

The Burden of Caring for Frail Parents

Statement of

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Madame Chairwoman and members of the committee, thank you for the opportunity to testify today about the financial challenges confronting family caregivers.

Many Americans provide crucial support to their frail older parents. Despite recent health improvements beyond age 65 (Manton, Gu, and Lamb 2006), most people continue to develop disabilities as they grow older and eventually require assistance with the basic tasks of everyday life. Spouses and adult children usually provide this help. Working without pay and often putting in long hours over many months or years, family caregivers significantly improve the quality of life for many frail older adults. The help they provide often keeps older people out of expensive nursing facilities and in their own homes, which most prefer. Informal family caregivers also save the public billions of dollars every year by reducing nursing home admissions and limiting the use of paid home care. Yet care responsibilities often impose serious burdens on caregivers, especially those balancing elder care duties with paid employment and care of their own children. These pressures will likely intensify as the population ages in coming decades. Although awareness of these strains is growing, we still have few public policies in place to support family caregivers.

In my testimony today, I would like to make the following points:

- Frail older adults are among the most vulnerable groups in the nation;
- Informal care provides crucial support to frail older Americans;
- Adult children provide much of the unpaid care frail elders receive;
- Elder care responsibilities often create financial hardship for caregivers;
- Care burdens will likely grow in the future as the population ages; and
- Family caregivers need better support.

Frail Older Adults Are among the Most Vulnerable Groups in the Nation

About 10 million Americans ages 65 and older, representing about 29 percent of the older population, need help today with basic personal activities or household chores and errands.¹ About 2 million older people living at home, or 6 percent of the older

¹ Except where otherwise noted, the figures cited in this section and the following one are drawn from Johnson and Wiener (2006). These estimates were based on data from the 2002 Health and Retirement Study, a nationally representative survey of older Americans conducted by the University of Michigan for the National Institute on Aging. The study classified respondents as disabled if they reported any difficulty because of health or memory problems with at least one activity of daily living (ADL) or instrumental activity of daily living (IADL). ADLs reported in the survey consisted of bathing, getting in and out of bed, eating, dressing, walking across the room, and using the toilet. IADLs consisted of shopping for groceries, preparing hot meals, using the telephone, taking medications, and managing money. Respondents were not

population living outside of nursing facilities, are severely disabled, requiring assistance with three or more activities of everyday life, such as bathing, eating, dressing, or getting in and out of bed. These numbers will rise in the future as the population ages.

Frail older adults are among the most vulnerable groups in the nation. Disproportionately female, widowed, and in their 80s and 90s, most older people with disabilities have little education and limited financial resources. For example, median household income in 2001 totaled \$30,264 among those with no disabilities, \$18,480 among those with moderate disabilities, and \$14,160 among those with severe disabilities. Severely disabled older adults are nearly four times as likely to live in poverty as older adults with no disabilities. Frail older people hold little wealth, and most of what they have is tied up in their homes. In 2002, median household wealth among those with severe disabilities totaled only about \$47,900, nearly three-fourths of which represented the value of their homes net of outstanding mortgage debt. Household financial assets, which can generally be liquidated easily to meet long-term care and other needs, amounted to only about \$7,800 for the median older adult with severe disabilities. So less than one-half of older people with severe disabilities have more than a few thousand dollars that they can easily draw on to meet their health care needs.

Besides physical limitations, many frail older adults have mental health problems and cognitive impairments. About 31 percent of older people with any disabilities and 45 percent of those with severe disabilities report depressive symptoms. Additionally, about 15 percent of frail older people are cognitively impaired. Cognitive impairments and depression and other psychological problems often limit physical functioning and intensify long-term care needs and caregiver burdens (Ormel et al. 2002; Ory et al. 1999).

Informal Care Provides Crucial Support to Frail Older Americans

Most frail older adults live at home, not in nursing facilities, and rely on unpaid help from family and friends. Only about 1.4 million older adults resided in nursing homes in 2002 (Spillman and Black 2005), representing less than one-seventh of the frail older population. About 57 percent of frail older adults living at home received help from unpaid caregivers, including about 81 percent of those with severe disabilities.

