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Staying the Course: Trends in Family Caregiving

by

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The AARP Public Policy Institute, formed in 1985, is part of the Policy and Strategy group at AARP. One of the missions of the Institute is to foster research and strategy on public policy issues of importance to mid-life and older Americans. This publication represents part of that effort.

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FOREWORD

The unpaid care provided by family caregivers has been the predominant source of long-term services and supports for older persons with disabilities in the U.S. for many years. The help that family caregivers provide ranges from occasional assistance with shopping to intensive round-the-clock care for persons with severe physical or cognitive disabilities, such as Alzheimer's disease.

Family caregivers are generally acknowledged to be the foundation of the nation's system of long-term services and supports. Debate continues, however, about how family caregiving patterns may be changing over time. For example, are there fewer family caregivers available to provide care than in the past, due to such demographic trends as increasing numbers of women in the labor force? Is less informal support being provided, producing pressure on public budgets as a result of the need for more paid, formal care?

This paper examines key trends in family caregiving patterns based on the most reliable national data source available for persons age 65 or older with disabilities, the National Long-Term Care Survey. The AARP Public Policy Institute commissioned this paper to explore changes from 1994 to 1999, the most recent waves of survey data available, in both informal and formal care, and in the characteristics of both family caregivers and care recipients.

The findings should help to inform public policy debates across the nation. In a nutshell, they show that formal, paid care declined over the period examined, while sole reliance on family caregivers increased. Spouses and adult children not only "stepped up to the plate" to help relatives in the face of declining use of formal care, but the caregivers themselves were older, and they were caring for persons with higher levels of disability. The data in this paper provide evidence of the need to provide adequate long-term services for persons with disabilities and support for their family caregivers.

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EXECUTIVE SUMMARY

I. INTRODUCTION

Informal caregiving—unpaid help primarily provided by spouses and children—has long been the most common source of long-term care for older persons with disability in the United States. However, a number of factors, such as demographic trends that may reduce the supply of traditional family caregivers and changes in the long-term care delivery system, indicate the need to track how caregiving is changing.

II. PURPOSE

One key purpose of this paper is to examine trends in the use of formal and informal care using the most recent data available from the National Long-Term Care Surveys. Earlier research using the National Long Term Care Surveys of 1984 and 1994 found a significant decline in the number of family caregivers, accompanied by a significant increase in the use of formal care provided by paid workers, especially among older persons also receiving informal care. The increase in formal care was in part due to large increases in access to and use of Medicare home health benefits. Since 1994, a number of factors are likely to have affected patterns of family caregiving, notably Medicare home health payment system changes after passage of the Balanced Budget Act of 1997 (BBA), which dramatically reduced the availability of these benefits. As a result, provision of care may have shifted back to informal caregivers.

Using data from the 1999 National Long Term Care Survey and earlier waves of that survey, this study updates information on provision of formal and informal care to persons age 65 or older with disability and on the profile of care recipients and family caregivers. The study examines:

- Trends in disability and formal and informal care among older persons since the mid-1980s as a context for examining changes since 1994, in the aftermath of the BBA
- The profile of all older persons with disability in 1994 and 1999
- Formal and informal care for older persons with disability living in the community, including older persons in community residential care in 1999
- Changes in the sources of informal care between 1994 and 1999
- Changes in the profile of care recipients and their family caregivers since 1994

III. METHODOLOGY

Estimates in this study are based on data from the four most recent waves of the National Long Term Care Survey (NLTCS), i.e., 1984, 1989, 1994, and 1999. The NLTCS is a nationally representative survey of Medicare beneficiaries age 65 or older. Although the 1999 survey is now 6 years old, it is the most recent one available for analysis. (Public use data from the 2004 survey are expected to be available next year.) A particular strength of the survey for this paper is its central focus on disability and its consistent core questions on both disability and caregiving over all waves of the survey.

The survey collects a wide range of information about disability, long-term care, health and health service use, and personal and demographic characteristics, including in 1999 whether respondents lived in assisted living facilities. The survey also collects demographic and other information on the spouse and living children of all sampled persons selected for a detailed interview, regardless of residence, so that it is possible to describe these *potential family caregivers* for both community and institutional residents.

The survey collects information about *actual caregivers*, however, only for older persons with chronic disability *who live in the community* (including community residential care settings). Information about the characteristics of caregivers is limited primarily to *spouses and children*. However, information on these family caregivers is particularly valuable because they:

- represent a large majority of informal caregivers;
- are most likely to be involved in decisions about how long-term care is provided; and
- are most likely to be affected by public and private policies, such as family leave policies, tax incentives, and caregiver allowance programs.

IV. PRINCIPAL FINDINGS

Focus on 1984–1994

Among persons age 65 or older, the *rate* of chronic disability in personal care and other daily activities necessary for independent living fell between the mid-1980s and mid-1990s. However, the *number* of older persons with chronic disability rose, owing to growth in the number of persons age 65 or older and an upward shift in their age distribution. The number of older persons with chronic disability who live in the community (that is, not in an institution such as a nursing home) also increased.

The number and proportion of older community residents with disability who received no formal or informal help with personal care or independent living activities increased significantly between the mid-1980s and the mid-1990s. Personal care activities, commonly called activities of daily living (ADLs), include such activities as bathing or getting around inside, and independent living activities, commonly called instrumental activities of daily living (IADLs) are activities such as shopping and meal preparation. Among older community residents with disability, nearly all of the decline in help with personal care or independent living activities reflects greater use of assistive devices, such as shower or tub seats, walkers, or canes.

Among older persons in the community with disability who did receive personal assistance, the proportion receiving any informal care (informal care only or a combination of informal and formal care) fell somewhat, from 94.9 percent in 1984 to 93.2 percent in 1994. At the same time, the use of formal care rose from 31.1 percent in 1984 to 42.9 percent in 1994.

Focus on 1994–1999

Some of the key the trends between 1984 and 1994 seem to have stabilized or reversed.

- Most of the decline in the rate of disability occurred between 1984 and 1994, with insignificant declines between 1994 and 1999.

Among older community residents who received personal assistance:

- Use of any *formal care, which had been increasing steadily,* declined dramatically, from 43 percent in 1994 to 34 percent in 1999.
- *A larger proportion of care recipients were relying entirely on their informal caregivers in 1999 than in 1994*—nearly two-thirds, compared with about 57 percent in 1994—as a result of the decline in formal care.

One key trend continued: The proportion of older community residents with disability who received no formal or informal help increased from 22 percent in 1994 to 28 percent in 1999, again, almost entirely because of increased use of assistive devices.

The decline in disability assistance from 1994 to 1999 occurred in most groups of older community residents with disability—whether defined by gender, race, disability level, availability of family caregivers, or residential setting.

Characteristics of Older Persons with Disability and Care Arrangements in Community Settings, 1999

No formal or informal care: Older persons with fewer family resources and older persons with lower levels of disability were more likely to manage without help.

- A third of older persons *without either a spouse or a child* received no care in 1999, compared with a quarter of older persons with a spouse and a child (or children).
- Sixty percent of persons with one or two disabilities in activities of daily living (ADLs) received no assistance, compared with a negligible proportion of persons with disability in five or six ADLs.

Informal care: Alone or combined with formal care, informal care continued to be the most common type of care nearly all groups received in 1999. The only exception was older persons living in residential care settings in the community, and even 59 percent of this group received some informal care.

The groups *most likely to receive any informal care* were:

- Older persons with five or six ADL limitations (91 percent)
- Older persons living with others (78 percent)
- Older persons who had both a spouse and children (about 76 percent)

The groups *most likely to rely entirely on informal care* were:

- Older persons with both a spouse and child and older persons living with others (about 62 percent for both groups)

Formal care: Key characteristics associated with use of formal care, alone or with informal care, include disability level and family availability.

Those *most likely to receive any formal care* were:

- Older persons living in residential care settings (60 percent)
- Older persons with five or six ADL limitations (50 percent)
- Older persons with neither a spouse nor a child (40 percent)

The groups *most likely to rely entirely on formal care* were:

- Older persons with neither a spouse or a child (nearly 20 percent)
- Older persons living in residential care settings (17 percent)
- Older persons living alone (12 percent)

Changes in Care Arrangements, 1994–1999

The proportion of nearly all groups of older persons with disability receiving no formal or informal help increased as the proportion using any informal and any formal care declined. Exceptions were older persons with the highest disability level and older persons who had a spouse (with or without children). *In most cases, absolute declines in formal care were larger than declines in informal care*.

The largest declines in use of any formal care from 1994 to 1999 were among:

- Older persons with only a spouse (23.3 percentage points)
- Older persons age 85 or older (12.6 percentage points)
- Older persons with five or six ADL disabilities (nearly 11 percentage points)

How older persons compensated for the decline in formal care differed by family availability and disability level.

- Among older persons with only a spouse, the proportion receiving no care and the proportion relying entirely on informal care increased about equally (11 and 12.3 percentage points, respectively).
- Among older persons with both a spouse and child, most of their 10.1 percentage point decline in formal care was offset by increased reliance on informal care alone.
- Virtually all older persons with five or six ADLs continued to receive care, but the proportion receiving only informal care or only formal care increased (nearly 11 percentage points and nearly 5 percentage points, respectively).

Source of informal care: Spouses and children continue to be the most common source of informal care. Eighty-four percent of all older persons with chronic disability who received informal care received some care from these family caregivers in 1999, up from about 80 percent in 1994. Among those receiving informal care, nearly all older persons who had a spouse and 86 percent of older persons with a child only were receiving care from these closest relatives in 1999.

Number and Characteristics of Potential and Actual Family Caregivers, 1994-1999

The ratio of *potential family caregivers* (spouses or children) and the ratio of *actual family caregivers* to the number of older persons with disability remained about the same between 1994 and 1999. In 1999:

- 17.7 million spouses and children had a spouse or parent with disability, and
- 3.8 million actually provided care (about 1.1 family caregivers per older person who had a spouse or child and received help).

A larger proportion of actual family caregivers were caring for persons with higher levels of disability in 1999 than were doing so in 1994. More than half of family caregivers were providing help to spouses or parents with three or more ADL disabilities in 1999, up about 5 percentage points from 1994.

Both care recipients and family caregivers were older in 1999 than in 1994.

- Eleven percent of caregiving spouses were age 85 or older, up from 8.6 percent in 1994.
- Nearly 40 percent of caregiving children were assisting parents who were age 85 or older, compared with about 34 percent providing such care in 1994. Nearly 13 percent of caregiving children were age 65 or older themselves.

