**Plotting a Future of Integrated Care for the Elderly**

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1. **Introduction**

The notion of respecting our elders is ingrained in us from a young age. Yet, a pervasive lack of respect for the elderly is glaringly obvious in the quality of health care they receive today. Illustrative of this point is the fact that theCOVID-19 pandemic killed more than 182,000 residents and staff of nursing homes and other long-term care facilities, representing about one-third percent of all coronavirus fatalities in the U.S.[[1]](#footnote-1) The subject matter of this Comment will generally speak to improving access to quality health care within a targeted, vulnerable population: the elderly. Elders have higher rates of hospitalization and institutionalization that are exacerbated by social isolation and placement in institutional settings.[[2]](#footnote-2) As a class, elders incur an estimated annual cost of nearly $800 billion to our nation’s healthcare system.[[3]](#footnote-3) The current pro-institutionalization system must be replaced with new models that effectively address problems such as quality of care, unpaid family caregivers, and excessive costs.

Elder abuse and neglect are critical social, public health, and economic problems and the heartbreaking statistics speak to the fact that the elderly population is vulnerable and in need of improved protection.[[4]](#footnote-4) Scandals around widespread elder abuse, corruption, and mistreatment in nursing homes during the COVID-19 pandemic have shed light on the problems related to institutionalization and highlighted the need to shift focus upon keeping the elderly at home and in the community for as long as possible. This need existed prior to the pandemic but is undeniable now as we look in hindsight to the way in which this would have changed the trajectory for seniors during the pandemic. For the purposes of this paper, institutionalization will refer to long-term nursing home settings that provide 24-hour care.

It is unsurprising that the elderly population prefers to live and age within the comfort of their own homes. However, the cost of receiving long-term care at home is high, and those in need are left with few choices. If the status quo for receiving long-term services and supports (“LTSS”) is maintained, the elderly population will continue to be underserved, unserved, or at risk for expensive medical bills or years of unpaid family caregiving.[[5]](#footnote-5) For too long Medicaid has exhibited a bias for institutional, rather than community-based care, despite the evidence of the benefits of the latter. For the purposes of this paper, community-based care will encompass the array of supports and services designed to help community-dwelling, elder adults remain safely in their homes and delay or prevent institutionalization. Community-based care provides specific resources for older adults and their caregivers that include wellness programs, nutritional support, educational programs about health and aging, and counseling services for caregivers, as well as general assistance with housing, finances, and home safety.[[6]](#footnote-6) While a shift to organized community and home-based care is necessary, the way in which we achieve this goal is riddled with complexities.

Transitioning elders from institutional settings back to their homes by utilizing and expanding on current health systems that promote community-based supports, will reduce overall costs, promote community inclusion, and ensure quality and efficiency when delivering health care services to the elderly. Because the whole-person care model envisioned depends on who the payer is, it is important to note that the largest payers of LTSS today are Medicaid and individuals paying for LTSS out-of-pocket. The stark reality is that unpaid family caregivers provide the bulk of LTSS. As health care shifts toward more creative and holistic models of care, there are opportunities for health care providers to collaborate amongst themselves and with beneficiaries toward the goal of maintaining patients’ health and enabling them to remain safely in the community. Because health care providers are ideally positioned to educate older patients and their caregivers about community-based supports and to refer them for services and supports when appropriate, they serve a critical role in bringing the various existing services together in a coordinated way.

This Comment will address why we should focus efforts on deinstitutionalization of the elderly, and how we can achieve this through existing home and community-based supports and organizing systems. Part II sets the landscape for those who need LTSS and explains why deinstitutionalization and integration of the elderly into their communities, without imposing onerous caregiving burdens on loved ones, is important. Part III discusses how to provide care in the community effectively and analyzes the health systems that have developed over the past few decades. Part IV provides an overview of two coordinated care models that have the potential to improve access, coordination, quality of care, and cost containment in providing LTSS in the community.

1. **The Shifting Focus of LTSS**

Those receiving LTSS services from Medicaid, Medicare, or private insurance are among the most health-compromised and are “high need, high-cost patients” that have multiple chronic conditions or disabilities.[[7]](#footnote-7)In 2018, 14 million adults of all ages in the United States needed LTSS and over half of LTSS recipients were age 65 or older.[[8]](#footnote-8) In addition to nursing home services, LTSS also includes support services, often non-medical, that allow individuals to live independently and safely in their homes or their communities despite any inability to perform daily activities independently.[[9]](#footnote-9) Those needing LTSS require assistance with either, or both, activities of daily living (“ADLs”) and instrumental activities of daily living (“IADLs”).[[10]](#footnote-10) ADLs consist of personal care activities such as eating, bathing, dressing, using the bathroom, and getting around the house.[[11]](#footnote-11) IADLs consist of more complex care, such as medication and finance management, meal preparation, grocery shopping, and laundry.[[12]](#footnote-12) According to the Congressional Budget Office (“CBO”), 20 percent of individuals over age 65 and 41 percent of individuals over age 85 need assistance with at least one ADL.[[13]](#footnote-13) Where an older adult wishes to age-in-place at home, as opposed to nursing homes or other residential institutions, they are largely dependent on family and unpaid caregivers for LTSS and overall care management.[[14]](#footnote-14)

Nursing home care is disfavored for a variety of reasons. First, it is expensive, and often includes more services than the individual needs. Moreover, public opinion has been more critical of institutionalization in nursing homes because they are often clinically inferior, socially inferior, and the last choice for the elderly. Elders deteriorate faster in nursing homes because individuals become apathetic and withdrawn because of social isolation. As seen in the context of the COVID-19 pandemic, unethical care and substandard living conditions are also possible in these congregate living spaces. Hasty moves can be extremely harmful to elderly patients, whereas well-planned and smoothly implemented relocations, that let patients feel they are in control, can promote health and enhance quality of life.[[15]](#footnote-15) In contrast to nursing home care, home and community-based services refer to a range of health and supportive services, delivered in non-institutional settings, that are needed by individuals who lack the capacity for self-care because of a physical, cognitive, or mental disability or chronic condition resulting in functional impairment for extended time periods.[[16]](#footnote-16) Community-based services and supports are underutilized by older adults and due to a lack of awareness, reluctance, unavailability, and unaffordability.

