

#2006-25
December 2006

**Just Getting By: Unmet Need for Personal
Assistance Services Among Persons 50 or Older
with Disabilities**

by

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The Public Policy Institute, formed in 1985, is part of the Policy and Strategy Group of AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of interest to older Americans. This paper represents part of that effort.

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AARP, 601 E Street NW
Washington, DC 2004

ACKNOWLEDGMENTS

We wish to thank the many individuals who provided thoughtful comments on drafts of this paper. They include the following staff of the AARP Public Policy Institute (PPI): Elizabeth Clemmer, Wendy Fox-Grage, Marc Freiman, John Gist, Enid Kassner, and Donald Redfoot. Ari Houser of PPI assisted with data analysis, in addition to providing insightful comments. We also benefited from the comments of Rhonda Richards and Lisa Stand of AARP.

Finally, we are grateful for the helpful suggestions of several external reviewers, including Harriet Komisar of Georgetown University and Susan Mor of Brown University.

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EXECUTIVE SUMMARY

INTRODUCTION

Persons with disabilities who do not receive all of the assistance they need with essential activities, such as bathing, dressing, and cooking, face daily challenges in doing simple things that people without disabilities take for granted. Such unmet need has important implications, not only for individuals' quality of life but also for public policy. If needs remain unmet, these individuals are at risk for increased morbidity, more severe disability, acute care hospitalization, and institutionalization.

PURPOSE

The purposes of this report include: (1) broadening knowledge about two key subgroups of persons with unmet needs for personal assistance services (PAS)—both those who receive *some help* (predominantly from family members) and those who receive *no help* at all; (2) identifying changes that individuals with unmet need report would cause a major difference in their quality of life; (3) exploring respondents' differing preferences for whom they want to provide PAS and in what settings; and (4) identifying those factors that are *most predictive* of unmet need, differentiating between those with some—but insufficient—help and those with no help at all.

METHODOLOGY

Data are drawn from a nationally representative telephone survey of 1,102 persons age 50 and older with disabilities conducted by Harris Interactive for AARP in September 2002. The sample in this study consists of the 865 persons who reported they had difficulty with one or more of three types of activity: (1) dressing, bathing, or getting around inside their home; (2) going out alone, for instance, to shop or visit a doctor's office; or (3) working.

All respondents, including both those who were receiving help from another person and those who were not, were asked if they needed more help than they were receiving with “everyday activities like bathing, dressing, and cooking.” The sample was divided into four groups: (1) persons who said their needs were met (“met needs group”); (2) persons who said they needed more help (“unmet needs” group); (3) among the unmet needs group, those who did not receive regular help from another person (“no help” group); and (4) among the unmet needs group, persons who received regular help from at least one person (“insufficient help” group).

Two types of analysis were used: (1) Univariate analyses were used to compare groups according to sociodemographic and other characteristics; views on changes that would cause a major improvement in their quality of life; and preferences for assistance. (2) Two multivariate logistic regression models were developed to identify which variables had an independent effect, after controlling for other variables in the model, on the likelihood of (a) having unmet needs, and (b) receiving insufficient help rather than no help at all.

PRINCIPAL FINDINGS

Almost three of 10 respondents (29%) reported having unmet needs for assistance. Among those with unmet needs, more than one-third (37%) received no help, while about two-thirds (63%) received some—but insufficient—help. The primary reason given by respondents for not receiving enough help was that it was “too expensive/can’t afford it.”

Family members, predominantly spouses or adult children, were the primary sources of assistance. Of persons receiving help, including both those whose needs were met and those whose needs were not, the great majority (about 75%) lived in the same household with the caregiver. Only a small minority (12%) received help from paid sources.

Total Population with Unmet Needs for PAS. While persons in the unmet needs group differed significantly by age, race, and ethnicity from persons whose needs were met, in the univariate analyses, these differences were *not* significant when other variables were controlled in the multivariate analyses.

Financial barriers and the type of disability were the most important factors in *increasing* the likelihood of unmet needs when other variables were controlled. The “top five” predictors of having unmet needs for PAS, all significant at 5% or less, are:

- needing a way to pay for long-term services and equipment¹;
- difficulty with bathing, dressing, or getting around inside the home;
- low income (less than \$15,000 per year, compared with \$35,000 or more);
- having a cognitive disability; and
- living in the East or South rather than the Midwest.

Other factors, all significant at 5% or less, *decreased* the likelihood of having unmet needs for PAS:

- having coverage for both Medicare and Medicaid, called being “dually eligible”²;
- living with a spouse, family member, or other informal caregiver;
- having unpaid help from someone living in the same household; and
- having a disability that is “moderate or somewhat severe” rather than “very severe.”

When asked about 14 possible changes that would cause improvement in the quality of their lives, the top changes respondents said would cause a *major* improvement in the quality of their

¹ The survey asked a series of hypothetical questions about what would cause a major, minor, or no improvement in respondents’ quality of life. One item in this series, “having a way to pay for long-term care services and equipment,” was included in the regression model because of its close relationship to respondents’ financial resources.

² Six categories of insurance were examined, including no insurance, private insurance, Medicare, and Medicaid. Only one category was significant: coverage for *both* Medicare and Medicaid was found to decrease the likelihood of having unmet need.

lives all involved more help with daily activities—being able to pay for such assistance, having more control over who provides it, and having a known and trusted person available to help.

Persons with Unmet Needs Who Receive Insufficient Help: It is not surprising that living with a spouse or family member was the most powerful predictor of having some rather than no help. Several characteristics of persons with insufficient help may lead to social isolation: they generally have very severe disabilities and have difficulty going out alone, and many do not drive at all. Possibly because of their need to rely on others for help with daily activities, they more frequently report having lost some control over routine life decisions, such as when they go out.

Persons in this group identified several changes that would cause a major improvement in their quality of lives, including better medical insurance, more control over decisions about help needed, and being able to get to places safely.

Persons with Unmet Needs with No Help: The characteristics and preferences of those in the group with unmet need who receive no help at all portray a much a different picture. These individuals are more likely to live alone and are disproportionately unmarried or divorced. Their disabilities are generally less severe than are those among the group receiving some help, but they more frequently report that their disabilities have nonetheless prevented them from reaching their full abilities as a person. Their preferences for assistance vary substantially. Possibly because they do not have potential informal caregivers available, they are more likely to prefer that assistance be provided by a home care agency rather than by family or friends, and to rate assisted living and other residential care options more highly.

CONCLUSIONS AND POLICY IMPLICATIONS

This study is unique in measuring not only the key factors associated with unmet need but also individuals' preferences for services and the changes they say would cause a major improvement in the quality of their lives. Its results help to inform policy decisions about ways to reduce unmet needs for help with daily activities among different groups of persons with disabilities. In particular, they suggest the need to expand publicly funded home and community-based services (HCBS), provide greater support for unpaid informal caregivers, and provide more financing options for long-term services and supports (LTSS) in general.

Identifying at-risk older persons in the community: The prevalence of unmet need found in this study (almost 30%) indicates the need to identify at-risk older persons with disabilities in the community and link them to appropriate HCBS.

Expanding HCBS: The findings underscore the need for states to accelerate their efforts to rebalance their Medicaid long-term care programs toward greater provision of HCBS services, especially in states that remain highly biased toward institutional services.

In addition, they point to the importance of differentiating between two different populations who have unmet needs. The *no help* group, most of whom live alone and have less severe disabilities, may be at the beginning of a trajectory of functional decline that could result in loss

of independence if needs remain unmet. Targeting PAS only to individuals with unmet needs who receive no assistance, however, would be a mistake. The group reporting *insufficient help* has multiple vulnerabilities, more severe disabilities, and may be at more immediate risk of institutionalization than is the group receiving no help. Although they overwhelmingly prefer assistance from family members/friends, they also report needing more help than they are receiving now. This finding suggests the need for a *mix* of both formal and informal services for those with severe disabilities whose informal caregivers are unable or unwilling to provide more help.

The need for *consumer-directed service models*, which give consumers choice about how, when, and from whom they receive services, is also buttressed by these findings. Such models are gradually expanding in Medicaid and some state-funded programs.

Need for Better Family Support Policies: In addition to the need to expand HCBS, the results suggest a need to adopt a family-centered approach to service provision, which would include assessments of the needs of *both* care recipients and caregivers. For example, the care recipients in this study often needed help purchasing additional assistance and locating reliable and trusted individuals to supplement their informal support. It is also important to recognize the limits of relying exclusively on family caregivers, some of whom are not able to provide sufficient help.

Addressing Financial and Coverage Barriers: Lack of affordability is one of the primary reasons respondents with unmet need for PAS say they are not receiving the assistance they need, and financial barriers are the most powerful predictor of unmet need for PAS. While these are not surprising findings, they contribute to the very sparse literature with *explicit* data on why needs for help with daily activities are unmet.

The need to protect and strengthen programs for the “dually eligible” emerged as another clear policy implication of this study. In addition, aside from Medicaid and some state-funded programs, there are few sources of financial or other assistance for persons who need HCBS (Medicare pays for only a limited amount of medically oriented home health care). The need for more and better financial options to pay for LTSS is pressing.

The results of this study raise many concerns about the ability of persons 50 and older with disabilities to pay for necessary long-term services and supports and to find trusted and reliable formal caregivers. In addition, in a society that encourage a sometimes overwhelming choice in goods and services by persons who can afford them, it is unsettling to find how many persons with disabilities have lost a great deal of choice regarding their most basic daily decisions and activities.

A. Background

The number of persons 50 and older with disabilities is large and growing, despite declines in general rates of disability over the last few decades. An estimated 11% of persons age 50 and older have a limitation in mobility or self-care (Houser, 2006). The vast majority of persons with disabilities live in the community, primarily with the unpaid support from family members and friends, rather than in institutions. The economic value of personal assistance provided to adults with disabilities living at home has been estimated at \$200 billion in 1996, with only 16% of this total being paid (LaPlante, Harrington, and Kang, 2002).

Both population aging and strong preferences among consumers for independent living make the adequacy and affordability of home and community-based services (HCBS), such as personal assistance services, increasingly pressing public policy issues. Many states have gradually expanded HCBS in recent years, but such expansions remain at risk due to fiscal constraints. Of total Medicaid long-term care spending in FY 2005, over one-third (37%) went toward home and community-based services. Most of this spending went to HCBS waivers; only one-quarter of waiver spending was for services for older persons and adults with physical disabilities (Eiken, Burwell, and Selig, 2006).

The general term “disability” has many meanings. Disabilities may be physical, sensory, cognitive, or emotional. They may be visible or hidden, and they vary widely in their causes, the age of their onset, and the activity limitations that result. Disability typically involves difficulty with basic tasks of daily living, such as bathing, dressing, or shopping, or getting around one’s community. Researchers commonly distinguish between two types of disability. “Activities of daily living” (ADLs) refer to basic personal activities essential to daily life and to survival, such as eating and dressing. “Instrumental activities of daily living” (IADLs) refer to more complex activities that permit one to manage one’s affairs independently, such as shopping and managing money.

