



**Trends in Family Caregiving and
Paid Home Care for Older People
with Disabilities in the Community:
Data from the National
Long-Term Care Survey**

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Research Report

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This report is dedicated to the memory of Korbin Liu for his seminal work in home care.

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EXECUTIVE SUMMARY

I. INTRODUCTION

A companion report to this one (Redfoot and Houser 2010) demonstrates that increasing numbers of older people with disabilities are living in the community, even with very high levels of disability. Between 1984 and 2004, the older population (age 65+) in the United States grew by 28 percent, from 27 million to 35 million. At the same time, rates of disability in the older population declined. As a result of these two countervailing trends, the number of older people with disabilities remained nearly unchanged between 1989 and 2004, at approximately 7 million.

Despite the declining overall disability rate, the number of older people with disabilities living in the community has increased substantially—from 4.7 to 5.7 million, an increase of 22 percent—largely because of declining rates of institutional use. The number of older people with two or more activities of daily living (ADLs) disabilities increased by 1.2 million, an increase of two-thirds, between 1984 and 2004.

To remain independent, people with disabilities often need assistance with basic activities of daily living. Policymakers at both federal and state levels have increasingly recognized the need to provide more home and community-based services (HCBS). However, the options available to individuals remain limited, especially for those who cannot afford to purchase the home care services they need. Family caregiving—unpaid help provided primarily by spouses and children—has long been the most common source of long-term care for older people with disabilities in the United States. Understanding recent trends in the types of assistance that older people with disabilities receive and sources of payment for this assistance is increasingly important as the nation prepares for rapid growth in the older population.

II. METHODOLOGY AND PURPOSE

This paper reports data from the National Long-Term Care Survey (NLTC), a nationally representative survey of Medicare beneficiaries ages 65 and older. It examines changes in sources of assistance for older people living in the community with chronic disabilities, including the use of assistive equipment as well as care from family (unpaid) and formal (paid) caregivers between 1984 and 2004. The report includes trend data on the characteristics of family caregivers, the hours of services received, and sources of payment for formal services.

III. FINDINGS

Building on the research of Redfoot and Houser (2010), this report presents major findings from the NLTC on the growing number of older people with disabilities in the community and their care arrangements, which can be summarized by seven trends that organize the report.

Trend #1: The number of older people managing disabilities exclusively with assistive devices has increased dramatically.

- The number of community residents age 65+ with disabilities who relied on assistive equipment instead of human help with personal care or independent living activities increased by 155 percent, from about 630,000 in 1984 to 1.6 million in 2004, and now exceeds the number of older people living in institutional settings.
- Sixty percent of people with one or two limitations in ADLs relied on assistive equipment only, compared with 22 percent of those with three to four ADLs, and only a negligible proportion (0.2 percent) of people with the most severe disabilities (limitations in five or six ADLs).
- Nearly half (46 percent) of people living alone relied solely on equipment, compared with 22 percent of those living with others in a private residence and 17 percent of those living in community residential care, such as assisted living.

Trend #2: The number of older people with disabilities living in the community who received care from family, friends, or paid caregivers has changed little over time, despite substantial growth in the older population.

- The number of community residents age 65+ with disabilities receiving assistance from other individuals (family care, paid formal care, or both) remained almost the same in 1984 and 2004, at about 4.1 million.
- The proportion of the total age 65+ population who were living in the community with disabilities and receiving care from other individuals declined from about 15 percent in 1984 to 12 percent in 2004.

Trend #3: A small but growing number of community residents age 65+ with disabilities is receiving only formal services, but the vast majority continues to receive family care.

- The number of older people living in the community who receive care (family care, paid formal care, or both) has remained nearly constant from 1984 to 2004.
- In all years, at least 90 percent of older people receiving care in the community received family care, either alone or in combination with formal care; the proportion declined slightly from 95 percent in 1984 to 90 percent in 2004.
- The number of older people living in the community who received only formal services almost doubled from 210,000 in 1984 to 410,000 in 2004.
- People in residential care settings accounted for a substantial share of the growth in the number receiving only formal care after 1999.

Trend #4: Among older community residents with disabilities who received family care, the number receiving supplemental formal care increased from 1984 to 1994 but has since declined back to 1984 levels.

- The vast majority of community residents with disabilities age 65+ receives family care. The number of older people in the community receiving family care declined only slightly from 3.9 million in 1984 to 3.7 million in 2004.
- The proportion of people receiving family care who also received supplemental formal care increased from 28 percent in 1984 to 39 percent in 1994, before declining back to 28 percent by 2004.
- The people receiving family care who were most likely to also receive supplemental formal care in 2004 were those living in residential care settings (81 percent), those with no spouse and no children (44 percent), and those with five or six ADL disabilities (42 percent)
- The largest increases in people relying entirely on family care between 1994 and 2004 were among people with a spouse but no children (25 percentage points) and those with five or six ADL disabilities (16 percentage points).

Trend #5: Spouses and children continue to be the primary family caregivers; gender disparities persist.

- Eighty-five percent of older family care recipients received care from their spouses or children in 2004, up from 80 percent in 1994.
- Care by a spouse or child increased significantly among almost all subgroups of older people with disability, with the largest increase occurring among black care recipients.
- In 2004, spousal and child caregivers were providing assistance to older people who had higher levels of disability and were older than their counterparts in 1994.
- Gender disparities in caregiving persisted: Wives represented 57 percent of all caregiving spouses in 2004, as they did in 1994, while daughters represented almost two-thirds of all caregiving children in both years.

Trend #6: Private resources have been the primary payment source for services in the community.

- The most common source of payment for home care was out-of-pocket payments by the care recipients themselves. In both 1999 and 2004, 53 percent of older people and/or their families reported making such payments, with most payments being for “unskilled” help with daily activities.
- Medicare’s share as a payment source for home care was 28 percent in 1999 and 25 percent in 2004, possibly due to a shift in Medicare payment incentives for home health agencies. Medicaid’s share as a payment source increased slightly (15 percent in 1999 and 17 percent in 2004), perhaps reflecting a slightly greater emphasis on HCBS in the Medicaid program.

- Private insurance remained essentially unchanged as a source of payment, at 8 percent in 1999 and 9 percent in 2004.
- The primary source of payment for paid home care services comes from private sources (46 percent). Public sources represent only a little over one-fifth of the total (23 percent), while private and public sources together are about one-tenth. The remainder (about one-fifth) is “other/unknown,” which includes unspecified payment sources as well as no sources at all.
- Roughly 11 percent of all older community residents with disabilities received any publicly funded home care services in 2004, either alone or combination with family care. Among those with the most severe disabilities, that proportion was 23 percent.

Trend #7: The total hours of formal “skilled care” have declined, while the hours of family care have held steady.

- Older people who receive help in the community from family and/or formal sources receive substantial support, which varies by level of disability. For example, people with limitations in IADLs alone received 18 hours of care per week in 2004, compared with 66 hours per week for people with the most severe disabilities.
- Among people receiving any family care, the hours of family care remained stable at 32 hours per week in both 1994 and 2004, on average, and at 43 hours per week for people with limitations in three or more ADLs. In contrast, hours of formal care for those with three or more ADL limitations declined significantly, from 39.5 hours to 33 hours per week.
- The steepest drops in formal care occurred at higher levels of disability and in hours of nursing services provided at home by someone such as a visiting nurse, home health aide, or nurse’s aide (skilled care). Older people with disabilities who paid out of pocket for formal services received more hours of formal care and more hours of skilled care than those who did not.

IV. CONCLUSION

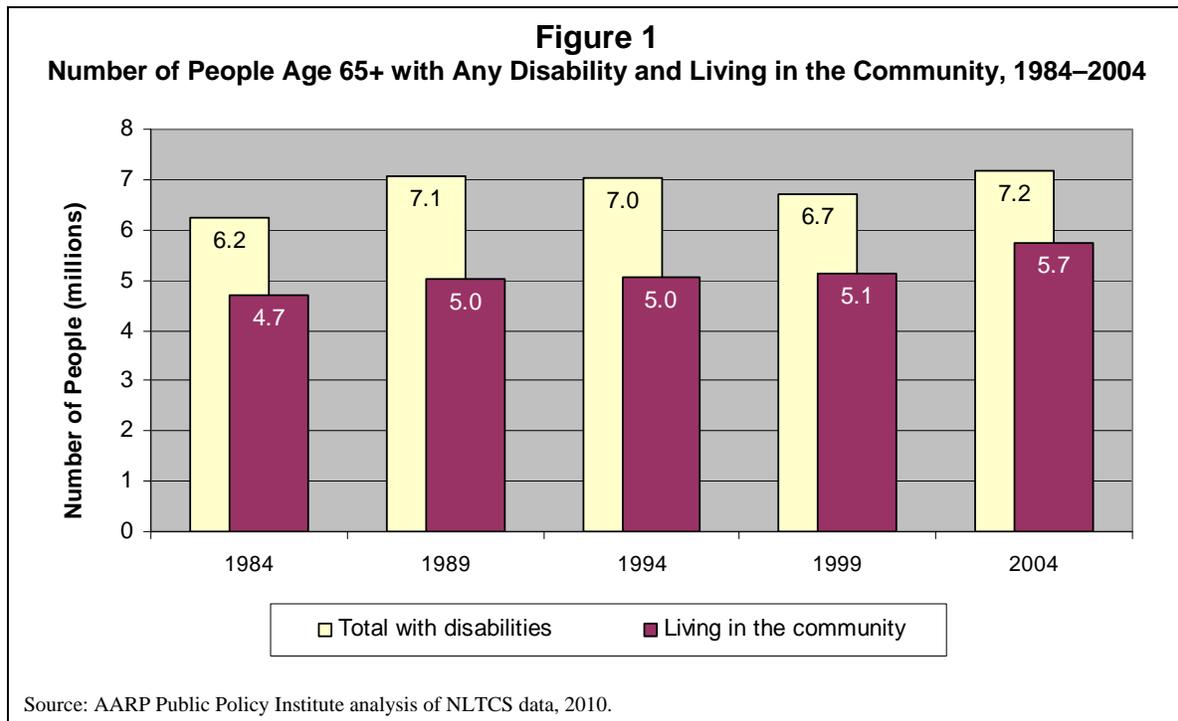
The data in this report shine light on the need for far more financial and professional support for older people with disabilities in the community. The good news is that many older people with lower levels of disabilities are increasingly able to manage in the community with simple assistive devices rather than human assistance. In addition, the declining use of institutional care is a welcome finding, but one that also means that growing numbers of older people are living in the community with higher levels of disability. Yet the share of older people receiving formal home care services remains distressingly low. Moreover, out-of-pocket payments remain the primary funding source for such services, despite the low incomes of those needing the services. Family caregivers, themselves older and caring for people with more severe disabilities, continue to be the safety net. Until the mid-1990s, family care was being increasingly supplemented by formal care, but that trend has reversed, and more family caregivers today are left to carry the load alone.

Current policy discussions often focus on promoting more home and community-based options for older people with disabilities. Clearly, most older people want to stay in their

homes and communities when disability strikes, and the data presented in this report and its companion (Redfoot and Houser 2010) document the strong trend toward greater independence among older people with disabilities. But policy discussions have been too focused on saving money and too little focused on providing the supports needed to enable older people to retain their independence. And far too little attention is paid to providing the financial, technical, and respite support needed by family caregivers who are increasingly bearing the burdens of care. Building the network of services and supports for people with disabilities and their family caregivers should be a national priority today so that tomorrow's much larger cohorts of older people can look forward to aging with dignity and independence.

