

Testimony of

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Hearing on *Populations in Need of LTSS and Service Delivery Issues*

Good afternoon, members of the Commission. I am Dr. Joanne Lynn, and on behalf of the Center for Elder Care and Advanced Illness at Altarum Institute, I am pleased to be invited to contribute to this pivotal national discussion of how we can come together to transform our health and long-term care systems to achieve reliable care at a sustainable per capita cost.

As a geriatrician, researcher, educator, public health official, and Medicare medical officer, I have served thousands of very ill elderly people in various settings, including their homes. Having also served public policy at the federal and local levels, I understand various perspectives on the health care issues that face frail older adults in our society. And as an old person in training, I have some perspective on what my own future holds in this regard. Indeed, most of us in this room will live to become frail when we are old. Some will succumb to cancer or another disease that shortens life — but most of us will live into our 80s, 90s and perhaps even beyond. During that phase of life, we will experience a trajectory of increasing disability and frailty – enjoying all we can of life despite various illnesses, worsening muscle weakness and a gradual decline of overall reserves. And half of us will also struggle with cognitive impairment. We will have years of depending on others for help with our daily care.

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As matters stand now, care provided to frail elderly persons is usually poorly planned and regularly inflicts inappropriate services, unnecessary and unwanted treatments, and overwhelming personal, financial, and emotional costs.

So how can we change our own futures? Not by relying on federal resources alone, or state resources alone. And certainly not by expecting that each individual has to figure it out for himself or herself. Too many people are already too old or too poor to save enough, and the system is too complicated. Any one of those approaches, by itself, ensures failure. And failure would mean crippling costs or abandonment – both even more serious failures.

Simply put, services for frail elder persons, individually and as a group, need to be planned far better than they are currently— which, in many instances, is that there is no planning at all. Most things that go wrong are predictable and many are preventable — and nearly all can be improved with forethought. Now is the moment for us to review, confirm and, organize what we know, and make the greatest possible use of our combined federal, state, local, private, and volunteer resources.

My experience working with patients, care teams, and communities aiming to improve care for frail elders has taught me much, but this in particular: This country can do better. Those who are involved in serving frail elderly people should be expected to (and freed to) implement best practices in geriatrics and to use insights from gerontology research. We have models of care that meet the needs and reflect the priorities of frail elder people; but tradition, habits, rules, and incentives keep us mired in dysfunction. We do not even have the practices and rules that call for clinicians and frail elderly patients and their families to come to understand the patient's situation and what lies ahead.

A major opportunity lies in having some community-level management of the delivery system for frail older people. Frail elder persons are highly dependent on what their immediate community can offer. If someone needs to be spoon fed, for example, that person will not be able to travel somewhere to obtain that assistance. They have to stay home, wherever that was, and wait for health and long-term care services to come to them. We need to be efficient in the way we provide these and other home-based services.

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That strategy starts with acknowledging — using as a vehicle, a carefully designed, comprehensive care plan — that people in the latter phase of life have priorities that are quite different from those held by people in this room. As we approach the end of life, we will value relationships and shun isolation; we will value keeping control of what we can manage and we will disdain being regimented or warehoused. We will also seek comfort and reliability and we will certainly want to avoid disruptive or painful interventions. We will not generally be eager to leave this life, but most of us will have come to terms with the fact of our mortality.

Contrast this vision with the care system we have today, which is structured around the hopes and fears of middle-aged men and women: ready access to emergency services and dramatic medical interventions. But what we now need — immediately — is to build a care system that takes into account the hopes and expectations of an 88 year old person who is living alone with disabilities and other limitations.

A care plan to meet the needs of most people in this room could be fairly simple; but the plan that is needed when you are frail and disabled is usually complicated and must take many disparate factors into account. Most of the services that younger adults seek and receive reflect a single symptom or diagnosis.

In old age, waiting to react reflects poor planning and inadequate knowledge and yields suffering and costs. For a 92-year-old man to show up at an emergency room where no one knows his situation, preferences, or plans indicates a thoughtless lack of planning. For that same man to show up at his physician's office where no one knows his situation, preferences, or plans is thoroughly outrageous. Yet, that's the standard. We don't even have a way to put a comprehensive care plan into our evolving electronic health record system.

