

**Written Statement of Suzanne Mintz
Founder Family Caregiver Advocacy
CEO Emeritus Caregiver Action Network
to the
Commission on Long-Term Care
August 20, 2013**

I am honored to have been asked to speak to the commission regarding the role of family/friend caregivers in providing long-term services and supports. Thank you.

I've been a family caregiver for 39 years and a family caregiver advocate for 21, currently as the Founder of Family Caregiver Advocacy but for the majority of my career as the Co-founder, President and CEO of the National Family Caregivers Association. This combination of roles has had a direct impact on my beliefs and ideas regarding long-term care which I believe would not have developed if my personal and professional lives were not intertwined.

My husband Steven was diagnosed with Multiple Sclerosis, a degenerative neurological disease that generally affects young adults, when he was 31. Last month he turned 70, and now needs help with all the IADLs and ADLs as well as some medical interventions on a daily basis such as catheterization, wound prevention and care, and monitoring of vital signs. We do have some help two evenings/mornings a week, but I am Steven's primary caregiver and also his unlicensed nurse.

Because I came to caregiving as a young adult and because my husband has a chronic disease that has over time severely disabled him, I've never believed that long-term care (LTC) is solely an issue for a senior population. Nor have I believed that it is primarily about getting goods and services to those who need it in the community or ensuring that nursing home care meets high standards.

I firmly believe that care over a long period of time for anyone who cannot care for themselves, in an age-appropriate way, requires an integrated approach to that person's health, their goals, and their overall wellbeing, and that of their primary caregiver, who most likely is a family member or close friend.

The long-term care issues confronting America are well known. They include:

- An aging population,
- A fragmented healthcare system based on providing acute care on a fee for service basis as opposed to integrated holistic family- centered care for all situations

Family Caregiver Advocacy
9621 E. Bexhill Drive
Kensington MD 20895
301 949/3638

- Inadequate healthcare workforce at all levels
- Ever shrinking state and federal budgets to support needed change and needed services

For individuals and families there is the:

- Fear and isolation of dealing with unknown and frightening circumstances
- Difficulty of navigating the healthcare system
- Lack of knowledge about, and access to, available HCBS resources,
- High cost of providing LTC at home, despite the low wages of paraprofessionals
- The cost for those not on Medicaid and the general undesirability of LTC institutionalization

The negative impacts of family caregiving are also well known. They include:

- Greater risk of chronic conditions, including depression
- High rates of stress and substance abuse
- Premature aging
- Decreased income both in terms of employment and retirement

Because all of these issues have been well documented I will not discuss them here but it is important to remember that caregiving is a relatively new phenomenon. 1900 the average age of death was 46. Penicillin first became available during WWII. Since then modern science has discovered medicines, treatments, diagnostic equipment, and sometimes cures that have helped millions of people live longer and healthier lives. Add to this advances in environmental science and policy and what we have learned about good nutrition, it is no wonder that the average age of death is now 78 and people over 85 are fastest growing cohort in the country. Ironically all these advances have helped to create today's long-term care crisis because with advanced age comes more physical and mental chronic illness and frailty.

Progress has certainly been made in helping families deal with the long-term care issues they confront. These include: the National Family Caregiver Support Program and paid family and medical leave in a number of states.

These important programs help people deal with the consequences of being a family caregiver but they do not address the underlying causes. I believe we need to look at the problems of long-term care through a different lens. No one needs long-term care unless they have a chronic disease or disability or live with the frailties and consequent physical and/or mental problems that come with old age. The silo approach that has always existed between

Family Caregiver Advocacy
9621 E. Bexhill Drive
Kensington MD 20895
301 949/3638

healthcare and long-term care needs to be broken down and the two integrated just as they are integrated within all of us.

Although the majority of family caregivers care for loved ones who are elderly, it is now accepted that caregiving is a lifespan phenomenon, and there is a growing recognition that the solutions to the problems associated with family caregiving and long-term care need to be holistic, combining both healthcare and social services and supports in a well coordinated, and dynamic way that is individualized to the needs of each person and their primary caregiver.

Unpaid caregivers assist family members or friends who have chronic conditions and/or disabilities or who are living with the frailties of old age. This population cohort interacts with the healthcare system more than any other. Their need for supportive goods and services stem from their condition and needs to be part of their coordinated treatment plan. For too long healthcare and long-term care needs have been seen as separate and meeting them has been done in silos and not been coordinated, but in the lives of people living with these needs everyday they are not at all separate. They are intertwined. It is my hope that although the name of this commission is the Commission on Long-term Care that it's focus is on the health and well being of Americans with physical and or mental needs over the long term.

Recommendations for Assisting Family Caregivers and Their Loved Ones Needing LTC

Recognize that the primary caregiver and care recipient are a dyad and therefore should be treated as such in terms of both healthcare and support services.

I recognize implementing the dyad concept would be extremely complicated for many reasons, not the least of which is that not all persons with chronic conditions and their caregivers have the same health insurance, so who picks up the tab to cover the costs related to the health of the family caregiver. It is generally believed that family caregivers improve their loved ones health and save the system money and there is some evidence that this is so. In the recent report, "Home Alone: Family Caregiver Providing Complex Chronic Care by AARP and the United Hospital Fund "patients" with family caregivers were able to delay or avoid institutionalization. It will take a lot more evidence to prove that supporting family caregivers is in the financial interest of Medicare and other insurers, but one way to do that is to institute dyad care for a designated portion of the chronic care/disability population and measure the results.