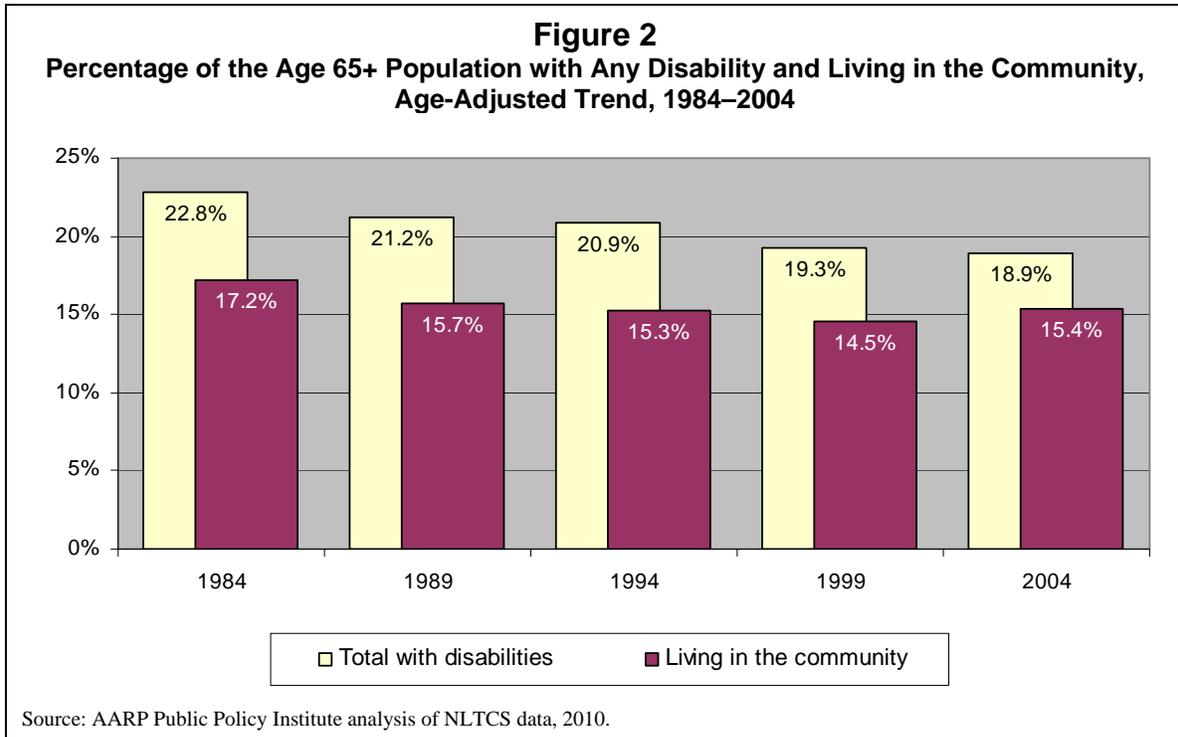
INTRODUCTION

Between 1984 and 2004, the older population (age 65+) in the United States grew by 28 percent, from 27 million to 35 million. At the same time, as noted in Redfoot and Houser (2010), rates of disability in the older population declined. As a result of these two countervailing trends, the number of older people with disabilities remained nearly unchanged between 1989 and 2004 at approximately 7 million (see figure 1).



Despite the declining overall disability rate, the number of older people with disabilities living in the community has increased substantially—from 4.7 to 5.7 million, an increase of 22 percent—because of declining rates of institutional use among older people with disabilities. The number of older people with two or more activity of daily living (ADLs) disabilities increased by 1.2 million, or two-thirds, between 1984 and 2004. Roughly the same percentage of people age 65+ was living with disabilities in the community in 2004 (15.4 percent) as in 1989 (15.7 percent) (see figure 2). Although the overall percentage decreased slightly, there was a significant decrease in the percentage with instrumental activities of daily living (IADLs)-only disabilities and a moderate increase in the proportion with ADL disabilities.¹

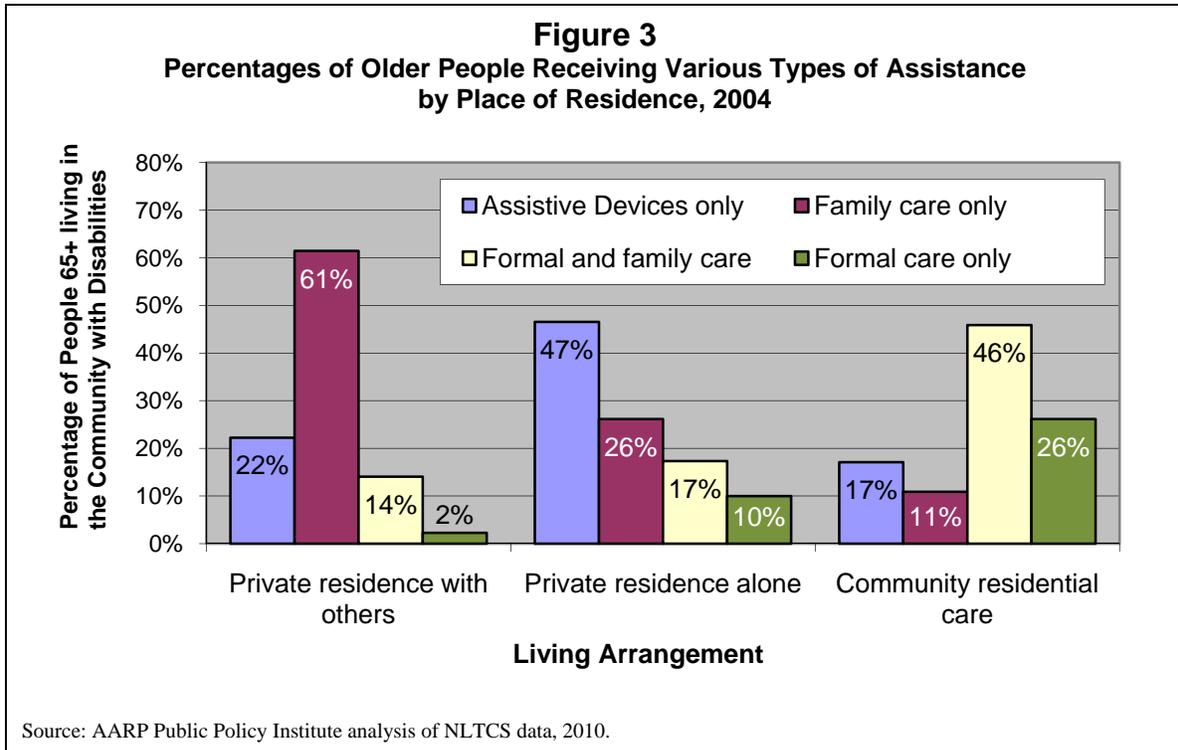
¹ For more detail on trends in demographics, disability, and the use of institutional care, see Redfoot and Houser (2010).



This report uses twenty years of data from the National Long-Term Care Survey (NLTC), a nationally representative survey of Medicare beneficiaries age 65 or older, to look more closely at the growing number of older people with disabilities in the community and the types of assistance they have been receiving. It describes, by demographics and type and severity of disability, the people who rely on various types of assistance and sources of payment for home care.

Specifically, this report analyzes trends in three types of assistance: (1) from family (unpaid) caregivers, (2) from formal (paid) caregivers, and (3) the exclusive use of assistive equipment to meet needs. The mix of assistance for the growing population of older people with disabilities in the community reflects to a large degree where they live and the supports available to them. As figure 3 shows, older people living in private residences with others tended to rely primarily on family care. Older people living in a private residence alone were most likely to rely solely on assistive devices. Those living in community residential care settings (such as assisted living) were the most likely to rely on formal paid services.

If policymakers and other stakeholders do not have accurate data on changes in the number of people using assistance to manage disabilities and how that assistance is provided, they will not be able to make informed public policy decisions.



Moreover, virtually all projections of the need for and cost of formal long-term care services depend heavily upon assumptions about potential changes in the mix of family and formal caregiving. Understanding recent trends is therefore critical for anticipating financial demands on public programs that fund formal services, including Medicaid and Medicare.

These trends also have major implications for older adults and their families. Older Americans overwhelmingly prefer assistance at home, especially if they need less than 24-hour care.² Family care (unpaid assistance provided by family caregivers and friends, usually spouses and adult children) is the primary source of support for older adults. Family care is sometimes supplemented by formal services. However, formal home care services may be unavailable or unaffordable to many people with disabilities.

² M. J. Gibson et al. (2003), p. 145.

METHODOLOGY

To measure trends in community-based care for older people, the AARP Public Policy Institute (PPI) contracted with Dr. Brenda Spillman of the Urban Institute to update data from earlier waves of the NLTCs published in prior PPI reports: (1) by Brenda Spillman and Kirsten Black in 2005 on family caregiving³ and (2) by Korbin Liu, Kenneth Manton, and Cynthia Aragon in 2000 on payment sources for home care.⁴ AARP PPI staff analyzed the data in this report on the basis of tables generated by Dr. Spillman in order to identify key trends and their implications for public policy.⁵

Estimates in this report are based on reweighted data from the five complete waves of the NLTCs that include both institutional and community residents: 1984, 1989, 1994, 1999, and 2004. The NLTCs is a nationally representative survey of Medicare beneficiaries age 65 or older that collects a wide range of information about disability, long-term care, health, and health service use by beneficiaries. For this report, we focused on survey respondents living in the community who have one or more limitations in personal care activities of daily living (ADLs) or instrumental activities of daily living (IADLs) associated with independent living.

In the NLTCs, survey respondents who indicated an ADL or IADL limitation were asked to identify all persons who help them with ADLs or IADLs. Those who received help within the last week are also asked about the number of days and hours of help received from both formal and family caregivers, as well as the sources of payment for formal care.⁶

The NLTCs also included information about family caregivers—primarily about spouses and adult children—for people with disabilities living in the community, including in assisted living settings in 1999 and 2004. While friends and relatives other than spouses and children may also provide care, the NLTCs focuses on spouses and adult children because they represent the majority of family caregivers and are the most likely primary caregivers for older adults.

In the companion piece to this report (Redfoot and Houser 2010), some multiyear data related to trends in rates of disability and institutional use are age-adjusted so as not to confound underlying trends with the changing age composition of the older population.

³ Spillman and Black (2005).

⁴ Korbin, Manton, and Aragon (2000).

⁵ See Redfoot and Houser (2010) for additional information on the NLTCs data.

⁶ Among people with disabilities reporting human help, there were some missing data about type of care arrangement: people with IADL disabilities who reported receiving help but did not identify any regular caregivers. The frequency of missing data varies by year and ranges from 0.6 to 2.6 percent of all community disabled age 65+. For the purpose of reporting total numbers—for example, a trend in the number of older people receiving family care—care arrangement data were assumed to be missing at random. The effect of this assumption is that persons with IADL disabilities who reported receiving human help but did not identify regular caregivers were assumed to have the same proportional distribution of care arrangement (family care, formal care, or both) as those with IADL disabilities who *did* report their care arrangement when estimating the total number of people having each type of care arrangement. They are *not*, however, included in the analysis of the *characteristics* of older people with disabilities having a specific type of care arrangement (family care, formal care, or both).

However, with the exception of the background and introduction, the data presented in this report have as a denominator older people who have disabilities and are living in the community, obviating the need for age-adjustment. Unless otherwise noted, all reported findings are statistically significant.

Definitions and Terminology

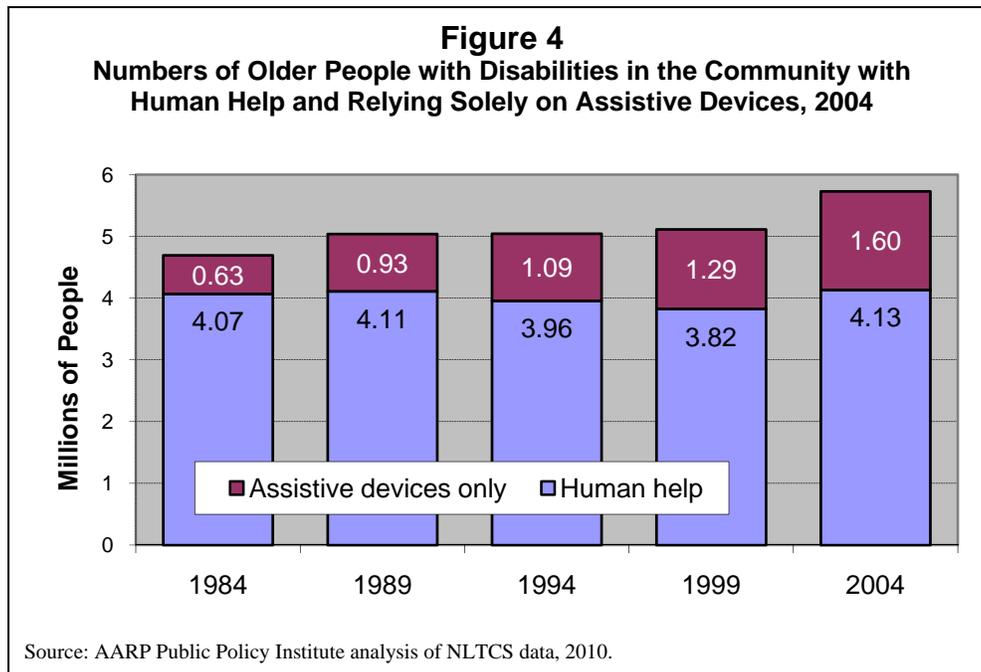
- (1) The NLTCS measures disabilities related to two types of activities: ADLs and IADLs. ADLs are measured in six basic personal care activities: bathing, dressing, toileting, getting in or out of bed, indoor mobility, and eating. IADLs are measured in eight activities related to managing a household and living independently: light housework, laundry, meal preparation, shopping, getting around outside, managing money, taking medications, and using the telephone. Chronic disabilities are defined as receiving help or supervision or using equipment to perform an ADL for at least three months, or being unable to perform an IADL without help because of health or disability for at least three months.⁷
- (2) “Caregivers” in the NLTCS are defined as persons who provide ADL or IADL assistance to older people with chronic disability. The term “family caregiver” refers to unpaid caregivers, who are predominantly spouses and adult children. Note that the survey does not ask relatives if they are paid. The term “formal caregiver” refers to paid professionals, including those who provide “skilled” nursing care at home, as well as those who provide “unskilled” help with other types of daily activities.
- (3) In the NLTCS, care recipients were asked whether they receive nursing services at home from someone such as a visiting nurse, home health aide, or nurse’s aide. There is no way to further classify the care provider or the type of nursing services received. We refer to paid helpers providing these services as providing “skilled” care, while other paid helpers provide “unskilled” care.
- (4) The most common assistive devices reported by NLTCS respondents were mobility devices, such as walkers, canes, and wheelchairs, and bathing and toileting aides used by people with ADL disabilities. The data from the NLTCS were not collected in a way that consistently identifies assistive equipment users who have only IADL disabilities.
- (5) “Community residential care” in the NLTCS refers to people living in settings with three or more unrelated persons who do not receive “substantial nursing care of any kind.” Because this definition excludes assisted living residents who receive some nursing services, this approach may understate the number of people living in residential care settings outside of nursing homes.⁸

⁷ There is a slight difference in the way the NLTCS treats ADL and IADL limitations. Those with ADL limitations must have received assistance in the past week or used assistive equipment, while those with IADL limitations must have been unable to do the activity if they needed to.

