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Committee on Family Caregiving for Older Adults
Keck Center
500 5th St. NW
Washington, DC 20001

Statement of
Joanne Lynn, MD, MA, MS
Director, Center for Elder Care and Advanced Illness
Altarum Institute
Joanne.Lynn@altarum.org

For the Institute of Medicine Study of Family Caregiving for Older Adults

I am Dr. Joanne Lynn, and on behalf of the Center for Elder Care and Advanced Illness at Altarum Institute, I am pleased to contribute to the Institute of Medicine’s long-awaited examination of the state of family caregiving support and how it can be improved during an age of longevity.

The past century has seen a fundamental shift in the structure of family life, which is particularly evident in the way we care for frail elders. Until recently, most people did not live long with disabilities and fragile health. The few frail elders needing long-term care usually lived with their relatives, where they were cared for by a family member, usually a woman. The situation has changed. Today’s 65 year olds will need an average of 3 years of long-term care. But today, fewer families are able to provide full time care—women cannot afford to stay out of the workforce full time, and risk their own retirement security when they do. Adult children often live far away from their parents, although some continue to provide limited care from a distance. The adult children are themselves older, have less adequate retirement security, and often live in housing that is inadequate for the frail elderly person. In the foreseeable future, due to declining birthrates and changing family composition, a sharply declining number of caregivers will be available to care for a dramatically increasing number of Americans who need substantial daily support due to conditions associated with aging.

Nevertheless, family caregivers will continue to play a vital role in our health and long-term care systems. Caregiving, in many ways, is what defines family and neighbors. In 2009, about 43.5 million Americans were caregivers to adults over the age of 50. Family caregivers have traditionally been the backbone of the long-term care system, and also fill many gaps in the health care system, functioning as care managers and coordinators and care providers. This frequently means not only assisting with activities of daily living, such as eating, toileting, and bathing, but also providing complex medical care. A 2012 study
found that nearly half of family caregivers reported providing care that health care professionals would have traditionally performed only in a hospital setting, including tasks such as managing medications, cleaning wounds, and giving injections. vi

Addressing these challenges is central to the health and well-being of family caregivers themselves and also for the elders relying on their voluntary support. Volunteer caregivers routinely are not mentioned in care plans for dependent seniors, are not asked what assistance they need for themselves, and are often not provided any training for the extensive tasks they perform. vii When caregivers are unavailable or no longer able to perform the necessary tasks, whether due to stress, an injury or illness of their own, or other circumstances, an alternative plan is rarely pre-planned to ensure that elders receive the support they need. Yet despite the fundamental role that caregivers play, their activities are not tracked and only rarely acknowledged as a key source of support for long-term care.

New approaches are badly needed. America’s fragmented health system is failing to meet the needs of frail elderly beneficiaries and their caregivers. One comprehensive approach, MediCaring viii Accountable Care Communities (ACCs), viii locally run organizations that integrate health care and social supports for frail elders, could be chartered to monitor and manage health and social services together, thereby ensuring that communities can appropriately assist family caregivers. Care teams would engage elders and their loved ones in the development of a comprehensive and goal-oriented care plan for the frail elder they are supporting. MediCaring ACCs would ensure that family caregivers were asked about their health status and ability to provide care, and that that they knew how to readily find the resources and help they need, such as hands on training, emotional and coping strategies, and access to respite services. Importantly, every care plan will integrate the needs of the caregiver, too.

Harnessing the energy of non-family neighborly volunteers is another important solution for supplementing the role of family caregivers and addressing the emerging care gap. The Caregiver Corps Act, introduced in 2014 by Senator Casey of Pennsylvania, and the National Care Corps Act, introduced by Rep. Lujan Grisham of New Mexico, aim to help local organizations recruit, train and organize volunteer caregivers to provide practical assistance and companionship to frail elders and people with disabilities in their communities. Locally organized Care Corps could improve the quality of life for homebound frail elders and individuals with disabilities and help family caregivers by allowing them a much-needed break or the ability to spend a few extra hours at work. Policymakers can and should consider doing more to support membership programs at the community level, such as the Village to Village Network, which allows elders to remain in their homes by coordinating the services they need through paid assistance and volunteers. ix

There are a number of additional steps that we can take to ensure that family caregivers have the vital support required to continue providing health care and long-term services and supports. Approximately 75% of caregivers of adults 50 and over have been or are currently employed while providing care, and caregivers will continue to juggle work and caregiving duties. x Given this reality, employers should develop and routinely offer flexible scheduling, telecommuting, and paid leave to working caregivers.
Currently, the U.S. offers caregivers significantly less support than other developed countries provide. For example, much of Europe has enacted laws guaranteeing caregivers access to respite, health care, and continued pension contributions. In order to enact real change here, family caregivers themselves must be encouraged to take action and demand a seat at the policy table to discuss possible reforms. For a variety of reasons, caregivers of the elderly in America have not organized as a political group. Yet nearly all of us will be caregivers at some point in our lives. Together, we must assemble to demand much better access to respite services, credits under Social Security for those who provide care full-time, and flexible scheduling for the many who both provide care and work.

In a recent blog for Altarum, Alice Bonner and I laid out additional concrete steps caregivers can take to advocate for change: Reach out to your local town council members or commission on aging and get long-term care on their agendas. Or, form a local coalition of health and social services providers to discuss how to launch a program that is designed to provide more appropriate, less wasteful care and that uses saved funds for buttressing supportive services that are essential to the stability of frail elders – and family caregivers. Now is the time for action that can ensure our own futures, both as family caregivers and as people who will one day also need care.

Sincerely,

Joanne Lynn, MD
Director, Center for Elder Care and Advanced Illness

The Center for Elder Care and Advanced Illness focuses on optimizing care transitions and continuity and quality of care for frail elders, so many of whom experience medical errors and gaps as they move around within our fragmented care system. Altarum Institute is a nonprofit research and consulting organization that integrates independent research and client-centered consulting to create comprehensive, systems-based solutions that improve human health.

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