



Forum Session

Meeting Announcement

Friday, September 21, 2007
11:45am–12:15pm — Lunch
12:15–2:00pm — Session

Informal Care of the Frail Elderly: Policy and Practices to Support Family Caregivers

A Discussion Featuring:

Brenda C. Spillman, PhD
Senior Research Associate
Health Policy Center
The Urban Institute

Carol Levine
Director
Families and Health Care Project
United Hospital Fund

Donna Wagner, PhD
Director of Gerontology
Towson University

Laura Trejo
General Manager
City of Los Angeles Department of Aging

Location

**Reserve Officers Association
of the United States**
One Constitution Avenue, NE
Congressional Hall of Honor
Fifth Floor
*(Across from the Dirksen Senate
Office Building)*

Registration Required

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Informal Care of the Frail Elderly: Policy and Practices to Support Family Caregivers

OVERVIEW

The vast majority of the frail elderly, those who have long-term care needs because of physical, cognitive, or mental impairments, live at home, not in institutions. Family members and other informal unpaid caregivers—not formal paid providers—provide most of their care. This informal support may include help with activities of daily living, such as bathing, dressing, eating, and using the bathroom, as well as assistance with specialized medical equipment and medication management, and arranging and coordinating medical and health services. Congress has supported specific assistance to caregivers in several pieces of legislation, including the Older Americans Act (National Family Caregiver Program), the Lifespan Respite Act of 2006, and the Family and Medical Leave Act of 1993. While these programs offer needed assistance, the aging of the population will intensify demands on family caregivers and increase the number of families who will provide caregiving services. This Forum session will focus on trends in informal caregiving, including the increasing complexity of caregiving tasks families assume; the role of employer eldercare assistance programs; and, considering issues affecting people with Alzheimer’s disease in underserved ethnic communities as an example, policy issues relevant to providing services to caregivers.

SESSION

National surveys have documented the extent of informal, unpaid care provided to people with chronic illnesses or disabilities. About 3.8 million elderly people, or 15.9 percent of the total elderly population, receive assistance with activities of daily living (ADLs) or other activities necessary to live in the community.¹ Two-thirds of these elderly rely exclusively on assistance from informal caregivers—spouses, children, and others—to live in the community, and virtually all (91.4 percent) receive at least some assistance from these caregivers.

The aging of the population is expected to intensify demands on family caregivers. One study estimated that almost 60 percent of people who turned age 65 in 2005 will need informal care at home during their lifetimes; 13 percent will need such care for one to two years, and 23 percent will need such care two years or more.² The increasing longevity of older people living with chronic illnesses or disabilities may increase the extent and intensity of care needed from informal caregivers. Moreover, multiple demographic factors and changing family dynamics, such as lower fertility rates, smaller family size and increased divorce rates, may decrease

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the availability of informal caregivers in the future. Also, some informal caregivers live far away from impaired or ill family members, requiring often difficult and complicated long-distance caregiving.

Researchers have shown that the range and intensity of medical and health care services being provided by family caregivers is growing. Some caregivers provide services similar to those offered in nursing facilities and hospitals. They not only assist family members with ADLs, they may also provide assistance with pain management, supervision of medications and use of medical equipment, and skilled nursing care, as well as arrange medical and health care services and providers.³ Some observers have called for greater coordination between family caregivers and medical and health care professionals in order to ease the transition of patients from hospitals or skilled nursing facilities to home. This might include assessment of caregivers' abilities to perform caregiving tasks as well as tailored caregiver training.

Caregiving responsibilities often lead to physical and emotional stress, which can negatively affect the health of caregivers. Some research has concluded that efforts to reduce caregiver stress, such as making respite care more available, training caregivers, increasing access to assistive technology, and offering assistance with management of disruptive behavior, could help caregivers stay involved longer and avert costly nursing home placement.⁴ Caring for people with Alzheimer's disease poses special challenges for caregivers; the duration of the illness and intensity of the disability as it progresses can cause enormous strain. This may be especially salient in underserved minority and ethnic communities, where access to information and assistance may be limited due to cultural or language barriers.⁵

