

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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PRINCIPLE 1

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

- 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,¹⁴ 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.¹⁵
- Respite has been shown to help sustain family stability, avoid out-of-home placements, and reduce the likelihood of abuse and neglect.¹⁶ New preliminary data from an outcome based evaluation pilot study show that respite may also reduce the likelihood of divorce and help sustain marriages.¹⁷

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.¹⁸
- 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.¹⁹ 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.²⁰

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.²¹
- 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.²²

- 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 institutional 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:

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¹³ Schulz, R. & Beach, S. R. (1999). Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association*, 282(23).

¹⁴ National Alliance for Caregiving & AARP (1997). *Family Caregiving in the U.S.: Findings From a National Survey*. Bethesda, MD: Authors, 1997.

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