

## Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving

### *Introduction*

The contributions of America's family caregivers, along with many friends and neighbors, often go unrecognized in public policy discussions about the financing and costs of health care and long-term services and supports (LTSS). Yet these unpaid caregivers provide by far the majority of long-term services and supports received by persons with disabilities of all ages. Many of these "informal" caregivers also provide health-related services. In fact, their contributions to loved ones and friends are not only the foundation of the nation's long-term care system but an important component of the U.S. economy, with an estimated economic value of about \$350 billion in 2006.

This issue brief discusses the financial impact of caregiving on the caregivers themselves as well as the economic value of their contributions to society. It compares the economic value of informal caregiving to other benchmarks in order to underscore the magnitude of these unpaid contributions, presents estimates of productivity losses to U.S. businesses from caregiving, and highlights the critical role that family caregivers play in the nation's long-term care system. Finally, it recommends ways to support informal caregivers through public policies and in the private sector.

### *How many family caregivers are there? How many hours of care do they provide?*

We identified five recent publications with estimates of the prevalence of caregivers based on nationally representative surveys. Because these surveys varied in the definition of caregiving and the age groups represented, we adjusted these estimates to a common definition encompassing the entire adult population and projected them forward to 2006. We found the following:

In November 2006, **between 30 million and 38 million adult caregivers** (age 18 or older) provided care to adults with a limitation in an activity of daily living (ADL) or instrumental activity of daily living (IADL). **Caregivers provided an average of 21 hours of care per week, or 1,080 hours per year.** See technical notes, p. 8, for more details.

This definition includes the majority of informal caregiving in the United States, including the 17% of "family caregivers" who are non-relatives,<sup>1</sup> but it does not capture all caregiving. For example, it does not include those providing care to children under 18 with disabilities,<sup>2</sup> caregivers under age 18 who are providing care to adults (primarily parents or grandparents),<sup>3</sup> or grandparents providing care for grandchildren under the age of 18.<sup>4</sup> Nor does it include caregivers who

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provide assistance to adults who have chronic health conditions but do not have an ADL or IADL limitation.

This caregiving definition also presents estimates at a narrow point in time: that is, the number of U.S. adults currently providing care or providing care within the last month. Because caregiving activities may begin or end during a calendar year, the total number of people providing care during the year is significantly higher—for example, the widely cited 2004 NAC/AARP report *Caregiving in the U.S.* estimated for 2003 that 44 million adults provided care in the last year, about 50 percent higher than the number who were currently providing care.<sup>5</sup>

***What is the economic value of unpaid caregiving?***

Estimating the economic value of unpaid caregiving—which requires assumptions

about the cost of replacing the services of informal caregivers, as well as estimates of the prevalence of caregiving and the hours of care given—cannot be done with precision. But with even the most conservative assumptions and estimates, the value is huge, dwarfing the value of paid home health care and nearly matching the total national spending on home health care and nursing home care.

Table 1 below contains estimates of the economic value of informal caregiving activities for high and low estimates of the number of caregivers and four estimates of the economic value of one hour of caregiving.<sup>6</sup> These estimates do not include the value of any non-wage benefits, such as health insurance. They also do not include the value of the time family members devote to providing assistance in residential care settings, such as assisted living, and in nursing homes.

Table 1: Annual Economic Value of Unpaid Caregiving Activities in 2006, Assuming 1,080 Hours of Care per Year, for Varying Caregiving Prevalence and Cost Estimates

Number of Caregivers	High Estimate (38 million)	Low Estimate (30 million)
Cost of Caregiving per Hour		
High (\$19/hr) Average private pay cost of hiring a home health aide	\$780 billion	\$616 billion
Medium (\$14.70/hour) Average wage for aides and other workers in the home health industry	\$603 billion	\$476 billion
Low (\$9.04/hr) Median wage for all home health aides	\$371 billion	\$293 billion
Very Low (\$5.15/hr) Federal minimum wage	\$211 billion	\$167 billion
AARP Public Policy Institute estimate, assuming 34 million caregivers and a cost of \$9.63 per hour, the average of the medium, low, and very low costs per hour.	\$354 billion	

Depending on assumptions, the economic value of caregiving activities could be as low as \$167 billion or as high as nearly five times that amount. The truth lies somewhere in the middle. Caregivers provide a mix of types of care, ranging from highly skilled care planning and negotiation with health care providers and insurers to help with daily activities such as bathing or grocery shopping, which could have high, medium, low, or very low economic value per hour. Because we do not know the exact mix of types of care, we present a conservative estimate of **about \$350 billion per year**. This estimate assumes the number of caregivers to be at the midpoint of the high and low estimates in table 1 and the cost of caregiving to be \$9.63 per hour, the average of the medium, low, and very low costs per hour.

