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Plotting a Future for Integrated Care

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I. Introduction

The notion of respecting our elders was 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 the COVID-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] 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, at an estimated annual cost to our nation's healthcare system of nearly $800 billion, and social isolation, prompted by placement in institutional settings, increases these risks.[2, 3]

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 proper protection.[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 the need to shift our focus to keeping the elderly at home and in the community for as long as possible. This need is undeniable now as we look in hindsight to the

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[1] *AARP Nursing Home COVID-19 Dashboard*, AARP PUBLIC POLICY INSTITUTE (April 2021), https://www.aarp.org/ppi/issues/caregiving/info-2020/nursing-home-covid-dashboard.html.
[2] Terri D. Keville, *Studies of Transfer Trauma in Nursing Home Patients: How the Legal System Has Failed to See the Whole Picture*, 3 HEALTH MATRIX 421 (1993) (stating that the term "transfer trauma" was coined in the early 1960s when gerontologists first became concerned that involuntary relocation of the elderly might have adverse health effects and is now a generally recognized phenomenon that must be considered in transfer decisions).
[3] *NHE Fact Sheet*, CMS.GOV, (last visited Apr. 25, 2021), https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NHE-Fact-Sheet.
[4] *Elder Abuse: A Public Health Issue that Affects All of Us*, (June 15, 2018), ADMINISTRATION FOR COMMUNITY LIVING, https://acl.gov/news-and-events/acl-blog/elder-abuse-public-health-issue-affects-all-us-0 (estimating that approximately 10 percent of adults age 60 and older have experienced physical abuse, psychological or verbal abuse, sexual abuse, neglect, or financial exploitation).

way in which this would have changed the trajectory for seniors during the pandemic. For purposes of this paper, institutionalization will refer to long-term nursing home settings, where 24-hour care is provided.

It is unsurprising that the elderly population prefers to live at home and age in place 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] Despite the evidence of the benefits of community care, for too long Medicaid has exhibited a bias for institutional, rather than community-based care. For purposes of this paper, community-based care will encompass the array of supports and services designed to help community-dwelling older 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] 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 home, or allowing them to remain in their homes in the first instance, by utilizing and expanding current health systems that

[5] Melissa M. Favreault, *Incorporating Long-Term Services and Supports in Health Care Proposals: Cost and Distributional Considerations*, URBAN INSTITUTE AND COMMONWEALTH FUND (2020), https://www.urban.org/sites/default/files/publication/102311/incorporating-long-term-services-and-supports-in-health-care-proposals.pdf (discussing the trade-offs between increasing public LTSS financing and the need to choose specific groups of vulnerable people).
[6] *See* Eugenia L. Siegler, et al., *Community-Based Supports and Services for Older Adults: A Primer for Clinicians*, JOURNAL OF GERIATRICS, (Feb. 1, 2015).

promote community-based supports will reduce overall costs, promote community inclusion, and ensure the quality and efficiency in delivering health care services to the elderly. Because the whole-person care envisioned depends on who the payer is to a large extent, it is important to note that the largest payers of LTSS today are Medicaid and individuals paying for LTSS out-of-pocket, with unpaid family caregivers providing 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.

II. The Shifting Focus of LTSS

Those receiving LTSS services from Medicaid, Medicare, or private insurance are among the most health-compromised among us and are the "high need, high-cost patients" that have multiple chronic conditions or disabilities.[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] LTSS include nursing home services, but also support services, often non-medical, that allow individuals to live independently and safely in their homes or the community when they cannot perform daily activities on their own.[9] Those needing LTSS require assistance with either, or both, activities of daily living ("ADLs") and instrumental activities of daily living ("IADLs").[10] ADLs consist of personal care activities such as eating, bathing, dressing, using the bathroom, and getting around the house.[11] IADLs consist of more complex care, such as medication and finance management, meal preparation, grocery shopping, and laundry.[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] Older adults who wish to age-in-place at home, as