A growing but still relatively small body of literature has demonstrated that some individuals with disabilities are not receiving all of the hands-on personal assistance they need, from either unpaid sources, such as family members, or paid sources, such as in-home aides. Such unmet need has important implications for both individuals’ quality of life and for public policy. For instance, if needs for personal assistance go unmet, individuals may be at risk for increased morbidity, more severe disability, acute care hospitalization, and institutionalization (Komisar, Feder, and Kasper, 2005; Long et al., 2005; Sands et al., 2006).

1. Types of unmet need. Much of the literature on unmet need for home and community based services has focused on unmet need for personal assistance services (PAS), such as help with bathing, dressing, and shopping. However, the literature on unmet need for other types of supports services, such as home modifications, is growing (Newman, 2003). In addition, some researchers are now addressing whether the use of assistive technologies can reduce the need for hands-on personal care (Agree and Freedman, 2003).

2. Identifying unmet need. A number of studies have addressed the prevalence of unmet need for PAS among different age groups, including persons 18 and older (Allen and Mor, 1997; LaPlante et al., 2004) and persons age 70 and older; Desai, Lentzner, and Weeks, 2001).

Unmet need for PAS can be measured in diverse ways, including: (1) individuals' own perceptions of their need for more help (Morrow-Howell, Proctor, and Rozario, 2001); (2) professional clinical assessments of individuals' needs; and (3) evaluations by public health professionals, such as state Medicaid directors, of the aggregate need for services (Harrington et al., 2002). While popular notions may devalue the importance of "self-reported" data by individuals, a wide body of research supports the validity of data based on self-reported need. For example, the validity of self-reported need for PAS is similar to that of self-reported health status, which is an "excellent, if not the best, predictor of use of health services" (Williams, Lyons, and Rowland, 1997).

Older persons may identify fewer problems and service needs than do professionals. For example, older persons receiving in-home services rate the amount of care they are receiving as more adequate in meeting their functional needs than do professional nurses using clinical reports based on in-home interviews (Morrow-Howell, Proctor, and Rozario, 2001). At the same time, the validity of older adults' reports of hours of formal personal care received, when matched against administrative records, is remarkable, even in complex care situations (Albert et al., 2004).

The burgeoning literature on unmet need for PAS is now differentiating among subgroups of individuals whose needs are unmet, such as those in a variety of living environments (Newcomer et al., 2005). In addition, there are important differences in the characteristics and situations of those persons who receive only inadequate help and those who receive no help at all (Lima and Allen, 2001).

3. Consequences of Unmet Need. Persons with disabilities who experience unmet need for PAS can experience a range of negative consequences, including increased use of health services (Allen and Mor, 1997), as well as institutionalization (Long et al., 2005). Rates of acute care admission are higher for frail older persons living with unmet needs for PAS, but not after their needs are met (Sands et al., 2006). In one study, nearly half of persons 70 and older with unmet need for personal assistance with ADLs experienced a negative consequence (such as being unable to eat when hungry or use the toilet when needed) as a result of their unmet need (Desai, Lentzner, and Weeks, 2001). Similarly, over half (56%) of persons dually eligible for Medicare and Medicaid with unmet need for help with ADLs reported one or more serious consequences, such as falling or not being able to bath, dress, or eat (Komisar, Feder, and Kasper, 2005).

B. Purpose/Objectives

This study has several purposes. First, it seeks to identify the sociodemographic and other correlates of unmet need for personal assistance services among a sample of persons 50 and older with disabilities, and then to identify those factors that are *most predictive* of unmet need among this population. It also seeks to broaden our knowledge about key subgroups of persons with unmet needs for PAS—those who receive *insufficient help*, predominantly from family members, and those who receive *no help* at all. Perhaps most important, it is unique in (1) identifying the changes individuals themselves with unmet need report would cause a major improvement in their quality of life, and (2) distinguishing among the specific changes that

would be most helpful to those who have no help at all versus those who have insufficient help. Finally, it discusses respondents' differing preferences for whom they want to provide PAS and in what setting.

The seven specific research questions are:

1. What is the prevalence of unmet need for PAS among persons age 50 and older with disabilities?
2. How do socioeconomic characteristics, type of condition, and severity of disability vary among persons with disabilities who report their needs are met and those who report their needs are unmet, including both those who receive some, but insufficient, help and those who receive no help at all?
3. How do persons with unmet needs compare with those whose needs are met with respect to several major problems, such as being dissatisfied with life?
4. What are the most essential changes persons with unmet versus met need say would make a major improvement in their quality of life? Do these changes differ between those who receive no help at all versus those who receive insufficient help?
5. Do preferences about who provides assistance and in what setting also vary among these groups?
6. What are the key predictors of having unmet needs versus having needs met?
7. Among persons with unmet need, what are the key predictors of having some (insufficient) help versus no help at all?

C. Methods

1. Data Source and Methods. AARP commissioned Harris Interactive in 2002 to conduct a nationally representative telephone survey of persons 50 and older, with disabilities, living in the community to learn their views on issues related to their quality of life and experiences in their communities. Some data from this survey were presented in **Beyond 50.03: A Report to the Nation on Independent Living and Disability**³, part of a series of annual reports to the nation by AARP on our country's 50-and-older population. The data, previously unpublished, and analyses presented below offer an in-depth look at the most vulnerable respondents: persons who reported unmet needs for help with essential everyday activities, such as bathing, dressing, cooking, and shopping.

Interviews by telephone took place in September 2002, among a prescreened sample of 1,102 persons age 50 and older with disabilities. Data were weighted to be representative of the national population of persons 50 and older with disabilities living in the community.

³ Gibson et al., 2003; available at www.aarp.org.

2. Disability screening. Households previously identified in earlier studies conducted by Harris Interactive for the National Organization on Disability as having a resident age 18 or older with a disability were contacted by phone. Eligibility for this study was determined using three disability screening questions similar to those used in the Census 2000 long-form questionnaire. These questions inquired about the presence of any of three categories of long-lasting conditions that can result in disability:

- blindness, deafness, or a severe vision or hearing impairment;
- a condition that substantially limits one or more basic physical activities, such as walking, climbing stairs, reaching, or lifting; and
- a physical, mental, or emotional condition that increases the difficulty of learning, remembering, or concentrating.

In addition, respondents were included in the sample if their disability prevented them from participating fully in work, school, housework, or other activities. (See the Appendix for details about the sampling methodology.)

3. Measures of Functional Status. Once respondents were screened into the survey on the basis of the disability screening questions discussed above, they were asked about (1) the severity of their disability (slight, moderate, somewhat severe, very severe), and (2) the age at which their disability began. They were also asked three questions about their difficulty in performing the following daily activities:

- difficulty dressing, bathing, or getting around inside their home;
- difficulty going out alone, for instance, to shop or visit a doctor's office; and
- difficulty working at a job or business.

The first question refers to limitations in activities of daily living (ADLs), which typically include bathing, dressing, transferring from a bed or chair, using the toilet, walking, and eating. The second question refers to limitations in instrumental activities of daily living (IADLs), more complex activities, which typically include housework, meal preparation, shopping, using the telephone, and managing money. Getting outside, one of the measures we use is generally classified as an IADL (LaPlante, Harrington, and Kang, 2002). Our third measure, difficulty working at a job or business, was included because it is a critical measure for the Americans with Disabilities Act (ADA) and for determination of eligibility for Social Security Disability Insurance. It also permitted direct comparisons with data obtained in earlier surveys conducted by Harris Interactive for the National Organization on Disability.

Both ADL and IADL measures have been widely used in research on functional physical status for decades and are commonly used in public policy research as indicators of the need for long-term services and supports.

4. Analytic sample. The sample used in this study consists only of those persons in the original sample who reported having difficulty with one or more of the three activities identified in the

following section. Therefore, the analytic sample for this study consists of 865 of the original 1,102 respondents.

The 240 individuals who met the broader study's screening criteria but who were *not* included in this study were disproportionately older (age 65 and older) rather than younger (age 50–64). Those who were not included were also significantly more likely to have a vision or hearing impairment only; to report their disability as being slight or moderate rather than somewhat or very severe; to have a higher income (\$50,000 or more); and to have a college degree or higher.

The margin of error for estimates based on the entire analytic sample of 865 is ± 3.3 percentage points at the 95% confidence level, 4.4 percentage points at the 99% confidence level, and 5.6 percentage points at the 99.9% confidence level.

Data reported in raw numbers correspond to the actual (unweighted) counts. Unless otherwise indicated, when the data are reported as percentages, sample weights are used.

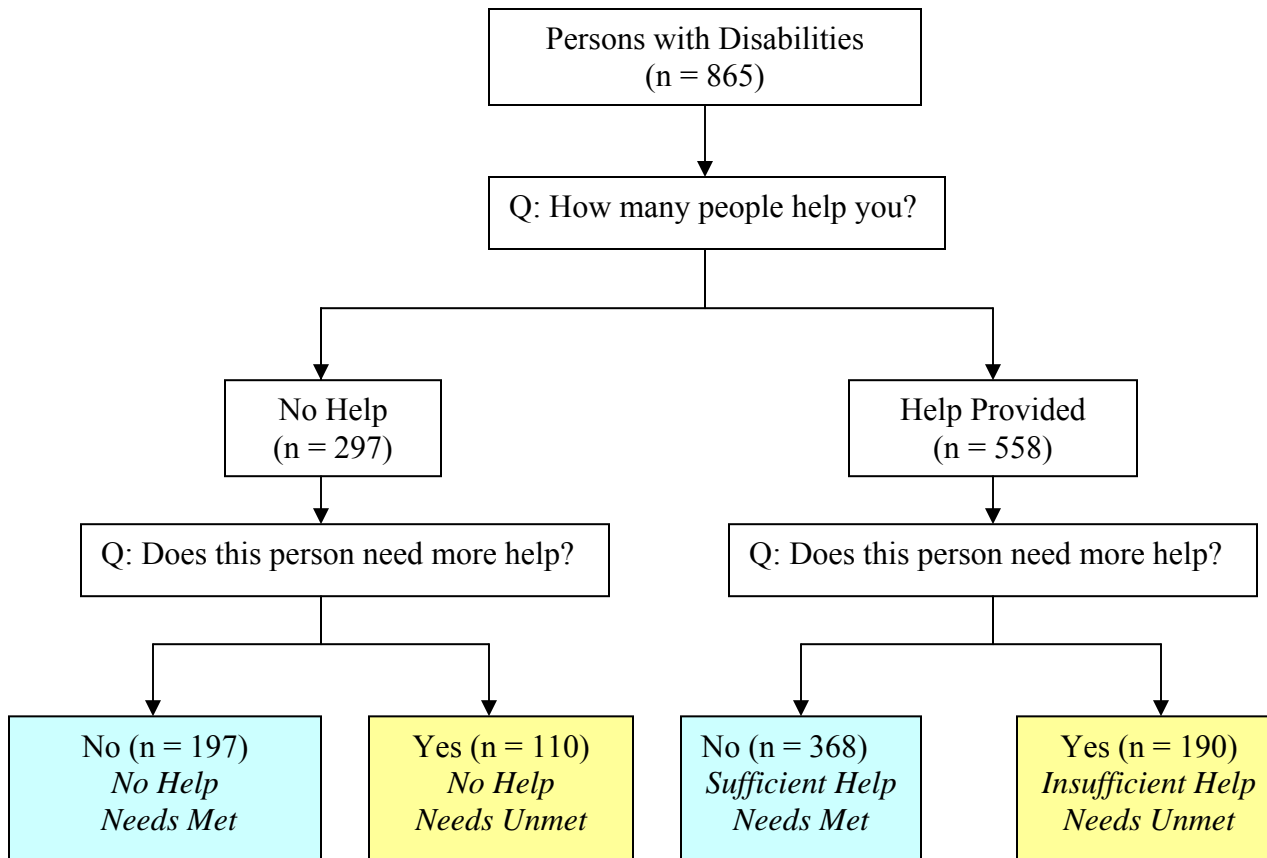
5. Measures of Unmet Need. With respect to measures of unmet need, the survey first asked respondents how many persons regularly help them with “everyday activities like bathing, dressing, cooking, and shopping because of their disability or health condition.” It then asked all respondents if they needed more help than they were receiving (with these activities). Only persons who said they needed more help were classified as having unmet needs.

