Looking Into The Future of Family Caregiving in the U.S.

Proceedings From
A White House Conference on Aging Mini-Conference
Convened June 15, 2005

Sponsored by the
MetLife Mature Market Institute®
and
National Alliance for Caregiving
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I. Executive Summary

Since the 1995 White House Conference on Aging there has been increased attention directed at the very complex issues associated with family caregiving for an older adult. Family caregivers provide an estimated 80% of all of the long-term care services used by older Americans. Their unpaid work makes significant contributions to our nation's ability to support and sustain a growing population of very old Americans. A Mini-Conference on Family Caregiving was convened in June of 2005 in order to discuss family caregiving in the U.S. and to develop a set of recommendations to present to the Policy Committee of the 2005 White House Conference on Aging. The conference was sponsored by the MetLife Mature Market Institute and the National Alliance for Caregiving.

Participants of the conference included experts, advocates and professionals as well as members of the general public interested in the topic. A series of presentations by experts on key topics within the family caregiving arena including emerging issues and trends, employed family caregivers, health of caregivers, diversity among caregivers and legislative and public policy issues. Work groups identified key action items and recommendations. The final event of the one-day conference was a plenary session in which a consensus was reached about the three recommendations to send forward to the White House Conference on Aging Policy Committee.

The three policy recommendations are listed below. The full Proceedings document provides more detailed information about expert presentations, work group recommendations and testimony that was provided during the conference.

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.

II. Introduction & Overview

Since the 1995 White House Conference on Aging, the awareness of and involvement in family caregiving for older adults has increased dramatically. It is estimated that nearly one in every five households (17%) of all American households has some experience with providing assistance and support to an older person (NAC/AARP, 2004). In the past ten years, the US has experienced not only an increase in families with eldercare responsibilities, but in organizations and advocates working on behalf of family caregivers as well.

The June 15, 2005 Mini-Conference on Caregiving was the only Mini-Conference officially designated to address the issues and public policy implications of family caregivers. Sponsored by the MetLife Mature Market Institute® and the National Alliance for Caregiving, the event was designed to provide participants with a state-of-the art understanding of issues and public policy challenges associated with family caregiving in order to develop a set of recommendations for consideration by the White House Conference on Aging Policy Committee and Delegates. This document contains a detailed set of information about the expert presentations, the process and the discussion topics that emerged in the work groups during the Mini-Conference as well as the recommendations that were developed by the participants. We hope that the content of these proceedings will be useful to all of the stakeholders in the dialogue about family caregiving including advocates, service providers, policy makers, researchers, educators and students, employers and the many family caregivers who give their time and energy to support their loved ones and who make such an important contribution to our nation's long-term care system.
The White House Conference On Aging

Earlier Conferences
The White House Conferences on Aging have taken place approximately every ten years since 1961. These Conferences provide a forum for elders, policy makers and advocates to debate the issues of central importance to older Americans and to plan ahead for the aged of the future. In 1961, the White House Conference on Aging (WHCoA) resulted in the passage of the Older Americans Act, Medicare and Medicaid. In 1971, the Conference fostered the development of Supplemental Security Income (SSI) and the National Institute on Aging. In 1981, the Conference debated reforms in Social Security, expansion of home care benefits through Medicare and changes in the Older Americans Act.

Previous Conference
The 1995 White House Conference on Aging expanded the dialogue about aging to include a focus on the aging process, the connections between generations and affirmed the following guiding principles:

- Value independence
- Promote personal security
- Encourage personal responsibility
- Recognize interdependence
- Provide a “safety net” to support vulnerable populations
- Recognize and respond to America’s growing diversity
- Ensure the quality of life of all Americans as they age. (1995 WHCoA, p. 18).

Family caregiving, while not a central focus of the recommendations passed by the Delegates to the Conference, was a factor in the deliberations and resolutions that emerged from Conference-related events and discussions. As one of the “Challenges” identified in the planning for the Conference, family caregivers were recognized as the primary source of long-term caregiving for American elders. In the funding and implementation strategies outlined for recommendations, family caregivers were most prominently considered under the “Social Well-Being” recommendations that included specific resolutions adopted by the Delegates to: “Support Family Caregivers”. The Delegates adopted the following implementation strategies for this recommendation:

- Provide culturally sensitive educational material
- Better training for informal and formal caregivers
- Tax credits for caregivers
- Respite care services
- Expansion of the Family and Medical Leave to include family caregivers to elderly relatives and grandparents raising grandchildren. (WHCoA, 1995: 107)
Since the 1995 White House Conference on Aging, family caregiving has become a more visible public policy issue. In part this is due to policy innovations that occurred after the Conference including the passage of the National Family Caregivers Support Program (2000) and expansion of Family Medical Leave Act (FMLA) benefits as well as respite programs nationwide. Although some proposals have been put forth in Congress since the 1995 Conference in support of tax credits for family caregivers, no action has been taken on this item.

Call to Action for 2005 Conference
The Policy Committee of the 2005 White House Conference on Aging identified the Baby Boom generation as an important stakeholder in the White House Conference on Aging discussions and activities, establishing the following theme for the event: “The Booming Dynamics of Aging: From Awareness to Action” (WHCoA, 2005). The agenda for the event includes the following items:

- Planning along the Lifespan
- The Workplace of the Future
- Our Community
- Health and Long Term Living
- Social Engagement
- The Marketplace.

Family caregiving is a cross-cutting element in all of these agenda items. The Baby Boom generation is the generation most likely to be involved in family caregiving today and their involvement in helping an elder, for many, intersects with the workplace, the community, the health and long-term care system and the marketplace. Finally, some family caregivers tell us that their caregiving experience is influencing their own perspective on personal planning and long-term care needs.

The Planning Process for the Mini-Conference
Planning for the White House Mini-Conference on Caregiving began in late 2004 under the leadership of a planning committee. The two organizational sponsors, the MetLife Mature Market Institute and the National Alliance for Caregiving convened the planning committee and provided staff support during the planning process. Planning Committee members are listed in the appendix to this document.

The purpose of the Mini-Conference was to provide a forum in which advocates, experts and other stakeholders could come together to examine the role and status of family caregivers in the U.S. today and to reach a consensus on recommendations to put forth to the Policy Committee of the White House Conference on Aging. Recommendations to the Policy Committee will be prioritized and presented to the delegates at the White House Conference on Aging event in December,
2005. Because the conference will address a broad range of topics and issues, the planning committee members for the Mini-Conference on Caregiving, in addition to submitting its top three recommendations, agreed to authorize a proceedings document in order to reach a broader audience and provide specifics on issues raised during the conference.

The Planning Committee identified key stakeholder groups from which representatives were to be invited to participate in the Mini-Conference. These groups included the following:

- Policy
- Advocacy
- Practice
- Business
- Research and Education
- Aging
- Diversity
- Disability
- Technology
- Philanthropy

All of these stakeholder categories were represented at the event. In addition, the general public was invited to register through the WHCoA website established for that purpose. There were a total of 129 participants who took part in the one-day conference.

The agenda for the event included presentations from experts on the following topics considered to be of key importance to the development of recommendations. The topics identified by the planning committee included:

1. Emerging Issues in Family Caregiving
2. Employed Caregivers
3. Health of Family Caregivers
4. Diversity Among Caregivers
5. Legislation and Public Policy

Each presenter was asked to identify 3 to 4 recommendations for consideration by the participants. After presentations were complete, the participants had a chance to suggest additional recommendations from the floor prior to breaking into small work groups for the purpose of recommendation development. The final event of the day was a plenary session devoted to reaching consensus on three recommendations to put forth to the WHCoA Policy Committee.
Each of the four work groups was supported by a facilitator and a recorder who are listed in the appendix.