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[7] *See* Blumenthal et al., *Caring for High Need, High-Cost Patients- An Urgent Priority,* N ENGL J MED. (Sept. 8, 2016).
[8] *See* H. Stephen Kaye et al., *Long-Term Care: Who Gets It, Who Provides It, Who Pays, and How Much?*, HEALTH AFF. (Jan. 2010), https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2009.0535.
[9] *See Long Term Services and Supports*, MEDICAID.GOV, (last visited Apr. 25, 2021), https://www.medicaid.gov/medicaid/ltss/index.html.
[10] *See* Amber Willink, et al., *Use of Paid and Unpaid Personal Help by Medicare Beneficiaries Needing Long-Term Services and Supports*, THE COMMONWEALTH FUND, (Nov. 2017), https://www.commonwealthfund.org/sites/default/files/documents/___media_files_publications_issue_brief_2017_nov_willink_medicare_ltss_needs_ib_v2.pdf. The study uses data from the National Health and Aging Trends Study (NHATS) from 2015 to examine care received by Medicare beneficiaries who require LTSS.
[11] *Id*.
[12] *Id*.
[13] Everette James and Meredith Hughes, *Embracing the Role Of Family Caregivers In The U.S. Health System,* HEALTH AFFAIRS (Sept. 8, 2016), https://www.healthaffairs.org/do/10.1377/hblog20160908.056387/full/ [hereinafter Health Affairs Blog].

opposed to nursing homes or other residential institutions, are largely dependent on family and unpaid caregivers for providing LTSS, including daily activities and overall care management.[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 on institutionalization in nursing homes because they are often clinically inferior, socially inferior, and disfavored by people due to personal preference. Elders deteriorate faster in nursing homes because individuals become apathetic and withdrawn as a result 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. Poorly planned and executed involuntary 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] 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] 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,

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[14] Marshall B. Kapp, *Home and Community-Based Long-Term Services and Supports: Health Reform's Most Enduring Legacy?*, 8 ST. LOUIS U.J. HEALTH L. & POL'Y 9 (2014).
[15] Terri D. Keville, *Studies of Transfer Trauma in Nursing Home Patients: How the Legal System Has Failed to See the Whole Picture*, 3 HEALTH MATRIX 421 (1993).
[16] *Medicaid's Home and Community-Based Services State Plan Option: Section 6086 of the Deficit Reduction Act*, CONGRESSIONAL RESEARCH SERVICE (Jan. 31, 2008), https://www.everycrsreport.com/files/20080131_RS22448_285ea90badcf237c95d83a0060ef5f91eeabf893.pdf.

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. Because of the potential for shortfalls in quality as a result of such fragmented care, the FFS model is 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] 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] The current sources of support for LTSS have already proved ineffective and will be increasingly inadequate as the population ages.

A. 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 need arises, at which time it can disrupt an informal caregiver's life and consume time previously devoted to gainful employment,

[17] *See* Kali S. Thomas, et al., *Long-term Services and Supports (LTSS): A Growing Challenge for an Aging America*, 25 PUBLIC POLICY & AGING REPORT 2, 56–62 (Spring. 2015).
[18] *Id*.

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, providing great savings to the health care system annually.[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 caregiving can 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]

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, providing three quarters of all long-term care to elderly friends and family members.[21] The extent of this informal care is one indication of the effects 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%) of all informal caregivers were performing medical, nursing tasks for family members with multiple chronic physical and cognitive conditions.[22] Many caregivers performing these complex tasks have taught themselves how to effectively care for their loved ones. Despite the fact that family caregivers report feeling joy and satisfaction in their critical role of helping their loved one remain "independent," almost

[19] In 2013, the AARP valued the unpaid care provided by these family caregivers at $470 billion. *See* Health Affairs Blog, *supra* note 13.
[20] Thomas, et al., *supra* note 17.
[21] Maria Iacobo, *Raising Awareness, Enabling Support for Unpaid Caregivers*, THE GERONTOLOGY INSTITUTE BLOG AT THE UNIVERSITY OF MASSACHUSETTS BOSTON (Jan. 11, 2021), https://blogs.umb.edu/gerontologyinstitute/2021/01/11/raising-awareness-enabling-support-for-unpaid-caregivers/.
[22] Susan C. Reinhard, et al., *Valuing the Invaluable: 2015 Update*, AARP PUBLIC POLICY INSTITUTE (July 2015), https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf.

