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Unsticking The Sandwich Generation

Help for Families Caring for Aging Parents

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The Problem: More families are joining the "sandwich generation"—juggling jobs, kids and caring for aging parents.

The Solution: Relieve the pressure with financial help and more resources for families with aging parents.

Overview

One of the most significant new challenges faced by modern families is the challenge of balancing work and family. In 1975, nearly two-thirds of mothers with children under 6 stayed at home. Today, nearly two-thirds of these mothers are in the workforce. Moreover, two-thirds of American households are dual-earner families.[1]

While it's hard enough to raise children while one or both parents pursue a career, adding to the complexity is that a growing number of families are caring not only for young children but for aging parents. These so-called "sandwich generation" families are coping with a challenge for which government has yet to provide an adequate solution: how to manage and afford the long-term care needs of fragile seniors. "Long-term care" means not only medical care or nursing home care (which account for just a fraction of seniors' long-term care needs) but the vast array of support services that many aging Americans need to maintain their independence at home. Those services include everything from help with shopping and cleaning to help with taking medication or getting to doctors' appointments.

So far, families and individuals are shouldering the lion's share of these responsibilities on their own. Government help for these families—particularly those in the middle class—is either sparse or non-existent.

We think policymakers should be doing much more to help modern families deal with this very modern problem. In our report, *The New Rules Economy*, we described a

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number of ways in which the path to middle-class success has changed in the last 30 years, and the ways in which government policy has failed to stay in tune with the times. Assisting families with the responsibilities of elder care is among those major policy gaps.

In this policy memo, we lay out why we think long-term care is a critical one to tackle, and we propose a set of policy goals for answering this challenge.

Ten Things to Know about Long-Term Care

1. The "sandwich generation" is growing.

Several major demographic trends are contributing to the rise of the "sandwich generation":

- **People are living longer in retirement.** In 1989, 60 percent of adults between the ages of 41 and 59 had at least one living parent. In 2005, it was 71 percent.[2]
- **People are marrying and having children later in life.** In 1975, the typical birth mother was 24 years old. By 2004, she was nearly 28.[3]
- **The fastest-growing segment of the population is people over the age of 85.** Over the next 20 years, the number of people aged 85 or over is expected to increase by half.[4]

As a consequence, a growing share of families faces multi-generational caregiving obligations. In 2001, 44 percent of adults aged 45 to 55 had aging parents or in-laws as well as children under 21.[5]

2. Most seniors will need some form of long-term care at some point in their lives.

Today's seniors are perceived to be not only longer-lived than prior generations, but more active and healthier. Nevertheless, the vast majority of seniors will face significant needs for long-term care during the course of their lives (defined here as formal and informal in-home care or institutional care, such as in a nursing home).

- **The average American turning 65 today can expect to need three years of long-term care.** According to recent research, on average, women can expect to need 3.7 years of long-term care, versus 2.2 years for men.[6]
- **Long-term care needs increase as people age.** In 1999, 16 percent of all seniors received long-term care services, including one fourth of all seniors aged 80 to 84.[7] According to the Congressional Budget Office, the number of disabled elderly persons is projected to rise by one-third from 9.2 million in 2010 to 12.3 million by 2030.[8]
- **Most seniors have chronic health problems, which increases the likelihood of needing long-term care.** Eighty percent of seniors have at least one chronic condition and 50 percent have two or more. Half of all seniors have been diagnosed with hypertension, more than a third have arthritis, one in five is

being treated for cancer, and one in six is diabetic.[9] In addition, 2.5 million seniors suffer from dementia.[10]

- **High rates of obesity and diabetes among all Americans could signal greater future needs for long-term care.** Between 1980 and 2005, diabetes rates increased dramatically for most age groups, and baby boomers and their parents were especially ill-affected. The prevalence of diabetes increased from 5.5 percent to 10.2 percent for adults aged 45 to 64, and from 9.1 percent to 18.5 percent for those aged 65 to 74.[11] In 2005, 17 states reported adult obesity rates of 25 percent or higher.