Meaningful use requirements for hospitals and physicians to earn financial support for electronic health records do not require documentation of function, likely future course, or care plans. We don't have any way to measure the quality of care plans against outcomes – even though, for frail elderly people, this is nearly all that matters: are we serving the person's priorities effectively? The most important outcome in frail elder persons — from their perspective — is how you can live in the life remaining.

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Today, a physician can order up any treatment or test for a frail elderly patient, with virtually no regard to cost. Yet, we cannot get a home health aide to keep the person clean, or a good nutritious meal, or a place to live, thus saving a huge amount in medical costs down the road, unless we place the patient in nursing home facilities and the like. This has to be the most expensive scheme for supporting housing, food, hygiene, and personal care that one could imagine, and it has been the source of all manner of dysfunction. Virtually every other country, even “underdeveloped” ones, provide housing and food for its disabled elderly persons, but we do not. Virtually every other country provides support for family caregiving, but we provide so little that you can hardly see it.

In fact, we begrudge providing social support services, leaving them as a set of poverty programs that come and go, causing service gaps and frustration, while we treat medical services as an open-ended entitlement. This pattern does not match the needs of frail elders now, and unless we do something about it, the mismatch will become extremely severe and the consequences extremely expensive, as the number of frail elder persons in this country rise.

For those who continue to hope that the family can step in to save the day, the facts are against you. We will have too few 21st century family caregivers, and they will often have to work or will be disabled themselves. Similar to the declining ratio of workers to retirees, the number and availability of family caregivers will decrease dramatically during the coming age wave.

The budget-focused proposals that are now circulating in Washington seem to presume that the main strategy is to get the financial incentives right in Medicare and Medicaid. The prevailing wisdom seems to be that, if we can just get the financial incentives right, the clinical service array would follow. This is implausible, both in terms of logistics and cost.

Instead, this Commission must be more direct in working to reshape the existing service delivery system. We should talk, for example, about how we can enable local governments, public health offices, coalitions of providers, and Area Agencies on Aging to take a leading role in measuring and managing the supply and quality of services for all frail elderly residents across each community. That care, like so much in life, is — and must be — local.

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This type of community-based planning could readily be implemented on a broad scale. Once we require good care plans for every frail elderly person, a local coalition or agency could monitor performance by aggregating and geo-mapping the service needs from those care plans. This would make it easy to see where the community has undersupply, oversupply, or poor quality; this would pave the way for efficient action to optimize services. We would see, for example, that it is not efficient to have multiple home care agencies traveling across a metropolitan area twice a day to serve clients who live in adjacent apartments. At Altarum Institute, we are working to establish multi-disciplinary networks of providers in urban and rural communities who can follow each frail older person's unique care plan, and who will be accountable for meeting quality measures.

For your consideration, we've developed some achievable policy recommendations. I won't go through them now, but am happy to take questions now or to have follow-up conversations. We wish you the greatest success possible in the short time you have, and hope you will count on us to serve as full and enthusiastic partners in our mutual quest to improve long-term care.

Thank you.

Recommendations to the Long-Term Care Commission from Altarum Institute's
Center for Elder Care and Advanced Illness

Recognizing that the Long-Term Care Commission is charged with advancing policy recommendations to improve the coordination and quality of care and the competency and quality of the workforce, we suggest that the Commission consider making strong recommendations in the following areas:

1. Quality/coordination of care metrics for physicians should be broadened to incentivize, and then require, comprehensive care planning for frail elders;
2. Direct care workers should be given a fair deal on income, access to their own health care services, solid baseline training, and ongoing opportunities for further education and expansion of skills;
3. Family caregivers should be provided with both general guidance and hands-on training about how they can — if they agree to do so — provide supportive services to an ill or disabled loved one and given access to their own respite services.
4. Communities should be allowed and enabled to take on some monitoring and management of their elder care system, including hospitals, housing, care at home, rehabilitation, hospice, transportation, nutrition, and other essential needs. To do so requires standardization and availability of some data sets and re-examination of the role of geographic concentration and provider competition.