This range of estimates is consistent with prior studies, all of which have found that the value of informal home care vastly exceeds the value of paid home care. Mitchell LaPlante and colleagues found that the value of unpaid personal assistance provided to adults with disabilities ages 18 and older approached \$168 billion in 1996, compared with the value of paid formal assistance in the home of \$32 billion.<sup>7</sup> In 1997, Peter Arno and colleagues estimated the national economic value of informal caregiving to be \$196 billion, compared with \$32 billion for paid home care in that year.<sup>8</sup> The Congressional Budget Office (CBO) adjusted this estimate for inflation to \$218 billion in 2004 dollars.<sup>9</sup> The most recent estimate, by Arno, was \$306 billion in 2004.<sup>10</sup>

Caregiving costs for certain populations can be much higher than the averages reported above. For example, the cost of

caring for a person with Alzheimer's disease has been valued at about \$43,000 annually.<sup>11</sup> By comparison, the \$9.63 per hour economic value estimate puts the value of informal caregiving at about \$10,400 per caregiver per year, less than one-fourth of the estimate for a person with Alzheimer's disease.

### *How much is \$350 billion?*

Some benchmarks can help to put this figure in more meaningful context. The estimated \$350 billion is:

- As much as the total expenditures for the Medicare program (\$342 billion in 2005).<sup>12</sup>
- More than total spending for Medicaid, including both federal and state contributions and both medical and long-term care (\$300 billion in 2005).<sup>13</sup>
- Far more than the total spending (public and private funds) for nursing home and home health care in the United States (\$206.6 billion in 2005).<sup>14</sup>
- More than four times the total amount spent on formal (paid) home care services (\$76.8 billion in 2005).<sup>15</sup>
- As much as the total sales of the world's largest companies, including Wal-Mart Stores (\$349 billion in 2006) and ExxonMobil (\$335 billion).<sup>16</sup>
- More than \$1,000 for every person in the United States (301 million people as of March 1, 2007).<sup>17</sup>

- About 2.7 percent of the U.S. gross domestic product (\$13 trillion in 2006).<sup>18</sup>
- More than the amount of the U.S. budget deficit (\$248 billion in fiscal year 2006).<sup>19</sup>

### ***What are the other costs of caregiving?***

#### Out-of-pocket costs to caregivers

Many caregivers make direct out-of-pocket expenditures to help support a family member or friend with a disability. In the NAC/AARP survey, nonspousal caregivers were asked how much money they spend in a typical month for groceries, medicines, or other kinds of cash support for the care recipient. About half of caregivers contributed financially, spending an average of \$200 per month (\$2,400 per year). Caregivers who had the greatest level of caregiving burden reported spending \$324 per month (\$3,888 per year) out of pocket.<sup>20</sup>

About 23 percent of caregivers overall said that caregiving is a financial hardship.<sup>21</sup> The top predictors of caregivers' perception of financial hardship were the level of caregiving burden that they reported and whether they felt that they had a choice in taking on the caregiving role. Other factors that were associated with financial hardship among caregivers were advanced age, poor health, and low income.

#### Lost wages and retirement income

In addition to direct out-of-pocket expenditures made by caregivers, many caregivers experience other significant economic losses. The majority of caregivers in the United States (59

percent) are employed either full or part time.<sup>22</sup> The financial impact of caregiving on caregivers in the workforce can involve multiple aspects of their income security, including their wages, job security and career paths, and employment benefits such as health insurance and retirement savings.

The "typical" caregiver in the United States is a 46 year old woman who works outside of the home.<sup>23</sup> Changes in work patterns resulting from caregiving responsibilities in midlife can have particularly serious consequences for income, job security, and retirement savings. Johnson and Lo Sasso (2006) found that caregiving reduces paid work hours for middle-aged women by about 41 percent.<sup>24</sup> Caregivers may experience reduced Social Security benefits due to lower earnings, more limited access and contributions to employer-sponsored pensions and 401(k) plans due to working part time, and more limited personal savings due to less time in the workforce.<sup>25</sup>

A Metlife Mature Market Institute "Juggling Act" study found that most employed caregivers initially underestimate the time caregiving will require. Subsequently, they often experience sharp drops in income, totaling huge losses in wages, Social Security benefits, and pension benefits over time.<sup>26</sup> Another study of the long-term effects of caregiving on women's economic well-being found that caregiving for a parent substantially increased women's risks of living in poverty and receiving public assistance in later life.<sup>27</sup>

While some caregivers in the workforce report making no or limited adjustments in their work life, the vast majority (92

percent) of those with the most intense level of caregiving responsibility report major changes in their working patterns.<sup>28</sup>

- 83 percent report arriving late/leaving early, or taking time off during the day.
- 41 percent report having to take a leave of absence.
- 37 percent report going from working full time to part time.
- 35 percent report giving up work entirely.
- 15 percent report losing job benefits.
- 14 percent report turning down a promotion.
- 12 percent report choosing early retirement.