Most adult children balance their caregiving responsibilities with employment: a majority of caregiving adult children are employed full-time (53.1 percent) or part-time (about 10 percent).⁶ The need for workplace eldercare benefits and programs has become a legitimate workplace issue, and some employers have responded by making information and referral services available to assist employees. Although costly and not widely available, some employers are offering tailored assistance, such as services of geriatric care managers, to working family members. Although programs have increased in number, few workers overall have access to eldercare assistance through the workplace.⁷

A key issue for policymakers is to find ways to help families maintain informal caregiving efforts. National spending on long-term care services and supports to people of all ages is already significant—about 12.4 percent of all personal health care spending in the United States, or about \$206.6 billion in 2005—and does not include the value of informal care. As a way to demonstrate its economic value, various studies have estimated the imputed “cost” of informal care ranging from tens to hundreds of billions of dollars.⁸ Whatever the economic cost of caregiving, it is clear that these services cannot be replaced by public sources that already finance almost 72 percent of total U.S. long-term care spending. Moreover, the supply of

formal long-term care providers is often inadequate and will become even more strained as the baby boom population moves into old age.

SPEAKERS

Brenda C. Spillman, PhD, will present an overview of selected data on caregiver research findings from the National Long-Term Care Survey, a nationally representative survey of the Medicare elderly population, including characteristics of caregivers of the elderly, trends in use of formal versus informal care, and the disability levels of the elderly long-term care population who live in the community and the type of care they receive.

Dr. Spillman is a health economist specializing in research on disability and long-term care use and financing among the older population, including the role of informal care in the long-term care system. She has been with the Urban Institute's Health Policy Center since August 1998. Before that, she was a research fellow at the Agency for Healthcare Research and Quality (then the Agency for Health Care Policy and Research). Her recent work includes studies of trends in informal caregiving and the impact of caregiver stress on nursing home entry, as well as projects examining public and private long-term care financing, and projections of service use and cost for the Medicare elderly.

Carol Levine will discuss why caregiving is an important public policy issue, the increasing burdens faced by caregivers as complex medical and health care services are delivered the home, the emerging need for caregiver assessment and training, and the importance of involving family caregivers in transitions in care settings to prevent error and improve quality. She will also discuss work commissioned by the United Hospital Fund on the economic value of caregiving.

Ms. Levine joined the United Hospital Fund in New York City in October 1996, where she directs the Families and Health Care Project. This project focuses on developing partnerships between health care professionals and family caregivers. She was director of the Citizens Commission on AIDS in New York City from 1987 to 1991 and director of the Orphan Project from 1991 to 1996. Her work and reviews have been published in the *New England Journal of Medicine*, *Journal of the American Medical Association*, *Journal of the American Geriatric Society*, and *Health Affairs*, among others.

Donna Wagner, PhD, will discuss the effects of caregiving on employment, recent trends in workplace eldercare programs, and why eldercare programs are beneficial to both employees and employers. Dr. Wagner will also discuss various models of eldercare interventions as well as their successes and challenges and the effect that the Family Medical Leave Act (FMLA) has had on caregivers' ability to balance work and caregiving.

Dr. Wagner is the founding director of the Center for Productive Aging and the academic gerontology programs at Towson University. Prior to joining Towson, she was the vice president for research and development

at the National Council on the Aging (NCOA). Dr. Wagner's research has focused on the intersection of family and work, community elders, the aging work force and rural elders. Her research and publications in the area of family caregiving and employment began in the mid-1980s and include a history of workplace eldercare programs. Her current research includes an examination of the efficacy of workplace eldercare programs and an analysis of the outcomes associated with use of the National Family Caregivers Support Program.

Laura Trejo, general manager for the Los Angeles Department of Aging, will discuss the policy issues relevant to providing services to people with Alzheimer's disease and their caregivers in underserved ethnic communities and the challenges of conducting outreach to help these caregivers access diagnostic and support services for their family members. Ms. Trejo will discuss how the El Portal Dementia Care Network model, funded by the Public Health Service Act, provides support, education and respite services to caregivers in the Latino and other ethnically diverse communities in California.

