

**Testimony of Joanne Lynn, MD, MA, MS**

**To the Ways and Means Committee of the**

**U.S. House of Representatives**

**Caring for Aging Americans**

**Thursday, November 14, 2019**

Good morning. Chairman Neal, Ranking Member Brady, and other Members of the Committee: Thank you for holding this hearing, focusing attention on the challenges that doubling the numbers of elderly persons living with progressive disabilities will pose – and within just fifteen years. I commend the Committee for your work on retirement security and Medicare coverage for hearing, vision, and dental care; and I am heartened to find that you are seeking to address the set of long-term disability challenges that are most often ignored. Most Americans will live with serious disabilities in old age, for an average of two years. We should be able to count on living comfortably and meaningfully in those years, with costs and burdens that elders, their families, their communities, and the nation can manage.

I have been a physician for 45 years, mostly serving elderly persons and hospice patients in Washington, DC. I have written hundreds of professional articles, books, and chapters; and dozens of publications with and for public bodies. I have been a tenured professor at two medical schools, a senior researcher at Rand, and an official at the Centers for Medicare and Medicaid Services (CMS) and at the Washington, DC, public health department. I am an elected Member of the National Academy of Medicine. I am now a Health & Aging Policy Fellow and am continuing to work on innovative projects at Altarum's Program to Improve Eldercare. However, my work, like so many others, amounts to little if our country continues to drift into tolerating the effective abandonment of elderly persons in their last years.



When I was a child, thoughtful people already realized that the Boomer generation, celebrated as “Man of the Year” on TIME in 1967, would eventually grow old together and that we should make plans. We did not. Medicare passed in 1965. Perhaps we thought we had addressed the major barrier to good health in old age – the cost of medical care. Medicare has succeeded in protecting older adults and their families from many of the costs of surgery and drugs. But the size of the elderly population and its needs have changed. Between 2010 and 2035, the population of elders in the U.S. will double – and will grow as a proportion of the overall population for at least a dozen years more. Many elders are healthy when they turn 65, the traditional retirement age. But virtually all of us, Members and staff

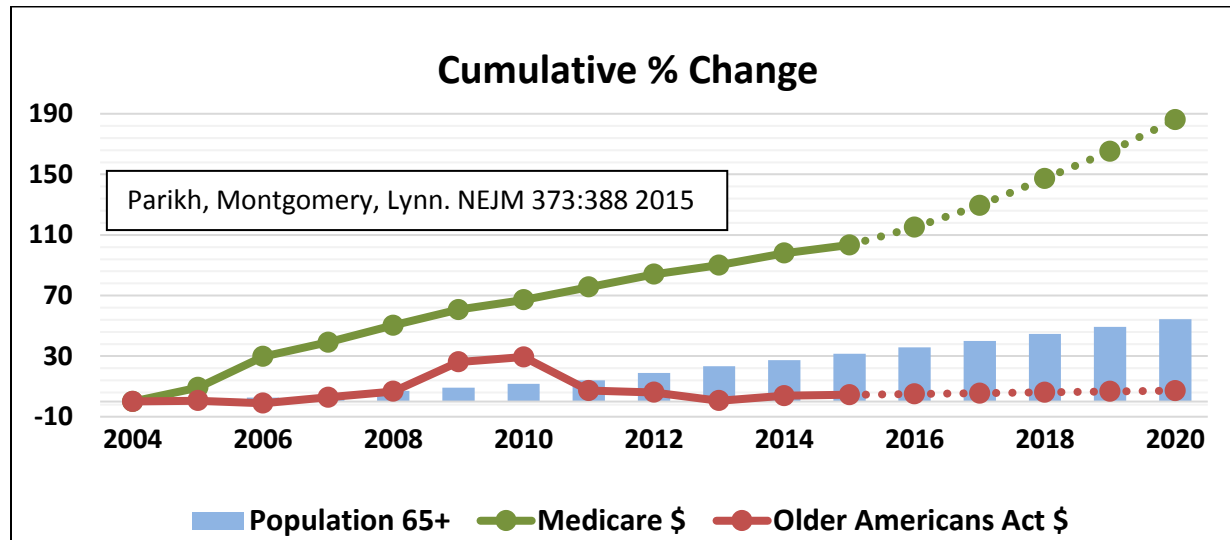
included, will have serious degenerative conditions causing progressive illness and disability in our last years. We all know this in a vague way, but mostly we remain unaware of how expensive and dysfunctional our long-term services and supports (LTSS) arrangements are – until we must support an older relative or friend. Very few of us die suddenly, without antecedent illness, except from violence.