### Lost productivity

The economic impact on U.S. businesses from informal caregiving is also striking. Almost one-fifth of workers (19 percent) are informal caregivers.<sup>29</sup> Productivity losses to U.S. businesses related to informal caregiving have been estimated to be as much as \$33.6 billion in 2004 for full-time employed caregivers. These costs include those associated with replacing employees, absenteeism, care crises, workday interruptions, supervisory time, unpaid leave, and reductions in hours from full-time to part-time. The average cost to employers per full-time employed caregiver was \$2,110. For caregivers with intense caregiving responsibilities, the cost rose to \$2,441.<sup>30</sup>

The \$33.6 billion estimate of productivity losses related to informal caregiving is substantial. It represents:

- More than half the estimated value of all lost productive time and cost due to common pain conditions, such as arthritis, headache, back, and other musculoskeletal conditions (estimated at \$61.2 billion per year).<sup>31</sup>
- About three-fourths of the value of lost productive work time among workers with depression (estimated at \$44 billion per year).<sup>32</sup>

As these examples attest, the “order of magnitude” of productivity losses due to caregiving is worthy of much greater attention by both the private and public sectors. The American labor force is aging, and the nation is expected to face labor shortages in critical industries and occupations in the coming years. Keeping informal caregivers and other older workers in the labor force longer will be essential to the health of the economy.

Many European countries also are facing the need to increase labor force participation in a rapidly aging population. Increases in government spending for formal services for older persons and other supports for caregivers have been found to be a cost-effective way to increase women’s labor force participation rates in Europe.<sup>33</sup>

### Health effects and associated costs

Caregiving can place caregivers’ own health at risk, a problem that is beginning to be recognized as an emerging public health concern.<sup>34</sup> Caregivers report having one or more chronic conditions at nearly twice the rate of noncaregivers (45 percent

vs. 24 percent).<sup>35</sup> Spousal caregivers (age 66–96) who have a history of chronic illness and who experience mental or emotional stress have a 63 percent higher mortality rate than noncaregivers.<sup>36</sup>

The more hours of care provided per week, the greater the number of limitations in ADLs or IADLs of the care recipient, and the longer caregivers have been providing care, the more likely caregivers are to report fair or poor health status.<sup>37</sup> Among caregivers in fair to poor health who said that their health worsened as a result of caregiving, 91 percent reported suffering from depression, and 53 percent said this downward health spiral also negatively affected their ability to provide care.<sup>38</sup>

The health effects of caregiving have other major costs. Three of five adults age 19 to 64 with informal caregiving responsibilities reported having medical bill problems or medical debt, compared with 39 percent of noncaregivers, and half reported at least one health care access problem because of inability to pay, significantly higher than their peers without caregiving responsibilities.<sup>39</sup> In addition, out-of-pocket health costs are much higher for people who have a relative with a disability.<sup>40</sup>

#### Effects on the long-term care and health care systems

Informal caregiving has been shown to help delay or prevent the use of nursing home care, a finding of critical importance to public policymakers at both federal and state levels. For example, frequent help from children with basic personal care reduces the likelihood of nursing home use among persons age 70 and older with disabilities over a two-year period by

about 60 percent.<sup>41</sup> Moreover, caregiver stress is a strong predictor of nursing home entry. Reducing key stresses on caregivers, such as physical strain and financial hardship, would reduce nursing home entry.<sup>42</sup>

Caregivers provide many critical forms of assistance not captured in research based only on the help they provide with care recipients' personal care and other daily activities. Two other important forms of assistance are providing nursing care and providing help in navigating the health care system. Many care recipients have chronic conditions requiring intermittent hospitalizations, in which caregivers must manage what have been described as “rough crossings” between home, hospital, and other institutional settings.<sup>43</sup> In addition to managing health insurance complexities and serving as overall care coordinators, many family caregivers also must manage medications as well as medical equipment in the home, including oxygen equipment, catheters, and intravenous infusion equipment.<sup>44</sup>

Caregiving by adult children has been shown to reduce the likelihood that beneficiaries will have Medicare expenditures for skilled nursing home care and home health care.<sup>45</sup> Moreover, recent health care trends may be placing increasingly complex responsibilities on informal caregivers. For example, the trend toward shorter hospital stays for Medicare patients continues. The average length of stay of Medicare inpatients has fallen from 11.7 days in 1973 to 7.3 days in 1994 to 5.5 days in 2004.<sup>46</sup> Most of these patients are released to their homes, where care is typically provided by spouses or other informal caregivers. While most Medicare beneficiaries discharged from the hospital have at least

limited access to home health care, a significant decline occurred between 2001 and 2004 in the proportion of discharge planners who reported being able to place all of the beneficiaries who needed home health care.<sup>47</sup> In addition, the trend toward fewer Medicare home health visits per user continues, falling from an average of 73 in 1996 to 37 in 2000 to 27 in 2005.<sup>48</sup>

