing heavy housework = 1	0.7847**	0.117	0.2753**	0.051
Doing light housework = 1	0.6374**	0.119	0.6333**	0.050
Getting to places outside the home = 1	1.2100**	0.124	0.5794**	0.050
Managing medications = 1	0.8828**	0.188	0.7460**	0.060
Multiple activities (range 0–13)	-0.3979**	0.122	-0.3194**	0.047
Multiple activities squared	-0.0152**	0.005	-0.0121**	0.001
Cognitive symptoms $= 1$	0.0127	0.087	0.0738*	0.033
Proxy or assisted interview due to cognitive condition = 1	0.6925**	0.190	0.3756**	0.047
Proxy interview for other reason $= 1$	-0.2374	0.139	0.2328**	0.055
Individual income below 300% SSI level = 1	0.0622	0.070	0.0701*	0.030
Sample size	9,646	5	7.886	1
Weighted n (1,000s)	15,06		12,274	
χ^2/F statistic	< 0.000		< 0.000	
Pseudo R^2 /adjusted R^2	0.172		0.485	

Notes: IADL = instrumental activity of daily living; ADL = activity of daily living; WLS = weighted least-squares; SSI = Supplemental Security Income. Data source: 1994–1997 National Health Interview Survey on Disability.

estimated to need an additional 16.6 hours of help per week. Those living alone receive 24.1 hours of help and need an additional 18.7 hours, a relative shortfall of 43.7% of their total needed hours. Those who live with others receive substantially more help (66.1 hours) but need an additional 16.0 hours; their relative shortfall is a more modest 19.5%. People with fewer than two ADLs with unmet need are omitted owing to their relatively small shortfall (4 hours) and lesser policy import.

Cost of Eliminating Unmet Need

We made a simple estimate of the cost of eliminating the shortfall in hours among people with low income (below 300% of the SSI eligibility level) who live alone and have perceived unmet need. The calculation is based on what it would cost to supply enough paid hours annually to eliminate the gap in weekly hours associated with unmet need. We assumed paid helpers would receive an hourly rate of \$10. This comes to

about \$1.9 billion annually for the 195,000 people with incomes below 300% of the SSI level (see Table 4) who live alone, and the 95% confidence interval is from \$1.2 to \$2.7 billion. The cost of eliminating the shortfall in hours associated with unmet need among the half-million people with low income who live with others comes to about \$4.7 billion; the 95% confidence interval is from \$2.2 to \$7.1 billion.

Negative Consequences of Unmet Need and Dissatisfaction

Even people whose needs are usually met can experience adverse consequences owing to lack of help, if a helper is not available at the right time and place, or if the quality of help is inadequate. But we would generally expect people with perceived unmet needs to have a higher frequency of adverse experiences. For all comparisons where a significant difference is observed, people with unmet needs have a higher rate of

^{*}p < .05, **p < .01, based on two-tailed t test.

Table 4. Estimated Shortfall in Hours of Help per Week for Adults With Two or More ADLs Needing More Help, by Living Arrangement and Income

							of Eliminating S lours (\$ Billion/	
Living Arrangement and Income Level	Persons (000s)	Hours Received	Hours Shortfall	SE	Shortfall (%) ^a	Cost Estimate	SE	95% CI
Total	948	56.2	16.6	3.5	22.9	8.2	1.8	4.7–11.7
Living with others	724	66.1	16.0	4.2	19.5	6.0	1.6	2.8-9.3
Living alone	224	24.1	18.7	3.2	43.7	2.2	0.4	1.3-3.0
Income level and living arrang	ement							
<300% SSI	724	59.8	17.5	3.5	22.6	6.6	1.4	3.8-9.4
Living with others	529	72.8	16.9	4.4	18.8	4.7	1.2	2.2-7.1
Living alone	195	24.7	19.1	3.3	43.7	1.9	0.4	1.2-2.7
<100% SSI	290	64.4	17.7	3.6	21.5	2.7	0.6	1.5-3.8
Living with others	215	75.5	16.8	4.4	18.2	1.9	0.5	0.8 - 2.9
Living alone	75	32.5	20.2	3.7	38.3	0.8	0.2	0.4 - 1.1
100-300% SSI	435	56.8	17.4	3.5	23.4	3.9	0.9	2.2-5.6
Living with others	315	70.9	16.9	4.4	19.3	2.8	0.8	1.2-4.3
Living alone	120	19.7	18.4	3.3	48.3	1.2	0.3	0.6-1.7
>300% SSI	224	44.2	13.9	3.4	23.9	1.6	0.4	0.8-2.5
Living with others	195	47.8	13.6	3.7	22.2	1.4	0.4	0.6-2.2
Living alone	29	20.2	16.0	3.7	44.2	0.2	0.1 ^b	0.1-0.4