In a long life, a period of disability is expectable; yet the average retiree now often has insufficient assets and income to provide for housing and food while that person is still independent and well. Half of Americans ages 65–74 have no retirement savings at all.<sup>1</sup> A recent simulation of population dynamics for the next ten years showed, stunningly, that most people who had a middle-class income during their working years would be unable to purchase housing, food, and medical care as retirees in 2029.<sup>2</sup>

The experiment of abandoning most pensions and giving individuals the responsibility to manage their savings thoroughly failed in the recession of 2008. Many middle-aged Americans found their mortgages upside down and had to use savings to keep their families afloat, even though they would not have enough years to recover before retirement. Furthermore, the erosion of the buying power of wages has made saving nearly impossible for many. Also, the cumulative effects of disadvantage over a lifetime affect women and minorities severely. For example, in their sixties and seventies, the average Black adult has one-seventh of the wealth held by a White adult.<sup>3</sup> Women bear the brunt of the challenges of old age,

first as unpaid caregivers for parents, spouses, and/or disabled adult children, and then as disabled widows. Fewer adult children or other younger potential caregivers are available nearby to help, as families have fewer children, who often move away or must work two or three jobs themselves.

Our social support arrangements are inadequate, since the Older Americans Act (OAA) has never been funded at a level that meets the needs. Thus, many cities now have more than six-month waiting lists for home-delivered food; a disabled man in Memphis waited a year for home-delivered meals.<sup>4</sup> The waiting lists for disability-adapted and affordable housing are routinely longer than the lifespans of those in need. Federal funding for supportive services has lagged behind population growth for many years.



Old age could be rewarding, and we could accomplish that without stunting the economy or abandoning our elders. We urgently need a vigorous discussion of the honest facts and a spirit of innovation and learning that moves us to action. We could build a social system that makes it possible to count on living as comfortably and meaningfully as possible through that period of disability and illness that will eventually take our lives. In this written testimony, I will sketch out the scope of needed reforms. But, do be aware that addressing financing and housing will require long lead times and thus must be on the agenda now. In addition, current performance of the care system is so frustrating and hazardous to elderly people and their families that we must also address those dysfunctions soon.

### **Reforms in Financing**

The growing ranks and the older ages of older adults will double the needs for medical and supportive services by the early 2030s. The escalating prices of medical treatments and personal care will also increase the costs. Elders eligible for Medicaid will increase dramatically, but state budgets will be unable to escalate to match the needs, so states will probably have to restrict enrollment. Ever more elders will fall into the gap between Medicaid coverage and adequate personal assets; they will be unable to afford essential supports and will have to confront homelessness, food insecurity, inability to manage personal hygiene, and being unable to pay the premiums, co-pays, and deductibles in Medicare.

Addressing these challenges requires pragmatic planning. The financing of personal care for disabled elders cannot come entirely from escalating taxes. Not only would that be politically difficult, but the numbers in need and the costs of their care are likely to exceed the capacity of the economy to generate

enough revenue at the time needed. In contrast, personal savings, including buying insurance, stimulate the economy. At present, society provides few financial vehicles that make it easy, expected, or appealing to save for illness and disability in old age, even for middle class families where lifelong savings would be plausible. Rearranging certain social policies to generate private savings adequate to cover a substantial proportion of the costs of disabilities in old age is an urgently needed strategy.

The Bipartisan Policy Center contracted a simulation of an appealing strategy to finance long-term services and supports (LTSS).<sup>5</sup> In short, a state or federal government would cover long durations of LTSS needs, called the “tail” of long-term care. The “front end” then might be addressed, in part, with state initiatives like the one implemented in Washington state;<sup>6</sup> otherwise, the first years of covering the costs of LTSS would remain with elders, their families, and their communities. For impoverished elders, Medicaid would continue to cover services. The time that individuals would need to cover would depend upon that person’s income during their working years. A person earning low income might only need to self-fund the first year of needing LTSS, while a person with high income might have to fund five years.

When modeled in this way, the social insurance component could be financed with less than 1% added to the current Medicare tax. Public coverage of the “tail” of long-term care would make risks and costs predictable, thus stimulating a market for front-end coverage. At age 50 or so, people could estimate their risk of needing LTSS and their likely family situation. They could prudently save or insure to cover the predicted costs, thus avoiding incurring unexpected financial hardship on themselves and their family. An approach like this would encourage savings and investment to mitigate risk, and the model shows a 23% reduction in Medicaid costs as well. Other options should be tested, like adding some LTSS coverage to Medigap plans, as is being considered in Minnesota.

