

Staying the Course: Trends in Family Caregiving

Introduction and Purpose

This In Brief summarizes major findings of the AARP Public Policy Institute (PPI) issue paper, “Staying the Course: Trends in Family Caregiving,” by Brenda C. Spillman and Kirsten J. Black of The Urban Institute.¹ 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 disabilities in the United States. This paper uses data from the 1999 National Long-Term Care Survey, a nationally representative survey of Medicare beneficiaries ages 65 and older, and earlier waves of that survey to examine trends in disability and in formal (paid) and informal (unpaid) care for older persons.

Key Findings

Earlier research using NLTCs data found a significant decline in the number of family caregivers and an increase in the use of formal care provided by paid workers between 1984 and 1994. These trends, however, seem to have reversed. **Between 1994 and 1999, the number of spouses and children providing care to an older person with disabilities increased, while the use of any formal care by older persons with disabilities who received care in the community declined. Over the same period, the proportion relying solely on family care increased dramatically.**

Among older community residents with disabilities:

- Among those who received assistance, the use of any formal care (formal care only or a combination of formal and informal care) was down from 43% in 1994 to 34% in 1999. At the same time, reliance on informal care only increased significantly. In 1999, nearly two-thirds (66%) of persons with disabilities ages 65 and over who received help relied solely on family caregivers, compared with 57% in 1994 -- a result of the decline in formal care.
- The number and proportion who received no formal or informal help with personal care or independent living activities increased from 22% in 1994 to 28% in 1999. Does this finding mean that there is more unmet need? Not necessarily. Those managing without help in 1999 had lower disability levels, such as only one or two limitations in activities of daily living,² than those who received help. Nearly all of the decline in help between 1994 and 1999 reflects greater use of assistive devices, such as shower or tub seats or walkers.

Among family caregivers:

- A larger proportion were caring for persons with *higher levels of disability* in 1999 than in 1994;
- Both family caregivers and care recipients were *older* than in 1994, with nearly 40% of caregiving children assisting parents age 85 or older in 1999, compared with 34% in 1994; in 1999, nearly 13% of caregiving children were themselves age 65 or older;

- About 30% of children with a parent in a *community residential care setting*, such as assisted living, were providing care; caregiving in these settings was measured for the first time in the 1999 survey.

The bottom line: Family caregivers continue to provide the vast majority of the long-term care received by older persons with disabilities in the U.S. More than 90% of care recipients received informal care (informal care only or a combination of informal and formal care) in 1999 (91.5%) and in 1994 (93.2%).

Conclusion

The decline in formal care may be explained in part by the changes in Medicare home health payment after passage of the Balanced Budget Act of 1997 (BBA), which dramatically reduced the availability of these benefits. More analysis is needed to understand other factors, such as possible changes in the ability of older persons to afford privately paid home care or changes in the supply of home care workers, that may be contributing to the decline.

Three findings in particular raise concern about the potential adverse impacts of reduced formal care on older persons: The largest declines in use of any formal care were among:

- Older persons with only a spouse
- Older persons ages 85 or older
- Older persons with the highest levels of disability (5 or 6 ADL disabilities).

The increase in those receiving no formal or informal help also needs further study. For example, the downward trend in any assistance may reflect environmental improvements, such as telephone banking and shopping or home modifications, that reduce the need for help. Less than 1 percent of persons managing ADLs without help say they need help. Increases in unmet needs among older persons receiving informal care may have occurred, however, because of an increased burden on informal caregivers, as the use of formal care decreased. If so, policies such as workplace accommodations and more liberal family leave, as well as direct supports for caregivers, such as respite care and tax credits, may reduce both stress and financial strains.

Finally, results suggest that children of older persons with disability in community residential care, such as assisted living, were more likely to provide care than were children whose parents lived in private residences. This finding is important because the number of older persons living in residential settings is increasing, and family caregivers may be playing important roles in helping to ensure their quality of life and quality of care.

¹ Brenda C. Spillman and Kirsten J. Black, “Staying the Course: Trends in Family Caregiving,” PPI Issue Paper #2005-17. November 2005

² 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. The six ADLs are bathing, dressing, getting around indoors, getting in and out of bed, using the toilet, and eating. Eight IADLs are included, such as shopping and managing money.