Paid help with basic personal care and household chores is rare. About 14 percent of all frail older adults living outside of nursing homes received paid home care in 2002, generally in combination with unpaid help from family and friends. Only 4 percent of frail older people living at home relied solely on paid helpers, without any unpaid supplemental help from family or friends. Nearly three-quarters of frail older recipients

considered disabled if they expected their limitations to last no more than three months. The study also classified all older nursing home residents as being disabled.

Other surveys generate somewhat lower estimates of old-age disability rates. For example, data from the National Long-Term Care Survey, conducted by Duke University for the National Institute on Aging, show that only 19 percent of older adults were disabled in 2004 (Manton, Lamb, and Gu 2006).

of paid home care services also obtained unpaid care from family and friends. About 82 percent of all the assistance with basic personal activities and household chores received by frail older adults comes from unpaid helpers.

Frail older people rely heavily on informal care largely because paid services are expensive. In 2006, the average hourly rate for home health aides was \$19 (MetLife Mature Market Institute 2006). For people who receive 60 hours of paid care each month—the median amount among recipients—costs average about \$13,700. Private long-term care insurance can help defray some out-of-pocket costs, but coverage rates are low. In 2002, only about 10 percent of adults ages 65 and older had private coverage, including only about 7 percent of those with disabilities living at home. High premiums partly account for low coverage rates. Average annual premiums for a policy purchased at age 65, for example, stood at \$2,346 in 2002 (America's Health Insurance Plans 2004). Medicaid coverage, available to people with limited financial resources, also reduces the out-of-pocket price for paid home care, but only about one in six frail older adults living at home had coverage in 2002, though many had little income and few assets.

Adult Children Provide Much of the Unpaid Care Frail Elders Receive

About 34 million adults provided care in 2004 to frail Americans ages 50 and older, representing about 16 percent of the adult population (National Alliance for Caregiving and AARP 2004).² Although the number of men providing care has increased in recent years (Spillman and Pezzin 2000), women still make up the majority of caregivers. For example, 64 percent of primary caregivers in a recent survey were women (Donelan et al. 2002). And women devote about 50 percent more time to care activities than men (U.S. Department of Health and Human Services 1998). Most people caring for adults are middle-aged, although about one in eight is age 65 or older (National Alliance for Caregiving and AARP 2004).

Adult children, primarily daughters, provide much of the care received by frail older adults, especially those not married. Daughters and daughters-in-law account for about 36 percent of unpaid caregivers to all frail older Americans (Johnson and Wiener 2006). Sons and sons-in-law account for another 16 percent of unpaid caregivers. Slightly more than one-half of unpaid caregivers, then, are the children or children-in-law of the care recipient. (Spouses account for about 28 percent of caregivers.)

Children play larger caregiver roles when their parent is widowed and unable to rely on help from a spouse. Nearly three-quarters of unmarried older care recipients receive help from their children, with almost one-half receiving help from daughters and almost one-quarter receiving help from sons. Daughters serve as primary helpers with basic personal care for about two-thirds of unmarried older care recipients.

² Another 10.6 million adults, or 5 percent of the adult population, provided care to disabled adults ages 18 to 49 (National Alliance for Caregiving and AARP 2004).

Care responsibilities are generally quite time-consuming. On average, daughters who help their frail older parents provide about 134 hours of care each month (Johnson and Wiener 2006). Daughters who serve as primary caregivers with basic personal care devote about twice as many hours—266 on average—to their parents. Caregiver responsibilities typically last about four years (National Alliance for Caregiving and AARP 2004).