Notes: ADL = activity of daily living; CI = confidence interval; SSI = Supplemental Security Income. Data source: 1994–1997 National Health Interview Survey on Disability.

adverse consequences. Of individuals who need help with two or more ADLs, those with unmet needs have significantly greater probability of adverse consequences than those whose needs are met on 29 of 34 measures tested (Table 5). These measures include discomfort, distress, mobility restriction, doing activities oneself that the person needs help with, and more serious concerns such as going hungry, running out of food, getting burned, unintentional weight loss, and dehydration. Many of these measures specifically attribute lack of help as the cause of the events, such as going hungry because no help was available to eat.

People with unmet needs also experience a variety of secondary conditions (Table 6) at rates significantly higher than those whose needs are met, including falls and injuries due to falls, bedsores, and contractures. Of those with unmet needs, 51% attributed their falls to lack of help in getting around or inability of their helper to prevent their falling compared with 32% of those whose needs are met. People with unmet need are much less satisfied with their primary helper's availability and the amount of assistance they give as well as other aspects of their helping abilities, and they are more likely to be left alone and to lack backup helpers.

We stratified by whether individuals lived alone or with others, and within each group, we tested for differences between those with unmet versus met needs. Among people living with others, we found that those with unmet needs were significantly more likely to report problems on 44 of the 53 measures tested (see Tables 5 and 6). Among people who live alone, those with unmet needs were significantly more likely to have problems on 38 of the 53 measures tested. Many of these differences are alarmingly large. In particular, people who live alone and have unmet need are 10 times as likely to go hungry because no one is available to help them eat as those whose

needs are met (24.5% versus 2.1%), 20 times more likely to miss a meal because of lack of help with shopping (15.3% versus 0.7%), and 5 times as likely to lose weight unintentionally (52.2% versus 10.0%). On 24 measures, people who live alone and have unmet needs are significantly more likely to have problems than those who live with others and have unmet needs (opposite of expected, having a weak helper was significantly lower). Finally, of those whose needs are met, those who live alone have similar rates of adverse consequences to those who live with others: Only 8 measures were significantly different. Thus, people who live alone and have unmet needs fare worse than people with unmet needs who live with others, but both have higher risk of adverse consequences than those whose needs are met. If needs are met, rates of adverse consequences and dissatisfaction are comparable between those living alone or with others.

DISCUSSION

Unmet need is prevalent among adults of all ages who have substantial needs for PAS. About 29% of adults needing help in two or more of the five basic ADLs need more help than they receive. In a society where 85% of hours of help come from family and friends (LaPlante et al., 2002), the problem of unmet need for PAS is magnified among people who live alone, 45% of whom have unmet need, compared with 26% of those who live with others. This study demonstrates that an association exists between perceived unmet need and reduced hours of help, independent of level of disability, race, age, and income level. People who live alone and have unmet need (almost a quarter-million people) are estimated to lack 18.7 hours of help per week (95% confidence interval = 12.3–25.1) or 44% of the hours they need. Those with unmet needs who live with

^aShortfall as % of needed hours (shortfall/shortfall + hours received).

^bEstimate has low statistical precision (SE exceeds 30%).

Table 5. Prevalence of Adverse Consequences Associated With or Attributed to Lack of Help Among Adults Needing Help With Two or More ADLs, by Living Arrangement and Unmet Need: United States, 1994–1997