### ***Informal services and formal services***

The data presented in this issue brief illustrate the magnitude of the economic impact of informal caregiving, both on the caregivers themselves and on the U.S. economy. By any measure, even the most conservative, the impact is huge. Without families' contributions, both state and federal health and long-term care budgets would be overwhelmed by the need for services. In addition, the nation simply does not have a sufficient supply of direct care workers to replace informal caregivers.<sup>49</sup> Family and other informal caregivers are literally "irreplaceable" because their help springs from feelings of love and duty based on intimate personal relationships. However, both caregivers and care recipients often benefit when formal services are available to supplement the assistance of family caregivers and to relieve caregiver stress. Such services can also help to keep family caregivers in the workforce longer and help to delay or prevent nursing home use.

Some observers fear that unpaid family caregivers will not "stay on the job" in the future. However, in the United States, a higher proportion of older persons with disabilities receiving care in the community were relying *solely* on informal caregivers in 1999 than in 1994 (66 percent vs. 57 percent). An additional 26 percent were relying on a mix of

informal and formal care, while only 9 percent received just formal care.<sup>50</sup> Similarly, in 2002, among frail older persons receiving community care, more than three out of four relied exclusively on unpaid informal caregivers. Only 17 percent were relying on a mix of informal and formal care and 6.5 percent received just formal care.<sup>51</sup>

Insurance coverage, both public and private, to help pay for formal services for persons with disabilities can supplement and complement the help provided by family caregivers, who then may be able to continue to work. For example, a report for the Department of Health and Human Services found that informal caregivers of persons with disabilities receiving paid in-home services under private long-term care insurance policies were about four times more likely to be employed than those caring for non-privately insured elders with disabilities—35 percent compared to 9 percent. At the same time, the report concluded that "the presence of insurance-financed formal care does not significantly reduce the magnitude of caregiver effort."<sup>52</sup>

### ***Conclusions***

For both economic and ethical reasons, it is essential to prevent family caregivers from being overwhelmed by the demands placed upon them. The cost of funding more services and supports for caregivers is minute compared to the value of their contributions. The following policy recommendations could all be implemented at small fractions of the value of unpaid caregivers' services:

- Implement "family-friendly" workplace policies that include flextime and telecommuting, referral to

supportive services, and caregiver support programs in the workplace. Although more large employers have been offering “eldercare” programs to help employees with caregiving responsibilities, these are still among the least offered work/life benefits.<sup>53</sup>

- Preserve and expand the protections of the Family and Medical Leave Act, which allows individuals who work for employers with 50 or more employees to take up to 12 weeks of unpaid leave to care for themselves, a child, spouse, or parent in the case of serious illness.
- Expand funding for the National Family Caregiver Program. The total budget for NFCSP funding, including the funding for Native American Caregiver Support, is \$162.4 million for FY 2007. This represents approximately one twentieth of 1 percent of the economic value of caregivers’ contributions.
- Provide adequate funding for the recently enacted Lifespan Respite Care Act. The amount authorized for FY 2008 is \$40 million. This represents about one hundredth of 1 percent of the economic value of caregivers’ contributions.
- Provide a tax credit for caregiving. A \$3,000 tax credit, the amount that would be provided as part of several federal legislative proposals, would help to offset some of the direct expenses of eligible caregivers.<sup>54</sup> Many of these caregivers would still bear high costs associated with caregiving, including lost wages and employment benefits, lower retirement benefits, poorer health status, and higher medical expenses of their own.

- Permit payment of family caregivers through consumer-directed models in publicly funded programs, such as Medicaid home and community-based services waivers. Such models allow consumers and their families to choose and direct the types of services that best meet their needs. Waiver programs provide the flexibility to offer services not provided under the traditional Medicaid program, such as respite and caregiver education and training.<sup>55</sup>
- Assess family caregivers’ own needs, such as through publicly funded home- and community-based service programs, and refer them to supportive services.

**The bottom line:** Adequate funding for family caregiver support will provide an excellent return on investment. Providing better supports for family caregivers is essential to the well-being of our health care system, our long-term care system, and our economy.

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## Technical Notes: Estimates of the number of caregivers and hours of care

We searched for recent studies based on nationally representative surveys that included estimates of the number of caregivers and/or the number of hours of care. We identified five publications from 2004 to 2006, which are based on different data sources and use different definitions of caregiving, shown below in table 2. These publications provide estimates of the number of caregivers and the hours of care that they provide.