The benefits of unpaid family care to older Americans are substantial. These activities enhance the lives of millions of frail adults and permit many to live in their own homes instead of in nursing homes. In fact, frail older adults who receive frequent help from their children with basic personal care are about 60 percent less likely to enter nursing homes over a two-year period than those who receive less help (Lo Sasso and Johnson 2002). If the adult sons and daughters who provide unpaid help to their frail older parents were paid the average hourly wage nursing aides receive for each hour of help, the cost in 2005 would total about \$45.9 billion.³ The value of unpaid help from all family and friends totaled about \$102.7 billion in 2005. (Even if valued at the 2005 minimum wage of \$5.15 per hour, the unpaid help children provide would be worth about \$22.9 billion in 2005, and the assistance all unpaid helpers provide would be worth about \$51.2 billion.) By comparison, national spending for paid long-term care services in 2005 totaled about \$206.6 billion (Komisar and Thompson 2007).

Elder Care Responsibilities Often Create Financial Hardship for Caregivers

Many unpaid caregivers to older Americans must balance their care duties with workplace demands and care responsibilities for their immediate families. About 53 percent of people caring for their frail parents are employed full time, and another 10 percent are employed part time (Johnson and Wiener 2006). About 11 percent of children caring for parents are ages 30 to 39 (Johnson and Wiener 2006), a life-course stage when many people are raising young children. Another 68 percent of caregivers are in their 40s and 50s, ages when many people still have dependent children at home. Overall, 37 percent of caregivers had children under age 18 (National Alliance for Caregiving and AARP 2004).

Care responsibilities often interfere with paid employment. About 57 percent of employed caregivers report that they sometimes have to go to work late, leave early, or take time off to attend to their care duties, and 17 percent said they had to take a leave of absence (National Alliance for Caregiving and AARP 2004). About 4 percent said their care responsibilities forced them to turn down a promotion. Only 23 percent of companies with 100 or more employees have programs to support elder care (Families and Work Institute 1997).

³ These estimates are based on the average help hours frail older adults receive, as reported in Johnson and Wiener (2006). The average hourly wage for nursing aides was \$10.33 in 2005 (Bureau of Labor Statistics 2006). The computations exclude the cost of fringe benefits paid to nursing aides.

Elder care often takes place from a distance, which can make it more burdensome. Less than one-third of adult children providing elder care live with their frail parents, and more than one-quarter live more than 10 miles away from their parents (Johnson and Wiener 2006). Many long-distance caregivers live much further from the people they help. In a survey of 1,130 long-distance caregivers, the average distance between caregiver and recipient was about 450 miles (MetLife Mature Market Institute 2004). Nearly three-fourths of these caregivers were helping with transportation and household activities, such as shopping, cooking, and managing finances, on which they spent an average of about 22 hours per month. More than 4 in 10 had to rearrange their work schedules to accommodate their care responsibilities, and more than one-third reported missing workdays.

In a recent study, Anthony Lo Sasso of the University of Illinois at Chicago and I examined the impact of time spent helping frail older parents on paid employment hours for women ages 55 to 67 (Johnson and Lo Sasso 2006). We found that women who spend time helping their parents, either with basic personal activities or with household chores and errands, cut back their work hours by 367 hours per year. These work-hour reductions translate into average compensation losses of about \$8,600 (\$6,300 in lost wages and \$2,300 in lost benefits) in 2006.⁴

Care responsibilities also take emotional and physical tolls on caregivers. Caregivers exhibit higher levels of depressive symptoms and mental health problems than their peers who do not provide care (Marks, Lambert, and Choi 2002; Pinquart and Sorensen 2003; Schulz et al. 1995). Caregiver depression intensifies as the care recipient's functional status declines. For example, between 30 and 40 percent of dementia caregivers suffer from depression and emotional stress (Alzheimer's Association and National Alliance for Caregiving 2004; Covinsky et al. 2003). Care responsibilities also appear to impair physical health. Caregivers are more likely to develop serious illness than noncaregivers (Shaw et al. 1997) and are less likely to engage in preventive health behaviors (Schulz et al. 1997). Stressed elderly spousal caregivers exhibit higher mortality rates than people of the same age who do not provide care (Schulz and Beach 1999). Caregiver stress also appears to push older people into nursing homes. For example, frail older adults with a highly stressed caregiver are about 12 percentage points more likely to enter a nursing home within one year than those with less-stressed caregivers (Spillman and Long 2007).