We divided the sample into four groups, similar to those identified by Lima and Allen (2001), based on responses to these two questions. These groups are: (1) persons who said their needs were met (“met need” group); (2) persons who said they needed more help (“unmet need group”); (3) among the “unmet need” group, those who said that no one regularly helped them with their daily activities (“no help” group); and (4) among the “unmet need group, those who said that least one person regularly helped them with daily activities (“insufficient help” group).

6. Analytic Approach. Descriptive analyses were used to compare groups according to demographic characteristics, and to address the first five research questions. Differences between the met and unmet need groups, and between the two unmet need groups, were tested for significance at the 5% level using chi-square tests.

To answer questions 6 and 7, two logistic regression models were developed to identify the key predictors of having needs met or unmet and, among those whose needs were not met, receiving some help versus receiving no help at all. The flow chart in Figure 1 explains how the two models were designed from the questionnaire:

Figure 1: Samples for Logistic Regression Models



Model 1: Needs Met (n = 368 + 197 = 565)
Needs Unmet (n = 110 + 190 = 300)

Model 2: No Help (n = 110)
Insufficient Help (n = 190)

(See the Appendix for more details on analytic procedures and models.)

The independent variables were grouped into three broad categories related to the use of PAS that earlier research has shown to predict health care utilization and access to long-term services and supports (Andersen, 1995; Borroyo et al., 2002). These categories are: (1) *disability characteristics*, related to the need for PAS; (2) *predisposing characteristics*, which reflect sociodemographic factors; and (3) *enabling characteristics*, which reflect resources and access to assistance. The specific variables used in each category are:

- Disability characteristics: (1) severity of disability; (2) type of disability, that is, physical, sensory, and cognitive/emotional; and (3) functional limitations, that is, going out alone, such as to shop or go to the doctor; and difficulty dressing, bathing, or getting around inside of the house.

- Predisposing characteristics: (1) age; (2) gender; (3) education; and (4) race and ethnicity.
- Enabling characteristics: (1) health insurance coverage; (2) use of assistive devices; (3) living arrangements; (4) region of residence; (5) income; and (6) having a way to pay for long-term services and supports.

7. Analytic issues and caveats. Most earlier studies on unmet need for PAS have used large, population-based data sets, primarily the National Health Interview Survey (NHIS) Disability Supplement, the NHIS Supplement on Aging, and the NHIS Followback and NHIS Supplement. The data in these surveys were collected in the mid-1990s. These data sets permit far greater specificity in measuring limitations in both ADLs and IADLs, and in the specific types of help needed, than could be obtained in the Harris telephone survey. However, while the NHIS disability data sets are rich in detail, they are now more than a decade old. To the best of our knowledge, the data used in this study are the most current nationally representative data available that address unmet need among persons age 50–64 and age 65 or older. The National Long-Term Care Survey collects data on a wide range of issues affecting persons with disabilities, including unmet needs for services, but it surveys only Medicare beneficiaries age 65 and older.

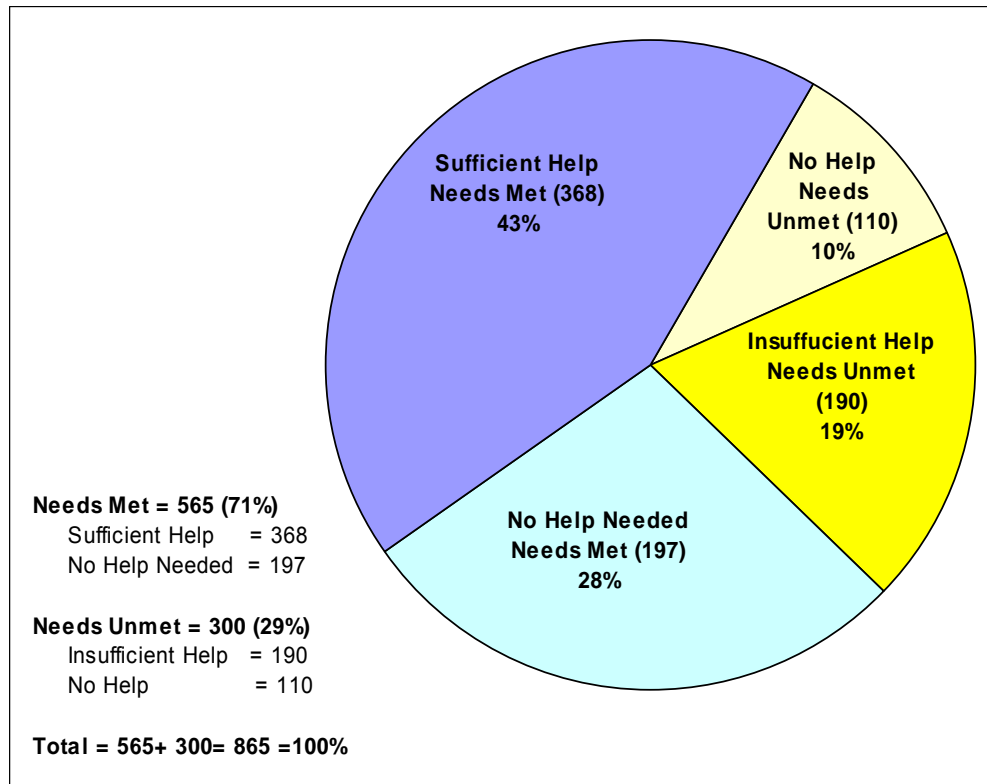
The data in this study, as well as those in the NHIS data sets referenced above, are all cross-sectional (collected at one point in time). In the absence of longitudinal data that follow the same individuals over time, our analysis of the predictors of unmet need can at best be suggestive of causal ties.

D. Findings

1. What is the prevalence of unmet need for PAS among persons age 50 and older with disabilities?

Among this sample of persons 50 and older with disabilities who report difficulty in one or more daily activities, 71% reported having no unmet needs for assistance, while 29% reported needing more help than they currently received (see Figure 2). Among the unmet need group, more persons received insufficient help than received no help at all.

Figure 2: Prevalence of Unmet Need Among Persons 50+ with Disabilities



The primary reason respondents gave for not receiving enough help was that it was “too expensive/ [respondent] can’t afford [it]” (see Table 1). It is interesting to note that no differences in responses emerged between persons with no help and those with insufficient help.

Table 1: Reasons for Not Receiving Enough Help

Main Reason	No Help	Insuff. Help
Too expensive/can’t afford to pay	70%	68%
Can’t find anyone reliable	10%	17%
Did not want to ask friends/family	10%	7%
Other	11%	8%

No significant differences between groups.

Table 2: Prevalence of Needs Met, Insufficient Help, and No Help by Sociodemographic Characteristics (n = 865)^a

Characteristics ^b	Needs Met (n = 565)	Needs Unmet			Characteristics ^b	Needs Met (n = 565)	Needs Unmet		
		All (n = 300)	Insuff. Help (n = 190)	No Help (n = 110)			All (n = 300)	Insuff. Help (n = 190)	No Help (n = 110)
Gender					Area				
Male	41.2	35.3	45.9	44.9	Urban	20.4	29.2	31.2	25.7
Female	58.8	64.7	54.1	55.1	Suburban	45.3	43.3	42.9	44.0
Race					Rural	34.2	27.5	25.9	30.3
White	89.0	86.4	87.6	84.3	Marital Status				
Nonwhite	11.0	13.6	12.4	15.7	Married	61.3	45.0	55.3	27.3
Origin					Widowed	15.8	19.8	17.0	24.5
Hispanic origin	3.0	5.3	5.9	4.5	Separated/Divorced/ Single/Living w partner	22.9	35.2	27.7	48.2
Non-Hispanic	97.0	94.7	94.1	95.5	Age Acquired Disability				
Income					(Before 40)	19.1	22.7	20.0	27.6
Income < \$15,000	32.1	46.8	40.0	58.8	(40 to 55)	46.1	50.5	50.5	50.5
Income \$15 - \$35,000	36.9	33.0	35.9	27.8	(56 to 64) *	17.7	13.2	14.7	10.5
Income >= \$35,000	27.2	20.2	24.1	13.4	(After 65: Base)*	17.2	13.6	14.7	11.4
Region					Education				
East	18.2	20.7	17.4	26.4	Less than High School	11.6	9.5	10.7	7.3
South	38.8	43.7	42.1	46.4	High School	31.7	26.4	28.9	22.0
Midwest	21.6	14.7	14.2	15.5	Some College	35.1	40.5	38.5	44.0
West	21.4	21.0	26.3	11.8	College	21.6	23.6	21.9	26.6
Living Status					Age				
Live alone	18.3	33.0	18.7	57.3	50-59	44.1	55.7	55.8	55.5
Live w/spouse or partner	60.2	44.1	55.1	25.5	60-69	29.7	26.0	24.2	29.1
Live w/family or others	21.5	22.9	26.2	17.3	70-79	18.4	13.0	14.2	10.9
					80+	7.8	5.3	5.8	4.5

^a. All ratios are significantly different from one another except the ones marked with an asterisk.

^b. Percentages add to 100 for each characteristic.

2. How do socioeconomic and other characteristics, such as type of condition and severity of disability, vary among persons with disabilities who report their needs are met and those whose needs are unmet, including both those who receive some, but insufficient, help and those with no help at all?

Socioeconomic Characteristics

Table 2 above provides descriptive results of the socioeconomic characteristics of persons who report their needs are met (sufficient help) versus those who report needing more help, that is, the “insufficient help” and “no help” groups.

These data show substantial variations among the three groups on almost all of the socioeconomic characteristics examined, with the exception of gender. For example, compared with those whose needs are unmet, higher proportions of persons whose needs are met are older, white, and non-Hispanic. Differences between the two distinct unmet needs groups are also substantial. Persons who receive no help, for example, are much more likely to be low income as well (less than \$15,000) and to live alone than those who receive insufficient help.

