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**Changes in Home Care Use by Older People
With Disabilities: 1982–1994**

by

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The Public Policy Institute, formed in 1985, is part of the Research Group of the 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.

The views expressed herein are for information, debate, and discussion, and do not necessarily represent formal policies of the Association.

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Foreword

A major issue in the field of long-term care is how to expand the use of home care services. Although older people have an overwhelming preference for receiving services in their own homes, our nation's long-term care system remains oriented more toward institutional care. Over the past two decades, policy makers and researchers have made numerous attempts to develop new alternatives for financing home-based care. It is critical that such efforts be informed by data on how the use of home care services by older people with disabilities has changed over time.

To contribute to the state of knowledge on the use of home care services by older people, AARP is pleased to have the opportunity to present this analysis of the 1982, 1989, and 1994 National Long-Term Care Surveys (NLTCS). It updates the authors' analysis of the changes in home care use by older people with disabilities between 1982 and 1989 that was published by the Congressional Research Service in 1994. This report includes data from the 1994 NLTCS, and it documents trends in the disability status of community residents age 65 and older, their sources of help, hours of help received, and sources of payment for long-term care help. In addition, this report analyzes the out-of-pocket payments for long-term care services incurred by older people with disabilities. It also differentiates payment levels by certain characteristics that are generally associated with higher long-term care expenditures.

These data can help to shape a better understanding of who needs long-term care, the role that various public programs play in financing this care, and the magnitude of the out-of-pocket costs incurred by older people with disabilities. Understanding these trends can help to influence the policy debate on financing long-term care, as our nation attempts to develop a more coordinated system that is affordable and accessible for people with disabilities.

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Executive Summary

Background

Rapid growth of the population age 65 and older will increase the demand for long-term care services in the coming years. In particular, home care services will be in demand, as most older people prefer them to institutional care. Recent research suggests that states have saved money through the use of home and community-based long-term care programs. Research also indicates that the expansion of these programs has improved the quality of life of older people with disabilities, and that of their family caregivers as well. Despite these factors, policy makers have been slow to embrace home care services because of a fear that expansions in home-based care could result in rapid growth of public expenditures for such services.

Purpose

The purpose of this paper is to present recent trends and statistics on the use of home care services by older people with disabilities. As policy makers consider long-term care options, it will be helpful to know who receives home care services, what the sources of payment are, and how much beneficiaries pay out of pocket for such services.

Methodology

This study analyzed data from the 1982, 1989, and 1994 National Long-Term Care Surveys (NLTCs). The NLTCs were designed to measure the prevalence of chronic disability and institutionalization in the U.S. population age 65 and older that is enrolled in Medicare. These surveys also measure changes experienced by those individuals. The interviews with community residents in 1982, 1989, and 1994 elicited information on people identified as chronically disabled, based on duration of disability and ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Data also were collected on caregivers of older people with disabilities, sources of payment, and hours of care received.

Principal Findings

Disability Rates

- For both time periods, 1982 to 1989 and 1989 to 1994, the proportion of the older population with disabilities declined, both in the community and in institutions.

Shift Toward Paid Caregivers

- Between 1982 and 1994, the proportion of older people with disabilities who relied only on informal helpers declined from 74 percent to 64 percent.

- The proportion of people who used both paid and informal helpers grew with increasing levels of ADL dependency. This finding implies that the more severely disabled a person is, the less likely it is that either informal or paid care, by itself, can meet all the person's needs.

Helper Hours

- The number of helper hours received was directly related to ADL dependency level. Helper hours increase with ADL dependency.
- However, between 1989 and 1994, helper hours decreased, particularly for people with high levels of ADL dependency.

Payment Sources

- For any type of home care assistance, the most common source of payment was the people with disabilities themselves: about 57 percent of those with paid care in 1994 contributed to the payment of that care themselves.
- Between 1982 and 1994, the proportion of people with disabilities receiving care paid for by Medicare increased from 16 percent to 21 percent. The proportion receiving care paid for by Medicaid fell from 12 percent in 1989 to 9 percent in 1994 – slightly below the 1982 level.
- The role of private insurance was small and virtually unchanged between 1982 and 1994, reaching just 5 percent of people who had paid helpers in 1994.

Paid Helper Hours

- On average, people with any paid helpers used 15 hours of such help per week in 1989 and 13 hours in 1994.
- Among those people with only program-related sources of payment (Medicare, Medicaid, and private insurance), the number of hours declined, on average, from 14 hours per week in 1989 to 10 hours in 1994.
- The number of hours of paid help increased with ADL level, regardless of the source of payment. People with lower levels of ADL or IADL dependencies tend to pay for home care themselves.
- Overall, the trend between 1989 and 1994 was toward fewer paid hours per week, regardless of ADL levels.

Out of Pocket Payments and ADL Status

- The average out-of-pocket payment for all people with ADL or IADL dependencies was \$257 per month in 1989 and \$250 in 1994.
- For people with only IADL needs or one ADL dependency, the average out-of-pocket payment was \$100 per month in 1989 and \$110 in 1994.
- In contrast, people with three or more ADL dependencies spent, on average, \$546 per month in 1989 and \$578 in 1994.

Out of Pocket Payments and Personal Characteristics

- The overall 1994 average among people with 3+ ADLs was \$576 in out-of-pocket expenses in a month; however, people who were 75 years of age or older spent, on average, \$631 in a month.
- Unmarried individuals with 3+ ADLs spent, on average, \$756 per month in 1994.
- Overall, people who were incontinent had the highest average monthly out-of-pocket expenses.

Conclusions

The finding that disability rates among older people declined in recent years suggests the possibility that the future demand for long-term care services may be less than it would be otherwise. However, the projected increases in the number of older people in the U.S. imply that long-term care still will need policy attention in coming years.