V. CONCLUSION

The downward trend in both the rate of disability and any disability help between 1984 and 1994 continued between 1994 and 1999, although the small decline in the total disability rate between those two years was not significant. Contrary to the previous trend, however, use of formal care fell dramatically, and the rate at which spouses and children provided care remained stable. Increased reliance on assistive devices only or informal care only accompanied the decline in formal care. In general, the greatest increase from 1994 to 1999 in use of assistive devices without help occurred among older persons who had fewer informal resources and lower levels of disability.

Three findings in particular raise concern about the potential adverse impact of reduced formal care on older persons:

- The largest decline in such care between 1994 and 1999 occurred for persons with disability who had a spouse only.

- More than half of older persons caring for spouses (53 percent) were themselves age 75 or older.
- A larger than average decline occurred for persons with the highest disability level.

Our analysis does not examine whether informal caregivers increased hours or types of care to compensate for the missing formal care, or whether reduced use of formal care resulted in unmet or undermet needs.

The decline of about 9 percentage points in use of formal care between 1994 and 1999 seems too large to be explained entirely by changes in Medicare reimbursement for home health care, since only about 12 percent of *all* care recipients received such care in 1994. Thus, more analysis is needed to understand other factors contributing to the decline in formal assistance from paid workers. Reported increases in both Medicaid and privately paid care between 1996 and 1999 suggest that formal care should have held its own or declined less than was observed. Other possible factors include changes in private insurance coverage for home care, changes in the ability of older persons with disabilities to afford privately paid home care, or changes in the supply of home care workers. It will be important to see whether the decline in formal caregiving continues or reverses in the next wave of the NLTCS, now underway.

We also need to know more about the reasons for declines in use of any informal care and the upward trend in use of assistive devices only. It remains to be shown whether the downward trend in assistance reflects environmental improvements that reduce the need for help or improved health among older persons. Less than 1 percent of older persons reporting no care report unmet need for care, so that unmet need does not appear to be driving reduced use of *any* help.

Increases in unmet need among older persons *receiving care* may have occurred, however, as the use of formal care decreased. If so, policies that provide support or incentives for caregivers may have some positive impact on family caregivers' participation. On the other hand, if declining receipt of care reflects other factors, such as improvements in the physical environment or improved health, such policies may be more effective in supporting or increasing efforts of those already providing care than in calling forth additional informal caregivers.

Finally, children who have a parent in residential care are more likely to be providing care than are children whose parents with disabilities live in private residences. It is important to monitor caregiving as the number of older persons in residential care settings increases. It also may be desirable to expand collection of informal caregiving information to include institutional settings to improve our understanding of the role of informal caregivers. Oversight by and involvement of informal caregivers may be important to the quality of life and the quality of care for older persons in both residential care and institutional settings.

I. INTRODUCTION

Informal caregiving—unpaid help provided primarily by family members—has long been the most common source of long-term care for older persons in the United States. However, a number of factors indicate the need to track how caregiving may be changing.

- Recent declines in aggregate disability rates among older persons have occurred primarily at less severe levels of disability (Spillman, 2004; Shoeni, Freedman, and Wallace, 2001; Waidmann and Liu, 2000).
- Older persons who *have* disability have a somewhat higher *level* of disability (Spillman, 2004).
- Growth in the number of persons age 65 or older and an upward shift in their age distribution have resulted in an increase in the *number* of older persons with disability despite disability rate declines.

Although their impact may not be felt for several decades, demographic trends are likely to reduce the number of family caregivers available over time. These trends include delayed childbearing, lower fertility rates, and greater labor force participation by women, who traditionally far outnumber men as informal caregivers to aging spouses or parents. On the other hand, continued narrowing of the gender gap in mortality may increase the number of husbands available to provide care (Redfoot and Pandya, 2002).

Using the National Long Term Care Surveys of 1984 and 1994, Spillman and Pezzin (2000) found that the proportion of older persons with disability who had spouses or children increased slightly between the mid-1980s and the mid-1990s, but the number of these family members actually providing care fell, accompanied by an increase in the level of disability among care recipients. *These near relatives were less likely to be providing care, but if they were, they were more likely to be the primary caregiver to an older person with more severe disability than in earlier years*.

Over the same period, the proportion of older persons using formal care—paid care provided by agency workers or other employees—rose, even among older persons receiving informal care. One reason was a dramatic increase in access to and use of Medicare home health benefits over the period. Private spending for home care also increased dramatically, however.

Since 1994, a number of factors may have affected patterns of family caregiving. Most directly, *Medicare home health payment system changes following the Balanced Budget Act of 1997 dramatically reduced the use of these benefits*. While the interim payment system (IPS) was in place between 1997 and 2000, access to any Medicare home health benefits and the amount of less skilled supportive services provided through this benefit fell sharply (McCall, Komisar, Petersons, and Moore, 2001). These supportive services represent the most common type of care also provided by informal caregivers. Thus, the result may have been shifting care provision to informal caregivers under the IPS. Conversely, *growth in assisted living and other community-based residential care options* may imply less need for family caregiving and less burdensome responsibilities for those who do provide care

(Spillman, Liu, and McGilliard, 2002). Although they include only services provided by freestanding home health agencies—only a part of formal long-term care—estimates from the National Health Accounts indicate *continued growth in private spending for home health* while the IPS was in effect (Heffler et al., 2001). This growth may indicate increased preference for formal services, either influenced by or independent of Medicare home health.

At the same time, states have continued to expand community care options in their Medicaid programs, although recent budget stresses have exerted pressure on these efforts. Public and private policies to encourage and support family caregiving have also increased. For example, the National Family Caregiver Support Program helps fund such direct services as state respite care programs, and tax credits are available for caregivers in some states. Other supportive policies for family caregivers include family and medical leave, workforce initiatives by private employers, and programs to allow cash payments to informal caregivers. However, such policies and programs tend to be limited in scope, and availability is highly uneven across states (Feinberg, Newman, Gray, and Kolb, 2004).

II. PURPOSE

Family caregiving affects the recipients' and caregivers' quality of life as well as public and private spending for long-term care. Thus, it is important to understand how care is being provided and how patterns of care are affected by changes in disability, public policies, and the long-term care delivery system. Using data from the 1999 National Long Term Care Survey and earlier waves of the survey, this study provides an updated overview of informal and formal care for older persons with disability and the profile of care recipients and their family caregivers. The study examines:

- Trends in disability and formal and informal care among older persons since the mid-1980s as a context for examining changes since 1994, in the aftermath of the BBA
- The profile of all older persons with disability in 1994 and 1999
- Formal and informal care for older persons with disability living in the community, including older persons in community residential care in 1999
- Changes in the sources of informal care between 1994 and 1999
- Changes in the profile of care recipients and their family caregivers since 1994

III. DATA AND METHODS

Estimates in this study are based on data from the four most recent waves of the National Long Term Care Survey (NLTCS), a nationally representative survey of Medicare beneficiaries age 65 or older conducted by the U.S. Census Bureau under the direction of the Center for Demographic Studies at Duke University (CDS). All estimates are weighted to be nationally representative, and standard errors take into account the survey's complex design. Unless otherwise noted, all differences across years or between subgroups discussed are significant at the 5 percent level in a two-tailed test.

***Sample design and survey content*:** The NLTCS began in 1982 as a survey of older Medicare beneficiaries living in the community. The four subsequent rounds used in this study were conducted in 1984, 1989, 1994, and 1999 and included older persons with disability in both the community and institutions. The NLTCS sample is drawn from Medicare enrollment files and is refreshed in each wave with a sample of persons who turned 65 after the previous survey. The survey collects a wide range of information about disability, long-term care, health and health service use, and personal and demographic characteristics.

In 1994 and 1999, the survey added supplemental samples of those age 95 or older to increase precision of estimates for the very old. Samples of older persons without disability also were added to the detailed questionnaire, expanding the range of comparisons between the disabled and nondisabled. The 1999 survey identified for the first time whether respondents lived in assisted living facilities. About 21,000 respondents, including persons not selected to receive a detailed interview, were screened for disability or included based on past disability in 1984, 16,000 in 1989, and 17,000 each in 1994 and 1999. About 7,600 persons in 1984 and 6,000 in the later years responded to the detailed interview.

Although the 1999 survey is now five years old, it is the most recent one available. A particular strength of the NLTCS for the current paper is its central focus on disability and how older persons cope with it, including receiving care from others. The core questions on disability and caregiving also have been remarkably consistent over all waves of the survey, minimizing one source of uncertainty about comparability of estimates over time.

Disability Measurement: Disability in this study is *chronic* disability in personal care or independent living activities. Chronic is defined as lasting three months or longer. On the NLTCS, disability is measured as *receiving help (including supervision)* with or *using assistive devices* to perform activities of daily living (ADLs) or being *unable to perform* instrumental activities of daily living (IADLs) because of health or disability.[1] ADLs are personal care activities such as bathing and dressing that are associated with more severe disability. IADLs are activities such as shopping and meal preparation that are necessary for independent living.

The six ADLs included in the study are bathing, dressing, getting around indoors, getting in or out of bed, using the toilet, and eating. Eight IADLs are included: shopping, meal preparation, light housekeeping, laundry, getting around outdoors, managing money, taking medicine, and telephoning. With the exception of getting around outdoors, reporting of assistive device use is limited to ADLs. Examples of the most commonly used devices are mobility devices, such as walkers or canes, and devices to assist with bathing, such as shower or tub seats. In the study, disability should be understood to be *chronic* disability, that is, persons identified as disabled have reported receiving help or using assistive devices with at least one ADL or IADL for three months or longer.

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[1] For most IADLs, respondents are asked whether they usually do the activity and, if not, whether they could if they had to. Only those who report inability to perform an activity *because of health or disability* are classified as having disability in that activity.

Caregivers in this study and in the NLTCS are defined as persons identified as *regularly providing ADL or IADL assistance to recipients with chronic disability*. This focus on a well-defined population of older persons with disability and the array of persons from whom they report receiving regular assistance, yields estimates far lower than estimates from household surveys. Examples are estimates from a recent survey sponsored by the National Alliance for Caregiving and AARP (NAC, 2004) and national surveys such as the Survey of Income and Program Participation (Alecxih, Zeruld, and Olearczyk, 2002; Arno, Levine, and Memmott, 1999). Chief among the reasons for the larger estimates from such surveys is that they start from a sample of persons identifying themselves as providing care. Both the needs and condition of the recipient and the care provided are determined by the caregiver's assessment. There is also wide variation in age of care recipients (in the case of the NAC study, age 18 or older) and in the range of qualifying conditions for care recipients, such as serious illness, chronic illness, or disability, as defined by the caregiver (Mintz and Ford, 2005).