⁸ A more extensive discussion of the definitional issues related to “institutional” and “community residential care” can be found in Redfoot and Houser (2010), pp. 4 and 40.

TREND #1: THE NUMBER OF OLDER PEOPLE MANAGING DISABILITIES EXCLUSIVELY WITH ASSISTIVE DEVICES HAS INCREASED DRAMATICALLY.

The number of people age 65+ with disabilities in the community relying solely on assistive devices now exceeds the number of older people in institutional settings.



HIGHLIGHTS

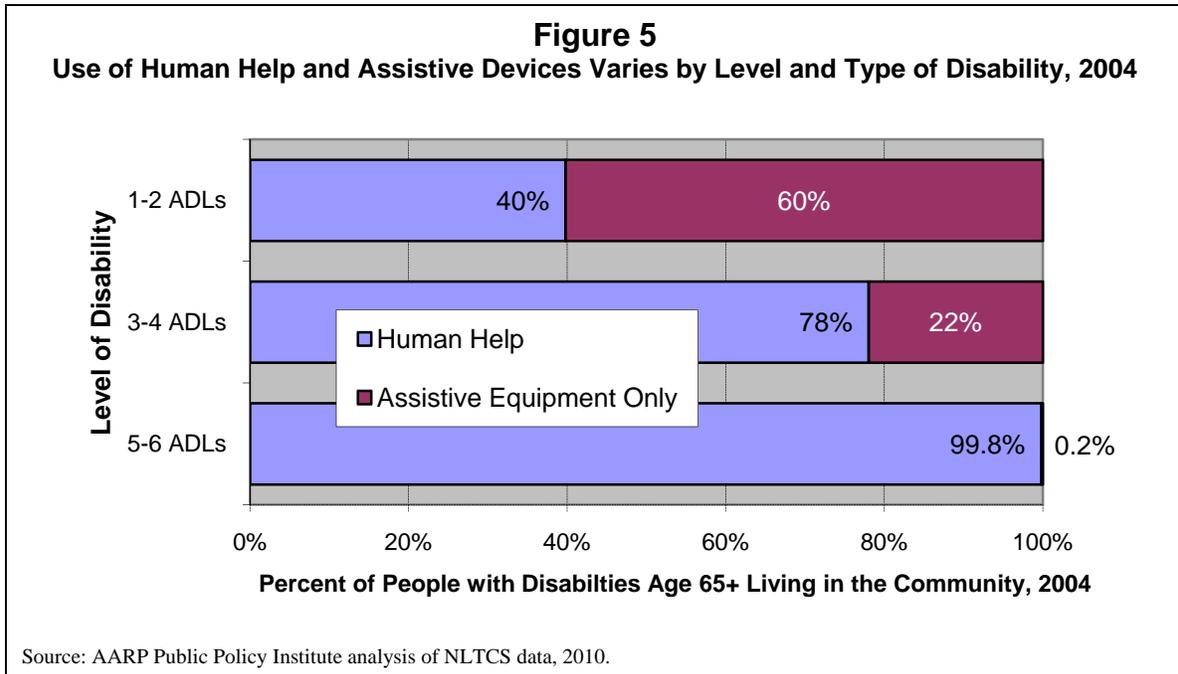
- The number of community residents age 65+ with disabilities who rely on assistive equipment instead of human help with personal care or independent living activities has increased by 155 percent, from about 630,000 in 1984 to 1.6 million in 2004, and now exceeds the number of older people living in institutional settings.
- Sixty percent of people with one or two limitations in ADLs relied on assistive equipment only, compared with 22 percent of those with three to four limitations in ADLs, and less than 1 percent of people with limitations in five or six ADLs.
- Nearly half (46 percent) of people living alone rely solely on equipment, compared with 22 percent of those living with others in a private residence, and 17 percent of those living in community residential care, such as assisted living.

DETAILED TREND

Over the twenty years between 1984 and 2004, the number of older people living in the community who are managing disabilities through simple assistive devices, such as walkers and bathing aids, has increased steadily. As shown in figure 3, the number of older community residents with disabilities who rely on assistive equipment instead of

human help with personal care or independent living activities has increased by 155 percent, from about 630,000 to 1.6 million.

These NLTCs findings are consistent with research by Freedman and colleagues (2005) using a different data source.⁹ They found that the use of assistive technology increased substantially among older Americans with difficulty in ADLs between 1992 and 2001, and that shifts toward use of assistive technology accounted for about half of the decline in numbers of people dependent on personal care over this period.



WHO USES ASSISTIVE DEVICES ONLY?

Older people with lower levels of ADL disability are far more likely to manage without human help, instead relying upon assistive devices (see figure 5). Three out of five (60 percent) of people age 65+ living in the community with one or two ADLs limitations rely on assistive technology only, compared with 22 percent of those with three to four ADL limitations and less than 1 percent of people with five or six ADL limitations. While the increasing reliance on assistive equipment raises concerns about unmet need, other research has shown that this is not the case: unmet need among people relying on equipment alone was lower than unmet need among people using both human help and assistive equipment.¹⁰

⁹ Freedman et al. (2005). The 1992–2001 Medicare Current Beneficiary Survey was used in this analysis.

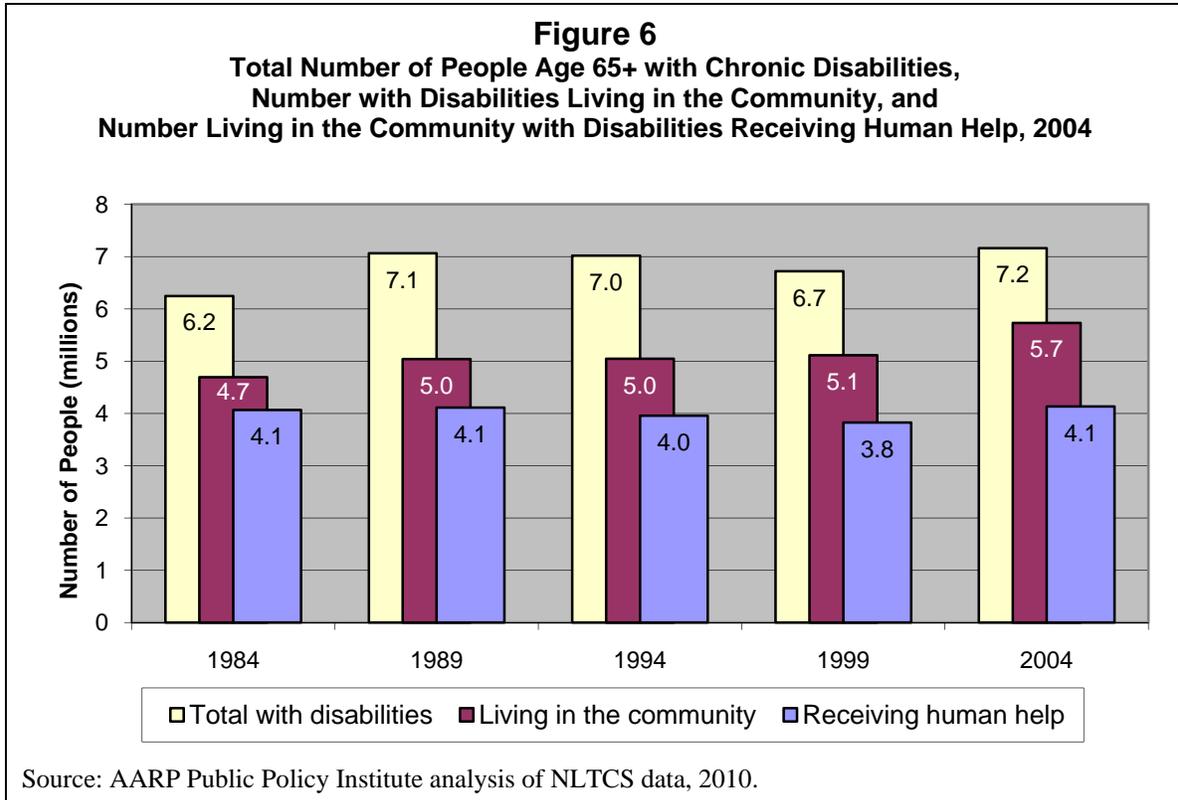
¹⁰ Spillman (2005). Bathing was the activity with the strongest upward trend in independent use of equipment, but significant increases also occurred for the other mobility-related disabilities in ADLs and IADLs: toileting, getting around inside the home, and getting around outside the home.

The increase in the use of assistive devices alone to maintain independence occurred among almost all subgroups of older people with disabilities, including those age 85+ (see table 1). The only exception was among people with the most severe level of disabilities: fewer than 1 percent of those with five to six ADL limitations relied completely on assistive technology in both 1994 and 2004.

Table 1			
Utilization of Assistive Devices by Older People with Disabilities Living in the Community, by Various Characteristics, 1994 and 2004			
Characteristic	Proportion Receiving No Human Help*		
	1994	2004	
All Community Disabled	22.6%	29.4%	**
Male	25.0%	28.9%	
Female	21.4%	29.6%	**
Black	15.5%	18.2%	
White or Other	23.4%	30.3%	**
65–74	26.4%	28.8%	
75–84	24.6%	32.8%	**
85+	13.4%	24.8%	**
IADL Only	15.8%	24.1%	**
1–2 ADLs	50.4%	60.2%	**
3–4 ADLs	14.6%	22.0%	**
5–6 ADLs	0.2%	0.2%	
2+ ADLs	14.1%	19.1%	**
Has Spouse or Child	21.5%	29.0%	**
Spouse and Child	21.0%	26.4%	**
Spouse only	16.5%	26.7%	
Child only	22.2%	30.9%	**
Neither Spouse nor Child	29.5%	32.1%	
Private Residence Alone	31.4%	46.5%	**
Private Residence with Others	17.1%	22.2%	**
Community Residential Care		17.1%	
<p>* This group is predominantly people who manage all chronic disability with assistive devices but also includes the small proportion who have only IADL disability but did not identify anyone regularly providing assistance.</p> <p>** Statistically significant increase from 1994 to 2004.</p>			

TREND #2: THE NUMBER OF OLDER PEOPLE WITH DISABILITIES LIVING IN THE COMMUNITY WHO RECEIVED CARE FROM FAMILY, FRIENDS, OR PAID CAREGIVERS HAS CHANGED LITTLE OVER TIME, DESPITE SUBSTANTIAL GROWTH IN THE OLDER POPULATION.

The proportion of the 65+ population living in the community with disabilities and receiving care declined from about 15 percent in 1984 to 12 percent in 2004.



HIGHLIGHTS

- The number of community residents age 65+ with disabilities receiving assistance from other individuals (family care, paid formal care, or both) remained almost the same in 1984 and 2004, at about 4.1 million.
- The proportion of the total 65+ population who were living in the community with disabilities and receiving care from other individuals declined from about 15 percent in 1984 to 12 percent in 2004.