This analysis identified recent changes in the sources and amounts of home care received by the older population with disabilities. Such patterns are important because they indicate how the use of currently available public and private resources has been changing. Four important trends were identified:

1. The proportion of older people with disabilities who relied on only paid helpers or on only informal helpers declined between 1989 and 1994, while those using both sources increased. Despite the increased use of paid sources of care, the analysis did not indicate a diminished role of informal caregivers.
2. Between 1989 and 1994, Medicare coverage for home care continued to increase, while Medicaid coverage declined. Notably, while Medicare coverage of nursing helpers leveled off, there was a notable increase in Medicare coverage for ADL and IADL helpers. As provisions intended to reduce Medicare spending (contained in the 1997 Balanced Budget Act) take effect, it will be important to monitor the extent to which state Medicaid programs respond to Medicare reductions and to determine if these provisions result in a larger burden for older people with disabilities and their families.
3. The number of hours of home care per week, either in terms of combined paid and informal care or only paid care, declined between 1989 and 1994. Possible explanations for this trend include the increasing availability and use of technical and mechanical aids and a shift from relying on Medicaid to Medicare, which limits coverage to people with conditions that require skilled care.
4. Only small changes in out-of-pocket payments were observed, with the possible exception of the most disabled and those at the high end of the spending distribution, where out of pocket costs appeared to increase between 1989 and 1994. Despite the growth of Medicare home care, about 20 percent of older people with disabilities spend money out-of-pocket for home-based care to compensate for ADL and IADL dependencies.

I. Introduction

Expanding public financing for home-based, long-term care for older people with disabilities is an issue that policy makers have debated for almost two decades. There are a number of reasons for this. Relatively limited public support is currently available for home care, largely through the Medicare and Medicaid programs, and then only under certain circumstances. In addition, public spending for home care amounts to only a fraction of spending for nursing home care, even though the great majority of older people needing long-term care reside in the community and prefer home care to nursing homes. Finally, the vast majority of home care received by older people with disabilities is provided by family members, many of whom have to incur substantial personal and economic costs for prolonged periods of time.

The rapid growth of the older population will increase the demand for long-term care services in coming years. How long-term care requirements will be met in the future, in terms of financing sources and provision of services, is an important question for older people and their families. As policy makers consider long-term care options, it will be helpful to know who is receiving home care services, what the sources of payments are, and how much beneficiaries pay out of pocket for such services. To obtain recent national data on trends and patterns of use of home care and sources of payment for this care, we analyzed the 1982, 1989, and 1994 National Long-Term Care Surveys. This paper presents findings on the use of home care by older people with disabilities and payment for this care between 1982 and 1994.

II. Background

Long-term care, which encompasses a range of health, social, and residential services, is generally provided to compensate for disabilities caused by physical, cognitive, or mental impairments. Physical disabilities can be measured in terms of dependencies in activities of daily living (ADLs) or in instrumental activities of daily living (IADLs) (Katz et al., 1963; Lawton and Brody, 1969). ADL dependencies result in a need for assistance with personal care functions. Five such functions have been widely used in policy contexts to measure disability and the need for long-term care services – bathing, dressing, transferring from bed or chair, toileting, and eating. Dependency in IADLs reflects difficulties in performing household chores such as meal preparation, shopping for groceries, and managing money. Some IADLs reflect cognitive as well as physical impairments.

In 1982, approximately 75 percent of older people with disabilities resided in community settings and received long-term care assistance only from informal sources such as spouses and other family members (Liu and Manton, 1994). A smaller proportion of these individuals received long-term care help from both informal sources and paid caregivers. The relative roles of informal and paid caregivers differ, depending upon the particular circumstances of the older person with disabilities. For example, whereas paid care might serve as a substitute for informal care in some situations, it could be used as a complement for informal care in others (Greene, 1983). In a very small proportion of cases, older people with disabilities use only paid assistance. This situation

tends to occur when the informal care network is fragile, and when only small amounts of home-based, long-term care are needed. Whether people with disabilities receive home-based care from informal sources only, from both informal and paid sources, or only from paid sources reflects a number of factors, including the type and level of disability, the strength of the informal caregiver network, financial resources, and the availability of publicly supported services.

Long-Term Care Expenditures

In 1996, an estimated \$109 billion was spent on long-term care, of which \$79 billion was for nursing home care and \$30 billion was for home-based care (Levit et al., 1997). Of the latter figure, Medicare financed 45 percent, while state and local sources, particularly Medicaid, paid for another 14 percent. Individuals paid out of pocket for another 20 percent, while all other sources, including private insurance, financed the balance of home care services.

Medicaid is the federal-state health program for the poor. It limits coverage to those people who are poor by welfare program standards or who have become poor as the result of incurring large health care expenses. Medicaid's long-term care expenditures are concentrated on nursing home care; in 1996, for example, these expenditures for the population age 65 and older were \$31 billion, of which 82 percent was for nursing home care. The remaining long-term care expenditures were incurred for home health care, personal care, and other home and community-based services. Because States have not been uniform in providing home and community-based services under Medicaid plans, access by Medicaid-eligible people to such services varies greatly across states (Coughlin, Ku, and Holahan, 1994).

Medicare, the federal health insurance program for older people and people with disabilities, is focused primarily on coverage of acute health care costs and was never envisioned to cover long-term care. For example, Medicare pays for only limited amounts of community-based, long-term care services through the program's home health benefit. To qualify for home health services, a person must be homebound and in need of skilled nursing care or therapy services on an intermittent basis. Most people with chronic disabilities do not require skilled care; rather, they need nonmedical, supportive services and help with basic self-care functions and daily routines.

To a much smaller extent, three other federal programs – the Social Services Block Grant (SSBG), the Older Americans Act, and the Supplemental Security Income (SSI) program – support community-based long-term care services for older people with impairments. Because the funding for these three programs is limited, their ability to address the financing problems in long-term care is also limited. In addition to these federal programs, some States use "state-only" funds to support home and community-based long-term care services.

Policy Context for Home Care

Public policy interest in home care services has evolved for a number of reasons. They include the financial burden of Medicaid nursing home spending on federal and state governments, the impoverishing consequences of the use of nursing homes by older people with disabilities, and the general preference of older people for home care. In addition, some analysts believe that expanded home and community-based long-term care services could be a lower-cost alternative to nursing home care, thereby reducing total public expenditures for long-term care.

