

*Women and Aging:
Bearing the Burden of Long-Term Care*

A Joint Hearing of
Special Committee on Aging
&
Aging Subcommittee
of the Health, Education, Labor, and Pensions Committee

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Mr. Chairman, Madame Chairwoman, and distinguished Members of the Committee:

I appreciate your invitation to testify today on this critical issue of women and caregiving. The Older Women's League (OWL) commends you and your respective committees for engaging in the important discussion of addressing the critical needs of America's caregivers, and especially for your recognition of women, who bear the burden of caregiving.

My testimony today will focus on how caregiving affects women, including its long-term financial and health consequences. I will also highlight a few policy recommendations that OWL believes would greatly assist caregivers.

As the executive director of OWL, the only national grassroots membership organization dedicated exclusively to the unique concerns of women as they age, I can assure you that our members have a very personal stake in the issue of caregiving.

Women Are America's Caregivers

OWL's 2001 Mother's Day Report, *Faces of Caregiving*, released last May on Capitol Hill, addresses the value, scope and consequences of informal caregivers' work. "Informal caregiving" is a catch-all phrase that refers to unpaid care and financial support provided by family members or friends to people with chronic illness or disabilities. It is the backbone of long-term care and support in America.

The report reminds us that women provide the majority of informal caregiving — and often pay a steep price for their efforts. Caregivers suffer reduced wages and job security, which inevitably lead to diminished retirement security. Informal caregivers also experience emotional and physical stress that can take a toll on their own health.

When we speak of caregiving, OWL uses a broad definition that encompasses raising children, assisting people with disabilities, and caring for frail elders. As the voice of midlife and older women, OWL stresses that caregiving truly spans the generations. We also underscore the one common denominator to all forms of caregiving — women do the majority of caregiving work, both paid and unpaid.

I would like to begin by describing the scope of informal caregiving in America. We know that as many as 52 million Americans, or 31 percent of the adult population, are informal caregivers. Almost one-quarter of American households provide care to friends or relatives age 50 or older. We also know that informal caregivers provide an irreplaceable service, estimated at nearly \$200 billion annually. When formal home care expenditures are added to the \$200 billion "public good" of informal care, the economic value of community-based care dwarfs the value of institutional care by a ratio of nearly three to one. In fact, informal caregivers provide more care in the home — free of charge — than the federal government provides in all settings combined.

Gender makes a difference when it comes to informal caregiving. Nearly three-quarters of informal caregivers to seniors are women. Women on average provide 50 percent more hours of informal care per week than men. Women also provide informal care for longer periods of time than men — in many cases, for more than five continuous years.

The typical informal caregiver is a married woman in her mid-forties to mid-fifties. She is employed full-time and also spends an average of 18 hours per week on caregiving. In addition to juggling her career with caring for a parent, partner, or spouse, she may be the primary caregiver for her children and, increasingly, for her grandchildren as well. Between 20 and 40 percent of caregivers are members of the “sandwich generation,” caring for children under age 18 in addition to other family members. Because women are more likely than men to assume caregiving roles, they are also more likely to be sandwiched by the needs of two or more generations.

Beyond the averages, we cannot forget that different communities tackle their own unique caregiving challenges in different ways. African Americans women have higher rates of providing informal care than women in general, and are more likely to be raising grandchildren. Hispanics are the fastest-growing segment of the population and face unique language barriers to accessing formal services. The gay, lesbian, bisexual, and transgendered community faces its own set of issues regarding caregiving, especially because they are less likely to have certain sources of support, such as government and employer assistance policies. Meanwhile, Asian American caregivers tend to be younger, which lends a unique twist to their needs. In our efforts to respond to the needs of caregivers and those they are caring for, we must remember that such needs are as diverse as the faces of those who provide the care.

The common denominator is that the majority of caregivers in all of these communities are women. It is women who provide the unpaid care and support to parents, children, grandchildren, spouses, and partners. And it is women who pay a financial, emotional, and physical price for the care they provide.

Caregiving Affects Women’s Financial Security

So we know that caregiving is a gender issue. But OWL also sees caregiving as a retirement security issue. Women’s earnings and retirement security are put at risk by informal caregiving, increasingly so the longer women provide care.

Informal caregivers often curtail their professional opportunities and thereby imperil their financial security in retirement. Fifty-four percent of caregivers in the paid labor force report their career is affected in some way by caregiving, which may require them to arrive for work late, leave work early, take unscheduled leave days, or have intermittent absences during the workday. Seven percent of informal caregivers who are employed report they moved from full-time to part-time work or took a less demanding job in order to accommodate their caregiving work. It is extremely difficult to balance caregiving with a career given society’s reluctance to value informal caregiving and paid employment equally. Yet informal caregivers are expected to find this balance.