DETAILED TREND

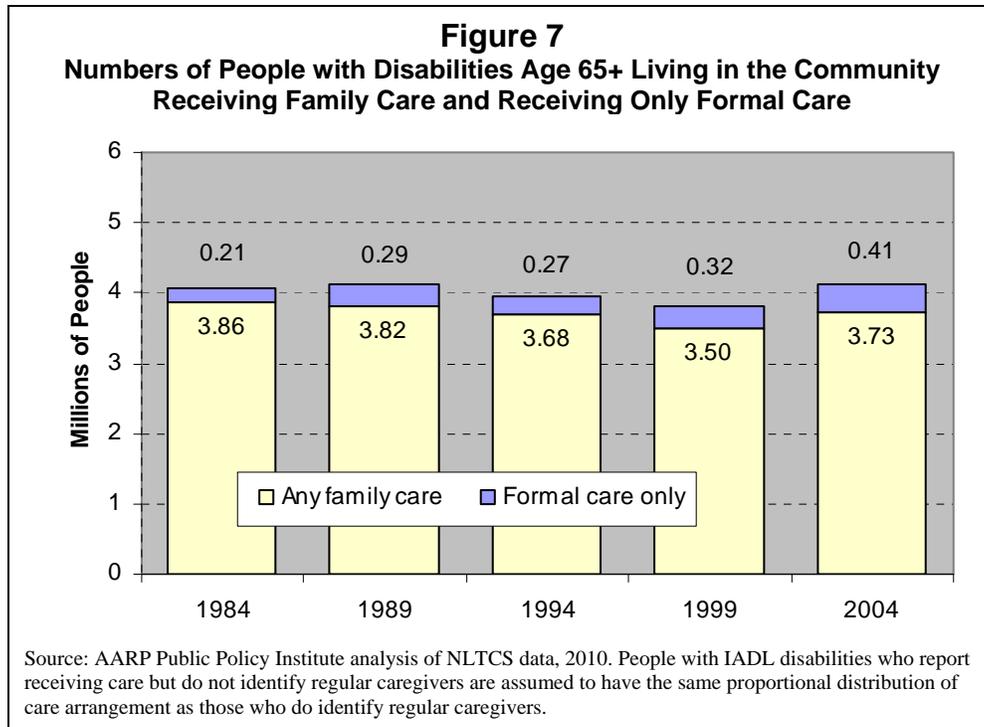
As shown in figure 6, the number of older people with disabilities living in the community increased from about 4.7 million in 1984 to about 5.7 million in 2004. As seen in trend 1 and figure 4, over the same period, the number of older community residents managing their disability entirely through the use of assistive equipment

increased by nearly a million. The combination of these two trends means that the number of older community residents with disabilities who are receiving personal care has not changed substantially between 1984 and 2004, remaining at about 4.1 million. Because of the overall increase in the older population, the proportion of the 65+ population who were living in the community with disabilities and receiving any care from other individuals (family care, paid formal care, or both) declined from 15 percent in 1984 to 12 percent in 2004.

People living in the community with disabilities who are receiving help with activities of daily living are a distinct and often vulnerable population. Changes in patterns of who is providing this care—primarily unpaid family caregivers and paid formal providers—are of particular interest in policy discussions about long-term care because of their cost implications. Although the number of older people with disabilities living in the community receiving care has not changed significantly, the type and amount of human help that these 4.1 million people receive has changed significantly. Trends 3 through 7 discuss the changing picture of long-term services and supports (LTSS) in the community.

TREND #3: A SMALL BUT GROWING NUMBER OF COMMUNITY RESIDENTS AGE 65+ WITH DISABILITIES IS RECEIVING ONLY FORMAL SERVICES, BUT THE VAST MAJORITY CONTINUES TO RECEIVE FAMILY CARE.

The number of people 65 or older with disabilities living in the community and receiving only formal services almost doubled, from 210,000 in 1984 to 410,000 in 2004.



HIGHLIGHTS

- The number of older people living in the community who receive care (family care, paid formal care, or both) has remained nearly constant from 1984 to 2004.
- In all years, at least 90 percent of older people receiving care in the community received family care, either alone or in combination with formal care; the proportion declined slightly from 95 percent in 1984 to 90 percent in 2004.
- The number of older people living in the community who received only formal services almost doubled from about 210,000 in 1984 to about 410,000 in 2004.
- People in residential care settings accounted for a substantial share of the growth in the number receiving only formal care between 1999 and 2004.

DETAILED TREND

A small but steady trend is the growing proportion of older people with disabilities who receive only formal, paid services to address their needs. On average, the number of older

people receiving only formal services increased by 10,000 each year between 1984 and 2004. Though the percentage increase is large, the actual numbers are still a small proportion of the total number of people receiving care. See table A1 in the appendix for more detail on the characteristics of people receiving only formal care.

WHO RECEIVES FORMAL CARE ONLY?

In 2004, the groups of older people receiving care who were most likely to rely entirely on formal care were those who—

- Had neither a spouse nor a child (33 percent)
- Were living in residential care settings, such as assisted living (32 percent)
- Were living alone (19 percent)

Most of the growth in community-dwelling older people relying only on formal services after 1999 (the NLTCS only began measuring care in these settings in that year) was among those living in residential care settings, such as assisted living. However, the rapid growth of assisted living and other residential care settings in recent years has not meant that families no longer provide substantial support. In 2004, 68 percent of older people who received formal care in residential care settings in the community also received family care.

WHO RECEIVES FAMILY CARE?

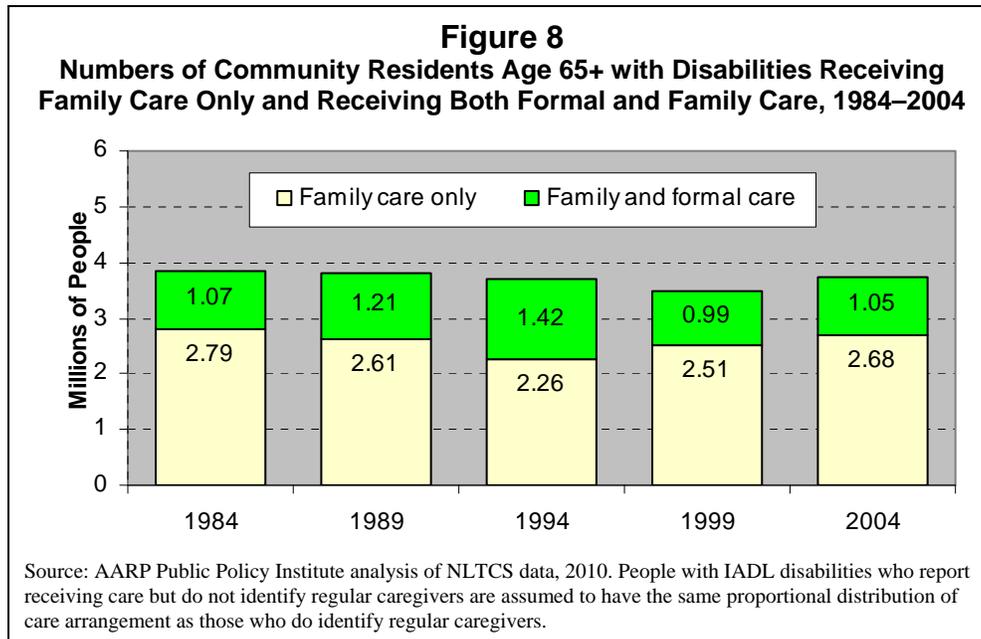
In 2004, family care continued to be more prevalent than formal care for nearly all groups of older people receiving human help. The only exception was older people living in residential care settings in the community, 87 percent of whom received formal care.

The groups most likely to receive any family care (that is, least likely to receive only formal care) in 2004 were those who—

- Were living with others (97 percent)
- Had a spouse (96 percent)
- Had three or four ADL limitations (93 percent)

TREND #4: AMONG OLDER COMMUNITY RESIDENTS WITH DISABILITIES WHO RECEIVED FAMILY CARE, THE NUMBER RECEIVING SUPPLEMENTAL FORMAL CARE INCREASED FROM 1984 TO 1994 BUT HAS SINCE DECLINED BACK TO 1984 LEVELS.

A larger proportion of family care recipients were relying entirely on their family caregivers in 2004 than in 1994.



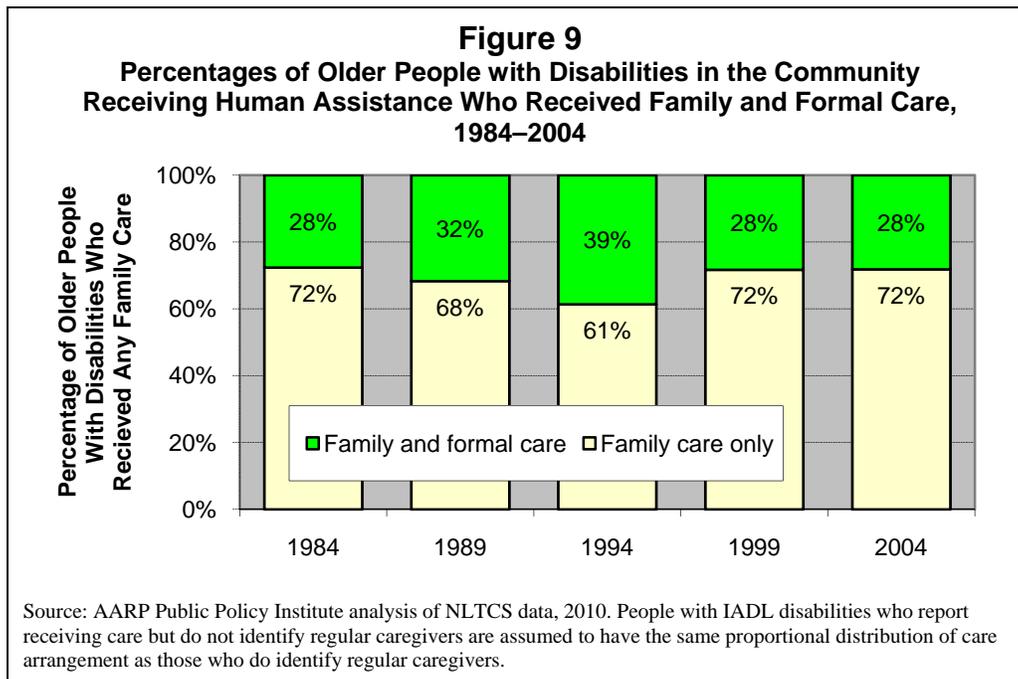
HIGHLIGHTS

- The vast majority of community residents with disabilities age 65+ receive family care. The number of older people in the community receiving family care declined only slightly from 3.9 million in 1984 to 3.7 million in 2004.
- The proportion of people receiving family care who also received supplemental formal care increased from 28 percent in 1984 to 39 percent in 1994, before reverting back to 28 percent by 2004.
- In 2004, the people receiving family care who were most likely to also receive supplemental formal care in were those living in residential care settings (81 percent), those with no spouse and no children (44 percent), and those with five or six ADL disabilities (42 percent).
- The largest increases in people relying entirely on family care between 1994 and 2004 were among people with a spouse but no children (25 percentage points) and those with five or six ADL disabilities (16 percentage points).

DETAILED TREND

The earlier trend toward more formal care in support of those receiving family care (1984–1994) has reversed in recent years (1994–2004).

Between 1984 and 1994, fewer older people with disabilities in the community relied solely on family care, as growing amounts of formal care supplemented the family care. However, those trends reversed between 1994 and 2004. As shown in figure 9, the proportion of people receiving family care who also received formal care changed significantly during this period, increasing from 28 percent in 1984 to 39 percent in 1994. But the proportion of older people receiving family care who also received formal care reverted back to the 1984 level of 28 percent by 2004.



Relatively little research has focused on changes in the mix of family and formal care or on the characteristics of older adults receiving both types of assistance. Yet this population typically has high levels of need, relying on formal providers in addition to family caregivers. Disproportionate shares of this group have the most severe disabilities (five or six ADL disabilities), are age 85+, and are women. See table A2 in the appendix for more detail on the characteristics of people receiving supplemental formal care.

These data show that formal care increasingly supplemented family care up until 1994, after which more family caregivers again were carrying the load alone. Formal care has the important functions not only of helping to ensure that older people receive all the care they need but also relieving some of the stress on family caregivers and helping to prevent caregiver “burnout.” A substantial body of literature indicates that family

caregivers often experience high levels of stress,¹¹ and that caregiver stress is a strong predictor of earlier nursing home placement.¹²

WHO RECEIVES BOTH FAMILY AND FORMAL CARE?

The people receiving family care who were most likely to also receive supplemental formal care in 2004 were—

- Living in residential care (81 percent)
- With neither spouse nor children (44 percent)
- With limitations in five or six ADL disabilities (42 percent)
- Living alone (40 percent)
- Age 85+ (38 percent)
- With children but no spouse (34 percent)
- Women (32 percent)

The biggest declines in use of supplemental formal care between 1994 and 2004, a possible cause for concern because of the increased burden on family caregivers caring for these individuals without formal support, were among those who—

- Had a spouse but no children (25 percentage points)
- Had limitations in five or six ADLs (16 percentage points)
- Were men (13 percentage points)

While formal support for family caregivers has declined since 1994, family care for older members with disabilities remains robust, even when formal care is available. In 2004, 72 percent of all older people with disabilities and 79 percent of those with the most severe disabilities receiving paid care also received family care. Conversely, only 28 percent of people receiving family care were also receiving formal care in 2004. Even among those with the most severe disabilities, fewer than half are receiving formal support.

WHO RECEIVES FAMILY CARE ONLY?