Care Burdens Will Likely Grow in the Future

Caregiver burdens are likely to increase in coming decades as the baby boomers age and the number of older people with disabilities grows. Between 2000 and 2050 the

⁴ This estimate assumes that workers receive hourly wages of \$17 (the median value for women in 2006), 60 percent receive employer-sponsored health benefits, and 50 percent participate in 401(k) retirement plans. The estimates also assume that the average monthly employer contribution for health benefits was \$297 for covered workers (Kaiser Family Foundation and Health Research and Educational Trust 2006), and that employers contributed 5 percent of salary to 401(k) plans for covered workers.

size of the population ages 65 and older is projected to increase from 35 million to 87 million, while the population ages 85 and older, which has the highest disability rate of any age group, is expected to increase from 4 million to 21 million (U.S. Census Bureau 2004).

The number of older people with long-term care needs depends, of course, on the evolution of old-age disability rates, which is difficult to forecast. There is a growing consensus that limitations in instrumental activities of daily living, such as difficulty performing household chores and errands, and functional limitations, such as difficulty bending, reaching, and stooping, declined during the 1990s (Freedman, Martin, and Schoeni 2002). There is less agreement, however, about recent trends in the more severe type of disability that involves limitations with basic personal care, such as eating, dressing, and bathing. Although one study found that the share of the older population with these types of limitations declined by about 20 percent between 1982 and 2005 (Manton, Gu, and Lamb 2006), other studies have found no significant changes or small increases (Crimmins and Saito 2000; Crimmins, Saito, and Reynolds 1997; Liao et al. 2001; Schoeni, Freedman, and Wallace 2001; Waidmann and Liu 2000).

There is no guarantee, of course, that disability rates will decline in the future, even if they declined in the recent past. Disability associated with the rising prevalence of diabetes and obesity in the younger population might offset future declines in disability rates at older ages (Lakdawalla et al. 2003; Mokdad et al. 2000, 2001). In fact, between 1984 and 2000, disability rates increased at ages 40 to 49 while falling at ages 60 to 69 (Lakdawalla, Bhattacharya, and Goldman 2004). Recent research also found that adults born between 1948 and 1953 reported worse health in 2004, when they were ages 51 to 56, than those born 12 years earlier reported in 1992, when they were the same age (Soldo et al. 2006). Other research, however, found that mortality rates at ages 55 to 74 were lower between 1999 and 2002 than between 1971 and 1975, largely because of lower smoking rates and better control of blood pressure (Cutler, Glaeser, and Rosen 2007).

Any plausible assumptions about future disability rates imply that the number of frail older Americans and the ratio of frail older adults to people ages 25 to 64 will increase in coming decades. For example, even if we assume that disability rates decline by 1 percent per year between 2000 and 2040—a cumulative drop in the old-age disability rate of about one-third over the period—the total number of older adults with disabilities will increase by about 50 percent (Johnson, Toohey, and Wiener 2007). Moreover, the number of people ages 25 to 64, who generally work and pay taxes that finance government services for people with disabilities, will drop over the period, implying that overall care burdens will likely intensify. Under the more plausible assumption that old-age disability rates will decline by only 10 percent between 2000 and 2040, the number of frail older Americans will more than double over the period.

The growth in the size of the frail older population relative to the younger population, combined with likely employment gains for women, will raise future caregiver burdens. A recent Urban Institute study found that the average educational

attainment of frail older Americans' adult daughters will steadily improve over time (Johnson, Toohey, and Wiener 2007), reflecting recent increases in college graduation rates among young women. These educational gains will boost women's average earnings, but will also increase the financial cost of unpaid elder care as women who reduce paid work to provide care in the future will have to forgo higher wages. The Urban Institute study predicted that the share of frail older adults receiving unpaid family care will decline by a few percentage points as the financial costs of elder care grow and as rising old-age incomes make paid home care more affordable. Nonetheless, most older care recipients will continue to rely on unpaid help from their adult children.

