

Recommendations to the Services Committee Work Group Caring for the Caregiver

Goal:

1. Enable family and other informal caregivers to meet the caregiving responsibilities that they have assumed by providing support and mitigation of financial and other harms that caregiving can cause.

Priority Objectives:

1. To improve adult day services so that they are available in most, if not all, communities, at a cost that caregivers can afford so that they can have blocks of time to address their own needs.
2. To offer a minimum of 60 hours of respite services on an emergency and on a planned basis so that caregivers have available resources when needed.
3. To provide an allowance to caregivers, whose relatives are receiving services through CCP, to cover the basic out-of-pocket costs of linens, energy, OTC drugs, and similar costs that can amount to over \$5,000 a year for many low income caregivers.

Rationale

When any of us need assistance with activities that we ordinarily do for ourselves we enter into an interdependent relationship with another person or persons. The quality of care that we receive and how we experience the care within this relationship is very dependent upon the sense of the caregiver sense that she or he too is also cared for, supported and enjoys a sense of well-being. To give good care, caregivers need care. Such care facilitates the non-technical aspects of caregiving of being attentive, responsive and respectful. In its absence, care can become distorted, mechanical and instrumental. This result occurs with paid and unpaid informal caregivers and has a potential to result in financial and emotional stress, including abuse, neglect and exploitation of the care receiver.

Yet care must be given, particularly, if we are not to abandon the oldest and frailest members of our society. They cannot be assumed independent in our classical understanding of the term, since their ability to manage their activities of daily living is a collaborative enterprise. Because of this interdependency, to pit personal rights and the autonomy of the care receiver vs. the caregiver is to ignore the essential relational aspects of the situation.

Further it is important to note that caregiving has long-term practical consequences except for perhaps the most affluent caregivers. The most prominent of these consequences are lost wages and benefits and the reduced ability to save for their own retirement. This occurs partly as the result of the significant out-of-pocket costs associated with caregiving.

To make caregiving go as well as it can, we need to attend to the caregiver in many ways. It is estimated that caregivers are making an enormous social contribution to the tune of about \$400 billion a year. Adult day care, other respite services, and assistance with out of pocket costs are good beginnings. We cannot ask caregivers to set aside most of their dreams, aspirations and autonomous wishes to become the caregiver of older family members without finding ways to make it go as well as possible for them.