For many women, caregiving influences their employment from the very first job. As a result of their caregiving patterns, most women work in lifetime low-wage jobs that give them the flexibility to move in and out of the workforce. In general, women make up the majority of the part-time and contingent jobs that rarely offer the benefits women need for a secure financial future, such as pensions. Twenty-five percent of all female wage and salary workers are part-time, compared to about 11 percent for men.

Caregiving doesn't just impinge on the course of a caregiver's career; it can often preclude her from working at all. Six percent of caregivers who were previously employed reported they stopped working because of caregiving, 11 percent took a temporary leave of absence, and another 4 percent took early retirement. All told, roughly a quarter of caregivers who were previously employed stopped working for an extended period of time because of their caregiving roles.

The sacrifices that informal caregivers routinely make during midlife — a peak earning period — reduce lifetime earnings and retirement savings. It is estimated that caregivers lose an average of \$550,000 in total wage wealth, and their Social Security benefits decrease an average of \$2,100 annually, as a result of caregiving. These figures would be even larger if losses associated with childcare responsibilities were also included.

These financial sacrifices can be particularly troubling for women: time out of the workforce diminishes their earning power, which is already reduced by the wage gap. As a result, women are more likely than men to face poverty in retirement: 12 percent vs. 7 percent.

As the number of women who provide informal caregiving increases — and if caregiving continues to negatively impact women's earning power — the number of poor older women will inevitably increase as well.

Caregiving's Impact on Women's Health

Women with caregiving responsibilities often face more than financial stresses; mental and physical challenges are also part and parcel of informal caregiving. Although the overwhelming majority of adults who provide informal care to a parent age 65 or older say they feel loved, appreciated, and proud of the care they provide, a substantial number feel worried, frustrated, sad, depressed, or overwhelmed.

These emotional stresses can be accompanied by physical impairments as well. One-third of informal caregivers describe their health status as fair or poor. In reality, the situation is far worse. One study found that two out of three informal caregivers were in ill health. Although most caregiving is short-term, prolonged responsibilities take a toll on the emotional and physical health of caregivers.

Approximately one-third of informal caregivers are “very” or “somewhat concerned” about juggling caregiving with other aspects of life. Caregivers worry about not having enough time to spend with their spouse, partner, or children, or by themselves. Concerns about maintaining personal health or missing work as a result of caregiving are also very common.

In some cases, this emotional stress leads to depression, which can impair a caregiver's ability to provide care and also endanger her own health. The incidence of depression is higher among informal caregivers than in society at large, and women are diagnosed with depression at twice the rate of men. Other common physical manifestations of caregiving stress include insomnia, indigestion, changes in appetite, and increased frequency or intensity of headaches. Informal caregivers can become so overwhelmed with caregiving that they neglect their personal health until a crisis arises, and such crises are often costly. An expectation that women will bear additional health-related costs due to increased informal caregiving could have a devastating impact on their retirement security.

Routine caregiver tasks such as heavy lifting and moving; changing of bedding; dressing; bathing; and helping with the toilet can cause acute and chronic physical strain, particularly when caregivers lack appropriate training. Forty-four percent of informal caregivers report physical strain as a result of their caregiving activities. Stress imposed by daily caregiver tasks may render informal caregivers more susceptible to illness. One study found that chronic stress in informal caregivers can weaken the caregiver's immune system. Because the majority of informal caregivers are over age 50, their risk of experiencing health problems is already relatively high.

Bearing the Burden

There are some in the long-term care community who in fact object to the use of the word "care," who prefer instead the phrase "long-term services and support." OWL supports that preference, but for us the reality is that women *do* care — emotionally, physically and financially. OWL just doesn't believe women — or anyone else — should be expected to willingly sacrifice their own retirement security or health as a consequence of caring.

So America depends upon women as caregivers, and in many ways expects them to assume this role — that's nothing new. The important question is why. OWL would submit that the answer is deceptively simple: America depends on women because it can. As long as words like love and commitment, duty, and family are used in relation to caregiving, society will always see it as "women's work."

Unfortunately, women's work is consistently devalued, and too often policy solutions reflect this bias. Caregiving is a perfect case in point. Current long-term care policy assumes women will continue in this role, and many of the "solutions" — while well-meaning and even helpful in the short term — revolve around encouraging women to continue to do this work. Changing the way we talk and think about the work of caregiving would also lead us to focus more on the person who needs the service and the service itself. OWL is convinced that changing the focus as such would produce better long-term care policy.