***Family and caregiving information*:** The NLTCS collects information on the spouse and living children of all sampled persons selected for a detailed interview. Thus, it is possible to describe the characteristics of spouses and children (age, gender, marital status, presence of minor children) for both community and institutional residents. The paper refers to this network of close relatives as *potential family caregivers*. The survey collects information on spouses, children, and others who *actually* provide care only for persons with disability who live in the community. No information is elicited on informal care for institutional residents.

All persons living in the community (including those living in noninstitutional residential care settings, such as assisted living) and reporting help with or supervision of either IADLs or ADLs are asked to identify all persons, if any, who regularly provide care. The survey then collects additional information about care provided by each person who helped *within the last week*, including whether the helper was a paid, or formal, caregiver. Relatives providing care are not asked whether they are paid.

The survey limits collection of additional information about the characteristics of caregivers largely to spouses and children. Being able to examine these closest relatives is valuable for a number of reasons.

- They represent a large majority of informal caregivers. Two-thirds of all informal caregivers in 1994 were spouses or children of care recipients, and these family members were a source of care for 80 percent of *all* older persons receiving informal help and about 90 percent of older persons receiving informal care who had a spouse or child (Spillman and Pezzin, 2000).
- They are most likely to be involved in decisions about how long-term care is provided.
- They are most likely to be affected by public policies, such as family leave policies, tax incentives, and caregiver allowance programs.

Before 1999, respondents were asked the number of hours employed per week for each spouse or child. Only spouses in the 1999 survey were asked this question, so analysis of the relationship between market work and caregiving by children is not possible in that year.[2]

Residential information**:** The NLTCS defines institutional residence as living in an institutional or group setting where medical supervision is available. In all waves of the survey, this includes primarily residents of certified, licensed, and unlicensed nursing homes, but also residents of domiciliary or personal care facilities and facilities for the mentally disabled or mentally ill. In 1999 the survey added new probes to identify all persons in assisted living. Persons in assisted living who reported receiving "substantial nursing care of any kind" were assigned, however, to the institutional questionnaire and treated the same as nursing home residents for purposes of data collection. **Thus, in this study, the term, "community residential care," includes only respondents who did not report receiving nursing care.** Comparisons of community residential care in 1994 and 1999 are not possible, because the survey did not include the additional assisted living probes in 1994.

IV. PRINCIPAL FINDINGS

A. OVERVIEW OF TRENDS IN DISABILITY AND CARE ARRANGEMENTS

Broad trends in disability and care arrangements among older persons since the mid-1980s provide a context for the analysis of more recent changes. In this section, we examine relevant trends as a backdrop for our more detailed examination of changes between 1994 and 1999 in the characteristics of older persons with disability, their care arrangements, and the characteristics of their family caregivers in the sections that follow.

Both the overall disability rate among older persons and the proportion who have disability and remain in community settings fell from the mid-1980s through the 1990s (Figure 1). The overall disability rate fell from 22.1 percent in 1984 to 19.7 percent in 1999. The proportion of older persons who were community residents with disability fell from 17 percent in 1984 to 14.9 percent in 1999.

Despite the declining disability rate, the *number* of older persons with disability rose, placing increased demands on community and institutional long-term care resources. The total number of older persons with disability rose from 6.2 million in 1984 to 6.8 million in 1999 because of growth in the number of persons age 65 or older and an upward shift in the age distribution of older persons. The *number* of community residents with disability also rose, from 4.8 million to 5.1 million. Although the rate of institutional residence remained a fairly stable 5 percent of the population age 65 or older, the *number* of persons living in institutions as defined by the NLTCS also rose, from 1.4 million to just under 1.7 million, between 1984 and 1999.

Although the trend in the rate of disability overall and in disability in the community was uniformly downward throughout the period between 1984 and 1999, most of the decline

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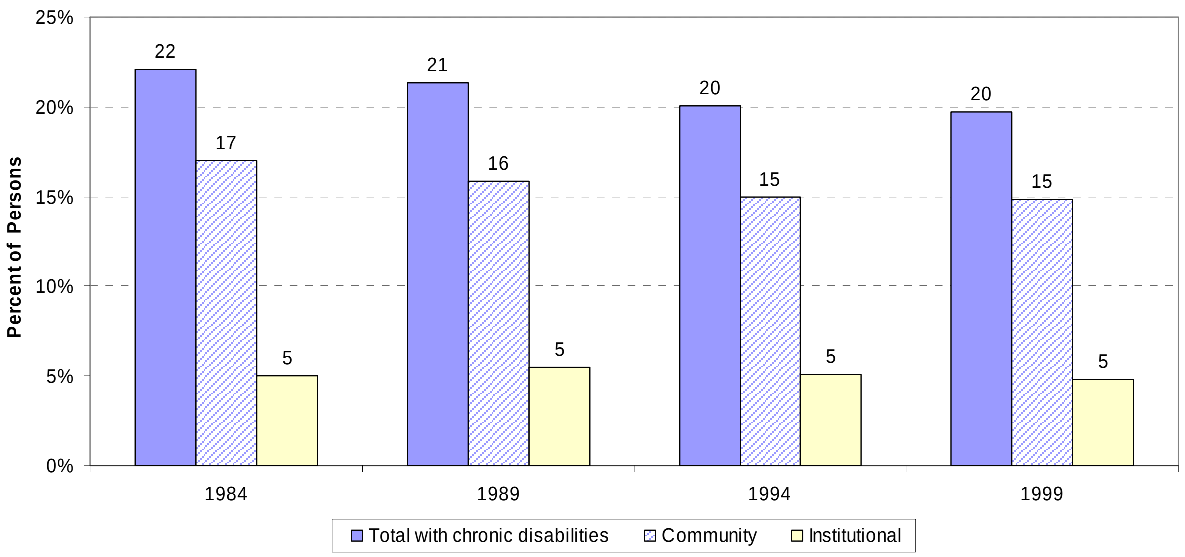
[2] The question has been restored for all household members and for children in the 2004 wave of the survey.

occurred between 1984 and 1994. The decline in these rates between 1994 and 1999 was smaller and not statistically significant. Therefore, the 1994–1999 period may provide a relatively stable context for examining changes in the characteristics of older persons with disability, their care arrangements, and the characteristics of their family caregivers that may have occurred during a period of change in the payment system for Medicare-financed formal care.

Figure 1. Trends in Chronic Disability Among Persons Age 65 or Older, 1984-1999



As disability declined between 1984 and 1999, substantial changes occurred in how all *older persons who had chronic disability* managed their disability (Figure 2). The proportion of older persons with chronic disability who were community residents receiving help from other persons fell from two-thirds to about 55 percent. As a result, even though the total number of community residents with chronic disability rose, *the number reporting assistance from other persons declined, from 4.1 million to 3.8 million*. Concurrently, the proportion of older persons with disability who remained in the community and managed without regular disability help nearly doubled between 1984 and 1999, rising from about 11 percent in 1984 to 21 percent in 1999. This upward trend was due to the increase, from 10.3 percent in 1984 to 19.0 percent in 1999, in the proportion of older persons managing their disability without formal or informal help by using assistive devices, chiefly mobility aids, such as walkers, and bathing aids, such as shower or tub seats (Figure 2).[3] A small number of persons with only IADL disability in each year (fluctuating between 0.5 percent and 2.0 percent of older persons with chronic disability) reported *usually* receiving help but identified no one who helped *regularly*. We cannot resolve this apparent reporting inconsistency, and in remaining exhibits, this group is combined into a category of “No formal or informal care” with persons who manage their disability by using assistive devices without formal or informal help.

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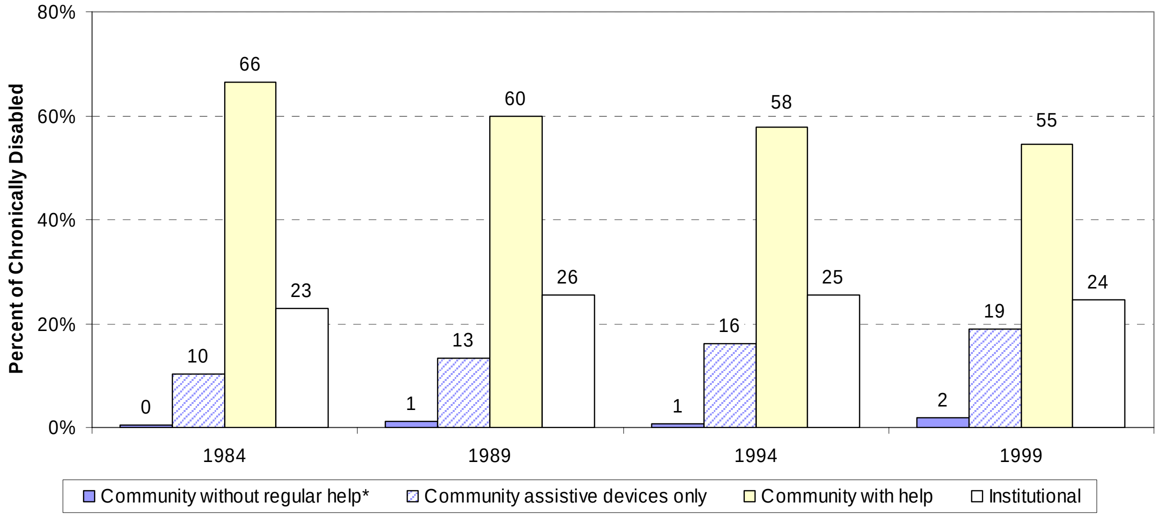
[3] The importance of assistive device use in disability trends was demonstrated in a paper by Freedman et al. (2004). That study, which focused on ADL disabilities, found that estimates from several national surveys confirmed a small downward trend in help with ADLs, but that the evidence for a consistent trend was more mixed when defining disability to include both personal assistance and assistive device use.