Research and demonstration projects conducted to test home and community-based, long-term care services as a substitute for nursing home care have yielded mixed findings. Research in the 1980s generally found that expanding home-based care did not significantly reduce nursing home use (Kemper, Applebaum, and Harrigan, 1987). Recent research suggests, however, that states have saved money through the use of home and community-based long-term care programs (GAO, 1994; Alecxih, Lutzky and Corea, 1996). Earlier studies also found that expansion of these programs improved the quality of life, both of older people with disabilities, and family caregivers. Some studies also reported significant improvements in the health and functioning of older people and increases in their level of social interaction (Kemper et al. 1987).

Despite their interest, public policy makers have been slow to embrace home care services because of a fear that program expansions in home-based care could result in rapid growth of expenditures for such services (Wiener and Hanley, 1992). There is much uncertainty about the future financial obligations that will accrue to both states and the federal government from home-based care. Because of the expected popularity of this type of care, policy makers also have been apprehensive about the possibility of a strong "woodwork effect" if access to such services were expanded.

The issue of cost gives the long-term care debate its focus. The overriding issue, as yet unresolved, is whether the public or private sectors, or some combination of both, should be financing expanded long-term care services. Various legislative proposals introduced over the past several years took different positions on the issue of who should provide additional financing for care. At one end of the spectrum were proposals that would establish a new social insurance program for long-term care, or include long-term care benefits in a national health insurance program. At the other end were proposals that would provide a variety of tax incentives for the purchase of private long-term care insurance. In between were proposals that included new public funding for care, but did not provide coverage for all people with disabilities or cover all expenses that people might incur.

As strategies for reforming the financing and provision of long-term care services continue to evolve, data on the population with disabilities and its use of long-term care services will be helpful in informing policy makers about the beneficiaries of various reform options. This paper presents recent statistics on a subset of all people requiring long-term care services: older people (age 65+) with disabilities who reside in the community.

III. Data Sources

The data sources for this study are the National Long-Term Care Surveys (NLTCs), which were designed to measure the prevalence of chronic disability and institutionalization in the U.S. Medicare-enrolled population age 65 and older, as well as changes experienced by those individuals (DHHS, 1988). This paper uses data from the 1982, 1989, and 1994 surveys. Because the three surveys used essentially the same survey methodology (Manton, Corder, and Stallard, 1993), comparisons could be made between years to determine trends in the use of home care services between 1982 and 1994.

The detailed community interviews in 1982, 1989, and 1994 elicited information on people identified as chronically disabled (i.e., having a disability that lasted, or was expected to last, at least 90 days) according to 9 ADL or 11 IADL questions. Of relevance for policy initiatives, the NLTCs collected data on the five "core" ADLs – bathing, dressing, transferring, toileting, and eating. These five ADLs were used in this analysis, as were the following 11 IADLs: heavy housework, light housework, laundry, meal preparation, grocery shopping, inside mobility, outside mobility, distance travel, money management, medicating, and telephone use.

Another set of questions available in each NLTCs refers to caregivers of older people with disabilities. Specific information collected included the relationship of the caregiver to the disabled person, whether the caregiver was paid, the sources of payment if the caregiver was paid, and how much the disabled person paid out of pocket. The 1989 and 1994 NLTCs elicited information on how many hours of care were received in the preceding week from the caregivers, although comparable information was not directly available from the 1982 NLTCs.

In addition to the information on disability levels and caregiver profiles, the NLTCs collected data on prior use of health care services, income, living arrangements, and demographic characteristics. These data are useful in estimating how subgroups of the older population with disabilities differ in their use of home-based, long-term care services.

IV. Findings

Results are presented in three sections. The first discusses the total population of older people with disabilities, their disability status, and their informal and paid caregivers. The second discusses the subgroup of older people with disabilities who received paid home care services, and the sources of payment for those services. The third discusses characteristics of those people who paid for their home-based services out of pocket, the amounts paid, and the relationship between characteristics of those people and the size of their out of pocket payments.

Older People with Disabilities

The number of older people in 1982, 1989, and 1994 residing in institutions and in the community, according to their disability level, are presented in Table 1. The number of people age 65 and older increased from approximately 27 million to 33 million between 1982 and 1994. In each of the three years, 16 to 18 percent of the total older population had a disability and resided in the community, while 5 to 6 percent resided in institutions. Although the number of older people with disabilities residing in the community increased from 4.8 million to 5.3 million between 1982 and 1989, it actually decreased slightly between 1989 and 1994. In addition, the number of people in institutions increased only slightly between 1989 and 1994.

Table 1: Disability and Residential Status of People 65+

Disability Level*	1982		1989		1994	
	Population (1,000s)	Percent	Population (1,000s)	Percent	Population (1,000s)	Percent
Nondisabled	20,537	76.3%	23,866	77.3%	26,136	78.9%
Community-disabled	4,854	18.0%	5,321	17.2%	5,296	16.0%
IADL only	1,837	6.8%	1,808	5.9%	1,781	5.4%
1 ADL	1,145	4.3%	1,325	4.3%	1,300	3.9%
2 ADLs	583	2.2%	781	2.5%	803	2.4%
3 ADLs	345	1.3%	526	1.7%	464	1.4%
4 ADLs	396	1.5%	481	1.6%	435	1.3%
5 ADLs	549	2.0%	399	1.3%	512	1.5%
3+ ADLs	1,291	4.8%	1,407	4.6%	1,412	4.3%
Institutional residents	1,532	5.7%	1,685	5.5%	1,693	5.1%
Total population	26,924	100.0%	30,871	100.0%	33,125	100.0%

* Bathing, dressing, transferring (bedfast), toileting, and eating are the (5) ADLs. Heavy ~~work~~ work, light housework, laundry, meal preparation, grocery shopping, inside mobility, outside mobility, distance travel, money management, medicating, and telephone use are the (11) IADLs. Note that inside mobility has moved from ADL to IADL status for the purposes of this paper.

Source: Liu and Manton analysis of the National Long-Term Care Surveys, 1998

Because the number of older people increased steadily between 1982 and 1994, the decline (between 1989 and 1994) in the number of community-resident, disabled, older people was attributable to a declining rate of disability. For both time periods, 1982 to 1989 and 1989 to 1994, the proportion of the older population that had a disability and resided in the community or lived in institutions declined. Although this is a striking finding, the disability decline in the older population (estimated from the 1982 to 1994 NLTCS) is consistent with findings from other surveys of recent disability trends in the U.S. (Waidmann and Manton, 1998). Statistics in Table 1 also indicated declining rates of disability in most ADL categories during the 1989 to 1994 time period.

