

# Aging Institute

*of UPMC Senior Services and the University of Pittsburgh*

Caring for the Caregiver: Testimony to Senator Bob Casey on Sandwich Generation Caregivers, 6/30/14

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Senator Casey: thank you for the work you do on behalf of seniors and their caregivers, both in Pennsylvania and in the Nation as a whole, through your work on the US Senate Aging Committee.

In the United States, more than 65 million people have provided care to a chronically ill, disabled, or aged family member or friend in the past year. Of these, about 20% or 12.9 million have provided care to both adult and child recipients (the “sandwich” generation caregiver). (National Alliance for Caregiving and AARP, 2009) The market value of “free” services provided by family members is \$350 billion annually. With respect to Alzheimer’s disease and related disorders, 15 million people provided 17.4 billion hours of unpaid care, and of those, 60% rate the emotional stress of caregiving as high or very high, and 1/3 to 1/2 reporting high levels of depression.

Family caregivers are the backbone of the long-term care system, providing millions of hours of care every year for no compensation and frequently at great cost to their own emotional health. They’re burned out and exhausted from juggling work, family responsibilities, and care giving. In addition, many caregivers have to reduce their work hours or quit their jobs to care for a loved one. Additionally, American businesses lose \$11 billion - \$29 billion each year due to employees’ need to care for loved ones age 50 and older. We need policies supporting care givers, enabling them to cope with the burden of care giving and relieving the stressors associated with their role.

At the same time, and for a variety of reasons, the overall availability of “informal” caregivers (especially those in the sandwich generation) is decreasing. The factors behind this trend include: (1) the entry of more women into the workforce (increasing the number of other obligations they face); (2) decreased birthrates (resulting in fewer children to provide care); and (3) the geographic dispersion of families (stemming from job migration and increased divorce and marriage rates).

AgingCare.com explains some of the particular issues faced by “sandwiched” caregivers as illustrated by Mary and her daughter: Mary, a 74-year old Florida woman, suffered a stroke, then required assistance with all the basics of daily life: bathing, dressing, food shopping, meal preparation, laundry and housekeeping. Her daughter took time off work to care for Mary—time that, from a financial perspective, she could ill-afford. Part of the dilemma Mary and her daughter faced was that while their state Medicaid plan covered the cost of a home health care worker to provide

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those services, local agencies were short-staffed and couldn't send aides on the schedule Mary needed. Mary and her daughter required a more flexible approach that would allow them to use the Medicaid-provided personal assistance budgets to hire their own personal care aides as well as purchase items or services, including home modifications that would help Mary live independently. I'd like now to place this case example within a broader public health and policy framework, and then return to Mary and her "sandwiched" daughter a bit later, in the context of recommending specific policies.

As you know, the journey of care giving is long and arduous, often spanning a decade or longer. The journey covers the "territory" of occasional sporadic care (appointments to physicians, light errands, checking in and monitoring), progresses to care in the instrumental activities of daily living (cooking, cleaning, shopping, managing finances and household tasks, coordinating care, monitoring symptoms and meds, and providing emotional support), and expands to care in the highly personal activities of daily living (bathing, dressing, toileting, monitoring behavior and location, dealing with insurance issues, providing acute care and managing symptoms). As the burden of heavy-duty caregiving increases on this journey, additional issues of long-term care placement (advance care planning, personal care, emotional support) are confronted, and may or may not end in death (depending upon the duration and complexity of grief). Becoming a heavy-duty caregiver is associated with increased depression, poor health, poor self-care, loss of weight, and increased chronic illness. Over time, heavy-duty caregivers decline more rapidly than non-caregivers. Care giving is a risk factor for mortality.

We understand the problem, but what can we do about it?

**Recommendation:** disseminate information about the 10 characteristics of caregivers (especially in the sandwich generation) at highest risk. They (1) provide high levels of care, (2) have lower income (< \$30K), (3) live with the care recipients (adult and child), (4) have less education (HS or less), (5) are female, (6) had no choice in taking on caregiving duties, (7) show impaired self-care and health behaviors, (8) have low levels of social support, (9) experience care recipient problem behaviors, and (10) endorse high levels of depression/anxiety.

**Recommendation:** incentivize clinicians and health care agencies to tailor interventions to the journey of caregiving, intervening early if possible to prevent the adverse health effects of caregiving: (1) address safety issues with home assessments and alterations, patient monitoring devices, and removing access to guns; (2) address self-care and preventive health behaviors via "health passports", education, monitoring, and facilitating access; (3) provide informational, instrumental, and emotional support through assistance in navigating to needed resources and to support groups; (4) help with depression and distress by facilitating relaxation/pleasant events training/respice, assistance with care coordination, counseling, treatment for prolonged grief, and coaching to resume previous and new roles.

Since, informal caregivers have a profound effect on long-term care processes and outcomes, what policies will support the engagement of families in patient care to improve outcomes, especially in dementia, and to postpone institutionalization? The Institute of Medicine of the National Academies of Science has made two recommendations (Retooling for an Aging America: Building the Healthcare

Workforce, 2008):

**Recommendation:** “Federal agencies (including the Department of Labor and the Department of Health and Human Services) should provide support for the development and promulgation of technological advancements that could enhance an individual’s capacity to provide care for older adults. This includes the use of ADL technologies and health information technologies, including remote technologies that increase the efficiency and safety of care and caregiving.” (Recommendation 6-1, “Retooling for an Aging America”)

**Recommendation:** “Public, private, and community organizations should provide funding and ensure that adequate training opportunities are available in the community for informal caregivers.” (Recommendation 6-2, “Retooling for an Aging America”)

These initiatives may be modeled after those provided by the Area Agency on Aging, which has established programs to assist caregivers in making decisions and solving problems related to their roles. Other potential models include those developed by CMS, HRSA, Geriatric Education Centers, a UK program that trained informal caregivers of hospitalized stroke patients in basic nursing and personal-care tasks, resulting in reductions of annual health care costs by more than 4,000 pounds (roughly \$8K), and the NIH sponsored REACH study (Resources for Enhancing Alzheimer’s Caregiver Health), whose intervention yielded improvements in caregiver burden, quality of life, and depression after 6 months.

Some states, including Pennsylvania, allow for the payment of family members as caregivers, and some Medicaid waiver programs allow for respite support. If we return to the case of Mary and her daughter, they were able to access Florida’s *Cash and Counseling*, a non-traditional Medicaid program that allows people to hire privately someone to provide care, deciding if they would rather hire a home health aide to cook for them, or pay a friend or relative to do it. The difference with *Cash and Counseling* is that family members and friends chosen by the elder are providing those services instead of an agency worker.

More general flexibility in HCBS waivers as we move toward managed long-term care and the integration of Medicare and Medicaid funding will produce better value for families and greater responsiveness, as well. Models like *Cash and Counseling*, exhibit more flexibility in approaching the needs of caregivers. But recall that even with *Cash and Counseling*, family caregivers are typically paid lower than average wages and, in most cases, are paid only a fraction of the hours of service they provide.

In summary, these policy recommendations recognize that family members and other unpaid caregivers provide the backbone for much of the care that is received by older adults in the US. And, although informal caregivers are vital members of the healthcare team, little has been done to impart the necessary knowledge or skills to these team members. The type of education and training needed is not currently reimbursable under most insurance plans, including Medicare and Medicaid. If caregivers (and patients) are able to manage their conditions more effectively, they are likely to use fewer healthcare resources and reduce the strain on the healthcare workforce.