half are overwhelmed by their caregiving responsibilities.[23] In part 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.[24] Intensive caregivers also have more health problems than less intensive caregivers. This is important because caregiver burnout and stress is important predictor of a care recipient's ultimate nursing home placement and an important risk factor for caregiver morbidity and mortality.[25]

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 as a result 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 were employed.[26] This disproportionately impacts women, who are more likely to provide informal care to older adults than men.[27] Because hours of unpaid care are not substantially lower when paid care is also received, 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.[28] 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

[23] *Id*. at 7.
[24] 58% of caregivers reported a chronic health condition; 39% providing intensive care reported depression and anxiety. Reinhard, et al., *supra* note 22, at 7.
[25] Brenda C. Spillman and Sharon K. Long, *Does High Caregiver Stress Predict Nursing Home Entry?*, 46 INQUIRY 140–161 (June 1, 2009), https://journals.sagepub.com/doi/10.5034/inquiryjrnl_46.02.140; Richard Schulz & Scott R. Beach, *Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study*, JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, (Dec. 15, 1999), https://jamanetwork.com/journals/jama/fullarticle/192209.
[26] *Caregiving in the United States 2020*. AARP AND NATIONAL ALLIANCE FOR CAREGIVING, (May 2020), https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf.
[27] *Id*.
[28] Willink, et al., *supra* note 10, at 4.

assertion.[29] 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.[30] 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.[31] The study results found that significant numbers of community-residing older adults with LTSS needs do not receive help.[32] 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 all argue that adequate supports and training must be made available.[33] 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

[29] Willink, et al., *supra* note 10, at 4.
[30] Willink, et al., *supra* note 10, at 4.
[31] Willink, et al., *supra* note 10, at 4.
[32] Willink, et al., *supra* note 10, at 4.
[33] Thomas, et al., *supra* note 17.

that patient values guide all clinical decisions."[34] 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.[35] Patients engage in shared decision-making with their families and providers to design and manage a customized and comprehensive care plan.[36]

The shift to a patient-centered, coordinated care model will improve the well-being of elders and respect their preference to remain home and in the community, thereby potentially reducing the need for formal, institutional level care down the line.[37] 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.[38]

[34] *What Is Patient-Centered Care?* NEJM Catalyst, (Jan. 1, 2017), https://catalyst.nejm.org/doi/full/10.1056/CAT.17.0559
[35] *Id*.
[36] *Id*.
[37] Health Affairs Blog, *supra* note 13.
[38] Juleen Rodakowski et al., *Caregiver Integration During Discharge Planning for Older Adults to Reduce Resource Use: A Metaanalysis*. 65 JOURNAL OF THE AMERICAN GERIATRICS SOCIETY 8 (Apr. 3, 2017), https://agsjournals.onlinelibrary.wiley.com/doi/epdf/10.1111/jgs.14873.

III. 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.[39] Gradually, different programs have evolved to promote and support community-based alternatives to institutional care. This section will first examine the growth of HCBS 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.

A. Medicaid's Shift from Institutions to the Community

Pursuant to Title XIX of the Social Security Act,[40] the Medicaid program provides medical assistance to low-income individuals and individuals with disabilities, covering 1 in 5 Americans.[41] 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.[42] The Medicaid entitlement guarantees both that individuals are entitled to a defined set of benefits and states are entitled to federal matching funds.[43] 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.[44] States have the option of covering medically needy

[39] Thomas, et al., *supra* note 17.
[40] 42 U.S.C. § 1396.
[41] *Id*.
[42] Robin Rudowitz et al., *10 Things to Know about Medicaid: Setting the Facts Straight*, KFF (Mar. 6, 2019), https://files.kff.org/attachment/Issue-Brief-10-Things-to-Know-about-Medicaid-Setting-the-Facts-Straight.
[43] *Id*.
[44] THE AGING POPULATION IN THE TWENTY-FIRST CENTURY: STATISTICS FOR HEALTH POLICY (National Academies Press ed. 1988).

