ISSUE BRIEF
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Use of Paid and Unpaid Personal Help by Medicare Beneficiaries Needing Long-Term Services and Supports

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ABSTRACT

ISSUE: Older adults who reside in communities, as opposed to nursing homes or other residential institutions, are largely dependent on family and unpaid caregivers for assistance with daily activities, like preparing meals or laundry, and self-care tasks like bathing or dressing. For low-income older adults, assistance with such activities, also known as long-term services and supports (LTSS), can also come from Medicaid. These sources of support will be increasingly inadequate as the population ages.

GOALS: To examine the extent of paid and unpaid personal care assistance used by community-residing people who require LTSS; and to analyze how this differs by demographics and the economic status of Medicare beneficiaries.

METHODS: Descriptive analyses of the National Health and Aging Trends Study (NHATS), 2015.

FINDINGS AND CONCLUSIONS: Medicare beneficiaries needing LTSS rely predominantly on unpaid care. Hours of unpaid care are not substantially lower when paid care is also received. Findings suggest that public financing of LTSS would not replace but rather supplement the contribution of family and unpaid caregivers to support individuals living independently in the community.

KEY TAKEAWAYS

- **Long-term services and supports are not covered under Medicare, even though many beneficiaries need help with self-care tasks like bathing or dressing.**
- **The amount of unpaid care provided varies little between those who receive both paid and unpaid support and those who receive unpaid support only, suggesting that paid care does not replace unpaid care but supplements it.**
- **A public financing solution that supports individual and family caregivers would improve the supply and quality of long-term services and supports, enabling older adults to live safely in the community.**

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INTRODUCTION

Despite the increasing number of adults with functional disabilities and cognitive impairments, financing for long-term services and supports (LTSS) has made little policy progress in the past few decades.[1] One possible reason for the impasse is policymakers' concern about the cost of undertaking such an initiative. Currently, financing for LTSS is split between the federal and state governments through the Medicaid program, which accounts for two-thirds, and private sources, which pay the other one-third. Of the $211 billion spent on LTSS in 2011, $45.5 billion (22%) was paid out of pocket.[2] For low-income Medicare beneficiaries who meet income and asset eligibility, as well as the institutional level of need requirement, Medicaid covers some LTSS, although availability and accessibility vary greatly across states.[3] As estimated by the Congressional Budget Office (CBO), family caregivers contribute the most care, at an estimated economic value of $234 billion in 2011.[4] Many policymakers fear that providing public financial support for LTSS will replace the care that is currently being provided for free by family caregivers. This issue brief uses data from the National Health and Aging Trends Study (NHATS) from 2015 to examine use of paid and unpaid care among community-residing people who need LTSS.