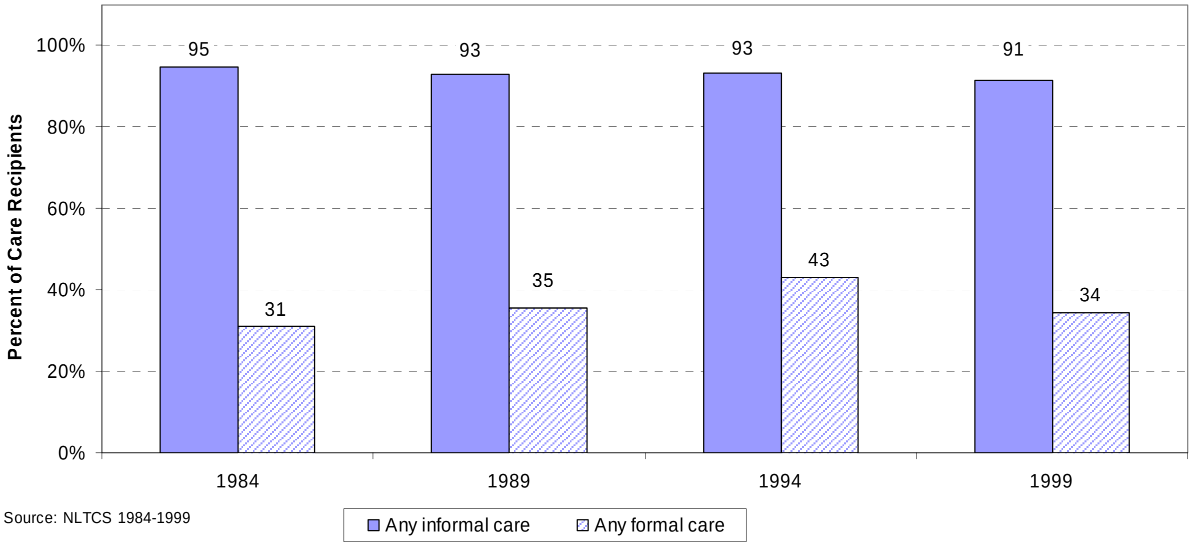
Figure 2. Trends in Managing Disability Among Older Persons With Chronic Disability, 1984-1999



* This group is older persons who report *usually* receiving help with and and being unable to perform IADLs but do not identify a person who *regularly* provides help. They are combined with the group relying solely on use of assistive devices (with the combined group labeled "No formal or informal care") in all remaining tables in which they

Patterns of formal and informal care use among those receiving care also changed (Figure 3), although informal care remained by far the most common type. In all years, more than 90 percent received some informal care, either alone or in combination with formal care, despite a small but significant decline, from 95 percent to 91.5 percent between 1984 and 1999. The decline between 1994 and 1999, from 93.2 percent in 1994 to 91.5% in 1999, was only marginally significant (p <.10).

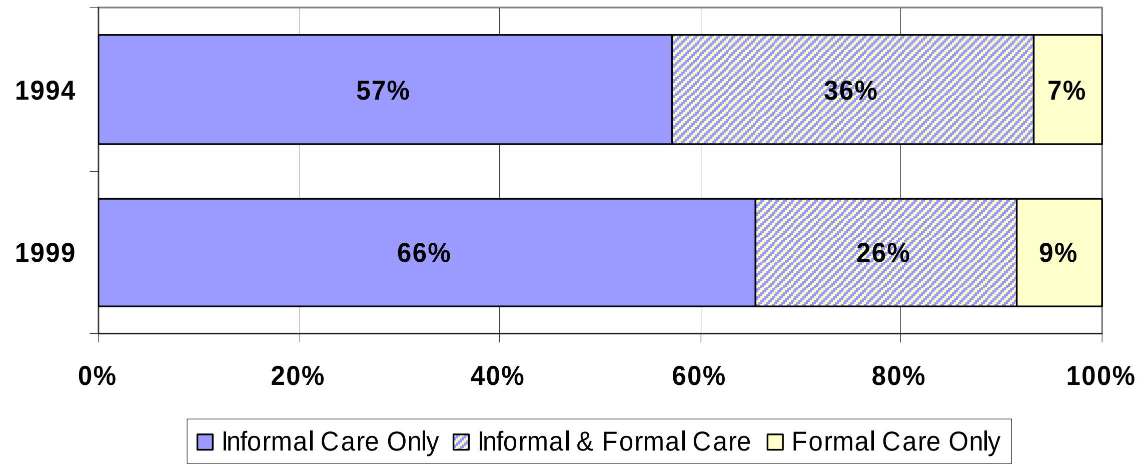
Figure 3. Trends in Informal and Formal Care Among Older Community Residents Receiving Care, 1984-1999



Source: NLTCS 1984-1999

The trend in use of formal care is mixed, with an increase in the total proportion using *any* formal care only through 1994. After peaking at almost 43 percent in 1994, the proportion using any formal care fell about 9 percentage points, to about 34 percent between 1994 and 1999, contemporaneous with initial effects of the Medicare home health payment system changes. *As a result of the decline in formal care, a larger proportion of care recipients were relying entirely on their informal caregivers in 1999 than were doing so in 1994*—nearly two-thirds, compared with about 57 percent in 1994 (see Figure 4). This increase in the proportion receiving only informal care represents a decline in the proportion whose informal care was supplemented by formal care—about 26 percent, compared with about 36 percent in 1994—as formal care declined. The proportion receiving only formal care also increased, from about 7 percent in 1994 to about 9 percent in 1999.

Figure 4: Older Persons with Disabilities Living in the Community and Receiving Care, by Type of Care, 1994 and 1999



The drop of about 9 percentage points in formal care between 1994 and 1999 would seem to be too large to attribute it only to the direct effects of the change in Medicare policy. According to respondent reports, Medicare was a payment source for about 27 percent of formal care recipients in NLTCS in 1994 (Liu, Manton, and Aragon, 2000) *and* in 1999 (Spillman and Black, 2004). This proportion would be only about 11.6 percent of *all* 1994 care recipients in Figure 3, and 9 percent of all recipients in 1999. Thus, it is unlikely that the Medicare payment system change fully explains the decline in formal care between 1994 and 1999, although it may also have affected whether older persons with chronic disability received *any care*, which conceivably may have had a small impact on institutional placement and may have had spillover effects on other sources of formal care.

Characteristics of Older Persons with Disability in Both Institutional and Community Settings, 1994 and 1999

Table 1 focuses on 1994 and 1999 to provide a profile of the characteristics of *all* older persons with chronic disability in those years, corresponding to the population including *both* community and institutional residents in Figure 2. Continuing the trend Spillman and Pezzin

(2000) found between 1984 and 1994, both age and disability level increased between 1994 and 1999. These factors have implications for the availability of family caregivers and the demands on them.

Table 1. Older Persons with Disability, Their Family Availability and Care Arrangements, 1994 and 1999

	1994		1999		
	Number of persons	Percent	Number of persons	Percent	
All chronically disabled	6,653,609	100.0	6,785,253	100.0	
Male	1,980,343	29.8	2,061,755	30.4	
Female	4,673,265	70.2	4,723,498	69.6	
Black	719,727	10.8	718,617	10.6	
White or other	5,933,881	89.2	6,066,637	89.4	
65-74	1,928,003	29.0	1,667,988	24.6	**
75-84	2,649,484	39.8	2,825,964	41.6	
85+	2,076,121	31.2	2,291,301	33.8	**
IADL only	1,919,567	28.9	1,797,935	26.5	**
1-2 ADLs	1,558,392	23.4	1,559,000	23.0	
3-4 ADLs	1,151,201	17.3	1,262,649	18.6	
5-6 ADLs	2,024,448	30.4	2,165,669	31.9	
2+ ADLs	3,852,564	57.9	4,074,097	60.0	*
Has spouse or child	5,423,652	81.5	5,780,283	85.2	**
Spouse and child	1,890,959	28.4	1,926,511	28.4	
Spouse only	238,200	3.6	217,906	3.2	
Child only	3,294,494	49.5	3,635,867	53.6	**
Neither spouse nor child	1,229,956	18.5	1,004,970	14.8	**
No formal or informal care[a]	1,115,275	16.8	1,423,224	21.0	**
Community with formal or informal care	3,844,871	57.8	3,700,889	54.5	**
Institutional care	1,693,462	25.5	1,661,140	24.5	

Source: NLTCS 1994 and 1999

Note: ** (*) = change from 1994 differs from zero at the 5% (10%) significance level in a two-tailed test.

[a] This group is predominantly persons who manage all chronic disability with assistive devices but also includes the small proportion of persons who have only IADL disability but did not identify anyone regularly providing assistance as shown in Figure 2 above.

Neither the gender nor race profile of older persons with disability changed. Although they represent about 60 percent of older persons, women accounted for 70 percent of those with disability in both years, owing to their higher rate of chronic disability. Nearly a quarter of older women have disability, compared with about 15 percent of men (not shown). Similarly, although they are about 8 percent of the older population, blacks accounted for about 11 percent of all persons with disability in both years. Again, this is because of their higher disability rate, also about 25 percent.

The proportion of older persons with disability age 75 or older increased to three-quarters, and the proportion of all persons age 85 or older increased to just over one-third, although the increase in the latter group is only marginally significant ($p < .10$). Concurrent with the upward shift in age, the proportion of older persons with disability who had more severe levels of disability rose. The proportion reporting disability only in IADLs declined from 29 percent to 26.5 percent, and the proportion reporting disability in one or two ADLs remained at 23 percent. The proportion reporting disability in three or more ADLs, however, increased significantly, rising from 48 percent to 51 percent of older persons with disability. The apparent increase in the proportion with two or more ADLs, a common trigger for long-term care insurance benefits, was only marginally significant.

Older persons with disability were *more likely* in 1999 than in 1994 to have either a spouse or children available to provide care. The increase was entirely in the proportion that had only children, again most likely reflecting the upward shift in age of older persons with disability, because the likelihood of being widowed increases with age. There was a complementary decline in the proportion with neither a spouse nor child. Persons with only children and persons with neither spouse nor children, who together composed more than two-thirds of older persons with disability in both years, are:

- more than three years older on average than those who still have a spouse;
- much more likely to have chronic disability (nearly 30 percent, compared with 20 percent of all elderly); and
- much more likely to be institutionalized (about 8 and 11 percent, respectively, compared with about 5 percent of all elderly).

As shown in Figure 2 on page 7, care arrangements changed dramatically among older persons with disability between 1994 and 1999. Changes were concentrated among community residents, with about a quarter of older persons with disability living in institutions in each year. The proportion of older persons with disability who received neither formal nor informal care increased, from about 17 percent to 21 percent, driven by the continuing upward trend in reliance on assistive devices.

B. CARE ARRANGEMENTS IN COMMUNITY SETTINGS, 1994–1999

Nearly 28 percent of *older persons with chronic disability living in the community* in 1999 managed their chronic disability without help, about 47 percent received only informal care, about 19 percent received a combination of formal and informal care, and about 6 percent relied entirely on formal care (Table 2). These arrangements differed significantly, in some cases dramatically, by gender, race, disability level, availability of family caregivers, and type of residential situation.

