



Final Report and Recommendations
of the
Mini-Conference on the Future of Caregiving
held
June 15, 2005
The Washington Court Hotel
Washington, DC

Submitted to the 2005 White House Conference on Aging
Policy Committee

2005 WHITE HOUSE CONFERENCE ON AGING

Mini-Conference on the Future of Caregiving

Introduction

The White House Conference on Aging is convened every ten years to explore the issues affecting our nation that are related to the aging of our population. The 2005 White House Conference on Aging has defined its work as exploring a set of issues that are likely to influence the nation over the next 10 years, and to include, in all of its considerations, the Baby Boom generation in the dialogue. It can be argued that one of the most compelling issues facing the Baby Boom generation is the care of their aging parents and grandparents. Moreover, in the not-too-distant future, increasing numbers of Boomers may find themselves providing care for spouses and other family members. Family caregiving is therefore becoming a familiar activity for millions of American families with profound implications for all aspects of our family, civic, and work life.

In recognition of the above, a mini-conference on the “Future of Caregiving” was convened on June 15, 2005, to provide a forum in which these implications were discussed and a set of policy recommendations developed for presentation to the White House Conference on Aging Policy Committee. This report outlines the forum, issues discussed at the forum, and the recommendations developed by the participants.

The Process

Planning for the “Future of Caregiving” event began early in 2005 under the leadership of the representatives of the conference sponsors:

- The National Alliance for Caregiving
- The MetLife Mature Market Institute

The planning committee included the following individuals:

- Robert B. Blancato Matz, Blancato & Associates, Inc.
- Lynn Friss Feinberg Family Caregiver Alliance
- Gail Gibson Hunt National Alliance for Caregiving
- Laura Howard Matz, Blancato & Associates, Inc.
- Kathy O’Brien MetLife Mature Market Institute
- Les Plooster National Alliance for Caregiving
- Lisa Stand AARP
- Sandra Timmermann MetLife Mature Market Institute
- Donna Wagner Towson University

The planning committee developed the agenda, managed the logistics and developed the invitation list. Individuals who were invited to participate were selected to represent the following categories of expertise and advocacy: policy, practice, business, research, education, aging, population diversity, disability, technology, and philanthropy.

There were 129 participants at the event including individuals representing the general public who gained access to the event through the White House Conference on Aging website. In addition, members of the White House Conference on Aging Advisory Committee in attendance included Rudy Arredondo, Sonny Carlota, Peggye Dilworth-Anderson, Katherine Freund, Cynthia Hughes-Harris, Edward Martinez, Lawrence Polivka, and William Scanlon. Mel Woods of the White House Conference on Aging Policy Committee was in attendance, as was staff member Remy Aronoff.

The Agenda

Participants were welcomed by representatives of the sponsors of the event. Gail Gibson Hunt, President and CEO, National Alliance for Caregiving, provided an overview of family caregiver issues and the White House Conference on Aging. Expert presentations focused on the following topics:

- Emerging Issues in Family Caregiving – Lynn Friss Feinberg, MSW, National Center on Caregiving, Family Caregiver Alliance
- Employed Caregivers – Donna Wagner, Ph.D., Center for Productive Aging, Towson University
- Health of Caregivers – Richard Schulz, Ph.D., University Center for Social and Urban Research, University of Pittsburgh
- Diversity of Caregivers – Donna Benton, Ph.D., Los Angeles Caregiver Resource Center, University of Southern California.
- Legislation and Public Policy – Robyn Golden, LCSW, Rush University Medical Center and Robert Blancato, MPA, Matz, Blancato and Associates.

The Honorable Dorcas Hardy, Chair of the White House Conference on Aging Policy Committee, addressed the group about the White House Conference on Aging - to be held December 11-14 in Washington, DC - and the importance of family caregiving to the deliberations of the delegates.

A plenary session was convened to allow participants to make recommendations or raise issues that would complement those addressed in the morning session. The luncheon speaker was Senator Hillary Rodham Clinton, who highlighted the key role of family caregivers in bipartisan legislation titled the “Lifespan Respite Care Act”.

The afternoon was dedicated to small working groups to discuss the issues and develop a set of recommendations. The final plenary session, which followed these working groups’ discussion, was dedicated to reaching consensus on the four sets of recommendations emerging from the work groups.

Final recommendations/resolutions were accepted by Robert Blancato and Gail Gibson Hunt, members of the White House Conference on Aging Policy Committee.

The Recommendations

The four working groups identified several important issues central to the well-being of family caregivers and their need to play an active role in policy discussions during the next ten years. These issues included:

- the need for an expanded definition of family caregivers to incorporate the diverse caregiving situations and family configurations present in contemporary life. This includes diversity in terms of race, ethnicity, lifestyle, geography (urban/rural) and income levels as well as an expanded definition of “family” to include non-traditional families and non-kin informal caregivers.
- the need to strengthen existing government programs providing respite care and related supports, notably, the National Family Caregivers Support Program, expansion of support to caregivers of all ages with passage of the Lifespan Respite Care Act, and broadening of the Family and Medical Leave Act as well as enactment of caregiver tax credits for qualified employees and employers.
- the need for increased visibility and more research about the economic importance of family caregiving to the U.S. long-term care system, and, more broadly, caregivers’ contributions to society.
- the need for an instrument and program to assess informal and family caregivers that can accurately determine their needs for targeted services.
- the need for more flexible support for employed caregivers so that they can continue to be both family caregivers and productive members of the workforce.
- the need for caregiver experts and organizations to be closely involved in policy discussions about possible reforms of long term care programs and financing mechanisms for long-term care services to ensure that family caregivers and those for whom they care are properly supported.

The participants were passionate about all of these issues as well as others but, after discussion among the whole group, participants came up with the following three recommendations to send to the White House Conference on Aging Policy Committee.

Recommendation I

We recommend that government programs be expanded to better support the diverse population of caregivers including:

- increased funding for the National Family Caregiver Support Program through 2015 tied to an index reflecting cost of living increases and the increase in the number of caregivers
- enactment of the Lifespan Respite Care Act
- development of a national assessment program for all family and informal caregivers that can assess their need for support services and which can be integrated into the development of care plans
- enactment of tax credits for caregivers and paid family medical leave with employer tax incentives.

Recommendation II

We recommend that all employers, large and small, be encouraged to develop voluntary flexible workplace policies and programs that support employed caregivers. Government should work with employers to provide technical assistance and incentives such as tax advantages to develop and support a larger array of paid and unpaid leave options including: flex time, phased retirement and programs that are responsive to diverse caregiver populations.

Recommendation III

We recommend that a bipartisan commission on caregiving be established by the White House and Congress to bring visibility to the issues of caregiving and the importance of supporting caregivers for our families and our society. Furthermore, this commission should be charged with fostering research to improve assistance for employers and community organizations regarding outreach and support for caregivers.