The challenges of financing LTSS costs for elders living with disabilities point to the urgency of ensuring that young adults are well-equipped to be productive in economic terms.<sup>7</sup> Other countries such as Japan have recognized that a shrinking pool of workers requires higher productivity per worker. Nearly half of American childbirths are now covered by Medicaid,<sup>8</sup> signaling very impoverished mothers and limited opportunities for the child. One-third of our young Black men experience incarceration over their lifetime.<sup>9</sup> The well-being of all Americans requires investing in young people to build a healthy economy.

In addition to exploring needed major reform, the federal government should undertake some more modest reforms, such as removing the HIPAA requirement to offer 5% compound inflation with long-term care insurance (LTCI) policies, permitting penalty-free distributions from tax-privileged retirement accounts to purchase LTCI, allowing tax-advantaged long-term care savings accounts, and sponsoring substantial public education about retirement security and LTSS needs.<sup>10</sup>

Altarum’s Program to Improve Eldercare modeled improved medical care for elders living with disabilities, showing that implementing known quality improvements and efficiencies in medical care in a geographic community would net savings of \$267-\$537 per beneficiary per month, which could be a substantial contribution to meeting LTSS needs, if there were a way to harvest and employ the savings.<sup>11</sup>

### **Reforms in Housing**

Without improvements, more than half of Americans who lived their working lives in the middle class will be unable to afford housing in retirement, within ten years.<sup>12</sup> This risk of being homeless in old age hits even before these elders encounter serious disabilities and illnesses and those costs. We already have a

growing population of elderly nomads who live in cars and tents. Without serious attention and planning, we will have elderly paupers on our streets and in our parks in large numbers.

The housing we need for elders must be adapted to living with disabilities. Most of our housing has steps, narrow halls and doorways, and dangerous bathtubs and showers. Still, most elderly people strongly prefer to stay in their homes. The CAPABLE (Community Aging in Place—Advancing Better Living for Elders) project, a successful innovation sponsored by the Center for Medicare and Medicaid Innovation (CMMI), enabled minor housing renovations to improve safety and usefulness of existing housing and showed remarkable reductions in hospitalizations, falls, and nursing home placement.<sup>13</sup> In 1985, Singapore started requiring that all new or renovated residential housing be adapted for living with disabilities. Elders now have many places to live in Singapore. To my knowledge, everywhere in the U.S. we continue to build showers without bars, bathroom doors too narrow for wheelchairs, and entries requiring a step up to the front door. Furthermore, the SASH project in Vermont has shown that adding social services to senior housing reduces hospitalization and nursing home placement.<sup>14</sup>

Now is the time to enact legislation to build greater capacity in housing that works for people across their lifespan through state grants. Housing stock that would be safe, affordable and accessible, would prevent having to live in a nursing home when disability sets in (often paid by Medicaid) for lack of available housing. When disasters ruin a great deal of housing, replacements could be required to be accessible. Housing codes could start requiring basic disability adaptation in all units. Low income housing vouchers could be more readily available. Elderly persons living in tents and cars could have some priority in obtaining housing before exposure makes them so sick as to require nursing home care.

### **Defeating Malnutrition**

By federal standards, 7.7% of elderly persons are food-insecure for financial reasons.<sup>15</sup> At least that many more have the money, but not the transportation or the ability to carry or prepare food. Food supports for elderly and disabled persons have been a mainstay of the OAA, the supportive services statute enacted with Medicare and Medicaid. While Medicare and Medicaid funding has increased more rapidly than the population, OAA funding has nearly stagnated, and it shows. Too many elders live on “tea and toast” or “rice and beans.” Waiting lists for home-delivered food (e.g., Meals on Wheels) are longer than six months in many cities and the service is not available in many rural areas. Food needs to be appealing, meeting medical and religious requirements, and nutritious, or it is worthless or harmful. Medicare Advantage (MA) plans can now pay for some social supports and are testing the effects of delivering food to high-utilizing elders. Tying food delivery to MA plans, rather than to preventing hunger and improving nutrition in the whole community, will create inequities and inefficiencies.

What can be done? The cost of delivering food to homes generally runs around \$8 per day. We could resolve to pay enough to eliminate the waiting lists. We could encourage participation of eldercare nutrition programs in local food systems to make available produce, healthy variety, and culturally appropriate food. We could have better data on nutrition of older adults living with disabilities. A July 2019 analysis found that a Medicare benefit to deliver meals to persons living with complex illness would yield \$1.57 of savings for every \$1 spent.<sup>16</sup> Saving older adults from the pains of hunger and the exacerbating effects of malnourishment keeps these people out of hospitals.