Table 2: Recent Studies Giving Estimates of Caregiving Prevalence and/or Hours

Publication	Source Data & Year	Caregiver Definition
<i>Estimated Prevalence and Economic Value of Family Caregiving, by State (2004)</i> , Peter S. Arno, National Family Caregivers Association & Family Caregiver Alliance, 2006	Estimates for 2004, updated from 1986 Survey of Income and Program Participation (SIPP) and 1987–88 National Survey of Families and Households (NSFH)	SIPP: Care recipient 15+, with health condition, caregiver 15+, within last month; NSFH: Care recipient 18+, caregiver 18+, with long-term illness or disability, within last month
<i>Many Older Americans Engage in Caregiving Activities</i> , Richard W. Johnson & Simone G. Schaner, Urban Institute, 2005	2002 Health and Retirement Study (HRS)	Care recipient any age, caregiver 55+, within last month (for care of spouse) or last 2 years (for care of parents/in-laws)*
<i>A Profile of Frail Older Americans and Their Caregivers</i> , Richard W. Johnson & Joshua M. Wiener, Urban Institute, 2006	2002 Health and Retirement Study (HRS)	Care recipient 65+, ADL or IADL dependency, caregiver 18+, within last month
<i>Caregiving: A National Profile and Assessment of Caregiver Services and Needs</i> , Sarah L. McKune et al., Rosalynn Carter Institute, 2006	2000 Behavioral Risk Factor Surveillance System (BFRSS)	Care recipient 60+, with long-term illness or disability, caregiver 18+, within last month
<i>Caregiving in the U.S.</i> , National Alliance for Caregiving & AARP, 2004	Survey designed for the publication, 2003	Care recipient 18+, ADL or IADL dependency, caregiver 18+, within last year

\* Johnson and Schaner also include persons age 55 or older who are providing child or grandchild care, but as these are mostly likely to be minor children without special needs, we look only at spousal and parent/in-law care in this analysis.

### How many caregivers are there?

Because of the differing definitions of caregiving in each survey instrument and the various dates of the surveys, the number of caregivers is not directly comparable between sources. However, using Census population estimates<sup>56</sup> and data from the *Caregiving in the U.S.* and *AARP Beyond 50.03* surveys,<sup>57</sup> we can adjust these estimates to a common year and definition.<sup>58</sup> When data from these sources are projected forward to November 2006 and adjusted to give the total number of caregivers 18 or older who are providing care within the last month to persons 18 or older who have a limitation in an ADL or IADL, we estimate that there are between **30 and 38 million caregivers**. Table 3 below shows the number of caregivers from recent studies using source definitions, as well as the adjusted estimates when projected forward to November 2006 using both the source definition and the common definition. Where sources gave only the total number of caregivers or the percentage of the target population, Census Bureau population estimates were used to fill in the blanks.

Table 3: Estimates of the Number of Caregivers

Source (year data were collected)	# Caregivers and % of target population* (reported by source)	Projected # caregivers, Nov 2006**	Estimated # of caregivers, Nov 2006 common definition***
<i>Caregiving in the U.S. (2003)</i>	44.4 million (21%)	48 million	31 million
Arno (2004 based on 1986 SIPP)	27 million (12%)	28 million	26 million
Arno (2004 based on 1987-88 NSFH)	30.7 million (14%)	32 million	33 million
<i>Low estimate (avg of Caregiving in the U.S. and Arno)</i>			<i>30 million</i>
Johnson & Schaner (2002)	12 million**** (19.2%)	13 million	39 million
McKune et al. (2000)	33 million (15.6%)	35 million	37 million
<i>High estimate (avg of Johnson &amp; Schaner and McKune et al.)</i>			<i>38 million</i>

\* The target population is the population that is “eligible” to be a caregiver using the source definition. For example, if the source definition of caregivers included “caregiver age 20+” then the target population would be Americans age 20 or older.

\*\* AARP Public Policy Institute estimate, the source estimate adjusted only for population growth between the source data year and November 2006, and not adjusted for caregiver definition. See note 58 for methodology.

\*\*\* AARP Public Policy Institute estimate, adjusted for population growth between the source data year and November 2006 and to a common definition: caregivers 18 or older who are providing care within the last month to persons 18 or older who have a limitation in an ADL or IADL. See note 58 for methodology.

\*\*\*\* There was assumed to be no overlap between people providing care to a spouse and people providing care to a parent or in-law. The existence of overlap would reduce this number somewhat.

How many hours of care do caregivers provide?

In addition to estimating the total number of caregivers, several sources also estimate the average numbers of hours of care per week, or per year, that informal caregivers provided. Despite drawing estimates from different source data and different definitions of caregiving, the reports show a remarkable convergence on a consensus estimate of about **21 hours of care per week, or about 1,080 hours per year**. See table 4.