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.[45] For dually eligible recipients, Medicare is the first payer Medicaid is the second payer so that 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") administer the program and approve 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 covered population and services, health care delivery models, and payment methods.[46] This flexibility results in significant variation across state Medicaid programs.[47]

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.[48] 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.[49] 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.[50] Together, these two groups make

[45] *Id*.
[46] Rudowitz et al., *supra* note 42.
[47] Rudowitz et al., *supra* note 42.
[48] Rudowitz et al., *supra* note 42.
[49] CENTER FOR MEDICARE & MEDICAID SERVICES, MEDICAID LONG TERM SERVICES AND SUPPORTS ANNUAL EXPENDITURES REPORT: FEDERAL FISCAL YEARS 2017 AND 2018, (Jan. 7, 2021), https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures-2017-2018.pdf [hereinafter Medicaid LTSS Annual Expenditures Report].
[50] Kimberly D. Tuck and Jennifer E. Moore, *Leveraging Opportunities in Medicaid Managed Long-Term Services and Supports (MLTSS)*, INSTITUTE FOR MEDICAID INNOVATION (2019), https://www.medicaidinnovation.org/_images/content/2019-IMI-MLTSS_in_Medicaid-Report.pdf.

up 1 in 4 beneficiaries but account for almost two-thirds of Medicaid spending.[51] 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.[52] 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 home.[53] However, in 1981, Congress passed amendments to the Social Security Act which enabled states to create Medicaid Home and Community-Based Services ("HCBS") programs, and other personal care services, that allowed for Medicaid payment for home-based services for elderly or disabled individuals under Section 1915(c)[54] waivers.[55] 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.

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[51] Rudowitz et al., *supra* note 42.
[52] Favreault, *supra* note 5.
[53] Willink, et al., *supra* note 10.
[54] Sec. 1915 42 U.S.C. § 1396n.
[55] Home and Community-Based Services Waivers, 79 Fed. Reg. 2948, 2949 (Jan. 14, 2014). [hereinafter Home and Community-Based Services Waivers].

Spending on HCBS surpassed spending on institutional care for the first time in 2013 and comprises 57% of total Medicaid expenditures on LTSS as of 2016.[56] HCBS provide two categories of care, including both standard medical services and non-medical services to beneficiaries who would otherwise require institutional care.[57] Standard medical HCBS provide home health care options and include things like skilled nursing care, pharmacy care, dietary management, durable medical equipment, caregiver training, and hospice care.[58] Non-medical HCBS 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.[59]

Section 1915(c) state HCBS waiver programs remain the primary vehicle through which states deliver HCBS today.[60] 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.[61] Within broad federal guidelines, states can develop HCBS waivers to meet the needs of people who prefer to get LTSS in their home or community, rather than in an

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[56] Medicaid LTSS Annual Expenditures Report, *supra* note 49, at 15.
[57] Mary Sowers, et al., *Streamlining Medicaid Home and Community-Based Services: Key Policy Questions,* KFF, (Mar. 11, 2016), https://www.kff.org/report-section/streamlining-medicaid-home-and-community-based-services-key-policy-questions-issue-brief/
[58] Home and Community-Based Services Waivers, *supra* note 55.
[59] Home and Community-Based Services Waivers, *supra* note 55.
[60] *Home-and Community-Based Services*, (Jan. 10, 2014), CENTER FOR MEDICARE & MEDICAID SERVICES, https://www.cms.gov/newsroom/fact-sheets/home-and-community-based-services. In FY 2018, Medicaid HCBS enrollment ranged from 81,000 individuals receiving Section 1915 (i) state plan services to 1.8 million individuals receiving Section 1915 (c) waiver services, with joint federal and state spending across all HCBS authorities totaling $92 billion.
[61] The CFC state plan option offers enhanced federal matching funds for states to provide attendant care services and supports, provided that states meet certain criteria, with the goal of remedying the historic institutional bias. *See Home & Community-Based Services 1915(c)*, MEDICAID.GOV, (last visited Apr. 25, 2021), https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html.

institutional setting such as a hospital, nursing facility, or intermediate care facility.[62] 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.[63] 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, state's 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.[64] 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.[65] However, these costs are ethically justified by the increased number of eligible people who would receive needed services in their homes and communities.