### **Reforms in Medical and Nursing Care**

The medical and nursing care of elderly persons needing LTSS is only rarely excellent. The most glaring problem is the near-total lack of continuity across settings and time. The growth in hospitalists, SNFists (physicians who work only in skilled nursing facilities, or SNFs), and every sort of specialty is in stark contrast to the dearth of geriatricians and primary care physicians. It is now quite rare to have a trusting relationship with a practitioner who understands your medical and functional situation, your living situation, and your priorities and preferences. Very few physicians know geriatric syndromes, the importance of function and cognition, the services available in the community, and the living situation of their elderly patients. Hospital staff rarely understand their patient's overall situation, and hospitalization routinely disrupts the arrangements the elder has built up into an adequate routine.

Incredibly, the federal electronic medical record certification requirements still do not require a place to record the patient's caregiver, preferences, functional status, and living situation. Very few electronic medical records include information collected from all local providers, which is necessary to guide the patient, caregiver, and providers. Physicians often encourage long-shot treatments for elderly patients who do not know the likely effects, which can include worsened disability and impoverishment. Indeed, no funding supports the studies and technologies that would make outcome information available.

Patients and families are caught up in a bewildering array of service providers who are not a cohesive team and therefore face daunting gaps and frustrations in trying to meet their needs. Original Medicare does not cover many of the services that are most important – including personal care. I appreciate this Committee having initiated a bill to allow coverage of eyeglasses, hearing aids, and dental care.

A similar effort should be made to have some critical LTSS benefits available in original Medicare and the various bundling and contracting efforts now being tested. Without this, “spending down” to Medicaid just to access LTSS will be the only resort. While nursing homes have been the mainstay of long-term care in Medicaid, home and community-based (HCBS) waivers and state options have enabled many beneficiaries to stay in their community, which they prefer and is usually less costly. But HCBS requires infrastructure: housing and transportation supports, family caregiver assistance and a larger workforce.

### **Reforms in the Paid Workforce**

Many occupations make up the workforce for supporting frail, ill, and disabled elders. Except perhaps for those handling sales and financing of durable medical equipment, drugs, and medical care, every other occupation in the support workforce is understaffed, poorly trained, and underpaid.

Personal care aides are in such short supply that elders known to need aides and be eligible for Medicaid coverage often simply cannot be served. I recently was in an Ohio city where 250 Medicaid beneficiaries living at home were known to need personal care, but the workforce was not available – so they went without, risking infections, poor nutrition, isolation, and avoidable medical care. Personal care aides earn an average of less than \$12 hourly, mostly without benefits. As it stands, local caregiving providers cannot offer more wages due to low reimbursement by most funders, including public programs. These are some of the hardest jobs, both physically and emotionally, and yet the workers do not earn livable pay and benefits. In a rather cruel irony, these workers will never have had an opportunity to save for their own retirement and period of disability. Personal care aides often spend a great deal of time in required minimum time blocks, and substantial efficiencies (and enhanced pay) are often possible if a suitable number of aides serve an apartment building or neighborhood, a strategy rarely implemented.

These jobs are mostly filled by recent immigrants, women of color, and poorly educated women, and they have high turnover and very limited career ladders. Most of these jobs offer little training in how to deal with behavioral problems in dementia, and many front-line aides are barred from administering medications (reserving this to family or nurses). Meanwhile, the demographic change marches on. The Bureau of Labor Statistics projects that the direct care workforce will have 7.8 million job openings between now and 2026. Direct care work will grow faster than any other employment category.<sup>17</sup>

The shortage of training and workforce numbers affects every other kind of job serving elders who are frail, ill, or disabled. For example, no geriatricians have appointments available in Washington, DC, unless the patient is a veteran. The number of physicians training in geriatrics is declining, since the work is hard and the pay is lower than for other physician specialties. Most physicians could be trained to serve elderly persons, but most receive no such training. This situation is strange, since Medicare pays for most of graduate medical education (GME) but requires no focus on the problems that are most pertinent to Medicare patients, suggesting that GME funding requirements should be modified.

Shortages in numbers and skills affect most occupations serving older adults who are frail or disabled. If we were to build eldercare anew, we would emphasize continuity, team-based care, supportive services, training in behavioral issues and multiple chronic conditions, and data to guide improvement activities for geographic communities. None of these are part of our current arrangements, though they could be.