Caregiver Characteristics

Table 3 below shows that of those receiving help, only a small minority say their primary source of help comes from formal, *paid* sources. The source of help is similar whether needs are met or not. Family members, predominantly spouses or children, are the front-line unpaid caregivers, and roughly three out of four respondents and caregivers are living in the same household.

Table 3: Caregiver Characteristics by Adequacy of Help Received

	Needs Met	Insufficient Help
Paid vs. Unpaid		
Paid	10%	17%
Unpaid	90%	83%
Relationship of Caregiver		
Family	82%	77%
Friend	9%	8%
Other	10%	15%
Type of Family Member		
Spouse	68%	63%
Child	17%	19%
Other	15%	18%
Live with Caregiver		
Yes	80%	72%
No	20%	28%

No significant differences between groups.

Disability Characteristics

Persons with unmet needs are more likely to have chronic physical conditions or cognitive/emotional conditions than are those whose needs are met. They are also more likely to have a cognitive condition *and* one or more other conditions, as well as several limitations in daily activities, as shown in Table 4. They are also less likely to drive at all.

Table 4: Disability Characteristics by Adequacy of Help Received

Disability Characteristic	Needs Met	Needs Unmet		
		All	No Help	Insuff. Help
Visual or sensory condition	26%	25%	27%	24%
Physical condition	86%	92%*	89%	94%
Cognitive/emotional condition	23%	36%*	34%	37%
Cognitive & 1+ other condition(s)	19%	34%*	30%	36%
Difficulty shopping or getting around	54%	71%*	49%	82%*
Difficulty bathing, dressing, or moving around inside the home	42%	60%*	49%	66%*
Difficulty working	78%	79%	84%	76%
Difficulty with 2 or more activities	55%	72%*	63%	77%*
Does not drive at all	28%	41%*	26%	48%*

*Significant at 5%. Note that in this and subsequent tables the asterisks in the “All” column reflect differences between the met and unmet need groups, while those in the “insuff. help” column reflect the differences between the insufficient help and the no help groups.

In addition, persons with unmet needs are more likely to report that their disability is very severe, as shown in Table 5.

Table 5: Severity of Disability by Adequacy of Help Received

Severity of Disability	Needs Met	Needs Unmet		
		All	No Help	Insuff. Help
Slight	6%	2%*	4%	1%
Moderate	26%	13%*	21%	9%*
Somewhat severe	44%	40%	47%	36%
Very severe	25%	45%*	29%	54%*

*Significant at 5%.

3. How do persons with unmet needs compare with those whose needs are met with respect to several major problems, such as being dissatisfied with life?

As shown in Table 6, persons with unmet needs are more likely to experience some major problems. It is disturbing to note that, due to cost, almost half of the individuals in this group (47%) have delayed seeking health services they thought were necessary. In addition, a very high proportion (87%) reports that their disability or health condition has prevented them from reaching their full abilities as a person.

Table 6: Problems by Adequacy of Help Received

Problems	Needs Met	Needs Unmet		
		All	No Help	Insuff. Help
Dissatisfied with life in general	23%	41%*	32%	45%
Condition has prevented reaching full abilities as a person	67%	87%*	91%	84%
Put off seeking needed health care due to cost	28%	47%*	50%	45%
Dissatisfied with health services	18%	26%*	26%	26%

*Significant at 5%.

Persons with unmet needs are significantly more likely to have lost control over many key aspects of their daily lives than are persons whose needs are met, as shown in Table 7. Those receiving insufficient help have lost more control over who provides services to them, when and where they are able to go out and when and what they eat than have persons receiving no help.

Table 7: Loss of Control over Daily Activities by Adequacy of Help Received

Disability has Resulted in Having “a Lot Less Control”	Needs Met	Needs Unmet		
		All	No Help	Insuff. Help
Over how they spend money	19%	43%*	46%	41%
Over who provides services to them	14%	32%*	18%	40%*
Over when and what they eat	12%	31%*	22%	35%*
Over when and where they are able to go out	31%	45%*	33%	51%*

*Significant at 5%.

4. What are the most essential changes people with unmet need versus met need say would cause a major improvement in their quality of life? Do these changes differ between those who receive no help at all versus those who receive insufficient help?

Persons with unmet need were more likely to say that specific changes in many areas of their lives would cause a major improvement in the quality of their lives than were persons whose needs were met (see Table 8 below).

We found significant differences between the unmet and met needs groups on all of the potential changes about which respondents were asked. Among those whose needs were not met, the top five changes were:

- Getting someone known and trusted to help with daily activities (73%)
- Having more control over routine life decisions (73%)
- Having a way to pay for long-term services and equipment (71%)
- Having better medical insurance (70%)
- Being able to get to places safely (65%)

Table 8: Factors Affecting Quality of Life by Adequacy of Help Received

Would Cause Major Improvement in Quality of Life	Needs Met	Needs Unmet		
		All	No Help	Insuff. Help
Having more control over decisions about services and help needed	42%	73%*	61%	79%*
Having someone known and trusted to help with daily activities	37%	73%*	63%	78%
Having a way to pay for long-term care services and equipment	36%	71%*	63%	76%
Having better medical insurance	57%	70%*	55%	77%*
Being able to get to places safely	49%	65%*	55%	70%*
Receiving more understanding and support from family and friends	39%	59%*	57%	60%
Having home better adapted to needs	35%	55%*	46%	60%
Getting help with personal finances	30%	55%*	52%	56%
More accessible public transportation	32%	51%*	34%	60%*
Better access to public facilities	40%	50%*	38%	57%*
Better job opportunities	19%	39%*	40%	39%
Having more opportunities to be involved in community activities	23%	38%*	25%	45%*
Having more personal privacy	22%	29%*	26%	31%

*Significant at 5%.

Persons receiving insufficient help were significantly more likely to say changes were needed in a number of areas than were those receiving no help at all. These areas included better medical insurance, someone trusted to help with daily activities, and more control over decisions. In addition, they felt their quality of life would be substantially improved if their homes were better adapted to their needs and they were able to be more involved in their communities, through more accessible public transportation, better access to public facilities, and more opportunities to be involved in community activities.

5. Do preferences about who provides assistance and in what setting also vary among these groups?

Persons with unmet needs were significantly more likely than were those whose needs were met to prefer that assistance be provided at home by an agency rather than by family members and friends (Table 9). Nonetheless, a majority of the unmet needs group (53%) still preferred informal care to formal care. That was not the case among persons with unmet needs who received no help. Individuals in that group were significantly less likely to prefer that family and friends provide all of the care at home (37%), and more likely to prefer care provided at home by an agency (49%) or in an assisted living or other residential setting (13%).

Table 9: Preferences for Care Arrangements by Adequacy of Help Received

Preference for Care Arrangement	Needs Met	Needs Unmet		
		All	No Help	Insuff. Help
Family/friends provide all care at home	68%	53%*	37%	62%*
Care provided at home by an agency	23%	39%*	49%	34%*
Care provided in an assisted living facility or other residential setting	8%	7%	13%	3%*
Care provided in a nursing home	2%	1%	1%	1%

*Significant at 5% (two-sided).

There were no significant differences between the needs met, no help, and insufficient help groups in choice for assistance if 24-hour help were to be needed.

Logistic Models

6. What are the key predictors of having unmet needs versus having needs met?

In contrast to earlier sections, the data in this section are based on logistic regression models and yield different results. Logistic regression permits researchers to control for the effects of variables that are closely related, such as severity of disability and level of income. In this study, it permits us to identify which variables have an independent effect in predicting unmet needs, holding other variables constant.

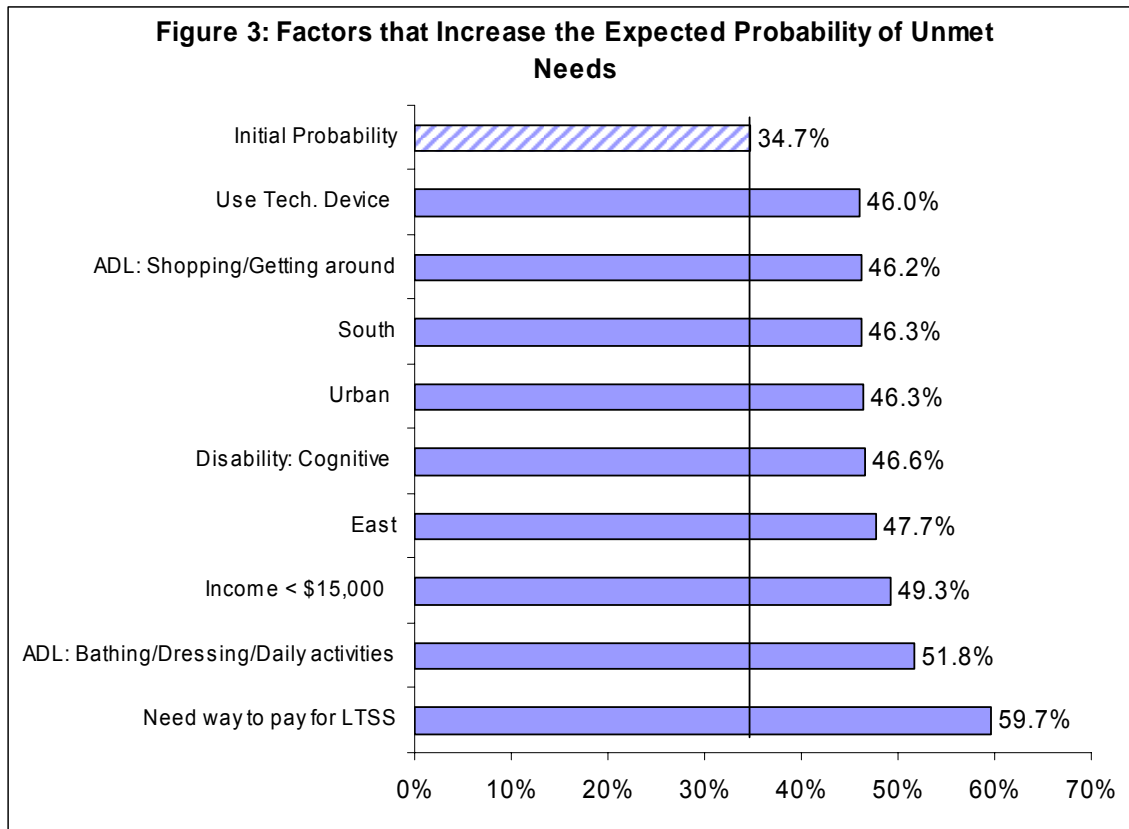
The detailed results of Model 1 are shown in the Appendix (see Tables A1 and A2). Note that the percentages reported in the regression model correspond to the unweighted counts and, hence, are not representative of the sample as a whole. They are portrayed here graphically only to show the relative strength of the various characteristics in predicting unmet need.

Expected Probabilities of Unmet Needs for PAS

Figures 3 and 4 show the expected probabilities of having unmet needs for PAS when all other modeled characteristics are controlled. Only those characteristics *that are statistically significant at 5% or less are shown* in these figures. For detailed results on odds ratios and their significance, see Appendix Table A1.