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

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[62] *Id*.
[63] MaryBeth Musumeci, et al., *Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists*, KFF, (Apr. 4, 2019), https://www.kff.org/medicaid/issue-brief/key-questions-about-medicaid-home-and-community-based-services-waiver-waiting-lists/.
[64] Mitchell LaPlante, *The Woodwork Effect in Medicaid Long-Term Services and Supports*, JOURNAL OF AGING & SOCIAL POLICY, (Apr. 2013), https://doi.org/10.1080/08959420.2013.766072.
[65] *Id*.

HCBS services for Medicaid beneficiaries.[66] 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 reduce Medicaid's institutional care costs.[67] 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.[68] 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 are abundant and have become an effective tool in keeping the elderly within the community before they require greater medical care. First, HCBS 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 home or small facilities within the community, which offers the elderly a sense of familiarity. Allowing them to stay within the community promotes the elders' best interests by making them comfortable while

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[66] *Medicaid's Home and Community-Based Services State Plan Option: Section 6086 of the Deficit Reduction Act*, (Jan. 31, 2008), https://www.everycrsreport.com/reports/RS22448.html.
[67] *Id*.
[68] *Id*.

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, and experienced 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. 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 of HCBS functionality and success remains to be their availability to eligible beneficiaries.

The fragmentation of Medicaid HCBS imposes administrative complexity for states and confusion for beneficiaries.[69] 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.[70] 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 results in substantial variation across states in enrollment and spending, reflecting states' different choices about which benefits are given and which populations are served.[71] States' ability to cap HCBS

[69] Sowers, et al., *supra* note 57.
[70] Sowers, et al., *supra* note 57. For example, Oregon operates six different HCBS waiver programs, offering different benefits to groups like children and adults with physical disabilities, children and adults with developmental disabilities, and those over age 65. Other states target populations by diagnoses.
[71] Favreault, *supra* note 5.

waiver enrollment also creates long wait lists for beneficiaries.[72] 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.[73] 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.[74]

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 or not to participate in any of the optional State Plan or waiver programs to promote HCBS for LTSS.[75] 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.

[72] Over 707,000 people were on HCBS waiver waiting lists in 40 states as of 2017, and over one-quarter were seniors and adults with physical disabilities. *See* Musumeci, et al., *supra* note 63.
[73] Sowers, et al., *supra* note 57.
[74] Sowers, et al., *supra* note 57.
[75] Kapp, *supra* note 14, at 28.

B. Keep Unpaid Caregiver's at the Center

As discussed, a majority of the LTSS population lives in community settings, and unpaid, informal caregivers are a critical element in helping the elderly to maintain independence.[76] Because this reduces reliance on state Medicaid programs, we need to have a national focus on ensuring that caregivers receive the adequate supports necessary to continue to provide the significant majority of LTSS.[77] Although the National Family Caregiver Support Program was added to the Older Americans Act ("OAA"), these funds represent a fraction of LTSS expenditures.[78] 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.[79]

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.[80] However, these tax credits are small, limited in scope, and many individuals are unaware of their existence.[81] 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.[82] 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.[83]

[76] Thomas, et al., *supra* note 17.
[77] Thomas, et al., *supra* note 17.
[78] Thomas, et al., *supra* note 17.
[79] Thomas, et al., *supra* note 17; *see infra* Part II.
[80] Health Affairs Blog, *supra* note 13.
[81] Health Affairs Blog, *supra* note 13.
[82] Health Affairs Blog, *supra* note 13.
[83] Health Affairs Blog, *supra* note 13.