AVAILABILITY OF HELP FOR OLDER MEDICARE BENEFICIARIES WHO NEED LONG-TERM SERVICES AND SUPPORTS

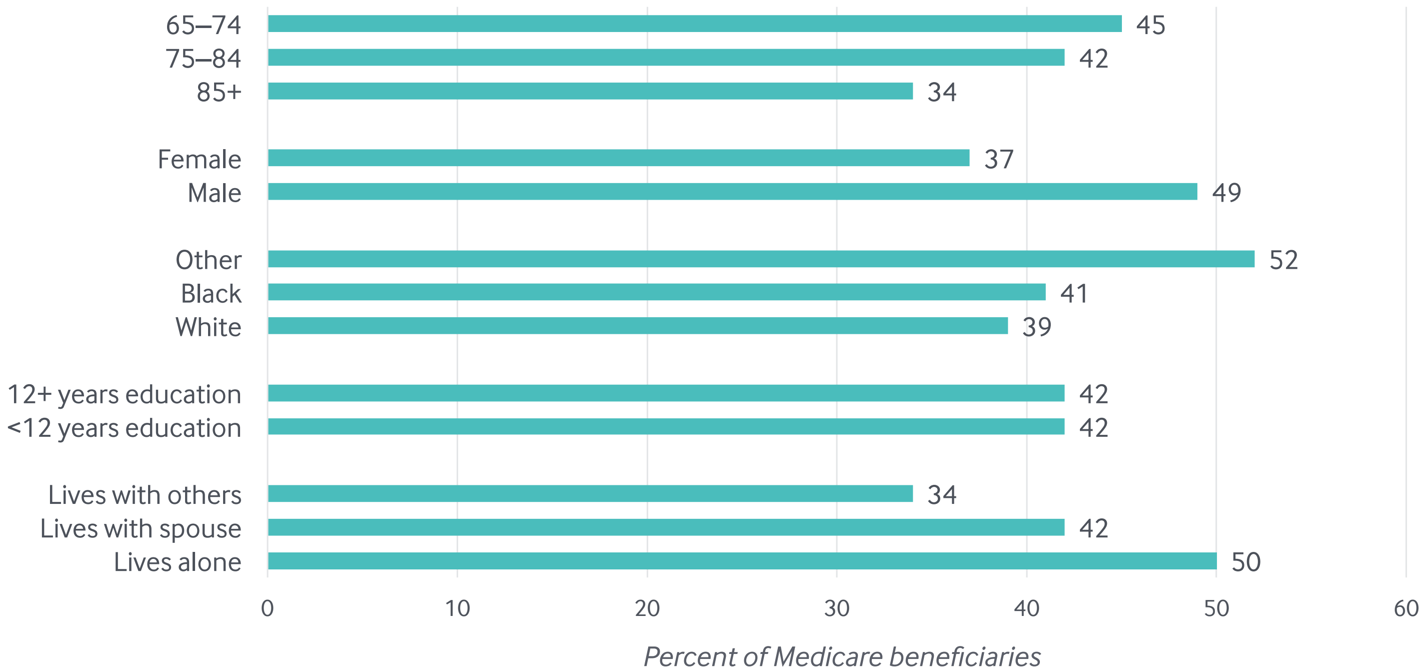
In this first part of our analysis, we focused on the people with probable dementia (see How This Study Was Conducted) or those who have difficulty with activities of daily living (ADLs) or instrumental activities of daily living (IADLs). ADLs are also known as "self-care activities" and include eating, bathing, dressing, transferring in and out of bed, toileting, and walking across the room. IADLs are higher-level activities that allow an individual to continue living independently, such as medication management, meal preparation, grocery shopping, finances, and laundry.

Two of five older adults in this population report not receiving any help. Older men were more likely to report not receiving any help than were older women (49% vs. 37%) (Exhibit 1). Rates of not receiving help were particularly high among blacks and other minority groups (41% and 52% respectively), as well as those who lived alone (50%). Even among those who lived with their spouse, two-fifths of respondents reported not receiving any help.

For older adults who need LTSS, rates of not receiving help were lowest among those who had both Medicare and Medicaid, albeit a third (32%) of dual eligibles still reported not receiving help (Exhibit 2). State Medicaid programs vary greatly in their availability, eligibility thresholds, and access to services. Most states report long waiting lists for waiver services that cover home- and community-based services, such as paid personal care services.[5] Dually eligible Medicare and Medicaid beneficiaries report the highest level of any paid support — more than double the rate as those who are not eligible for Medicaid — although the majority of dual eligibles are largely dependent on unpaid caregivers either alone or in addition to paid personal care (Exhibit 2).