		Total		L	iving A	lone	Living	With C	Others
Measure	N (1,000s)	Met Needs (%)	Unmet Needs (%)	N (1,000s)	Met Needs (%)	Unmet Needs (%)	N (1,000s)	Met Needs (%)	Unmet Needs (%)
ADLs									
Person needs help bathing or showering Does not receive a complete bath daily Does not receive a partial bath daily	2,950 2,685	54.6 53.2	59.9* 56.3	442 418	60.5 50.3	71.4** ⁺⁺ 58.1	2,508 2,267	53.9 53.6	56.3 55.7
Does not receive a complete or partial bath daily Discomfort due to not bathing often enough in last month Burned or scaled by hot water in last month	2,671 2,865 2,931	25.5 12.0 1.2	29.8* 34.6** 2.5*	412 438 444	27.8 13.0 1.5	39.3** ⁺⁺ 44.3** ⁺⁺ 1.5	2,260 2,427 2,487	25.2 11.9 1.2	26.8 31.4** 2.8*
Person needs help dressing	2,931	1.2	2.5	777	1.5	1.3	2,407	1.2	2.0
Does not get dressed for the day every day If does not get dressed, does not change night clothes every day Discomfort due to not changing clothes often enough in last month	2,789 493 2,699	17.3 48.2 5.7	20.2 61.5* 15.9**	404 75 398	21.0 52.7 7.0	17.8 83.5** ⁺⁺ 22.6** ⁺	2,385 418 2,301	16.8 47.5 5.5	20.8* 55.8 13.9**
Person needs help eating Went hungry owing to lack of help eating in last month Lost weight in last month (unintentionally)	916 877	4.2 14.1	14.5** 32.0**	114 103	2.1 10.0	24.5** ⁺⁺ 52.2**	802 775	4.4 14.9	12.3** 28.0**
Been dehydrated in last month	903	4.6	11.8**	102	7.0	17.3	801	4.3	10.8*
Person needs help getting in or out of bed or chair Stays in bed most of the time Stays in a chair most of the time	2,142 1,699	19.2 59.2	22.5 57.7	272 224	20.8	18.3 68.1 ⁺	1,870 1,475	19.1 59.1	23.5* 55.0
Does not get out of bed every day Person needs help using the toilet and getting to the toilet	1,706	0.9	1.8	224	0.8	2.5	1,482	0.9	1.6
Discomfort due to not being helped toileting as needed in last month Wet or soiled self because of lack of help toileting in last month Skin problems because of soiling in last month Used a bedpan or commode because of lack of help in last month	1,448 1,448 267 1,475	9.4 14.5 19.9 5.2	27.3** 29.7** 36.8** 19.5**	206 199 61 202	10.5 23.1 25.6 4.0	37.7** ⁺ 42.1* ⁺ 31.6 23.8**	1,242 1,249 206 1,273	9.2 13.4 18.5 5.4	24.9** 26.8** 38.7** 18.5**
	1,473	3.2	19.5	202	4.0	23.6	1,273	3.4	10.5
IADLs Person needs help walking Does not move around the house as desired	2,074	45.5	51.6*	290	40.5	54.3*	1,785	46.0	50.8
Person needs help preparing meals Went hungry owing to lack of help in food preparation in last month Unable to follow special diet owing to lack of help cooking in last month	2,011 2,028	4.1 1.4	18.1** 12.7**	302 305	4.3 1.9	25.4** ⁺ 20.9** ⁺	1,709 1,723	4.1 1.4	16.0** 10.3**
Unable to eat preferred food owing to lack of help cooking in last month Prepares own meals despite needing help	2,010 2,569	3.9 52.8	22.4** 69.8**	304 413	8.4 ⁺ 56.3	39.5** ⁺⁺ 80.4** ⁺⁺	1,706 2,156	3.3 52.3	17.3** 66.2**
Person needs help shopping for groceries and personal items Unable to follow special diet owing to lack of help shopping in last month Missed a meal owing to lack of help shopping in last month Does own shopping despite needing help	2,238 2,230 2,567	0.7 0.4 48.2	10.9** 10.6** 57.2**	360 359 395	0.0 0.7 48.4	19.7** ⁺⁺ 15.3** 53.7	1,878 1,871 2,172	0.8 0.3 48.2	7.9** 9.0** 58.4**
Person needs help managing money Manages own money despite needing help	2,685	66.1	78.0**	424	68.9	89.1**++	2,261	65.7	74.3**
Person needs help doing heavy housework Distress due to clothes going unwashed or house unclean in last month Does own heavy housework despite needing help	2,131 2,407	12.2 15.5	39.4** 22.1**	335 365	11.8 12.0	38.7** 18.9	1,796 2,041	12.2 16.0	39.6** 23.2**
Person needs help doing light housework Distress due to dishes going unwashed or house untidy in last month Does own light housework despite needing help	1,931 2,629	14.1 52.6	38.9** 61.6**	298 388	15.2 52.6	40.3** 62.9	1,633 2,241	14.0 52.6	38.4** 61.2**
Person needs help getting places outside of walking distance Missed a doctor appointment owing to lack of help in last month Missed going places due to lack of help in last month	2,303 2,276	2.8 4.8	12.7** 22.4**	359 353	1.9 5.8	9.8** 34.2** ⁺⁺	1,944 1,923	2.9 4.7	13.6** 18.7**
Ran out of food in last month because person could not get to the store	2,303	0.5	8.1**	359	0.0	12.6**	1,944	0.5	6.7**

Notes: ADL = activity of daily living; IADL = instrumental ADL. Difference between met and unmet need: *p < .05, **p < .01; difference between living alone and living with others: $^+p < .05$, $^{++}p < .01$.

others lack 16.0 hours per week (95% confidence interval = 7.7-24.4) or 20% of the hours they need.

