



NATIONAL FAMILY CAREGIVERS ASSOCIATION

PRINCIPLES, PLANS, AND POLICY RECOMMENDATIONS

2008 – 2009

REVISED DECEMBER 9, 2008

Giving care is not new, but the expectation that family members can be relied on to provide care for very ill or disabled loved ones in the absence of other support is a relatively recent phenomenon. Neighbors have always helped neighbors if they did not have family around, and communities have always helped to care for the ill among them. But as our society rapidly ages – at a time when calls for health care reform are growing again and uncertain economic growth is taking a toll on federal and state budgets – we must take a fresh look at what it means to be a family caregiver.

Today, family caregivers are being impacted by much longer life expectancies and the ability of the medical profession to save and extend the lives of individuals with extensive injuries or disabilities. People over 85 years of age are the fastest growing segment of our population. Scientists have mapped the human genome - ahead of schedule – and on virtually a daily basis, they are finding new and better ways to treat conditions previously considered untreatable.

The effects of these changes are compounded by the mobile nature of today's society and the consequent dispersal of family members across the country. In addition, 60% of women are now employed, and some put off having children until their late thirties or even early forties. Health insurance has become more costly for many, and tough questions about how we are going to provide and finance healthcare and extended care services in America in the next several decades have arisen. The outcome of these discussions will have a major impact on family caregivers as the baby boom tsunami begins to enter middle old age in 2021.

There is a paucity of services for children and adults with chronic conditions and disabilities. Medicare was enacted in the 1960s. It was designed to assist seniors with short-term acute care problems, such as a broken hip. Today's long-living seniors are presenting with on-going chronic problems such as diabetes, Alzheimer's and Parkinson's, but Medicare and the rest of our current healthcare system is limited in what it offers to such patients and the younger disabled population it also serves.

Healthcare costs are on the rise. More than ever before, today's seniors want to "age in place" at home or in a residence of their choice. There is a healthcare workforce shortage at all levels. Patients are being discharged from hospitals "sicker and quicker," and families are being asked to take on care that in the past was solely the province of those who were trained and paid to provide medical services. It is no wonder that the estimated market value of the services family caregivers provide is now \$375 billion annually, -- more than all federal and state Medicaid spending in 2007, approximately 2.7% of total of the United States' total GDP for that year. It is no wonder that study after study is showing the negative emotional, physical, and financial impact caregiving that is not properly supported often causes.

Giving care is not new, but the nature of what caregiving has become is very much so. It is time to come together to bring about the policy changes that we need to create a better tomorrow for all of us -- aged and young, those who are caregivers and those who need them.

POLICY RECOMMENDATIONS

This paper outlines the National Family Caregivers Association's (NFCA) position on policy initiatives to help family caregivers and their loved ones live full and productive lives free from depression, pain, and financial distress. Policy recommendations are presented in accordance with the *Statement of Principles* that NFCA and other family caregiver advocates developed in 2003. Over 40 national organizations endorsed the Principles. They were first presented publicly at NFCA's National Town Hall Meeting held on Capitol Hill in February 2004. The Principles' supporting statistics were updated in December 2008.

PRINCIPLE 1: FAMILY CAREGIVING CONCERNS MUST BE A CENTRAL COMPONENT OF HEALTH CARE, LONG-TERM CARE, AND SOCIAL SERVICE POLICYMAKING.

To begin to achieve this goal, it is essential to understand the full impact of family caregiving on patients, families, business, communities, and our health and long-term care systems. For this purpose, Congress should call for and fund an Institute of Medicine (IOM) report on family caregiving. This study should examine the interconnections among the various societal systems that impact the health and wellbeing of family caregivers and make recommendations on how we as a country should support them.

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.

The physical, emotional, and financial strains of caring for a loved one can seriously endanger caregivers themselves. Family caregivers are susceptible to depression, and severe financial difficulties. Adult children providing care are twice as likely to suffer from major depression as their non-caregiving counterparts and spouses are six times as likely. Research shows that caregivers' immune systems are weaker than non-caregivers, they age prematurely and are more likely to contract a chronic disease. Family caregivers providing intensive levels of care are the most likely group of caregivers to leave the work force; 16 percent of them do and in the process lose health benefits and the opportunity to add social security credits to help finance their own future caregiving needs. According to the U.S. Census, families in which one person has a disability tend to have incomes that are \$15,000 less than the norm. They also spend 2.5 times more (11.2 percent versus 4.1 per cent) on out of pocket medical expenses than non-caregiving families. Caregivers themselves can lose over \$650,000 over a lifetime if they leave the workforce

To help family caregivers provide high quality and loving care without experiencing these oppressive consequences, it is necessary to evaluate and assess the fiscal and social impacts of a variety of options to address the financial costs of family caregiving, including:

