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Special Article

Reimagining Financing and Payment of Long-Term Care

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A B S T R A C T

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The COVID-19 pandemic revealed fundamental problems with the structure of long-term care financing and payment in the United States. The piecemeal system that exists suffers from several key problems, including underfunding, fragmentation across types and sites of care, and substantial variation in payment across states and populations. These problems result in inefficient allocation of resources, limited access to care, substandard quality, and inequities in both access and quality. We propose a new federal benefit for long-term care, most likely as part of the Medicare program. Essential features of this benefit include taxpayer subsidies, along the lines of other Medicare benefits, and coverage across the range of long-term care services, including both residential and home- and community-based care. A new federal benefit has the most potential to break down administrative barriers and improve resource allocation, to ensure adequate payment rates across all states, to expand access to care by spreading risk across the entire Medicare population, and to improve equity by extending coverage to all Medicare beneficiaries who want it. A new federal benefit is politically challenging, requiring bold action by Congress, and entails the risks of administrative challenges and unintended consequences. However, in this case, retaining the status quo remains the far greater risk.

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The first reported coronavirus outbreak in the United States was in a nursing home in Kirkland, Washington, in February 2020. In the year that followed, COVID-19 swept through nursing homes, killing more than 184,000 residents and staff of nursing homes, close to one-third of all COVID-related deaths in the United States.¹ The fact that the COVID-19 pandemic touched nearly every nursing home in the country suggests there are underlying, broad-based, structural problems in US nursing homes that must be addressed.²

Although the tragedy of COVID-19 in nursing homes received significant recent media and policy attention, the underlying problems are longstanding, not only in nursing homes but for long-term care (LTC) generally. Since the inception of the LTC system in the 1960s, when Medicare and Medicaid formalized payment for LTC to licensed nursing homes, covering a narrow segment of the population, this system has been plagued by problems with access, quality, equity, and efficiency. Although a comprehensive set of reforms is necessary,

the current approach to financing and payment is at the root of many of these failures.

The Current Financing and Payment System

Most Organization for Economic Cooperation and Development (OECD) countries have developed and maintained an LTC financing system that provides near-universal coverage of LTC.³ Although the full effect of these programs on access, quality, equity, and costs of care is difficult to assess comprehensively, recent reviews have found that public LTC systems generally improve the health and life quality of older adults and may help alleviate the financial burden of LTC on families, though the evidence is mixed.⁴ In the United States, we lack a comprehensive approach to financing LTC.

The most common source of care for people living in the community who need assistance for functional or cognitive impairment remains unpaid assistance from family and friends (informal care). Despite worries that the availability of informal caregivers is shrinking over time owing to demographic changes and increased labor force participation by women, 3 of 4 older adults living in the community with LTC needs rely on family and friends for care, either solely or in conjunction with formal, paid care.⁵ This caregiving entails numerous costs to the family in the form of direct spending on care-related costs as well as the indirect costs of reduced labor force participation and

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physical and mental health care costs for caregivers. An adult child who cares for an aging parent will face losses equivalent to \$100,000 a year, on average⁶—roughly the same cost as a nursing home stay.

Formal LTC services and supports are paid through a patchwork of Medicaid funding, state and local public programs, Veteran's Administration funding, very limited private insurance, and out-of-pocket spending. It is estimated that spending on these services exceeds \$420 billion per year.⁷ With the establishment of Medicare and Medicaid, most formal LTC was provided in nursing homes. Medicaid finances more than half of all LTC for those who need help with daily activities, such as help with bathing, dressing, or eating. However, Medicaid is only available to people who have spent down their own assets, and it still has coverage gaps. Medicare funds LTC only temporarily and indirectly, by covering nursing home and home-based care for skilled needs, often after a hospital discharge, but not for ongoing help with activities of daily living.

Although Medicaid accounts for half of nursing home revenue, Medicaid rates are typically low, and up to two-thirds of residents in a nursing home rely on Medicaid to pay for their care. Payments for Medicaid nursing home residents are established by the individual state Medicaid programs, which use a variety of methods to set payment rates, subject to political deliberations in each state. The result is that payments vary considerably from state to state, averaging around \$200 per day in 2018,⁸ approximately 70% of private pay rates.⁹ Eligibility rules also differ, with most states allowing a maximum of \$2000 in assets in order for an individual to qualify for nursing home coverage.