3. Family and friends are the principal providers of long-term care, in both time and money.

In 2004, overall spending on long-term care services for the elderly totaled $211.4 billion. Perhaps surprisingly, private resources paid for 60 percent of these costs, while Medicaid paid for 22 percent and Medicare paid for 16 percent.[12] The bulk of private "spending" on long-term care is the value of "donated" care provided by family and friends (that is, the value of the time provided "for free" by caregivers, measured either in terms of foregone wages or the cost of hiring a paid caregiver). Such donated care comprised 36 percent of spending on long-term care for the elderly in 2004 ($76 billion).[13]

- **The majority of seniors receiving long-term care receive it from unpaid caregivers.** An Urban Institute (UI) study found that 57 percent of seniors receiving long-term care help were receiving only informal care from unpaid caregivers.[14] Slightly more than one-third were receiving care both from paid and unpaid caregivers, while only 7 percent received care only from paid caregivers.
- **Adult children are the most common providers of informal care.** The same UI study found that 41 percent of informal caregivers were adult children of the person receiving care, while 26 percent were other relatives, and 24 percent were spouses.[15] Women today, however, are bearing fewer children (the average number of children per married-couple family was 1.88 in 2006, versus 2.02 in 1977),[16] which could mean a future shortage of informal care providers.
- **Many adult children also provide financial help to their parents.** One survey of Baby Boomers found that two in ten are providing financial help to their parents, and slightly more than one in ten are providing financial help to a parent while raising or supporting a child.[17] Total out-of-pocket spending for long-term care in 2004 was about $44 billion.[18]

4. Many family caregivers (most of whom are women) must sacrifice earnings or career prospects to care for aging relatives.

A majority (59 percent) of caregivers are also holding down jobs, and between 25 percent and 35 percent of all workers report that they are currently providing or have provided care to a senior. A majority of these caregivers are also women.[19]

- **A majority of caregivers report losing earnings to meet caregiving obligations.** Two-thirds of working caregivers say they've had to rearrange their work schedule, decrease their hours or take unpaid leave. One in five say they switched from full-time to part-time work. Of all caregivers, 16 percent say they've even quit a job to meet caregiving obligations.[20]
- **Many caregivers say they've given up opportunities for career advancement because of caregiving obligations.** Twenty-nine percent of caregivers say they've forgone a promotion, training or assignment and 22 percent say they passed up a chance to acquire new skills.[21]
- **Families' long-term care obligations cost businesses too.** Some industry experts say that U.S. employers lose between $11.4 billion and $29 billion a year in costs for lost productivity and employee time because of caregiving obligations.[22]

5. More employers are providing flexible working arrangements, but most employees do not have flexibility on the job.

More and more employers are recognizing the need to give their workers flexibility, and many employers now provide leave time for workers who need extended time off to care for elderly family. Nevertheless, just a minority of workers have access to flexible work schedules to care for aging relatives on a day-to-day basis.

- **A majority of employers say they provide time off for workers with elder care obligations.** The 2005 survey of employers by the Families and Work Institute found that 79 percent of employers say they provide paid or unpaid time off for employees to provide elder care without jeopardizing their jobs (which is not required by the Family and Medical Leave Act), and that 29 percent provide employees with information about elder care services.[23] Very few employers, however, provide elder care benefits or financial assistance.
- **Yet only a minority of workers have day-to-day flexibility on the job.** Only about a third of employers allow workers to telecommute.[24] The Department of Labor reports that in 2004, only 27.5 percent of all full-time wage and salary workers nationwide worked a flexible schedule, and only 15 percent of workers regularly worked from home.[25]

6. Formal long-term care is expensive.

Roughly six in ten seniors will incur some costs for formal long-term care (e.g. nursing home care or paid home health services).[26] Given that the average annual cost of nursing home care in 2007 was $74,806 for a private room,[27] these costs can be significant.

- **Institutional settings are the most costly.** In 2004, 69 percent of long-term care expenditures (excluding donated care) were spent on institutional care (mainly nursing home care), even though only a minority of seniors needing long-term care used nursing home care.[28] A 2002 study found that the lifetime cost of caring for a disabled senior averages about $175,000 (or about $200,000 in 2006 dollars).[29]
- **New retirees seeking to cover their expected long-term care costs over the rest of their lifetime would typically have to invest over $50,000 of their money upon turning 65 years old.[30]** Nearly one in six would have to invest $100,000 or more, whereas fewer than one in five would have to set aside $10,000 or less.[31] These figures include only the cost of institutional and formal paid care and exclude the value of informal care provided by family and friends.