More specific ideas to achieve the four broad goals outlined above include:

Quality/coordination of care

- Recommendation to HHS to give higher updates under a reformed Sustainable Growth Rate (SGR) physician payment system to practitioners who can demonstrate that they (1) have comprehensive care plans for more than 50% of their patients who are over 80 years old or who have disabilities; (2) are providing continuity of care across settings to more than 70% of their patients; and (3) ensure that an appropriate clinician follows up within 24 hours of when a new issue arises for a disabled patient living at home or in a nursing home.

- Recommendation to the Office of the National Coordinator (ONC) for Health Information Technology to provide, as part of implementing “Meaningful Use” Stage 3 standards, an optional place for recording care plans in the electronic health record. Thus, practitioners and providers who are serving frail elders will at least have a place to record the plan and help move it across settings of care. This recommendation could also ask ONC to work with the Agency for Health Research and Quality and the Centers for Medicare and Medicaid Services to standardize some elements of the care planning process, the care plan documentation, the continuity of care plans across settings of care, and the evaluation of the performance of care plans.
- Recommendation to HHS, in consultation with outside experts, to identify a set of core quality care measures for persons who need long-term services and supports — a set that encompasses process, outcomes, and quality of life measures, which includes measuring whether the services helped the patient achieve important goals. This could be combined with a requirement for HHS to examine core quality measures for long-term services and supports that are collected by states from contracting providers as part of reviewing and approving Medicaid waivers and demonstrations, and for all programs serving dual eligible persons.
- Recommendation to HHS to develop a new option under Medicare and Medicaid for frail elder persons, in consultation with the Administration for Community Living, to establish a coordinated services delivery and payment reform model similar to ACOs, which explicitly requires including providers of long-term services and supports (including those offering options for counseling, housing assessments, nutrition services and transportation). Approved entities would provide services within defined geographic areas and include aging services network providers and relevant community-based organizations, as well as medical and nursing services.

Direct care workers

- Recommendation to the Obama Administration to issue a final rule broadening Fair Labor Standards Act protections to include personal and home care aides; prompt evaluation and widespread dissemination of the “best practices” training programs that have been developed under the

Personal and Home Care Aide State Training Program (PHCAST), along with seed funding for Sec. 5302, Subtitle D, of Title VII of the Public Health Service Act, which provides tuition assistance for direct care workers seeking to expand their skills.

Family caregivers

- Recommendation to Congress to require standardized assessments of all family caregivers who seek assistance for themselves or their loved ones through Area Agencies on Aging, Aging Disability Resource Centers, and Medicaid home and community-based waiver and demonstration programs; such assessments would include asking the family caregiver which services (e.g., respite, lifts, monitoring devices) would be most helpful.
- Recommendation to the Institute of Medicine to undertake an analysis of what kind of training and support would most benefit family caregivers who commit to caring for ill and disabled loved ones in a safe and voluntary manner.
- Recommendation to Congress to establish a “Caregiver Corps” of community-based volunteers (ranging from young college graduates to retired adults) who could be screened and trained to provide assistance to homebound frail elders in need of assistance with Instrumental Activities of Daily Living (e.g., chore services, shopping and household management) as a way of contributing to the community’s welfare, in return for a very modest stipend, credit, room and board, or other return.

Community monitoring and management

- Recommendation to HHS (CDC, CMS and AHRQ) to cooperate to develop public health metrics by geographic area for frail elders, so that trends can be monitored and priority needs identified at a community level.
- Recommendation to HHS (Medicare and Medicaid Innovation Center) to provide technical assistance to communities that are willing to learn how to monitor and manage a care system that is reliable, efficient and sustainable for its population.

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- Recommendation to HHS to provide technical assistance that enables shared savings among practitioners and providers willing to contract to serve a targeted population such as frail elders on an ACO –like model for communities that excel at high-quality services, delivered efficiently.