



United Hospital Fund

*Shaping New York's Health Care:
Information, Philanthropy, Policy.*

New York State Policy Agenda for Family Caregivers

Families and Health Care Project, United Hospital Fund
For release November 14, 2006

For information:

Carol Levine
Director, Families & Health Care Project

United Hospital Fund
350 Fifth Avenue
New York, NY 10118
clevine@uhfnyc.org
www.uhfnyc.org

The Families and Health Care Project of the United Hospital Fund proposes the following policy and program initiatives to support the nearly 2 million family caregivers throughout New York State. These relatively modest recommendations—compared to the approximately \$20.4 billion in the labor market value of caregiver services and the incalculable worth of the social values they promote—would set the Empire State on a course that would establish its leadership role in fostering quality patient care, sound use of scarce resources, and humane social policy.

Why a Family Caregiver Agenda? Why Now?

Family caregiving is an important public policy concern in New York.

- Although family caregiving has always been an important kinship obligation, changes in demographics, workforce patterns, and health care economics and services have resulted in a dramatic change in its extent and complexity.
- Most individuals with chronic conditions or disabilities in New York live in the community—approximately 2.3 million adults and more than 500,000 children—and most have inadequate or fragmented access to formal services. They rely heavily on personal care and daily assistance provided by family members. Family members, a quarter of whom are themselves old, provide between 75-80% of long-term-, home-, and community-based care for elderly people (Spillman and Pezzin, 2000).
- New York State is third in the nation (behind California and Texas) in the number of family caregivers and the economic value of the unpaid labor they provide. New York's 1.9 million family caregivers provide \$20.4 billion in unpaid care, out of a national total of an estimated \$306 billion, which is more than the cost of nursing home and formal home care combined (Arno, 2006; Arno, Levine, and Memott, 1999; National Family Caregivers Association, 2006). This is a valuable resource that the State should actively support, as the loss of even a small percentage of this unpaid care would result in further increases in public spending.

- Public policy promoting community care as an alternative to institutionalization depends on unpaid family caregivers to provide the major share of care for people who are ill or need assistance. An increased emphasis on community care, required to implement the requirements of the U.S. Supreme Court’s *Olmstead* decision, will put additional pressure on families.
- An increasing body of evidence demonstrates that family caregiving takes a major toll on the caregiver; not only in physical and mental health but also in mortality (Cannuscio et al., 2002; Evercare, 2006). Older family caregivers experiencing strain are 63% more likely to die than their non-caregiving peers (Schulz and Beach, 1999). Hospitalization of an ill spouse increases the risk of death for the well spouse (Christakis and Allison, 2006). Failing to address the needs of family caregivers can result in increased medical costs for two patients instead of one.
- Half of all family caregivers are employed. The losses to the economy when they leave or lose their jobs or fail to work to their full productivity are significant. Nationally these losses are estimated to cost businesses \$33.6 billion a year (MatureMarket Institute/National Alliance for Caregiving, 2006). There are no comparable estimates for New York State, but it seems likely that given the State’s population and economic prominence, the costs are substantial.

Elements of a Policy Agenda

This policy agenda includes five basic elements: (a) a strong statement of support for family caregivers; (b) a comprehensive mapping and evaluation of existing services and family caregiver needs; (c) a review of key policies and practices; (d) the establishment of a mechanism to coordinate these activities and to propose new and expanded services and policy imple-

mentation; and (e) a focus on strengthening local agencies, through the long-term-care Point-of-Entry* information offices or other mechanisms, to reach, assess, and support caregivers. In addition, a second document—an ethical framework**—has been created to complement the goals of the policy agenda.

* In May 2006 the New York State Office for the Aging and Department of Health issued a request for applications for the first year of a Long Term Care Point of Entry program, intended to provide a “single, coordinated system for accessing long-term care services for all persons, regardless of payor source.” Phase One is the development of an infrastructure, located in counties, which can provide information and assistance, screening, and public education.

** Available at www.uhfny.org

Awareness and Commitment

The Governor's **strong statement** that family caregivers are essential to the health and well-being of the State's elderly, ill, and disabled residents will establish the tone and direction for the Administration's approach. To implement the State's goal of expanding community-based care, which relies heavily on unpaid family care,

New York State must support the entire spectrum of family caregivers by reviewing **policies** and **programs** that affect them and by strengthening and expanding **services** to help them in their caregiving roles and in achieving a balance with other important goals and responsibilities.