Historically, LTSS payments for community-based care are made on a fee-for-service (“FFS”) model by which services are unbundled and paid for separately. As a result, coordination among caregivers, medical providers and other LTSS providers, continues to be lacking. Physicians are incentivized to provide more treatments because payment is dependent on the quantity of care, rather than quality of care. Such fragmented care has the potential for infinite shortfalls, leaving the FFS model as an unsatisfactory, inefficient way to pay for care. Medicare, the national health insurance program for people ages 65 and older or people with long-term disabilities, does not pay for extensive LTSS because coverage is limited to institutional nursing care, post-acute care and rehabilitation, and home health aide services. [[17]](#footnote-17) As a result, Medicare beneficiaries needing LTSS rely either on predominantly unpaid care from family and friends, or on the Medicaid program as a safety net. Both options are problematic and have led to a lack of quality care for the elderly and unnecessary rates of institutionalization. The number of Americans who need LTSS is expected to rise to over 27 million by 2050 and the CBO estimates that spending on LTSS as a percent of the GDP could more than double.[[18]](#footnote-18) The current sources of support for LTSS have already proved ineffective and will be increasingly inadequate as the population ages.

1. A Pervasive Assumption of LTSS Responsibilities are Undertaken by Family and Friends as Unpaid Caregivers Who Lack Adequate Support

A confluence of historical reliance on family members; personal preference; an increase in longevity and chronic conditions; the high costs of paid LTSS; and the limited availability of insurance coverage for such services, has contributed to the current reliance on unpaid family caregivers. This aspect of LTSS tends to be invisible until a caregiving need arises. At that time, it can disrupt an informal caregiver’s life and consume time previously devoted to gainful employment, self-care, and leisure activities.  Unpaid family caregiving has proved invaluable; family caregivers are a critical element of community living for many older adults. These caregivers shoulder the bulk of LTSS expenses and provide great savings to the health care system annually.[[19]](#footnote-19) But the pervasive application of the time and talents of these unpaid caregivers impacts the national economy, those receiving care, and the caregiver herself. Unpaid caregivingcan exact a large emotional and physical toll on the caregiver, deplete personal financial resources, and interfere with employment. As such,caregivers must be supported in a variety of ways if they are to continue to remain at the heart of home care.[[20]](#footnote-20)

Informal caregivers, typically untrained family members or friends, help keep the elderly at home or within the community for longer by assisting with ADLs and IADLs. Today it is estimated that over 43 million people nationwide serve as informal caregivers.[[21]](#footnote-21) These informal caregivers provide three quarters of all long-term care to elderly friends and family members.[[22]](#footnote-22) The extent of this informal care is one effect of our lack of comprehensive LTSS coverage.Increasingly, family caregivers are providing complex medical care to their older loved ones. A survey of family caregivers found that almost half (46 percent) of all informal caregivers were performing medical, nursing tasks for family members with multiple chronic physical and cognitive conditions.[[23]](#footnote-23) Many caregivers performing these complex tasks have taught themselves how to effectively care for their loved ones. Even though family caregivers report feeling joy and satisfaction in their critical role of helping their loved one remain “independent,” almost half are overwhelmed by their caregiving responsibilities.[[24]](#footnote-24) As a result of the extent and nature of the care they render, caregivers are more likely to report fair or poor physical and emotional health than non-caregivers.[[25]](#footnote-25) Intensive caregivers also have more health problems than less intensive caregivers.[[26]](#footnote-26) This is significant because caregiver burnout and stress is a predictor of a care recipient’s ultimate nursing home placement and an important risk factor for caregiver morbidity and mortality.[[27]](#footnote-27)

Moreover, unpaid caregiving exacts a large financial toll, as high out-of-pocket expenses are frequently shouldered by the caregiver. This perpetuates a vicious cycle, as these same individuals will likely rely on Medicaid services later because of the financial toll undertaken by serving as a caretaker. Elder care responsibilities can also interfere with employment, since almost 6 in 10 caregivers ages 20-64 are employed.[[28]](#footnote-28) This disproportionately impacts women, who are more likely to provide informal care to older adults than men.[[29]](#footnote-29) Hours of unpaid care are not substantially lower when paid care is also received; thus, public financing of LTSS would not replace, but rather supplement, the contributions of family and unpaid caregivers to support individuals living independently in the community.[[30]](#footnote-30) While this may sound counterintuitive, data from the 2015 National Health and Aging Trends Study (NHATS), which examined the use of paid and unpaid care among community-residing people who need LTSS, supports this assertion.[[31]](#footnote-31) The studied population included Medicare beneficiaries age 65 and older living in the community who required help with at least two ADLS or had probable dementia.[[32]](#footnote-32) The analysis concluded that the average number of unpaid helpers was only slightly lower among those receiving both paid and unpaid support, supporting the notion that public financing of LTSS will not supplant unpaid care, but complement it.[[33]](#footnote-33) The study results found that significant numbers of community-residing older adults with LTSS needs do not receive help.[[34]](#footnote-34) Because an individual who is not receiving any paid care is getting a fair amount of unpaid care from family members or friends, it is often the case that this individual is not getting all of the services she needs. Thus, when paid care is introduced, the burdens shift, and the unpaid caregiver continues to provide just as much care but focuses her attention to tasks the paid caregiver is not performing. The net result is more care provided to the elder who needs it, with a division of labor and coordinated efforts between paid and unpaid caregivers to meet these needs.