7. Medicare and Medicaid provide minimal coverage of long-term care.

One survey found that among seniors who chose not to obtain private long-term care insurance, a majority believed their costs would be covered by Medicare or Medicaid or that their families will take care of them.[32] But contrary to what many seniors and their caregiver families may believe, Medicare and Medicaid do not provide generous coverage of long-term care costs.

- **Because Medicare was originally designed to pay for seniors' acute care needs, coverage of skilled nursing care and home health care is limited.** Medicare coverage of nursing home care is limited to 100 days[33] per spell of illness (following a hospital stay of at least three days), even though the typical length of stay in a nursing home is 870 days (2.4 years).[34] Home health care includes skilled nursing care and specialized services such as occupational therapy, speech therapy and physical therapy, but is limited to people who meet Medicare's "homebound" requirement. Unskilled personal care services are typically not covered.
- **Seniors must meet Medicaid's eligibility requirements to receive coverage.** While eligibility requirements vary from state to state, all states limit the assets and income that seniors can have to qualify for the program.[35] Most states are generous about protecting home equity and spousal assets.
- **Although Medicaid can cover a wider variety of long-term care services, states vary in what they cover and often set caps.** Thirty states and the District of Columbia provide some coverage of personal care, and many states offer a wide variety of support services, such as transportation, home modification,

adult day care and respite care under Medicaid home and community-based waiver programs.[36] But because of limitations on funding and state requirements, many seniors do not receive the care they need. One 1999 study found that nearly 60 percent of "dual-eligible" seniors (those eligible for both Medicare and Medicaid) reported unmet needs for long-term care. Of these seniors, 56 percent reported that they had wet or soiled themselves, 42 percent reported being unable to bathe or shower and 18 percent said they had gone hungry.[37]

8. Most seniors are unprepared for the costs of long-term care.

Knowledge of long-term care costs and options is very low. A 2006 survey by AARP found that most Americans age 45 or over have extremely limited knowledge about the basics of long term care.[38] Among this survey's findings:

- **Americans underestimate the costs of care.** Only 8 percent correctly estimated the monthly cost of a nursing home within 20 percent of the national average cost.
- **More people believe they have private insurance for long-term care than actually do.** Twenty-nine percent said they had private long-term care insurance, although other data suggests that in 2002, only about 9 percent of Americans actually had this coverage.
- **A majority have misperceptions about Medicare coverage of long-term care.** Fifty-nine percent incorrectly believe that Medicare will pay for extended nursing home stays and assisted living costs. Large percentages also incorrectly believe that MediGap insurance plans will cover these costs.[39]

9. The private market for long-term care insurance needs improvement.

Private insurance accounts for a small but growing fraction of total spending on long-term care.[40] While long-term care insurance (LTCI) has tremendous potential to alleviate the burden of long-term care costs both on seniors and on federal spending, the current market for LTCI is still maturing and far from perfect (the first policies were written only 30 years ago).

- **LTCI is relatively expensive.** The average annual premium for an LTCI policy in 2005 was $1,973. Beneficiaries aged 55 to 64 paid $1,877 annually, on average, while those over age 75 paid $2,604.[41] One study found that only 10 to 20 percent of older adults can afford LTCI, and three-fourths of policyholders have annual incomes above $50,000.[42] While long-term care insurance can be significantly less expensive when purchased at a younger age, most buyers are older. At the time of purchase, the average age is 61.[43]
- **People with LTCI are still likely to incur out-of-pocket costs**. According to the AARP, most buyers of LTCI choose a daily benefit amount for nursing home care

that is less than the average cost.[44] On average, LTCI policies only pay 65 percent of nursing home daily costs.