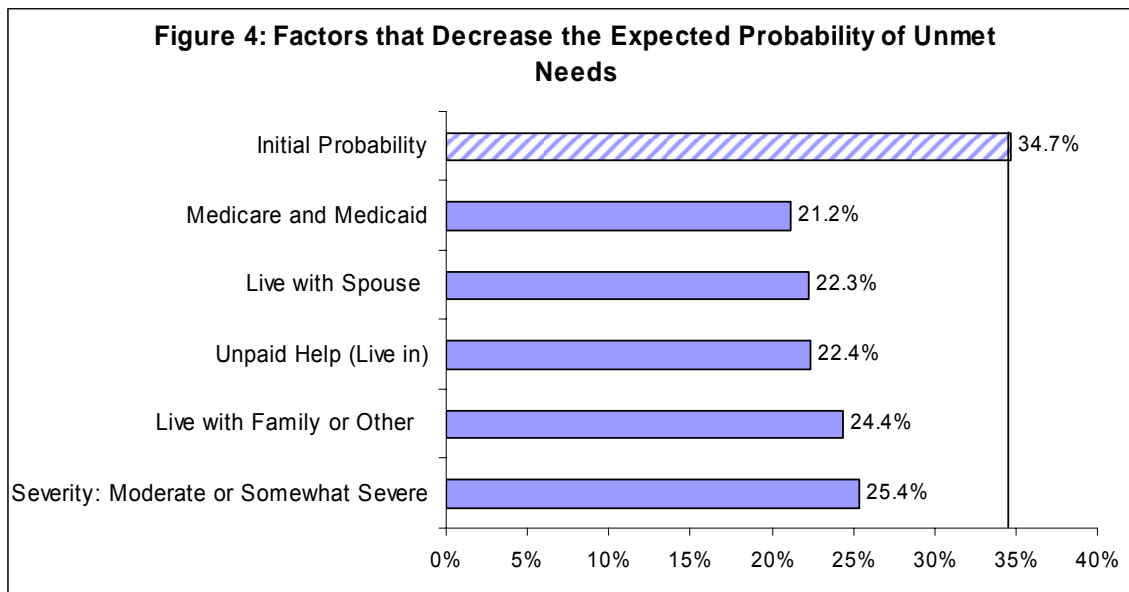
As shown in Figure 3 below, the initial probability⁴ of having unmet needs was 34.7% (unweighted), which is the same as the weighted prevalence of unmet need, or 29% (weighted), as shown in Figure 2.

Figure 3 shows the factors that *increase* the probability of having unmet needs in ascending order. For example, needing a way to pay for long-term services and supports (LTSS) increases the expected probability the most, to 59.7%, from the initial level of 34.7%. Similarly, difficulty with bathing or dressing increases the expected probability to 51.8%, and having an annual income of less than \$15,000, to 49.3%.



Some factors, however, *decrease* the probability of having unmet needs. Figure 4 shows these factors in descending order of probability, that is, the most significant factor in decreasing the probability of having unmet needs was being dually eligible for both Medicare and Medicaid, followed by living with a spouse.

⁴ The initial probability is the same as the prevalence of unmet need, without controlling for any of the socioeconomic characteristics or attributes that affect the probability of having unmet needs.



Below we report findings grouped by the broad categories of independent variables affecting unmet need for PAS identified on pages 6 and 7.

Disability characteristics, related to the need for PAS:

- **Severity of disability**: Persons who report less severe disabilities are much less likely to report having unmet needs, or, expressed another way, persons with more severe disabilities are much more likely to have unmet needs. The probability of having unmet needs declined from the 34.7% baseline to 25.4% for those reporting their condition was “moderately or somewhat” severe. Too few persons said their disability was only slightly severe to identify any significant effect.
- **Type of disability**: Limitations in bathing and dressing, as well as in shopping and getting around, increased the probability of unmet needs. Having a cognitive or emotional disability also was highly significant; many of those with a cognitive disability also had a physical disability (see Table 3 above). Having a sensory disability, however, did not increase the probability of unmet needs.
- **Age of onset of disability**: The age of onset of disability was not significant.

Predisposing characteristics, which reflect sociodemographic factors:

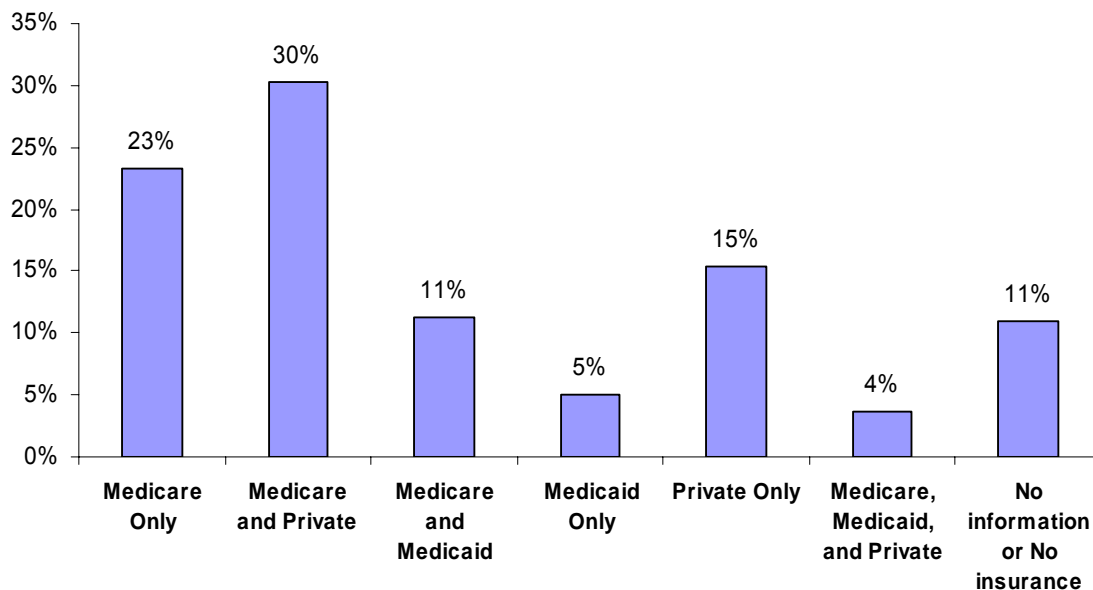
In contrast to earlier descriptive analyses of the data, age, race, and being nonwhite or of Hispanic origin did not have a significant effect in predicting whether needs were met or unmet after controlling for other variables.

Enabling characteristics, which reflect resources and access to assistance:

Almost all of the enabling characteristics examined had a significant independent effect on the likelihood of unmet need.

- **Medical insurance:** The probability of unmet needs varied with respondents' type of medical insurance. Although we examined six categories of insurance, only the combination of Medicare and Medicaid reached significance. Persons who were covered under *both* Medicare and Medicaid, a group referred to as the dually eligible, had a significantly lower probability of having unmet needs than did persons with other types of insurance or no insurance at all. Individuals eligible for both Medicare and Medicaid are much more likely to have coverage for both acute and long-term care. As shown in Figure 5, only a relatively small proportion of persons in this sample (11%) were eligible for both Medicare and Medicaid.

Figure 5: Proportion of Persons with Disabilities by Type of Medical Insurance (n = 865)



- **Use of assistive devices:** The use of assistive devices and technologies, such as wheelchairs, increased the probability of having unmet needs.
- **Living arrangements:** Rather than marital status, we included living arrangements in the model.⁵ Persons who live alone are more likely to have unmet needs than are those who live with spouse, family, friends, or others.

⁵ In a separate regression, not reported here, marital status variables were found to be less significant than living arrangement variables.

- Unpaid help (living in same household): Having unpaid help with daily activities from someone living in the same household, compared to unpaid help from someone not living in the same household, was highly significant in reducing the probability of unmet needs.
- Region of residence: Persons living in the East and the South had a significantly higher probability of having unmet needs than did those living in the Midwest. In addition, those who lived in urban areas rather than rural areas were more likely to have unmet needs.
- Income: Having income of less than \$15,000 per year was highly significant in increasing the probability of having unmet need, relative to persons with incomes of more than \$35,000 per year.
- Needing a way to pay for LTSS: The survey asked a series of hypothetical questions about what would cause a major, minor, or no improvement in respondents' quality of life. One item in this series, "having a way to pay for long-term care services and equipment," was included in the regression model because of its close relationship to respondents' financial resources. Because this variable also imbeds need for services with the ability to pay for them, one would expect that it would be more likely to have a major impact on the lives of those with unmet need. This variable had the strongest independent effect of any variable in the analysis. The probability of having unmet needs increased to 53.7% among persons who report that being able to pay for long-term care services and supports would cause a major improvement in their life. Hence, it was the primary predictor of having unmet needs for PAS.⁶

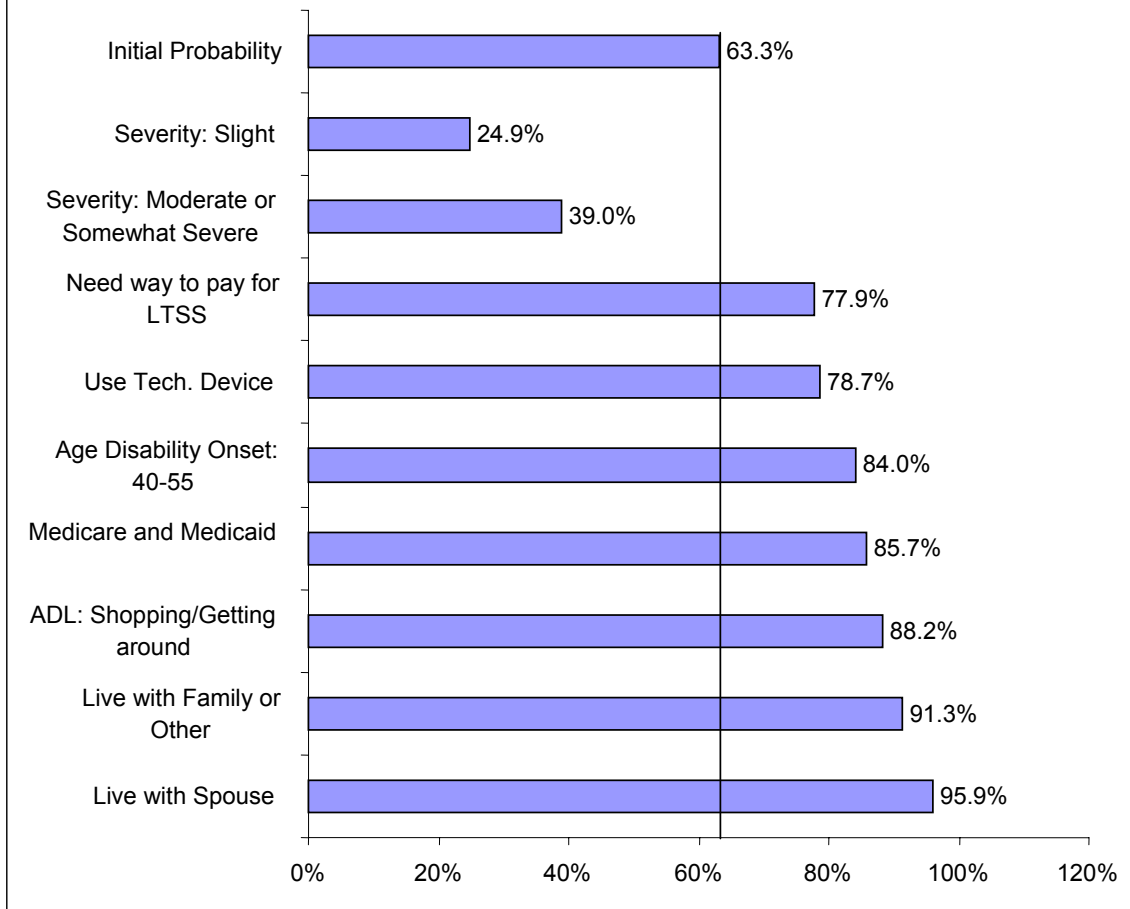
7. Among persons with unmet need, what are the key predictors of having some (insufficient) help versus no help at all?