### **Reforms in the Volunteer Workforce (family caregivers and a community care corps)**

Most care for frail, ill, and disabled elders is given without payment by family and friends, even though they get little recognition, support, or resources for this disruptive and difficult job. Nearly all Americans have been, will be, or are now caregivers to a disabled adult, and most will need caregivers. Yet, a woman who cares full-time for a family member averages more than \$250,000 lost from her income and retirement security.<sup>18</sup> Family caregiving is becoming a task that impoverishes families for generations. Half of volunteer caregivers handle complex treatments that would require a registered nurse if done in a hospital – e.g., dialysis, intravenous medications, or wound care.<sup>19</sup> Federal and state programs provide respite, training, and funding for volunteer caregiving, but these programs are so small that only a small percentage of caregivers benefit. Most employers give no flexibility to family caregivers and have substantial productivity losses from unscheduled leave, early retirement, and employees who are present but less productive due to competing concerns about an elder they are supporting.

A century ago, relatively few people lived long enough to have serious disabilities in old age; those few had scores of descendants who could provide support; and most lived on farms where taking in one more person was relatively simple. Now, families are dispersed, elders often have elderly children, many people live in housing that does not offer extra space, and most working-age adults work. Indeed, if one counts every adult aged 40 to 65 as a potential caregiver, already we have one elder over age 80 per seven working-age adults. In the next decade, that ratio will go down to 1:4.<sup>20</sup>

Caregivers routinely get little help or respect in the medical care system, epitomized by federal requirements for certification of an electronic medical record that lack a place to identify the caregiver. The AARP has led an initiative to get a statute (the CARE Act) at the state level that requires that hospitals identify the caregiver(s), train them as necessary, and notify them at the time of discharge.<sup>21</sup> The medical care system should not need a statute to require doing what is clearly essential; but it is also disappointing

that these statutes lack a mechanism for monitoring or other enforcement, enabling hospitals and nursing homes to continue to show little attention to caregivers.

Family and friends providing care to elders need respite, training, flexibility in their workplace, and support from their communities. They need to be identified in the record and included in planning. Many need financial support, medical insurance coverage, and friendly contact with others. When there is no family or friend caregiver, an elder with personal care needs must qualify for Medicaid and accept whatever service that contractor can provide – or must hire an aide with out-of-pocket funds, which requires recruiting, interviewing, establishing the job duties and boundaries, supervising the aide, and paying the aide and often the taxes. Clearly, these are challenging tasks for an elder who is disabled.

Many elders need help with “instrumental activities of daily living,” or IADLs (such as grocery shopping, minor household repairs, food preparation, and transportation), and with loneliness. Some elders will only need IADL help, since they can manage personal hygiene, mobility, and eating. For others, IADL needs accompany needs for personal care. When an elderly person cannot handle IADLs or is lonely, and no family or friend can fill in, the elder can either hire aides or move to a facility, increasing both suffering and out-of-pocket costs. Volunteer programs have arisen that recreate neighborliness and help with IADL needs. The Villages movement and the Stephen Ministry are widely known, though many local religious and service organizations also provide help. These non-medical, non-intimate services often help an elderly person stay at home safely. Indeed, they should be encouraged and available in all communities. Under a Congressional mandate, the Administration for Community Living initiated a program to develop the models and infrastructure for widespread implementation of volunteer networks, aiming to support persons living with disabilities in the community and their caregivers. This is the National Community Care Corps, with OASIS, Caregiver Action Network, the National Association of Area Agencies on Aging, and Altarum’s Program to Improve Eldercare working to get this underway.

### **Reforms to Prevent Abuse and Neglect**

Everyone can imagine the challenges of caring for an elderly person disabled by cognitive failure and behaving in difficult and unpredictable ways. A family caregiver must constantly attend to a loved one who is incoherent and at risk of endangering self and others. The elder will never be able to discuss the issue or give thanks to the caregiver, who needs to provide heavy lifting, embarrassing and unpleasant personal hygiene, and decisions about the eventual death of a dear family member. The same forces yield frustration and despair for overworked and underpaid aides in homes and nursing homes. Caregivers all too often become unable to provide adequate care, but they have no options for help. Taking the person to the emergency room will mostly get the patient sent home in worse condition. For a person at home, nursing homes are undesirable, expensive, and often simply unavailable — and home care aides are difficult to find or unaffordable. For a person already in a nursing home, staffing shortages are too often the norm, and aides and residents have no power to force improvements.<sup>22</sup>

These situations often eventuate in neglect and abuse, which annually harms one-tenth of America’s seniors.<sup>23</sup> In addition to the elder’s suffering, abuse doubles the use of hospitals and emergency rooms, quintuples the use of nursing homes, and more than doubles the risk of death within the next year.<sup>24</sup> The entity generally responsible for investigation and intervention when needed is Adult Protective Services, an underfunded and unempowered public service that often cannot investigate promptly or provide caregiver respite or qualified aides. The Elder Justice Act has not been funded or implemented, so it has not resolved this situation. Public health and medical personnel could take more active roles. A Federal



Office on Elder Justice could coordinate the required health, social, and legal resources. The National Background Check Program, which has provided grants for 29 states to establish multi-source screening systems, should be extended to all states, so that long-term care providers would have to conduct pre-employment checks as a condition of participation in Medicare and Medicaid.