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.[84] The initiative comprised of state and private organizations, including Medicaid, Departments of Aging and Health and Human Services, health plans, and community-based organizations.[85] These various organizations are coordinating in news 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.

C. 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 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").[86] Because BIP funding expired in 2015, we will focus on MFP's role in increasing access to HCBS through structural reforms. 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.[87]

[84] *Helping States Support Families Caring for an Aging America*, CENTER FOR HEALTH CARE STRATEGIES, (May 2018), https://www.chcs.org/project/helping-states-support-families-caring-for-an-aging-america/.
[85] *Id.*
[86] Sowers, et al., *supra* note 57.
[87] *See infra* Part III.A.

Medicaid's MFP is a Medicaid program created as part of the Deficit Reduction Act of 2005, subsequently extended by the Affordable Care Act.[88] 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.[89] These services typically include transition services, personal care, case management, habilitative care, and respite care.[90] 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.[91] States can choose the populations and types of facilities to target with their MFP transition efforts.[92] 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.[93] 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.[94] Despite

[88] MaryBeth Musumeci, et al., *Medicaid's Money Follows the Person Program: State Progress and Uncertainty Pending Federal Funding Reauthorization,* KFF, (Nov. 25, 2019), https://www.kff.org/medicaid/issue-brief/medicaids-money-follows-the-person-program-state-progress-and-uncertainty-pending-federal-funding-reauthorization/.
[89] *See* Molly O'Malley Watts, et al., *Money Follows the Person: A 2015 State Survey of Transitions, Services, and Costs*, KFF, (Oct. 16, 2015), https://www.kff.org/medicaid/report/money-follows-the-person-a-2015-state-survey-of-transitions-services-and-costs/.
[90] Musumeci, et al., *supra* note 88.
[91] Musumeci, et al., *supra* note 88.
[92] Musumeci, et al., *supra* note 88.
[93] Liao and Victoria Peebles, *Money Follows the Person: State Transitions as of December 31, 2019,* Mathematica, https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/mfp-2019-transitions-brief.pdf [hereinafter MFP State Transitions as of 2019].
[94] Musumeci, et al., *supra* note 88.

state variations, MFP programs offer older adults more of a choice in deciding where to receive their LTSS.[95]

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.[96] 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.[97] 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.[98] Over time, the program has helped states establish formal institution to community transition programs by enabling states to develop the necessary service and provider infrastructure.[99] 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.[100]

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.[101] In 2019, older adults represented more than three-quarters of all transitions (38%).[102] States with robust MFP programs have found declines

[95] MFP State Transitions as of 2019, *supra* note 93.
[96] Musumeci, et al., *supra* note 88.
[97] MFP State Transitions as of 2019, *supra* note 93.
[98] MFP State Transitions as of 2019, *supra* note 93.
[99] Watts, et al., *supra* note 89.
[100] Watts, et al., *supra* note 89.
[101] MFP State Transitions as of 2019, *supra* note 93.
[102] MFP State Transitions as of 2019, *supra* note 93.

in nursing home occupancy rates.[103] On September 23, 2020, CMS announced a supplemental funding opportunity available to the 33 MFP demonstration states currently operating.[104] 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 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.[105] MFP also has helped states control per enrollee spending, as providing enrollees with HCBS typically costs less than institutional care.[106]

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. [107] 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.[108] 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.[109] Without federal funding of MFP, states would have to discontinue a range of community transition related

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[103] H. Stephen Kaye, *Evidence for the Impact of the Money Follows the Person Program*, COMMUNITY LIVING POLICY CENTER, (July 2019), https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/reports/Evidence%20for%20the%20Impact%20of%20MFP_0.pdf.
[104] MFP State Transitions as of 2019, *supra* note 93.
[105] 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.
[106] MFP State Transitions as of 2019, *supra* note 93.
[107] *Money Follows the Person*, CENTER FOR PUBLIC REPRESENTATION, (Dec. 22, 2020), https://medicaid.publicrep.org/feature/money-follows-the-person/.
[108] *Id*.
[109] *Id*.

services and meaningful progress with LTSS rebalancing will be curtailed.[110] 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.[111]

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 abovementioned 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.