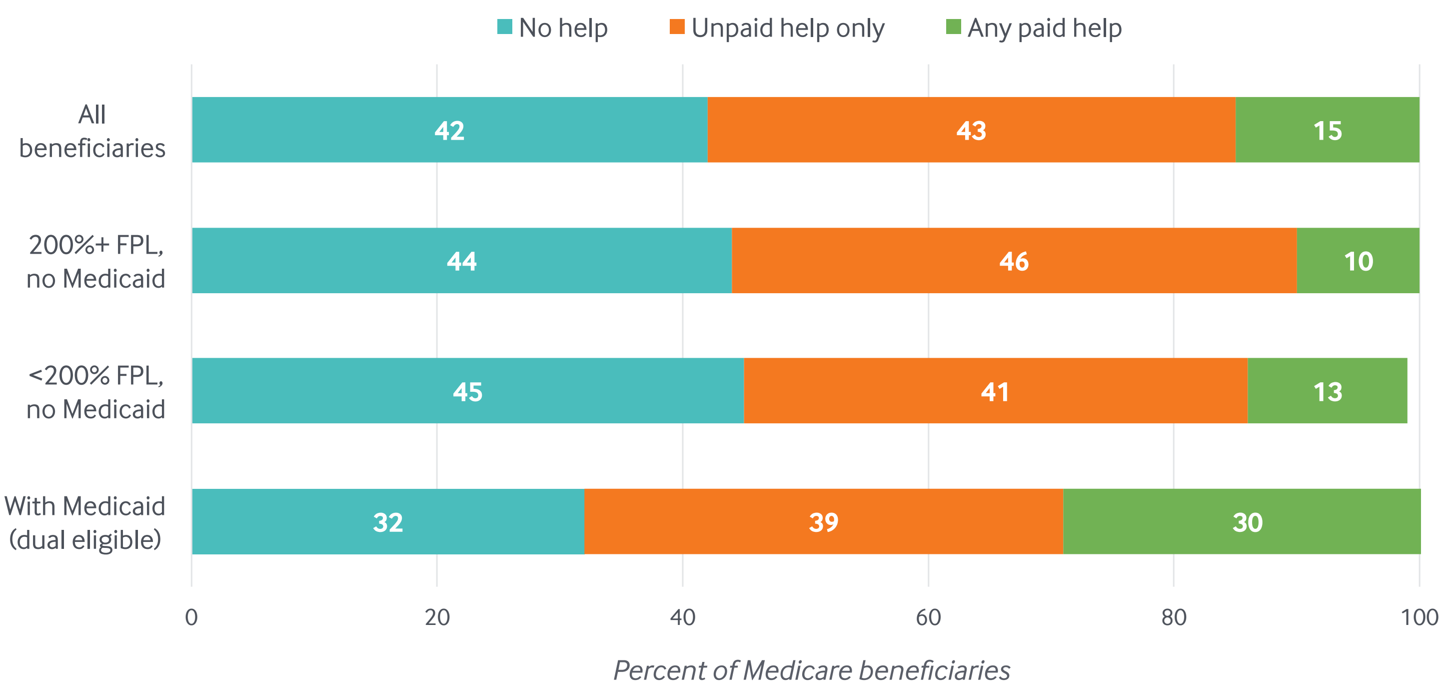
Slightly less than half (45%) of older adults with LTSS needs who have incomes less than 200% of the federal poverty level (approximately $23,000 per year in 2015) but are not covered by Medicaid do not receive any help (Exhibit 2). Of those who do receive assistance, most rely on unpaid help. Only 13 percent of Medicare beneficiaries who have low incomes but who are not on Medicaid report receiving paid personal care services. Interestingly, there is little difference between the distribution of unpaid and paid care for those above or below 200% of FPL who are not on Medicaid. Although those with incomes at 200% of FPL and above are slightly less likely to receive no help with their LTSS needs. Higher-income individuals have the resources to accommodate functional deficits with the use of assistive devices or environmental modifications, which may account for the lower rate of paid personal care services reported in Exhibit 2.

Exhibit 1. Older Adults Who Need Long-Term Services and Supports But Report Not Receiving Help



Note: Population limited to Medicare beneficiaries age 65 and older living in the community who require help with at least one activity of daily living or instrumental activity of daily living, or have probable dementia.
Data: Authors' analysis of the National Health and Aging Trends Study (NHATS), 2015.

Exhibit 2. Medicare Beneficiaries Needing Long-Term Services and Supports by Source of Assistance, Income, and Medicaid Status



Notes: FPL = federal poverty level. Segments may not sum to 100% because of rounding. Population limited to Medicare beneficiaries age 65 and older living in the community who require help with at least one activity of daily living or instrumental activity of daily living, or have probable dementia.
Data: Authors' analysis of the National Health and Aging Trends Study (NHATS), 2015.

