



Toward a National Caregiving Agenda: Empowering Family Caregivers in America

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As our population ages, caregiving is a responsibility that is expected to touch nearly all families. The experience should not be personally or financially devastating. For many in America today, it is.

Large-scale change to help family caregivers – through public laws, health care benefits, and workplace policies – is needed, but cannot happen without a unified political voice. Despite their huge numbers, at present, American caregivers have none. The task of unifying them is daunting, given the fact that many caregivers don't identify themselves as such, and don't recognize that their problems could be collectively addressed.

This July, thought leaders from government, advocacy groups for the elderly, caregiving and disability fields, and the health care industry gathered for a summit meeting in Washington to begin the work of creating a political voice for the more than 54 million – and growing – caregivers in the United States (see appendix A for list of participants.). This summit built on caregiver events held over the past three years by Pfizer, the National Health Council, the Family Caregiver Alliance, and the MetLife Mature Market Institute—but was the first to deal specifically with caregiver empowerment.

During the two-day meeting convened by the National Alliance for Caregiving in collaboration with Partnership for Caring, participants discussed the many changes needed in public and workplace policies to make family caregiving in the United States a more bearable task. Their primary goal for coming together, however, was to craft and begin executing a plan for organizing family caregivers into a political voice – to create a vigorous caregiver movement. The group successfully crafted the plan and began initial steps to implement it. It will be the work of this new movement to determine a policy agenda.



Background

A wife feeds, bathes, and clothes her 55-year-old husband who is disabled from a stroke. A mother provides everyday assistance to her developmentally disabled adult son who lives with her. A son visits his elderly mother daily to ensure she takes her medication and to do her shopping. A husband makes daily visits to a nursing home to help feed his elderly wife at mealtime.

Family caregiving is usually unpaid. Nevertheless, family and friends provide 80% of the care to older people. Family caregiving can precede, substitute for, or accompany paid caregiving inside or outside of the home. It is often what keeps disabled elderly people out of nursing homes; only 5 percent of elderly people are, at any one time, institutionalized.¹ Family caregivers are viewed as an unpaid extension of the health care system, providing the equivalent of an estimated \$196 billion in free care annually.² Oftentimes they perform sophisticated health care tasks that have traditionally required skilled nursing staff.

Between 1987 and 1997, the number of households in the United States caring for family members or friends over age 50 tripled to over 22 million.³ Caregiving now preoccupies one in every four households. Its prevalence is growing, as more than 7 million older adults have long-term care needs now. More than 10 million will have such needs by 2020 and 14 million by 2040.⁴

The medical progress that has brought us increased longevity has placed unforeseen pressures – both financial and emotional – on families. New medicines and treatments that allow people to leave the traditional hospital setting and return home sooner, especially the elderly, have also thrust family caregivers into new roles. Now many caregivers must oversee the in-home use of sophisticated machines such as feeding tubes and respirators that before were the bailiwick of only highly trained health care professionals. Often caregivers must also administer multiple medications properly, often for several medical problems, or risk complications and the re-hospitalization of the care recipient. One result of these medical advances is the caregivers' responsibility to act as advocates on behalf of their relatives, helping them to navigate the health care system



Family caregiving is nothing new to American culture. But the rapid growth in the elderly population has come at a time when families are less equipped than in previous decades to provide such care. Families today are smaller and more geographically dispersed, and far more women – traditionally the family caregivers – are juggling work and childrearing along with their caregiving duties. Forty percent of caregivers are raising their own children, and two-thirds are working, mostly full-time.⁵

Family caregiving demands are often intensive. On average, caregivers spend four and one-half years providing care, and about 12 hours a week doing tasks such as feeding, bathing, dressing, shopping, and monitoring, according to one landmark study.⁶

The Need

Caregiving is already an emotionally demanding and time-consuming task. For many in America it has become even more difficult because:

- ◆ There is insufficient help available. The types of assistance needed include: information on where to get help; home care workers who provide personal care and relieve caregivers periodically so they can rest or do errands; emotional counseling for caregiver and care recipient; transportation to shop or attend medical appointments; adult day care, etc. In rural areas, these services may be nonexistent.
- ◆ Services, where available, are often unaffordable. Given the intensity of care recipients' needs and the competing family pressures of caregivers, outside help is often needed to supplement family care. Costs vary with need, but even part-time custodial care in many cities can cost well over \$20,000 annually. When elderly people need round-the-clock care, 24-hour home care in some areas is almost as expensive as nursing home care. Nursing homes, which average \$50,000 per year nationwide, can run as high as \$100,000. Private long-term care insurance can help cover these costs but presently only 6 million people have purchased it and, as an underwritten product, people need to buy it while in relatively good health. Medicare, the government health insurance program for the elderly, covers predominantly acute care needs. Medicaid pays for long-term care in nursing homes and, in most states, in-home care, but a family must spend down almost all of its assets before becoming eligible for Medicaid.



