

Who is Helping the Caregivers?

By Jean Oxendine

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More than seven million Americans are informal caregivers, according to the 1994 National Long Term Care Survey. These caregivers, most of whom are spouses, are critical to the survival of their elderly loved ones. If these caregivers were to be replaced by paid home care staff, the cost to our nation would be \$94 billion per year.

With caregivers dedicating an average of 20 hours per week, and even more time when the older person has multiple disabilities, the physical and emotional toll can be extreme. Two-thirds of working caregivers report problems with juggling work and caregiving. According to the 1996 National Alliance for Caregiving and AARP survey, the typical caregiver is a 46-year-old woman who is employed and also spends around 18 hours per week caring for her mother who lives nearby. The average duration of caregiving is 4.5 years. And the typical recipient is a 77-year-old woman who lives alone and has a chronic illness. Caregiving is mainly a woman's role, both for white and minority populations. Fifty-two percent of Asian, 77 percent of African American, 74 percent of White, and 67 percent of Hispanic caregivers are women.

According to Jim Steen, aging program specialist with the Administration on Aging (AoA), "In the last 10 years, there has been increasing attention paid to differences in caregiving across racial and ethnic groups." Early studies compared African Americans and Whites, and more recently, researchers have studied Hispanic and Asian subgroups as well. The 1996 National Alliance for Caregiving and AARP survey reported a higher incidence of caregiving among Asian-American (31.7 percent), African-American (29.4 percent), and Hispanic (26.8 percent) households than in the general population.

Asian American, African American and Hispanic caregivers are more likely than the general population to provide care for more than one person. They were also more likely than White caregivers to live with the care recipient and to have help from other persons.

Legislation

The Older Americans Act (OAA) requires that priority in service provision be given to "older individuals with the greatest economic and social need, with particular attention to low-income minority individuals." The same priority applies to caregivers.

The issue of caregiving is garnering national attention with the announcement of President Clinton's Long Term Care Initiative which

proposes a number of measures to meet the country's long term care needs. Last year the Initiative included a proposed National Family Caregiver Support Program which would be funded as part of a reauthorized OAA and administered by AoA. This proposal is still under consideration by Congress. This year the Initiative includes a FY 2001 budget request of \$125 million, utilizing existing OAA authority. These funds would finance respite, adult day care, caregiver training, in-home assistance, and other caregiver support services identified by State and Area Agencies on Aging. In FY 2001 AoA also is requesting additional funds to meet the long term needs of American Indians, Alaska Natives, and Native Hawaiian elders, many of whom are living well into their eighties and nineties. A portion of these funds are to be devoted to caregiver support services.

Resources

Although the research is preliminary, most evidence shows that despite its high cost, respite is a desired service, whether it is several hours during the day, or for a night or weekend. Individual states decide which type of respite care they will cover.

Other critical assistance is outreach, information, and assistance to caregivers, caregiver training, counseling, and care management. Caregivers often do not realize that they are in a formal caregiving role; they see it as part of their job of being a spouse or a son or daughter. They often don't realize that there are supportive services out there, Steen says.

AoA supports a nationwide, toll-free information and assistance directory called the Eldercare Locator, which can locate the appropriate Area Agency on Aging to help an individual needing assistance for their loved ones, relatives, or friends. Older persons and caregivers can call the Locator at 1-800-677-1116.

AoA also provides assistance to elderly individuals and those who care for them, through its Web site. The "Elderspage: Information for Older Persons and Their Families" page includes fact sheets, informational booklets, information on taxes, prescriptions, financial planning, mental health, and housing at: www.aoa.gov/elderspage.html.

There is also *The Resource Directory for Older People*, administered by the National Institute on Aging and AoA, which contains names, addresses, phone numbers, and fax numbers. You can find the directory on the web: <http://www.aoa.gov/aoa/dir/intro.html>. ❖