- **People believe they don't need LTCI because of Medicare and Medicaid.** As mentioned above, a majority of seniors believe that Medicare covers most long-term care services. As a consequence, demand for LTCI products is weak, which leads to higher costs and less product variety.
- **LTCI products are complex.** Many seniors do not understand the many variables that go into selecting a policy or the level of coverage they will receive. In addition, the industry has also recently received unfavorable publicity about the practices of some insurers that have led to the denial of claims.[45]

10. Future long-term care costs will be a growing burden on both families and federal spending.

Long-term care already makes up a significant share of both total health care spending and the health care spending on seniors. This burden can only be expected to increase as Baby Boomers approach retirement.

- **Seniors are a large and growing share of the population.** By 2050, the number of seniors over age 65 is projected to more than double from what it is today to about 86.7 million people (or more than 20 percent of the population). Nearly a fourth of these seniors will be age 85 or over.
- **CBO projects that total long-term care spending for seniors could more than triple from current levels to $760 billion (in 2000 dollars) by 2040 (or $890 billion in 2006 dollars).**[46] Long-term care spending is expected to comprise as much as 3.3 percent of GDP by 2040, assuming that the level of impairment among seniors stays at today's levels.

Relieving the Strain: Policy Goals

Government policies must be modernized to recognize the depth and breadth of the need for help with long-term care. Medicare and Medicaid, as they currently stand, are far from adequate for fulfilling these needs, particularly for middle-class seniors who want to preserve their independence at home. Family caregivers have few supports—financial or otherwise—for providing long-term care services to elders. And for many families, the expenses of long-term care are neither expected nor planned for.

We propose four major policy goals to provide families with some immediate relief in managing the financial burdens and anxiety of caring for aging parents:

- Provide **financial assistance** to family caregivers with elder care obligations;
- Encourage more **employers to adopt practices** that better accommodate family caregivers;
- **Educate more Americans** about the need to plan for elder-care costs; and
- Expand and **improve the market** for long-term care insurance.

In the final section of this policy brief, we lay out some specific ideas for carrying out these goals. Later policy briefs will take on the related issues of long-term care quality and systemic reform of long-term care financing.

Policy Options

Goal 1: Provide financial assistance to family caregivers with elder care obligations.

- **Expand the Dependent Care Credit to include elder care costs.** Under current federal tax law, out-of-pocket caregiving expenses paid on behalf of an elderly relative living outside the taxpayer's home are not tax-deductible. Moreover, the Dependent Care Credit applies only to day care expenses for a child under 13 or for expenses paid on behalf of a spouse or other dependent living in the taxpayer's home. It does not apply to expenses paid on behalf of an elderly relative who requires temporary personal care for an illness or needs ongoing help on a sporadic basis. Modifying the Dependent Care Credit would enable taxpayers to use the credit for elder care expenses incurred on behalf of an elderly relative who is not a dependent.
- **Allow elder care costs to be paid out of employer-provided FSAs.** Expenses incurred for the care of non-dependent family members cannot be reimbursed under the current rules for Flexible Spending Accounts. These rules can, however, be modified to allow for the reimbursement of certain elder care expenses. Such a change could encourage more working caregivers to enroll in their employers' available plans or encourage an employer to offer an FSA if this option is not provided already.
- **Increase the budget for the National Family Caregiver Support Program (NFCSP) to $200 million.** The NFCSP was created under the Older Americans Act Amendments of 2000 to provide population-based formula grants to state agencies on aging, which in turn fund local agencies and community-service providers that provide access to information, individual counseling, support groups, training, respite care and other supplemental services to caregivers. Funding for NFCSP is modest—$155 million for FY 2007. An increase in funding for this program would allow states to reach more moderate-income families, as well as residents of urban and suburban areas. Currently, the program primarily targets low-income and rural families.
- **Expand so-called "Cash and Counseling" programs.** This Medicaid waiver program, created in the 1990s, provides elderly beneficiaries with a monthly budget to pay for personal care and can be used to pay friends and family under certain guidelines. So far, three states (New Jersey, Arkansas and Florida) have participated in this program. Expanding this program would permit more states to provide this option.

- **Allow the federal income tax deduction for elder care expenses for non-itemizers.** The current federal deduction for medical expenses applies only if a taxpayer itemizes (and only if the expenses are incurred on behalf of a "dependent"). However, a significant proportion of taxpayers do not itemize. As an alternative to the Dependent Care Credit expansion described above, the current federal deduction could be modified to allow non-itemizers to deduct some portion of elder care costs.