Financial scams have become a major scourge with elderly people being bombarded by illegitimate phone calls and social media. Elders living alone may be easy targets for scammers who claim, for example, to be a long-lost classmate curious about your family and situation – and who call later for money to get the named grandson out of jail. Privately-hired aides sometimes become unworthy trusted friends who divert the elder's assets to their personal gain. Recovery of funds is usually not possible, so a person who had adequate savings ends up impoverished overnight. Apart from trying to prevent financial abuse through comprehensive background checks, sorting out how to reduce these harms is challenging, since the elder's rightful claim to autonomy includes the authority to make imprudent decisions. Some banks are beginning to offer notice to a trusted family member or friend for an unusual transaction, and some families are setting up requirements of dual signatures on sizable expenditures.

### **Reforms Can Build on Proven Innovations**

Many have taken note of the serious dysfunctions and unaffordable costs of serious illnesses and disabilities in late life and scores of innovative improvements have been tested and proven worthwhile, though few have been widely adopted. Simple continuity of the care team matters greatly to the elderly person and to caregivers, but continuity is unlikely except in home-based primary care, PACE (the Program of All-Inclusive Care of the Elderly), and the Veterans Patient Aligned Care Teams (PACT). Having an established care team with 24/7 availability, multidisciplinary skills, and knowledge of the community's supportive services is quite rare. Comprehensive care planning to match the elderly person's situation and preferences with the best available services and treatments is accomplished only in some geriatric teams and PACE. Service delivery models like PACE, PACT, GRACE (Geriatric Resources and Care of Elders) and CAPABLE are well-established as being both more effective and more efficient than usual care. Reducing polypharmacy and following guidelines to avoid burdensome low-value treatments are known to improve how elders live and to reduce costs but are unevenly implemented.

With these and many more improvements available, why is it so difficult to get the care you need when you need it? Quite simply, we have built a care system that does not incentivize practitioners and provider organizations to learn, adapt, and improve quickly. Consider PACE, a widely applauded program for elders who are disabled enough to qualify for nursing home care. Now 40 years after its founding and 20 years after becoming part of Medicare, PACE serves only about 40,000 people. The National PACE Association is fielding a "PACE 2.0" initiative that aims to expand PACE, and Altarum's Program to Improve Eldercare has been focused on expanding PACE to a Medicare-only population. I strongly urge this Committee to take a close look at making it much more possible for Medicare beneficiaries to enroll in PACE, which few will do now because Part D costs are stunningly high. A Medicare-only potential enrollee who has been paying \$50 monthly for Part D coverage confronts a required PACE Part D plan costing over \$1,000 monthly, because a regulation precludes keeping that market-based Part D plan. Other regulatory constraints also limit the spread of PACE, e.g., by escalating start-up costs to around \$10 million. This rigidity affects much of health care. Pathways developed long ago stultify adaptation.

CMS is advancing changes in other models, including granting Medicare Advantage plans more flexibility in providing LTSS and offering to contract with new intermediaries taking on medical service delivery

management for large populations. These are catalytic changes, and their merits will require careful evaluation, but they are insufficient to address the needs of elders living with serious disabilities and their families and caregivers. For this part of our lives, we need a better model.

### **Reforms to Enable Community Management of Local Eldercare**

Much of the experience of serious illness and disability in old age, for elders and their families, depends upon how their community – the practitioners, businesses, and government in that area – have developed housing, transportation, and supportive services. For policymakers at all levels of government wishing to help their communities, these are some questions to ask: Is adapted and affordable housing available? Do medical care teams provide services at home? Are there enough personal care aides with suitable skills? Do employers offer flexible arrangements to support family caregiving? Are nursing homes offering good-quality care? If the answers to this kind of question shows shortcomings, there is work to be done to develop a coherent system from many parts. Fixing LTSS one elder at time a cannot work; in an era of longevity, the solutions have to work for all elders living in that community.



Current service arrangements to support elders living with disabilities are neither coordinated nor measured at a systems level. Medicare measures some elements of quality, setting by setting, but quality and cost are not measured across settings and time or for all affected elders in a community.