Unmet need is not a measure of individuals' insatiable demands for more help. The data confirm that unmet need is associated with higher rates of adverse consequences on 48 of 53 measures tested, including discomfort, going hungry, losing

weight, dehydration, falls, injuries due to falls, burns, and dissatisfaction, at much higher rates than those whose needs are met, particularly for people who live alone. These are serious problems that compromise the safety, comfort, and hygiene of individuals with unmet needs, reducing their ability to live independently and increasing their risk of institutionalization

Table 6. Prevalence of Secondary Conditions, Being Left Alone, Availability of Backup Help, and Dissatisfaction With Primary Helper Among Adults Needing Help With Two or More ADLs, by Living Arrangement and Unmet Need: United States, 1994–1997

		Total		L	iving Al	one	Living	With C	Others
Measure	N (1,000s)	Met Needs (%)	Unmet Needs (%)	N (1,000s)	Met Needs (%)	Unmet Needs (%)	N (1,000s)	Met Needs (%)	Unmet Needs (%)
Secondary conditions									
Falls in last year	3,251	45.8	55.1**	477	44.9	62.1*	2,774	45.9	53.0**
More than once	1,550	71.6	82.0**	250	60.1^{+}	87.5**+	1,300	73.1	80.1*
Injured	1,561	55.7	68.8**	249	66.4^{+}	73.3	1,312	54.4	67.2**
Because no help getting around or helper could not prevent falling	1,528	32.0	51.1**	239	24.5	64.5**++	1,289	32.9	46.5**
Because of dizziness	1,479	25.1	38.0**	239	18.1	41.4**	1,240	26.0	36.7**
Bedsores/pressure sores in last 3 months	3,252	6.0	9.1*	482	6.5	9.1	2,770	5.9	9.0*
Contractures in last 3 months	3,225	21.6	33.6**	470	15.6^{+}	42.6**+	2,755	22.3	30.9**
Being left alone and availability of backup help									
Ever home alone for >2 hr	3,202	49.5	65.5**	466	73.7++	96.5**++	2,735	46.3	56.6**
Better not to be left alone	1,574	18.6	39.3**	349	22.5	35.3*	1,225	17.9	41.3**
No informal helper would take care of person for a few days if needed	3,119	15.5	26.7**	443	19.5	35.8**++	2,676	14.9	24.2**
No informal helper would take care of person for a few weeks if needed	2,457	9.7	14.8**	311	15.5	24.3^{+}	2,147	9.0	12.6
Dissatisfaction with primary helper									
Not very satisfied with scheduled hours or availability when needed	2,953	7.6	23.7**	437	9.9	32.9**++	2,515	7.3	21.0**
Not very satisfied with the amount of assistance	2,954	5.9	21.2**	437	10.7^{+}	26.6**+	2,517	5.3	19.6**
Not very satisfied with willingness to do what is asked	2,941	5.5	17.1**	431	10.3^{+}	16.2	2,510	4.9	17.4**
Not very satisfied with ability to do what is needed	2,939	5.7	22.0**	435	8.4	21.2**	2,504	5.4	22.2**
(The following asked only if primary helper not present or helper is related)									
Not very satisfied with reliability	578	9.9	22.0**	273	10.6	23.6*	306	9.5	18.7*
Not very satisfied with trustworthiness	573	7.8	16.0**	271	8.5	17.4*	302	7.2	13.1
Not very satisfied with how treated	577	8.0	18.4**	272	10.2	20.2*	306	6.7	14.9*
Helper not strong enough (only of those with bathing or transfer needs)	2,553	12.0	32.4**	357	3.1^{++}	15.9**++	2,197	13.2	36.5**

Notes: ADL = activity of daily living. Difference between met and unmet need: *p < .05, **p < .01; difference between living alone and living with others: $^+p < .05$, $^{++}p < .01$.

and possibly death. Many of these events are specifically attributed by the respondent as resulting from lack of help. Inferring causality on other measures lacking such attributions, like contractures and bedsores occurring in the last 3 months, is hazardous because of the cross-sectional design of the survey. The occurrence of such events may have precipitated a need for more than the available level of help. Nevertheless, the weight of the evidence clearly suggests that unmet need is associated with and attributed to much greater adversity.