Table 4: Estimates of Weekly and Annual Care Hours

Source (data year)	Weekly Care Hours	Annual Care Hours
<i>Caregiving in the U.S. (2003)</i>	21	1,092
Arno (2004)	20.6*	1,071*
Johnson & Schaner (2002)	16.6**	860**
Johnson & Wiener (2002)	25	1,300
2002 HRS average***	20.8	1,080
<i>Consensus estimate</i>	<i>21</i>	<i>1,080</i>

\*Arno’s reported estimate of care hours is an average of four sources from the 1990s, which individually range from 18 to 24 hours of care per week.

\*\*AARP Public Policy Institute calculations based on data in Johnson & Schaner; hours estimate is for spousal and parent/in-law care only.

\*\*\*Average of Johnson & Schaner and Johnson & Weiner, which look at two subpopulations of caregivers using the same data source.

<sup>1</sup> National Alliance for Caregiving (NAC) and AARP, *Caregiving in the U.S.*, 2004.

<sup>2</sup> There are about 6 million children in the U.S. with severe disabilities, nearly all of whom are cared for at home by parents and families. These caregiving roles typically span the course of the child's life. Murphy, N.A. et al, "The Health of Caregivers for Children with Disabilities: Caregiver Perspectives," *Child: Care, Health, and Development*, 33(2):180-187, 2007.

<sup>3</sup> The number of caregivers between the ages of 8 and 18 is estimated to be 1.3 to 1.4 million. NAC and United Hospital Fund, "Young Caregivers in the U.S.: Findings from a National Survey," 2005. Available at <http://www.caregiving.org/data/youngcaregivers.pdf>.

<sup>4</sup> In 2005, almost 2.5 million grandparents were raising grandchildren, defined as being financially responsible for their basic needs. Source: AARP Public Policy Institute calculations using data from U.S. Census Bureau American Community Survey 2005, "Sex of Grandparents Living with Own Grandchildren Under 18 Years by Responsibility for Own Grandchildren," Table B 10056.

<sup>5</sup> NAC and AARP, *Caregiving in the U.S.*, 2004. Available at <http://www.caregiving.org/data/04finalreport.pdf>. AARP Public Policy Institute analysis of data from NAC and AARP, *Caregiving in the U.S. Survey*. Because caregiving activities may begin or end during a calendar year, the total number of people providing care during the year is higher than the number providing care at any one point in time. For the economic value of caregiving calculations in this report, the number currently providing care or providing care in the last month is the appropriate number to use.

<sup>6</sup> The high and low estimates for the number of caregivers come from AARP Public Policy Institute analysis of data from five of the most current publications with data on the number of caregivers in the United States. See tables 2 and 3 for more detail. The lower number (30 million) is the average of the three lowest estimates, and the higher number (38 million) is the average of the two highest estimates. The high cost estimate is from the MetLife Mature Market Institute, "2006 MetLife Market Survey of Nursing Home and Home Care Costs," 2006. The low and medium values come from Bureau of Labor Statistics, "May 2005 National Occupational Employment and Wage Estimates."

<sup>7</sup> LaPlante, M., Harrington, C., and Kang, T., "Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults Living at Home," *Health Services Research*, 37(2):397-413. 2002.

<sup>8</sup> Arno, P. S., Levine, C., and Memmott, M., "The Economic Value of Informal Caregiving," *Health Affairs*, 18(2):182-188. 1999.

<sup>9</sup> Holtz-Eakin, D., "The Cost and Financing of Long-Term Care Services," CBO Testimony before the House Subcommittee on Energy and Commerce, April 27, 2005.

<sup>10</sup> Arno, P.S., "Economic Value of Informal Caregiving: 2004," presented at the Care Coordination & Caregiver Forum, Dept. of Veteran Affairs NIH, Bethesda, MD, January 25-27, 2006.

<sup>11</sup> MetLife Mature Market Institute & LifePlans Inc., "The MetLife Study of Alzheimer's Disease: The Caregiving Experience," 2006.

<sup>12</sup> Centers for Medicare and Medicaid Services (CMS) Office of Public Affairs, "CMS Releases U.S. Health Spending Estimates Through 2005," January 9, 2007.

<sup>13</sup> Burwell, B., Sredl, K., and Eiken, S., "Medicaid Long-Term Care Expenditures FY 2005," Medstat, 2006.

<sup>14</sup> Georgetown University Long-Term Care Financing Project, "National Spending for Long-Term Care: Fact Sheet." Available at <http://lrc.georgetown.edu/pdfs/natspendfeb07.pdf>.

<sup>15</sup> Ibid.

<sup>16</sup> Forbes, "The World's Largest Public Companies, 2007." Available at [http://www.forbes.com/2007/03/29/forbes-global-2000-biz-07forbes2000-cz\\_sd\\_0329global\\_land.html](http://www.forbes.com/2007/03/29/forbes-global-2000-biz-07forbes2000-cz_sd_0329global_land.html). The Forbes definition of "largest" is a composite of four measures: sales, profits, assets, and market value.