CMMI, with other federal entities and willing state governments, is in a prime position to sponsor more innovative projects, anchored in standing up models that improve care and reduce costs for whole communities, aiming to learn how to organize eldercare to be far more reliable and efficient. This could involve enabling elders to select a highly supportive coverage plan, such as PACE, or organizing home care agencies to assign aides to work in particular buildings or neighborhoods, so that many more elders can be seen in a day, aides have less travel time, and care providers build relationships and create more local strategies to provide support. Potentially, such a community-anchored project would have a leadership entity (such as a board) to generate and review data about how well the eldercare system is working and to set priorities for improvement. Using this approach, we could learn very quickly what mix of financing and service arrangements serve elders efficiently and well.

### **Making the Policies Possible**

The movement to improve eldercare has two advantages: (1) everyone has a stake in having reliable and efficient arrangements for their own old age, and (2) nearly everyone will be a caregiver to an adult. Eventually, these will overcome the current tendency to see LTSS as a black hole of need that has little effective advocacy. Forward movement requires making the current and oncoming challenges widely known. About half of the public still thinks that Medicare covers long-term services and supports. They learn otherwise when a family member or neighbor suddenly needs help and they find a chaotic array of services that make no sense, leave huge gaps, and are quite expensive. Women now spend more years caring for disabled adults than for children. Altarum's Program to Improve Eldercare sponsored polling of voters in 2016, asking about caregiving. Nearly every respondent ranked the concern for caregiving's costs and burdens as being a high priority – no matter how they were voting. They wanted a better deal for

paid caregivers and volunteers, and a trustworthy system. Elders and caregivers are learning to demand a better deal. This is a leadership opportunity in a critically important but largely latent issue.

Elderly people with disabilities now face a scattered, inefficient set of care arrangements with incomprehensible and frequently changing eligibility for services, inadequate numbers and under-training of personal care aides, wrongheaded medical care, and a widespread avoidance of dealing with the situation now or as it worsens in the future. Scores of improvements are known and scores more are worth testing. We can do better. But doing better requires a mobilized citizenry and thoughtful and committed leaders. We need innovation and evaluation, along with strong commitment and vision. For eldercare to be reliable and affordable, we need to redesign our care arrangements, our housing and food supports, our transportation arrangements, and especially our financing. We will have our new demographics for the foreseeable future, and the numbers will be overwhelming within a dozen years without action now. But with action now, we could have trustworthy and efficient arrangements. The window of opportunity for instituting preventive reforms in financing of retirement and eldercare is still open, but it is closing. Leadership is essential, though many are ready to help. The issues are classically bipartisan: we all hope to grow old, and impoverished and disabled elders will affect every family.

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<sup>1</sup> GAO, “Most Households Approaching Retirement Have Low Savings,” (Washington, D.C.: Government Accountability Office, May 2015), <https://www.gao.gov/assets/680/670153.pdf>.

<sup>2</sup> Caroline F. Pearson et al., “The Forgotten Middle: Many Middle-Income Seniors Will Have Insufficient Resources for Housing And Health Care,” *Health Affairs* 38, no. 5 (April 24, 2019), <https://doi.org/10.1377/hlthaff.2018.05233>.

<sup>3</sup> Jesse Bricker et al., “Changes in U.S. Family Finances from 2013 to 2016: Evidence from the Survey of Consumer Finances,” *Federal Reserve Bull.* <https://www.federalreserve.gov/publications/2017-September-changes-in-us-family-finances-from-2013-to-2016.htm>

<sup>4</sup> Jalyn Soucek, “Wait List for Meals on Wheels Can Be Years-Long for Senior Citizens in Need,” *WATN - Local 24*, September 30, 2019, <https://www.localmemphis.com/news/wait-list-for-meals-on-wheels-can-be-years-long-for-senior-citizens-in-need/>.

<sup>5</sup> M Cohen, J Feder, M Favreault, “A New Public-Private Partnership: Catastrophic Public and Front-End Private LTC Insurance” <https://bipartisanpolicy.org/wp-content/uploads/2018/01/Public-Catastrophic-Insurance-Paper-for-Bipartisan-Policy-Center-1-25-2018.pdf>.