[110] 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.
[111] Musumeci, et al., *supra* note 88.

IV. 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 of these organizing systems show promise in streamlining 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 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 approaches.

A. 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.[112] It was formally established by CMS as a permanent Medicare Advantage option in 1997.[113] Today it is one of the oldest and most successful models of integrating care.[114] Care integration by

[112] NATIONAL PACE ASSOCIATION, https://www.npaonline.org/pace-you, (last visited Apr. 25, 2021).
[113] *PACE*, MEDICARE.GOV, (last visited Apr. 25, 2021), https://www.medicare.gov/your-medicare-costs/get-help-paying-costs/pace.
[114] Sara Karon et al., *Expanding the PACE Model of Care to High-Need, High-Cost Populations,* THE COMMONWEALTH FUND, (Oct. 2020), https://doi.org/10.26099/4454-z770.

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.[115] 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.[116]

PACE provides the entire continuum of care and services designed for older adults 55 years of age or older, who require a nursing-home level of care but can safely live in the community with PACE services.[117] The goal of PACE is to keep participants in the community "for as long as it is medically, socially, and financially feasible."[118] Different than other models, PACE is not an insurance vehicle, but rather itself 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.[119] PACE programs provide services primarily in an adult day health center and are supplemented by in-home and referral services depending on the

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[115] Jade Gong and Peter Fitzgerald, *PACE 2.0: PACE Programs Are Ready To Grow Exponentially*, HEALTH PROGRESS, (March-Apr. 2019), https://www.chausa.org/publications/health-progress/article/march-april-2019/pace-2.0-pace-programs-are-ready-to-grow-exponentially.
[116] Sara Karon et al., *supra* at note 114.
[117] *Programs of All-Inclusive Care for the Elderly Benefits*, MEDICAID.GOV, (last visited Apr. 25, 2021), https://www.medicaid.gov/medicaid/long-term-services-supports/pace/programs-all-inclusive-care-elderly-benefits/index.html.
[118] Martha Hostetter, et al., *Aging Gracefully: The PACE Approach to Caring for Frail Elders in the Community*, THE COMMONWEALTH FUND, (Aug. 12, 2016), https://www.commonwealthfund.org/publications/case-study/2016/aug/aging-gracefully-pace-approach-caring-frail-elders-community.
[119] *Program of All-inclusive Care for the Elderly (PACE)*, STATE OF NEW JERSEY DEPARTMENT OF HUMAN SERVICES DIVISION OF AGING SERVICES, (last visited Apr. 25, 2021), https://www.state.nj.us/humanservices/doas/services/pace/.

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.[120] 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.[121] 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.[122] 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.[123] PACE combines Medicare and Medicaid funding, as well as private funding, to provide necessary services to elders leaving in the community. Ninety-percent of individuals served by PACE are low-income adults, who are dual eligible for both Medicare and Medicaid.[124] However, the program also accepts participants who pay PACE premiums privately. [125] Premiums depend on the services required and the PACE service area.[126] Most commonly, each local PACE organization accepts a capitation payment from Medicare and

[120] *Id*.
[121] Victor Hirth, et al., *Program of All Inclusive Care (PACE): Past, Present, and Future*, N JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION, (Mar. 2009).
[122] *Id*.
[123] On the Medicaid 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.
[124] Jade Gong and Peter Fitzgerald, *supra* note 115.
[125] *Programs of All-Inclusive Care for the Elderly (PACE): Introduction to PACE*, MEDICAID.GOV, (last visited Apr. 25, 2021), https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/pace111c01.pdf.
[126] *Id*.