Among those who had unmet needs, some received no help and some received insufficient help. The second model shows characteristics that increase the probability of receiving insufficient help versus no help at all, when all other modeled characteristics are controlled (see Figure 6). Table A2 in the Appendix shows all of the results of the logistic regression from which this figure is derived. Because of the reduced sample size for this analysis (n = 300, compared with n = 865 for the regression of unmet need), a stronger effect was required to show statistical significance. About 63.3% of older persons with disabilities among those who have unmet needs received insufficient help, and 37% received no help.

Only two factors reduced the expected probability of receiving insufficient help rather than no help—"slightly" or "moderately/somewhat" severe disability, compared to "very severe" disability. As shown in Figure 6, many factors increased the expected probability of receiving some, but insufficient, help rather than no help at all. The most powerful variable was living with a spouse, followed by living with another family member.

⁶ The fact that 36% of those whose needs *are* met said that "having a way to pay for long-term services and equipment" would cause a major improvement in their lives suggests this variable has a strong effect independent of the need for personal assistance services and of income, an effect that is even stronger (at 71%) for those whose needs for these services are unmet.

Figure 6: Factors that Increase or Decrease the Expected Probabilities of Receiving Insufficient Help Rather than No Help



Disability characteristics:

- Severity of disability: A “moderate to very severe disability,” in contrast to a severe disability, reduces the probability of insufficient help compared to receiving no help.
- Type of disability and age of onset: While the type of disability—physical or cognitive/emotional—was significant in predicting whether needs were unmet, it did not have a significant effect on the likelihood of receiving some help compared to receiving no help. The age of onset of disability was marginally significant at 10% or less in predicting whether help was insufficient only if it occurred in age 40–55, but not in later years.
- Difficulty in performing daily activities: Those who have difficulty shopping or getting around were significantly more likely to have insufficient help.

Predisposing characteristics:

Age, race, and ethnicity were not significant in predicting whether persons received insufficient help compared to receiving no help once all other variables in the model were controlled. Education was also insignificant.

Enabling characteristics:

- Medical insurance: No medical insurance category was statistically significant, although having coverage for both Medicare and Medicaid was marginally significant at 10% or less.
- Assistive devices: Those who used an assistive device were significantly more likely to have insufficient help than no help at all.
- Living arrangements: It is not surprising that this variable was the most powerful predictor of receiving some help among all of the variables examined. Compared to persons who received no help, the probability of receiving some help—although it was insufficient—was 95.9% for persons who lived with a spouse and 91.3% for those living with other family members or others.
- Regional differences: Regional differences were not significant.
- Income: Although income was significant in predicting whether needs were met or unmet, the income variable was not statistically significant in distinguishing between persons with unmet who received insufficient help and those who received none at all.
- Needing a way to pay for LTSS: As it was in predicting whether needs were met or unmet, this variable was also significant in predicting whether persons received insufficient help rather than none at all.

E. Putting It All Together

Behind all of the numbers presented above are real people, many of whom are confronting serious challenges in their daily lives. In an effort to paint a picture of who they are, here are brief “profiles” of the characteristics of persons who need more help with essential daily activities, based on findings from both the univariate and multivariate analyses.

Profile of Total Population with Unmet Needs: Persons with unmet needs for help with daily activities have multiple vulnerabilities. Compared with those whose needs are met, they generally have more severe disabilities, which are often cognitive. They have lower incomes, despite having completed some college, but relatively few (only 11%) are dually eligible, that is, eligible for coverage from both Medicaid and Medicare. They are more likely to need a way to pay for LTSS. Many live alone and have difficulty getting out, for example, to go to the doctor or to shop. They are more likely to live in the South or the East than the Midwest. Possibly because of the severity of their disability, they are more likely to use special equipment, such as a wheelchair.

It is not surprising that such difficult life circumstances can lead to a host of problems, including postponing necessary health care due to cost; loss of control over many aspects of their lives, such as when and to where they are able to go out and how they spend their money; and being prevented from reaching their full abilities.

These individuals told us that better health insurance and access to long-term services and supports, as well as more opportunities for involvement in their communities, would cause a major improvement in the quality of their lives. The top changes they identified involve more help with daily activities—being able to pay for such assistance, having more control over who provides it, and having a known and trusted person available to help.

There are two distinct groups of persons with disabilities with unmet needs—persons who receive some but insufficient help and those who receive no help at all. They differ in the severity of their disability, living arrangements, region of residence, and preferences for assistance.

Profile of Persons with Unmet Need Who Receive Insufficient Help

Persons who receive insufficient assistance are much more likely to live with a spouse or other family members than are those who receive no help. Their disabilities generally are very severe. Several distinguishing characteristics of this group may lead to social isolation, for example, they have difficulty going out alone and are unable to drive. Possibly because of their need to rely on caregivers for help with daily activities, they frequently report having lost some control over routine life decisions, such as when they go out.

Given their life situations, it is not surprising that this group identified many changes that would cause a major improvement in their quality of life. Compared with persons with unmet needs receiving no help, those in this group were more likely to identify the following changes as very important in improving their well-being:

- having a way to pay for LTSS;
- having someone known and trusted to help with daily activities;
- having more control over help and services;
- having better medical insurance;
- being more involved in their communities; and
- having more accessible public transportation.

These respondents' desire to be able to pay for LTSS and equipment, and to have someone known and trusted to help with daily activities suggests that they need more help than their family caregivers are able to provide and/or that they would like to be less reliant on their family members for help. Three-quarters of persons in this group received help from a family member, typically a spouse or child. The other changes they identified are consistent with their apparent desire for more choice and control over their lives and more independence in their daily activities.

Profile of Persons with Unmet Need with No Help

The characteristics and preferences of those with unmet needs who receive no help at all portray a much a different picture. These individuals are likely to live alone and are disproportionately unmarried or divorced. Their disabilities are less severe than the disabilities of those with some help, but they are more likely to say that their disabilities have prevented them from reaching their full abilities as a person. Their preferences for assistance vary substantially from those of persons living with informal caregivers. Less than a majority of this group (37%) prefers family care. They are more likely to prefer that assistance be provided by a home care agency rather than by family or friends, possibly because they do not have potential informal caregivers available. Persons in this group also rate assisted living and other residential care more highly.

F. Comparison of Findings with Those of Other Studies

Prevalence of unmet need:

The prevalence of unmet need found in this study (29%) is slightly higher than that reported in studies based on NHIS data and its various supplements from the mid-1990s (LaPlante et al., 2004; Kennedy, 2001; Desai, Lentzner, and Weeks, 2001; Newcomer et al., 2005). For example, LaPlante et al. (2004) found a prevalence of unmet need among adults 18 or older with a limitation in any ADL or IADL of 21%. Kennedy (2001) found that roughly 10–20% of persons who needed any assistance with an IADL or ADL said help with that activity was unavailable or inadequate. Among persons age 70 and older needing help to perform one or more ADLs, 21% reported receiving no help or inadequate help (Desai, Lentzner, and Weeks, 2001).

In a community survey of adults with disabilities in Springfield, Massachusetts, conducted in 1993–1994, the prevalence of unmet need for help with ADLs ranged from 4% (eating) to 23% (transferring); for IADLs, it ranged from 16% (cooking) to 26% (shopping) to 35% (heavy housekeeping) (Allen and Mor, 1997). More recently, Komisar, Feder, and Kasper (2005) reported that 58% of persons eligible for both Medicare and Medicaid had unmet need for help with activities of daily living.

Many methodological differences could account for the variation in results, including whether the need for help includes measures of both ADLs and IADLs. The measure of unmet need used in this study combines examples of both ADLs (bathing, dressing) and IADLs (cooking, shopping). Even in studies that rely solely on ADL measures, estimates of unmet need may differ due to differences in study methods and definitions of unmet need (Newcomer et al., 2005).⁷ Other possible reasons for discrepancies are the type of prevalence measured. We used a measure of “point prevalence”—do you currently need more help than you receive now—rather

⁷ In this sample, a substantial share (23%) indicated that they received no help and needed no help (see Figure 1 above). Because of the way our questionnaire was designed, and to be consistent with earlier analyses of these data reported in **Beyond 50.03**, we included this group in our “met needs” group. By some definitions of unmet need, they should not have been included in the sample because they did not need help in the first place. If we had excluded this group from our “met needs” group, the overall prevalence of unmet need would have been considerably higher—that is., about 55% of those in the total sample would have had unmet needs for PAS and 45% would have their needs met. Thus, the 29% prevalence figure should be considered a conservative, “lower bound” estimate.

than a longer time frame (such as “have you needed more help within the last three months”), which is used in some studies (Allen and Mor, 1997).

Correlates of unmet need:

This study applies a model of health services use developed and elaborated by Andersen (1995) in examining individual and environmental attributes for association with unmet need. Especially in research related to public policy, it is important to distinguish among those factors related to unmet need that are subject to change. “Predisposing characteristics,” such as age and gender, are clearly not subject to change; disability characteristics can be mutable, but are often hard to change and depend greatly on individual characteristics. In contrast, “enabling characteristics” are often the focus of policies aimed at change, through social, environmental, and political intervention, although such changes also do not come easily. This section discusses the results of the current study with respect to these characteristics in the context of related literature on unmet need.

Predisposing Characteristics

Age: The age of respondents was not a significant predictor of unmet needs in our regression analysis, similar to the findings of other studies (Kennedy, 2001; LaPlante et al., 2004, Allen and Mor, 1997); Newcomer et al, 2005). In contrast, Lima and Allen (2001) found that younger persons (age 18–44) were significantly more likely to have inadequate help than were persons age 65 or older.

Gender: Earlier research on gender differences in unmet need reports is inconclusive. Our finding of no differences by gender are inconsistent with those of Lima and Allen (2001), who found that women with disabilities were more likely to receive inadequate care than were similar men, after controlling for other factors. Kennedy (2001) initially found that women were slightly more likely than men to report unmet or undermet needs for help with ADLs, but the difference was not significant when other factors were controlled. Similarly, Allen and Mor (1997) and Newcomer et al. (2005) did not find significant gender differences.