<sup>17</sup> U.S. Census Bureau home page, <http://www.census.gov/>, accessed March 1, 2007.

<sup>18</sup> Calculations based on Bureau of Economic Analysis, <http://www.bea.gov/national/index.htm#gdp>.

<sup>19</sup> Congressional Budget Office (CBO), "Monthly Budget Review, November 6, 2006." Available at <http://www.cbo.gov/ftpdocs/76xx/doc7679/11-2006-MBR.pdf>.

<sup>20</sup> NAC and AARP, *Caregiving in the U.S.*, 2004. To measure the intensity of caregiving, caregivers were classified into five different levels of burden, based on hours of care per week and types of caregiving tasks performed. At the highest level of burden, caregivers were helping with two or more limitations in ADLs and providing more than 40 hours of care per week.

<sup>21</sup> This proportion represents respondents who rated caregiving as three or higher on a scale of one to five, where one was no financial hardship and five was a great deal of financial hardship.

<sup>22</sup> NAC and AARP, *Caregiving in the U.S.*, 2004.

<sup>23</sup> Ibid.

<sup>24</sup> Johnson, R., and Lo Sasso, A., "The Impact of Elder Care on Women's Labor Supply," *Inquiry* 43: 195-210. 2006.

<sup>25</sup> Young, L., and Newman, S., "Caregiving and Retirement Planning: What Happens to Caregivers Who Leave the Work Force," Policy Brief, Family Caregiver Alliance, National Center on Caregiving, 2003.

<sup>26</sup> MetLife Mature Market Institute, National Alliance for Caregiving and the National Center on Women and Aging, "MetLife Juggling Act Study: Balancing Caregiving with Work and the Costs Involved," 1999. These estimates are based on 55 in-depth interviews with caregivers age 45 or older in 1996 who had made some type of work adjustment as a result of caregiving responsibilities, a subset of the original nationally representative sample of 1,500 caregivers in a 1997 NAC/AARP survey of caregivers.

<sup>27</sup> Wakabayashi, C., and Donato, K. M., "The Consequences of Caregiving for Economic Well-Being in Women's Later Life," Houston, TX: Rice University, Department of Sociology, 2004.

<sup>28</sup> NAC and AARP, *Caregiving in the U.S.*, 2004.

<sup>29</sup> AARP Public Policy Institute calculations based on Bureau of Labor Statistics, "Labor Force Statistics from the Current Population," seasonally adjusted employment, fourth quarter 2003, <http://www.bls.gov/data/home.htm>; and NAC and AARP, *Caregiving in the U.S.*, 2004.

<sup>30</sup> MetLife Mature Market Institute and the National Alliance for Caregiving, "The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business," 2006. MetLife has also created a tool to help employers estimate their productivity costs for caregivers; see [www.eldercarecalculator.org](http://www.eldercarecalculator.org). See also Koppel, R.,

“Alzheimer’s Disease: The Costs to U.S. Businesses in 2002,” which estimated the cost to U.S. businesses for workers who are caregivers for persons with Alzheimer’s disease at \$36 billion in 2002.

<sup>31</sup> Stewart, W. F. et al., “Lost Productive Time and Cost Due to Common Pain Conditions in the US Workforce,” *JAMA* 290:2443-2454. 2003.

<sup>32</sup> Stewart, W. F. et al., “Cost of Lost Productive Work Time among US Workers with Depression,” *JAMA* 289:3135-3144. 2003.

<sup>33</sup> Viitanen, T. K., “Informal and Formal Care in Europe,” Institute for the Study of Labor, IZA Discussion Paper No. 2648, IZA, Bonn, Germany, 2007.

<sup>34</sup> Talley, R. and Crews, J., “Framing the Public Health of Caregiving,” *American Journal of Public Health* 97(2):224-228. 2007. See also Family Caregiver Alliance in cooperation with California’s Caregiver Resource Center, “Caregiver Health”, 2007, available at [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?no\\_deid=1822](http://www.caregiver.org/caregiver/jsp/content_node.jsp?no_deid=1822)

<sup>35</sup> Ho, A. et al., “A Look at Working-Age Caregivers’ Roles, Health Concerns, and Need for Support,” Issue Brief, The Commonwealth Fund, 2005.

<sup>36</sup> Schultz, R. and Beach, S. R., “Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study,” *JAMA* 282(23):2215-2219. 1999.

<sup>37</sup> NAC and AARP, *Caregiving in the U.S.*, 2004.

<sup>38</sup> Evercare and National Alliance for Caregiving, “Caregivers in Decline: A Close-Up Look at the Health Risks of Caring for a Love One,” 2006.

<sup>39</sup> The Commonwealth Fund Biennial Health Insurance Survey, 2003.