Family Caregiver Advocacy
9621 E. Bexhill Drive
Kensington MD 20895
301 949/3638

Document family caregivers on their loved one's medical records and their own, in order to assess, train, support and enhance their ability to function as successful members of the care team

Recognizing a caregiver's existence is the first step in building a better care team. The Office of the National Coordinator recognized this in its first Stage Three recommendations by saying that care team members, including family caregivers need to be documented on medical records. A meeting is planned for October 25th to explore this issue in detail.

Assign care managers to designated patients and their primary caregivers

An active and multi-disciplinary care management team can provide support, education and training; alert the healthcare team to changes in symptoms before they become serious, coordinate with the healthcare team, research and help obtain goods and services that caregiving families need to have a good quality of life. Care managers can enable patients and caregivers to be more engaged and assertive and help them achieve their goals while keeping healthcare issues under control.

Create Community Health Teams.

There is a little known provision in the Affordable Care Act that calls for the creation of Community Health Teams to support patient-centered medical homes (section #3502).

These are multi-discipline teams that coordinate holistic care for patients, enabling them to access health and social services and supports. Although this provision has never been funded, there are examples around the country where this approach has been successfully implemented with Medicaid populations. Vermont is one of the states that have successfully implemented this concept. <http://content.healthaffairs.org/content/30/3/383.extract> Putting together health teams like the one described in the link for designated dyad Medicare beneficiaries is an approach worth trying.

Create a Chronic Care Benefit in Medicare.

Long-term care is an expensive proposition whether provided in a facility or at home. Private LTC insurance has not proved to be a highly successful means of covering the costs for most of the population and the CLASS Act provision of the ACA, which would have permitted employees to fund some of their future LTC costs, was dropped.

A number of other solutions have been proposed for helping families with the cost of LTC including providing family caregivers with an income tax credit. This could be a complicated and expensive approach and would still require caregivers to fund care out of their own pockets.

Family Caregiver Advocacy
9621 E. Bexhill Drive
Kensington MD 20895
301 949/3638

Giving social security credits to family caregivers who leave the workforce has merit but given the current climate in Washington would not fare well in Congress.

One alternative for ameliorating the costs of LTC is to lessen the out-of-pocket expenses of caregiving families. This could include creating a Chronic Care Benefit in Medicare to cover a portion of the costs of products and services that are used extensively by caregiving families and which they now must pay for on their own.

Non-medical homecare, accessibility safety items and incontinent supplies are among those goods and services most frequently asked for. Covering at least partial costs of these goods and services as part of a chronic care benefit would provide both respite and some financial relief for caregiving families. According to the National Alliance for Caregiving 35% of caregivers pay for homecare services now. Ironically Medicare will pay to fix someone's broken hip if they fall in the bath, but not for the means to prevent the fall in the first place.

Support the growth of volunteer communities.

Not all solutions to the problems of LTC require funding. Volunteerism is playing an important and growing role in assisting family caregivers in providing LTC.

The internet and the aging in place movement have led to the availability of free help for those who need and want it. On line programs such as www.lotsahelpinghands.com let family, friends, and neighbors sign up to become a community of helpers for a specific caregiving family during a crisis and beyond. The site's scheduling software coordinates the caregiver's needs with the volunteers who have signed up to provide those services. Since its inception in 2005 thousands of Lotsa communities have been established.

The village movement is a more sophisticated approach to meeting the needs of those living in place. NCB Capital Impact leads a national effort to support and help grow the village movement across the country via the Village to Village Network. www.vtvnetwork.org. Villages are incorporated non-profit entities that often use both volunteer and paid services to meet the needs of its members who pay an annual fee to participate in the village. Over 220 villages have been established to date. They provide non-medical and medical supports in accordance with independent living principles and also social activities in an integrated framework to meet the needs of those wanting to age in place.

With so many Americans living far from family and formal LTC services so expensive programs such as Lotsa Helping Hands and Villages are on the cutting edge of a new approach to solving at least some of the problems associated with LTC. As more baby boomers age into needing care themselves they will likely use the knowledge they have gained in caring for their parents, the first generation to need significant caregiving, to develop ever-more innovative ways to

Family Caregiver Advocacy
9621 E. Bexhill Drive
Kensington MD 20895
301 949/3638

meet these challenges of LTC with an emphasis on solving the problems that they themselves faced as the vanguard of America's family caregivers.

In summation

Treat family caregivers and their loved ones as a dyad when it comes to their health and social support needs.

Document family caregivers on medical records as a first step in this process and for improving patient care and safety and family caregiver wellbeing

Assign care managers to designated caregiving families to enhance their ability to obtain the care they need, improve their quality of life, and meet their goals, while simultaneously aiding the healthcare system to achieve better care outcomes for their most vulnerable patients. Incorporate them into the broader concept of Community Health Teams that break down silos to provide a comprehensive set of services to caregiving families.

*

Once again thank you for the opportunity to present my ideas to the Commission. I am available to answer your questions and explore their possibilities.

Family Caregiver Advocacy
9621 E. Bexhill Drive
Kensington MD 20895
301 949/3638