- The Congressional Budget Office should look into the economic impact (for the government and eligible taxpayers) of lowering the current 7.5% medical deduction threshold for caregiving families and individuals with disabilities. Medicare and private insurance does not pay for many of the goods and services needed by the disabled and chronically ill. While substantial, the cost of these items and services does not always add up to 7.5% of income, which is required before these costs can be deducted under the tax code. Lowering the medical deduction threshold for eligible individuals and families would acknowledge the high financial burden on caregiving families. If the CBO study shows a savings for a significant proportion of disabled individuals and family caregivers, it will be one way to help them maintain financial stability. Several other measures would also assist in relieving some of the financial strain of caregiving:
- Amend Title II of the Social Security Act to provide working “credits” of deemed wages for up to five years in the Social Security system for family caregivers who leave the workforce to provide full-time support and care for an ill, disabled, or elderly family member.
- Allow individuals who have lost their health insurance due to caregiving to buy into Medicare or group insurance programs, such as the Federal Employees Health Benefits Plan (FEHBP) at rates commensurate with their income.
- Extend the time period for which employees can maintain COBRA (coverage allows employees, their spouses, and dependants to maintain their employment based health insurance for a certain amount of time after they terminate their employment) from a maximum of eighteen months to thirty six months
- Have Medicare pay for some of the most ubiquitous of caregiving supplies such as adult incontinence products which can easily cost \$1800 a year or more, or grab bars and ramps to prevent falls, thereby minimizing the number of recipients with broken hips.

PRINCIPLE 3: FAMILY CAREGIVERS MUST HAVE ACCESS TO AFFORDABLE, READILY AVAILABLE, HIGH-QUALITY RESPITE CARE AS A KEY COMPONENT OF THE SUPPORTIVE SERVICES NETWORK.

Congress should fund the Lifespan Respite Care Act passed in 2006. Providing care for a loved one gives caregivers little time to tend to their own needs as well as other responsibilities and relationships. Family caregivers often do not have anywhere to turn when they need to take time away from their loved one to take care of other personal responsibilities, seek medical attention for themselves, or take a break from caregiving for their own mental wellbeing. Affordable, available, and reliable respite care would allow caregivers the time to tend to their own personal needs while ensuring that their loved one is cared for. These important services, however, are not nearly as available as they need to be.

To promote the availability and quality of respite care, Congress should appropriate \$53 million for fiscal 2009 authorized in the Lifespan Respite Care Act, and the funding authorized in each succeeding year. Despite being passed by Congress and signed by the President, the funds to put this program into action have not been appropriated and family caregivers are still without the respite services they need.

PRINCIPLE 4: FAMILY CAREGIVERS MUST BE SUPPORTED BY FAMILY-FRIENDLY POLICIES IN THE WORKPLACE IN ORDER TO MEET THEIR CAREGIVING RESPONSIBILITIES.

Family caregivers often have difficulties balancing their work schedules with the demands of caring for their loved one. These issues have forced many family caregivers out of the workforce. Others struggle to work two full time jobs, their formal employment and caring for their loved one to maintain income and keep their health insurance.

Several actions could be taken to assist family caregivers:

- Provide wage replacement at the federal level and incentives for states to develop paid family leave policies that include job protection for all workers who choose to take the leave.
- Expand the definition of eligible employees under the Family and Medical leave Act (FMLA) to include domestic partners and siblings, in-laws, and/or grandparents.
- Enact legislation that requires employers to provide at least five paid sick days annually for employees. For example, San Francisco has an ordinance to allow five paid sick days for workers in organizations/companies with 10 or fewer employees and nine days of paid sick leave in businesses with eleven or more employees based on an accrual rate of one hour for every 30 hours worked. There needs to be national legislation to ensure that all Americans have the security to take time away from work to care for themselves.

PRINCIPLE 5: FAMILY CAREGIVERS MUST HAVE APPROPRIATE, TIMELY, AND ON-GOING EDUCATION AND TRAINING IN ORDER TO MEET THEIR CAREGIVING RESPONSIBILITIES AND TO ADVOCATE FOR THEIR LOVED ONES AND THEMSELVES ACROSS CARE SETTINGS.

Family caregivers fill multiple roles, some of them traditionally filled by trained healthcare providers. They provide services that require specialized knowledge that many of them have acquired by trial and error. They need ongoing support, education, and training to help them provide the best care possible, to develop their confidence, protect their own health and maintain financial stability. Family caregivers should be trained in the basic skills necessary to meet the ADL requirement of their loved one. They should be educated about the legal documents that are necessary and beneficial to providing good care and lessening the potential for financial insolvency, and they should receive training in core competencies for interacting with the healthcare system, such as the basics of health literacy and effective communication techniques for working with healthcare professionals.