Because no payment system will obviate the need for unpaid caregivers, it is likely that the health care system is going to continue to rely on these unpaid, untrained caregivers to provide increasingly complex and expensive care to elders requiring LTSS. The intensity of the services, the need for respite care, and the financial strain of informal caregiving support the argument that adequate supports and training must be made available.[[35]](#footnote-35) One mechanism for the provision of these supports is a shift of focus to patient-centered care to supplement and support informal caregivers. The Institute of Medicine defines patient-centered care as “Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.”[[36]](#footnote-36) Such care is collaborative, coordinated, and accessible. Under a patient-centered model, care teams work to know and treat the full patient. An individual’s specific health needs and desired health outcomes are the driving force behind all health care decisions and quality measurements.[[37]](#footnote-37) Patients engage in shared decision-making with their families and providers to design and manage a customized and comprehensive care plan.[[38]](#footnote-38)

The shift to a patient-centered, coordinated care modelwill improve the well-being of elders and respect their preference to remain at home and in the community, thereby potentially reducing the need for formal, institutional level care down the line.[[39]](#footnote-39) This will help alleviate the burden felt on all sides, both stabilizing the increasing enrollment in Medicaid, and ensuring that family caregivers and those they care for are able to lead happy, healthy, and productive lives.[[40]](#footnote-40)

1. **Health Systems Analysis: Providing Care in the Community**

In the last 25 years, the United States has made significant progress in reforming the LTSS system.[[41]](#footnote-41) Gradually, different programs have evolved to promote and support community-based alternatives to institutional care. This section will first examine the growth of HCBS programs made available through Medicaid waivers or state options. Then we will turn to the mechanisms for supporting unpaid caregivers within the community. Lastly, we will look at Money Follows the Person (“MFP”) programs, which support Medicaid eligible people who might otherwise be institutionalized.

1. Medicaid’s Shift from Institutions to the Community

Pursuant to Title XIX of the Social Security Act,[[42]](#footnote-42) the Medicaid program provides medical assistance to low-income individuals and individuals with disabilities, covering 1 in 5 Americans.[[43]](#footnote-43) Medicaid, a joint federal and state public insurance program, continues to be the primary payer for institutional and community based LTSS today, accounting for about 52 percent of all LTSS spending.[[44]](#footnote-44) The Medicaid entitlement guarantees both that individuals are entitled to a defined set of benefits and states are entitled to federal matching funds.[[45]](#footnote-45) While Medicaid has evolved since 1965 from a medical insurance program for the “worthy poor” to a complex multi-dimensional one, eligibility still depends primarily on income and assets. With respect to the elderly, Medicaid pays for the medical care for those who meet Supplementary Security Income (SSI) standards.[[46]](#footnote-46) States have the option of covering medically needy individuals with incomes slightly above the SSI levels and individuals who have incurred sufficiently high medical expenditures that they “spend down” to Medicaid income eligibility levels, entering the Medicaid program when they can no longer afford to pay for medical expenses or LTSS out of pocket.[[47]](#footnote-47) For dually eligible recipients, Medicare is the first payer and Medicaid is the second payer; therefore, Medicaid will pay the cost-sharing amounts that would normally fall to the patient. At the federal level, the Centers for Medicare & Medicaid Services (“CMS”) administers the program and approves several types of Medicaid state plan benefit packages and waiver programs for LTSS services. Thus, states administer Medicaid programs subject to federal standards and have flexibility to determine the covered population and services, health care delivery models, and payment methods.[[48]](#footnote-48) This flexibility results in significant variation across state Medicaid programs.[[49]](#footnote-49)

Medicaid has evolved into the primary public funding source for long-term services for the elderly because there is limited coverage under Medicare for LTSS, and few affordable options in the private insurance market.[[50]](#footnote-50) Medicaid covers long-term care including both nursing home care and many home and community-based LTSS, which help seniors and people with disabilities with self-care and household activities.[[51]](#footnote-51) Although the elderly and people with disabilities make up a relatively small group of Medicaid beneficiaries, they account for a disproportionately large percentage of the program’s costs.[[52]](#footnote-52) Together, these two groups make up 1 in 4 beneficiaries but account for almost two-thirds of Medicaid spending.[[53]](#footnote-53) Research estimates that approximately 5.2 million people used some type of Medicaid-financed LTSS in 2013 and about 2.3 million were older adults, age 65 and older.[[54]](#footnote-54) As such, the need for LTSS is clear, and shifts in LTSS expenditure patterns across settings and service types have created a need to reexamine the model in our health care system.

In the early decades of the Medicaid program, institutional care was the dominant form of LTSS. Medicaid-eligible people who needed help with daily activities and things such as remembering to take medications, buying groceries, preparing meals, bathing, etc. would have been institutionalized in a nursing home or other long-term care setting. Medicaid did not pay any form of LTSS provided outside of institutional settings, posing a problem for elders who wish to age in the comfort of their own homes.[[55]](#footnote-55) However, in 1981, Congress passed amendments to the Social Security Act that enabled states to create Medicaid Home and Community-Based Services (“HCBS”) programs, and other personal care services and allowed for Medicaid payment for home-based services for elderly or disabled individuals under Section 1915(c)[[56]](#footnote-56) waivers.[[57]](#footnote-57) Under this authority, states have the option to receive a waiver of Medicaid rules governing institutional care, creating support for home and community-based care. States can tailor waiver services to meet the needs of a particular target group by offering a combination of medical and non-medical services in limited geographic areas.

The use of HCBS has become an increasingly popular method of providing LTSS, thus enabling elderly adults to receive care in their homes, rather than institutions or care facilities. Spending on HCBS surpassed spending on institutional care for the first time in 2013 and comprises 57 percent of total Medicaid expenditures on LTSS as of 2016.[[58]](#footnote-58) HCBS programs provide two categories of care, including both standard medical services and non-medical services to beneficiaries who would otherwise require institutional care.[[59]](#footnote-59) Standard medical HCBS programs provide home health care options and include things like skilled nursing care, pharmacy care, dietary management, durable medical equipment, caregiver training, and hospice care.[[60]](#footnote-60) Non-medical HCBS programs aim to provide human services to support daily living, including things like senior centers, adult daycares, congregate meal sites and home-delivered meal programs, personal care services, and transportation services.[[61]](#footnote-61)