Facilitators for the final plenary session that was convened to develop the final recommendations to go forth to the Policy Committee of the White House Conference on Aging were Wendy Fox-Grage and Enid Kassner of AARP.

In addition to the agenda described above, the event featured a welcome by the Honorable Dorcas Hardy, Chair of the White House Conference on Aging Policy Committee. Senator Hillary Rodham Clinton spoke at the luncheon. Both Chair Hardy and Senator Clinton reminded the participants of the importance of their work and the issue of family caregiving to elders today and in the future.

A report to the WHCoA Policy Committee summarizing the agenda and recommendations was submitted after the event and is included in an appendix to this document.

**Family Caregiving in the U.S.**

Informal caregiving, the services and support that are provided by a family member or friend, is the backbone of the nation’s long-term care system. In 1987, it was estimated that 80% of all of the long term care services used by older adults were being provided by family and friends (Select Committee on Aging, 1987). Nearly twenty years later, family and friends continue to provide the majority of services for elders. Arno (2002) estimates that the value of the contribution to the nation’s long term care system is $257 billion per year. Today, however, social and demographic changes challenge many families’ ability to provide the support needed by their loved one.

- The nation is aging.
- More women are entering and remaining in the workforce.
- The workforce is aging.
- Health care has become even more “informalized” than ever before as a cost-saving mechanism.
- Families are smaller in size, a trend that is likely to dramatically affect the availability of informal caregivers in the future.

Only about 15% of the informal care received by older adults is provided by friends and neighbors (Barker, 2002), with family members providing the majority of care.
Although the services provided by family and friends are often seen as “free” services, this important contribution to our nation’s long-term care system has costs associated with it that are born by families, employers and communities (Wagner, 2004). Families involved in care absorb costs related to lost wages and out of pocket costs. The employers of family caregivers subsidize their efforts through reduced productivity, turn-over and missed time from work. One estimate of the cost of caregiving employees to employers suggests that costs may range from $11.4 billion per year to $29 billion per year nationally (MetLife, 1997).

Employed caregivers make sacrifices that affect their personal lives, careers, and health. Familial responsibility norms persist regardless of the cost associated with them. One study estimated that lost work hours due to caregiving results in a lifetime decrease of wealth for women of $659,139 (National Alliance for Caregiving and National Center for Women and Aging at Brandeis Univ., 1999).

Today in America, millions of families are managing the care decisions for their older loved ones, providing assistance when needed and helping pay for medical supplies or services. To date the support available to family caregivers has been limited to education and information about available community services provided through the area agency on aging network and, in part, funded by the National Family Caregivers Support Program and respite services provided in some states. The Family and Medical Leave Act (FMLA) provides unpaid leave for family caregiving that protects a caregiver’s job while they are providing care. In California, paid leave for family caregiving has been in place since July 1, 2005 and the state sponsors a network of caregiver support resource centers.

The White House Conference on Aging, which meets every 10 years, provides an opportunity for elders and their advocates to discuss and plan for the future. The 2005 Conference, with its goal of planning for the future and including in this planning process a focus on Baby Boomers, is a chance for advocates and policy makers to review the needs of family caregivers and address these needs in an effort to strengthen their important contributions.

In 2003, the Family Caregiving and Public Policy: Principles for Change was developed by a collaborative group of family caregiver advocates to provide a blueprint for public policy change. These principles were included in the participant packet of the White House Conference on Aging Mini-Conference on Caregiving and guided the discussion during the day. They can be found in the appendix of this document.
III. Proceedings

Plenary Presentations

Opening Remarks
The participants were welcomed to the event by conference sponsor representatives Sandra Timmermann, Director of MetLife's Mature Market Institute and Moderator for the Mini-Conference and Joyce Ruddock, Vice President, MetLife. Gail Hunt, Executive Director of the National Alliance for Caregiving (NAC), and member of the WHCoA Policy Committee, provided an overview of the White House Conference on Aging process and reviewed recent social changes and trends that have elevated the importance of family caregiving.

Presentation 1: Emerging Issues Influencing Family Caregiving
Lynn F. Feinberg, MSW,
National Center on Caregiving, Family Caregiver Alliance, San Francisco, CA.

Ms. Feinberg reminded the participants that a number of emerging issues were influencing family caregiving today and likely to be important trends in the next ten years. Family caregiving is at the core of what sustains frail elders and adults with disabilities. Today, and for the next decade, the need to strengthen family and informal caregivers, and to recognize their rights to their own support services is a central and growing issue in our aging society.

Caregiving is becoming not only more widespread but more complex for family caregivers due to health system trends and social changes. Patients of the health care system are being sent home “quicker and sicker” from hospital stays and more procedures are now being performed on an out-patient basis. Scheduling of health care appointments is based upon the needs of the health care professional and not the patient or their family members and often there is little coordination between providers requiring the patient and caregiver to coordinate needed services. The service and health systems available are increasingly fragmented and confusing to the average caregiver who also is frequently juggling the demands of employment in addition to providing care. In this presentation of emerging issues, key issues identified and discussed included changing demographics and social trends affecting the family, technology, consumer direction and caregiver assessment issues.
Population aging and family changes.
Population aging is affecting all aspects of contemporary life and will continue to do so until well into the middle of this century. Population aging occurs when there is a drop in the birth rates and death rates. Fewer births and increased longevity are trends with profound implications for the family structure. When we think of adult children as caregivers, we typically think of a woman in her mid-40’s. However, with the increasing longevity of the older population, it is becoming much more commonplace for a woman to be in her 60’s or 70’s and having care responsibilities for an aging parent. Chart I. below illustrates key structural changes in contemporary families.

Chart I.

<table>
<thead>
<tr>
<th>Family Structure Has Changed</th>
<th>Circa 1960</th>
<th>Circa 2000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Age of Marriage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>22.80</td>
<td>26.90</td>
</tr>
<tr>
<td>Women</td>
<td>20.30</td>
<td>25.30</td>
</tr>
<tr>
<td>Divorce Rate (per 1,000)</td>
<td>2.20</td>
<td>4.00</td>
</tr>
<tr>
<td>Divorced Women Age 65 and Older (%)</td>
<td>2.50</td>
<td>8.00</td>
</tr>
<tr>
<td>Unmarried Household of the Opposite Sex (millions)</td>
<td>0.40</td>
<td>4.90</td>
</tr>
<tr>
<td>Unmarried Household of the Same Sex (millions)</td>
<td>NA</td>
<td>0.60</td>
</tr>
<tr>
<td>Births to Unmarried Mothers (%)</td>
<td>21.60</td>
<td>33.50</td>
</tr>
<tr>
<td>Household Size</td>
<td>3.33</td>
<td>2.58</td>
</tr>
</tbody>
</table>


Population aging changes illustrated include smaller family size and later age for marriage of both men and women. Social changes include an increasing divorce rate, increasing number of births to unwed mothers, and increasing numbers of households headed by unwed couples. Implications for family caregiving include a reduced number of potential family caregivers, increasing age of spousal caregivers, more elders living alone as a result of divorce, and an increase in “non-traditional” family caregivers. Family definitions are moving beyond “blood” kin and inclusive of friends, neighbors and other types of relationships.