A shift toward paid caregivers. To facilitate analysis of trends in types of caregivers assisting older people with disabilities between 1982 and 1994, we grouped the care recipients into three broad categories: "only paid helpers," "only informal helpers," and "both paid and informal helpers." Table 2 contains information only on older people with disabilities who were recorded by the NLTCS as having caregivers in the reference weeks of the 1982, 1989, and 1994 surveys (approximately 90 percent of the community-disabled older population).

From 1982 to 1994, most people used only unpaid helpers. Between those years, however, the proportion of older people with disabilities who had caregivers and relied on only informal helpers declined from 74 percent to 64 percent. Hence, by 1994, more than one-third of older people with disabilities used paid care, either alone or in combination with informal care.

The proportion of older people with disabilities who used both paid and informal helpers grew with increasing levels of ADL dependency. This result was offset by decreases, with increasing ADL dependency, in the proportions of people using only paid or only informal care. The important implication of these results is that the more severely disabled one is, the less likely it is that either informal or paid care, by itself, can meet all the needs of that person. In 1994, 28 percent of older people with any level of IADL or ADL disability had both informal and paid assistance, while 55 percent of people with 5 ADLs received assistance from that combination of helpers.

The collective information indicates a clear trend toward a greater role of paid care between 1982 and 1994 among older people with disabilities receiving home-based, long-term care services. The increase could be due to many factors, such as higher incomes, worse health status, or less availability of informal caregivers. At the same time, policy changes in publicly financed home care services, under Medicaid and Medicare (e.g., expansion of home and community-based care services under Medicaid, and liberalization of coverage requirements under Medicare's home health benefit), could also account for increases in paid care between 1982 and 1994.

**Table 2: People 65+ with Disabilities Who Have Caregivers,
by Disability Level and Sources of Assistance**

Survey year	Disability level*	Number of people (1,000s)	Distribution of People **		
			Only paid helpers	Only informal helpers	Both paid and informal helpers
1982	IADL only	1,687	7.1%	80.8%	12.1%
	1 ADL	1,068	5.7%	74.5%	19.8%
	2 ADLs	569	6.1%	68.6%	25.3%
	3 ADLs	341	4.7%	66.0%	29.3%
	4 ADLs	394	2.6%	65.4%	32.1%
	5 ADLs	548	1.5%	65.3%	33.2%
	Total	4,607	5.4%	73.6%	21.0%
1989	IADL only	1,509	9.7%	77.7%	12.6%
	1 ADL	1,153	10.5%	69.0%	20.5%
	2 ADLs	734	12.0%	61.1%	26.9%
	3 ADLs	519	6.5%	58.7%	34.8%
	4 ADLs	479	5.5%	53.3%	41.2%
	5 ADLs	399	4.0%	54.4%	41.6%
	Total	4,783	9.0%	66.6%	24.4%
1994	IADL only	1,488	9.5%	78.3%	12.2%
	1 ADL	1,114	10.7%	64.9%	24.4%
	2 ADLs	745	7.3%	62.8%	30.0%
	3 ADLs	443	5.4%	57.4%	37.2%
	4 ADLs	434	2.6%	51.1%	46.2%
	5 ADLs	512	3.3%	41.4%	55.3%
	Total	4,737	7.8%	64.3%	28.0%

* See Table 1.

** Row percentages sum to 100%± 0.2 due to rounding.

Source: Liu and Manton analysis of the National Long-Term Care Surveys, 1998.

Total helper hours increase with ADL dependency. We also examined data from the 1989 and 1994 NLTCs on the hours of helper assistance in the preceding week received by people with disabilities; comparable information was not available in the 1982 NLTCs. Table 3 presents the distribution of older people with disabilities by number of helper hours received during the week, plus summary measures of helper hours in terms of the mean (average) and the median (50th percentile) for each ADL category. The "none" category indicates that no help was provided during the reference week.

Table 3: People 65+ with Disabilities Who Have Caregivers, by Disability Level and Hours-Per-Week of Helper Assistance

Survey year	Disability level*	Number of people (1,000s)	Distribution of People **				Mean hours	Median hours
			None***	1-24 hours	25-56 hours	57+ hours		
1989	IADL only							
	1 ADL	1,509	14.7%	68.4%	13.9%	2.9%	13.6	8
	2 ADLs	1,153	11.7%	66.9%	17.4%	4.1%	16.5	9
	3 ADLs	734	6.4%	59.1%	25.9%	8.6%	23.7	15
	4 ADLs	519	6.5%	41.2%	34.1%	18.3%	35.3	26
	5 ADLs	479	4.4%	21.1%	36.1%	38.4%	61.0	45
	Total	399	4.6%	5.1%	29.0%	61.4%	82.8	71
		4,783	9.9%	53.7%	22.2%	14.1%	28.7	15
1994	IADL only							
	1 ADL	1,488	20.4%	64.8%	11.5%	3.3%	12.0	5
	2 ADLs	1,114	16.9%	67.0%	12.7%	3.4%	13.1	6
	3 ADLs	745	14.2%	61.7%	18.9%	5.2%	17.7	9
	4 ADLs	443	7.9%	62.6%	20.0%	9.5%	23.6	14
	5 ADLs	434	8.1%	41.5%	27.4%	23.0%	37.4	24
	Total	512	6.8%	20.7%	28.5%	44.0%	58.9	48
		4,737	14.8%	57.7%	17.0%	10.4%	21.6	10

* See Table 1.

** Row percentages sum to 100%± 0.2 due to rounding. Hours reflect the sum of ADL and IADL.

*** Individuals who relied on helper assistance, but not during the survey's reference week.

Source: Liu and Manton analysis of the National Long-Term Care Surveys, 1998

Among all older people with disabilities who reside in the community and have caregivers, more than half (54 percent in 1989 and 58 percent in 1994) received between 1 and 24 hours of helper assistance in a week. In contrast, 14 percent in 1989 and 10 percent in 1994 received more than 57 hours in a week; this amount is equivalent to 8 hours per day, every day of the week. As expected, the number of helper hours received was directly related to ADL dependency level. In 1994, for example, whereas two-thirds of people with only IADL dependencies received fewer than 25 hours of help in a week, only one-fifth of people with 5 ADL dependencies received that small amount of help. In fact, nearly half of people with 5 ADLs (44 percent) received more than 57 hours of help in a week.