As a result of the decline in the share of people receiving both formal care and family care after 1994, a larger proportion of family care recipients were relying entirely on their family caregivers in 2004 than in 1994: 72 percent in 2004 compared with 61 percent in

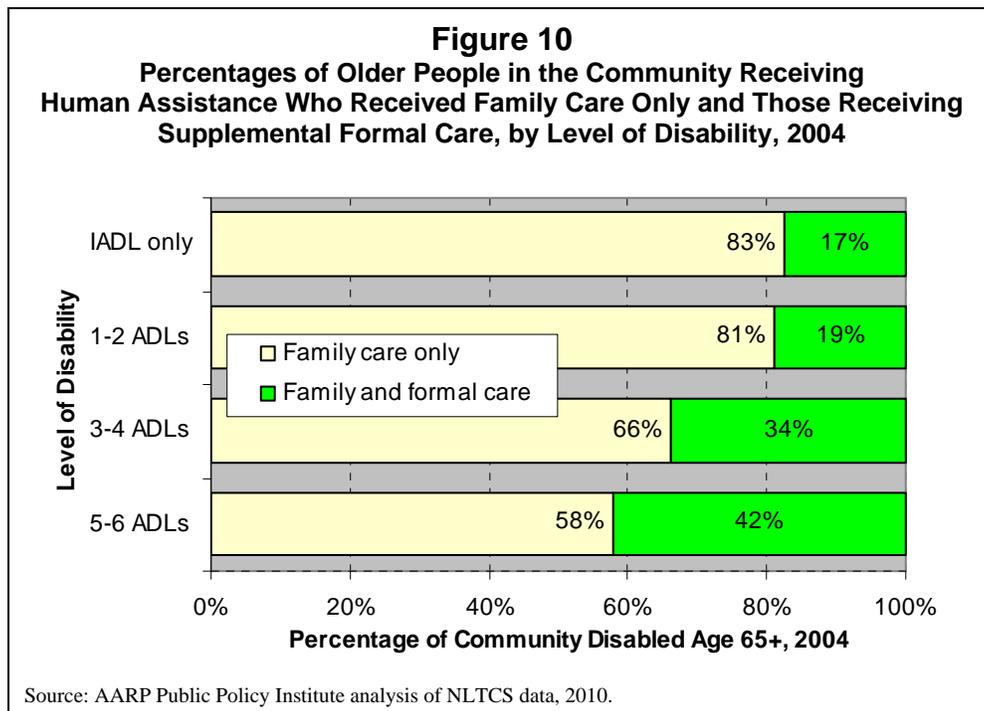
¹¹ Schulz and Sherwood (2008).

¹² Gaugler et al. (2003).

1994 (see figure 8). The following groups receiving family care were most likely to receive no formal support in 2004:

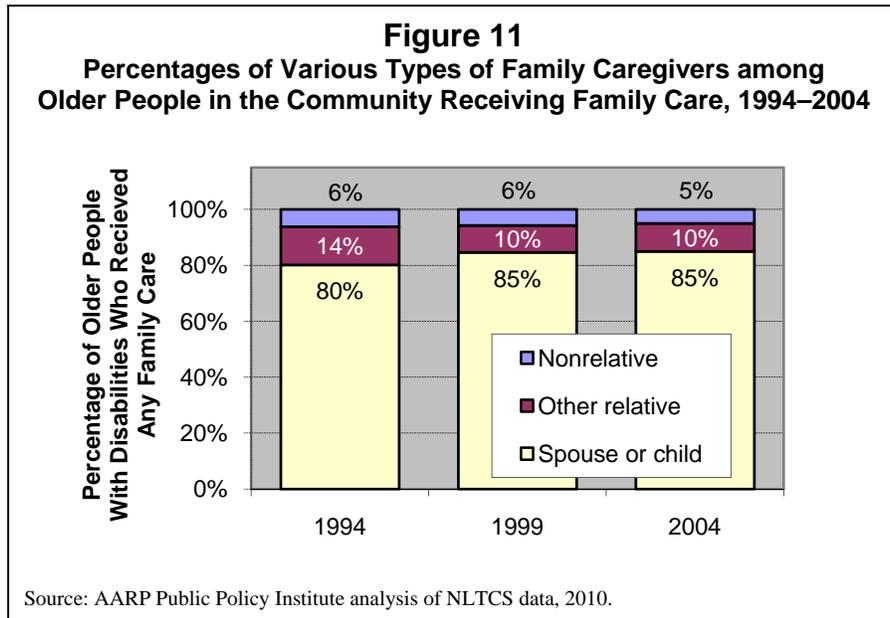
- Those with IADL limitations only (83 percent)
- Those with both a spouse and one or more children (82 percent)
- Living with others (81 percent)
- Those age 65–74 (81 percent)
- Those with one or two ADL disabilities (81 percent)
- Men (80 percent)

In addition, older people living with others were less likely to receive both formal support and family care than those living alone, and older people with close relatives (spouse or children) were less likely to receive supplemental formal care than those without. In every subgroup except people living in residential care settings, more than half of those receiving family care did not receive supplemental formal care in 2004. People with the most severe disabilities (five or six ADL disabilities) continued to be more likely to receive supplemental formal care than those with less severe disabilities. However, as shown in figure 10, fewer than half (42 percent) of those with the highest levels of disabilities (five or six ADL disabilities) received formal care in addition to family care.



TREND #5: SPOUSES AND CHILDREN CONTINUE TO BE THE PRIMARY FAMILY CAREGIVERS; GENDER DISPARITIES PERSIST.

More than half of family caregivers were providing help to spouses or parents with three or more ADL disabilities in 2004.



HIGHLIGHTS

- Eighty-five percent of older family care recipients received care from their spouses or children in 2004, up from 80 percent in 1994.
- Care by a spouse or child increased significantly among almost all subgroups of older people with disability, with the largest increase occurring among black care recipients.
- In 2004, spousal and child caregivers were providing assistance to older people who had higher levels of disability and were older than their counterparts in 1994.
- Gender disparities in caregiving persisted: Wives represented 57 percent of all caregiving spouses in 2004, as they did in 1994, while daughters represented almost two-thirds of all caregiving children in both years.

DETAILED TREND

Spouses and children continue to be the most common source of family care. Among older people with chronic disabilities who received family care, 85 percent received care from family caregivers in 2004, up from 80 percent in 1994. Care by a spouse or adult child increased significantly among almost all subgroups of community-dwelling older people with disabilities. The largest increase occurred among blacks, from 67 percent in 1994 to 78 percent in 2004. The proportion of primary caregivers who were relatives other than spouses or children declined from 14 percent to 10 percent.

Among community-dwelling older people with disabilities receiving family care, 99 percent of those with both a spouse and one or more children received care from their spouse or child, as did 95 percent of those with only a spouse and 88 percent those with only a child. Only older people with neither a child nor a spouse commonly received care from another relative or a nonrelative (see table 2).

Living family members	Primary Caregiver		
	Spouse or Child	Other Relative	Nonrelative
Spouse and Child	99%	1%	0.4%
Spouse Only	95%	3%	2%
Child Only	88%	7%	5%
Neither Spouse nor Child		73%	27%

Source: AARP Public Policy Institute analysis of NLTC data, 2010.

Family caregivers in 2004 were providing assistance to people age 65 or older who had higher levels of disability and were older than their counterparts in 1994:

- Care recipients were older in 2004 than in 1994. The proportion of family care recipients who were 85+ increased from 29 percent in 1994 to 34 percent in 2004. The proportion who were 75+ increased from 72 percent to 80 percent.
- More than half (53 percent) of caregiving spouses and children were providing help to a spouse or parent with three or more ADL disabilities in 2004, up from 46 percent in 1994.

CHARACTERISTICS OF SPOUSES AND CHILDREN PROVIDING CARE, 1994–2004

In addition to caring for older and more disabled relatives in 2004 than a decade earlier, caregivers themselves have become older. In 2004, 52 percent of spousal caregivers were age 75 or older, up from 47 percent in 1994, although this was not a statistically significant increase. Caregiving children were also more likely to be older: 81 percent were 45 or older in 2004, up from 73 percent in 1994.

Gender disparities in caregiving persisted. Wives represented 57 percent of all caregiving spouses in 2004, approximately the same as 1994, while daughters represented almost two-thirds of all caregiving children in both years.

Fewer caregivers were providing help to older people living alone, which may reflect the increase in older people with disabilities relying on equipment only. The proportion of spouses and children providing help to older people living alone decreased from 25 percent in 1994 to 19 percent in 2004.

Geographic proximity of caregiving children to their parents remained almost the same. In both 1994 and 2004, more than one-third of caregiving children lived in the same residence with the care recipient, more than a quarter lived fewer than 10 minutes away, and about 20 percent lived within 11 to 30 minutes. Only about 15 percent lived more than 30 minutes away.

A sizable proportion of adult children were providing care to both older parents and to their own children in both 1994 and 2004. The proportion of adult children providing

care to older parents who also had children under age 15 fell from 20 percent (about one in five caregivers) in 1994 to 16 percent (about one in six caregivers) in 2004, although this was not a statistically significant decline.

See tables A4 to A6 in the appendix for more information on the characteristics of family caregivers.

POTENTIAL FAMILY CAREGIVERS, 1994–2004

The NLTCs collect information on the spouse and living children of all people with disability in the sample, whether or not they are currently providing care. These close relatives can be considered potential family caregivers.¹³ The “supply” of potential family caregivers increased by 12 percent between 1994 and 2004, nearly keeping pace with the number of older people with disabilities in the community over these ten years (which grew by 14 percent). The growth in number of potential caregivers reflects both declining rates of widowhood in old age and the fact that current older cohorts are the parents of the baby boomers.¹⁴

The demand for family caregiving involves not only the number of people with disabilities in the community but also their level of disability and whether or not they can manage their disabilities without family care. These factors have all changed between 1994 and 2004. The number of older people with disabilities in the community has increased, particularly at higher levels of disability, increasing the need for family caregivers. At the same time, more have been able to manage their condition through assistive devices and formal services alone, reducing the demand for the family caregivers. When these factors are combined (see table 3), the number of older people with two or more ADL limitations receiving human help increased 19 percent from 1994 to 2004) and the number receiving family care increased by 15 percent.

The 12 percent increase in the supply of potential family caregivers nearly kept pace with this increased demand. However, this is not likely to be the case going forward. The cohort of people with disabilities age 65+ in 2004 are largely the parents of the baby boom generation. Future age 65+ cohorts have fewer children, and so will likely have fewer potential caregivers.

¹³ Spillman and Pezzin (2000).

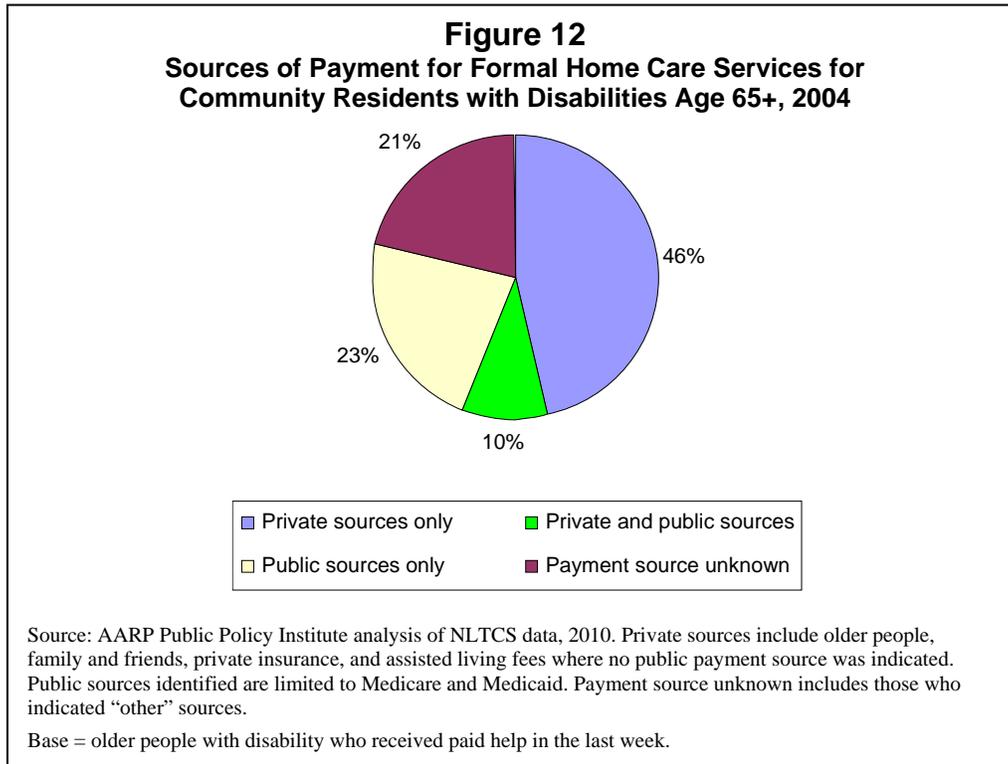
¹⁴ Carlson (2008).