To accomplish this goal, funding should be increased for the National Family Caregiver Support Program and Aging and Disability Resource Centers with specific allocations for providing caregiver education and alerting family caregivers to other educational opportunities in their communities. Medicare and Medicaid should pay for caregiver training through home health and other agencies/organizations providing direct service for their beneficiaries, and hospitals should be required, and funded, to provide detailed education to family caregivers regarding the specific knowledge and skills that they will need to care for their loved one at home prior to discharge with in home follow up and direct Q & A access as part of the program. In addition funding should be available through the Department of Health and Human Services, on a grant basis, for development of education and training programs for family caregivers by organizations not directly mentioned above. The funding level authorized in the National Family Caregiver

Support Program (NFCSP) under Title III-E of the Older Americans Act should be doubled to provide further support for these efforts.

PRINCIPLE 6: FAMILY CAREGIVERS AND THEIR LOVED ONES MUST HAVE AFFORDABLE, READILY AVAILABLE, HIGH QUALITY, AND COMPREHENSIVE SERVICES THAT ARE COORDINATED ACROSS ALL CARE SETTINGS.

Patients with long-term healthcare and social needs often have multiple chronic conditions that require coordination among many healthcare providers across different healthcare settings and across the home and community-based services network to ensure that their health, social support, and homecare needs are met. Good coordination of this care and communication between healthcare providers is essential, but equally important is the continuity of care across all settings, medical and non-medical. Care and support for those with chronic conditions must be person centered and family focused and not provided solely for the treatment of a specific disease, but rather as a way to achieve physical, emotional, and social wellbeing, while also returning economic savings to Medicare. The Medical Home concept is a good step in this direction.

However, to be truly effective for the most complex and expensive of Medicare's beneficiaries, they must include the services of a patient/family advocacy and navigator team. Although there is no consensus on the definition of navigator as it applies to healthcare, the National Family Caregivers Association envisions this team being comprised of nurses, social workers, and others as deemed appropriate, that are assigned to patients and their primary family caregiver who meet certain established criteria. A member of the team would stay in contact with the patient and their primary caregiver as long they continue to meet the established criteria so they may assist that patient/caregiver during periods of crisis, transition, and also stasis to help ward off further crises. The team would steer the family through the healthcare/social support maze by being their advocate with the various entities involved, getting them information so they can better make decisions, providing them with a shoulder of support, ensuring that coordination is comprehensive, continuous, and holistic so that patient safety, high quality care and the health and wellbeing of family caregivers is achieved.

To assist in this goal, Congress should pass legislation that authorizes Medicare to establish a care coordination and continuity of care benefit for those populations that meet established criteria aimed at reducing Medicare costs and enhancing, safety, health and wellbeing for eligible beneficiaries and their primary family caregiver. For those beneficiaries who don't have a primary family caregiver, but rather a paid personal care attendant, provisions must be made to ensure that these patients and their paid caregiver receive the benefit of coordinated and continuity of care as well.

PRINCIPLE 7: FAMILY CAREGIVERS AND THEIR LOVED ONES MUST BE ASSURED OF AN AFFORDABLE, WELL-QUALIFIED, AND SUSTAINABLE HEALTHCARE WORKFORCE ACROSS ALL SETTINGS

The recent IOM report, *Retooling for an Aging America: Building the Health Care Workforce*, clearly documents the shortage of healthcare providers at every level. Each year fewer and fewer new doctors are pursuing careers in primary care and geriatrics. There has been a growing

interest in the field of nursing, but there is a shortage in the number of teachers of nursing. The problems affecting the paraprofessional workforce have been known for years, low pay, no benefits, no career ladder, and insufficient training. The report also recognizes the role of family caregivers as part of the healthcare team.

To address these problems, incentives should be provided to draw physicians into primary care, a national standard should be set for the training of personal care attendants, and requirements for the training of other paraprofessional homecare providers should be increased. To maintain an adequate supply of healthcare paraprofessionals such individuals need to have a livable wage and health benefits of their own. The rules for how healthcare services are provided and paid for needs to be overhauled to meet the needs of our aging society with its ever more complex and long-term health needs. Training in teamwork, coordination, and continuity need be part of provider education and a new profession of chronic care advocates and navigators should become part of the Medicare payment structure. Such changes are critical to providing quality and cost-effective care as the baby boomers march toward their 70s, 80s, and 90s.

Principle 8: Family caregivers must have access to regular comprehensive assessments of their caregiving situation to determine what assistance they may require.

Caregivers themselves have many needs that more often than not fall by the wayside in their efforts to provide care for their loved ones. Scientific research has shown that the stresses and strains of family caregiving can exact a heavy toll by affecting the immune system, and a caregiver's emotional health, this in turn impacts other aspects of their life, including their employment and finances and can also impact the wellbeing of the family members for whom they provide care.

Programs should must be put in place to assess the specific needs of family caregivers, separate and apart from those of their loved one. Congress should establish a family caregiver assessment demonstration program in Medicaid. Such a program will provide an assessment of a primary caregiver's own needs as part of the process that already exists for assessing a beneficiaries needs for HCBS. By assessing the family caregiver's self-rated health and well-being, willingness to provide care, and other support needs, appropriate services, education, and training, and can be put in place to promote person-centered and family-focused care and help assure the health and safety of both beneficiaries and their family caregivers.