The relationship between ADL dependency and helper hours in a week is also highlighted by the mean and median values. In 1989, people with 3 ADLs, for example, received an average of 35 hours of assistance in a week; those with 5 ADLs received an average of 83 hours. In

contrast, people with only IADL dependencies received an average of only 14 hours of assistance in a week, and half of them received fewer than 8 hours of help in a week.¹ Between 1989 and 1994, these mean and median values decreased, particularly for people with high levels of ADL dependency. The reasons for this finding are not totally clear, but the decline in the proportion of people with unpaid caregivers could be one cause, if unpaid caregivers provide more hours of assistance, on average, than do paid caregivers.

Sources of Paid Care

The proportion of older people with disabilities who received help from paid caregivers increased, on average, from about one-quarter in 1982 to more than one-third in 1994. This section examines the specific sources of their paid care.

Increased participation by most payment sources. Table 4 gives information on how frequently each type of payment source was mentioned by people with disabilities who had paid helpers in 1982, 1989, and 1994. This information is provided for specific types of help received (e.g., nursing, ADL assistance). For any type of home care assistance, the most common source of payment was people with disabilities themselves: about 57 percent of people with paid care in 1994 contributed to the payment of that care themselves. Table 4 also shows that this phenomenon increased from 1982 to 1989 for each type of home care assistance. The greatest percentage increase was in the payment for ADL help (45 percent to 53 percent). Between 1989 and 1994, however, levels of payment by older people with disabilities decreased slightly for ADL and IADL helpers, but increased from 36 percent to 44 percent for help with nursing needs.

The proportion of older people with disabilities who received care paid for by Medicare or Medicaid increased between 1982 and 1989. Among all payment sources, Medicare was most frequently mentioned as a source of payment for nursing helpers; its coverage of nursing help increased from 39 percent in 1982 to 45 percent in 1989. For any type of care, Medicare's role increased from 16 percent in 1982 to 21 percent in 1989. Medicaid as a payer for nursing services increased by half, from 16 percent to 24 percent; Medicaid as a payer for IADL services increased by about one-third, from approximately 9 percent to more than 12 percent.

Between 1989 and 1994, the proportion of older people with disabilities receiving care paid for by Medicare continued to increase, but the amount receiving care paid for by Medicaid decreased. Medicare coverage for nursing helpers leveled off during this period, but there was a large increase in the percentage of Medicare coverage for ADL and IADL helpers. This is

¹A study in New York City found that Medicaid home care recipients with 3+ ADLs receive approximately the same total hours of care, regardless of the amount of informal family contributions – in 1995, an average of 65 hours per week (Hokenstad, et al., 1998).

Table 4: Percentage of People with Disabilities Age 65+ with Paid Helpers Who Had Specific Sources of Payment, by Type of Help Received

	1982				1989				1994			
Payment source*	Any helpers	Nursing helpers	ADL helpers	IADL helpers	Any helpers	Nursing helpers	ADL helpers	IADL helpers	Any helpers	Nursing helpers	ADL helpers	IADL helpers
Disabled person	52.7%	32.6%	45.1%	53.1%	60.5%	36.4%	52.7%	60.4%	56.7%	43.9%	51.0%	57.0%
Family or Friend	4.7%	4.1%	7.5%	4.8%	8.7%	6.8%	10.9%	8.7%	4.2%	5.5%	5.4%	4.3%
Any Medicare	16.3%	39.4%	25.3%	16.0%	20.9%	45.4%	32.7%	21.1%	26.9%	45.7%	39.1%	26.9%
Any Medicaid	9.0%	15.6%	12.4%	8.9%	11.9%	24.0%	15.4%	12.0%	8.9%	10.2%	11.2%	8.8%
Insurance	3.5%	8.2%	6.4%	3.4%	4.6%	8.3%	7.6%	4.6%	5.0%	8.9%	7.4%	5.0%
Other	32.8%	33.3%	30.9%	32.8%	21.4%	27.3%	22.4%	21.4%	25.2%	26.3%	26.0%	25.2%
No. of people (1,000s)	1,217	351	624	1,206	1,600	483	791	1,578	1,693	698	886	1,668

* The sum of percentages in any column may total more than 100% because individuals may have had more than one payment source.

Source: Liu and Manton analysis of the National Long-Term Care Surveys, 1998

consistent with the changes seen in Medicare home health agency use. For example, there have been more visits per person, and more visits by aides, who tend to perform ADL and IADL services. The proportion of older people with disabilities receiving Medicaid assistance for any helper fell to 9 percent – slightly below the 1982 level. The largest reduction in Medicaid assistance was in the payment for nursing helpers, which decreased from 24 percent to 10 percent.

"Other" sources were proportionally less often involved in the payment for home care services in 1989 than in 1982, although the decline in the participation rate of this source was greatest in the case of ADL and IADL assistance, as opposed to nursing care. From 1989 to 1994, the use of other sources increased for ADL and IADL helpers and decreased slightly for nursing helpers. We included, in "other" sources, cases in which paid care was indicated, but no specific source was mentioned. In these cases, we reasoned that the payment sources that would most likely not be known by the older people with disabilities receiving paid care were other public programs, such as Social Service Block Grant (SSBG) or Older Americans Act grants. Finally, Table 4 shows that the role of private insurance was minimal between 1982 and 1994.

Trend shifts toward reliance on program sources. We combined payment sources in Table 5 to differentiate between "personal," out of pocket sources (i.e., disabled person, family and friends) and "program-related" payers (i.e., Medicare, Medicaid, private insurance, and "other"). Between 1982 and 1989, the proportion of people with only personal sources increased, on average, from 44 percent to 51 percent, while those with only program-related payment sources decreased from 45 percent to 36 percent. Between 1989 and 1994, the trend was reversed, with higher proportions of people using only program-related payment sources and lower proportions using only personal sources. The proportion of people using both personal and program-related sources of payment increased throughout the period between 1982 and 1994, but increased only slightly from 11 percent to 14 percent.