We need to expand the FMLA to cover different types of relationships including GLBT.
Ingrid Jacobson
Frederick County. Dept. of Social Services
Technological Changes

Technology has changed how we live, do business and practice health care. It is likely that rapid changes in technology will continue into the future in the area of health, business and individual lifestyles. Telemedicine and telehealth, as well as assistive technology, improves access to health care services. Information technology improves access to information about health and services as well. However, there is a policy lag between what technology can do and how we regulate technology, ensure that privacy and patient safety is protected and that the negative effects of the “digital divide” are mitigated. Technology is also focused on formal systems and not consistent with family approaches to service delivery. More “family-oriented” technology is needed in order to appropriately support family caregivers. And, finally, the “paradox of choice” has many implications for family caregivers as they face overload of information and difficulties determining the quality of information available.

Consumer Direction

Consumer direction is a philosophical approach to service payment that shifts the locus of decision-making to individual consumers and their families. Consumer direction in general includes a variety of models and offers a range of options for family caregivers. In some instances the “consumer” is not the individual, but is the dyad or family involved in the care. Currently, the national Cash and Counseling demonstration programs include family caregivers as do some of the services available through the National Family Caregiver Support Program. All but six states (Arkansas, Delaware, Mississippi, Nevada, Pennsylvania and Tennessee), allow payment to families to provide care in at least one of their state-administered programs. While this has been controversial in the past, research has demonstrated that for many families paying a family member to provide care does not lead to fraud and abuse but to better care. Research has also shown that the effects on family caregivers of consumer directed systems have been quite positive.

Caregiver Assessment

Although researchers have examined family caregiving for decades, the idea that the family caregivers are “clients” is a paradigm shift in the service system. Within the home and community based care systems serving older adults, the idea that caregivers might need assessment to determine their own needs is just beginning to be included in policy and practice circles. When, as one person stated “Families are now being asked to do tasks that would make nursing students tremble”, assessment can result in critical support and educational services that not only support the family caregiver but the patient as well. Caregiver assessment can:

- Determine eligibility for caregiver support services
- Increase understanding of the caregiver’s everyday experience
- Help families with decision-making
- Recognize and validate the work that caregivers do
- Legitimize the needs of family caregivers themselves as distinct from, but related to, the care recipient
- Serve as a basis for measuring outcomes and quality.
Action Items

- Strengthen existing federal laws and problems to explicitly recognize family caregivers as an integral part of health and long-term care system as individuals with rights to their own support and assessment of their own needs.

- Commission an Institute of Medicine study and policy blueprint on family caregiving in America.

We must begin to think of the relationship between paid caregivers and family caregivers. How can we support the interconnectedness between the two?

Deb Lipson
Institute for the Future of Aging Services, AAHSA

Presentation 2: Employed Caregivers
Donna L. Wagner, Ph.D., Director of Gerontology
Towson University, Towson, MD

For an increasing number of American families, care work for an older family member is part of a normal work schedule. Men and women are scheduling their time to care around their work responsibilities, occasionally making accommodations both in order to manage a problem at work or a problem with care. In 1987, an AARP survey of Americans about family caregiving found that 40% of those helping an older person were employed. By 2004, this number had increased to nearly 60%. It is estimated that 15% of the workforce is providing care to an older person today.

The trends that have led to this increase are based on economics, demographics and lifestyle choices that American families are making in this post-industrial age. The key trends affecting the work-family interface issues for American families include:

- Increasing involvement of women in the workforce (80% of women ages 25-54 years by 2010)
- Gains in life expectancy and increasing number and proportion of elders
- Decreasing reliance upon institutional options for eldercare
- Smaller families reducing kin availability.
Our family obligation and norms that support familial care persist despite competing responsibilities and fewer family members available and able to help with care. Family caregiving supports important values of independence and autonomy in a way that is not possible in institutional settings. These family obligations are not without cost, however. While the healthy care system may be benefiting from “free” care provided by family members, the cost to families and their employers is increasing.

Effects of Caregiving on the Employed Caregiver
For the employed family caregiver, the cost of providing eldercare to an older relative includes effects on their career and worklife as well as their personal life and include:

- Distractions at work that reduce their presenteeism and satisfaction with work products
- Unplanned absences from work
- Increasing dependence on co-workers to help with unfinished projects and absences
- Lack of personal time outside of work
- Health effects

Employed caregivers report that there is often friction at work due to unplanned absences and, as a result satisfaction with work and the workplace is reduced.

Costs to Employers
Costs to employers of employee caregivers can also be significant. The 2004 National Alliance for Caregiving/AARP survey of caregivers found that 10% of the working caregivers moved from full-time work to part-time work; 17% took leaves of absences and nearly 10% retired or quit work altogether as a result of caregiving. More than half of the employed caregivers report that they were required to modify their work schedules. One estimate of the overall cost to employers of employee caregiving is between $11.4 billion and $29 billion per year (MetLife, 1997). These costs reflect estimated effects of reduced productivity, lost time and replacement costs for employees who have left the workplace.

How can we address the problems associated with lifetime earnings of caregivers?
Celia Hayhoe
Virginia Cooperative Extension, Virginia Tech
Needs of Employed Caregivers

Employed caregivers report that they need flexibility and support at work. In some cases, family caregivers report that they are looking for a more “family friendly” workplace because of a lack of flexibility in their current work situation. Other needs reported by these caregivers include:

- Information about health conditions and care options
- Assistance in managing care situations
- Information about community support services
- A supportive work environment

Those employed caregivers most likely to have difficulty at work are those who are co-resident with the elder they are helping, those who did not anticipate having to provide help to an elder and those with complicated and difficult care situations.

Large employers have responded to employee needs by developing workplace eldercare programs. It is estimated that 25% of large employers have some program to support employees with care responsibilities. Few small employers have programs or formal policies in place and most programs rely on the community-based aging network of services. The models of workplace eldercare include:

- Resource and referral model (first offered in 1988)
- Education Model including lunch and after work educational sessions, on-site libraries, web-based material
- Decision support model (first offered in 1999) included geriatric care management services, elder law and assistance with benefits such as insurance.

Emerging issues in work and care include an increase in male caregiving, increasing numbers of employed caregivers reporting that they are not only providing hands-on care, but are also helping financially and changing expectations of workers regarding the role of the employer in providing support services. Today’s younger workers are more likely than the mid-life and older worker to have an expectation that they can have some flexibility at work and support for work-family issues. This expectation is likely to increase the demand for programs at work in the future.

Action Items

- Paid Family/Medical Leave Options for all Americans.
- Develop a national program for area agencies on aging to serve working caregivers including a template for programming, a focus on serving small and mid-sized employers, that includes an ongoing technical assistance office for support of area agency on aging personnel.
Presentation 3: Health Effects of Caregiving
Richard Schulz, Ph.D. University of Pittsburgh, PA

The health effects of caregiving are well-documented and researched. There is a relationship between the health of the caregiver, the health of the care recipient and the trajectory of care. Key benchmarks of this trajectory include:

- The initiation of instrumental activities of daily living (IADLs) such as cooking, cleaning and shopping, by the caregiver
- The expansion of care activities to include activities of daily living (ADLs) including bathing, dressing, eating
- The decision to place the care recipient in a supportive living environment
- And, finally, the death of the care recipient.

Health effects of becoming a caregiver can begin when the caregiver moves into the caregiver role and begins to provide IADL services to his or her loved one. The effects can become more noticeable and acute as the caregiver becomes a “strained” caregiver and begins to have difficulty with their care responsibilities. “…Few studies have examined the health and mental health effects resulting from transition into caregiving and the effect of multiple years in a caregiving role.” (Burton, et al, 2003: 230). The health and mental health effects of caregiving can be most problematic when the caregiver is an older person, a growing group of the caregiving population.

