

National Family Caregiver Program as an Element of
the Older Americans Act
by
Jean Root, D.O., M.P.H.
Founder and Faculty Member of
The Oklahoma Academy of Palliative Care Education

Enormous strides have been made in the Aging Services Network since I went into practice 27 years ago. Fledgling agencies were about the business of piecing together goods and services that were available in cities and states and making that information available to those serving the elderly population. Failure to reauthorize the Older Americans Act (OOA) is unthinkable due to the enormous number of citizens that have been able to utilize its benefits. The National Family Caregiver Program is an element of the OOA that is my particular concern today. I am in awe of the broad scope of the Program whose goals are assistance, support and education of caregivers of the elderly and disabled. One of the key aspects of the National Family Caregiver Program is Consumer Direction. This is defined as more involvement, control and choice in identifying, accessing and managing the services they (the consumer) obtain to meet their personal assistance needs. This philosophy would appear to be born out of recollections of the past when consumers were at the bottom of the list of decision makers in regard to their own care or the care of a loved one. We truly can pat ourselves on the back because of the strides we have helped consumers make. Participation in directing their own or their dependent elder's care has come to be the standard. While there are still strides to be made in Consumer Direction this is not a sufficient goal to move us up to the next level of care and coordination needed for the coming decades.

As a practicing geriatrician, I used many of the services available through the Older Americans Act to step in to troubled situations and provide basic needs to elders who could not provide for themselves. What troubles me, however, is the piecemeal nature of our approach. In reviewing the projects underway in the various states it is clear that we are still like the blindfolded men trying to identify the elephant. Crisis intervention, respite care, counseling, caregiver education and information and referral services are all admirable and necessary. The elephant, however, is the serious, chronic nature of conditions that afflict elders and require ongoing, coordinated team management. Even though the rhetoric of the Older Americans Act recognizes the chronic nature of the problems exhibited by their clientele, funding appears to be directed toward programs and services that may further fragment care and that doesn't necessarily emphasize coordination and teamwork with other entities who are also delivering elder care goods and services. Geriatric care managers are available in some locations but typically are available on a private pay basis, putting them out of the reach of many seniors with low and moderate incomes.

Palliative care is a term that in the minds of many has come to mean terminal illness care. Palliation simply means treating to achieve symptom control rather than achieving a cure. When your doctor treats your high blood pressure or your diabetes or your osteoarthritis, you are receiving palliative care

because we don't know how to cure those conditions. As we move up the ladder to more serious, chronic conditions such as degenerative neurologic diseases, and serious mental illness, 99% of the care is palliative. The inability of medicine to cure terminal illness was recognized and addressed when the Hospice movement was born. It is a wonderful model of pain and symptom management carried out by a team of professionals that tailor a plan to each individual they serve. Not only are the physical needs addressed, but the spiritual, psychological and social needs are also identified and met to the best of the team's ability. A number of studies have shown that this saves Medicare dollars. In my opinion, what is lacking in the National Family Caregiver Program is 1) the recognition of the chronic, serious nature of illnesses and conditions that lead to the need for chronic care management, 2) the establishment of a comprehensive system of palliative care based on an interdisciplinary team model, 3) the willingness to provide these services to individuals regardless of their location. Home and community based services are a worthy goal and part of the mandate of the OOA, but people move in and out of institutions and their need for palliative care doesn't change. Programs such as Money Follows the Person (deinstitutionalization) and Project 2020 (nursing home diversion) attempt to address the need to be in the least restrictive environment, but they don't really address the underlying issue of ongoing, hands on team management. In my opinion an artificial barrier exists between Long Term Care and Home and Community Based Care created by budgetary and financial exigencies and philosophical differences. No single entity is as well positioned as the AoA and the National Family Caregiver Program to initiate a national model of comprehensive, team based Palliative Care. When the OOA is reauthorized, I implore the Agency to look more seriously at a model that addresses the ongoing, chronic needs of older Americans as well as the intermittent, short-term needs. Not only is there a need to look at current models of care giving and how they can be massaged; there is a need to change how we think about the needs of the population we serve and make radical changes in how we approach them.

Respectfully,

Jean Root, D.O., M.P.H.