



*Advocacy. Action. Answers on Aging.*

## Home and Community-Based Services for Older Adults: Informal Caregiving

**F**amily care of older adults is an important and valued role in our society, and one that is important to family preservation and well being. Most older adults with long-term care needs live at home, either in their own homes, with or without a spouse, or in the home of a close relative or friend. In this setting the major long-term provider is the family and, to a lesser extent, other unpaid "informal" caregivers. The overwhelming majority of non-institutionalized older adults with disabilities — about 95 percent — receive at least some assistance from relatives, friends and neighbors. Almost 67 percent rely solely on unpaid help, primarily from wives or daughters.

### **Issue Background**

**L**ong-term care of older adults by family members is central to the functioning of current social and health care systems and is therefore a critical policy issue. Informal caregiving has always been the dominant source of care to most individuals in need. Nearly one out of every four households (23 percent or 22.4 million households) is involved in caregiving to persons age 50 or older. In fact, caregivers now provide nearly \$200 billion in unpaid care. Without this essential component of care, the long-term care system and the Medicare and Medicaid programs would not be able to meet the needs of our older population. With the current system facing growing demands for support services, it is essential to provide family caregivers with the resources they need to provide this valuable care.

Research on family caregiving has not only consistently validated its significant role in long-term care, but has also illuminated the problems and needs experienced by informal caregivers which have been of increasing concern to both aging advocates and policymakers. The caregiver role frequently results in enormous emotional, physical, and financial hardships, even though it is willingly undertaken and often is a source of great

personal satisfaction. Caregivers commonly experience a sense of burden, fair-to-poor physical health and high rates of depression. Among caregivers who provide unpaid care for a family member or friend age 50 or older, some 15 percent report that they have experienced a physical or mental health problem due to their caregiving duties. Worries over paying for care especially plague middle income families, who are not eligible for public benefits, yet cannot afford the out-of-pocket costs of care.

Half or more of family caregivers juggle work, family and caregiving responsibilities, resulting in work disruptions and lost productivity. The cost in lost wages and benefits to family caregivers has been estimated to be \$109 per day, according to a report by the American Council of Life Insurers in March 2000. While the Metlife Mature Market Group in June 1997 estimated the cost of informal caregiving in terms of lost productivity to U.S. businesses to be \$11.4 billion annually.

### **Need for Overall Policy**

**D**espite vast research on family caregivers, widespread awareness of the volume of family care, and general agreement that family care is necessary to balance the costs of long-term care, a comprehensive policy on family care of frail older adults has not emerged. A patchwork of family support programs of various kinds does, however, exist. These include community-based programs designed to help family members who are giving care, such as educational programs, support groups, and respite services. They also include long-term care services, usually for low-income people, that provide benefits directly to the older person and thus relieve family members to some extent.

In addition, many states support the family financially through tax incentives or direct payment. Taken together, these activities represent meaningful efforts to support family caregivers. In the last three to four years,

significant progress has been made at the national level with the advent of such policy initiatives as The Family and Medical Leave Act and The National Family Caregiver Support Program (NFCSP) under the Older Americans Act Amendments of 2000. In particular, the NFCSP enables local communities to connect families with information on caregiver resources and local services, provides counseling, training and peer support for caregivers, and provides services needed by older adults and their families, such as respite care, in-home services and adult day care.

### **Policy Recommendations**

**A**s the home and community continue to be promoted as the preferred setting for the delivery of long-term care services to older adults and persons with disabilities, national policy must recognize and support the significant role that family members and other informal caregivers play in the provision of that care. The coming retirement of the baby boom generation and increased demand for long-term care will only intensify demands on family caregivers. A national policy on long-term care should provide services available in the recipient's preferred surroundings, be characterized by privacy, choice, and control over daily decisions, and maintain any self-selected mutually agreed upon relationships between caregiver and care recipient.

#### **n4a urges policymakers to:**

- **Promote consumer direction in long-term care;**
  - **Assure that family caregivers of adults with physical, as well as cognitive, impairments have a place to turn to for support; and**
  - **Encourage the use of the Internet and other information technology to improve access to and information about caregiver support services and community resources.**
- **Double the initial \$125 million appropriation for the NFCSP to ensure that the much-needed benefits this vital program provides could reach thousands more caregivers and their families;**
  - **Offer a range of financial and other incentives, including tax credits/deductions and cash vouchers to all family caregivers, and affordable health insurance and guaranteed retirement security for individuals who leave the workforce to provide care to a family member;**