

## CAREGIVING IN THE UNITED STATES

### INTRODUCTION

Caregivers remain the backbone of the long-term supportive services system in the United States. They provide the majority of care for people who need help with activities of daily living, such as bathing and eating, and instrumental activities of daily living, which include paying bills and taking medication. While this care is unpaid, its value has been estimated at 257 billion dollars annually.<sup>1</sup>

### PREVALENCE OF INFORMAL CAREGIVING

A 2004 study\* by the National Alliance for Caregiving (NAC) and AARP estimates that 21% of the U.S. population provides unpaid care to friends and family age 18 and older. This translates into 44.4 million caregivers in the U.S. today. According to this study:

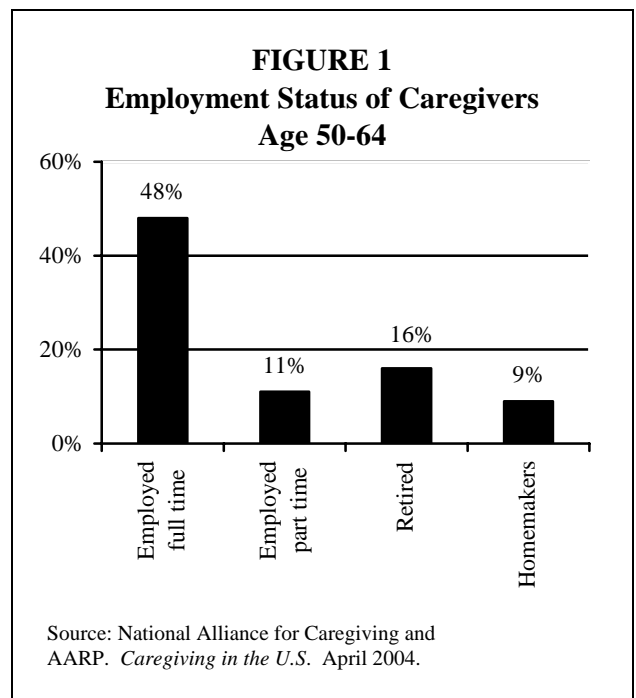
- The typical *caregiver* is a 46 year old female with some college experience and provides more than 20 hours of care each week to her mother.
- Nearly 39% of caregivers are male.
- Most caregivers live in close proximity to the person for whom they provide care. One quarter (25%) of caregivers report living in the same household as the care recipient; four in ten (40%) say they live within 20 minutes of the recipient; few (15%) live over an hour away.

\*This study was based on telephone interviews with 1,247 caregivers identified from an initial sample of 6,139 adults in the U.S. The study defined a caregiver as anyone over age 18, living in the U.S., and providing assistance with one or more activities of daily living or instrumental activities of daily living for someone age 18 and older.

- Nearly eight in ten (79%) of *care recipients* are 50 and older and the average age of care recipients 50 and older is 75.
- Most care recipients are female (65%) and many (42%) are widowed.
- Caregivers of older adults report that the main problem or illness of the person they care for is old age (15%), followed by cancer, diabetes, and heart disease (9% each), and Alzheimer's disease (8%).
- More than half of care recipients (55%) live in their own homes and about 25% live alone.

### WORKING CAREGIVERS

Many caregivers juggle work with caregiving responsibilities. Nearly six in ten (59%) caregivers are currently employed. See Figure 1.



Those who are not working are most likely retired or are homemakers. Male caregivers are more likely to be employed full-time than female caregivers. Among working caregivers age 50-64, 48% work full-time; only 3% of working caregivers 65 and older work full-time.

## SUPPORTS FOR CAREGIVERS

The vast majority of employer-based and publicly funded support in the U.S. is available for *family* caregivers, i.e., those who care for a relative. For instance, The Family and Medical Leave Act<sup>2</sup> (FMLA) is the first U.S. national policy designed to assist working caregivers in meeting their work and caregiving responsibilities. The FMLA allows employees to take up to 12 weeks of *unpaid* leave to care for an ill family member or newborn child. Since its passing in 1993, 35 million Americans have taken leave under this law.

The state of California has taken the FMLA a step further and created an explicit *paid* family leave law. Through this law, passed in late 2002, most employees may receive 55% to 60% of wages (capped at \$728 per week) for up to 6 weeks of leave per year to care for a seriously ill family member or newborn child. The program is funded by the employees themselves at an estimated \$27 per worker per year.

Publicly funded services are also available for family caregivers. In October 2000, Congress established the National Family Caregiver Support Program<sup>3</sup> (NFCSP) under the amended Older Americans Act. It was modeled after successful programs in California, New Jersey, Pennsylvania, and Wisconsin. This program provides support services for family members

caring for persons with disabilities and grandparents caring for grandchildren.

Most funds are allocated to states through a congressionally mandated formula that is based on a proportionate share of the population age 70 and older. Until passage of the NFCSP, state general revenues provided the majority of public funding for caregiving. Other sources of state revenue for caregiver services have included casino funds, lottery money, and tobacco settlement funds. States can also cover respite care (temporary assistance that allows caregivers to take a break from caregiving responsibilities) under Medicaid Home and Community-Based waiver programs. For more information about caregiver support services, please see PPI fact sheet number 112, "Family Caregiver Support Services: Sustaining Unpaid Family and Friends in a Time of Public Fiscal Restraint."

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<sup>1</sup> Arno, P.S. Economic Value of Informal Caregiving. Annual Meeting of the American Association of Geriatric Psychiatry, Orlando, FL, February 24, 2002.

<sup>2</sup> Family Medical Leave Act of 1993 (Public Law 103-3). Text of law available at: <http://www.dol.gov/esa/whd/fmla/>

<sup>3</sup> National Family Caregiver Support Program, established in October 2000 as part of amendments to the Older Americans Act (Public Law 106-501). More information available at: <http://www.aoa.gov/prof/aoaprogram/caregiver/overview/overviewcaregiver.asp>

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April 2005  
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