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*A Call for National Leadership  
in the 2004 Campaign*

# Family Caregiving and Long-Term Care: A Crucial Issue for America's Families

POLICY BRIEF

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FAMILY CAREGIVER ALLIANCE®  
*National Center on Caregiving*

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The opinions expressed in this policy brief are those of the authors and do not necessarily reflect the views of the Archstone Foundation.

## **ABOUT FCA**

Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy.

Long recognized as a pioneer among caregiver organizations, FCA operates programs at local, state and national levels. FCA is the lead agency and model for California's statewide system of Caregiver Resource Centers. In 2001, FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country.

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## POLICY BRIEF

# *A Call for National Leadership in the 2004 Campaign* **Family Caregiving and Long-Term Care:** **A Crucial Issue for America's Families**

### INTRODUCTION

Caregiving, once one of the most personal and private matters in family life, is a growing public issue. The challenges of family care in an aging society are a reality of daily life for millions of baby boomers as they seek or provide care for their parents, spouses, other relatives or friends, and as they think about long-term care options for themselves.

As America rapidly ages, policymakers are becoming increasingly aware of the central role played by ordinary families caring for loved ones with chronic illnesses or disabilities. Yet, in the 21<sup>st</sup> Century, family caregivers continue to be the most neglected group of the health and long-term care system,<sup>1</sup> despite their contributions worth \$257 billion (2000 dollars) in unpaid services and support—more than double the annual spending on home care and nursing home care combined.

Unless we adopt a better solution and provide adequate support to sustain caregiving families, our health and long-term care problems will only worsen. *National leadership on this issue has never been more urgent.* This policy brief explores and substantiates why family caregivers should be on

the national agenda and a campaign issue in 2004.

### BACKGROUND

The dramatic aging of our nation and heightened attention to broader health care reform are prompting policymakers to examine the needs, values and long-term care preferences of frail elders, persons with disabilities and their families. The demographic trends help explain why:

- ◆ The population aged 65 and over is expected to double, growing from 35 million persons in 2000 to an estimated 1 in 5 Americans or 70.3 million by 2030.<sup>2</sup>
- ◆ The very old (age 85 and over)—those most in need of long-term care—are the fastest growing population group in the country. This age group is expected to grow from about 4 million persons in 2000 to an estimated 8.9 million persons in 2030.<sup>3</sup>
- ◆ Baby boomers—those born between 1946 and 1964—begin turning 65 in just seven years.

In recent years, changes in our health care delivery system, including shorter hospital stays, have shifted even greater cost and responsibility for the care of frail elders and persons with disabilities onto families. When American families do

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turn to formal care options—such as in-home care, assisted living or nursing home care—they are faced with critical health care worker shortages, fragmented and uncoordinated services, major cuts to home care, and skyrocketing health and long-term care costs.

### **Long-Term Impact: A Case Study**

The cost of long-term care exacts a financial toll on many middle-income American families. Donna F., for example, is a caregiver residing in Northern California. Donna's mother was diagnosed with Alzheimer's disease and her father cared for her until he, too, became ill. Donna moved in to care for both of her parents until her father passed away. Donna is 45 and has been residing with and providing care for her mother for a year. The demands on Donna were substantial—she initially needed to take a three-month unpaid leave of absence from her job. When her leave ended she resigned, still providing full-time care. She gave up her salary and her pension. In this regard, she says, "I'm giving up my financial future that I've been working towards." In addition to these losses, she no longer has health insurance. She cites that as one of the major challenges she's facing. She has two children in college and one of those children was also on her health plan. Currently, both Donna and her child are uninsured.