In each of the survey years, 1982, 1989, and 1994, the proportion of people with only personal sources decreased as ADL dependencies increased. The declining role of personal sources with increasing levels of ADL dependency was offset by higher proportions of people using program-related payers, alone or in combination with personal funds. This relationship is consistent with the fact that some third-party payers (e.g., Medicaid) may have eligibility criteria that trigger benefits at more advanced levels of disability.

Paid helper hours. Table 6 presents the number of paid worker hours in a week received by people with such helpers in 1989 and 1994. It also distinguishes between the number of hours paid by personal, out of pocket sources and the number paid by program-related sources. On average, people with any paid helpers used 15 hours of paid help in a week in 1989 and 13 hours in 1994. Among older people with disabilities who had only personal sources of paid help, the average number of hours of help was about 14 in 1989 and 13 in 1994. Among those people with only program-related sources of payment, the number of hours declined, on average, from

**Table 5: People with Disabilities Age 65+ with Paid Care,
by Disability Level and Sources of Paid Help**

Survey year	Disability level*	Number of people (1,000s)	Distribution of People **		
			Only personal sources***	Only program sources****	Both personal and program sources
1982	IADL only	324	54.2%	40.2%	5.6%
	1 ADL	272	50.9%	37.0%	12.1%
	2 ADLs	179	41.1%	44.2%	14.7%
	3 ADLs	116	35.0%	53.5%	11.4%
	4 ADLs	137	31.6%	57.0%	11.4%
	5 ADLs	190	36.2%	49.3%	14.5%
	Total	1,217	44.4%	44.6%	11.0%
1989	IADL only	337	65.9%	26.3%	7.8%
	1 ADL	357	59.0%	28.9%	12.0%
	2 ADLs	286	46.8%	40.0%	13.2%
	3 ADLs	214	49.0%	39.1%	11.9%
	4 ADLs	224	34.1%	45.7%	20.2%
	5 ADLs	182	39.7%	44.8%	15.5%
	Total	1,600	51.3%	35.9%	12.9%
1994	IADL only	323	60.1%	35.5%	4.4%
	1 ADL	391	48.3%	39.5%	12.2%
	2 ADLs	278	47.2%	42.0%	10.9%
	3 ADLs	189	36.0%	53.4%	10.7%
	4 ADLs	212	31.4%	44.9%	23.7%
	5 ADLs	300	31.3%	42.7%	26.1%
	Total	1,693	43.8%	41.9%	14.2%

* See Table 1.

** Row percentages sum to 100% ± 0.2 due to rounding.

*** Includes only older person with disabilities, family, and friends.

**** Includes only sources not considered personal (above).

Source: Liu and Manton analysis of the National Long-Term Care Surveys, 1998

14 hours in 1989 to 10 hours in 1994. People who received paid help financed by both personal and program-related sources had the highest number of hours of help, but those average hours declined from 24 in 1989 to 20 in 1994.

The number of hours of paid help generally increased with ADL level, regardless of source of payment, in both 1989 and 1994. Among the people who used only personal sources, the patterns of ADL-specific paid helper hours increased with ADL levels and was similar for 1989 and 1994. In 1994, the number of hours of paid help for people with only program-financed care leveled off somewhat at about 3 ADLs. This result may reflect a number of factors, such as the possibility that those people with only program-related paid help may have had more informal care or were healthier in ways not measured by ADLs alone. The lower amount of paid helper hours received by people with only program-related sources could also have reflected limits in helper hours of coverage prescribed by the programs.

Table 6: Average Paid Worker Hours-Per-Week Used by People 65+ with Disabilities, by Disability Level and Personal Versus Program Sources ♦

Survey year	Disability status*	Average paid hours per week **			
		Only personal sources***	Only program sources****	Both personal and program sources	All sources
1989	IADL only	4.62	6.56	7.93	5.38
	1 ADL	5.75	8.68	8.15	6.88
	2 ADLs	7.51	10.33	9.16	8.85
	3 ADLs	16.55	14.85	8.89	14.97
	4 ADLs	38.27	20.38	46.64	31.78
	5 ADLs	47.79	25.53	60.51	39.79
	All people	13.83	14.06	24.02	15.22
1994	IADL only	5.32	5.28	8.62	5.46
	1 ADL	4.36	6.17	3.31	4.94
	2 ADLs	8.56	6.36	8.54	7.64
	3 ADLs	14.82	12.56	11.51	13.26
	4 ADLs	27.45	12.05	30.99	21.37
	5 ADLs	41.34	16.74	30.23	27.95
	All people	13.06	9.66	19.48	12.55

♦ This table contains data only on people with paid helpers.

* See Table 1.

** Hours reflect the sum of ADL and IADL hours reported.

*** Includes only older person with disabilities, family, and friends.

**** Includes only sources not considered personal (above).

Source: Liu and Manton analysis of the National Long-Term Care Surveys, 1998

Overall, the trend between 1989 and 1994 was toward fewer paid hours per week, regardless

of ADL levels. Reductions in paid hours were most dramatic in only program-related sources and in the combination of personal and program sources. This finding is consistent with shifts in sources of program-sponsored payment from Medicaid and other program sources (which are more oriented toward extended durations of home care) to Medicare, with its skilled care requirements.

In sum, the findings in this section point to a general pattern. People with disabilities who have lower levels of ADL or IADL dependencies tend to pay for home care themselves. With increasing levels of dependency, other sources – notably Medicare, Medicaid, or insurance – play a more important role, either as the sole payment source or in combination with personal sources. This pattern is observed for 1982 and 1989, but the period through 1994 suggests a different trend. Medicare use continues to rise, but Medicaid coverage of home care decreases.

Out of pocket Payments by Older People with Disabilities

Although the 1982, 1989, and 1994 NLTCS elicited information that could be used to measure changes in payment sources, data were not available from the surveys to determine the amounts of payments from each of the sources. Data were collected in the NLTCS only on the amounts of payments made by people with disabilities themselves for home-based, long-term care. Because this type of information was not provided by all respondents from the surveys, the data were not necessarily representative of all people with such payments. From the 1989 NLTCS, for example, about 80 percent of the respondents who indicated that they had out of pocket payments actually provided a dollar amount. Nevertheless, the data that were available provide some insight on the distribution of out of pocket payments made by older people with disabilities in 1982, 1989, and 1994.