Section 1915(c) state HCBS waiver programs remain the primary vehicle through which states deliver HCBS today.[[62]](#footnote-62) The program must demonstrate that providing waiver services will be cost neutral to government and cost no more than institutional care; ensure the protection of people’s health and welfare; provide adequate and reasonable provider standards to meet the needs of the target population; and ensure that services follow an individualized and person-centered plan of care.[[63]](#footnote-63) Within broad federal guidelines, states can develop HCBS waivers to meet the needs of people who prefer to get LTSS in their homes or communities, rather than in institutional settings such as a hospitals, nursing facilities, or intermediate care facilities.[[64]](#footnote-64) Once approved, a state can create a HCBS program that offers benefits to a particular population and limits how many people are served. Unlike other Medicaid programs, states have the ability to cap HCBS waiver enrollment, despite their ability to theoretically operate as many HCBS waivers as they want. This ability to create enrollment caps creates long wait lists for beneficiaries seeking access to HCBS.[[65]](#footnote-65)It seems nonsensical that states would continue to set enrollment caps if HCBS are truly cheaper than nursing homes. While HCBS are cheaper than nursing homes on a per-person basis, states’ continued reliance on enrollment caps reflects the pervasive “woodwork effect” fear. In health policy terms, the “woodwork effect” describes the fear that publicly financing a program and increasing access to it will encourage more eligible participants to “come out of the woodwork” to enroll.[[66]](#footnote-66) In the context of elders living within the community, the woodwork effect refers to the concern that those who previously forewent services available in institutional settings, will now use publicly funded services like HCBS that are offered within the community. Increased enrollment in HCBS can lead to increased costs if the expense of treating more participants outweighs the cost savings from avoiding or delaying institutional care.[[67]](#footnote-67) However, these costs are ethically justified by the increased number of eligible people who would receive needed services in their homes and communities. Break up paragraph…

In addition to the waiver programs, Section 6086 of the Deficit Reduction Act (“DRA”) of 2005 established an optional Medicaid benefit giving states a new method with which to cover HCBS services for Medicaid beneficiaries.[[68]](#footnote-68) This authority gave state Medicaid programs the flexibility to cover HCBS without the need to seek a federal waiver. The HCBS-state plan optional benefit, Section 1915(i), differs from both existing Medicaid state plan benefits and Section 1915(c) waivers in two important ways. First, unlike Medicaid HCBS waivers under Social Security Act Section 1915(c), 1915(i) eliminates the budget-neutrality provision and therefore does not require states to show that HCBS reduces Medicaid's institutional care costs.[[69]](#footnote-69) Second, under 1915(i), states can define beneficiaries’ needs, and do not have to require that beneficiaries meet institutional levels of care to qualify for services.[[70]](#footnote-70) States can target specific populations based on identified risk factors, preventing higher rates of institutionalization and allowing more people to transition out of institutional LTSS.

The benefits to HCBS programs are abundant and have become an effective tool in keeping the elderly within the community before they require greater medical care. First, HCBS programs are thought to be cost effective, in that the community care they support usually costs less than half the cost of residential care. Second, they are culturally responsive, in understanding that allowing an individual to remain involved in her faith and social communities can play an important role in maintaining an individual’s health. Religious institutions are commonly a well-trusted component of affiliated seniors’ lives, especially in ethnic minorities where a level of mistrust of medical institutions can influence their receptiveness to medical treatment and services. Importantly, under such programs, patients enjoy the comfort of their own homes or small facilities within their communities, which offers the elderly a sense of familiarity. Allowing them to stay within their communities promotes the elders’ best interests by making them comfortable while keeping them safe and preventing the negative impact of isolation that is often seen in institutional settings. There is a robust connection between feelings of independence and self-determination, fostered by participation in HCBS programs, and quality of life. Lastly, some waivers contain “participant-directed” components that permit the waiver recipient to select and pay their own caregivers, including family members.[[71]](#footnote-71) This alleviates some of the burden that falls on unpaid caregivers, as described above, and promotes feelings of autonomy and self-direction in the elderly individual. The most significant impediment to the functionality and success of HCBS programs is their availability to eligible beneficiaries.

The fragmentation of Medicaid HCBS programs imposes administrative complexity for states and confusion for beneficiaries.[[72]](#footnote-72) Each state has its own review and approval processes, financial and functional eligibility criteria, available services, reporting requirements, quality measures, and other features. States combine multiple authorities, administer different sets of eligibility rules, and oversee distinct quality measures for each HCBS option. Because states have created HCBS programs to target particular populations, eligibility for HCBS benefits varies from state to state.[[73]](#footnote-73) Under 1915(c) waivers, benefits are not available for people who are not at risk of institutionalization and states’ rules about institutional level of care vary. Because state Medicaid programs are still minimally required to cover nursing facility services, most HCBS remain optional, and the institutional bias persists. The optional nature of most HCBS programs results in substantial variation across states in enrollment and spending, reflecting states’ different choices about which benefits are given and which populations are served.[[74]](#footnote-74) States’ ability to cap HCBS waiver enrollment also creates long wait lists for beneficiaries.[[75]](#footnote-75) States face fiscal pressures that drive a desire to control costs by limiting program enrollment and/or placing utilization controls on services, as described in the woodwork effect theory above.[[76]](#footnote-76) The current Medicaid HCBS system also creates confusion for individuals in need of services. Those seeking services remain largely uninformed about how to navigate the program’s complexities and requirements, leaving those in need of LTSS unable to determine which benefit package best meets their needs.[[77]](#footnote-77)

Federal and state policymakers have collaborated over the years and Congress has amended Medicaid law extensively to ameliorate the issue of continued institutional bias by creating new incentives and authorities to offer HCBS and similar programs. Waiver programs and other state plan amendments have allowed states greater flexibility to provide Medicaid HCBS. However, each state can ultimately exercise its prerogative concerning whether to participate in any of the optional State Plan or waiver programs to promote HCBS for LTSS.[[78]](#footnote-78) This leaves the fate of those who currently require LTSS, or will in the future, largely uncertain. Thus, streamlining Medicaid HCBS is necessary to eradicate the current variation in state plan authority, financial and functional eligibility rules, and benefit packages across HCBS authorities. For these reasons, shifting to a managed long-term service and supports (“MLTSS”) model might be a preferable way to organize care. MLTSS, which will be discussed in Part IV, has the potential to streamline Medicaid state plan authority, enabling more elderly beneficiaries to receive care in their communities and homes.