Research conducted by the presenter and his colleagues, on caregiving spouses, examined the nature of the transition experienced by caregivers as they moved into the caregiver role and the changes that occurred in mental health and health status by the degree of intensity of the care. For the purposes of this study, moderate levels of care were operationalized as the provision of at least one “Instrumental Activity of Daily Living” (IADL) including transportation, shopping, managing money and the like, but no help with any of the “Activities of Daily Living” (ADL) including toileting, feeding, bathing, transferring and grooming. A “heavy” caregiver was someone who provided help with at least one ADL. They found that, even among spousal caregivers who were providing “moderate levels of care”, symptoms of depression as reported by the caregivers increased after making the transition to caregiver. Those who were involved in “heavy” caregiving roles had much higher levels of depression than those who transitioned into lower levels of caregiving. Similarly, health risk behaviors such as not having time to exercise, not getting enough sleep, neglecting their own medication regimes, not enough time to see their own physician or missing appointments with their physician, increased after making the transition to caregiving for both those providing “moderate” levels of care and those providing “heavy” care services. Charts II and III on the following pages show comparisons of both caregiving levels pre- and post-transition and levels of depression and health risk behaviors.
Repeated measures ANCOVA statistics. Main test for transition group, $F=4.06$, $P<.05$. Main effects test for time, $F=4.66$, $P<.05$. Interaction of transition category and time not significant. Control variables: age, education, gender, self-reported health, race and income.

Possible range of depressive symptoms 0-30. Higher scores indicate more symptoms of depression.

When looking at the caregiver groups we also note that the “heavy” caregiver has a different pattern of disease than the non-caregiver or the “moderate” caregiver. Heavy caregivers have more disease over time than do either of the other two groups.

The shortage of allied health professionals and the difficulty recruiting people into the health professions is a cross-cutting issue.

Maureen Peterson
American Occupational Therapy Association
**Health Effects of Caregiver Exit Transitions**

For caregivers, the exit from caregiving is generally due to the death of the care recipient or the placement of the care recipient in a care facility. Among those caregivers who exit the caregiver role because of death, the effects on caregivers vary by level of care being provided. Those who were providing the heaviest levels of care actually have some relief from depressive symptoms. Those who are providing moderate levels of care have an increase in depressive symptoms after the death of their loved one. Although there is a “spike” in depressive symptoms at death, over time there is a gradual decrease (see Chart IV) among previously strained caregivers.

When spousal caregivers exit the caregiving role as a result of institutional placement, the decrease over time in depression or anxiety does not occur. This suggests that, for the caregiver, institutional placement has little benefit. Although they are no longer entirely responsible for the care of their spouse, the depression and anxiety they were experiencing during caregiving is not affected by making the transition from caregiver to “visitor” of their spouse. Chart V. summarizes the chronic stress trajectory and outcomes for late life spousal caregivers.
Summary
Providing heavy levels of care is associated with increased depression, poorer health, reduced self-care, weight loss and increased chronic illness. Over time, heavy caregivers decline more rapidly in health and mental health functioning than non-caregivers. And, finally, caregiving strain increases mortality for older caregivers.

Action Items
- Support the development and implementation of new care models that protect the health of family caregivers.
- Commission an Institute on Medicine (IOM) study and policy blueprint on family caregiving in America.
Today the U.S. is no longer a melting pot of diverse people and cultures; it is more like a salad that is made up of a variety of ingredients. When designing policies and programs for caregivers that address the diverse group of caregivers it is important that decisions not only address the needs of caregivers in general, but the needs of the diverse groups (the ingredients) in the caregiving population as well (the salad). Diversity is also more than ethnicity and culture. For the purposes of planning for caregivers’ needs, diversity must be viewed as including the following:

- Age
- Ethnicity
- Income
- Language
- Gender
- Sexual Orientation
- Economic Status
- Geography.

The profile of caregivers differs significantly according to race, age and gender.

*We need to assure the quality of the paid caregiver workforce. We also need to address the needs of older parents caring for adult children with developmental disabilities.*

Alan Factor
University of Illinois at Chicago
RRTC on Aging with Developmental Disabilities
Chart VI below provides examples of these differences. While fewer than a quarter of the white population between the ages of 18 and 34 were caregivers, more than a third of Blacks and Asians in that age group were caring and a third of Hispanics between 18 and 34 years of age were caregivers. Similarly, among Asian caregivers, more than half were men. Among Blacks, Whites and Hispanics, fewer men are providing care.

Chart VI.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Total</th>
<th>White</th>
<th>Black</th>
<th>Hispanic</th>
<th>Asian</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>39%</td>
<td>38%</td>
<td>33%</td>
<td>41%</td>
<td>54%</td>
</tr>
<tr>
<td>Female</td>
<td>61</td>
<td>62</td>
<td>67</td>
<td>59</td>
<td>46</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age of caregiver</th>
<th>Total</th>
<th>White</th>
<th>Black</th>
<th>Hispanic</th>
<th>Asian</th>
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</thead>
<tbody>
<tr>
<td>18-34</td>
<td>26%</td>
<td>22%</td>
<td>35%</td>
<td>33%</td>
<td>38%</td>
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<td>35-49</td>
<td>32</td>
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<td>36</td>
<td>33</td>
<td>27</td>
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<td>31</td>
<td>24</td>
<td>24</td>
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<tr>
<td>65 or older</td>
<td>13</td>
<td>15</td>
<td>5</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Mean (years)</td>
<td>46 yrs</td>
<td>48 yrs</td>
<td>41 yrs</td>
<td>43 yrs</td>
<td>42 yrs</td>
</tr>
</tbody>
</table>

CAREGIVING IN THE U.S report by National Alliance for Caregiving and AARP April 2004
Funded by MetLife Foundation
Minority Caregivers

A range of different issues confront minority caregivers and create different needs and challenges when compared to white caregivers. For many, language is a barrier. For example, Asian Pacific Islanders and Hispanic elders are more likely to be born outside the U.S. and, therefore, to have English as a second or even third language. For Asian Pacific Islanders, the eldest son is the responsible individual for aging parents. In this culture there is also a level of dependency that is unrelated to frailty.

Hispanic caregivers are more likely than other groups of caregivers to manage the care entirely in the family without the benefit of formal services. Black caregivers are likely to be adult children or non-relatives and the black church is an important source of support for caregivers and the care recipients. Black female caregivers are more likely to be single than other groups of female caregivers.

There is also a wide range of definitions of “burden” within minority groups. The extent to which dependency is viewed as normal or as a burden varies between different ethnic groups. And, there is wide variation within minority groups as a function of family norms, values and individual characteristics.

Gay, Lesbian, Bi-sexual, Transgender (GLBT) caregivers must be included in the diversity categories for important reasons that transcend ethnicity and race. For example, LGBT partner caregivers are less likely to have support from their family of origin than others. These caregivers are also likely to experience discrimination in housing, homecare and medical care and, as a result of social stigmatization may choose to remain “safe” and isolated. Many partnered LGBT caregivers also have few legal rights or protections. And, finally, we anticipate that in the future we will see an increase in LGBT who are willing to define themselves as LGBT and who will need and demand services in parity with others.

Caregiving needs in the next ten years must address the needs of caregivers in general as well as the diverse populations that make up the caregiving population. Programs to address caregivers must meet the diversity standard of being:

- Appropriate
- Accessible
- Acceptable
- Adaptable
**Action Items**

- Develop funding to support research on the development of culturally appropriate caregiver interventions in terms of culture, language, sexual orientation.
- Develop a National Technical Assistance Center on Diversity and Caregivers to assist caregiver programs.