Goal 2: Encourage more employers to adopt practices that better accommodate family caregivers.

- **Create a Family Flexibility Tax Credit to reward companies for providing family-friendly benefits such as child care assistance or telecommuting.** Current federal law offers few incentives for employers to adopt family-friendly benefits. While an employer incentive could be structured in a variety of ways, one possible model is legislation that recently passed in Georgia, which will provide businesses with a state income tax credit of up to $1,200 per employee for telework expenses and $20,000 if they conduct studies on how to implement a teleworking program.

Goal 3: Educate more Americans about the need to plan for long-term care costs.

- **Expand public campaigns to increase awareness of the need for long-term care planning.** The National Clearinghouse for Long-Term Care Information began a campaign in 2005 called *Own Your Future* in which governors of 15 states sent packets offering long-term care planning assistance to every household with individuals aged 50 to 70. The overall response rate was approximately 8 percent, which is significantly higher than the typical response rate to comparable private sector direct mail campaigns. A national program that builds on this model could prove to be equally successful.

Goal 4: Expand and improve the market for long-term care insurance.

- **Create a national, standardized disclosure policy for LTC insurance.** One of the most common complaints about long-term care insurance is the complexity and ambiguity of coverage options. Consumers often complain that different companies describe their coverage options in different ways, making it difficult to understand exactly which services policyholders are entitled to under the policy. Standardized disclosure requirements would make the descriptions of policy options uniform across all LTCI companies, reducing confusion and relieving stress for individuals purchasing long-term care insurance.

Endnotes

[1] U.S. Census Bureau, Current Population Survey, March Supplements.
[2] Pew Research Center, "Baby Boomers: From the Age of Aquarius to the Age of Responsibility," December 8, 2005.
[3] U.S. Census Bureau, *Statistical Abstract of the United States: 2002*, table 81.
[4] U.S. Census Bureau, *Statistical Abstract of the United States: 2002*, table 13.
[5] Belden, Russonello and Stewart and Research/Strategy/Management, "In the Middle: A Report on Multicultural Boomers Coping with Aging and Family Issues," AARP, July 2001.
[6] Peter Kemper, Harriet L. Komisar, and Lisa Alecxih, *Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?* Inquiry 42:335-350 (Winter 2005/2006).
[7] Ellen O'Brien, *Long-Term Care: Understanding Medicaid's Role for the Elderly and Disabled*, Kaiser Commission on Medicaid and the Uninsured, November 2005.
[8] Congressional Budget Office, *Projections of Expenditures for Long-Term Care Services for the Elderly*, (March 1999). <http://www.cbo.gov/ftpdocs/11xx/doc1123/ltcare.pdf>
[9] Wan He, Manisha Sengupta, Victoria A. Velkoff, and Kimberly A. DeBarros, 65+ in the United States: 2005, U.S. Census Bureau, Current Population Reports, December 2005.
[10] Centers for Disease Control and Prevention and The Merck Company Foundation. *The State of Aging and Health in America 2007*.
[11] Centers for Disease Control and Prevention. *National Diabetes Surveillance System.* <http://www.cdc.gov/diabetes/statistics/prev/national/tablebyage.htm>
[12] Congressional Budget Office, *CBO Testimony: The Cost and Financing of Long-Term Care Services,* before the Subcommittee on Health, Committee on Energy and Commerce, U.S. House of Representatives, April 27, 2005. <http://www.cbo.gov/ftpdocs/63xx/doc6316/04-27-LongTermCare_testimony.pdf>
[13] Ibid.
[14] Jane Tilly, Susan Goldenson, and Jessica Kasten, *Long Term Care: Consumers, Providers, and Financing, a Chart Book*, Urban Institute, March 2001.
[15] Ibid.
[16] U.S. Census Bureau, Current Population Survey, Table FM-3, "Average Number of Own Children Under 18 Per Family, By Type of Family: 1955 To Present." <http://www.census.gov/population/www/socdemo/hh-fam.html>
[17] Pew Research Center, "Baby Boomers: From the Age of Aquarius to the Age of Responsibility," December 8, 2005.
[18] Congressional Budget Office, *Financing Long-Term Care for the Elderly,* April 2004. <http://www.cbo.gov/ftpdocs/54xx/doc5400/04-26-LongTermCare.pdf>
[19] Family Caregiver Alliance, National Center on Caregiving. *Fact Sheet: Selected Caregiver Statistics,* 2007.
[20] MetLife Mature Market Institute, "The MetLife Juggling Act Study: Balancing Caregiving with Work and the Costs Involved," November 1999.
[21] Ibid.
[22] Ibid.
[23] James T. Bond, Ellen Galinsky, Stacy S. Kim and Erin Brownfield, "2005 National Study of Employers," Families and Work Institute, 2005.
[24] Telework Facts, The Telework Coalition. <http://www.telcoa.org/id33.htm>
[25] U.S. Bureau of Labor Statistics, "Workers on Flexible and Shift Schedules in May 2004."
[26] Peter Kemper, Harriet L. Komisar, and Lisa Alecxih, *Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?* Inquiry 42: 335-350 (Winter 2005/2006).
[27] *2007 Cost of Care Survey: Home Care Providers, Assisted Living Facilities and Nursing Homes,* Genworth Financial, March 2007.
[28] Congressional Budget Office, *Financing Long-Term Care for the Elderly*, April 2004.