1. Keep Unpaid Caregiver’s at the Center of Integrated Elderly Care

As discussed, a majority of the LTSS population lives in community settings, and unpaid caregivers are a critical element in helping the elderly to maintain independence.[[79]](#footnote-79) Because this reduces reliance on state Medicaid programs, we need to have a national focus on ensuring that caregivers receive the adequate support necessary to continue to provide the significant majority of LTSS.[[80]](#footnote-80) Although the National Family Caregiver Support Program was added to the Older Americans Act (“OAA”), these funds represent a fraction of LTSS expenditures.[[81]](#footnote-81) Public financing of LTSS will support, not supplant, family efforts and addressing and supporting the need for LTSS can result in savings to individuals and the government through delayed nursing home and Medicaid entry.[[82]](#footnote-82)

Proposed solutions aim to alleviate financial hardships, promote flexible employment, and provide services and supports. To alleviate financial hardships, several states offer tax benefits to family caregivers, to compensate for spending on LTSS.[[83]](#footnote-83) However, these tax credits are small, limited in scope, and many individuals are unaware of their existence.[[84]](#footnote-84) To promote flexible employment, states have enacted the FMLA, allowing qualified workers to claim up to 12 weeks of unpaid leave to care for a sick family member.[[85]](#footnote-85) The National Family Caregiver Support Program and Lifespan Respite Care Act provide funding to states to meet family caregiver needs by increasing the availability of respite care, providing resources for education and training, and offering supplemental services such as support groups, home modifications, and supplies.[[86]](#footnote-86) However, these programs remain massively underfunded due to the absence of a national, public financing program.

In recent years, through the national initiative Helping States Support Families Caring for an Aging America, the Center for Health Care Strategies (“CHCS”) has worked with states committed to increasing services and supports for family caregivers.[[87]](#footnote-87) The initiative is comprised of state and private organizations, including Medicaid, Departments of Aging and Health and Human Services, health plans, and community-based organizations.[[88]](#footnote-88) These various organizations are coordinating in new ways to prioritize and advance family caregiving programs, foreshadowing the ultimate transition to a patient-centered, coordinated care model, such as PACE and MLTSS, discussed in Part IV.

1. Money Follows the Person Programs

Over the years, Congress also has authorized time-limited grant programs that have enabled states to increase beneficiary access to HCBS programs with enhanced federal matching funds. These include the Real Choice Systems Change grants, the Money Follows the Person (“MFP”) demonstration, and the Balancing Incentive Program (“BIP”).[[89]](#footnote-89) Because BIP funding expired in 2015, we will focus on MFP’s role in increasing access to HCBS through structural reforms.[[90]](#footnote-90) Only individuals already in nursing homes qualify for MFP programs. Therefore, this program avoids the aforementioned woodwork effect that has driven states to proceed cautiously with otherwise obviously beneficial programs.[[91]](#footnote-91)

Medicaid’s MFP is a Medicaid program created as part of the Deficit Reduction Act of 2005, subsequently extended by the Affordable Care Act.[[92]](#footnote-92) The MFP demonstration provides states with enhanced federal matching funds for services and supports to transition Medicaid-dependent, elderly individuals from institutions back to the community.[[93]](#footnote-93) These services typically include transition services, personal care, case management, habilitative care, and respite care.[[94]](#footnote-94) States also receive the enhanced matching rate for “demonstration services,” which are additional HCBS, such as peer support, transition coordination services, or additional personal care hours, to facilitate the transition.[[95]](#footnote-95) States can choose the populations and types of facilities to target with their MFP transition efforts.[[96]](#footnote-96) Eligible participants include only Medicaid beneficiaries residing in an inpatient facility who move to a qualified residence, which includes homes owned or leased by the participant or a family member, apartments, and small group homes.[[97]](#footnote-97) The activities most frequently financed by MFP funds include expanding HCBS waiver capacity, providing access to transition services, improving access to affordable accessible housing, conducting community outreach, training caregivers and medical providers, developing enrollee needs assessments, and supporting administrative data and tracking systems.[[98]](#footnote-98) Despite state variations, MFP programs offer older adults more of a choice in deciding where to receive their LTSS.[[99]](#footnote-99)

MFP seeks to increase the use of HCBS and reduce Medicaid’s institutional bias, which persists because nursing facility services must be covered while HCBS are provided only at state option.[[100]](#footnote-100) MFP also strives to eliminate barriers in state law, state Medicaid plans, and state budgets that restrict the use of Medicaid funds for LTSS outside of institutional settings.[[101]](#footnote-101) Lastly, MFP strengthens the ability of Medicaid programs to provide HCBS to eligible Medicaid beneficiaries and establishes procedures to provide quality assurance and improve access to HCBS programs.[[102]](#footnote-102) Over time, the MFP program has helped states establish formal institution to community transition programs by enabling states to develop the necessary service and provider infrastructure.[[103]](#footnote-103) States have also used MFP funds to offer housing relocation assistance because beneficiaries’ ability to locate affordable accessible housing is routinely cited as a major barrier to transitions.[[104]](#footnote-104)

MFP programs have been successful in driving down nursing home occupancy rates. For all the reasons discussed in Part II of this Comment, lower nursing home occupancy rates are desirable.From the start of the program in 2008 through the end of 2019, states have transitioned 101,540 people to community living under MFP.[[105]](#footnote-105) In 2019, older adults represented more than three-quarters of all transitions (38 percent).[[106]](#footnote-106) States with robust MFP programs have found declines in nursing home occupancy rates.[[107]](#footnote-107) On September 23, 2020, CMS announced a supplemental funding opportunity available to the 33 MFP demonstration states currently operating.[[108]](#footnote-108) Under this opportunity, eligible states can receive $5 million in MFP grant funds, which is expected to accelerate and support state efforts to rebalance their LTSS systems and to expand HCBS program capacity. Unlike other health programs, there is no substantive debate over MFP and its effectiveness. MFP has contributed to tipping the balance of LTSS spending, with spending on HCBS surpassing spending on institutional care for the first time ever in 2013.[[109]](#footnote-109) MFP also has helped states control per enrollee spending, as providing enrollees with HCBS typically costs less than institutional care.[[110]](#footnote-110)