- ◆ Caregiving demands often interfere with caregivers' job responsibilities. According to one study, caregivers can lose more than \$650,000 in wages, Social Security benefits, and pensions over a caregiving "career."⁷ American businesses lose between \$11 billion and \$29 billion a year in productivity costs due to workplace disruptions, scheduled and unscheduled absences, leaves of absence, reduction from full- to part-time work, opting for early retirement, or leaving work entirely.⁸
- ◆ There is too little training to teach caregivers how to perform difficult personal care tasks or deal with medical equipment and procedures that must be administered at home. Caregivers are not adequately prepared for the transition from acute care or rehabilitation to home care, neither in terms of what to expect when the family member comes home nor in terms of the caregiver's own needs for support. They also do not receive training or support to function as the patient's health care advocate or to work to increase compliance with recommended health care treatments.

In short, families, employers, and the American health care system are unprepared to meet the needs of a growing aging society, and families are the first to feel it. The sheer volume of these problems demands public attention, as does the dollar implication on long-term financing and service delivery.



Discussion of Solutions

As in previous meetings on family caregiver needs, there was much discussion around which policy options to pursue. A variety of federal and private sector funding streams could be used to increase the supply of programs and services and make them affordable. Each has its advantages and drawbacks. Summit participants agreed that once formation of the national movement begins, a first priority should be construction of a national policy agenda. They acknowledged the following five points as categories around which specific policy solutions should be developed:

Affordability

- ◆ Changing the way long-term care is financed by making caregiving more affordable for the middle class. Such a system could include a mix of subsidized insurance, private insurance, tax credits and deductions;
- ◆ Promoting consumer choice by giving stipends to family caregivers who choose to provide the care themselves and Social Security credits to those who leave the workplace to do full-time caregiving.

Availability

- ◆ Developing local information and referral programs, caregiver ombudsmen, caregiver registries, caregiver joint purchasing, and care management services so that consumers know where to turn for a variety of services;
- ◆ Developing enough programs and providers at the local level so that all communities have access to a range of caregiving services, such as information and referral, respite care, adult day care, and caregiver support groups and counseling; and
- ◆ Building a pool of trained paid caregivers large enough to meet the need.



Advocacy and Activism⁹

Participants agreed that caregivers must engage in both advocacy and activism to forward a national movement. Caregivers are advocates when they speak on behalf of themselves and their care recipient to health care providers, insurance companies, employers, family members, and others to get needed assistance. Activism entails a different level of involvement. Activists work for policy changes to improve the situation of *all* caregivers.

Summit participants acknowledged that not all caregivers have the time or inclination to be activists at the local, state, and/or federal levels. Major progress would be made (and a cumulative momentum begun), however, even if most caregivers just became advocates for themselves and their own family.

Ultimately, both advocacy and activism are needed to achieve lasting change. Activists need a large and visible constituency of individual advocates to capture political attention, and advocates then benefit from the more global changes that activists achieve.

Organizational Vision of Success

The group agreed that the primary signs of successful organizing would include:

- ◆ A large and powerful national movement of family caregivers (with chapters at the local level) and their natural allies to advocate for the needs of caregivers;
- ◆ Consensus among organizations representing caregivers, people with disabilities, and older persons on a unified national caregiving political agenda and public awareness message; and
- ◆ Recognition of family caregivers by having them included on a variety of policy-making and decision-making boards – in government, the health care industry, and at the workplace.



Achieving the Vision: Action Plan to Create a Voice

To achieve these successes, the group created a plan to organize and mobilize a national movement to champion the needs of family caregivers. Participants divided themselves into three groups and assigned responsibility for achieving the following tasks within one year:

Task 1 – Strengthen the National Coalition of Natural Allies to Address Caregiver Problems

Goals:

- ◆ Identify likely allies (among corporations, professional groups, organized labor, insurance companies, faith communities, foundations, health care organizations);
- ◆ Be a conduit for information to these allies;
- ◆ Help allies promote activism among their constituents;
- ◆ Develop common ground among coalition members around caregivers' needs;
- ◆ Create a political agenda on caregiving; and
- ◆ Create a “Caregiver Bill of Rights” – a list of principles that constitute essential supports for caregiving.