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*Caregiving is a rural issue; 62% of rural people doing some type of family caregiving.*

Mary Harper  
J&J/RCD Family Caregiving

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**Presentation 5: Legislation and Public Policy**

Robyn Golden, LCSW, Rush University Medical Center  
and  
Robert B. Blancato, President, Matz, Blancato, & Associates, Inc.

Ms. Golden provided the assembled with the policy trends of importance to long-term care and family caregiving. These included:

- Maximizing choice for consumers and caregivers: Consumer Directed Options
- Increasing respite care options as a result of federal and state funding
- Expansion of Family and Medical Leave coverage
- Recognition of the workforce shortage crisis in the nation
- An improvement of tax treatments of caregiver expenses
- Using state revenues for family caregiver support

Ms. Golden added that the principles for change provide a useful policy tool when assessing proposed policies or examining policy gaps for caregivers. Both the principles and the collaborative groups that developed them are in the appendix.
While there is much to do, there has been some progress in policy development for long term care and caregiving. Some of the highlights include a second round of funding for the “Cash and Counseling Demonstration” which provides consumer-directed options to families in long term care. In addition, changes have occurred to the FMLA that provides some expansion of the benefits and coverage and caregiver education and support has expanded under Medicare and the Geriatric Care Act. The Lifespan Respite Care Act was passed by the Senate in 2003 and is now in the House Energy and Commerce Committee. This Act would direct the HHS Secretary to award grants or cooperative agreements to develop statewide lifespan respite care programs. Caregivers who are experiencing health or mental health effects as a result of caregiving would benefit from this Act through expanded availability of respite care services. And finally, the Ronald Reagan Alzheimer’s Breakthrough Act would double funding for NIH-funded Alzheimer’s Research, require a national summit to set an agenda on Alzheimer’s Disease, implement a national public awareness campaign, increase services to caregivers including a tax credit. This Act was passed in 2005 but has not been funded.

Bob Blancato, a member of the Policy Committee of the White House Conference on Aging and Director of the 1995 White House Conference on Aging reminded the group of Yogi Bera’s statement: “If the world was perfect; how would you know anyway?” He cautioned the participants that there were political environmental realities today that would likely influence caregiver legislation. These included:

- It is a difficult legislative environment due to a record deficit and limited number of active legislative vehicles.
- Policy process is gradual and is based upon building a strong, bi-partisan base.

Blancato suggests that an effective strategy would be to pursue individual bills, build support and look for a vehicle to attach the bills to.

The National Family Caregivers Support Program (NFCSP), in its fifth year of funding, is the primary support vehicle for family caregivers. The funding for FY 2005 is $155,744,000 and the President has requested the same funding level for FY 2006. In reality, a doubling of the funding is necessary in order to achieve policy goals of the Program. The Older Americans Act is set to be reauthorized in 2005. This reauthorization may be delayed until after the WHCoA is convened at the end of the year. Nonetheless there are a number of questions that remain about the reauthorization including the level of support for the OAA and whether we can expect to see the OAA expanded. The NFCSP is part of the OAA and the cornerstone caregiving initiative. The 1995
WHCoA was a pro-caregiver conference and 2005 could be a short-term advocacy opportunity for caregiver legislation. Caregiver delegates should be identified and coalitions built around the Caregiving Principles described earlier. It is possible that the ten year mandate of the final WHCoA could include a commitment to adopt these principles.

**Action Items**

- Ensure appropriate caregiver provisions are included in all long-term care legislative proposals.

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**IV. Work Groups Summary**

Attendees were assigned to groups, each of which had a designated facilitator and recorder. Groups were asked to consider the issues, identify gaps, review provided action items, and add new actions if appropriate. Working groups were charged with developing two resolutions which were to be brief, realistic, concrete, and clear. Additionally, implementation strategies were recommended as a component of any submitted resolutions. During the group discussions, participants addressed cross-cutting issues including the definition of caregiver and family, the relationship between family caregivers and the long term care system, geographic location of families and ethnic and racial issues as well as the diversity in family types including grandparents raising grandchildren and aging parents caring for adult children with long term care needs.

**Group 1**
Facilitator: Brian M. Duke, WHYY Caring Community
Recorder: Anne Montgomery, Alliance for Health Reform

**Group 1 Working Recommendations**

- A broad public relations campaign should accompany the selection of recommendations to support caregivers. A public engagement campaign is needed to make caregivers more prominent and more recognized in the community, in business and elsewhere.

- The government should be asked to generate a report similar to a Surgeon General's report on caregiving.

*Japan began a Long Term Care insurance program in 2000. We need a comprehensive long term care insurance program.*

Dan Kuhn
Mather Lifeways
- The financing of community-based care through bereavement support or counseling for caregivers should be reviewed.

- The recommendations from the Panel given to today’s participants included a bullet on creating a National Technical Assistance Center on Diversity and Caregivers to assist caregiver programs. Technical Assistance should be expanded to include other issues and topics related to caregiver support.

- Flex leave and flex careers should be available to caregivers who are working or need to leave careers to care for a family member. This would include a review of the Federal Medical Leave Act and its enhancement to be more supportive of caregivers.

- Provide funds to create educational programs for caregivers.

- Support the establishment of training programs for volunteers to support caregivers.

- Enhance funding and support of respite and in-home care.

- Develop and implement a national caregiver navigator program that offers intensive case management for health, housing, financial, legal and advocacy services.

- Create an accessible resource to educate caregivers including self-assessment tools and self-education tools.

**Priority Recommendations:**

1) Call for the formation of a Bi-partisan Commission on Caregiving appointed by the President and Congress. The call to the Commission would be based upon the *Family Caregiving and Public Policy Principles for Change*.

2) Provide funds and benefits for services in various programs to support caregivers in the workplace.

3) Develop, fund and implement a nationwide program that assesses family and other informal caregivers for their needs and offers intensive case coordination encompassing health, housing, financial, legal and advocacy services.

**Group 2**

Facilitator: Cindy Hounsell, WISER  
Recorder: Rick Greene, U.S. Administration on Aging

**Working Recommendations and Issues:**

- There isn’t a dichotomy between paid providers and unpaid caregivers. Both are providing care. Trained allied care professionals are very important in the family caregiving process. Efforts should be made to get more people into these professions.
• Respite is a critical aspect of caregiver support and should be reflected as such in public policy.
• Existing public programs for caregivers should have a stronger emphasis on personal, one-on-one counseling and education.
• The importance of explicitly addressing diversity issues associated with gay, lesbian, bisexual and transgendered caregivers who face discrimination, in the WHCoA recommendations.

**Priority Recommendations:**

1) Fully fund the expansion of caregiver services through 2015 that would include increases in support for: paid family and medical leave, NFCSP, respite care and other paid caregiver services, in order to allow caregivers to be employed and continue normal lives.

2) Strengthen existing and future federal and state laws and programs to explicitly recognize family caregivers in all their diversity as an integral part of the health and long-term care system.

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**Group 3**

Facilitator: Margaret B. Neal, Institute on Aging, Portland State University
Recorder: Donna Phillips, National Council on the Aging

**Working Recommendations and Issues:**

• The need for a focus on rural family caregiving—62% of rural population are women and half of those are family caregivers—1/3 of those live in poverty.
• Caregiving should be considered as a part of long-term care—reconceptualize definition of LTC and family caregiving—including mental health as well as physical health issues.
• Develop a caregiving program to increase awareness of options and availability of existing caregiving resources including respite.
• Recommend passage of Lifespan Respite Care Act.
• National Family Caregiver Support Program needs to support aging parents who are caring for children with disabilities.
• Revise current language of the NFCSP to include the following,
  – strike phrase 50+
  – increase funding to accommodate the expansion of program and with some sort of indexing based on need
  – grandparents of any age or other relatives who are older than 50
  – change the term “child” to mean not more than 18 years of age or a child with a disability.