Table 2. Care Arrangements among Older Community Residents with Disabilities, 1999

		Distribution by Care Arrangement					
	Number of persons	No formal or informal care[a]	Informal care only	Formal and informal care	Formal care only	Any informal	Any formal
All community disabled	5,124,113	27.8	47.3	18.7	6.2	66.1	24.9
Male	1,613,163	24.9	54.4	16.9	3.9	71.3	20.8
Female	3,510,950	29.1	44.1	19.6	7.2	63.7	26.8
Black	599,067	21.9	51.6	20.0	6.5	71.6	26.5
White or other	4,525,046	28.6	46.8	18.6	6.1	65.3	24.7
65-74	1,452,562	28.5	53.9	12.8	4.8	66.7	17.6
75-84	2,210,511	31.7	44.1	17.8	6.4	61.9	24.2
85+	1,461,040	21.2	45.7	26.1	7.1	71.7	33.2
IADL only	1,705,570	22.2	57.4	13.1	7.3	70.5	20.4
1-2 ADLs	1,459,280	59.2	31.1	7.1	2.6	38.2	9.7
3-4 ADLs	906,707	19.6	50.5	22.9	7.0	73.4	29.9
5-6 ADLs	1,052,556	0.3	50.7	40.4	8.6	91.2	49.0
2+ ADLs	2,547,289	17.9	47.8	27.4	6.9	75.2	34.3
Has spouse or child	4,525,074	27.0	50.0	18.6	4.4	68.6	23.0
Spouse and child	1,720,446	23.1	62.1	14.4	0.4	76.5	14.8
Spouse only	175,736	27.3	53.8	17.0	2.0	70.7	19.0
Child only	2,628,892	29.6	41.9	21.4	7.1	63.3	28.6
Neither spouse nor child	599,039	33.4	27.1	19.9	19.6	47.0	39.5
Private residence alone	1,737,473	41.3	27.8	19.0	12.0	46.7	31.0
Private residence with others	3,064,549	20.6	61.8	16.0	1.7	77.8	17.6
Community residential care[b]	322,091	23.6	15.5	43.8	17.1	59.3	60.9

Source: NLTCS 1994 and 1999. (Complete estimates for 1994 provided in Appendix Table A1)

[a] This group is predominantly persons who manage all chronic disability with assistive devices but also includes the small proportion of persons who have only IADL disability but did not identify anyone regularly providing assistance shown in Figure 2.

[b] Includes assisted living and other community residential care settings without medical supervision.

Table 2 continued. Differences in Care Arrangements among Older Community Residents with Disabilities, 1994-1999

	Difference 1994-1999					
	No formal or informal care[a]	Informal care only	Formal and informal care	Formal care only	Any informal	Any formal
All community disabled	5.3 **	3.1 **	-9.3 **	0.9	-6.2 **	-8.4 **
Male	0.0	6.3 **	-7.2 **	0.9	-0.9	-6.3 **
Female	7.7 **	1.6	-10.2 **	0.9	-8.6 **	-9.3 **
Black	5.6	1.7	-8.5 **	1.2	-6.8	-7.3
White or other	5.2 **	3.3 **	-9.4 **	0.8	-6.0 **	-8.5 **
65-74	1.9	6.1 *	-8.4 **	0.5	-2.3	-7.9 **
75-84	7.4 **	0.5	-9.5 **	1.6	-9.0 **	-7.9 **
85+	7.3 **	5.3 *	-12.4 **	-0.2	-7.1 **	-12.6 **
IADL only	6.4 **	2.6	-9.6 **	0.7	-7.0 **	-8.9 **
1-2 ADLs	8.6 **	- 1.0	-6.5 **	-1.1	-7.5 **	-7.6 **
3-4 ADLs	4.6 *	4.0	-8.9 **	0.3	-5.0	-8.6 **
5-6 ADLs	0.1	10.9 **	-15.7 **	4.8 **	-4.9 **	-10.9 **
2+ ADLs	3.8 **	5.1 **	-11.4 **	2.4 **	-6.3 **	-9.0 **
Has spouse or child	5.5 **	3.2 *	-9.6 **	0.8	-6.4 **	-8.7 **
Spouse and child	2.4	7.8 **	-8.9 **	-1.3 **	-1.1	-10.1 **
Spouse only	11.0	12.3	-21.8 **	-1.5	-9.5	-23.3 **
Child only	7.2 **	0.0	-9.3 **	2.2 **	-9.4 **	-7.1 **
Neither spouse nor child	4.7	- 1.0	-7.3 **	3.6	-8.3 *	-3.7
Private residence alone	9.4 **	1.3	-11.4 **	0.7	-10.1 **	-10.7 **
Private residence with others	3.8 **	6.7 **	-10.6 **	0.1	-4.0 **	-10.5 **
Community residential care[b]	--[c]	--[c]	--[c]	--[c]		

Source: NLTCS 1994 and 1999. (Complete estimates for 1994 provided in Appendix Table A1)

Note: ** (*) = change from 1994 differs from zero at the 5% (10%) significance level in a two-tailed test.

[a] This group is predominantly persons who manage all chronic disability with assistive devices but also includes the small proportion of persons who have only IADL disability but did not identify anyone regularly providing assistance shown in Figure 2.

[b] Includes assisted living and other community residential care settings without medical supervision.

[c] Not available in 1994.

Relative to 1994, persons in nearly all groups were less likely to receive any formal care, and persons in a majority of the groups examined also were less likely to receive any informal care. Because the decline in formal care was larger than the decline in informal care, *older persons with chronic disability were also more likely to rely entirely on informal care* (Figure 5).

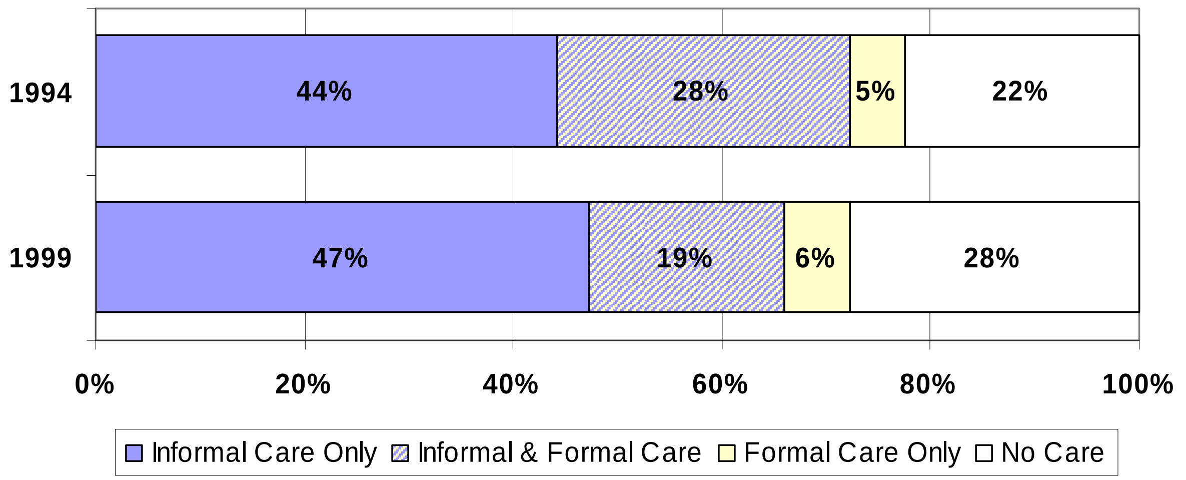


Figure 5: Older Persons with Disabilities Living in the Community, by Type of Care, 1994 and 1999

No formal or informal care: Two important factors in managing disability were availability of family caregivers and disability level. In 1999, persons with disability who had few family caregiving resources were more likely to do without personal assistance while relying on assistive devices. Persons with higher levels of disability were less likely to do without help, as were men, blacks, and persons age 85 or older.

For example, a negligible proportion of persons with five or six ADL limitations received no personal help, compared with nearly 20 percent of persons with three or four ADL limitations, and nearly 60 percent of persons with only one or two ADL limitations. Differences related to the availability of family caregivers are less dramatic, but still large. A third of persons who had neither a spouse nor a child and about 30 percent of persons with children only received no formal or informal care, compared with about a quarter of persons who had both a spouse and children.

Living alone or with others also is related to whether an elder receives help. Two in five older persons with disability who lived alone received no assistance, compared with one in five who lived with others and one in four who lived in community residential care settings. Older persons who cannot manage without assistance may be more likely to live with others if they have that option or to choose a residential care setting. In fact, 71 percent of persons who lived alone had fewer than three ADL disabilities, compared with about 58 percent of persons living with others and half of persons in residential care settings. Also, older persons with readily available caregivers, particularly a spouse, were more likely to receive help at all disability levels.

Informal care, alone or with formal care: Alone or combined with formal care, informal care continued to be by far the most common type of care nearly all groups received in 1999. Even among persons in community residential care, 59 percent received some informal care. The groups most likely to report getting informal help were older persons with five or six ADL limitations, older persons living with others, and older persons with both a spouse and children available to provide care. Persons with only one or two ADL limitations were least likely to report informal care (38 percent), whereas those with five or six ADL limitations were most likely to report such care (91 percent).

Whether older persons reported receiving only informal care varied with availability of informal caregivers. For example, women, who more commonly outlive their spouses, were less likely than were men to be receiving only informal care. Persons who had both a spouse and child and those who live with others were most likely to rely entirely on informal care (about 62 percent in both cases).

Formal care, alone or combined with informal care: As with informal care, key characteristics related to use of formal care are disability level, family availability, and residential situation. The group most likely to receive any formal care, not surprisingly, was older persons living in residential care settings (60 percent). Half of older persons with five or six ADL limitations and nearly 40 percent of older persons with neither a spouse nor a child relied in part or entirely on formal care. Conversely, less than 20 percent of persons living with others, persons who were married (with or without children), and persons in the youngest age group received any formal care. The group least likely to receive formal care was older persons with one or two ADL limitations (9.7 percent). They were also least likely to be receiving any informal care.

Sole reliance on formal care, like sole reliance on informal care, is strongly related to informal care resources and residential setting. Older persons most likely to rely only on formal care were those with neither a spouse nor a child (nearly 20 percent), those in residential care settings (17 percent), and those who lived alone (12 percent).

Changes in care arrangements, 1994–1999: The proportion of nearly all groups of older persons with disability who received no formal or informal help *increased* between 1994 and 1999. The largest significant increases were among persons who lived alone, persons with the lowest disability levels, and persons who had children but not a spouse. The only groups that showed no significant increase in managing without personal help were men, blacks, persons in the youngest age group, persons with the highest disability level, and those who had a spouse (with or without children).