Trends in Family Caregiving and Paid Home Care for Older People with Disabilities in the Community:
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Table 3			
Change in Supply of Potential Family Caregivers and Demand for Family Caregiving, 1994–2004			
	Number (millions)		% Change
	1994	2004	
Supply of Potential Family Caregivers			
Spouses and children of people 65+ with disabilities living in the community	18.3	20.4	+12%
Demand for Family Caregiving			
People 65+ with disabilities in community	5.0	5.7	+14%
With 2+ ADL limitations	2.4	3.0	+27%
Receiving human help	4.0	4.1	+4%
With 2+ ADL limitations	2.0	2.4	+19%
Receiving family care	3.7	3.7	+1%
With 2+ ADL limitations	1.9	2.2	+15%
Source: AARP Public Policy Institute analysis of NLTCS data, 2010.			

TREND #6: PRIVATE RESOURCES HAVE BEEN THE PRIMARY PAYMENT SOURCE FOR SERVICES IN THE COMMUNITY.

Only 11 percent of community residents with disabilities received any publicly funded home and community-based care in 2004, including just 23 percent of those with the most severe levels of disabilities (five or six ADL disabilities).



HIGHLIGHTS

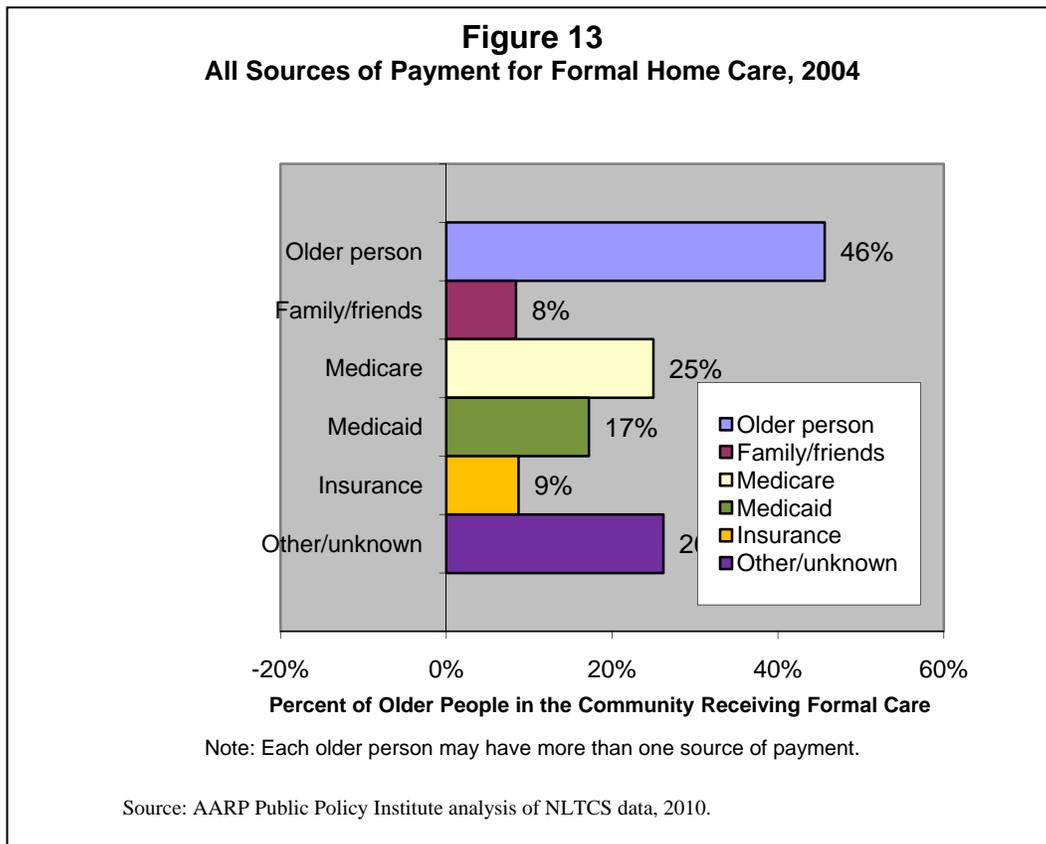
- The most common source of payment for home care was out-of-pocket payments by the care recipients themselves. In both 1999 and 2004, 53 percent of older people and/or their families reported making such payments.
- Medicare's share as a payment source for home care was 28 percent in 1999 and 25 percent in 2004, possibly due to a shift in Medicare payment incentives for home health agencies. Medicaid's share as a payment source increased slightly (15 percent in 1999 and 17 percent in 2004), perhaps reflecting a slightly greater emphasis on HCBS in the Medicaid program.
- Private insurance remained essentially unchanged as a source of payment, at 8 percent in 1999 and 9 percent in 2004.
- Private sources are the primary source of payment for paid home care services (46 percent). Public sources represent a 23 percent, while private and public sources together are about one-tenth. The remainder (about one-fifth) is "other/unknown," which includes unspecified payment sources as well as no sources at all.

- Roughly 11 percent of all older community residents with disabilities received any publicly funded home care services in 2004, either alone or combination with family care. Among those with the most severe disabilities, that proportion was 23 percent.

DETAILED TREND

Who actually pays for home care services is one of the most important questions in long-term care policy. Policymakers fear that the long-term care needs of an aging population will overwhelm state and federal budgets. However, out-of-pocket payments by older people or their families are the most commonly reported source of funding for home care. Twice as many older people use only private funds as a payment source for home care (46 percent) as rely entirely on public sources (23 percent), while 10 percent use a combination of public and private sources (see figure 12). For the remainder, about one-fifth of all formal home care recipients, the payment source is classified as “other/unknown.” No significant changes in payment sources occurred between 1999 and 2004, and the distribution of payment sources did not differ significantly by disability level.

Figure 13 shows more specifically the various sources of payment for formal services in the community. Out-of-pocket payments by older people and their families were by far the most common source of funding for home care services in 2004, followed by Medicare and Medicaid. Because the share of home care paid by private long-term care (LTC) insurance remains quite small, the vast majority of private payments are made by individuals and their families out of pocket.



Combining the number of older people living in the community receiving formal long-term care services with those receiving formal long-term care in institutions such as nursing homes, about 2.9 million people age 65+ received formal LTC in 2004, or 8 percent of the age 65+ population. Formal LTC recipients were nearly equally split between institutional and community settings: 1.43 million in institutions and 1.46 million in the community.¹⁵ While most nursing home residents used public sources of payment, either alone or in conjunction with private sources (about 68 percent),¹⁶ most community residents did not (only 41 percent).¹⁷ Together, about 4.5 percent of the age 65+ population received publicly funded LTC in 2004.

Only a small proportion of older people with disabilities living in the community received any publicly funded HCBS in 2004. Just 11 percent received any publicly funded HCBS, including just 23 percent of those with the most severe disabilities (five or six ADL disabilities).¹⁸ These data include people receiving formal care only as well as those receiving formal care to supplement family care.

As figure 14 indicates, older people are much more likely to pay out-of-pocket for “unskilled” helpers (53 percent) than for skilled helpers (20 percent).¹⁹ On the other hand, more older people use Medicare to pay for skilled services (35 percent) than to pay for unskilled services (17 percent). Medicare limits coverage for unskilled services in the home to people with conditions that require skilled nursing care or physical, speech-language, or occupational therapy, so it is not surprising that it was more likely to pay for skilled services than unskilled services. Medicare was the most common public payment source, reported as a source of payment by 25 percent of older community residents with disabilities receiving formal services.

Medicaid was a payment source for about 15 percent of care recipients receiving skilled and unskilled help in 2004. Family members, friends, and “other or unknown” were more common sources of payment for skilled helpers than for unskilled helpers.

¹⁵ See Redfoot and Houser (2010) for NLTC institutional population; the 1.46 million receiving HCBS includes 410,000 receiving formal care only (figure 4 in this report) and 1.05 million receiving both family and formal care (figure 8).

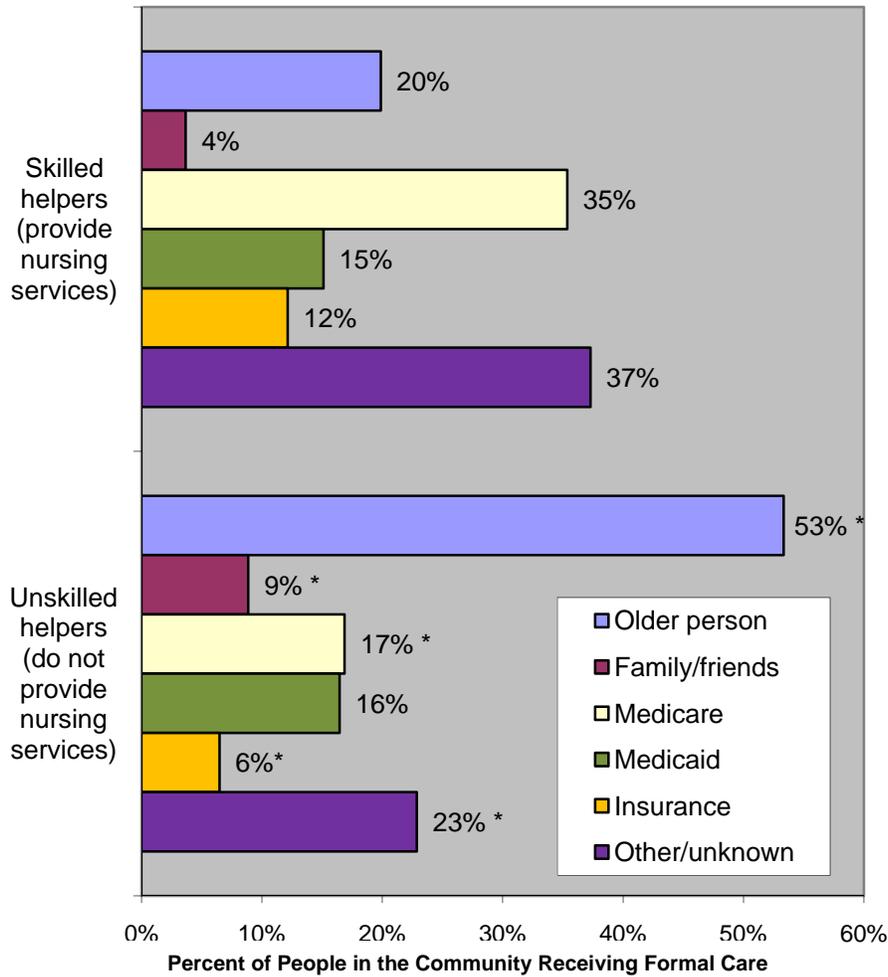
¹⁶ Sixty-eight percent of nursing home residents age 65+ used public sources of payments, including Medicaid, Medicare, Veterans Administration, and other public sources (AARP Public Policy Institute analysis of data from the 2004 National Nursing Home Survey, 2009).

¹⁷ Because of the large number of respondents indicating “other/unknown” as a source of payment, there is significant uncertainty in this figure, but among disabled community dwellers age 65+ receiving formal LTC and reporting public and/or private sources of payment, 41 percent used public sources (alone or in conjunction with private sources), and 59 percent used only private funds.

¹⁸ As stated in note 15, those reporting “other/unknown” were assumed to have the same public/private ratio as those reporting public and/or private sources.

¹⁹ Skilled care is defined as nursing services at home from someone such as a visiting nurse, home health aide, or nurse’s aide, while unskilled care is defined as other types of assistance with daily activities.

Figure 14
Sources of Payment for Formal Home Care by Skilled and Unskilled Helpers, 2004



Note: Each older person may have more than one source of payment.
* difference between skilled and unskilled helpers is statistically significant at $p = 0.05$

Source: AARP Public Policy Institute analysis of NLTCS data, 2010.

We also examined trends in the sources of payment for home care between 1999 and 2004 reported by older people who received paid home care services, and compared trends in payment for skilled and unskilled helpers.