Ms. Trejo is responsible for the overall administration of the Los Angeles Department of Aging; serves as technical and policy advisor to the Los Angeles mayor and a 15-member city council; and represents the City of Los Angeles before the public, community, and private groups on matters affecting senior citizen affairs. Ms. Trejo has consulted and trained extensively throughout the United States and has worked with individual countries and international organizations on the development of programs for the elderly with an emphasis on cultural competence, mental health, health, Alzheimer's disease and rehabilitation. She was the founding director of the El Portal: Latino Alzheimer's Project. During its most active phase, El Portal was the largest program serving Latino families coping with Alzheimer's disease.

KEY QUESTIONS

- What are the major trends in family caregiving, and how are they affected by the health and long-term care needs of older people? How have caregiving needs of older people changed over time? Are families increasingly relying on paid assistance to help them in caring for older family members?
- What factors affect continued care in the home, and what effect does highly stressed caregiving have on increasing the probability that care recipients will enter nursing homes?
- With complex medical treatment often provided in the home, how are families coping with the need to administer these treatments and what can be done to ease the transition from hospital to home for patients and their caregivers? What role should family caregiver assessment and training play in providing medical and long-term care services to the older population?

- How effective are current public and private sector policies and programs in meeting the needs of family caregivers? What role should the public and private sectors play in assisting current and future caregivers in their efforts to provide care to family members with long-term care needs?

ENDNOTES

1. William D. Spector *et al.*, *The Characteristics of Long-Term Care Users*, Agency for Healthcare Research and Quality, Research Report, Publication No. 00-0049, September 2000; available at www.ahrq.gov/RESEARCH/ltcusers/. Activities of daily living (ADLs) refer to eating, bathing, using the toilet, dressing, walking, and getting in or out of bed. Other activities necessary for community living, or instrumental activities of daily living (IADLs), include preparing meals, managing money, shopping, performing housework, and doing laundry. Estimates based on the 1999 National Long-Term Care Survey, a nationally representative survey of elderly Medicare beneficiaries conducted by the National Institute on Aging and Duke University.
2. Peter Kemper, Harriet L. Komisar, and Lisa Alecxih, "Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?" *Inquiry*, 42, no. 4 (Winter 2005–2006): pp. 335–350.
3. Carol Levine *et al.*, "Family Caregivers on the Job: Moving Beyond ADLs and IADLs," *Generations* (Winter 2003–2004).
4. Brenda C. Spillman and Sharon K. Long, "Does High Caregiver Stress Lead to Nursing Home Entry?" prepared for the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, January 26, 2007; available at <http://aspe.hhs.gov/daltcp/reports/2007/NHentry.pdf>.
5. Maria P. Aranda *et al.*, "El Portal Latino Alzheimer's Project: Model Program for Latino Caregivers of Alzheimer's Disease-Affected People," *Social Work*, 48, issue 2, April 2003.
6. Richard W. Johnson and Joshua M. Weiner, *A Profile of Frail Older Americans and their Caregivers*, The Urban Institute, The Retirement Project, Occasional Paper Number 8, February 2006; available at www.urban.org/publications/311284.html.
7. Donna Wagner, "The Development and Future of Workplace Eldercare," in *Dimensions of Family Caregiving: A Look into the Future*, monograph developed for September 12, 2000, conference sponsored by MetLife Mature Market Institute; and Donna L. Wagner, *Workplace Programs for Family Caregivers: Good Business and Good Practice*, Family Caregiver Alliance, August 2003, available at www.caregiver.org/caregiver/jsp/content/pdfs/op_2003_workplace_programs.pdf.
8. Estimates vary widely depending on the number of caregivers counted, the ages and characteristics of the population being cared for, and the differences in methods used to impute the hourly rates for care provided. One study estimated that the economic value of caregiving ranged from \$149 billion to \$483 billion (Peter S. Arno, "Economic Value of Informal Caregiving: 2004," presented at the Care Coordination and the Caregiver Forum, Department of Veterans Affairs, held at the National Institutes of Health, Bethesda, MD, January 25–27, 2006; available at www.va.gov/occ/Conferences/caregiverforum/Docs/Arno-Handout.pdf). The Congressional Budget Office (CBO) estimated that the value of informal care for the elderly in 2004 was about equal to both Medicare and Medicaid long-term care spending (CBO, *Financing Long-Term Care for the Elderly*, April 2004; available at www.cbo.gov/ftpdocs/54xx/doc5400/04-26-LongTermCare.pdf).



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