OWL also believes we need to build a new paradigm for long-term care policy that values caregiving and, moreover, is aimed at getting the best and most appropriate care to those who need it — without requiring women to sacrifice their economic security in retirement to achieve it. This repositioning would put caregiving on a whole new plane. Caregiving relationships are as

varied as the faces of those who provide care, and the motivations for providing such are more complicated than obligation or familial love.

Now, the challenge: There is no simple remedy in sight. Public policy and community services should be improved, but we also must confront difficult and pervasive social norms that expect women to care for others more than they care for themselves.

The aging population and increased longevity are two trends that could drain the nation's informal caregiving resources if a comprehensive long-term care and support system is not developed and implemented. Appropriate public policy responses are critical if we are to address the emotional, physical, and financial challenges facing caregivers today and to ensure that caregiving does not jeopardize their own health and retirement security tomorrow.

Public Policy Recommendations

OWL feels the following policy recommendations would help to lighten some of the load for caregivers, and provide retirement security protections that are particularly critical for women.

Expand the Family and Medical Leave Act (FMLA) to Make It More Inclusive and Effective

First, there should be a broader definition of immediate family member whose care qualifies as a covered event. Second, the law should be expanded to cover smaller workplaces. To the extent that small businesses express concern with such an expansion, consideration should be given to tax policies to help mitigate any adverse impact. Third, the FMLA should be amended to extend prorated benefits and protections to caregivers who work less than the current minimum of 1,250 hours a year, or who have worked for a particular employer for less than a year. Fourth, serious consideration should be given to wage supplementation during a period of leave to enhance use of the benefit.

Finally, federal policymakers should expand the worker benefits that are protected under the law. Like the mandatory continuation of health benefits under current law, the FMLA should also require employers to continue any employer contributions to qualified retirement plans during a covered leave period. This requirement would ensure that caregivers do not risk their own retirement as a result of their commitments to family and community. Given their higher rates of poverty in retirement, this is a particularly critical issue for women.

Modify the Medicare Program to Support Informal Caregiving

The Medicare program should become a reliable partner for informal caregivers. First, Medicare should be amended to allow informal caregivers who do not have access to employer-sponsored coverage, and who care for Medicare-eligible or enrolled spouses or relatives, to buy into Medicare. Women who leave the workplace early or shift from full-time to part-time jobs to be caregivers can lose access to affordable health insurance. Women without coverage will sometimes forgo preventive medical care, diagnosis, and treatment, which can result in more serious and costly illness down the road. In light of the numerous emotional, physical, and financial stresses caused by informal caregiving, access to affordable health insurance is crucial.

Second, the Medicare program should be amended to provide a comprehensive prescription drug

benefit. Prescription drugs are a critical component of health care for older Americans and people with chronic illness or disabilities. A Medicare prescription drug benefit is of vital importance to people in need of informal care as well as to those who care for them. Affordable prescription drugs help individuals maintain their health and functioning, which could reduce the need for informal care and perhaps prolong their ability to provide such care.

Any discussion of “modernizing” Medicare’s benefit package should recognize that Medicare has a critical role to play in meeting the chronic health care needs of beneficiaries, which in turn will limit medical emergencies, prevent excess disability, and support informal caregivers. Medicare should provide a chronic care benefit and cover respite care, adult day care, and other community-based long-term care and support services.

Strengthen Social Security by Recognizing the Work of Informal Caregivers

Informal caregivers who work less than full-time or who take a leave of absence from work should be protected in retirement. There are several approaches to help ensure that benefits are not reduced in retirement due to caregiving during working years.

One approach is to disregard up to five years of lower income when calculating Social Security retirement benefits if income has been reduced due to unpaid caregiving. For example, a worker who moves from full-time to part-time work, or who leaves the workforce temporarily to provide care, should not have that period of lower income included in a Social Security base year computation. Alternatively, a worker could receive credits in the Social Security system for up to five years of work for unpaid caregiving. Either of these revisions would help reduce the extent to which women are penalized in retirement for fulfilling caregiving responsibilities during prime earning years.

Improve Pension Coverage for Caregivers in the Paid Workforce

Federal pension law should be revised to better protect the retirement security of caregivers. While pension reform will benefit all women, it particularly resonates with the needs of women who are informal caregivers. OWL was pleased that in 2001 Congress changed pension laws to reduce vesting requirements from five to three years, better reflecting women’s work patterns.

However, we should take it one step further and count leave time under the Family and Medical Leave Act as service time, and it should accrue to help meet any pension vesting requirements. Such revisions would allow more women to qualify for pension coverage and would also help protect informal caregivers who move in and out of the paid workforce due to caregiving. Further, employers should not be allowed to exclude part-time and temporary workers from pension benefits or contributions as the law currently permits. Women who work part-time because of informal caregiving are particularly affected by this policy.

