

“The National Family Caregiver Support Program”

**A Hearing before the Senate Special Committee on Aging
U. S. Senate
May 17, 2001**

**Testimony of Deborah Briceland-Betts, J.D.
Executive Director
Older Women’s League**

Mr. Chairman and distinguished Members of the Committee:

I appreciate your invitation to testify today on the timely issue of caregiving and the new National Family Caregiver Support Program (NFCSP). OWL commends you and the Committee for engaging in the important discussion of addressing the critical needs of America’s caregivers. My testimony today will focus on how caregiving affects women, including its long-term financial consequences. I will also highlight a few policy recommendations to address some of these consequences, with special attention paid to the NFCSP.

This past weekend the nation observed Mother’s Day. Our celebrations typically praise women for the caregiving roles they play in our families and communities. One day a year, the country acknowledges the irreplaceable contributions mothers, grandmothers, aunts, sisters and daughters offer their families and friends. These celebrations are part of the rewarding side of caregiving, but its important to remember there are consequences to caregiving as well – and there is no better time to discuss them than Mother’s Day.

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.

OWL’s 2001 Mother’s Day Report, *Faces of Caregiving*, released just last week 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 an irreplaceable source of long-term care and support in America.

The report reminds us that women provide the majority of informal caregiving work — 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 which 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.

And 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 over 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 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 caregiving needs of two or more generations.

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, and increasingly so the longer they provide care.

Informal caregivers often curtail their professional opportunities and thereby imperil their financial security in retirement. 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.

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 economic sacrifices can be particularly devastating to older women, whose quality of life is seriously constrained by social and economic policies that are not responsive to their life patterns.

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.

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.

OWL's 2001 Mother's Day report highlights some policy recommendations that OWL feels would help to lighten some of the load for caregivers, and provide retirement security protections that are particularly critical for women. Chief among these recommendations are improvements to the National Family Caregiver Support Program.

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. Policy makers took an important first step last year when Congress launched the NFCSP with the 2000 reauthorization of the Older Americans Act. Under a \$125 million appropriation, the program is intended to provide informal caregivers with critical information, training, counseling and respite services. It is the largest new assistance program under the Act since Congress established nutritional programs for older Americans in 1972.

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. Families thrust into such situations don't worry about policy implications, they simply need accurate, timely information about services and options. The NFCSP, as it is implemented across the country, will provide an important point of entry for caregivers and their families as they make these difficult choices.

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 down the road.

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. Older women with caregiving responsibilities often face mental, physical and financial stresses. Midlife women face these challenges while simultaneously being pinched by career responsibilities and preparing for their own retirement. Caregiving is stressful in its own right, and even more so when combined with these other demands.

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. 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. The opportunity for caregivers to talk about these challenges with counselors and peers in similar situations can be an invaluable source of emotional support.

The NFCSP will provide an important opportunity to bring together community agencies to begin to address the critical needs of caregivers. This is the good news. But the bad news is that we already know the program is woefully underfunded. In fact, the current funding level translates to roughly \$5.00 in services 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.

Lastly, the NFCSP was developed as an initial effort to meet the needs of only a segment of the caregiver population. This new initiative 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. Aside from its limited funding, these eligibility restrictions represent a significant shortcoming of the program.

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 1250 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 utilization 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.

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. Such reforms 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. Pension law should be amended to reduce vesting requirements from five to three years, a change which would better reflect women's work patterns. The Grassley-Baucus bill, S. 742, would implement this change if passed. 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.

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 caregiving 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. The NFCSP is a very good start, but federal policymakers have a unique opportunity to make additional important reforms designed to benefit informal caregivers in the context of examining the Medicare and Social Security programs.

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. Public policy responses such as those described in OWL's 2001 Mother's Day Report 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.

OWL 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.

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. If we can do that, caregiving work will be truly valued -- not just on Mother's Day, but on every day of the year.