Medicaid to provide all required care to low-income and frail elders.[127] The capitated funding arrangement rewards providers who are flexible and creative in providing high quality care and gives them the ability to coordinate care across settings and medical disciplines and an incentive to provide quality services.[128] This allows providers to deliver all services to participants rather than only those reimbursable under the Medicare and Medicaid FFS plans.[129] 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.[130]

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.[131] 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.[132] Nationally, there are 124 PACE organizations in 235 communities across the U.S. serving almost 50,000 seniors.[133] This number represents less than 10 percent of the eligible population in communities served by PACE.[134] Because PACE programs are currently serving

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[127] *Id*.
[128] Victor Hirth, et al., *Program of All Inclusive Care (PACE): Past, Present, and Future*, N JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION, (Mar. 2009).
[129] *Id*.
[130] Jade Gong and Peter Fitzgerald, *supra* note 115.
[131] 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,* AMERICAN SOCIETY ON AGING, (Oct. 22, 2018).
[132] Jade Gong and Peter Fitzgerald, *supra* note 115.
[133] Jade Gong and Peter Fitzgerald, *supra* note 115.
[134] Jade Gong and Peter Fitzgerald, *supra* note 115.

only a small number of those eligible for it, the PACE 2.0 initiative was formed to expand the reach of PACE programs nationally.[135] 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.[136]

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.[137] 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.[138]

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[135] Jade Gong and Peter Fitzgerald, *supra* note 115.
[136] Jade Gong and Peter Fitzgerald, *supra* note 115.
[137] Jade Gong and Peter Fitzgerald, *supra* note 115.
[138] Jade Gong and Peter Fitzgerald, *supra* note 115.

B. MLTSS

In recent years, state Medicaid agencies have increased the use of managed long-term services and supports ("MLTSS") in an attempt to revamp the patchwork LTSS financing system, improve quality of care, and enhance care coordination for Medicaid-eligible individuals.[139] 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 receive a per-member-per month capitated payment, to provide LTSS to eligible Medicaid beneficiaries.[140] 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.[141] 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.[142] 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

[139] Rudowitz et al., *supra* note 42.
[140] Tuck & Moore, *supra* note 50, at 4.
[141] Kathleen Gifford et al., *A View from the States: Key Medicaid Policy Changes: Results from a 50-State Medicaid Budget Survey for State Fiscal Years 2019 and 2020*, KFF (Oct. 18, 2019), https://www.kff.org/report-section/a-view-from-the-states-key-medicaid-policy-changes-long-term-services-and-supports/.
[142] *Id*.

HCBS.[143] 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 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.[144] For example, New Mexico reduced their percentage of individuals residing in nursing facilities from 18.7 in 2011 to 14.3 in 2015.[145] 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.[146]

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 56% of people were using Skilled Nursing Facility (SNF) services and 44% were using HCBS.[147] By June 2018, the enrollees receiving these services shifted to 43% and 57%, respectively, which caused the cost per individual to drop 10%.[148] Because Florida has historically been one of the lowest ranking states with access to LTSS, this shift indicates MLTSS model effectiveness. Thus, 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.

[143] Tuck & Moore, *supra* note 50, at 4.
[144] Tuck & Moore, *supra* note 50, at 4.
[145] Tuck & Moore, *supra* note 50, at 11.
[146] Tuck & Moore, *supra* note 50, at 11.
[147] Tuck & Moore, *supra* note 50, at 11.
[148] Tuck & Moore, *supra* note 50, at 11.

V. 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.[149] Certain populations and risk pools would have to be identified, thus leaving out others. However, projections for those needing LTSS in the future are just as clear; the number of people needing LTSS will continue to grow, and the current supports 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 in ensuring adequate, appropriate care to elders, we must move towards a patient-centered, coordinated system. Such coordination of care, possible under the PACE or MLTSS models described above, is important not just to rationalize LTSS care, but to connect and coordinate care between LTSS and other medical care.

In plotting a future for integrated care for the elderly, we must recognize the inadequately met needs of increased access to home and community-based supports and offer a way to improve access to, and quality of services, along with appropriate cost containment measures. Those in home or community care settings need supportive services in order to function in a way that allows them to integrate into society and flourish to the extent possible. Thus, we must continue to identify programs that offer high-quality, integrated care at lower costs and accelerate the adoption of these programs on a national level.

[149] Favreault, *supra* note 5.