MEDICARE BENEFICIARIES WITH HIGH NEED FOR LTSS

The second part of the analysis looks at people with a high need for long-term services and supports, defined as those who receive assistance with at least two activities of daily living or probable dementia. Medicare beneficiaries in this group who relied solely on unpaid care had 1.7 helpers, on average (Exhibit 3). For those who reported receiving any paid help, the average number of helpers was slightly higher (2.8 helpers). The average number of unpaid helpers was only slightly lower (1.5 vs. 1.7) among those receiving both paid and unpaid support, suggesting that the paid assistance supplements rather than replaces the unpaid caregiving support for people with high needs.

People with a high need for LTSS who report receiving help receive 271 hours of assistance per month, which is approximately nine hours per day (Exhibit 3). Older adults who rely on unpaid care only receive an average 231 hours of assistance per month; those who have paid and unpaid support receive 337 hours per month.

Exhibit 3. Average Number of Helpers and Monthly Hours of Care for Older Adults with High Need for Long-Term Services and Supports

	Older adults who receive any paid help			Older adults who receive unpaid help only	All older adults who receive help
	Paid	Unpaid	Total		
Percentage of population who receive help (row %)			40%	60%	100%
Weighted mean numbers of helpers	1.29	1.50	2.80	1.70	2.11
Weighted mean monthly hours of care	162	175	337	231	271

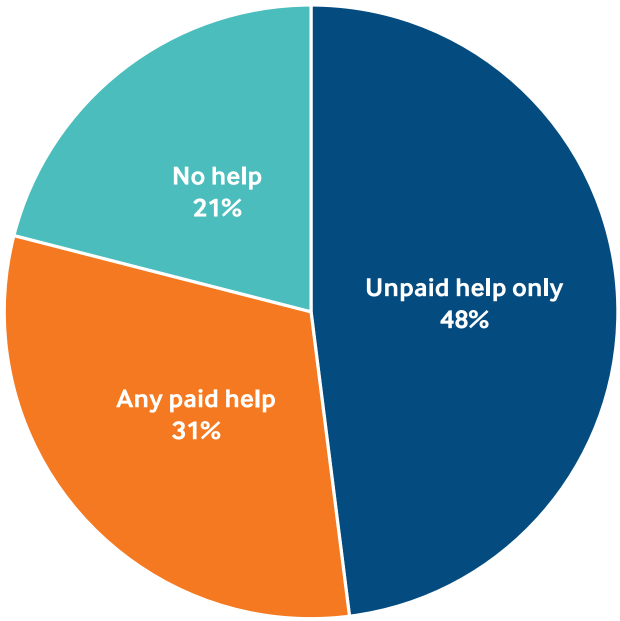
Note: Population limited to Medicare beneficiaries age 65 and older living in the community who require help with at least two activities of daily living or have probable dementia.
Data: Authors' analysis of the National Health and Aging Trends Study (NHATS), 2015.

Medicare Beneficiaries with High Need for LTSS and Multiple Chronic Conditions

Three-quarters of Medicare beneficiaries with a high level of need for LTSS have three or more chronic conditions.[6] One of five older adults with both high LTSS and high medical needs report not receiving any help with self-care activities; just under half rely on unpaid care only (Exhibit 4).

Within the high-need population, the use of paid and unpaid help varies. People with probable dementia have more helpers and receive more hours of care than the other population of high-need beneficiaries (defined as those receiving help with two or more ADLs). This reflects the fact that some people living with dementia require around-the-clock supervision. People in this category depend heavily on family and unpaid caregivers, which puts this caregiving population at high risk for burnout.[7] The amount of unpaid care provided varies little between those who also receive assistance from paid caregivers and those who only receive unpaid care, reaffirming that paid care is a supplement and not a substitute in this population (Exhibit 5).

Exhibit 4. Assistance for Older Medicare Beneficiaries with High Need for Long-Term Services and Supports and Three or More Chronic Conditions



Note: Population limited to Medicare beneficiaries age 65 and older living in the community who require help with at least two activities of daily living or have probable dementia.
Data: Authors' analysis of the National Health and Aging Trends Study (NHATS), 2015.