Create a Dependent Care Tax Credit Building on the Childcare Tax Credit

The existing childcare income tax credit is designed to compensate in a small way for the childcare costs of working parents, but it does not offset broader dependent care costs. In addition to the age restrictions for dependents, the tax credit has a number of other shortcomings. The definition of “dependence” is too restrictive to be an effective relief mechanism for most family caregivers. The test of “dependence” should be made less restrictive in terms of the

dependent care reimbursement account and patterned more closely after the California informal care tax credit law. The credit should also be refundable. Some dependent care tax credit proposals before Congress require a doctor certify that a care recipient needs assistance with three or more activities of daily living (ADLs), but OWL is concerned that this is overly restrictive.

Provide Greater Support for Public Caregiver Assistance Programs and Innovations

Funding for federal and state programs that assist informal caregivers by providing information, training, referrals, and respite care should be expanded. Policymakers took an important first step two years ago when Congress launched the National Family Caregiver Support Program (NFCSP) with the 2000 reauthorization of the Older Americans Act. Currently under a \$141.5 million appropriation for FY 2002, the program is intended to provide informal caregivers with critical information, training, counseling, and respite services.

The direct services for caregivers that will be implemented through the NFCSP are clearly critical to older women. Information is power to anyone struggling with a long-term care situation, and the NFCSP will provide an important one-stop shop for caregivers. The training piece of the NFCSP is also important, not just in its positive affect on the care provided, but for the protections it could provide the caregiver. This can be physically demanding work, and proper training — lifting techniques, for example — can avoid debilitating injuries to caregivers. The support group and respite components of the NFCSP are also a significant step in the right direction towards minimizing the negative consequences for caregivers. The opportunity for caregivers to talk about these challenges with counselors and peers in similar situations can be an invaluable source of emotional support.

However, more can be done. The NFCSP was developed as an initial effort to meet the needs of only a segment of the caregiver population. NFCSP targets only the informal caregivers of older adults, as well as older individuals who are raising their grandchildren or caring for children with disabilities. As a result, many of America's caregivers cannot avail themselves of these important programs. For example, a spouse caring for a partner under the age of 60 is not eligible for these services. These eligibility restrictions represent a significant shortcoming of the program.

It is also worth mentioning that the program is woefully underfunded. In fact, the current funding level translates to just a few dollars for every caregiver in America. This lack of resources is already a problem today. As the baby boomers age, it could easily become a crisis tomorrow.

Create Incentives to Private Sector through Tax Policy

Tax policy should provide incentives to the private sector to develop programs that assist women in the paid workforce who provide informal care. While there should be tax incentives for the whole range of caregiver assistance services that employers might provide, the incentives should provide the greatest benefit for employer policies that promote the development of eldercare programs and services made available to the entire community.

Build a Larger Workforce of Formal Caregivers

Federal policy should be designed to improve the quality and quantity of the formal caregiving

workforce, such as home health workers. Formal caregivers assist and supplement the work of informal caregivers and play an important role in providing comprehensive care to individuals requiring long-term care and support. Public program reimbursement should be adequately targeted to formal caregivers. Additionally, public policies and programs should be designed to provide low-wage health care workers with access to affordable health insurance when their employers do not provide such benefits. Low wages and a lack of benefits create high turnover among portions of the health care workforce, adding to the work of informal caregivers.

Make Dependent Care Spending Accounts Applicable to Eldercare

Dependent care spending accounts offered by employers to employees have been successful in offsetting childcare expenses but have been less successful with expenses related to eldercare. They would be useful to workers with eldercare costs if federal tax policy were changed to allow more claims for eldercare. For example, the definition of “dependence” should be modified so that adult family members would not be required to spend eight hours a day in the home of the worker in order to qualify. Current rules also require that any unused portion of the spending account revert to the employer at the end of the year. Allowing unused funds to roll over at year’s end would permit greater flexibility for eldercare costs, which, unlike childcare, can vary significantly from year to year. Additionally, employees should have at least two opportunities during the course of a year to establish and fund a dependent care spending account; current law permits only one opportunity per year.

Conclusion

America lacks an effective system to address caregiving. As a result, caregivers — the majority of whom are women — are often pushed beyond their means and suffer long-term consequences as they struggle to meet the needs of those who depend on them. The demographics are clear, and now is the time for Congress and the Administration to take the appropriate steps to head off a national caregiving crisis by instituting important reforms designed to benefit informal caregivers. Thank you for taking the lead by holding this hearing on women’s role in caregiving and its consequences.