

FAMILY CAREGIVING AND LONG-TERM CARE

Introduction

Family caregivers are the backbone of the long-term care system in the United States. They provide about 80 percent of the care for people who need help with daily activities, such as bathing and dressing, taking medications, and paying bills. This form of care is generally unpaid (“informal” caregiving) compared to caregiving services from paid workers (“formal” caregiving).

One study (Arno et al., 1999) estimated the value of family caregiving at \$196 billion in 1997, assuming that the average annual number of hours of informal caregiving was replaced with paid services.

Prevalence of Informal Caregiving

Estimates of the number of family caregivers vary between 45 million (Kaiser Family Foundation, 2002) and 52 million individuals (National Survey of Families and Households, 1987/1992).

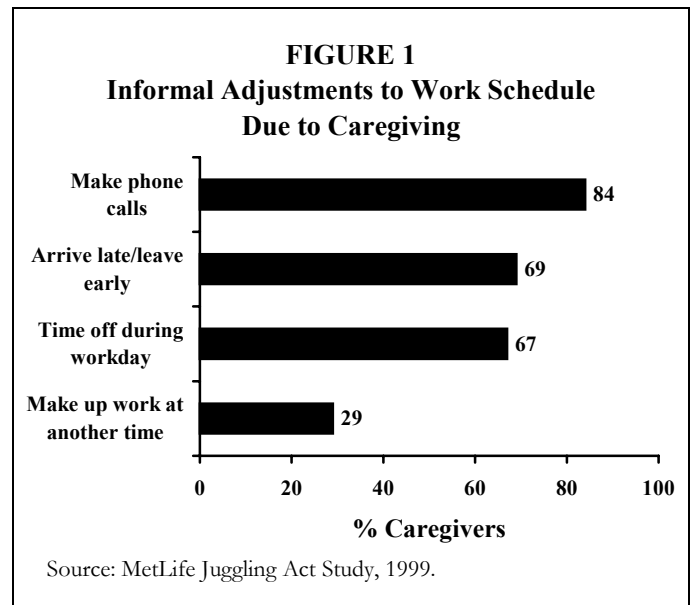
- The average caregiver is a 46-year-old woman who is married and employed outside the home (National Alliance for Caregiving/AARP, 1997).
- More than one in five caregivers say they take care of someone with mental confusion, dementia, Alzheimer’s disease, or forgetfulness (National Alliance for Caregiving/AARP, 1997).
- Twenty-two percent of persons aged 45 to 55 are caring for or financially supporting older relatives. In this age group, 43 percent of Asian and 34 percent of Hispanic family members provide support to older relatives, compared to 28

percent of blacks and 19 percent of whites (AARP, In the Middle, 2001).

- In addition, more than one in 10 grandparents (10.9 percent) at some point raise a grandchild for six months or longer. More than half of grandparent caregivers are aged 60 and older. Three-quarters are women (AARP, In the Middle, 2001).

Employed Caregivers

As shown in Figure 1, caregiving responsibilities seriously affect the productivity of employed caregivers, particularly because of altered work schedules.



The 1997 National Alliance for Caregiving/AARP national survey reported that two in 10 working caregivers turned down chances to work on special projects; almost as many avoided work-related travel. Forty percent of the survey respondents said that caregiving affected their ability to advance in their jobs. Other examples included:

- Twenty-nine percent passed up a job promotion, training, or assignment;
- Twenty-five percent passed up an opportunity for a job transfer or relocation; and
- Twenty-two percent were not able to acquire new job skills.

Publicly Funded Services for Caregivers

In October 2000, Congress enacted the National Family Caregiver Support Program (NFCSP) under the Older Americans Act. This program provides support services for family members caring for persons with disabilities and grandparents caring for grandchildren. Program components include education and training, counseling, support groups, and respite care. Congress appropriated \$125 million for FY 2001 and \$141.5 million for FY 2002.

Until passage of the NFCSP, state general revenues provided the bulk of public funding for family caregiving. Other sources of state revenue for caregiver services have included casino funds (for respite care in New Jersey), lottery money, and tobacco settlement funds. States can also cover respite care under Medicaid Home and Community-Based Waiver programs.

Examples of comprehensive statewide family caregiver programs include:

- *California's Caregiver Resource Centers* were funded at \$12.25 million in 2000 (state general revenues) and annually serve 11,700 caregivers of people with cognitive impairments.
- *Pennsylvania's Family Caregiver Support Program* was funded at close to \$11 million in 2000 (state general revenues) and serves more than 6,000 caregivers annually. The program provides financial

assistance to families to purchase services or supplies for the care of family members.

Examples of other initiatives include:

- *South Carolina's Care Options and Public Information* program provides information and referral to persons in rural areas through a telephone helpline and respite services.
- *Oregon's Lifespan Respite Program*, supports local networks that recruit and screen paid and unpaid respite care providers, and connects clients with respite services.

Tax Benefits for Family Caregivers

Twenty-two states help family caregivers with their financial burdens by providing tax credits or deductions. State tax credit programs build on the federal tax credit, which reduces the amount of income taxes a family owes. If payment is made by an employed caregiver to a third party for expenses incurred for the care of a dependent person, the federal dependent-care tax credit can be claimed.

Both Presidents Clinton and Bush have proposed a \$3,000 tax credit to assist persons with long-term care needs and the family members who care for them.

Sources: AARP, *In the Middle: A Report on Multicultural Boomers Coping with Family and Aging Issues*, July 2001; Arno et al., "The Economic Value of Caregiving," *Health Affairs* 18(2), March/April 1999; Kaiser Family Foundation, *Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective*, June 2002; The MetLife Juggling Act Study, *Balancing Caregiving with Work and the Costs Involved*, 1999; National Alliance for Caregiving/AARP, *Family Caregiving in the U.S.: Findings from a National Survey*, 1997; University of Wisconsin, Center for Demography, *National Survey of Families and Households*, 1987/1992.

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AARP Public Policy Institute, November 2002
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