Exhibit 5. Average Number of Helpers and Monthly Hours of Care for Older Adults with Probable Dementia vs. Older Adults with Two or More ADLs Without Probable Dementia

	Older adults who receive any paid help			Older adults who receive unpaid help only	Average for all older adults who receive help
	Paid	Unpaid	Total		
Probable dementia					
Weighted mean numbers of helpers	1.28	1.53	2.81	1.73	2.14
Weighted mean monthly hours of care	192	232	424	266	326
Two or more ADLs, no probable dementia					
Weighted mean numbers of helpers	1.27	1.55	2.82	1.65	2.03
Weighted mean monthly hours of care	98	104	202	171	181

Note: Population limited to Medicare beneficiaries age 65 and older living in the community who require help with at least two activities of daily living or have probable dementia.
Data: Authors' analysis of the National Health and Aging Trends Study (NHATS), 2015.

CONCLUSION

Long-term services and supports are not covered under Medicare despite many beneficiaries reporting needing help with self-care activities.[8] The resistance to a public financing option for LTSS is based largely on the costs of such a program and the concern that it would substitute for care that is already being provided by family caregivers.[9] This issue brief confirms that older adults who need LTSS rely heavily on family caregivers. However, this method of providing care is unsustainable, given the increasing numbers of older adults who will require LTSS as well as the declining availability of family caregivers.[10] In addition, study results find that significant numbers of community-residing older adults with a need for LTSS do not receive help.

This analysis shows that the amount of unpaid care provided varies little between those who receive both paid and unpaid support and those who receive unpaid support only, suggesting that paid care does not replace unpaid care, but supplements it. Addressing and supporting the need for LTSS can result in savings to individuals and the government through delayed nursing home and Medicaid entry.[11] A public LTSS financing solution, like Medicare Help at Home,[12] that supports individuals and family caregivers would improve the supply of long-term services and supports and allow for their quality to be monitored to ensure older adults can live safely in the community.

NOTES

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HOW THIS STUDY WAS CONDUCTED

This study uses data from the National Health and Aging Trends Study (NHATS) from 2015 to examine care received by Medicare beneficiaries who require long-term services and supports (LTSS). The NHATS is a longitudinal, nationally representative survey of Medicare beneficiaries age 65 years and older. The first wave of the study was conducted in 2011, with the population followed yearly. A resampling of the Medicare population was conducted in 2015 to account for death and loss to follow-up and ensure the population surveyed continued to represent the Medicare population. Descriptive analyses were conducted on the 2015 survey data to create cross-tabulations of receipt of help, number of helpers, and weighted monthly hours of care by demographic, income, and Medicaid status in 2015. A composite variable for income and Medicaid status was developed to represent the differences between those who receive LTSS in the Medicaid population, compared to similarly low-income individuals not covered by Medicaid.

For the purposes of this analysis, two populations needing LTSS are examined, first a broader population (referred to as "LTSS need") that encompasses those who have difficulty with activities of daily living (ADLs), instrumental activities of daily living (IADLs), or probable dementia. The second population consists of those with a high need for LTSS (referred to as "high need"), defined as receiving help with at least two activities of daily living or probable dementia, which is comparable with most states' institutional level of care threshold to receive LTSS benefits in the Medicaid program. ADLs or self-care activities include eating, bathing, dressing, transferring in and out of bed, toileting, and walking across the room. IADLs include those higher-level activities that allow an individual to continue living independently, such as medication management, meal preparation, grocery shopping, finances, and laundry. Probable dementia as defined in the NHATS is determined by a combination of self-report of a diagnosis of dementia, and a participant or proxy evaluation of memory, orientation, judgment, and function administered in the survey. LTSS represent a broad spectrum of assistive options to address ADL or IADL needs of an individual and can range from adult day care, personal care, and transportation services in a community setting, to nursing homes or residential care facilities.

ABOUT THE AUTHORS

Amber Willink, Ph.D., is an assistant scientist in the Department of Health Policy and Management and assistant director of the Roger C. Lipitz Center for Integrated Health Care at the Johns Hopkins Bloomberg School of Public Health. Her research uses predictive modeling to examine trajectories and health outcomes of older adults and inform policy for health and long-term services and supports. She is also focused on issues of access to and cost burdens of noncovered Medicare services. Dr. Willink received her doctoral degree in health services research and policy from Johns Hopkins University.

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