The use of both any informal care and any formal care declined significantly for most groups between 1994 and 1999, but absolute declines in formal care were larger in most cases. The distribution of these decreases in any formal care was somewhat surprising, however.

- The smallest declines occurred for men (6.3 percentage points), who tend to have greater informal care resources, and for persons with neither a spouse nor child, who have fewer informal care resources
- The largest declines were among persons:
    - with only a spouse (23.3 percentage points);
    - age 85 or older (12.6 percentage points);
    - with five or six ADL disabilities (10.9 percentage points);
    - who lived alone (10.7 percentage points) or with others (10.5 percentage points); or
    - who had both a spouse and child (10.1 percentage points).

Both informal care resources and disability level appear to have been important in determining the extent to which declines in formal care were associated with a reduced likelihood of any care or an increased likelihood of relying solely on informal care. For example:

- Among older persons with a spouse only, the 23.3 percentage point decline in formal care was absorbed nearly equally by an 11 percentage point increase in the proportion receiving *no help* and a 12.3 percentage point increase in the proportion relying *solely on informal care*.
- Among those with both a spouse and child, most of their 10.1 percentage point decline in formal care was offset by increasing reliance on informal care only (7.8 percentage points); the proportion receiving no help increased by only 2.4 percentage points.
- Persons who lived with others primarily increased sole reliance on informal care; persons who lived alone primarily did without help.

The experience of persons with the highest disability level (five or six ADL limitations) provides insight into how severity of need may have contributed to changes in care arrangements as formal care declined. Virtually everyone in this group continued to receive help from formal or informal caregivers, but the distribution between formal and informal caregivers changed. The 10.9 percentage point drop in formal care was accompanied by a similar increase in sole reliance on informal care. The 4.9 percentage point decline in the proportion of this group receiving any informal care was among the smallest declines and was offset by a similar increase in the proportion relying solely on formal care. The latter finding may suggest that the decline in formal care strained informal care networks for a segment of this high-need group.

On the other hand, older persons with only one or two ADL limitations were less likely to use either type of care in 1999, so that the proportion receiving no help increased by 8.6 percentage points.

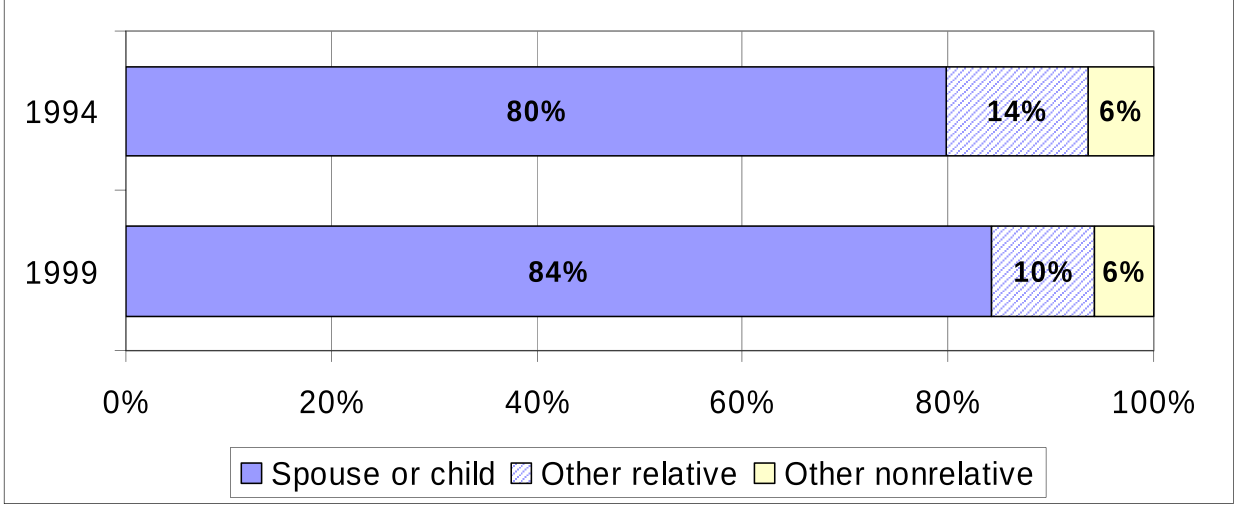
C. SOURCES OF INFORMAL CARE IN 1999

Spouses and children continue to be the most common source of informal care (Table 3). Among all older persons receiving informal care in community settings in 1999:

- about 84 percent received some care from spouses or children;
- another 10 percent received care from other relatives only; and
- less than 6 percent received informal care from nonrelatives only.

The proportion of informal care recipients receiving care from a spouse or child increased by more than 4 percentage points, consistent with the higher proportion of older persons with disability who had a spouse or child in 1999 shown in Table 1.

Figure 6: Providers of Informal Care, 1999



Ninety-two percent of older persons *who had a spouse or child*, nearly all who had a spouse, and 86 percent of those who had children only received some assistance from these closest family members in 1999. Those with neither a spouse nor a child also relied more heavily on relatives than on nonrelatives, with 58 percent receiving at least some care from other relatives, and 42 percent receiving all informal care from other nonrelatives.

Remaining differences in source of informal care across race, gender, and other groups, in Table 3, generally reflect the availability of a spouse or child, with spouses being the more important source of informal care. Thus, for example, both blacks, who are more likely to be receiving informal care from any source, and persons who live alone have a lower likelihood of receiving informal care from a spouse or child. Both groups are less likely to have a surviving spouse and more likely to have neither a spouse nor child (not shown).

Table 3. Providers of Informal Care among Older Community Residents Receiving Informal Care, by Characteristics of Care Recipient, 1994-1999

		Source of informal care			Difference 1994-1999					
	Number of persons	Spouse or child	Other relative	Other non-relative	Spouse or child		Other relative		Other non-relative	
All receiving any informal care	3,385,237	84.3	10.0	5.7	4.5	**	-3.9	**	-0.6	
Receiving informal care only	2,425,683	86.1	9.2	4.8	3.2	*	-3.5	**	0.3	
Receiving formal & informal care	959,554	79.8	12.1	8.1	4.8	*	-3.7	*	-1.2	
Male	1,149,669	88.3	6.2	5.5	3.0		-1.3		-1.7	
Female	2,235,568	82.2	12.0	5.8	4.9	**	-4.8	**	-0.1	
Black	428,787	73.8	15.4	10.8	6.8		-9.3	**	2.5	
White or other	2,956,450	85.8	9.2	5.0	4.1	**	-3.0	**	-1.1	
65-74	969,445	84.5	9.1	6.3	3.3		-2.9		-0.4	
75-84	1,368,634	86.8	7.9	5.2	5.1	**	-5.1	**	0.0	
85+	1,047,157	80.7	13.6	5.7	5.6	**	-3.8		-1.8	
IADL only	1,202,795	81.0	11.6	7.4	5.2	**	-4.5	**	-0.8	
1-2 ADLs	557,759	85.3	8.1	6.7	7.3	**	-7.3	**	0.0	
3-4 ADLs	665,685	86.8	8.4	4.8	8.4	**	-7.6	**	-0.7	
5-6 ADLs	958,997	86.0	10.4	3.6	-2.1		2.4		-0.2	
2+ ADLs	1,914,043	86.0	9.0	4.9	3.1	*	-3.2	**	0.0	
Has spouse or child	3,104,377	91.9	5.7	2.4	2.7	**	-1.0		-1.7	**
Spouse and child	1,315,383	98.5	1.3	0.2	0.7		0.0		-0.7	
Spouse only	124,292	98.7	1.3	0.0	5.2		-4.1		-1.1	
Child only	1,664,702	86.1	9.5	4.4	3.8	**	-1.3		-2.5	**
Neither spouse nor child	280,860	0.0	58.1	41.9	--		-17.1	**	17.1	**
Private residence alone	811,697	68.4	16.3	15.4	3.9		- 5.2	*	1.3	
Private residence with others	2,383,104	90.0	7.8	2.1	3.8	**	- 2.9	**	-0.9	
Community residential care[a]	190,436	79.9	10.8	9.3	--[b]		--[b]		--[b]	

Source: NLTCS 1994 and 1999. (Complete estimates for 1994 provided in Appendix Table A2)

Note: ** (*) = change from 1994 differs from zero at the 5% (10%) significance level in a two-tailed test.

[a] Includes assisted living and other community residential care settings without medical supervision.

[b] Not available in 1994.

D. POTENTIAL AND ACTUAL FAMILY CAREGIVERS, 1994–1999

The number of spouses and children who had a spouse or parent with disability and the number actually providing care to these older persons rose between 1994 and 1999, about in proportion to the number of older persons with disability. Thus, although demographic projections suggest that informal caregiving may suffer in the future because older persons in later generations will have fewer children available to provide care, such is not yet the case. In fact, with the first waves of the Baby Boom generation nearing retirement age, their parents are beginning to age into frailty with greater potential family caregiving resources (Redfoot and Pandya, 2002). In all, 17.7 million persons were spouses or children of older persons with disability in 1999, up from about 17.5 million in 1994 (Table 4).[4]

The number of *potential family caregivers* per disabled older person remained at 2.6 in 1999. As seen earlier, the increase in the proportion of older persons who had a spouse or child was entirely in the proportion who had children only. Thus, potential family caregivers in 1999 were more likely to be children of older persons who did not have a spouse to share caregiving responsibilities. The number of spouses or children actually providing care *per older person with a spouse or child receiving care in the community* remained at 1.1.

Potential Family Caregivers: A larger proportion of potential family caregivers had older, more severely disabled spouses or parents in 1999, consistent with the upward trend in age and disability level of older persons with disability. About 70 percent of potential family caregivers had spouses or parents with disability who were age 75 or older in 1999, compared with about 65 percent in 1994. About 48 percent had a spouse or parent with three or more ADLs, compared with 44 percent in 1994. There also was a small upward shift in the age of potential family caregivers, but no significant change in their relationship to the older person with disability. As in 1994, most potential caregivers were between the ages of 45 and 64, and there were slightly larger proportions of wives and daughters than of sons and husbands.

Fifty-eight percent of potential family caregivers had a disabled elder who lived with them or other persons in 1999. Slightly more than one in five had a spouse or parent with disability who lived in an institution (17.5 percent) or a community residential care setting (3.7 percent). A similar proportion had a spouse or parent with disability who lived alone. (Estimates are provided for residential situation in 1994, but they are not comparable with estimates for 1999 because of the change in survey methodology in 1999 to identify assisted living settings.)