Ethnicity: Unlike Lima and Allen (2001), we did not find that minorities are disproportionately represented among persons with unmet needs for PAS. However, our finding that race is not independently associated with unmet need is consonant with that of some other studies (Allen and Mor, 1997; Desai, Lentzner, and Weeks, 2001).

Enabling Characteristics

Income: As in this study, various measures of low income have been shown to be significant variables in predicting unmet needs for PAS in several other studies as well (Allen and Mor, 1997; Desai, Lentzner, and Weeks, 2001). Most recently, Komisar, Feder, and Kasper (2005) found that older adults in lower-income households may not be able to purchase additional formal help when informal help is insufficient.

Region: Little earlier research has identified regional variations in unmet need for PAS, and our findings of higher levels of unmet need among persons living in the East and the South, rather than the Midwest, and in urban rather than rural areas, are hard to interpret. Possible contributing factors include variations in (1) living arrangements and marital status that might affect the availability of informal support; (2) state policies for providing paid HCBS for persons with disabilities; and (3) cultural factors affecting perception of unmet needs.

Health insurance: In this study, persons with coverage for both Medicare and Medicaid—the dually eligible—had lower levels of unmet need than did those in other insurance categories or those with no insurance at all. Newcomer et al. (2005) found that Medicaid eligibility was associated with less unmet need for help with ADLs. Komisar, Feder, and Kasper (2005) recently found that, even among the dually eligible, there are widespread gaps, with more than half (58%) of respondents with ADL limitations reporting unmet needs.

Living alone: This study only partially supports the finding in several studies (LaPlante et al., 2002; Kennedy, 2001; Desai, Lentzner, and Weeks, 2001) that persons living alone were much more likely to report unmet need or undermet need. We found that those with unmet need who received no help were far more likely to live alone ($p < .001$). However, that was not the case for the group receiving insufficient assistance, whose rates of living alone were similar to those of persons who reported no unmet needs for PAS.

Use of assistive technology: We found persons with disabilities who used assistive technologies to be more likely to have unmet needs for PAS, and among those with unmet needs, persons who used assistive technology were more likely to receive insufficient help than were those with no help. These results remained after controlling for severity of disability. Agree and Freedman (2003) found that fewer assistive technology users report a desire for hands-on personal care, and AT users equally or more often report that tasks are tiring, time consuming, or painful as do those using personal care.

G. Conclusions and Policy Implications

This study is unique in measuring and analyzing not only factors associated with unmet need but also individuals' preferences for services and the specific changes persons with unmet need say would cause a major improvement in the quality of their lives. Its results help to inform policy decisions about ways to reduce unmet needs for help with daily activities among different groups of persons with disabilities. In particular, they have implications for policies to expand publicly funded HCBS, provide greater support for unpaid informal caregivers, and provide better financial options to pay for LTSS. In addition, our findings of marked differences between the characteristics of persons with unmet need who have no assistance versus those with insufficient assistance extend the findings of earlier research (Lima and Allen, 2001).

Identifying at-risk older persons in the community

The prevalence of unmet need found in this study (almost 30%) indicates that greater efforts are needed to identify at-risk older persons with disabilities in the community and attempt to link them to available services.

The relatively high degree of consistency between our findings based on two simple questions⁸ and those from studies of unmet need based on multi-item measures of functional status is encouraging. A single question of general self-reported health status has been shown to predict mortality and health care utilization as accurately as have longer instruments (DeSalvo et al, 2005). Hence it is plausible that valid short instruments based on respondents' self-report of the severity of their disability and whether they have unmet needs for help with daily living activities could be developed, and could prove to be an efficient screening tool for targeting resource allocation and service delivery to those in need of HCBS.

Expanding HCBS

Unmet need for personal assistance among midlife and older persons may be even more pronounced today than it was in 2002, when this survey was conducted. During the fiscal crises in the states in 2003 and 2004, a number of states limited the availability of formal (paid) assistance, and many have remained reluctant to take on new obligations even though their fiscal situations have improved. Even in the late 1990s, before the state fiscal crises, states offering HCBS waiver services reported inadequate waiver slots and waiting lists for services (Harrington et al., 2002). In addition, the regional variations in unmet need found in this study suggest the need for greater access to HCBS in some areas. Other studies have shown considerable variation at the state level in unmet need among persons with disabilities related to the proportion receiving paid care (Komisar, Feder, and Kasper, 2005). Further, empirical data have demonstrated the persistence of wide interstate variations in the number of HCBS participants and expenditures (Eiken, Burwell, and Selig, 2006; Kitchener, Ng, and Harrington, 2001).

The need for *consumer-directed service models*, which give consumers choice about how, when, and from whom they receive services, is buttressed by these findings. Persons with unmet needs were significantly more likely than those without unmet needs to have lost control over many aspects of their daily lives, including who provides services to them and how they spend their own money. The need to "have more control over routine life decisions" was one of the most essential changes they said would cause a major improvement in their lives. Consumer-directed models are gradually expanding in Medicaid and some state-funded HCBS programs. In addition, through the National Family Caregiver Support Program funded under the Older Americans Act, states can make direct payments to family caregivers or provide a global budget for goods and services to help meet the needs of both family caregivers and care recipients (Feinberg, Wolkwitz, and Goldstein, 2006).

Lack of affordability is one of the primary reasons respondents with unmet need said they did not receive the assistance they need. While this is not a surprising finding, it contributes to the very sparse literature with *explicit* data on why needs for help with daily activities are unmet (Williams, Lyons, and Rowland, 1997).

⁸ These questions were: (1) How many persons regularly help you with everyday activities like bathing, dressing, cooking, and shopping because of your disability or health condition? and (2) Do you need more help than you receive now?

Needing a way to pay for LTSS was the most powerful predictor of unmet need in the regression analysis. However, we cannot determine from the data which is cause and which is effect: some people may only indicate that they need a way to pay for PAS if they have unmet need for PAS (whereas, without significant need for LTSS, they would not indicate a need even though they might not be able to afford to pay for such services), or they may have unmet needs for PAS because they do not have a way to pay for these services. Either way, among those with unmet need, 71% said that having a way to pay for long-term care services and equipment would cause a major improvement in their quality of life, compared to 36% of those whose needs were met who said the same thing. Persons in the latter group, who say their needs for PAS are currently being met, may wish they had a way to compensate those persons who are currently providing unpaid care, that they had funds to purchase formal services instead of relying on unpaid caregivers, or that they could use the money for other purposes, such as paying for a grandchild's education.

Implications for Persons with Unmet Needs with No Help

The findings in this study underscore the importance of differentiating between two different populations who have unmet needs. The “no help” group, most of whom live alone and have less severe disabilities, may be at the beginning of a trajectory of functional decline that could result in loss of independence if their needs remain unmet. In addition to the normative value of providing services to vulnerable individuals who may be struggling to maintain independent living in their communities, providing PAS to at-risk persons may help some of these individuals recover independent functioning. Recent research now shows that newly disabled persons recover independent ADL function at rates far exceeding what has been reported previously. Recovery, however, is often transient and disability is recurrent, suggesting that interventions to help maintain independence are needed (Hardy and Gill, 2004). The conditions of older persons who experience disability can worsen, stabilize, or improve, with accompanying changes in their need for care (Freedman et al., 2004).

In providing services, it is important to remember that almost one half (49%) of those currently receiving no help say they prefer agency-provided services to informal care provided only by family or friends, possibly because they have few informal support resources available. This finding underscores the importance of choice in service providers.

Implications for Persons with Unmet Needs with Insufficient Help

Targeting PAS only to individuals with unmet needs who receive no assistance would be a mistake. The group reporting *insufficient help* has multiple vulnerabilities, more severe disabilities, and may be at more immediate risk of institutionalization than is the group receiving no help. The great majority of these individuals receive help from family caregivers, predominantly spouses or children, mostly in the same households.

While we did not include measures of depression in our study, the high levels of loss of control over basic daily decisions and life dissatisfaction in this subgroup may be correlated with negative mental health outcomes. Other research indicates that the adequacy of instrumental informal support, as well as perceived reciprocity and respect afforded by one's primary

caregiver, are associated with the likelihood of depression among older women with disabilities (Wolff and Agree, 2004).

Another concern is the potential for social isolation among members of this group. The overwhelming majority does not drive at all, and most report having lost control over when and where they go out. Other findings in this study demonstrate the need to expand mobility options for these individuals, who may be homebound much of the time, including transportation to go to the doctor or to go shopping. Services such as adult day services and friendly visiting volunteer services could also help promote social engagement.

Although this group prefers assistance from family members/friends, its members also report needing more help than they receive now. This finding suggests the need for a *mix of both formal and informal services* for those with severe disabilities whose informal caregivers are unable or unwilling to provide more help.

Need for Better Family Support Policies

In addition to the need to expand HCBS, the results suggest the need to adopt a family-centered approach to service provision, which would include assessment of the needs of care recipients and caregivers. For example, the care recipients in this study often needed help purchasing additional assistance and locating reliable and trusted individuals to supplement their informal support.

While this study did not address unmet need from the perspective of caregivers or assess the level of caregiver burden, findings from a recent national survey of caregivers age 18 and older (NAC and AARP, 2005) are helpful in interpreting our results. The NAC/AARP study found that those caregivers who experienced the greatest level of burden disproportionately cared for persons 50 and older with very severe disabilities (three or more ADLs) living in the same household—similar to the profile of the unmet needs group receiving some help in the current study. The two greatest predictors of both physical strain and emotional stress were the caregivers' poorer health and whether they felt they had a choice in taking on caregiving responsibilities. Hence, the degree of choice and control over basic decisions are important factors in the well-being of both caregivers and care recipients.

Addressing Financial and Coverage Barriers

This study did not capture data on the number of hours of additional help needed or on the specific type of help needed, for example, help with eating compared with help with dressing. However, analysis of detailed data on volume and type of care from the NHIS indicates that about 17 hours of care per week are needed to meet the shortfall in help among persons with unmet needs for assistance with two or more activities of daily living (LaPlante et al., 2004).

The findings underscore the need for states to accelerate their efforts to rebalance their Medicaid long-term care programs toward greater provision of HCBS services, especially in states that remain highly biased toward institutional services. The need to protect and strengthen programs for the dually eligible is another clear policy implication of the study. Persons with coverage

from both Medicare and Medicaid—the dually eligible—had lower levels of unmet need than did those in other insurance categories or those with no insurance at all. This finding points to the critical importance that these programs have for eligible populations. Even among the dually eligible, however, there are widespread gaps and considerable unmet need (Komisar, Feder, and Kasper, 2005).

Aside from Medicaid and some state-funded programs, there are few sources of financial or other assistance for persons who need HCBS. (Medicare pays for a limited amount of medically oriented home health care.) Hence, better options to pay for LTSS are a pressing need.