• Advocate for working caregivers—create outreach programs/increase awareness of services and respite-support working caregivers (tax breaks/outreach programs/education for small and midsize employer and working caregivers/catch-up retirement benefit program).

• Amend the nurse practice act to include a mandate to train health professionals in family caregiving.

• Create a national office on caregiving that coordinates public awareness/education/research/service—
  – office of caregiving within HHS coordinate caregiving related services and research which then brings in NIA and AOA.
  – increase value and needs of caregivers
  – Coordinate research and services aimed at caregiver
  – Increase public education around caregiving issues
  – Increase recognition of the emotional needs and biopsychosocial needs of caregivers.

• Support working caregivers through
  – Expand family medical leave to paid leave
  – Refundable tax credit
  – Flexible working schedules (job sharing/vacation sharing)
  – Catch up retirement benefits

**Priority Recommendations:**

1) Expand National Family Caregiver Support Program

• The Federal Government should expand the National Family Caregiver Support Program to cover family caregivers caring for anyone 18+ including grandparents of any age or other relatives 50+.

• Increase level of funding to $250 million to accommodate the expansion of the program in proportion to the population served.

• Pass Lifespan Respite Care Act
2) Support working caregivers by implementing the following:

- Paid family medical leave with employer tax credits
- Refundable tax credits
- Encourage employers to implement flexible working schedules, job sharing/vacation sharing
- Catch up retirement benefits

3) Create a national office on caregiving within the Department of Health and Human Services to coordinate caregiving-related services and research. In partnership with NIA and AoA the Office of Caregiving would be charged with coordinating and facilitating the following: public awareness, education, increasing the value and needs of caregivers, and increasing recognition of the biopsychosocial needs of caregivers

**Group 4**
Facilitator: Gloria Cavanaugh, American Society on Aging
Recorder: Adrienne Dern, National Association of Area Agencies on Aging

**Working Recommendations and Issues:**

- Definitions of “family” must include diversity issues related to ethnicity, race, sexual orientation. In addition, a family could be a “family of choice”, not only a family of origin or legally designated family.

- The term of choice for family caregivers who are employed needs to be modified in order to distinguish between paid caregivers and family caregivers.

- In designing programs to support family caregivers, efforts should examine and build upon existing models that focus on family caregivers and include where appropriate the pieces of those models which have been proven to effectively meet caregiver needs.

- Physicians need to be educated regarding the importance of supporting family caregivers. They need to be part of a national awareness campaign on the impact of caregiving and an important entree point to resources for many caregivers who would not otherwise know what resources are available.
  - Funding could be provided for the production of a general packet of information with resources for caregivers that could be placed in physicians’ waiting rooms.
  - There is a need for a code to reimburse physicians for providing caregiver and care recipient education about available resources and supports.

- As partners in care all family caregivers need to be integrated into care planning at all levels and be considered an integral part of any care plan

- Caregivers need assessment services to ensure that they are provided with the support they need.
Priority Recommendations:

1) Strengthen and expand existing government laws and programs to explicitly recognize the diverse population of family caregivers as part of our nation’s health and long-term care system by
   - Commissioning an IOM study and policy blueprint
   - Enacting the Lifespan/Respite Bill
   - Increasing funding for the NFCSP to $250 million

2) Encourage the development of workplace/workforce innovations through incentives to employers to offer their employed caregivers programs such as:
   - Flex time
   - Phased retirement
   - Eldercare programs that are responsive to diverse populations
   - LTC insurance

We need recommendations related to end of life issues. Many caregivers report that they should have had hospice earlier. Can we include this in our assessment of caregivers?

Kathy Brandt
National Hospice and Palliative Care Organization

V. Final Plenary Session – Reaching Consensus

The final plenary session was facilitated by Wendy Fox-Grage and Enid Kassner who received the Work Group reports and their recommendations. The recommendations were reported out by the group facilitator and are summarized below:

Group 1

1) Create a Bipartisan commission on caregiving to be appointed by the President and Congress and informed by “Family Caregiving and Public Policy Principles for Change” (full document included in the appendix of this report).

2) Develop, fund and implement a national program to assess caregivers for needs and link caregivers to case coordination services.
3) Fully fund expansion of caregiver services through 2015 including paid family and medical leave, the National Family Caregiver Support Program, respite care and other paid services in order for caregivers to be employed and continue normal lives.

4) Strengthen existing and future federal and state laws and programs to explicitly recognize family caregivers in all their diversity as an integral part of the health and long term care system.

5) Expand the National Family Caregiver Support Program to cover family caregivers caring for any one 18+ years of age including grandparents of any age or other relatives 50+, increase level of funding to $250 million to accommodate the expansion and pass and fund the Lifespan Respite Care Act.

6) Support working caregivers by implementing paid family medical leave, refundable tax credits (allowing low-income families who do not owe taxes to receive a credit), encourage employers to implement flexible working schedules and job sharing/vacation sharing and catch-up provisions for retirement benefits.

7) Strengthen and expand existing government laws and programs to recognize the diverse population of family caregivers as part of our nation's health and long-term care system by an IOM study, passage of the Lifespan Respite Bill and increasing the NFCSP funding to $250 million.

8) Encourage the development of workplace/workforce innovations through incentives to employers to offer employed caregivers flex time, phased retirement, eldercare program responsive to diverse caregiving situations and long term care insurance.

The facilitators of this plenary consensus-building session identified three clear themes present in the priority recommendations submitted by the 4 working groups:

- Government actions including expansion and strengthening of government programs such as NFSCP, respite care, and a national assessment program.
• Private actions with incentives for employers to support employees with caregiving responsibilities.

• The commissioning of a high profile study to increase awareness of the importance of family caregiving, foster new research in the area of family caregiving assessment and interventions.

Participants reiterated the importance of the inclusion of diversity issues in any recommendations put forth. The diversity should include expansion of the definition of “family”.

Consensus about the type of high profile study or commission was difficult to reach with some of the groups favoring the Institute of Medicine report and others favoring a National Commission with a broader agenda that would be included in an IOM report. The final recommendation on this item was determined by a hand vote of the assembled participants. Three recommendations were developed and presented to the two members of the WHCoA Policy Committee in attendance, Bob Blancato and Gail Hunt. The recommendations are outlined below. These recommendations were also presented to the full WHCoA Policy Committee in a final report which can be found in the appendix of this document.

**Final Recommendations**

**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.

There are important issues related to long distance caregivers, workforce and diversity that need to be addressed.

Jan Busby-Whitehead M.D.
American Geriatrics Society

The sponsors are pleased to contribute to the public discussion of these very important issues, however, the views expressed are not necessarily shared by the sponsors.
Appendices:

A. Bibliography

B. Agenda of the WHCOA Mini-Conference on the Future of Caregiving

C. Final Report and Recommendations of the Mini-Conference Submitted to The Policy Committee of the WHCOA

D. Family Caregiving and Public Policy Principles for Change

E. Acknowledgements

F. Speaker Bios

G. Participant List
Appendix A

Bibliography


Mini-Conference on the Future of Caregiving
June 15, 2005 _ Washington, D.C.

AGENDA

8:30a.m.-9:00a.m. Registration and Continental Breakfast [Atrium Ballroom]
Moderator – Sandra Timmermann, Ed.D., MetLife Mature Market Institute
Welcome – Joyce Ruddock, MetLife
Overview – Gail Hunt, National Alliance for Caregiving

9:00a.m.-9:30a.m.