Because MFP has improved the lives of older adults, saved states money, and led to better health outcomes, permanent funding for this critical program is necessary to undertake the structural reforms needed. Congress has passed five short-term extensions of MFP since funding expired in 2018. Most recently, the Consolidated Appropriations Act was passed in December 2020. [[111]](#footnote-111) The COVID-19 relief provisions did not include dedicated funding for HCBS, but the bill did extend funding for the MFP program for three years.[[112]](#footnote-112) Proponents believe that permanent funding for the MFP program provides a solution to the crisis in nursing homes and other congregate settings brought to light with the COVID-19 pandemic.[[113]](#footnote-113) Without federal funding of MFP, states would have to discontinue a range of community transition related services and meaningful progress with LTSS rebalancing will be curtailed.[[114]](#footnote-114) Thus, to maintain the progress states have made, continued federal funding of MFP is necessary, especially as the demand for LTSS is expected to grow as the population ages.[[115]](#footnote-115)

The aforementioned programs have been successful in rethinking our strategies for providing LTSS in the community and address unmet needs. Despite good progress in the last 25 years, the system is not where it needs to be. Given the impending demographic shifts and estimates of those needing LTSS doubling by 2040, the programs must be more widely accessible. As our health systems become more complex and different schemes continue to emerge, we must find a way to enable elders to navigate through the complexities and determine how to get access, when they can get access, and which benefits they can receive. Evidently, an organizing system is necessary. Part IV will discuss two organizing mechanisms for the delivery of LTSS in the community that are newly gaining traction in various parts of the country.

1. **Organizing Systems for Delivery of Care: PACE and MLTSS**

Perhaps the largest gap in the LTSS system is the lack of care coordination. As non-institutional arrangements continue to develop and evolve to meet the growing demand for LTSS and promote community-based care, care coordination is necessary to ensure consumers are getting value and are not lost among the weeds in the various programs. Especially because it can be cheaper to support elders in the community depending on how well we allocate funds to meet LTSS needs, an organizing system is needed. In recent years, interest has arisen in coordinated care options such as PACE and MLTSS to improve access, coordination, and cost containment. Both organizing systems promise to streamline health care services provided to elders who remain at home or in the community. Both PACE and MLTSS are consistent with the notion that LTSS supports should be comprehensive, coordinated, and community based. PACE and MLTSS offer integrated care programs that provide efficient care coordination in a person-centered, rather than the traditional siloed care, approach.

1. PACE

One model for organizing the kinds of care for people with LTSS needs is the Program of All-Inclusive Care for the Elderly (“PACE”). The PACE model was developed in San Francisco in the 1970s as the Chinese American community’s alternative to nursing home placement.[[116]](#footnote-116) It was formally established by CMS as a permanent Medicare Advantage option in 1997.[[117]](#footnote-117) Today it is one of the oldest and most successful models of integrating care.[[118]](#footnote-118) Care integration by PACE improves quality, achieves health care savings, accomplishes care coordination, institutes accountability of a single entity for covered services, and provides administrative simplicity.Gerontologists and those dealing with LTSS financing have identified PACE as a model of care that fosters effectiveness in health and well-being, care utilization, and costs.[[119]](#footnote-119) Notably, the PACE care model results in reduced rates of hospital admissions, emergency room visits, unnecessary long-term nursing home placements, mortality, functional decline, and better reported health status and quality of life.[[120]](#footnote-120)

PACE provides a designed continuum of care and services for adults 55 years of age or older, who require a nursing-home level of care but who can safely live in the community with PACE services.[[121]](#footnote-121) The goal of PACE is to keep participants in the community “for as long as it is medically, socially, and financially feasible.”[[122]](#footnote-122) Different than other models, PACE is not an insurance vehicle, but rather directly provides the necessary services, such as medical daycare, home nursing services, and medical care. PACE benefits include all Medicaid and Medicare covered services, without the limitations normally imposed by these programs, and any other services determined necessary to improve and maintain an individual’s health, such as transportation services to PACE centers.[[123]](#footnote-123) PACE programs provide services primarily in an adult day health center and are supplemented by in-home and referral services depending on an individual’s LTSS needs*.* An interdisciplinary team of professional staff assesses an enrollee’s needs, develops care plans, contracts for any other required services, and delivers these services in a coordinated manner.[[124]](#footnote-124) In this process, participants remain at the center of the care plan developed, which offers access to the full continuum of preventive, primary, acute, rehabilitative, and long-term care services.[[125]](#footnote-125) As such, PACE organizations serve both as health plans and as medical and long-term service providers to elders, preserving their independence and ability to remain in the comfort of their own home for as long as possible.

As the only current model of care that integrates Medicare and Medicaid funding at the point of care, PACE programs have the opportunity to truly integrate these funding streams in the most cost-effective way possible.[[126]](#footnote-126) The PACE care model achieves the goal of supporting seniors’ quality of care and quality of life in community-based settings for less than or the same cost as other programs.[[127]](#footnote-127) PACE combines Medicare and Medicaid funding, as well as private funding, to provide necessary services to elders living in the community. Ninety percent of individuals served by PACE are low-income adults, who are dual eligible for both Medicare and Medicaid.[[128]](#footnote-128) However, the program also accepts participants who pay PACE premiums privately. [[129]](#footnote-129) Premiums depend on the services required and the PACE service area.[[130]](#footnote-130) Most commonly, each local PACE organization accepts a capitation payment from Medicare and Medicaid to provide all required care to low-income and frail elders.[[131]](#footnote-131) The capitated funding arrangement rewards providers who are flexible and creative in providing high quality care because it incentivizes the ability to coordinate quality care across settings and medical disciplines.[[132]](#footnote-132) This allows providers to deliver all services to participants rather than only those reimbursable under the Medicare and Medicaid FFS plans.[[133]](#footnote-133) Since PACE organizations are fully responsible for meeting all of an individual's care needs, they are incentivized and empowered to address each person's care holistically.[[134]](#footnote-134)