The National Alliance for Caregiving, the host of this summit and itself a coalition of 27 national organizations, has pledged to work with other organizations to develop a caregiver empowerment group made up of corporations, professional and trade associations, advocacy groups, foundations, organized labor and health care and disease-specific organizations. This umbrella group will meet regularly in Washington in order to maintain effective ties to government. Good models for such empowerment coalitions can be found in the disability movement, such as the Consortium for Citizens with Disabilities. The first step will be a careful review of what worked and what did not in these groups, what increased their credibility, and how they achieved short-term successes.

One major function of the coalition will be to develop a legislative agenda that can be promoted through the coalition to its constituencies. A first step will be to develop a statement outlining a caregiving “common ground” which can be promoted to each organizations' chapters and through them to their members. Beyond developing a legislative agenda, such a coalition is a conduit for information and policy analysis about caregiving issues to local caregiving networks as well as to Congress and policymakers. A second step will be to expand the coalition beyond the obvious caregiving allies represented at this summit meeting. The coalition also will develop a set of easy-to-use tools, including web page templates, to help the groups in the coalition reach and unify their caregiving constituencies.



The coalition will develop a set of caregiving principles that represent caregivers' "rights." It will disseminate these principles through employers' human resource departments to working caregivers and through other organizations (e.g., health care groups, labor unions, professional associations) to reach other caregivers.

Task 2 – Develop a Public Awareness Campaign

Goals:

- ◆ Hire a public relations firm to conduct a multi-faceted public awareness campaign that will, among other things, help family caregivers to self-identify and create greater recognition of caregiving among the general public; and
- ◆ Use a variety of strategies to heighten the awareness of elected officials and policymakers about caregiving issues. Strategies could include having major national meetings sponsored by international and national entities, such as the White House, Congress, and the UN.

The purpose of the media campaign will be to sensitize the American public to caregiving issues in order to effect change. The campaign will work through the media toward greater awareness of caregiving by encouraging community dialogue about caregiving, and creating an informed public. An informed public will be more inclined to reach out to support caregivers, and a positive public image of caregiving as normative would make it easier for caregivers to identify themselves in this important role. Once again, the critical role of caregivers in underpinning the health care system by their free service must be recognized.

A nationally recognized public relations/social marketing firm will be hired to work on the mass media portion of the campaign. Buttons, ribbons, slogans, songs and other symbols could all be part of a coordinated public awareness campaign, along with town hall meetings, senior and health care expos. The campaign also would inform and influence Congressional and Presidential elections, by ensuring that candidates understand the economic and political value of caregivers and by encouraging candidates to state their positions on caregiving support.

Choosing the right national message will be critical – not the current view of the saintly, self-sacrificing caregiver – but more realistically: “Caregiving is hard but it’s the right thing.” Another message might be: “Without family caregivers, our health care system would be bankrupt.”



Besides mass media to create broad public awareness, other suggested strategies to mobilize public attention to caregiving include a Surgeon General's report on caregiving, a White House Conference on Caregiving, and designation of a UN Year of the Caregiver, increasing the visibility of National Family Caregivers Month, and identifying a celebrity to represent family caregiving.

Task 3 – Develop a Grassroots Plan to Promote Activism

Goals:

- ◆ Create a grassroots task force of summit participants to
 - identify state and local organizations that include family caregivers and
 - develop a means for communicating with them, such as through Web site links;
- ◆ Identify “natural leaders” at state and local levels;
- ◆ Develop a database of individual caregivers; and
- ◆ Train local leaders on how to advocate effectively.

A first step in Task 3 will be to create a grassroots task force of participants attending this summit, and others; the task force will mobilize around the same uniform agenda as the national coalition and will 1) create a national network of Web sites through which caregivers can access detailed information about programs and policies around the country, and 2) identify and train natural caregiving leaders at state and local levels.

At the Web sites, caregivers will be able to find out about issues affecting them as well as express their opinions on those issues. The Web sites will eventually provide training for caregivers on advocacy and serve as recruiting and training points for caregivers who wish to become activists. Over time and as the number of caregivers grows, the network of Web sites can become a mechanism for getting out the vote on issues that affect caregivers.