Family caregiving is at the core of what sustains frail elders and adults with disabilities and is a major part of the American family experience:

- ◆ An estimated 44.4 million Americans—or more than 1 in 5 (21%) adults in the U.S.—provide unpaid care to another adult age 18 or older.<sup>4</sup>
  - ◆ Most adults receiving long-term care at home—78%—rely exclusively on family and friends to provide assistance.<sup>5</sup>
  - ◆ Another 14% supplement family care with assistance from paid providers; only 8% depend exclusively on formal services alone.<sup>6</sup>
- As baby boomers confront long-term care for their parents—and increasingly for themselves—they will demand access to quality services, coordinated systems of care, information, education and training. One national poll found that nearly two-thirds of Americans under the age of sixty believe they will have to care for an older relative in the next decade.<sup>7</sup> Another poll finds that nearly six of 10 Americans say presidential and congressional candidates' views on health reform will be a "very important" factor in their vote this November.<sup>8</sup> That's why the private discussions among families—in households across America—about everyday long-term care concerns, must be part of the public discourse and policy debates.
- In addition, a number of compelling factors give rise to public support for family and informal caregivers:
- ◆ A substantial increase in the older population and aging of the baby boomer generation;
  - ◆ Continued rapid growth in health care and long-term care costs;
  - ◆ Critical shortages of health care workers whose availability would ease the burden on families;
  - ◆ Sizeable cut-backs in local, state and federal programs and services to better assist people to remain in their homes and in their communities;
  - ◆ Increased labor force participation of women, who have traditionally provided the majority of informal care;
  - ◆ Greater geographical mobility and fewer multigenerational households, resulting in more "long-distance" caregiving;
  - ◆ Reductions in retirement benefits including health care and pensions, leaving retirees with few options and greater insecurity; and

- ◆ Caring for parents and loved ones as a core American family value.

## CAREGIVING DEFINED

The caregiving experience is varied. For some, caregiving consists of occasional help with running errands, household chores or providing transportation and financial support. For others, caregiving means more intense help for loved ones who are ill or disabled and can no longer take care of themselves—feeding, dressing, bathing. Help may be needed for an extended period of time.

Research has shown that providing care to older people and persons with disabilities often exacts a heavy emotional, physical and financial toll, even while it is often a source of great personal satisfaction. Today, most family caregivers face multiple competing demands of providing long-term care in addition to work, childcare and other family responsibilities. The juggling act can contribute to burnout, depression and other adverse health effects. In fact, studies consistently find high levels of depressive symptoms and mental health problems among family caregivers as compared to their noncaregiving peers.<sup>9</sup> Various studies have also linked caregiving with serious health consequences including increased risk of coronary heart disease; elevated blood pressure and increased risk of developing hypertension; lower perceived health status; poorer immune function; slower wound healing; and an increased risk of mortality.<sup>10, 11, 12, 13</sup>

The health effects of caregiving are significant, and yet they do not tell the whole story. As illustrated by Donna's situation, caregiving also significantly impacts caregivers in the workplace. As many as 13 percent of working caregivers may leave the workforce entirely to provide care for a

loved one.<sup>14</sup> Other caregivers move from full-time to part-time work, take unpaid leave, or refuse advancement in order to fulfill caregiving responsibilities.<sup>15</sup>

This care comes at a price. Time out of the workforce means reduced Social Security benefits, pensions and savings. All told, caregivers lose an average of \$659,000 in total wealth as a result of caregiving.<sup>16</sup>

## CURRENT EFFORTS IN CAREGIVER SUPPORT

The National Family Caregiver Support Program (NFCSP), under the Older Americans Act, stands as the first major national recognition of and commitment to providing direct support services to caregivers. The NFCSP provides a bridge for

many low- to middle-income families caring for an older adult who are not eligible for services in other public programs. These services include information and assistance in locating help, supplemental services such as reimbursement for healthcare supplies, and respite care, which allows caregivers to take a break from their care responsibilities. These types of supports are often key factors in allowing families to remain in their caregiving role as long as appropriate, keeping loved ones out of expensive nursing home care. But the funding for the NFCSP is meager—\$159 million for all 50 states for fiscal year 2004.