Limitations to these findings include the fact that need and unmet need are self-reported or proxy reported, whereas professional assessment could yield different results. Hours for those whose needs are met are the standard against which the unmet-need shortfall is defined, and those hours are likely to be influenced by whether they are self-reported, proxy reported, or assessed by a professional. Item nonresponse necessitated imputation and proxy reporting raised questions of potential bias in reporting levels of need, unmet need, and hours. However, we determined that results were robust even when imputed hours and proxy reports were separately excluded in the analysis (results not shown). Nevertheless, professional assessment could yield a different estimate of the shortfall.

Working-age adults account for half the prevalence of met and unmet need among those needing help in two or more ADLs. We analyzed the working-age population separately and found the results robust, although the relative shortfall in needed hours is somewhat smaller than for all ages combined (18% versus 23%, results not shown). However, unmet need among people living alone is more an issue for the elderly,

because two thirds of those living alone and needing more help are age 65 or older. It is notable that both age and being non-White have positive relationships to hours received after controlling for level of need, which may represent sociocultural differences in informal helping.

Access to paid help is critical for people who live alone because they are much more likely to receive paid help than are people who live with others (62% versus 24%; p < .001, not shown). Of people who live alone, those whose needs are met are more likely than those whose needs are unmet to get paid help (70.2% versus 50.3%; p < .001, not shown). More than half of that paid help is reported to be paid by Medicare or Medicaid. Among people living with others, the difference in getting paid help by unmet need is much smaller (25.7% versus 19.4%; p < .001, not shown). Thus, expanding access to paid PAS appears crucial in reducing unmet need among those who live alone. A limitation of the data is that family helpers were not asked if they were paid, which may accentuate differences between paid and unpaid help by living arrangement.

If the estimated shortfall in hours were to be provided through public funds, the cost of eliminating unmet need among people who live alone with low incomes ranges from \$1.2 to \$2.7 billion, a relatively small amount. However, the cost for people who live with others is more than twice as large, from \$2.2 to \$7.1 billion.

People who live with others get twice as many hours of help per person, independent of need and unmet need. Is the lower level of help provided to people who live alone a problem? Actually, people who live alone and whose needs are met are no more likely to experience adverse consequences than people who live with others and have their needs met, which suggests that the difference in hours is not a problem. It seems more likely that the difference in hours represents a *different accounting* of help received. After all, among people who live alone, helpers come in to the home usually with a set of goals to be achieved in a limited time. It is a different case when the person lives with someone who provides help continuously throughout the day. A different accounting does not imply that the unmet-need shortfall in hours for people who live with others is not real. They do have higher risk of adverse consequences when their needs are unmet, although not as extreme as for those who live alone.

There are some problems to be dealt with in reducing unmet need for PAS. The potential for greater publicly financed help to displace unpaid help has been acknowledged (Kemper, 1992; Moscovice, Davidson, & McCaffrey, 1988). Some research suggests that paid services complement, rather than substitute for, unpaid care (Liu, Manton, & Aragon, 2000). The potential substitution effect is much less an issue for people who live alone, only one third of whom are helped by children or relatives, than it is among people who live with others and have unmet needs, of whom about 90% are helped by relatives, usually a spouse.

Greater public provision of help to low-income individuals is required to reduce unmet need among those who live alone, but it is not the only remedy for those who live with others. Other strategies may be considered to increase informal hours for those living with others by defraying the personal costs that helpers and their families incur, such as providing tax credits for helpers, and by other financial incentives to foster more informal help. However, these strategies do not focus on unmet need and would provide resources to those whose needs are already being met (or their caregivers) and who have lower risk of adverse consequences than those with unmet need.

Finally, human help is not always the best solution even for those who feel they need it. Trying to eliminate unmet need only by fulfilling people's wishes for more human help, without considering alternative ways to accomplish activities through use of assistive technology (Verbrugge & Sevak, 2002) and environmental modification (Lawton, 1982), could result in less empowerment, greater learned dependency, and greater societal expense.

Legal precedents such as the Supreme Court's Olmstead decision (U.S. Government Accounting Office, 2001) and legislative initiatives such as the Medicaid Community Attendant Services and Supports Act (MiCASSA; Harkin & Spector, 2001) would enable individuals to live in the least restrictive setting they desire. However, such efforts to reduce society's reliance on institutions cannot work if individuals' needs are not well met in the community.

Previous research, by looking only at the prevalence of unmet need for PAS, creates a false impression that unmet need is a large and costly problem to resolve. In fact, only 6.6% of all needed hours of help are unmet among adults needing help in two or more ADLs. The reduction, if not the elimination, of unmet need for PAS is a financially achievable goal for the nation and one that long-term care policy should focus on.

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