[29] Marc A. Cohen, Maurice Weinrobe, Jessica Miller, and Anne Ingoldsby, *Becoming Disabled After Age 65: The Expected Lifetime Costs of Independent Living,* AARP, 2005 (inflation adjustment calculated by TW staff). <http://assets.aarp.org/rgcenter/il/2005_08_costs.pdf>

[30] Kemper, et al., 2005/2006. The authors' finding has been inflated by TW staff to 2007 dollars.

[31] Ibid.

[32] *The Public's Views on Long-Term Care,* Kaiser Public Opinion Spotlight, based on surveys conducted April-June, 2005.

[33] Medicare Payment Advisory Commission, Report to the Congress: Medicare Payment Policy, March 2007. <http://www.medpac.gov/documents/Mar07_EntireReport.pdf>

[34] Celia S. Gabrel, *Characteristics of Elderly Nursing Home Current Residents and Discharges: Data from the 1997 National Nursing Home Survey*, Advance Data from Vital and Health Statistics: no. 312. National Center for Health Statistics, 2000. <http://www.cdc.gov/nchs/data/ad/ad312.pdf>

[35] O'Brien, 2005.

[36] Ibid.

[37] Ibid.

[38] *The Costs of Long-Term Care: Public Perception Versus Reality in 2006*, AARP Fact Sheet, December 2006. <http://assets.aarp.org/rgcenter/health/ltc_costs_fs_2006.pdf>

[39] Ibid.

[40] Congressional Budget Office, 2005 and Georgetown University, Long-Term Care Financing Project, "National Spending for Long-Term Care," Fact Sheet, February 2007.

[41] *The Policy Book: AARP Public Policies 2007*, section on Long-Term Services and Supports, AARP, 2007. <http://assets.aarp.org/www.aarp.org_/articles/legpolicy/7_ltc07.pdf>

[42] Richard W. Johnson and Cori Uccello, *Is Private Long-Term Care Insurance the Answer?* An Issue in Brief, Center for Retirement Research at Boston College, March 2005, number 29. <http://www.urban.org/UploadedPDF/1000795.pdf>

[43] America's Health Insurance Plans, "Who Buys Long-Term Care Insurance? A 15-Year Study of Buyers and Non-Buyers, 1990-2005," Prepared for America's Health Insurance Plans by LifePlans, Inc., April 2007.

[44] Enid Kassner, *Private Long-Term Care Insurance: The Medicaid Interaction*, AARP Public Policy Institute, 2004. <http://assets.aarp.org/rgcenter/health/ib68_ltc.pdf>

[45] Charles Duhigg, "Aged, Frail and Denied Care by Their Insurers," *The New York Times*, March 26, 2007.

[46] Congressional Budget Office, 2005.