



United Hospital Fund

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

An Ethical Framework for New York State Policy Concerning Family Caregivers

United Hospital Fund Families and Health Care Project

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To stimulate and provide an explicit foundation for recognition, support, and training for New York State’s 1.9 million **family caregivers**, the United Hospital Fund proposes an **ethical framework** for **public policy**. This ethical framework, together with the Fund’s proposed policy agenda for family caregiving*, are intended to guide New York State toward a set of actions and goals that will enhance the lives of individuals who need assistance and their family caregivers.

Definitions

An **ethical framework** is a statement of basic values, principles, and community norms that govern policy-making and implementation. It spells out the standards by which specific regulations, policies, and programs can be measured. An ethical framework is particularly important in the area of family caregiving, a responsibility that affects both intimate private relationships and public resources.

Family caregivers include relatives, partners, friends, or neighbors who provide essential assistance to an adult or child with chronic illness or disability or to a frail or cognitively impaired older person. Some of the ways in which the family may respond are emotional support, surrogate decision making, financial contributions, care management, and hands-on care. (Parents of well children or children with-

out disabilities are not considered family caregivers in this sense.) Family caregivers may provide or manage all or some of the care, either part-time or full-time, and may or may not live with the care recipient.

Public policy includes the laws, regulations, practices, and procedures that shape the ways medical care and social services are delivered, paid for, monitored, and evaluated.

Policymakers include elected and appointed officials, agency staff who implement policy at the local level, and managers in private organizations that contract with government agencies to administer public programs.

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Family Caregiving and Public Policy

In all societies family members have ethical obligations to care for each other in times of illness and frailty. These obligations derive from religious teachings, cultural tradition, emotional bonds, gratitude for past acts, or a sense of duty. Public policy that supports family caregivers puts into practice the widely held view that families are intrinsically important because they give meaning and depth to fundamental human relationships.

Public policy that supports family caregivers is a corollary to another deeply held societal and professional value: the primacy of providing benefit to the patient or client.

The assistance family caregivers provide is essentially irreplaceable, both because of their longstanding and often deeply personal relationships with and commitment to the person who needs care and because of the cost and difficulty of providing an alternative source of care. Professionals and paraprofessionals clearly serve an important function in their clients' lives; their involvement, however, is by definition conditional and limited.

Families usually take the first step toward accepting responsibility for providing care, but this decision should not be seen as irrevocable and unlimited. Families provide care within a social, economic, and political context; their involvement in care does not remove all responsibility from professionals, policymakers, com-

munity organizations, and society in general. Societies that value family care will also support families in providing that care.

Although some of New York's long-term care programs have included family caregiver support, public policy and practice in general have been built on the implicit premise that families are "resources," to be used until exhausted, not true partners in an individual's care or clients in their own right. This premise appears to stem partly from the fear, disproved in a multitude of studies, that public support for family caregivers will lead them to abandon their relatives.

Establishing family caregivers in a policy agenda as partners in their family member's care and as clients in their own right requires a fundamental shift in philosophy.

This shift also requires a recognition that family caregiving is a complex and dynamic interaction. Family caregivers have much in common, but each situation has distinct characteristics that require careful and sensitive assessment. Some family caregiving situations cannot be sustained because of the difficulty or duration of care; problems in current or past relationships; caregivers' employment responsibilities, capabilities, health and well-being; obligations to other family members; or for other reasons. Some individuals do not want their care, or some aspects of their care, provided by family members; these preferences may also limit family involvement.

Good ethics starts with good facts, and policies affecting family caregivers should be based on evidence, not myths or stereotypes.

Assumptions and Principles

The ethical framework for public policy we propose is based on several assumptions:

- Good ethics starts with good facts, and policies affecting family caregivers should be based on evidence, not myths or stereotypes. In many areas critical to family caregiving, up-to-date and reliable information is lacking. A policy agenda should include research and other efforts to fill these gaps, including regular surveys of caregivers and inventories and evaluations of services.
- Public policy should be “transparent,” that is, open to comment, critique, and evaluation by stakeholders, including, in this instance, family caregivers. At present family caregivers are seldom involved in policy discussions that affect them directly or indirectly. A policy agenda should involve them in meaningful ways, such as active membership on bodies that determine policy.
- Support for family caregivers should be multidimensional and involve many government agencies, including health, aging, finance, transportation, and others. Interagency collaboration on family caregiving should be further developed.
- While most family caregivers encounter public policy only indirectly, through the actions, attitudes, and behaviors of individuals at the local level, public policy influences all these interactions. It sets the tone, expectations, and rules by which individual interactions take place. A policy agenda should include staff training and assistance in implementing new processes and their underlying assumptions.