9:30a.m. Expert Panel:
Emerging Issues – Lynn Friss Feinberg, MSW, National Center on Caregiving, Family Caregiver Alliance
Working Caregivers – Donna Wagner, Ph.D., Center on Productive Aging, Towson University
Caregiver Health – Richard Schulz, Ph.D., University Center for Social and Urban Research, University of Pittsburgh

10:30a.m.-10:45a.m. Break

10:45a.m.-11:30a.m.

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 B. Blancato, President, Matz, Blancato & Associates

11:30a.m.-11:45a.m.
Remarks from WHCoA – The Honorable Dorcas Hardy, Chair, WHCoA Policy Committee

11:45a.m.-12:15p.m. Comments and Questions for Panel
Lunch

1:30p.m.-3:30p.m. Small Working Groups
Group #1 – Madison Room (Lower Lobby Level)
Group #2 – Senate Room (Mezzanine Level)
Group #3 – Capitol Room (Mezzanine Level)
Group #4 – Atrium Ballroom (Mezzanine Level)

3:30p.m.-4:00p.m. Break

4:00p.m.-4:50p.m. Reporting of Resolutions

4:50p.m.-5:00p.m. Acceptance of Resolutions – Member of WHCoA Policy Committee

5:00p.m. Adjourn
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
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:

- 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.

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.
Appendix D

Family Caregiving and Public Policy
Principles for Change*

Caregiving has always been a universal experience in our society affecting people of all races, ethnicities, lifestyles, and income levels, but in our time family caregiving has become more than an act of love and familial responsibility. It has become an essential element of our health and long-term care system. This is so for a number of reasons:

Historically caregiving was short-lived. Most people died from infectious diseases until the advent of antibiotics in the 20th century. The average lifespan in 1900 was just 47. Today it is in the mid 70s, and the majority of people die from the consequences of a chronic condition. This means caregiving situations typically last years or decades—or, in some cases, such as when children are born with congenital abnormalities or developmental disabilities, an entire lifetime.

Institutionalization of individuals with chronic or disabling conditions has given way to a growing movement toward mainstreaming and community living. This movement has now become the law of the land with the handing down of the Supreme Court’s *Olmstead* decision.

In the midst of these changes, major demographic trends are also having an impact on family caregiving.

Family members no longer live in close proximity to the extent they did in the past. Long distance caregiving is a result of our enhanced mobility and changing social order.

Women have traditionally played the role of family caregiver, but in this era when women make up almost half the labor force, they are less available to take on the role of family caregiver.

Add to these changes the fact that America is currently facing an ever-growing health care worker shortage at the same time that health and long-term care costs continue to rise. As a result of cost containment policies and practices, people with health needs are being discharged from hospitals or other acute care settings with more complex care needs and curtailed homecare services, which means more responsibility for families, who are inadequately prepared and trained.

It is clear that given these circumstances American health care is now on a collision course with the day-to-day reality of families coping with chronic conditions. Without attention to this situation, the $257 billion in unpaid supportive services provided by the more than 25 million family caregivers1—an amount comparable to Medicare spending in 2002 and exceeding Medicaid spending in the same year2—may well be jeopardized as these same family caregivers suffer from physical, emotional, and financial problems that impede their ability to give care now and support their own care needs in the future. As this pattern plays itself out, the quality of care provided to individuals with disabling or chronic conditions or the frail elderly will diminish and the costs to the nation’s health care system skyrocket.

Now more than ever, the United States needs to develop responsible social policy to address the needs of caregiving families who have unwittingly taken on the dual jobs of health care and social service provider. The following principles apply to caregivers in all situations, although how they would be implemented would vary by setting.

*These Principles were developed in 2003 by a collaborative group of family caregiver advocates including:

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December 1, 2003
PRINCIPLE 1

Family caregiving concerns must be a central component of health care, long-term care, and social service policymaking.

Family caregivers provide approximately 80% of all long-term services and supports for family members and friends across the lifespan.3, 4

Services provided each year by family caregivers are conservatively worth $257 billion, more than double the annual spending on home care and nursing home care combined, and comparable to 20% of all health care spending.5

Family caregivers put their own health and well being at risk in the service of their loved ones as they simultaneously save the health care system significant amounts of money.6, 7

Despite the wealth of services they provide, and in spite of their staggering numbers, family caregivers continue to be the most neglected group of the health and long-term care system. In return for family caregivers’ contributions to the public good, society, through its public and private sectors, must support caregivers through well-designed policies, programs, and practices.

PRINCIPLE 2

Family caregivers must be protected against the financial, physical, and emotional consequences of caregiving that can put their own health and well-being in jeopardy.

Among their many roles, family caregivers are integral but unpaid partners in the health care system. As such, they provide care at significant costs to themselves

Out-of-pocket medical expenses for a family that has a loved one with a disabling or chronic condition who needs help with activities of daily living (eating, toileting, etc.) are more than 2.5 times greater than for a family without a family member with a disabling or chronic condition (11.2% of income compared to 4.1%).8

The majority of caregivers are employed and many are forced to make changes at work to accommodate caregiving. Over the course of a caregiving “career,” family caregivers providing intense personal care can lose as much as $659,000 in wages, pensions and Social Security.9

Family caregivers who provide care 36 or more hours weekly are more likely than non-caregivers to experience symptoms of depression or anxiety. For spouses the rate is six times higher; for those caring for a parent the rate is twice as high.10

Caregivers use prescription drugs for depression, anxiety and insomnia two to three times as often as the rest of the population.11

The stress of intense family caregiving for persons with dementia has been shown to impact a person’s immune system both in terms of increased chances of developing a chronic illness and in significantly slowing wound healing.12, 13
PRINCIPLE 3

Family caregivers must have access to affordable, readily available, high quality respite care as a key component of the supportive services network.

Respite, often the most frequently requested family support service, provides caregivers with occasional relief necessary to sustain their own health or attend to other family members. In emergency situations, a temporary haven to ensure the safety of the person for whom they provide care and provide them with a quality experience as well becomes an absolute necessity.

Without respite, not only can families suffer economically and emotionally, caregivers themselves may face serious health and social risks as a result of stress associated with continuous caregiving.

Respite has been shown to help sustain family stability, avoid out-of-home placements, and reduce the likelihood of abuse and neglect. New preliminary data from an outcome based evaluation pilot study show that respite may also reduce the likelihood of divorce and help sustain marriages.

Respite, however, remains in short supply for all age groups, or is inaccessible to the family because of eligibility requirements, geographic barriers, cost, or the lack of culturally sensitive programs. Thus, lifespan systems need to be in place to identify and coordinate federal, state and community-based respite resources and funding streams across ages, disabilities, and family circumstances; to provide easy access to an array of affordable, quality respite services; to ensure flexibility to meet diverse needs; to fill gaps and address barriers in existing services; and to assist family caregivers with locating, training, and paying for respite.

PRINCIPLE 4

Family caregivers must be supported by family-friendly policies in the workplace in order to meet their caregiving responsibilities. Examples of family-friendly workplace policies include: flextime; work-at-home options; job-sharing; counseling; dependent care accounts; information and referral to community services; employer-paid services of a care manager and more.

Currently, only large Fortune 500 companies tend to have programs to support family caregivers—and then only for those caregiving for elderly relatives. Few small and mid-sized businesses—where most Americans work—have programs supporting family caregivers and are increasingly cutting paid health benefits as well. As a result, most family caregivers struggle to balance work and family responsibilities.