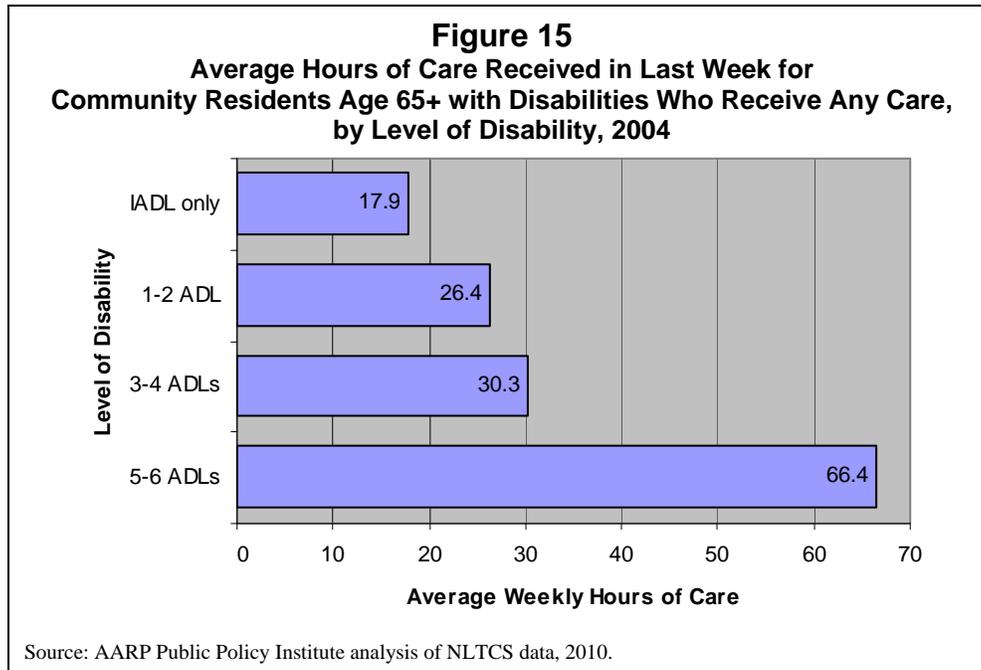
- The proportion of older people with disabilities and their family or friends who reported making out-of-pocket payments remained stable at about 53 percent in both years, with the majority of these payments for unskilled helpers.
- The proportion of older people who said private insurance was a source of payment for HCBS remained stable at 8 percent in 1999 and 9 percent in 2004.

- Medicaid's share as a payment source increased slightly, from 15 percent to 17 percent, perhaps reflecting a slightly greater emphasis on HCBS in the Medicaid program, although this change was not statistically significant.
- Medicare's share as a payment source for home care services declined from 28 percent in 1999 to 25 percent in 2004, although this change was not statistically significant.

Although the decline in the share of older people in the community who were supported by Medicare was not statistically significant, we believe that this change reflects a real decline in Medicare's role in funding home health care. Medicare's share differs markedly when comparing the funding of skilled and unskilled care. The amount of care from workers providing nursing services at home declined significantly between 1999 and 2004, while the amount of unskilled care held steady (see trend 7, below). In short, the decline in overall Medicare funding for home health services appears to be due to a dramatic decline in the amount of skilled home care paid for by the program.

TREND #7: THE TOTAL HOURS OF FORMAL “SKILLED CARE” HAVE DECLINED WHILE THE HOURS OF FAMILY CARE HELD STEADY.

Among all older community residents with disabilities, the hours of skilled care dropped by approximately half between 1999 and 2004.



HIGHLIGHTS

- Older people who receive help in the community from family and/or formal sources receive substantial support, which varies by level of disability. For example, in 2004 people with limitations in IADLs alone received 18 hours of care per week, compared with 66 hours per week for people with the most severe disabilities.
- Among people receiving any family care, the hours of family care remained stable at 32 hours per week in both 1994 and 2004, on average, and at 43 hours per week for people with limitations in three or more ADLs. In contrast, hours of formal care for those with three or more ADL limitations declined significantly, from 39.5 hours to 33 hours per week.
- The steepest drops in formal care occurred at higher levels of disability and in hours of nursing services provided at home by someone such as a visiting nurse, home health aide, or nurse’s aide (skilled care). Older people who paid out of pocket for formal services received both more hours of formal care and more hours of skilled care than those who did not.

DETAILED TREND

In 2004, older people with disabilities receiving care in the community received an average of 37 hours of care per week from all family and formal sources, with a median of 21 hours. These averages mask large variations by severity of disability, with hours of

care increasing steeply at the most severe levels of disability (see figure 15). People with five or six ADL limitations received an average of 66 hours of care per week. There were no significant differences in hours of care at any disability level between 1999 and 2004.

Tables 4 and 5 compare total weekly hours of care among those receiving any family or any formal care for the entire sample and for people with three or more limitations. Older community residents with disabilities receiving family care in 2004 received an average of 32 hours per week of unpaid care. Those with three or more ADL limitations receiving family care received 43 hours per week of unpaid care.

Older community residents with any disability receiving formal care in 2004 received an average of 27 hours per week of paid care. For those with three or more ADL disabilities, the average was 33 hours per week.

Table 4			
Average Hours of Care Received by Older Community Residents with Any Disabilities			
	1999	2004	Change
Average Hours of Family Care among Older People with Disabilities Receiving Any Family Care			
Family Care	31.6	32.1	0.5
Average Hours of Formal Care among Older People with Disabilities Receiving Any Formal Care			
Any formal Care	30.1	26.9	-3.2
Skilled Care*	10.0	4.9	-5.1
Unskilled Care**	20.1	22.0	1.9
Average Hours of Formal Care among Older People with Disabilities Receiving Any Out-Of-Pocket Formal Care			
Any Formal Care	31.3	30.2	-1.1
Skilled Care*	7.1	4.9	-2.2
Unskilled Care**	24.2	25.3	1.2
Source: AARP Public Policy Institute analysis of NLTCS data, 2010.			
* From workers providing nursing services at home.			
** From workers not providing nursing services at home.			

Between 1999 and 2004, the hours of family care provided did not change significantly, while the amount of formal, paid care declined. Among all older community residents with disabilities, the average amount of formal care declined from 30 to 27 hours per week. The decline in formal care was even more pronounced among those with three or more ADLs, from 39 to 33 hours per week.

The declines in formal care were entirely for skilled care. Among all older community residents with disabilities and among those with three or more ADL disabilities, the hours of skilled care dropped by approximately half between 1999 and 2004. The decline in skilled care was somewhat less pronounced among those who paid, at least in part, out of pocket, which means that the decline in the amount of skilled care received was especially pronounced among those who relied entirely on publicly funded and other nonpersonal sources of payment.

Trends in Family Caregiving and Paid Home Care for Older People with Disabilities in the Community:
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Table 5			
Average Hours of Care Received by Older Community Residents with Three or More ADL Disabilities			
	1999	2004	Change
Average Hours of Family Care among Older People with 3+ ADLs Receiving Any Family Care			
Family Care	42.9	43.1	0.2
Average Hours of Formal Care among Older People with 3+ ADLs Receiving Any Formal Care			
Any Formal Care	39.5	33.4	-6.2
Skilled Care*	13.3	6.7	-6.6
Unskilled Care**	26.2	26.7	0.5
Average Hours of Formal Care among Older People with 3+ ADLs Receiving Any Out-of-pocket Formal Care			
Any Formal Care	45.7	40.5	-5.3
Skilled Care*	12.0	7.6	-4.4
Unskilled Care**	33.7	32.8	-0.9
Source: AARP Public Policy Institute analysis of NLTC data, 2010.			
* From workers providing nursing services at home.			
** From workers not providing nursing services at home.			

DISCUSSION

The NLTCs data suggest that our nation's long-term care policies have yielded both positive and negative results. Growing numbers of older people with disabilities are living in the community rather than in institutions, even at the highest levels of disability (Redfoot and Houser 2010), a positive trend that is at least partly due to policies that support greater funding for home and community-based services. Many more older people, especially those with less severe disabilities, are now managing their disabilities with assistive devices. The small number receiving only paid formal care has increased, likely due in large part to the growth in assisted living.

But the NLTCs data also point to a continuing policy failure to keep pace with the growing needs of the majority of older people living with disabilities in the community and their family caregivers. Older people living in the community with disabilities and receiving help from family caregivers were older and more disabled in 2004 than in previous years, while their family caregivers were less likely to be supplemented by formal services. Among those who did receive any formal support, the hours of formal care also declined between 1999 and 2004.

ASSISTIVE DEVICES

One positive trend continued steadily from 1984 to 2004. Assistive equipment is increasingly helping older people with disabilities live independently in the community without human assistance. While those most likely to rely solely on assistive equipment had less severe ADL disabilities and were more likely to live alone, increased use occurred at all levels of disability except the most severe. Most research indicates that the increased reliance on assistive devices has not been due to a proliferation of complex assistive technologies but rather to an increased use of simple devices for mobility, bathing, and toileting—devices such as walkers, canes and crutches, tub or shower seats, and wheelchairs.²⁰

Increased use of equipment occurred even though public programs provide relatively little funding for assistive devices. Until 2005 (after the most recent NLTCs data were collected), Medicare reimbursement policies excluded devices that were designed for use outside of the home (such as portable wheelchairs) or those used mainly to enhance functioning or safety (such as grab bars). The NLTCs findings are important not only because of the improved independence of people with disabilities but also because of the potential of assistive devices to reduce the demands of care on families and public programs. Clearly more research is warranted to determine the types of devices and home modifications that would improve the quality of life for older people with disabilities living in the community and enable less reliance on paid and unpaid supportive services.

²⁰ Spillman (2005).

DECLINING FORMAL CARE SUPPORT

Over two decades of change in the American society and economy, the role of family caregiving in providing the overwhelming majority of long-term care for older people has changed very little. Among people receiving human assistance in the community, the mix of family and formal care was much the same in 2004 as in 1984; the proportion of older people receiving family care who also received supplemental formal care increased from 1984 and 1994, but reversed sharply between 1994 and 2004 despite greater labor force participation by women, who serve as family caregivers much more frequently than men.

One factor that has enabled family caregivers to shoulder a greater share of LTSS without formal support is that the supply of potential family caregivers has remained high. Most people with disabilities age 65+ in 2004 are the parents of the baby boom generation; the number of living spouses and children was higher in 2004 than in 1994 and 1999. This will not be the case for future cohorts of older people, who have fewer children than the parents of baby boomers. Decreased supply of potential caregivers, combined with continuing trends of increased labor force participation and geographic dispersion of families, suggests that the increased reliance on family caregiving alone without formal support may be unsustainable.

What accounts for the decline in formal care to supplement family caregiving from 1994 to 2004? Changes in the Medicare payment system and program may explain much of this decline. Between 1989 and 1994, the number of home health users and the use of services grew rapidly, sparking program changes to control utilization and costs, which began with a new interim payment system in 1997. Between 1997 and 2000, Medicare spending for home health services fell by half, from \$17.7 billion to \$8.5 billion. Over the same period, the number of Medicare home health beneficiaries declined by 30 percent, from 3.6 million to 2.5 million, while the number of home health visits fell by 65 percent.²¹ By 2004, Medicare home health spending had climbed back to \$11.5 billion and the number of users to 2.8 billion, still much less than seven years earlier.²²

During this period, Medicare also shifted from cost-based reimbursement to a prospective payment system that makes a standard payment for a 60-day episode of care. Under the prospective payment system, the payment for patients who receive rehabilitation therapy services is about double the amount for patients who do not. As a result, from 1998 to 2008, physical therapy visits increased by 51 percent while home health aide visits declined by 70 percent.²³ These findings are consistent with the NLTCS data showing a steep decline in the share of those receiving formal care in addition to family care after 1994, especially the significant decline in skilled care hours between 1999 and 2004.

The data presented in this report suggest that, if patient care did not suffer as a result of reduced support from formal care sources, increased reliance on family caregivers is likely to have played an important role in minimizing adverse consequences. Reliance on

²¹ MedPAC (March 2010), Table 3B-1.

²² Ibid., Table 3B-3.

²³ Ibid., Table 3B-8.

informal family caregivers is likely to increase even further as future changes take effect in Medicare payment for home health services.

FAMILY CAREGIVERS

Declining formal support to supplement family caregiving may create a number of problems. Some older people may not be receiving sufficient care from family caregivers alone. Previous research has shown that people with disabilities who receive family care report unmet needs for help more frequently than those receiving no help at all.²⁴ Moreover, a large body of literature indicates that family caregivers often experience high levels of stress with negative health consequences and express needs for more help from professionals.²⁵ Providing support to caregivers should be a critical part of public policy discussions related to LTSS.

The specific decline in skilled care support found in the NLTCS data is of particular concern because family caregivers are often called upon to perform complex health-related tasks, such as monitoring symptoms, coordinating care, and managing home infusion equipment. These forms of assistance are not captured in ADL and IADL measures such as those used in the NLTCS. Yet caregivers are often not confident about their ability to manage the chronic illnesses that generally cause or accompany severe disabilities, and perceive a lack of support from health care professionals.²⁶

While many men are caregivers, the NLTCS data show no significant changes in gender patterns, with women still being more likely to be the primary caregivers for both spouses and older parents. In addition, male care recipients receiving family care from their spouses were less likely to be receiving supplemental formal care than female care recipients, suggesting that women are also more likely to take on the entire burden of caregiving without outside support. The persistent gender disparity in caregiving is an important dimension in policy issues relating to caregivers, as women disproportionately bear the health and economic costs of caregiving. Increased morbidity and adverse health consequences for caregivers are well documented, and caregiving has been found to reduce paid work hours for middle-aged women by about 41 percent and can affect job benefits and retirement savings as well.²⁷

WHO PAYS FOR LONG-TERM SERVICES AND SUPPORTS?