<sup>6</sup> H Gleckman, <https://www.forbes.com/sites/howardgleckman/2019/05/15/what-you-need-to-know-about-washington-states-public-long-term-care-insurance-program/#7eb660ce2cdc>

<sup>7</sup> “Aging and the Macroeconomy: Long-Term Implications of an Older Population,” Report (National Research Council, Committee on Population, September 2012), <https://www.nap.edu/download/13465>

<sup>8</sup> AR Markus et al. “Medicaid Covered Births, 2008 through 2010...” *Women’s Health Issues* 2013;23:e273 [https://www.whijournal.com/article/S1049-3867\(13\)00055-8/fulltext](https://www.whijournal.com/article/S1049-3867(13)00055-8/fulltext)

<sup>9</sup> Executive Office of the President, “Economic Perspectives on Incarceration and the Criminal Justice System,” 2016 [https://obamawhitehouse.archives.gov/sites/default/files/page/files/20160423\\_cea\\_incarceration\\_criminal\\_justice.pdf](https://obamawhitehouse.archives.gov/sites/default/files/page/files/20160423_cea_incarceration_criminal_justice.pdf)

<sup>10</sup> “Long-Term Care Innovation (B) Subgroup: Federal Policy Options to Present to Congress” (National Association of Insurance Commissioners), [https://content.naic.org/sites/default/files/inline-files/cmte\\_e\\_res\\_mech\\_wg\\_related\\_federal\\_policy\\_issues.pdf](https://content.naic.org/sites/default/files/inline-files/cmte_e_res_mech_wg_related_federal_policy_issues.pdf).

<sup>11</sup> Antonia K. Bernhardt et al., “Making It Safe to Grow Old: A Financial Simulation Model for Launching MediCaring Communities...,” *Milbank Quarterly* 2016;94: 597–625, <https://doi.org/10.1111/1468-0009.12199>.

<sup>12</sup> Caroline F. Pearson et al., op. cit.

<sup>13</sup> Sarah L Szanton et al., “CAPABLE Bundle Payment Model: Community Aging in Place—Advancing Better Living for Elders,” October 2018, [https://aspe.hhs.gov/system/files/pdf/255731/CAPABLE\\_PTAC\\_Proposal\\_20181030.pdf](https://aspe.hhs.gov/system/files/pdf/255731/CAPABLE_PTAC_Proposal_20181030.pdf).

<sup>14</sup> Amy Kandilov et al., “Support And Services at Home (SASH) Evaluation: SASH Evaluation Findings, 2010-2016” (RTI International, July 2019), <https://aspe.hhs.gov/system/files/pdf/262071/SASH5.pdf>.

<sup>15</sup> James Ziliak and Craig Gundersen, “The State of Senior Hunger in America in 2017”

[https://www.feedingamerica.org/sites/default/files/2019-05/state-of-senior-hunger-2017\\_full-report.pdf](https://www.feedingamerica.org/sites/default/files/2019-05/state-of-senior-hunger-2017_full-report.pdf)

<sup>16</sup> “Next Steps in Chronic Care: Expanding Innovative Medicare Benefits” (Bipartisan Policy Center, July 2019), <https://bipartisanpolicy.org/wp-content/uploads/2019/07/Next-Steps-in-Chronic-Care.pdf>.

<sup>17</sup> Stephen Campbell, “New Research: 7.8 Million Direct Care Jobs Will Need to Be Filled by 2026,” *PHI Workforce Data Center*, January 24, 2019, <https://phinational.org/news/new-research-7-8-million-direct-care-jobs-will-need-to-be-filled-by-2026/>.

<sup>18</sup> “The MetLife Study of Caregiving Costs to Working Caregivers” MetLife Mature Market Institute & National Alliance for Caregiving, 2011, [www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf](http://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf)

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<sup>19</sup> National Academies of Sciences, Engineering, and Medicine; *Families Caring for an Aging America* (Washington, DC: The National Academies Press, 2016); <https://doi.org/10.17226/23606>.

<sup>20</sup> D Redfoot, et al. "The Aging of the Baby Boom ... Future Declines in the Availability of Family Caregivers" (2013), [www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/lrc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-lrc.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/lrc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-lrc.pdf).

<sup>21</sup> AARP, "New State Law to Help Family Caregivers" [www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html](http://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html)

<sup>22</sup> Jordan Rau, "'It's Almost Like a Ghost Town.' Most Nursing Homes Overstated Staffing for Years," *The New York Times*, July 7, 2018, sec. Health, <https://www.nytimes.com/2018/07/07/health/nursing-homes-staffing-medicare.html>.

<sup>23</sup> Karl Pillemer et al., "Elder Mistreatment: Priorities for Consideration by the White House Conference on Aging," *The Gerontologist* 55, no. 2 (April 1, 2015): 320–27, <https://doi.org/10.1093/geront/gnu180>.

<sup>24</sup> Xin Qi Dong, "Elder Abuse: Systematic Review and Implications for Practice," *Journal of the American Geriatrics Society* 63, no. 6 (2015): 1214–38, <https://doi.org/10.1111/jgs.13454>. Cf. table 3, "Consequences of Elder Abuse;" notes 5, 57, 61, and 97.