Service Development: Mapping Existing and Identifying New Program Possibilities

In its review of **services and programs**, New York State should:

- Obtain **up-to-date information** about family caregivers throughout the State by periodically conducting the CDC's Behavioral Risk Factor Surveillance Survey special caregiver module or another survey. (The BRFSS is a cross-sectional telephone survey conducted by state health departments with technical assistance provided by the CDC. All states use core questions annually, and most states choose to add questions of particular relevance to their constituencies.) It is important to know the number and demographics of the State's family caregivers, the characteristics of the people they are caring for, the extent and level of their responsibilities, their own health status, their experiences with the health care and social service sectors, their sources of support, and

unmet needs. Specific questions related to policy issues can be included as needed.

- Develop and maintain an **inventory of existing services available to assist family caregivers** across the State, with an evaluation of their accessibility, eligibility, and utilization (Feinberg et al., 2004). The results of this survey should be offered for public comment and repeated at regular intervals.
- Identify **unmet service needs** of family caregivers, such as respite, training, information about financial and legal options, and others.
- Develop plans to fill identified **service gaps** and to disseminate **model programs** and practices.

Policy Review

In its review of **public policies** that affect caregivers, New York State should:

- Assure that **Health Insurance Portability and Accountability Act (HIPAA)** is used appropriately in contacts with family caregivers. Family caregivers should not be inappropriately hindered in obtaining information about their sick family member in order to provide needed care. Family caregivers should receive easy-to-understand information that explains their rights under HIPAA, and health care providers should receive training on the right of a family caregiver to be informed about the medical information relevant to the care of the patient.
- Evaluate the implementation and utility of DOH's November 2005 guidelines on **discharge planning**, how well "consumers and families" are informed about these guidelines and are trained to provide needed care at home.
- Identify opportunities for improving the **training** of facility-based and community-based health care providers (professional and para-professional) that establish good working relationships with family caregivers.
- Examine possibilities for **financial relief** for family caregivers, such as protection from catastrophic expenses, paid family medical leave (as in CA), and state tax credits.

Family caregivers should not be inappropriately hindered in obtaining information about their sick family member.

Among the members of the Family Caregiving Council should be representatives of various caregiver populations, including spouses and adult children, partners, parents of children with special health care needs, and others.

Development, Coordination, and Implementation

The Governor should determine the best methods to accomplish these goals. One possibility is to establish a statewide **Family Caregiving Council** to develop policies and services, and coordinate and evaluate their implementation. Because children with special health care needs, elderly, ill, and disabled residents and their family caregivers are involved with both the health care and the social service systems, the Family Caregiving Council should be a joint effort co-led by the Department of Health and the State Office for the Aging, with the participation of other agencies, such as the Office of Mental Health, the Office of Mental Retardation and Developmental Disabilities, and appropriate legislative representatives.

While other states have family caregiver coordinating councils, New York would be the first state to create such a body that specifically links the health care, mental health, and aging service systems and that covers the lifespan.

Among the members of the Family Caregiving Council should be representatives of various caregiver populations, including spouses and adult children, partners, parents of children with special health care needs, and others. The membership should be geographically and ethnically representative.

The Family Caregiving Council should have adequate staff and budget to carry out its mission.

Because family caregivers are the bedrock of community care, for the proposed Point of Entry program to be meaningful to older residents and their families, and to children and adults with disabilities, the interests and needs of family caregivers must be integral to its operation.

Community Services and a Mandate to Improve Caregiver Support

The Family Caregiving Council should also develop a comprehensive service plan to ensure that caregiver issues are addressed by whatever local organization the State creates to guide access to long-term care services. Whether the State pursues the proposed Point of Entry strategy or some alternative approach, it is committed to community care, with institutional care as a last resort. Because family caregivers are the bedrock of community care, for this program to be meaningful to older residents and their families, and to children and adults with disabilities, the interests and needs of family caregivers must be integral to its operation. Specially trained and motivated staff must understand that their clients are not just the person in need of care, but the family caregivers as well.

Local Point of Entry information offices, or some alternative entity, must provide family caregiver **support services**, which should include assessment of the caregiver's needs (not just those of the ill or disabled person), in-home evaluation and training, and legal and financial advice, as well as the more commonly offered information and referral. These offices also should devise innovative strategies to connect with and serve rural, isolated, non-English-speaking, and other vulnerable caregivers.

Under the current proposal, each Point of Entry program must establish a Long Term Care Council that is "representative of the community it services." Family caregivers should be included in each council, not just to represent the populations they serve but also to represent themselves.