PACE is a comprehensive, innovative way of assessing LTSS needs and the “gold standard” of person-centered, integrated care for elders who need support and services to remain in their homes and communities.[[135]](#footnote-135) States will likely continue to expand PACE organizations as a way of structuring the delivery of care. The ability to create customized care that is planned and delivered by a coordinated, interdisciplinary team is invaluable, and conceptually, this model should be instructive going forward. As it currently exists, geographic limits restrict who has access to PACE organizations because to enroll in the program, you must live in a PACE service area. Today, PACE is a covered Medicare benefit and offered as an optional Medicaid benefit in 31 states.[[136]](#footnote-136) Nationally, there are 124 PACE organizations in 235 communities across the U.S., serving almost 50,000 seniors.[[137]](#footnote-137) This number represents less than 10 percent of the eligible population in communities served by PACE.[[138]](#footnote-138) Because PACE programs are currently serving only a small number of those eligible for it, the PACE 2.0 initiative was formed to expand the reach of PACE programs nationally.[[139]](#footnote-139) Non-profit groups such as West Health and The John A. Hartford Foundation are funding the initiative to expand the reach of PACE programs nationally by increasing the number of participants at each site and expanding to new geographic areas and populations.[[140]](#footnote-140)

ArchCare, the health care ministry of the Archdiocese of New York, has now adopted a PACE 2.0 growth strategy that seeks to exponentially increase the number of individuals who can benefit from PACE. To achieve this goal, ArchCare pursues strategic partnerships with hospitals and managed care plans that are expected to increase enrollment and seeks state approval to utilize operational flexibilities to support such expansion. ArchCare established its PACE program in 2009 and New York has supported PACE since its introduction as a demonstration. In recent years, New York’s PACE program has achieved annual growth rates exceeding ten percent.[[141]](#footnote-141) New York is continuing to make all efforts to support expansion of PACE programs due to the positive outcomes already realized. Because PACE organizations integrate all primary, acute, and long-term care, establishing them can be a complex undertaking that is capital-intensive. However, as demonstrated in New York, and in other states such as Oregon and Washington, expansion of PACE will provide an array of benefits. The key learning, based on findings from the growing PACE organizations and field testing of the expansion model from the PACE 2.0 initiative is that organizations must establish the capacity for growth without waiting for incremental increases in enrollment to justify adding resources to the program.[[142]](#footnote-142)

1. MLTSS

In recent years, state Medicaid agencies have increased the use of managed long-term services and supports (“MLTSS”) to revamp the patchwork LTSS financing system, improve quality of care, and enhance care coordination for Medicaid-eligible individuals.[[143]](#footnote-143) MLTSS serves as a mediating force and organizing mechanism for the various health systems working to provide efficient and effective care in the community to elders. At its conception, MLTSS was intended to be a coordinating entity for senior services with metrics and quality assurances to provide better, more comprehensive, care to the elderly. MLTSS creates a way to organize the delivery of care, and the timing and type of care provided, so that there is coordination among the various parts of LTSS. MLTSS is defined as an arrangement between a state Medicaid program and a managed care plan, which receives a per-member-per month capitated payment, to provide LTSS to eligible Medicaid beneficiaries.[[144]](#footnote-144) This value-based payment structure gives incentive to providers to contain the costs and improve the quality of care for populations that use the most resources and are at high risk for requiring LTSS.

As of July 1, 2019, 27 states reported having an MLTSS model.[[145]](#footnote-145) Two states reported having a managed fee-for-service (“FFS”) MLTSS model while roughly half of states covered LTSS through one or more of the capitated managed care arrangements.[[146]](#footnote-146) By moving away from a FFS model and rebalancing their LTSS systems, several states have reported improvement in transitioning members from institutional settings back to their home by utilizing HCBS programs.[[147]](#footnote-147) Twelve states have recently transitioned from the LTSS FFS payment model to a MLTSS model, seeking to rebalance LTSS spending by increasing the funding for HCBS programs while decreasing the proportion of spending for institutional care, increasing care coordination to improve quality of life and health for individuals, and addressing access gaps by decreasing or eliminating HCBS waiting lists.[[148]](#footnote-148) For example, New Mexico reduced their percentage of individuals residing in nursing facilities from 18.7 in 2011 to 14.3 in 2015.[[149]](#footnote-149) This reduced overall costs, since the cost of a nursing home in the state was over two-times the cost of an individual being cared for in the community.[[150]](#footnote-150)

The most successful models of decreased reliance on institutionalization have been constructed under the MLTSS models. Florida’s MTLSS program inception began in 2014 and at the time fifty-six percent of people were using Skilled Nursing Facility (SNF) services and forty-four percent were using HCBS.[[151]](#footnote-151) By June 2018, the enrollees receiving these services shifted to forty-three percent and fifty-seven percent respectively, which caused the cost per individual to drop by ten percent.[[152]](#footnote-152) Because Florida has historically been one of the lowest ranking states with access to LTSS, this shift indicates MLTSS model effectiveness. Moving forward states should adapt MLTSS models with the goal of expanding HCBS, promoting community inclusion, ensuring quality, and increasing efficiency in the provision of LTSS to the elderly.

1. **Conclusion**

Projections on incorporating LTSS in health care proposals make clear that any expansion of what currently exists for LTSS will be costly for the federal government and require tradeoffs.[[153]](#footnote-153) Certain populations and risk pools would have to be identified and others would have to be left out. However, projections for those needing LTSS in the future are just as clear; the number of people needing LTSS will continue to grow and current systems will prove inadequate to meet these demands. The patchwork approach to LTSS will continue to confuse beneficiaries, leave gaps in coverage, and present inefficiencies caused by care fragmentation. Because the current approach fails to ensure adequate care to elders, we must move towards a patient-centered, coordinated system through PACE or MLTSS models. These models rationalize LTSS care and allow coordination between LTSS and other medical care.

