

# InFOCUS

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## Family Caregiving: 20 Years of Federal Policy

**Family caregivers are a hidden workforce that is essential to meet the growing demand for long-term services and supports by older adults and people with disabilities.** Yet the policies and programs available in the United States are much less supportive than those in most other developed countries, both in offering direct financial support and in addressing the need to balance the time spent on care with the responsibilities of the caregiver's regular job.<sup>1,2</sup> A variety of economic and political forces have made policymakers reluctant to support more programs that alleviate the financial, emotional, and physical strains of caregiving.

In the past two decades, federal policy on family caregiving issues has evolved mostly through incremental changes and narrowly focused programs. In this brief, we review the progress and look forward at a variety of forces that may enhance the prospects for public policies in support of family caregivers.

**10%** of eligible employers are not in compliance with the FMLA's requirement for 12 weeks of unpaid family leave.<sup>3</sup>



### POLICIES ON FAMILY LEAVE: A PIECEMEAL EVOLUTION

- The Family Medical Leave Act (FMLA) of 1993 required public employers and those private employers with at least 50 employees to give workers a minimum of 12 weeks of unpaid leave from their job for the birth, adoption, or foster care of a child; their own serious medical condition; or the need to care for a child, spouse, or parent with a serious medical condition.
- Three-quarters of employers surveyed in 2014 said they provide paid or unpaid time off for employees to provide elder care. This is not required by FMLA.<sup>4</sup>
- Eleven percent of private-sector workers were entitled to paid time off to care for a family member as of 2012.<sup>5</sup>
- Efforts to add paid leave for caregiving as a federal benefit under Social Security, unemployment, or disability insurance have

met with little success, although three of the five states that have their own insurance programs for temporary disability do charge a payroll tax that funds four to six weeks of paid leave for caregiving.

- In 2013, four in five employers offered a range of flexible work options—including working from home, flexible hours, and part-time schedules—that can help caregivers stay in the labor force.<sup>6</sup>

### RESPIRE AND OTHER DIRECT SUPPORT FOR CAREGIVERS

- The National Family Caregiver Support Program (NFCSP) was established as part of the reauthorization of the Older Americans Act of 2000. Between 2004 and 2014, NFCSP had an annual budget of \$150 million, which was used to disseminate information to caregivers and refer them to community services, provide caregivers with individual counseling, start support groups, train caregivers, and offer respite services.

Federal and state support for programs that provide respite, training, and counseling to family caregivers represents **less than 1/20 of one percent** of the economic value of the caregivers' time and effort.<sup>8</sup>



In 2007, caregivers of persons ages 50 and over experienced high direct costs and lost income.

- **Spent an average of \$5,500** of their own money on expenses directly associated with caregiving.<sup>9</sup>
- **Lost an estimated \$283,716 for men and \$324,044 for women** in income, Social Security benefits, and pensions.<sup>10</sup>



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- The Lifespan Respite Care Act of 2006 awards about \$2.5 million annually in grants to states to develop, operate, or supplement services that give respite to caregivers.
- Most state Medicaid home and community-based service (HCBS) programs cover some respite for caregivers.
- In 2012, about half of state Medicaid agencies were conducting assessments of caregiver needs as part of the care recipients' service plans.<sup>7</sup>

## TAX INCENTIVES AND PAY FOR CAREGIVERS

- U.S. tax policy allows deductions of up to \$3,000 on taxable income for some direct caregiving expenses, but a number of restrictions can make it difficult to qualify for these deductions.
- Bills have been introduced in Congress nearly every year since 2002 to provide Social Security earnings credits to caregivers who have to take time off work, but none of the bills have passed.
- Federal Medicaid policy was changed in 2005 to allow states to establish self-directed care programs that permit family members to be hired as paid caregivers. By 2012, all states offered at least one such option under their Medicaid HCBS programs. The U.S. Department of Veterans Affairs made this option available as well.

## FUTURE PROSPECTS

Two major forces may drive the development of a more comprehensive national policy to support family caregivers—evidence that such a policy would save the government money, and an increasing number of policymakers who experience caregiving firsthand. Rigorous evaluations of programs that support family caregivers could reveal that such programs reduce the use of other, more expensive services, and that they can significantly delay institutionalization for the recipients of care. This would strengthen the case for more public investment in caregiver supports and services. In addition, the aging of the "baby boom" generation and the increase in life expectancy mean that more policymakers and their constituents will be touched by the physical, emotional, and financial burdens of caring for a family member. As a result, policymakers will likely gain a greater realization of the type of financial and direct support caregivers need.

## ENDNOTES

- <sup>1</sup> Organization for Economic Cooperation and Development (OECD). *Help Wanted? Providing and Paying for Long-Term Care*. Paris, France: OECD, June 2011.
- <sup>2</sup> Yang, Y. T., and G. Gimm. "Caring for Elder Parents: A Comparative Evaluation of Family Leave Laws." *The Journal of Law, Medicine and Ethics*, vol. 41, no. 2, 2013, pp. 501–513.
- <sup>3</sup> Matos, K., and E. Galinsky. *2014 National Study of Employers*. New York, NY: Families and Work Institute and Society for Human Resource Management, 2014.
- <sup>4</sup> Ibid.
- <sup>5</sup> Van Giezen, R. W. "Paid Leave in Private Industry Over the Past 20 Years." *Beyond the Numbers: Pay and Benefits*, vol. 2, no. 18, Washington, DC: U.S. Bureau of Labor Statistics, August 2013.
- <sup>6</sup> WorldatWork. *Survey on Workplace Flexibility 2013*. Scottsdale, AZ: WorldatWork, October 2013.
- <sup>7</sup> Kelly, K., N. Wolfe, M.J. Gibson, and L. Feinberg. "Listening to Family Caregivers: The Need to Include Family Caregiver Assessment in Medicaid Home-And Community-Based Service Waiver Programs." Washington, DC: AARP Public Policy Institute, no. 2013-13, December 2013.
- <sup>8</sup> Gibson, M. J., and A. Houser. "Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving." Washington, DC: AARP Public Policy Institute, no. 82, June 2007.
- <sup>9</sup> Evercare and the National Alliance for Caregiving. "Family Caregivers—What They Spend, What They Sacrifice: The Personal Financial Toll of Caring for a Loved One." Minnetonka, MN/Bethesda, MD: Evercare and the National Alliance for Caregiving, 2007.
- <sup>10</sup> MetLife Mature Market Institute. "The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents." Westport, CT: MetLife Mature Market Institute, June 2011.

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