Out of pocket Payments and ADL Status. Table 7 presents statistics on out of pocket payment amounts made by older people with disabilities. The top panel presents data for 1982. It shows, for example, that an average of \$259 was spent in a month by all people with out of pocket expenses in 1982. As expected, the amount of out of pocket payments increased with ADL dependency levels, ranging from \$128 for people with only IADL needs or 1 ADL dependency to \$544 for people with 3+ ADLs. In addition to the average monthly payment amount, Table 7 presents the payment amount at selected percentile levels for each of the disability groups. For example, half of the people with 3+ ADLs paid \$184 or more in a month (50th percentile), while 10 percent of that group paid \$1,227 or more in a month (90th percentile).

Analogous information is presented in Table 7 for 1989 and 1994, with the dollar amounts inflation-adjusted by the consumer price index for comparison purposes. The overall average monthly out of pocket payment was \$257 in 1989 and \$250 in 1994. For people with only IADL or 1 ADL dependency, the average monthly out of pocket payment was \$100 in 1989 and \$110 in 1994. In contrast, people with 3+ ADLs had monthly expenditures that averaged \$546 in 1989 and \$578 in 1994. As with 1982, the distribution of out of pocket spending was very skewed. For example, in 1994, one-half of people with 3+ ADLs spent \$40 or less in a month (50th percentile), whereas 10 percent spent more than \$1,800 in a month (90th percentile).

Table 7: Statistics on Reported Out of pocket Payments in a Month, by Disability Level ♦

(Dollar amounts inflation-adjusted to 1994 CPI)

Survey year		All people	IADL or 1 ADL	2+ ADLs	3+ADLs
1982	Number of people (1,000s)	834	461	373	249
	Average monthly payment	\$259	\$128	\$420	\$544
	Selected percentiles:				
	10th	\$9	\$9	\$12	\$15
	25th	\$23	\$18	\$38	\$61
	50th	\$61	\$46	\$123	\$184
	75th	\$207	\$92	\$436	\$552
90th	\$614	\$307	\$920	\$1,227	
1989	Number of people (1,000s)	842	424	418	276
	Average monthly payment	\$257	\$100	\$417	\$546
	Selected percentiles:				
	10th	\$6	\$6	\$12	\$12
	25th	\$18	\$12	\$24	\$36
	50th	\$47	\$30	\$90	\$142
	75th	\$171	\$66	\$412	\$570
90th	\$712	\$195	\$1,068	\$1,425	
1994	Number of people (1,000s)	346	181	164	97
	Average monthly payment	\$250	\$110	\$404	\$578
	Selected percentiles:				
	10th	\$5	\$3	\$5	\$5
	25th	\$10	\$10	\$10	\$10
	50th	\$30	\$24	\$40	\$40
	75th	\$113	\$60	\$316	\$680
90th	\$800	\$175	\$1,278	\$1,800	

♦ This table contains data only on people with out of pocket payments.
Source: Liu and Manton analysis of the National Long-Term Care Surveys, 1998

Although comparisons among the three years must be made with caution, data in Table 7 suggest two results. First, it appears that virtually no change occurred in the amounts of out of pocket expenses incurred by people with low levels of ADL dependency (i.e., only IADL or 1 ADL). Second, it appears that among people with high levels of ADL dependency, some increase in the amount of out of pocket expenses might have occurred among those who spent the most. For example, people with 3+ ADLs who paid the most out of pocket (e.g., at the 90th percentile

level) paid more in 1994 than in 1989 (\$1,800 versus \$1,425).

Because the NLTCs elicited out of pocket expenses for a reference month, the responses cannot be automatically extrapolated. For the purpose of simulation, however, data in Table 7 can be annualized. If expenses for the reference month were maintained over the course of a year, people with any out of pocket expenses would have spent about \$3,000 in 1994, while the subgroup of people with 3+ ADLs would have spent about \$6,900 for home care expenses in that year.

Out of pocket payments and personal characteristics. Table 8 presents out of pocket payments in 1989 and 1994 for subgroups of the older population with disabilities, according to selected personal characteristics. The characteristics were chosen because they are expected to be associated with higher than average expenses for out of pocket, home-based care. The total group of people with out of pocket payments was also sorted into three categories in terms of their ADL dependency levels. A review of the 3+ ADL subgroup serves to illustrate the findings. In comparison to the overall 1994 average of \$576 in out of pocket expenses in a month, people who were 75 years of age or older spent \$631 in a month. Unmarried individuals spent, on average, \$756, almost one-third more than the overall average. This result is consistent with an expectation that such people would not have informal assistance from a spouse, who would generally be an important caregiver. For a similar reason, people living alone had higher average out of pocket expenses (\$819) than did the average person with 3+ ADLs.

Overall, people who were incontinent had the highest average monthly out of pocket expense in both years. This finding indicates the degree to which paid care is important in the home care management of people who are incontinent. Interestingly, although people with hospital stays in the past year had higher out of pocket expenses than the average, people with a prior nursing home stay in 1994 actually had lower expenses than did those without prior nursing home stays. This latter result is counterintuitive, because one might expect use of nursing home care to be associated with worse health, beyond that controlled for by ADL dependency level. On the other hand, people with prior nursing home stays might be receiving more home health care from other paid sources such as Medicare or Medicaid, which would offset the need for out of pocket payments. Finally, urban residency is associated with slightly higher out of pocket payments, possibly because of higher prices in such areas.