Financing

To finance the beginnings of this critically needed development of family caregiver support services, New York State should allocate sufficient resources in FY 2007/8, which would be distributed to each county according to its population older than 65, adults with disabilities, and children with special health care needs. Each county would be able to expend this new state support in keeping with a schedule of approved services, and would report expenditures and service volumes to the Council and the State (DoH, SOFA).

Local offices also would be able to use new State support to address **gaps in local service capacity**. Two areas of need and opportunity for action are availability of assistive technology and respite care.

This action agenda recognizes the already substantial contributions of New York State's family caregivers and policy and program opportunities that would help give them the support and visibility they need to sustain their crucial role.

This action agenda recognizes the already substantial contributions of New York State's family caregivers and policy and program opportunities that would help give them the support and visibility they need to sustain their crucial role.

References

- Arno PS. 2006. Economic value of informal caregiving. Paper presented at the Care Coordination and the Caregiver Forum sponsored by the Department of Veterans Affairs. Bethesda, MD. January 25.
- Arno PS, C Levine, and M Memmott. 1999. The economic value of informal caregiving. *Health Affairs* 18(2):182-188.
- Cannuscio CC, C Jones, K Kawachi, GA Colditz, L Berkman, and S Rimm. 2002. Reverberations of family illness: A longitudinal assessment of informal caregiving and mental health status in the Nurses' Health Study. *American Journal of Public Health* 92(8):1305-1311.
- Christakis N and PD Allison. 2006. Mortality after the hospitalization of a spouse. *New England Journal of Medicine* 354(7):719-30.
- Evercare® Study of Caregivers in Decline: A Close-up Look at the Health Risks of Caring for a Loved One. September 2006.
- Feinberg LF, SL Newman, L Gray, KN Kolb, and W Fox-Grage. 2004. *The State of the States in Family Caregiver Support: A 50-State Study*. San Francisco, CA: Family Caregiver Alliance.
- Levine C, SM Albert, A Hokenstad, DE Halper, AY Hart, and DA Gould. 2006. "This case is closed": Family caregivers and the termination of home health care services for stroke patients. *Milbank Quarterly* 84(2):305-331.
- MatureMarket Institute/National Alliance for Caregiving. 2006. The MetLife Caregiving Costs Study: Productive Losses to U.S. Business. Available at www.maturemarketinstitute.com.
- National Family Caregivers Association, 2006. Economic value of family caregivers by states. www.nfca.org.
- Schulz R and SR Beach. 1999. Caregiving as a risk factor for mortality; The Caregiver Health Effects Study. *Journal of the American Medical Association* 282; 2215-2219.
- Spillman B and L Pezzin. 2000. Potential and actual family caregivers: Changing networks and the "sandwich generation." *Milbank Quarterly* 78(3):347-374.

Acknowledgments

The project “Family Caregivers and New York State Public Policy: Developing an Ethical Framework and an Action Agenda” was funded in part by the Greenwall Foundation.

The following individuals participated in Working Group discussions leading to the development of the ethics framework and policy agenda. Organizations are listed for identification only. The Working Group’s thoughtful and spirited advice is gratefully acknowledged. The Families and Health Care Project of the United Hospital Fund is solely responsible for the final products.

Jeffrey Berger, MD

Winthrop University Hospital

Kathy Brandt, MS

National Hospice and Palliative Care Organization

Barbara Devore

New York State Department of Health

William Dionne

Burden Center for Aging

Nancy Neveloff Dubler, LLB

Montefiore Medical Center

Lynn Friss Feinberg, MSW

Family Caregiver Alliance

Robin Fenley, LCSW

New York City Department for the Aging

Alan Fleischman, MD

New York Academy of Medicine

Janlori Goldman, JD

Columbia College of Physicians & Surgeons

Marcus Harazin

New York State Office for the Aging

Andrea Hoffman

New York State Office for the Aging

Lisa Kendall, LCSW

Family & Children’s Services of Ithaca

Nina Mogilnik

Altman Foundation

Ann F. Monroe

Community Health Foundation of Western and Central New York

Thomas M. Murray, PhD

The Hastings Center

James Lindemann Nelson, PhD

Michigan State University

Karen Porter, JD

Brooklyn Law School

Tia Powell, MD

New York State Task Force on Life and the Law

Susan Regan, JD

Consultant

Ruth Stein, MD

*Albert Einstein College of Medicine
Montefiore Medical Center*