The natural leaders at the state and local levels will be responsible for letting local caregivers know about the Web sites and for compiling the caregiver database so that the Web site network can become an effective tool for mobilizing caregivers. These leaders will also receive activist training so that they can engage state and local legislators and policy-makers. One specific goal could be to begin to establish “commissions on caregiving” or select committees on caregiving in each state, similar to statewide commissions on women and commissions on disability. These commissions on caregiving can develop ideas for state and local legislation to support caregivers as well as give feedback on the impact of proposed legislation. Another goal could be to support lifespan respite programs in each state or stronger end-of-life programs for caregivers.



Conclusion

The three tasks above are interrelated, all focused toward similar goals but from different approaches: impacting public policy, the general public's perspectives, and grass-roots caregivers. All three approaches are necessary to achieve true empowerment of family caregivers so that they can effect change.

Americans have always cared for family members. Today, increased longevity has collided with the new smaller, working American family to make the pressures on caregivers immense. Families are not asking to be free from caregiving duties, but it is clear that without large-scale improvement, most will not have the endurance or money to do the job. Advancements in medicine have made the prospect of caregiving inevitable for nearly all households. A collective, public response is essential if programs assisting family caregivers and paid caregiving services are to be more available and affordable. Family caregivers must come together and advocate as one powerful political voice if change is to occur.



Appendix A Caregiving Empowerment Summit Participants

<u>Name</u>	<u>Organization</u>
Paul Alper	The Caregivers Advisory Panel
Bob Blancato	Matz, Blancato and Associates
Myra Christopher	Midwest Bioethics Institute
Jennifer Dexter	Easter Seals
Brian Duke	Children of Aging Parents (CAPS)
Garey Eakes	Partnership for Caring
Aimee Falchuk	Pfizer Inc
Lynn Friss Feinberg	Family Caregiver Alliance
Sheila Forsyth	Rosalynn Carter Institute
Marsha Goodwin	Department of Veterans Affairs
Rick Greene	US Administration on Aging
Hope Cooper	Senate Finance Committee
George Hopper	Well Spouse Foundation
Dorothy Howe	AARP
Gail Hunt	National Alliance for Caregiving
Peter Juhn	Carepanion
Jill Kagan	National Respite Coalition
Karen Kaplan	Partnership for Caring
Jane Koppelman	Health care writer
Carol Levine	United Hospital Fund
Monette McKinnon	N4A
Mary Meyer	Partnership for Caring
Suzanne Mintz	National Family Caregivers Association
Katy Beh Neas	Easter Seals
Les Plooster	National Alliance for Caregiving
Skip Schlenk	AT&T
Talbott Smith	Pfizer Inc
Rhonda Talley	Rosalynn Carter Institute
Mary Thompson	Partnership for Caring
Sandra Timmermann	MetLife Mature Market Institute
Donna Wagner	Towson University

Footnotes

- ¹ Cohen, Marc and Jessica Miller, "Long-Term Care Financing and Family Caregiving: Public and Private Experience and Initiatives," *Dimensions of Family Caregiving: A look Into the Future, Monograph*, prepared for a national conference September 12, 2000, sponsored by MetLife Mature Market Institute.
- ² Arno, P.S., Levine, C., & Memmott, M.M.(1999). "The Economic Value of Informal Caregiving," *Health Affairs*. 18(2)
- ³ National Alliance for Caregiving/AARP (1997) *Family Caregiving in the U.S.: Findings from a National Study*. Washington, D.C.
- ⁴ Wagner, Donna, "The Development and Future of Workplace Eldercare," *Dimensions of Family Caregiving: A Look Into the Future, Monograph*, prepared for a national conference September 12, 2000, sponsored by MetLife Mature Market Institute.
- ⁵ Gutheil, Irene and Roslyn Chernesky, *Family Elder Caregiving: The Grotta Report on Philanthropic Trends and Best Practice Models*, 2000, prepared by the Ravazzin Center for Social Work Research in Aging, Fordham University Graduate School of Social Service.
- ⁶ U.S. Department of Labor (1998). *Work and Elder Care: Facts for Caregivers and their Employers*. Women's Bureau Facts on Working Women. No. 98-1, May.
- ⁷ *Dimensions of Family Caregiving: A Look Into the Future, Monograph*, prepared for a national conference September 12, 2000 sponsored by MetLife Mature Market Institute.
- ⁸ Metropolitan Life Insurance Company (1997). *The MetLife Study of Employer Costs for Working Caregivers*. Westport, CT, MetLife.
- ⁹ The distinction between advocacy and activism has been defined and explored by Ira R. Byock, MD in personal communications with Karen Kaplan, 2001.