Table 8: Average Out of pocket Payments in a Month by Selected Characteristics of People with Disabilities Age 65+ and Disability Levels

(Dollar amounts inflation-adjusted to 1994 CPI)

Characteristic	1989				1994			
	All people	IADL or 1 ADL	2+ ADLs	3+ ADLs	All people	IADL or 1 ADL	2+ ADLs	3+ ADLs
Overall average	\$257	\$100	\$417	\$546	\$250	\$110	\$404	\$576
75 years old or older	\$287	\$97	\$476	\$607	\$272	\$101	\$428	\$631
Female	\$276	\$102	\$460	\$596	\$262	\$124	\$404	\$597
Unmarried	\$281	\$108	\$459	\$626	\$301	\$119	\$500	\$756
Living alone	\$247	\$90	\$465	\$675	\$327	\$140	\$530	\$819
\$10,000+ income	\$277	\$83	\$442	\$556	\$229	\$126	\$360	\$578
Incontinent	\$407	\$211	\$423	\$520	\$372	\$26	\$418	\$528
Prior nursing home use	\$327	\$111	\$424	\$535	\$155	\$76	\$207	\$191
Prior hospital use	\$344	\$88	\$506	\$583	\$268	\$160	\$362	\$501
Urban residence	\$273	\$101	\$453	\$614	\$254	\$123	\$412	\$605

Source: Liu and Manton analysis of the National Long-Term Care Surveys, 1998

V. Discussion

Although expansion of publicly financed home and community-based long-term care is currently not on the agenda before either the Congress or the Administration, it is an issue that will undoubtedly be revisited in the future. The projected growth of the older population, particularly when the “baby boom” cohorts reach older age, foreshadows an increasing demand for long-term care services. Our finding that the disability rates among older people declined in recent years suggests the possibility that the future demand for long-term care services may be less than it would be otherwise. It will be important, however, to closely monitor future changes in the prevalence of disability. Notwithstanding the recent changes in disability rates, the projected increases in the number of older people in the U.S. still imply that long-term care must receive policy attention in coming years.

Besides the number of older people with disabilities and the recent declines in disability rates, our analysis identified recent changes in the sources and amounts of home care received by the older population with disabilities. Such patterns are important because they indicate how use of currently available public and private resources has been changing. Maintaining an elder with disabilities in his or her own home or other non-institutional setting often requires having a

combination of payer sources to meet the costs of care, in addition to the predominant presence of informal family caregiving. Focusing on changes between 1989 and 1994, we identified four important trends.

First, the proportion of older people with disabilities who relied on only paid helpers or on only informal helpers declined between 1989 and 1994, while those using both sources increased. Increases in the proportion of people relying on both sources of care were particularly large among disabled people with the highest levels of ADL dependencies (e.g., 5 ADLs). Changes in family demographics, increasing opportunity costs of informal caregivers, and increasingly more complex clinical profiles of older people with disabilities in the community are possible reasons that might explain this trend. For example, competing demands on the informal caregivers, who tend to be women, and the growing role of women in the economic workplace may account for some of the increase in reliance on both informal and paid caregivers. Consistent with this notion, a study of New York City Medicaid home care users found that the vast majority of family caregivers are female and children of the home care recipients, and that approximately 40 percent are otherwise employed full time (Hokenstad, 1998).

Despite the increased use of paid sources, our analysis did not indicate a diminished role for informal caregivers. In fact, other studies, such as the one in New York City, indicate that informal care continues to be an important source of care even for people eligible for program-sponsored services. For example, individuals with families who contribute to their care received about 40 percent of their total hours of assistance (Medicaid home care plus family care) from family members.

Second, between 1989 and 1994 Medicare coverage for home care continued to increase, while Medicaid coverage declined. Notably, while Medicare coverage of nursing helpers leveled off, there was a sizable increase in Medicare coverage for ADL and IADL helpers. This finding is consistent with Medicare home health use changes – more visits per person, and more visits by aides who tend to perform ADL or IADL services. It is also consistent with the rapid expansion in Medicare home health care spending after 1990, resulting from a liberalization of coverage guidelines (Scanlon, 1998).

Coverage by Medicaid, the other principal source of public funding for home care services, might have declined during this period because of states' increased interest in "maximizing Medicare" as a source of financing for services that might otherwise have been paid by Medicaid. Several studies have found that Medicare and Medicaid expenditures were inversely related (Kenney, Rajan, and Soscia, 1998; Cohen and Tumlinson, 1997). It should be noted, however, that Medicare is considered the primary payer when both Medicaid and Medicare cover the same services.

As a result of growing Medicare expenditures for home health, the 1997 Balanced Budget Act (BBA) contained several provisions that were intended to sharply reduce Medicare home health care spending. As the provisions take effect in coming years, it will be important to monitor the extent to which state Medicaid programs respond to Medicare reductions, as well as determine if the 1997 BBA provisions result in increased burden for older people with disabilities and their

families. Medicaid services often cannot substitute for reductions in Medicare, because many Medicare beneficiaries do not meet Medicaid's financial eligibility criteria.

Third, the number of hours of home care per week, either in terms of combined paid and informal care or only paid care, declined between 1989 and 1994. This pattern generally applied regardless of the level of ADL or IADL dependency. We do not have a clear explanation for this trend. One possible factor might be the increasing availability and use of technical and mechanical aids, such as personal emergency response systems, microwave ovens, and grab bars. Reductions in paid helper hours per week might also have been due to the shift in reliance on financing from Medicaid to Medicare, which limits coverage to people with conditions that require skilled care. Given the magnitude of the decline in hours of care received, further monitoring of this trend is warranted.

Fourth, only small changes in out of pocket payments were observed, except possibly among the most disabled and those at the high end of the spending distribution, where out-of pocket costs appeared to increase between 1989 and 1994. Despite the growth of Medicare home care, about 20 percent of older people with disabilities spend money out of pocket for home based care to compensate for ADL and IADL dependencies. In 1994, for example, people with 3+ ADLs had an average payment of \$576 in a month. Those people with the highest out of pocket payments tended not only to have the greatest disability levels, but also other characteristics that made them vulnerable. For example, people with 3+ ADLs who lived alone or were hospitalized in the preceding 12 months had higher than average out of pocket payments for home care services.

In conclusion, our analysis of trends in home care use between 1982 and 1994 found some notable changes in sources and amounts of care. Our findings continue to support the focus of prior analysts and past legislative proposals to expand public financing of home care for those with the most severe disabilities among the older population. They are the most likely to use paid services, use the most hours of paid care, and pay the most money out of pocket for such care. Not surprisingly, the most severely disabled older people and their families are also most likely to be negatively affected by contractions in publicly supported home care, as envisioned by the 1997 BBA provisions to constrain Medicare spending for home health.

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