Actual Family Caregivers: Like potential family caregivers, the 3.76 million *actual* family caregivers had spouses or parents who were older in 1999 than in 1994. Slightly more than 30 percent were caring for older persons who were age 85 or older, compared with a quarter who were doing so in 1994. The percentage who were assisting older persons with three or more ADL limitations rose from 47 percent in 1994 to about 52 percent in 1999.

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[4] The 1994 estimate is higher than that reported in Spillman and Pezzin (2000), because our definition of chronic disability is broader than the definition used in the earlier study. That study excluded community residents who did not receive formal or informal care.

Table 4. Characteristics of Spouses and Children of Older Persons with Chronic Disability by Whether They Provide Care, 1994 and 1999

	All Spouses and Children			Spouses and Children Providing Care		
	1994	1999		1994	1999	
Number of persons	17,475,398	17,699,258		3,720,169	3,761,882	
	Distribution by characteristics					
Age of disabled elder						
65-74	35.5	30.2	**	33.8	27.5	**
75-84	40.3	43.5	**	40.8	42.0	
85+	24.2	26.3	**	25.4	30.5	**
Race of disabled elder						
Black	11.4	11.0		11.9	10.8	
White or other	88.6	89.0		88.1	89.2	
Elder's disability type/level						
IADL only	30.6	27.7	**	36.2	32.0	**
1-2 ADLs	25.4	24.7		16.8	16.3	
3-4 ADLs	16.7	17.8	*	18.0	21.1	**
5-6 ADLs	27.3	29.7	**	29.0	30.7	
Elder's living arrangement						
Private residence alone	22.9	20.8		24.7	21.1	
Private residence with others	60.4	58.0		75.3	73.3	
Community residential care[a]	--[b]	3.7		--[b]	5.6	
Institutional resident	16.7	17.5		--[c]	--[c]	
Age of spouse or child						
< 35	6.6	4.1	**	3.5	2.5	*
35-44	22.8	19.4	**	14.1	11.6	**
45-54	31.7	34.0	**	23.6	24.1	
55-64	20.7	23.3	**	19.6	22.3	*
65-74	11.4	11.4		21.6	20.3	
75-84	5.4	5.9		14.5	15.3	
85+	1.4	1.9	*	3.1	3.9	
Relationship to recipient						
Wife	6.7	6.8		20.2	20.5	
Husband	5.5	5.3		15.7	14.3	
Daughter	44.9	45.4		41.5	41.6	
Son	42.9	42.5		22.6	23.6	

Source: NLTCS 1994 and 1999

Note: ** (*) = change from 1994 differs from zero at the 5% (10%) significance level in a two-tailed test.

[a] Includes assisted living and other community residential care settings without medical supervision.

[b] Not available in 1994.

[c] Informal care information is not collected for institutional residents.

Nearly three-quarters of actual caregivers were caring for a spouse or parent living with them or others, one-fifth for an elder living alone, and 5.6 percent for an elder in a community residential care setting. Spouses represented about 35 percent of actual caregivers in 1999, compared with only 12 percent of potential family caregivers. In contrast to potential caregivers, among *actual* caregivers, wives and daughters outnumbered sons and husbands by about three to two. About 4 percent of actual caregivers were themselves age 85 or older.

Spouses of Older Persons with Disability: A stable number of persons, 2.1 million, had an elderly spouse with disability in 1994 and 1999 (Table 5). The characteristics of these spouses were similar in 1994 and 1999, except for a small upward shift in their age, mirroring that of the spouse with disability. There was no significant upward shift in the disability level of married older persons with disability. Fewer spouses were actually providing care, however—1.31 million in 1999, compared with 1.34 million in 1994, consistent with the marginally significant increase discussed earlier in the proportion of married older persons with disability who received no care. Sixty-one percent of all spouses of older persons with disability and 69 percent of those with a community-residing spouse with disability were active caregivers in 1999.

About 64 percent of potential caregiving spouses and 60 percent of spouses actually providing care had a spouse with disability who was age 75 or older in 1999. About 57 percent of potential caregiving spouses and about 53 percent of those actually providing care were themselves in this age group, an increase of about 5 percentage points in each proportion over 1994. For active caregivers, however, the difference is only marginally significant ($p < .10$). It is not surprising that spouses age 85 or older were less likely than were younger spouses to be actually providing care. Nevertheless, 11 percent of caregiving spouses were age 85 or older in 1999.

The rate of caregiving by spouses does not appear to be affected by residential setting. Whether their spouses lived in private residences or community residential care settings, nearly 70 percent of potential caregiving spouses were actively providing care (not shown).

Older men with disability are more likely to have a surviving spouse than are older women. Thus, in both years, wives represented a larger proportion of both potential and actual caregiving spouses. About 64 percent of wives were active caregivers, compared with 57 percent of husbands (not shown).

Paid employment does not appear to affect caregiving by spouses. About 90 percent of spouses of older persons with disability were age 65 or older, and only a small proportion (less than 5 percent) worked 30 hours or more per week. These workers were no less likely, however, to provide care than were spouses working fewer hours or not at all. The apparent decline in the proportion working between 1994 and 1999, although consistent with the aging of the pool of potential spousal caregivers, is not statistically significant.

Table 5. Characteristics of Spouses of Older Persons with Chronic Disability by Whether They Provide Care, 1994 and 1999

	All Spouses			Spouses Providing Care	
	1994	1999		1994	1999
Number of persons	2,132,011	2,144,416		1,335,820	1,308,357
	Distribution by characteristics				
Age of disabled elder					
65-74	42.7	36.1	**	45.2	40.4
75-84	43.5	49.3	**	44.3	46.3
85+	13.8	14.6		10.6	13.3
Race of disabled elder					
Black	7.0	8.3		8.5	7.7
White or other	93.0	91.7		91.5	92.3
Elder's disability type/level					
IADL only	30.8	29.6		33.8	32.3
1-2 ADLs	25.0	24.5		18.2	18.2
3-4 ADLs	15.9	18.2		19.4	20.9
5-6 ADLs	28.3	27.7		28.5	28.7
Living arrangement					
Private residence	88.7	86.3		100.0	97.6
Community residential care[a]	--[b]	2.1		--[b]	2.4
Institutional resident	11.3	11.6		--[c]	--[c]
Age of spouse					
< 55	2.2	1.8		2.6	2.1
55-64	7.3	7.5		8.2	8.1
65-74	38.4	33.5	**	41.4	36.6
75-84	40.4	42.6		39.1	42.0
85+	11.7	14.5	*	8.6	11.1
Relationship to recipient					
Wife	54.8	56.2		56.3	58.9
Husband	45.2	43.8		43.7	41.1
Employment of spouse					
More than 30 hours per week	4.9	3.8		5.5	4.1
Not employed/less than 30 hours per week	95.1	96.2		94.5	95.9

Source: NLTCS 1994 and 1999

Note: ** (*) = change from 1994 is differs from zero at the 5% (10%) significance level in a two-tailed test.

[a] Includes assisted living and other community residential care settings without medical supervision.

[b] Not available in 1994.

[c] Informal care information is not collected for institutional residents.

Children of Older Persons with Disability: About 15.6 million children had a parent with disability in 1999, up slightly from 15.3 million in 1994 (Table 6). This was about 2.3 potential caregiver children per older person with chronic disability in both years, and about 3 per *parent* with disability. About 19 percent of children with a parent with disability living in the community actively provided care in 1999.[5]

About 71 percent of children who were potential caregivers had a parent with disability who was 75 or older in 1999, up from about 66 percent in 1994. Nearly 40 percent of children who were *actual* caregivers were caring for a parent age 85 or older, compared with about 34 percent in 1994. Most children of older persons with disability were in the 45–64 age range—64 percent of potential caregivers and nearly two-thirds of children actively providing care in 1999. However, more than 9 percent of children who were potential caregivers and more than 12 percent of children actively providing care were themselves age 65 or older.

Table 6. Characteristics of Children of Older Persons with Chronic Disability by Whether They Provide Care, 1994 and 1999

	All Children			Children Providing Care		
	1994	1999		1994	1999	
Number of persons	15,343,387	15,554,841		2,384,349	2,453,525	
	Distribution by characteristics					
Age of disabled elder						
65-74	34.5	29.3	**	27.5	100.0	**
75-84	39.9	42.7	**	38.8	20.7	**
85+	25.7	28.0	**	33.8	39.6	**
Race of disabled elder						
Black	12.0	11.4		13.8	12.4	
White or other	88.0	88.7		86.2	87.6	
Elder's disability type/level						
IADL only	30.6	27.5	**	37.5	31.8	**
1-2 ADLs	25.5	24.8		15.9	15.2	
3-4 ADLs	16.8	17.8		17.2	21.2	**
5-6 ADLs	27.2	30.0	**	29.3	31.7	
Living arrangement						
Private residence alone	25.6	23.4	**	36.5	31.8	**
Private residence with others	56.9	54.4	**	63.5	60.8	
Community residential care[a]	--[b]	3.9		--[b]	7.4	
Institutional resident	17.5	18.3		--[c]	--[c]	

Source: NLTCS 1994 and 1999

Note: ** (*) = change from 1994 differs from zero at the 5% (10%) significance level in a two-tailed test.

[a] Includes assisted living and other community residential care settings without medical supervision.

[b] Not available in 1994.

[c] Informal care information is not collected for institutional residents.

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[5] As a reminder, we cannot measure caregiving by children whose parents live in institutions.

Table 6 continued. Characteristics of Children of Older Persons with Chronic Disability by Whether They Provide Care, 1994 and 1999

	All Children		Children Providing Care	
	1994	1999	1994	1999
	Distribution by characteristics			
Age of child				
< 35	7.5	4.7 **	5.4	3.8 *
35-44	25.9	22.0 **	21.7	17.6 **
45-54	35.8	38.5 **	35.6	36.1
55-64	22.5	25.5 **	25.9	29.9 **
65-74	7.7	8.4	10.6	11.6
75+	0.6	1.0 **	0.7	1.1
Marital status of child				
Not married	29.1	31.9 **	39.7	40.2
Married	70.9	68.1 **	60.3	59.8
Relationship to recipient				
Daughter	51.1	51.6	64.7	63.8
Son	48.9	48.4	35.3	36.2
Distance to recipient				
Resident	8.1	7.9	37.2	35.3
Within 10 minutes	18.5	19.2	28.1	29.2
11 to 30 minutes	23.0	22.0	21.0	18.1 *
30 to 60 minutes	12.1	12.1	7.9	8.191
60 minutes to 24 hours	25.6	25.0	5.4	7.176 *
More than 24 hours	12.8	13.8 *	0.4	2.0 **
Child care responsibilities				
Has children under age 15	27.6	23.5 **	19.4	18.4
No children under age 15	72.4	76.5 **	80.6	81.6

Source: NLTCS 1994 and 1999

Note: ** (*) = change from 1994 differs from zero at the 5% (10%) significance level in a two-tailed test.