The results of this study raise many concerns about the ability of persons 50 and older with disabilities to pay for necessary long term services and supports and to find trusted and reliable formal caregivers. In addition, in a society that encourages sometimes overwhelming choice in goods and services by persons who can afford them, it is unsettling to find how many persons with disabilities have lost a great deal of control over the most basic daily decisions and activities.

APPENDIX: Detailed Methodology

Sampling Methodology: A total of 9,461 working household numbers were contacted. Contact was successful in 4,047 (43%) of these households, and a total of 3,048 households (75%) agreed to participate. Among the cooperating households, 1,946 were disqualified (65%) because they did not meet the study’s disability criteria (1,222) or age criteria (620), or because of a language barrier (104). This process yielded a final sample size of 1,102, of which 862 were used in this analysis, because they indicated they had difficulty performing at least one of these three daily activities:

- dressing, bathing, or getting around inside their home;
- going out alone, for instance, to shop or visit a doctor’s office; and
- working at a job or business.

Nonresponses were minimized by making up to six attempts to contact potential respondents at different times. Harris Interactive created weights for the data based on gender, age, race/ethnicity, education, income, region, type of disability, and number of phone lines in the household, so the weighted sample would be representative of the total population of persons age 50 and older with disabilities. This method also reduces demographic distortions due to nonresponse bias.

Fourteen percent of all interviews were conducted with a proxy on behalf of the adult in the household who had a disability; 23% of the interviews with persons age 75 and older were with proxies. Proxy interviews were conducted most commonly with a spouse or partner (73%), child (10%), or parent (9%).

Logistic Regression Models

Since the dependent variable is dichotomous, taking only the values 0 and 1 (or no and yes), a logistic regression model is postulated, defined as follows:

$$P_i(Y = 1) = \frac{1}{1 + e^{\beta_0 + \sum \beta_i X_i}}$$

By some algebraic manipulation, it can be expressed as

$$\text{Ln} \frac{P_i(Y = 1)}{1 - [P_i(Y = 1)]} = \beta_0 + \sum \beta_i X_i$$

Here, the left-hand side is the logit or log of the *odds ratio* (the probability of the *event* occurring divided by the probability of the *event* not occurring); the X_i 's are independent variables denoting various characteristics; the β 's are logit regression coefficients. The odds ratio is regressed over the independent variables, which we grouped in three broad categories related to the use of PAS: (1) disability characteristics, related to the need for PAS; (2) predisposing characteristics; and (3) enabling characteristics. These categories have been shown in earlier research to be predictive of health and LTC utilization (Andersen, 1995; Borrayo et al., 2002).

Table A1 presents the logistic regression of “Unmet Needs” ($Y = 1$) vs. “Needs Met” ($Y = 0$). We have used the unweighted sample for logistic regressions. The significant coefficients are marked with asterisks. If one had no knowledge of the model, and if all attributes and sociodemographic characteristics are variable, one would expect the probability of unmet needs to be 34.7%. This is defined as initial probability.

After having estimated the model, one can calculate the odds of having unmet needs if someone, for example, had a cognitive disability, assuming all other variables are constant. From odds, one can also calculate the expected probability⁹ of having unmet needs for this person with a cognitive disability. In this case, the odds ratio for cognitive disability is 1.6, which implies that someone with a cognitive disability is 1.6 times as likely to have unmet needs as is one without this disability. This increases the initial probability from 34.7% to 46.6%. Similarly, someone with an income of less than \$15,000 is 1.8 times as likely to have unmet needs as one whose income is greater than \$35,000, which increases the probability of having unmet needs to 49.3% (see Table A1).

Table A2 presents the second model of logistic regressions of getting “insufficient help” ($Y = 1$) vs. “no help” ($Y = 0$) for persons with unmet needs. The initial probability for the base case person receiving some help is 63.3%. This probability, for example, increases to 88.2% for someone who has a difficulty in shopping and getting around.

⁹ Expected probability (X_i) = [Initial Probability*(Exp(β_i)) / (1+ Initial Probability*(Exp(β_i))].

Table A1: Logistic Regressions of Needs Unmet vs. Needs Met

Variables	Coefficient	S.E.	Sig.	Odds Ratio Exp(β)	Expected Probability of Unmet Needs (%)
Initial Probability of Unmet Needs					34.7%
Initial Odds (Unweighted Sample)				0.531	
<u>Disability Characteristics</u>					
Severity: Slight (Base: Very severe)	-0.328	0.526	0.532	0.720	27.7%
Severity: Moderate or Somewhat Severe	-0.443	0.184	0.016 **	0.642	25.4%
Disability: Cognitive	0.497	0.172	0.004 **	1.644	46.6%
ADL: Shopping/Getting around	0.480	0.188	0.011 **	1.616	46.2%
ADL: Bathing/Dressing/Daily activities	0.704	0.175	0.000 **	2.021	51.8%
Age Disability Onset: 40-55 (Base: < 40)	-0.114	0.305	0.710	0.893	32.2%
Age Disability Onset: 56-64	0.031	0.220	0.887	1.032	35.4%
Age Disability Onset: 65+	0.467	0.363	0.199	1.595	45.9%
<u>Enabling Characteristics</u>					
Medicare Only (Base: No Insurance)	-0.091	0.280	0.746	0.913	32.7%
Medicaid Only	-0.144	0.427	0.736	0.866	31.5%
Private Only	-0.239	0.303	0.430	0.787	29.5%
Medicare and Medicaid	-0.681	0.340	0.045 **	0.506	21.2%
Medicare and Private	0.157	0.274	0.566	1.170	38.3%
Use Computers	0.351	0.235	0.135	1.421	43.0%
Use Tech. Device (Base: Use one)	0.473	0.175	0.007 **	1.605	46.0%
Live with Spouse (Base: Live Alone)	-0.615	0.259	0.018 **	0.541	22.3%
Live with Family or Other (Base: Live alone)	-0.497	0.275	0.071 **	0.608	24.4%
East (Base: Midwest)	0.542	0.279	0.052 **	1.719	47.7%
South	0.484	0.243	0.047 **	1.623	46.3%
West	0.244	0.280	0.385	1.276	40.4%
Urban (Base: Rural)	0.486	0.231	0.035 **	1.626	46.3%
Suburban	0.085	0.202	0.673	1.089	36.6%
Income < \$15,000 (Base: > \$35,000)	0.605	0.233	0.009 **	1.831	49.3%
Income \$15,000 to \$35,000	0.262	0.217	0.227	1.299	40.8%
Unpaid Help (Live in)	-0.610	0.211	0.004 **	0.543	22.4%
Need way to pay for LTSS	1.025	0.176	0.000 **	2.786	59.7%
<u>Predisposing Characteristics</u>					
Age: 65 to 74 (Base: 50-64)	-0.359	0.250	0.151	0.698	27.0%
Age: 75-plus	-0.497	0.397	0.210	0.608	24.4%
Female (Base: Male)	0.193	0.178	0.279	1.213	39.2%
Nonwhite (Base: White)	-0.153	0.264	0.562	0.858	31.3%
Hispanic Origin (Base: Else)	0.424	0.431	0.326	1.528	44.8%
Less than High School (Base: High School)	-0.134	0.309	0.664	0.874	31.7%
Some College	0.152	0.305	0.620	1.164	38.2%
College	0.110	0.332	0.741	1.116	37.2%
Constant	-2.384	0.571	0.000 **	0.092	
Number of Observations	731				
Log Likelihood Ratio	877.320				
Nagelkerke R-square	0.290				
Chi-square	194.587				
				Percent Correct Prediction	
				Overall =	73.1%
				** Significant at 5% or less	
				* Significant at 10%	

Table A2: Logistic Regressions of No Help Vs. Insufficient Help

Variables	Coefficient	S.E.	Sig.	Odds Ratio Exp(β)	Expected Probability of Unmet Needs (%)
Initial Probability of Insufficient Help	63.3%				
Initial Odds (Unweighted Sample)	1.725				
<u>Disability Characteristics</u>					
Severirty: Slight (Base: Very severe)	-1.648	1.039	0.113	0.192	24.9%
Severirty: Moderate or Somewhat Severe	-0.994	0.376	0.008 **	0.370	39.0%
Disability: Cognitive	0.006	0.343	0.987	1.006	63.4%
ADL: Shopping/Getting around	1.467	0.401	0.000 **	4.335	88.2%
ADL: Bathing/Dressing/Daily activities	0.181	0.354	0.608	1.199	67.4%
Age Disability Onset: 40-55 (Base: < 40)	1.114	0.680	0.101 *	3.047	84.0%
Age Disability Onset: 56-64	0.506	0.413	0.221	1.659	74.1%
Age Disability Onset: 65+	-0.202	0.819	0.805	0.817	58.5%
<u>Enabling Characteristics</u>					
Medicare Only (Base: No Insurance)	-0.389	0.527	0.461	0.678	53.9%
Medicaid Only	-0.139	0.785	0.859	0.870	60.0%
Private Only	-0.277	0.675	0.682	0.758	56.7%
Medicare and Medicaid	1.249	0.683	0.067 *	3.487	85.7%
Medicare and Private	-0.520	0.540	0.335	0.595	50.6%
Use Computers	-0.496	0.554	0.371	0.609	51.2%
Use Tech. Device (Base: Use one)	0.761	0.361	0.035 **	2.141	78.7%
Live with Spouse (Base: Live Alone)	2.604	0.499	0.000 **	13.521	95.9%
Live with Family or Other (Base: Live alone)	1.802	0.456	0.000 **	6.064	91.3%
East (Base: Midwest)	-0.913	0.610	0.135	0.401	40.9%
South	-0.738	0.554	0.182	0.478	45.2%
West	0.414	0.628	0.510	1.513	72.3%
Urban (Base: Rural)	0.690	0.470	0.142	1.995	77.5%
Suburban	0.177	0.425	0.677	1.193	67.3%
Income < \$15,000 (Base: > \$35,000)	-0.200	0.474	0.673	0.818	58.5%
Income \$15,000 to \$35,000	0.068	0.471	0.885	1.071	64.9%
Need way to pay for LTSS	0.714	0.386	0.064 **	2.042	77.9%
<u>Predisposing Characteristics</u>					
Age: 65 to 74 (Base: 50-64)	0.253	0.529	0.632	1.288	69.0%
Age: 75-plus	1.467	0.959	0.126	4.335	88.2%
Female (Base: Male)	0.286	0.354	0.419	1.331	69.7%
Nonwhite (Base: White)	-0.481	0.503	0.339	0.618	51.6%
Hispanic Origin (Base: Else)	0.501	0.835	0.549	1.650	74.0%
Less than High School (Base: High School)	0.314	0.669	0.639	1.369	70.3%
Some College	-0.021	0.631	0.973	0.979	62.8%
College	-0.343	0.688	0.618	0.710	55.0%
Constant	-2.147	1.178	0.068 *	0.117	

Number of Observations	300	Percent Correct Prediction
Log Likelihood Ratio	167.902	Overall = 80.8%
Nagelkerke R-square	0.558	** Significant at 5% or less
Chi-square	112.751	* Significant at 10%

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