In plotting a future for integrated care for the elderly, we must increase access to, and quality of, home and community-based supports and offer appropriate cost containment measures alongside them. Individuals in home or community care settings need supportive services to function in a way that allows them to integrate into society and flourish to the greatest extent possible. Thus, we must continue to identify programs that offer high-quality, integrated care at lower costs and accelerate the adoption of these currently existing programs on a national level.

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104. *Id*. [↑](#footnote-ref-104)
105. MFP State Transitions as of 2019, *supra* note 93. [↑](#footnote-ref-105)
106. *Id*. [↑](#footnote-ref-106)
107. H. Stephen Kaye, [Evidence for the Impact of the Money Follows the Person Program](https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/reports/Evidence%20for%20the%20Impact%20of%20MFP_0.pdf), Cmty. Living Pol’y Ctr. (July 2019), https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/reports/Evidence%20for%20the%20Impact%20of%20MFP\_0.pdf. [↑](#footnote-ref-107)
108. MFP State Transitions as of 2019, *supra* note 93. [↑](#footnote-ref-108)
109. Steve Eiken et al., *Medicaid Expenditures for Long-Term Services and Supports in FY 2016*, IBM Watson Health (May 1, 2018), http://www.advancingstates.org/sites/nasuad/files/ltssexpenditures2016.pdf. [↑](#footnote-ref-109)
110. MFP State Transitions as of 2019, *supra* note 93. [↑](#footnote-ref-110)
111. *Money Follows the Person*, Ctr. Pub. Representation (Dec. 22, 2020), https://medicaid.publicrep.org/feature/money-follows-the-person/. [↑](#footnote-ref-111)
112. *Id*. [↑](#footnote-ref-112)
113. *Id*. [↑](#footnote-ref-113)
114. Other services that states expect to discontinue include community case management, housing relocation assistance, and family caregiver training. Program staff positions and activities that states expect to discontinue without additional federal funding include outreach specialists, housing specialists, and training for care coordinators and providers, among other activities. *See* Musumeci et al., *supra* note 88. [↑](#footnote-ref-114)
115. *Id*. [↑](#footnote-ref-115)
116. *What is Pace?*, Npa Online, https://www.npaonline.org/pace-you (last visited Apr. 25, 2021). [↑](#footnote-ref-116)
117. *PACE*, Medicare.gov, <https://www.medicare.gov/your-medicare-costs/get-help-paying-costs/pace> (last visited Apr. 25, 202). [↑](#footnote-ref-117)
118. Sara Karon et al., *Expanding the PACE Model of Care to High-Need, High-Cost Populations,* Commonwealth Fund (Oct. 2020), https://doi.org/10.26099/4454-z770. [↑](#footnote-ref-118)
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121. *Programs of All-Inclusive Care for the Elderly Benefits*,Medicaid.gov, <https://www.medicaid.gov/medicaid/long-term-services-supports/pace/programs-all-inclusive-care-elderly-benefits/index.html> (last visited Apr. 25, 2021). [↑](#footnote-ref-121)
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123. *Program of All-inclusive Care for the Elderly (PACE)*, State N.J. Dep’t Hum. Servs. Div. Aging Servs., <https://www.state.nj.us/humanservices/doas/services/pace/> (last visited Apr. 25, 2021). [↑](#footnote-ref-123)
124. *Id*. [↑](#footnote-ref-124)
125. Victor Hirth et al., *Program of All Inclusive Care (PACE): Past, Present, and Future*, 10 J. Am. med. dirs. ass’n 155 (2009). [↑](#footnote-ref-125)
126. *Id*. [↑](#footnote-ref-126)
127. On the Medic aid side, states pay PACE programs on average 16.5 percent less than the costs of caring for a comparable population through other Medicaid services, including nursing homes and HCBS waiver programs. In Medicare, payments to PACE organizations are equivalent to the costs for a comparable population to receive services through the FFS program. *See* Jade Gong and Peter Fitzgerald, *supra* note 115. [↑](#footnote-ref-127)
128. *Id*. [↑](#footnote-ref-128)
129. *Programs of All-Inclusive Care for the Elderly (PACE): Introduction to PACE*, CMS.gov, <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/pace111c01.pdf> (last visited Apr. 25, 2021). [↑](#footnote-ref-129)
130. *Id*. [↑](#footnote-ref-130)
131. *Id*. [↑](#footnote-ref-131)
132. Hirth, *supra* note 121. [↑](#footnote-ref-132)
133. *Id*. [↑](#footnote-ref-133)
134. Jade Gong and Peter Fitzgerald, *supra* note 115. [↑](#footnote-ref-134)
135. Amy Herr and Amy Berman, *Let’s Pick Up the PACE: Expanding the Reach of the Gold Standard Program of All-Inclusive Care for the Elderly,* GenerationsAm. soc’y on aging (Oct. 22, 2018), <https://generations.asaging.org/lets-pick-pace>. [↑](#footnote-ref-135)
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137. *Id*. [↑](#footnote-ref-137)
138. *Id*. [↑](#footnote-ref-138)
139. *Id*. [↑](#footnote-ref-139)
140. *Id*. [↑](#footnote-ref-140)
141. *Id*. [↑](#footnote-ref-141)
142. Jade Gong and Peter Fitzgerald, *supra* note 115. [↑](#footnote-ref-142)
143. Rudowitz et al., *supra* note 42. [↑](#footnote-ref-143)
144. Tuck & Moore, *supra* note 50, at 4. [↑](#footnote-ref-144)
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146. *Id*. [↑](#footnote-ref-146)
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148. *Id*. at 4. [↑](#footnote-ref-148)
149. *Id*. at 11. [↑](#footnote-ref-149)
150. *Id*. [↑](#footnote-ref-150)
151. *Id*. [↑](#footnote-ref-151)
152. *Id*. [↑](#footnote-ref-152)
153. Favreault, *supra* note 5. [↑](#footnote-ref-153)