Family Caregivers Need Better Support

About two-thirds of caregivers in a recent survey said they needed more help or information (National Alliance for Caregiving and AARP 2004). More than one in three said they needed help finding more time for themselves, and about 3 in 10 said they needed help or information about balancing work and family responsibilities as a caregiver, and managing emotional and physical stress.

Despite the importance of unpaid care to frail older adults, few policies are in place to support family caregivers. The three primary federal initiatives for caregivers, the Family and Medical Leave Act (FMLA), the National Family Caregiver Support Program, and Medicaid home and community-based services, offer some help, but not enough.

Family and Medical Leave Act (FMLA)

Enacted in 1993, the FMLA guarantees workers up to 12 weeks of unpaid leave in any 12-month period to care for a newborn child (or newly adopted child); care for an ill child, spouse, or parent; or deal with one's own health problems. However, the law only covers workers in firms with 50 or more employees who have worked for the employer for at least 12 months and at least 1,250 hours that year. As a result, only about 47 percent of private-sector workers qualify for FMLA leave (Waldfogel 2001).

One-sixth of all employees participating in a 2000 survey took leave for family or medical reasons in the 18 months prior to the survey (Waldfogel 2001). Most use leave to deal with their own health problems or to care for a newly born or adopted child. Only 11 percent of leave takers in 2000 used it to care for ill parents, and only 6 percent used it to care for an ill spouse. The loss of pay while not working substantially reduces the use of FMLA leave.

California is the only state with a comprehensive *paid* family and medical leave insurance program. Funded solely by employee contributions, the program pays workers up to 60 percent of their wages when they take leave to care for newborns, newly adopted

children, newly placed foster children, or seriously ill family members or domestic partners. Workers can receive up to six weeks of paid leave per year.

Washington Governor Chris Gregoire signed a bill last week establishing a family and medical leave insurance program in her state. It will provide \$250 per week to beneficiaries for up to five weeks, but it only covers leave to care for a newborn or newly adopted child. Elder care benefits are not available.

National Family Caregiver Support Program

The National Family Caregiver Support Program, created in 2000 by the Older Americans Act, provides funds to states to support family caregivers helping older people. It finances the following services:

- Information to caregivers about community services;
- Assistance to caregivers in gaining access to supportive services;
- Individual counseling and training for caregivers;
- Respite care to allow caregivers to receive temporary relief from care obligations; and
- Limited supplemental services, such as emergency response systems and home modifications, to complement the care provided by family caregivers.

The funding provided to states by the National Family Caregiver Support Program has made an important difference for frail older Americans and their caregivers. Before the program began, for example, 18 states and the District of Columbia had no state program funded primarily through state general funds that served family or informal caregivers (Feinberg et al. 2004). Today programs exist in all 50 states and the district. However, inadequate funding levels have limited its impact (Wisendale forthcoming). The president's FY 2008 budget requests only \$154 million for family caregiver support services (Administration on Aging 2007).

Medicaid Home and Community-Based Services

Medicaid, mainly through its waiver programs, supplies the majority of public funding for home and community-based care. Financed by the federal government and the states, these programs focus on the care recipient but indirectly sustain family members in their caregiver roles. They have grown enormously over the past two decades (Reester, Missmar, and Tumlinson 2004). However, services are available only to low-income beneficiaries, generally with incomes at or below 300 percent of the federal Supplemental Security Income (SSI) level, and funding constraints in some states limit services even for those who qualify.

Conclusion

The important work of family caregivers deserves more public support. Informal help from family members enriches the lives of millions of frail older Americans and saves the nation billions of dollars each year in paid home care and nursing home costs. Yet it creates substantial financial, physical, and emotional burdens on caregivers, which will only intensify in coming decades as the population ages. Creating a system of paid leave, as in California, might benefit some caregivers, but a few weeks of paid leave will not help most people engaged in elder care for many months or years. Additional funding for the National Family Caregivers Support Program would likely have more impact by giving local governments the ability to provide more supportive services that family caregivers need.

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