Forty-two percent of parents of children with special needs lack basic workplace supports, such as paid sick leave and vacation time.

Family caregivers are doubly penalized when they temporarily leave the workforce for caregiving. Not only may they lose actual pay, but they also lose social security credits and this can impact their own ability to care for themselves in the future.
PRINCIPLE 5

Family caregivers must have appropriate, timely, and ongoing education and training in order to successfully meet their caregiving responsibilities and to be advocates for their loved ones across care settings.

Family caregiving is a complex responsibility, involving emotional support, household management, medical care, dealing with a variety of governmental and other agencies, and decision-making. Yet family caregivers consistently report that they were “not prepared” for these roles. This lack of training occurs throughout the caregiving experience, but is most apparent when care recipients are discharged from hospitals or short-term nursing home stays after an illness or accident. One national survey found that 43 percent of caregivers performed at least one medical task, defined as bandaging and wound care, operating medical equipment, or managing a medication regimen. Yet formal instruction is sporadic and inadequate. Families are expected to perform “skilled” nursing care, but without the training that professionals must receive.

Family caregivers’ needs for information and training change throughout the course of their loved one’s illness. They must have opportunities to learn new skills as they become necessary, access new resources, and learn about options for care as the situation changes. Families need honest information about the financial, social, and health-related consequences of various arrangements for care, and they must share in the decision-making about care arrangements.

Professionals must provide information in understandable, nonjudgmental and culturally competent ways that reflect sensitivity to the caregiver’s emotional involvement with the care recipient. Policy makers should support programs that bring family caregivers and professionals together to further collaboration.

PRINCIPLE 6

Family caregivers and their loved ones must have affordable, readily available, high quality, comprehensive services that are coordinated across all care settings.

People who need the assistance of family caregivers typically have complex, chronic medical conditions and functional limitations. As a result, they require services from many parts of the medical and long-term care systems. Unfortunately, coordination of information and services within each system and between these systems rarely occurs.

Use of community services increases with level of disability as well as with age. Thirteen percent of people over 85 use community services (home-delivered meals, transportation, care management, etc) compared to only one percent of persons ages 50 - 64. Case management services play an important role in linking persons with available services as well as managing public expenditures for long-term services.

Thirty-two percent of people with serious chronic conditions see four or more different physicians in a year. Medicare beneficiaries with five or more conditions see an average of 14 different physicians in a year.
In 2000, 50 percent of caregivers reported that different providers gave different diagnoses for the same set of symptoms and 62 percent reported that different providers gave other conflicting information. Another recent survey found that 44 percent of physicians believe that poor care coordination leads to unnecessary hospitalization, and 24 percent stated poor care coordination can lead to otherwise unnecessary nursing home stays.23

It is in this environment that caregivers must take on the complicated and difficult role of care coordinator – ensuring that treatments prescribed by different providers do not conflict and ensuring that important medical and functional information travels across providers, settings, and over time. Care coordination (within the medical system and across medical and supportive service systems) is not common in health care today.24 Lack of coordination, resulting in poor health outcomes, can drive inappropriate and potentially unnecessary spending.

PRINCIPLE 7

Family caregivers and their loved ones must be assured of an affordable, well qualified, and sustainable health care workforce across all care settings.

Millions of family caregivers and their loved ones require medical and non-medical assistance from direct care workers, either at home or in facility-based settings. Currently, there is a growing shortage of these paraprofessional and professional workers that is impacting the quality and continuity of care. The problem is projected to get worse as the Baby Boom generation ages.25

A shortage of well qualified, reliable, and affordable health care workers has a direct impact on the health and safety of persons with chronic conditions or disabilities. It also has a direct impact on the health and well being of family caregivers who must pick up the extra workload, much of which requires training and support they do not have, and which adds to their caregiving burden.26

PRINCIPLE 8

Family caregivers must have access to regular comprehensive assessments of their caregiving situation to determine what assistance they may require.

Social service and health care providers cannot assume that family members can always provide care for a frail elder or person with disabilities.

Family caregivers should be considered an integral part of the long-term care system, as individuals with rights to their own support and assessments of their own needs.

An assessment of the family caregiver’s strengths, needs and preferences constitutes the foundation for developing appropriate and quality long-term care.27, 28, 29

The availability of family members or others to provide uncompensated care should not be considered in allocating long-term care benefits (as in the Medicaid program).
ENDNOTES:


4 Agency for Healthcare Research and Quality (2000). The Characteristics of Long-Term Care Users. Silver Spring, MD: AHRQ.


Thank you to the expert panel and to the following individuals and organizations who contributed their time and efforts to this event:

**Conference Sponsors**
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Bob Blancato is President of Matz, Blancato & Associates, Inc., a firm integrating government affairs, association and coalition management, and advocacy services. He assumed this position in 1996. Immediately prior, he served as Executive Director of the 1995 White House Conference on Aging, appointed by President Clinton. Bob spent more than 20 years on Capitol Hill, mostly with the House Select Committee on Aging. He currently serves on the Policy Committee and Executive Committee of the 2005 White House Conference on Aging, appointed by Rep. Nancy Pelosi. Bob is currently the President of the National Committee for the Prevention of Elder Abuse, National Coordinator of the Elder Justice Coalition and President of Americans for Long-Term Care Security. He also serves on the Board of Directors of the American Society on Aging and the Greater Washington Urban League. He holds a BA from Georgetown University and an MPA from American University.

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Dorcas R. Hardy is President of DRHardy & Associates, a government relations and public policy firm serving a diverse portfolio of clients in the health services, disability insurance and financial industries. She was U.S. Commissioner of Social Security from 1986 to 1989 and also served as Assistant Secretary of Human Development Services for the U.S. Department of Health and Human Services. Ms. Hardy launched and hosted her own primetime, weekly television program, “Financing Your Future,” and has also hosted “The Senior American,” an NET political program for older Americans. She speaks and writes widely about domestic and international retirement financing issues and entitlement program reforms and is the author of Social Insecurity: The Crisis in America’s Social Security System and How to Plan Now for Your Own Financial Survival, Random House 1992. Ms. Hardy consults with seniors organizations, public policy groups and businesses to promote redesign and modernization of the Social Security and Medicare systems. She received her B.A. from Connecticut College, her M.B.A. from Pepperdine University and completed the Executive Program in Health Policy and Financial Management at Harvard University. She is a writer and advisor to Stroke magazine, a Certified Senior Advisor and serves on the Social Security Advisory Board.

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Joyce M. Ruddock is a gerontologist and the Vice President in charge of MetLife’s long-term care insurance business and the MetLife Mature Market Institute. She assumed this position in November 1999. In this role, Ruddock is responsible for all aspects of long-term care insurance and marketing, including individual and group distribution channels. Ruddock joined MetLife in 1995 from The Travelers where she managed the individual long-term care business. Prior to joining Travelers, she was the director of marketing for the Visiting Nurses Association of Rhode Island and manager of Brown University’s Long Term Care Gerontology Center. A well-known professional in the field of aging and long-term care, Ruddock has been interviewed by CNN, ABC, The New York Times and other media, including several trade publications. She has presented at national conferences for such organizations as the American Society on Aging, the National Association of Senior Living Industries, and the Washington Business Group on Health. Ruddock received both a master of public administration degree and master of education degree from Syracuse University and is the author of Caregiving and You: A Resource Guide for Long Term Care.

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Richard Schulz is Professor of Psychiatry and Director of the University Center for Social and Urban Research at the University of Pittsburgh. He has spent most of his career doing research and
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