Policies and programs should recognize that caregivers of different ages, from very young to very old, diverse backgrounds, and varying capabilities want and need different kinds of support and training.

Moving from Principle to Policy

The ethical framework is based on widely accepted principles:

- Respect for persons (honoring individual and family autonomy, and providing culturally competent services, maximizing options)
- Beneficence (promoting health and well-being)
- Nonmaleficence (preventing harm)
- Justice (fairness in access to and distribution of resources)

To implement the principle of *Respect for Persons*:

- Families should be broadly defined to encompass nontraditional relationships as well as ties of blood, marriage, or adoption.
- Policies and practices should be gender-neutral; men as well as women are caregivers, although women disproportionately provide the most intense levels of care.

- Policies and programs should recognize that caregivers of different ages, from very young to very old, diverse backgrounds, and varying capabilities want and need different kinds of support and training.
- Policies should respect and accommodate cultural, ethnic, and religious traditions around caregiving, while recognizing that family caregivers from these backgrounds interpret and act on their values in different ways.
- Policies and practices should not coerce or exploit family caregivers.
- Alternatives should be available to individuals who choose not to accept family care, for example, young people with disabilities who want to maximize their independence.
- Policies should support employed caregivers, who make up about half of the caregiving population. Their continued productivity and eco-

conomic contributions to the general welfare are important societal resources that cannot easily be replaced and that are often satisfying and meaningful for the individual employer. In particular, health care workers themselves are often family caregivers and the stability of the health care workforce is undermined when these workers cannot manage both roles.

- Policies should provide family caregivers sufficient and appropriate information to make informed choices about their ability and willingness to provide care of different kinds. Finding a reasonable and workable arrangement for each caregiving situation both acknowledges that importance of the family caregiver's own goals and is likely to sustain the caregiver for a longer time than the imposition of unacceptable and unwelcome responsibilities.

To implement the principle of *Beneficence*:

- Beneficence should encompass the family unit, as well as the care recipient.
- Policies should sustain families, not divide them, as they manage their caregiving responsibilities.
- In general, family caregivers and care recipients share common values. Conflicts may arise, however, over preferences for the setting of care, goals

of care, involvement of outside help, or other issues. Resolving these conflicts may require accommodation, negotiation, or mediation.

- Policies should encourage appropriate training and information sharing from medical and social service professionals as well as government officials.

To implement the principle of *Nonmaleficence*:

- Policies should prevent harm to both ill family members and family caregivers by recognizing potentially abusive or exploitative situations and providing appropriate interventions.
- Policies and practices should provide family caregivers with the information and authority to act as advocates for care recipients who cannot act on their own behalf and to seek assistance and information when they find themselves in doubt about instructions or unable to carry out the needed tasks.
- Policies should protect caregivers from placing their own physical or mental health at serious risk.
- Policies should protect caregivers from impoverishment or devastating financial harm.

Policies should encourage appropriate training and information sharing from medical and social service professionals as well as government officials.

To implement the principle of *Justice*:

- Allocation of resources should be fair, targeting groups of family caregivers based on defined criteria, while preventing harm to caregivers at risk because of mental or physical health problems, age, or other characteristics.
- Allocation of resources should consider the needs of different income groups, not just Medicaid-eligible individuals.
- Allocation of resources should balance the different needs of urban, suburban, and rural caregivers; and caregivers of different age groups.
- Caregivers of people with physical limitations and those with cognitive and behavioral limitations all need support, although the types of support may differ.
- While discussions of justice have traditionally excluded the family, this principle has implications for intrafamily and intergenerational distribution of resources and responsibilities as well as for societal allocations. Policies should not facilitate injustice within families, for example, by making it difficult for women to continue employment or young caregivers to continue their education.

This ethics framework builds on established principles and community values and makes explicit the assumptions and principles that should guide the development of policies, practices, and resources to support family caregivers as they strive to provide loving care in an increasingly complex health care and economic environment.

Allocation of resources should balance the different needs of urban, suburban, and rural caregivers; and caregivers of different age groups.

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