<sup>40</sup> Altman, B., Cooper, P., and Cunningham, P., “The Case of Disability in the Family: Impact on Health Care Utilization and Expenditures for Nondisabled Members,” *The Milbank Quarterly* 77(1):50. 1999.

<sup>41</sup> Lo Sasso, A., and Johnson, R., “Does Informal Care from Adult Children Reduce Nursing Home Admissions for the Elderly?” *Inquiry* 39:279-297. 2002.

<sup>42</sup> Spillman, B. and Long, S., “Does High Caregiver Stress Lead to Nursing Home Entry,” paper prepared for the Office of Disability, Aging, and Long-Term Care Policy, ASPE, U.S. DHHS, January 26, 2007.

<sup>43</sup> Levine, C., “Rough Crossings: Family Caregivers’ Odysseys through the Health Care System,” United Hospital Fund of New York, 1998.

<sup>44</sup> Reinhard, S., “The Work of Caregiving: What Do ADLs and IADLs Tell Us?” in *Family Caregivers on the Job*, edited by C. Levine, United Hospital Fund of New York, 2004. Donelan, K. et al., “Challenged to Care: Informal Caregivers in a Changing Health System,” *Health Affairs* 21(4):222-231. 2002.

<sup>45</sup> Van Houtven, C.H., and Norton, E., “Informal Care and Medicare Expenditures,” *Journal of Health Economics*, forthcoming 2007.

<sup>46</sup> MedPAC, Healthcare spending and the Medicare program, June 2006, Chart 7-5, page 81.

<sup>47</sup> Office of the Inspector General, DHHS, “Medicare Beneficiary Access to Home Health Agencies: 2004,” OEI-02-04-00260, 2006.

<sup>48</sup> <http://www.gao.gov/new.items/01/01176.pdf> (1996) CMS, “Medicare & Medicaid Statistical Supplement 2002,” Table 48, and CMS, “Medicare Home Health Utilization by State Calendar Year 2005.”

<sup>49</sup> Institute for the Future of Aging Services, “The Long-Term Care Workforce: Can the Crisis be Fixed?” prepared for the National Commission for Quality Long-Term Care, 2007.

<sup>50</sup> Spillman, B., and Black, K., “Staying the Course: Trends in Family Caregiving,” Washington, D.C.: AARP Public Policy Institute, 2005.

<sup>51</sup> Johnson, R.W. and Wiener, J., “A Profile of Frail Older Americans and Their Caregivers,” The Retirement Project, Occasional Paper Number 8, The Urban Institute, 2006.

<sup>52</sup> Cohen, M., Weinrobe, M., and Miller, J., “Informal Caregivers of Disabled Elders with Long-Term Care Insurance,” ASPE, DHHS, 2000.

<sup>53</sup> Society of Human Resource Management 2006 Benefits Survey.

<sup>54</sup> In many legislative proposals, caregivers who would be eligible for a tax credit are a relatively small, especially vulnerable subset of the broader unpaid caregiving population, (e.g., caregivers who live with a care recipient with severe disabilities, such as three or more limitations in activities of daily living).

<sup>55</sup> Feinberg, L. F., and Newman, S., “Aged/Disabled Medicaid HCBS Waiver Programs and Family Caregiving,” CSHP: Rutgers Center for State Health Policy Issue Brief, 2005.

<sup>56</sup> U.S. Census Bureau, Population Estimates Division, <http://www.census.gov/popest/estimates.php>, accessed January 22, 2007.

<sup>57</sup> NAC and AARP, *Caregiving in the U.S.*, 2004 and Gibson, M.J. et al., *Beyond 50.03: A Report to the Nation on Independent Living and Disability*, AARP Public Policy Institute, 2003.

<sup>58</sup> The adjustments were done in the following manner: First, the timeline adjustment was applied. The percentage of the target age group who are caregivers was assumed to be the same in November 2006 as at the time of the survey. This number is reported in the second data column of table 3. Then the adjustment to the common definition was applied. For example, if a study used a definition of caregiving that included 45 percent of the caregivers in the *Caregiving in the U.S.* weighted sample meeting the common definition (itself a subset of the caregivers in that study), the adjusted estimate would be  $E_1 = (\text{original number})/0.45$ . Two studies included a relatively small number caregivers who would not be included in the *Caregiving in the U.S.* data set or in the common definition; the relative number of such caregivers compared to caregivers meeting the common definition was estimated using the most similar caregivers in the *Caregiving in the U.S.* weighted sample and the adjusted estimate was reduced by this proportion. Finally, for the BRFSS data, a scaling factor of 0.737, computed from analysis of the Beyond 50.03 survey data, was used to convert from reported health condition to needing help with an ADL or IADL. The final adjusted number is reported in the third data column of table 3. More rigorous adjustments using covariates such as age, gender, and race could be performed, but the additional accuracy to be gained from such estimates is small compared to the difference between adjusted estimates from the different sources.