The lack of adequate financing for long-term care services in the home is a formidable problem for many Americans with disabilities and their families. Many cannot afford private long-term care insurance. Those who need formal services but are not eligible for Medicare home health services or Medicaid must locate and pay home care providers themselves, either through agencies or by hiring independent providers. Many individuals

²⁴ Caro and Stern (1995); Lima and Allen (2001); and Gibson and Verma (2006).

²⁵ Schulz and Sherwood (2008); and Yedidia and Tiedemann (2008).

²⁶ Given, Sherwood, and Given (2009).

²⁷ Johnson and Lo Sasso (2006).

who have substantial home care expenses are of advanced age, in frail health, and have limited financial resources. The companion to this report (Redfoot and Houser 2010) found that three out of five older people living in the community with two or more ADL disabilities reported annual incomes of less than \$20,000.

The NLTCs data in this report show that the primary source of financing for paid home care comes from older care recipients and their families, despite their limited resources. These findings are at odds with many aggregate national sources, such as National Health Expenditure data, which may underestimate private payments. Such sources may not include fees for care in assisted living, which are predominantly paid privately, or payments for unskilled HCBS.²⁸

While Medicaid is the primary source of financing for nursing home care in the United States, its role as a payer for home care is more limited. However, both the number of older people and adults with physical disabilities receiving Medicaid-funded HCBS and spending for these services have been increasing steadily in the past decade.²⁹ Hence, it is somewhat surprising that little increase was seen in Medicaid as a source of payment for home care (15 percent in 1999 and 17 percent in 2004). The growing numbers of older people living with disabilities in the community with low incomes documented in our reports highlight the need for an expansion in eligibility criteria and funding for HCBS in the Medicaid program. In 2007, only 27 percent of Medicaid long-term care dollars for older people and adults with physical disabilities supported HCBS, and only five states spent more on HCBS than on institutional care.³⁰

²⁸ For example, National Health Expenditure data (in which home health care + nursing home care is often used to describe sources of payment for LTSS) exclude assistive devices not billed through home health agencies and any nonmedical HCBS (most of which would be classified as “unskilled care” in the NLTCs).

²⁹ Houser, Fox-Grage, and Gibson (2009).

³⁰ Ibid.

CONCLUSION

The data in this report shine light on the changing characteristics and care arrangements of older people with disabilities living in the community, and underscore a need for expansion of publicly supported HCBS. The good news is that many older people with lower levels of disabilities are increasingly able to manage in the community with simple assistive devices rather than human assistance. The declining use of institutional care is also a welcome finding, but also it means that growing numbers of older people are living in the community with higher levels of disability. Yet the share of older people with disabilities receiving formal home care services remains very low, and in fact has declined significantly since 1994. Moreover, out-of-pocket payments by older people remain the primary funding source for such services, despite the low incomes of those needing the services; those not paying for services out of pocket have seen the greatest declines in the amount of care received. Family caregivers, themselves older and caring for people with more severe disabilities, continue to be the primary providers of LTSS, and since 1994, are more likely to carry the burden of caregiving alone, without supplemental formal care.

Policy discussions often focus on promoting more home and community-based options for older people with disabilities. Most older people want to stay in their homes and communities when disability occurs, and the data presented in this report and its companion document the strong trend toward greater independence among older people with disabilities. But policy discussions have been too focused on saving money and too little focused on providing the supports needed to enable older people to retain their independence. And far too little attention is paid to providing the financial, technical, and respite support needed by family caregivers who are increasingly bearing the burdens of care. Building the network of services and supports for people with disabilities and their family caregivers should be a national priority today so that tomorrow's much larger cohorts of older people can look forward to aging with dignity and independence.

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APPENDIX

Table A1			
Percentage of People Age 65+ Receiving Human Help Who Receive Only Formal Care by Various Characteristics, 1994 and 2004			
	Percentage Receiving Only Formal Care		
	1994	2004	
All People with Disabilities Age 65+ in the Community Receiving Human Help	6.9%	9.8%	**
Male	4.1%	8.7%	**
Female	8.1%	10.3%	*
Black	6.6%	8.0%	
White or Other	6.9%	10.0%	**
65-74	5.8%	9.3%	*
75-84	6.5%	8.7%	
85+	8.8%	11.8%	*
IADL Only	7.7%	11.8%	**
1-2 ADLs	7.6%	9.1%	
3-4 ADLs	8.2%	6.8%	
5-6 ADLs	4.0%	10.1%	**
2+ ADLs	5.5%	9.1%	**
Has Spouse or Child	4.7%	7.1%	**
Spouse and Child	2.2%	3.7%	
Spouse Only	4.7%	3.4%	
Child only	6.6%	9.8%	**
Neither Spouse nor Child	22.5%	32.5%	**
Private Residence Alone	16.6%	18.7%	
Private Residence with Others	2.0%	2.9%	
Community Residential Care		31.5%	
Numerator: People age 65+ with disabilities living in the community receiving only formal care.			
Denominator: People age 65+ with disabilities living in the community receiving any human help.			
**(*) statistically significant increase from 1994 to 2004 at 95% (90%) confidence level in a two-tailed test.			

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Table A2			
Percentage of People Age 65+ Receiving Family Care Who Also Receive Formal Care by Various Characteristics, 1994 and 2004			
	Percentage Receiving Supplemental Formal Care		
	1994	2004	
All People with Disabilities Age 65+ in the Community Receiving Family Care	38.8%	28.4%	**
Male	33.5%	20.4%	**
Female	41.1%	32.1%	**
Black	37.0%	27.0%	*
White or Other	39.0%	28.5%	**
65-74	30.7%	18.5%	**
75-84	38.8%	28.3%	**
85+	48.9%	37.7%	**
IADL Only	29.7%	17.3%	**
1-2 ADLs	29.9%	18.9%	**
3-4 ADLs	41.2%	33.8%	
5-6 ADLs	57.9%	42.0%	**
2+ ADLs	47.5%	36.4%	**
Has Spouse or Child	37.4%	27.0%	**
Spouse and Child	29.6%	18.1%	**
Spouse Only	47.7%	23.0%	**
Child Only	42.6%	33.9%	**
Neither Spouse nor Child	50.4%	44.0%	
Private Residence Alone	54.1%	39.8%	**
Private Residence with Others	32.1%	18.6%	**
Community Residential Care		80.8%	
Numerator: People age 65+ with disabilities living in the community receiving only formal and family care. Denominator: People age 65+ with disabilities living in the community receiving any family care.			
**(*) statistically significant increase from 1994 to 2004 at 95% (90%) confidence level in a two-tailed test.			

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Table A3					
Care Arrangements and Use of Assistive Technology for People Age 65+ with Disabilities Living in the Community, 2004					
	Number of People (millions)	Distribution by Care Arrangement			
		No Human Help *	Family Care Only	Family and Formal Care	Formal Care Only
Number of People (millions)		1.68	2.62	1.04	0.40
All Community Disabled	5.73	29.4%	45.6%	18.1%	6.9%
Male	1.79	28.9%	51.7%	13.2%	6.2%
Female	3.94	29.6%	42.9%	20.2%	7.3%
Black	0.46	18.2%	54.9%	20.3%	6.5%
White or Other	5.27	30.3%	44.8%	17.9%	7.0%
65–74	1.60	28.8%	52.6%	12.0%	6.6%
75–84	2.47	32.8%	44.0%	17.4%	5.8%
85+	1.66	24.8%	41.3%	25.0%	8.9%
IADL Only	1.78	24.1%	55.4%	11.6%	8.9%
1–2 ADLs	1.69	60.2%	29.3%	6.8%	3.6%
3–4 ADLs	1.07	22.0%	48.1%	24.6%	5.3%
5–6 ADLs	1.19	0.2%	52.0%	37.7%	10.1%
2+ ADLs	2.99	19.1%	46.7%	26.8%	7.3%
Has Spouse or Child	5.10	29.0%	48.1%	17.8%	5.1%
Spouse and Child	1.92	26.4%	58.0%	12.9%	2.7%
Spouse Only	0.21	26.7%	54.5%	16.3%	2.5%
Child Only	2.97	30.9%	41.2%	21.1%	6.8%
Neither Spouse nor Child	0.63	32.1%	25.7%	20.2%	22.1%
Private Residence Alone	1.79	46.5%	26.1%	17.3%	10.0%
Private Residence with Others	3.40	22.2%	61.4%	14.0%	2.3%
Community Residential Care	0.54	17.1%	10.9%	45.9%	26.2%

This group is predominantly people who manage all chronic disability with assistive devices but also includes the small proportion of people who have only IADL disability but did not identify anyone regularly providing assistance.

Table A4			
Proportion of Caregiving Children, by Characteristic			
	1994	2004	
Age of Disabled Older Person			
65–74	27.7%	19.0%	**
75–84	39.3%	44.7%	**
85+	33.0%	36.3%	
Race of Disabled Older Person			
Black	11.4%	11.4%	
White or other	88.6%	88.6%	
Older Person's Disability Type/Level			
IADL only	38.5%	32.3%	**
1–2 ADLs	16.3%	14.9%	
3–4 ADLs	16.9%	21.3%	**
5–6 ADLs	28.3%	31.6%	
Older Person's Living Arrangement			
Private residence alone	37.3%	27.6%	**
Private residence with others	62.7%	64.1%	
Community residential care		8.2%	
Age of Child			
<35	5.4%	2.9%	**
35–44	22.0%	16.0%	**
45–54	35.5%	37.4%	
55–64	25.7%	32.1%	**
65–74	10.6%	10.5%	
75+	0.8%	1.2%	
Marital Status of Child			
Not married	38.6%	42.5%	*
Married	61.4%	57.5%	*
Relationship to Recipient			
Daughter	64.7%	65.4%	
Son	35.3%	34.6%	
Distance to Recipient			
Resident	36.2%	38.4%	
Within 10 minutes	28.8%	26.8%	
11 to 30 minutes	21.0%	19.9%	
30 to 60 minutes	7.9%	7.1%	
60 minutes to 24 hours	5.7%	5.7%	
More than 24 hours	0.5%	2.0%	**
Child Care Responsibilities			
Has children under age 15	19.6%	15.9%	**
No children under age 15	80.4%	84.1%	**
**(*) statistically significant change from 1994 to 2004 at 95% (90%) confidence level in a two-tailed test.			

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Table A5			
Proportion of Caregiving Spouses, by Characteristic			
	1994	2004	
Age of Disabled Older Person			
65–74	46.9%	43.6%	
75–84	43.0%	44.6%	
85+	10.1%	11.7%	
Race of Disabled Older Person			
Black	7.0%	5.7%	
White or other	93.0%	94.3%	
Older Person's Disability Type/Level			
IADL only	34.6%	27.1%	*
			*
1–2 ADLs	18.9%	19.1%	
3–4 ADLs	18.9%	20.2%	
5–6 ADLs	27.6%	33.6%	*
			*
Older Person's Living Arrangement			
Private residence	100.0%	97.5%	*
			*
Community residential care		2.5%	
Age of Spouse			
< 55	2.7%	1.5%	
55–64	8.6%	9.0%	
65–74	42.0%	37.6%	
75–84	38.3%	42.5%	
85+	8.4%	9.4%	
Relationship to Recipient			
Wife	56.0%	56.7%	
Husband	44.0%	43.3%	
Employment of Spouse			
More than 30 hours per week	5.8%	6.8%	
Not employed/less than 30 hours per week	94.2%	93.2%	
**(*) statistically significant change from 1994 to 2004 at 95% (90%) confidence level in a two-tailed test.			

Table A6			
Proportion of Caregiving Spouses and Children, by Characteristic			
	1994	2004	
Age of Disabled Older Person			
65–74	34.7%	27.4%	**
75–84	40.6%	44.7%	**
85+	24.7%	27.9%	*
Race of Disabled Older Person			
Black	9.8%	9.5%	
White or other	90.2%	90.5%	
Older Person's Disability Type/Level			
IADL only	37.1%	30.5%	**
1–2 ADLs	17.3%	16.3%	
3–4 ADLs	17.6%	20.9%	*
5–6 ADLs	28.0%	32.3%	**
Older Person's Living Arrangement			
Private residence alone	25.2%	18.6%	**
Private residence with others	74.8%	75.2%	
Community residential care		6.3%	
Age of Spouse or Child			
<35	3.4%	1.9%	**
35–44	14.2%	10.7%	**
45–54	23.5%	25.0%	
55–64	19.5%	24.2%	**
65–74	22.0%	19.7%	*
75–84	14.4%	15.2%	
85+	3.0%	3.2%	
Relationship to Recipient			
Wife	20.3%	19.3%	
Husband	16.0%	14.7%	
Daughter	41.2%	43.2%	
Son	22.5%	22.8%	
** statistically significant change from 1994 to 2004 at 95% confidence level in a two-tailed test.			