States have led the way in advancing caregiver services, often with the recognition that investment in caregiver support *now* reduces expenditures *later*. Research has shown that that support services effectively reduce the burden, stress and depression of caregiving responsibilities<sup>17,18,19, 20</sup> and can even delay the institutionalization of a loved one.<sup>21</sup> But as states slash budgets in response to serious fiscal pressures, caregiver sup-

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port services are vulnerable to cuts. Although limited action and debate have occurred thus far, Congress has laid the groundwork for furthering its commitment to family caregivers through hearings and legislation. A national dialogue has never been more urgent, given the demographic trends, major state cutbacks and proposed changes to Social Security. Congressional proposals include:

- ◆ Doubling the funding of the NFCSP<sup>22</sup>
- ◆ Increasing funds for the NFCSP (to \$250 million) and the Alzheimer's Demonstration Grant Program (to \$25 million); creating a \$3,000 caregiver tax credit; and incorporating the Lifespan Respite provisions of S. 538 (S.2533)
- ◆ Ensuring workers have 7 paid days of sick leave a year to care for their medical needs or a family member's (S. 2520)
- ◆ Expanding the Family and Medical Leave Act to cover more employees or provide wage replacement (H.R. 956, H.R. 3780, S. 304)
- ◆ Providing a tax credit or tax deduction for family caregivers (S. 100, S. 1214, S. 2029, S. 2072, H.R. 2096/S. 1335)
- ◆ Enhancing respite care options throughout the country (H.R. 1083, S. 538)
- ◆ Social Security "credits" to account for lost years of contributions (H.R. 473)
- ◆ Increased research, education and training (H.R. 2342, H.R. 2883, H.R. 3451, S. 387, S. 1179)

## POLICY RECOMMENDATIONS

- ◆ *Double the funding for the NFCSP* over the next five years—to ensure that resources will be available to meet the emerging needs of aging baby boomers and their parents, spouses, other relatives and friends.
- ◆ *Promote tax credits and economic incentives* to help caregivers afford the high costs of caregiving, and to better enable them to remain in their caregiving role.
- ◆ *Strengthen Social Security by recognizing the work of informal caregivers.* Providing "credits" in the system would help account for some time out of the workforce or reduced time on the job, due to heavy care demands.
- ◆ *Encourage employers to increase support for working caregivers,* through tax breaks for the provision of paid leave and other caregiver-friendly programs.
- ◆ *Enhance the existing federal Child and Dependent Care Tax Credit* by easing the "dependence" test. This would enable more family caregivers to take advantage of this credit. Making the credit refundable would provide additional assistance to lower-income caregivers who may not have the tax burden sufficient enough to file taxes.
- ◆ *Expand the Family and Medical Leave Act (FMLA)* to include workers on the job less than the current minimum of 1,250 hours a year, or those who have worked for a particular employer for less than a year. This would better reflect caregivers' variable work patterns. Providing wage replacement through state law, similar to the paid family leave law passed in California in 2002, might assist caregivers' ability to contribute to a retirement savings vehicle. Additionally, allowing workers taking leave to continue contributing to Social Security would reduce the long-term impact of caregiving on Social Security benefits in retirement. The FMLA also should require employers to continue any employer contributions to qualified retirement plans during a covered leave period.
- ◆ *Make Dependent Care Spending Accounts applicable to eldercare* by modifying the definition of "dependence" so that adults with health conditions would not be required to spend eight hours a day in the home of the caregiver in order to qualify. Current rules also require that any unused portion of the spending account revert to the employer at the end of the year. Allowing unused funds to roll over at year's end would

permit greater flexibility for eldercare costs, which, unlike childcare, can vary significantly from year to year.

- ◆ Offer enhanced resources for technical assistance and training in caregiver support, including respite care, so that states and local communities can better implement services and replicate successful program models.
- ◆ Improve service delivery and coordination so that families aren't forced to constantly negotiate the often confusing, complicated system of long-term care.

## CONCLUSION

*The time to act on a national caregiving agenda is now.* Families desperately need help and support—not to supplant what they are already doing, but to sustain them as they struggle to care for a loved one who needs help. Incremental steps have been taken, but to truly impact the day-to-day lives of ordinary Americans, this important, urgent campaign issue must be addressed. A national caregiving agenda must be a central part of any health care reform. The need will only intensify as our population ages. Without national leadership, we will all pay a heavy price.

## NOTES

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