[a] Includes assisted living and other community residential care settings without medical supervision.

[b] Not available in 1994.

[c] Informal care information is not collected for institutional residents.

The proportion of children who were either potential or active caregivers caring for parents with only IADL disability fell between 1994 and 1999, while the proportion with parents with three or more ADL limitations increased. About 48 percent of children who were potential caregivers and 53 percent who were actual caregivers had elderly parents with at least three ADL limitations in 1999, up from 44 percent and 46 percent, respectively, in 1994.

Most children who were potential or active caregivers had an elderly parent who lived with them or others in 1999. However, a substantial proportion—23.4 percent of potential parental caregivers and about 32 percent of active caregivers—had an elderly parent with disability who lived alone. About 18 percent of potential caregiver children had an institutionalized parent. Only 3.9 percent of children who were potential caregivers, but 7.4 percent of those providing care had a parent living in community residential care. The high rate of caregiving among this group of children may provide some evidence that considerable informal caregiving occurs among children of institutionalized parents. About 30 percent of children with a parent in residential care were active caregivers, compared with about 22 percent of children whose disabled parent lived alone (not shown). Children whose parent lived with others were least likely to be providing care (17.6 percent, not shown), primarily because these older persons are most likely to be living with and receiving care from a spouse.

Other than the upward shift in age, there were few significant changes between 1994 and 1999 in the personal characteristics of children who were either potential or actual caregivers. Children actively providing care in both years were far more likely to be:

- married,
- daughters,
- living with or near their parent, and/or
- without competing responsibilities for child care.

Although the proportion of unmarried potential caregivers rose between 1994 and 1999, no significant change occurred in marital status of active caregivers. About 40 percent of children who were actual caregivers were unmarried, and about 60 percent were married in each year. The gender distribution of potential and active parental caregivers also was stable between 1994 and 1999. Slightly more than half of children who were potential caregivers, but 64 percent of children actively providing care were daughters, consistent with long-standing caregiving patterns.

Both distance and the presence of children under age 15 reduced the likelihood that a child provided care to a parent with disability. Children living with or within 10 minutes of parents with disability were far more likely to provide care, comprising 27.1 percent of children who were potential caregivers but 64 percent of active caregivers. Nearly 40 percent of children who were potential caregivers lived an hour or more away from their parents. Although this group remained less likely to provide care than did children who lived closer, the proportion who were active caregivers rose from 5.8 percent in 1994 to 9.2 percent in 1999 (not shown).

In 1999, fewer children who were potential caregivers also had children of their own under age 15 (23.5 percent, down from 27.6 percent in 1994), most likely owing to the upward shift in the age of potential caregivers. The difference in caregiving participation by children with competing child care demands was less striking, however, than the difference related to distance. About 12 percent of children who had children of their own were active caregivers, compared with almost 17 percent of children without this competing demand (not shown). As noted earlier, information on employment was not collected for children in 1999, so we could not examine changes in labor force participation among children who were potential and active caregivers.

V. DISCUSSION AND IMPLICATIONS

With notable exceptions, the trends in disability and care arrangements seen between the mid-1980s and mid-1990s continued between 1994 and 1999. The downward trend in the overall rate of disability continued, although the change between 1994 and 1999 was not significant. The proportion of older persons with chronic disability who received any assistance also continued to decline, accompanied by an increase in the proportion who reported managing their disability solely with assistive devices. Two trends did not continue:

- The prevalence of community-based formal care, which had been increasing and peaked at nearly 43 percent of older persons with disability receiving assistance in 1994, fell to about 34 percent in 1999.
- The declining participation of spouses and children as caregivers seen between 1984 and 1994 did not continue. Instead, both the number of spouses and children available and the number actually providing care roughly kept pace with growth in the number of older persons with disability. Thus the proportion of these family caregivers providing care to their spouses or parents did not fall between 1994 and 1999.

Reduced formal care following the BBA may have contributed to stemming the downward trend in family caregiving. The decline in family caregiving between 1984 and 1994 was among secondary family caregivers who were supplementing the efforts of the primary caregiver (Spillman and Pezzin, 2000). This reduction in the number of secondary family caregivers between 1984 and 1994 was accompanied by an increase in the proportion of older persons receiving a combination of informal and formal care, suggesting that formal care may have substituted for the efforts of secondary informal family caregivers. The ratio of active family caregivers to older persons receiving disability help in the community fell from 1.23 to 1.1 between 1984 and 1994. We found, however, that this ratio remained constant between 1994 and 1999, as reductions in formal care resulted in a larger proportion of older persons, including older persons with spouses or children, relying solely on informal care. A larger proportion, however, also relied solely on assistive devices.

Thus, older persons appear to have compensated for declines in formal care by increasing their reliance on either assistive devices only or informal care only. The largest increases in sole reliance on assistive devices were among older persons who had *fewer* family resources. Increases in sole reliance on informal care were larger among older persons with *more* family resources. For example, older persons with both a spouse and child compensated primarily by increased reliance on only informal care. The response among older persons with only a spouse was divided about equally between increased reliance on assistive devices and informal care only.

It is interesting to note that older persons with children had substantially smaller reductions in formal care than did older persons with only a spouse, suggesting the possibility that children provide financial or advocacy resources beyond those provided by a spouse. The smaller reductions also may reflect changing attitudes toward receiving some types of care from children or indicate that paying for formal care may be a solution to logistical problems for children who are less likely to live nearby and more likely to have competing demands on their time.

Two findings raise questions about the potential adverse effects of reduced formal care on older persons:

- The largest decrease in any formal care (more than 23 percentage points) from 1994 to 1999 occurred among persons with a spouse only.
- More than half of older persons caring for spouses (53 percent) were themselves age 75 or older.

We also found striking differences by disability level in the response to reduced formal care. Persons who had the highest level of disability had a surprisingly large—nearly 11 percentage points—decline in any formal care accompanied by no reduction in the proportion receiving care, owing to a smaller than average decrease in any informal care and a compensating increase in sole reliance on formal care. These shifts may reflect both the extent to which informal caregivers respond to changing needs and the possibility that reductions in formal care may tax the informal care resources of those with greater needs.

Without analysis beyond the scope of the present study, we cannot measure the extent to which decreased use of formal care may have resulted in increased amount or intensity of care informal caregivers provided or the extent to which there may have been increases in unmet need or undermet need as patterns of informal and formal care changed. We measure only access to any formal or informal care, not hours and types of care caregivers provided.

The decline in formal caregiving seems to be too large to be explained solely by direct effects of reductions in Medicare home health. It also runs counter to reported increases in both Medicaid and privately paid care between 1996 and 1999 (Heffler et al., 2001). Although both Medicaid and private payments fell in 2001 (Levit et al., 2003), this occurred after the period covered by our estimates. Thus, we might have expected formal care to hold its own or fall less than we observed between 1994 and 1999. It will be important to see whether the decline in formal caregiving continues or reverses in the next wave of the NLTCS, now underway. Medicare home health spending increased in both 2001 and 2002 under the prospective payment system, which replaced the interim payment system in October 2000 (Levit et al., 2003; Levit et al., 2004).

The key feature of the patterns we observe seems to be the increased proportion of older persons who report sole reliance on assistive devices. The decline in disability help—either formal or informal—and the rise in use of assistive devices in recent years have yet to be understood fully. One hypothesis might be that the lack of informal care resources provides an incentive and necessity for older persons to manage disability with only assistive devices, whether or not that arrangement is ideal. Indeed, the results here indicate that older persons with disability who have neither a spouse nor children are somewhat more likely to report no formal or informal care. However, *all* older persons, including those with family caregivers, were more likely in 1999 than they were in 1994 to be managing without formal or informal care. Only for older persons with *both* a spouse and children was the increase not statistically significant. Thus, although our results suggest that having fewer informal care resources may contribute to the increased proportion of older persons with disability who are managing without formal or informal care, this situation but does not explain it entirely. Neither the number of family caregivers available to provide care nor the rate at which they provide care has declined. Although demographic trends indicate such declines are likely in the future, in the short run, the number of potential family caregivers is expected to increase (Redfoot and Pandya, 2002).

Other potential contributing factors not easily examined using existing survey data may explain the disability rate declines and the increased rate of assistive device use. They include:

- underlying improvements in the physical environment, particularly general improvements such as telephone and Internet banking and shopping, which may affect whether IADL disability is reported and whether help is required;
- home modifications that enhance performance or remove barriers;
- improved health among older persons; and
- changes in attitudes toward relying on family caregivers.

We have not examined the extent to which reports of unmet need increased among persons receiving help between 1994 and 1999 as patterns of formal and informal care changed. However, only a very small number of NLTCS respondents who receive no help with ADL activities (less than 1 percent of this group in each year) say they need help. Thus, self-reported need does not appear to contribute to the trend toward sole reliance on assistive devices. There is no corresponding need measure for IADL activities.[6] Persons who say they do IADL activities and those who report that they could do them if they “had to” are not counted on the NLTCS as having disability. They are not asked whether they need help, and no information is collected about how difficult performance may be.

Although unmet need does not appear to account for reduced use of disability help, increases in unmet need among older persons *receiving care* may have occurred because of the increased burden on informal caregivers as use of formal care decreased. If so, policies that provide support or incentives for caregivers may reduce barriers to informal caregiving and have some impact on participation by family caregivers. They may also be effective in reducing hardships for those who are already providing care, maintaining their ability to participate, or increasing the amount of care they can provide. Measures such as workplace accommodations, more liberal family leave policies, and direct supports for caregivers, such as respite care, tax credits and caregiver allowances, could reduce both stress and financial strains.

Caregiver support policies do not always consider spouses and children of older persons living in residential care and nursing homes. These family caregivers may be ineligible for most caregiver supports. Although we cannot measure informal care for older persons in institutions, we found that children of older persons with disability in community residential

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[6] Persons who report receiving no help with IADL activities are asked whether they need help, but the questions are not conditioned on whether the need arises because of health or disability.

care were more likely to provide care than were children whose parents lived in private residences. This may be true for potential family caregivers with older persons in institutions as well. Expanding collection of informal caregiving information to include institutional settings would improve our understanding of the role of informal caregivers. Oversight and participation by informal caregivers may be important to the quality of both life and care for older persons in residential care and in institutional settings.

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