Over the last few decades, care has been moving into care recipients' homes, partially in response to a US Supreme Court decision requiring that care be provided in the least restrictive setting possible. In 1990, 87% of Medicaid spending on long-term services and supports went to institutional care; today, more than half goes to home- and community-based services (HCBS).¹⁰ However, there is wide state-to-state variation in coverage of HCBS alternatives to nursing home care, as states must get federal approval for funding these alternatives through 1915(c) waivers to the Social Security Act, and states have flexibility in the services and populations covered through these waivers. The percentage of LTC funding that states spend on HCBS ranges from a low of less than 30% in Mississippi to almost 80% in Oregon.¹⁰

Key Problems with the Current Financing and Payment System for LTC

In this section, we discuss several key problems with the current financing and payment system for LTC in the United States, focusing on how the current system creates barriers to access, quality, equity, and efficient allocation of resources.

Barriers to Access

The heavy reliance on Medicaid funding for LTC has the obvious, but often forgotten, problem that Medicaid coverage does nothing for the vast majority of older adults who do not qualify for Medicaid and yet face potentially daunting LTC costs. Medicaid is not part of a continuum or overall insurance system but rather a payor of last resort. Although Medicaid covers care for those with few financial assets (or after they have spent down their assets), over a quarter of the burden of LTC is paid out of pocket or through LTC insurance.¹¹ There is a small, costly, and shrinking set of options for private LTC insurance, the costs of which are often paid by individuals. Without insurance, individuals have the choice of going without care, relying on informal caregivers (which has its own costs—both direct and indirect—which are often large), or paying out of pocket until they impoverish themselves in order to qualify for Medicaid. Unlike other

uncertain but high-cost events like hospital care, for which the Medicare program limits individual responsibility and spreads risk over all beneficiaries, use of Medicaid for LTC entails a significant burden on those who are unlucky enough to need extensive LTC. Spending down to Medicaid has been characterized as an implicit tax on care recipients equal to the entirety of their wealth,¹² with clear consequences for family resources and intergenerational wealth transfer. At the same time, the majority of middle-income seniors are unlikely to have the resources to pay for expensive private-pay options such as independent or assisted living facilities.¹³ This gaping hole in the patchwork of payment means that many middle-income seniors will suffer from unmet needs.

This access problem stemming from reliance on Medicaid funding extends to HCBS and includes those who have already qualified for Medicaid. Because coverage of HCBS is a state decision, beneficiaries residing in different states face significant variation and potential inequities in their access to HCBS. And although waiting lists for HCBS services are a poor proxy for unmet need given variation in whether and how states use waiting lists, the fact that at least 700,000 people have signed up for services but not received them¹⁴ is a sign that demand for HCBS far exceeds the Medicaid funding currently allocated to these services.

Barriers to Quality

Quality challenges in nursing homes are endemic. The reliance on Medicaid, with variable and arguably low payment rates, is likely to play an important role. The care financed by Medicaid has long been plagued by quality and safety problems, ranging from inadequate staffing to high rates of infection and hospitalization.^{15,16} Although major regulatory policies, including the Nursing Home Reform Act of 1987 and subsequent revisions, have attempted to address deficiencies in the quality of care, concerns remain. Recent efforts to increase the transparency of nursing home quality and tie nursing home quality directly to payment have also produced only modest improvements in nursing home quality.¹⁷ On average, nursing homes with a higher percentage of residents on Medicaid tend to be of lower quality, and increasing Medicaid rates has been shown to increase quality.^{18,19}

There is some controversy over whether low Medicaid payment rates for nursing homes are the cause of poor quality, or whether the rates are objectively too low. Some argue that Medicaid rates are inadequate to cover care in most states, often lower than a nursing home's average daily cost and associated with a negative margin.²⁰ At the same time, for-profit facilities continue to stay in business despite serving large Medicaid populations. The true nature of nursing home financing is unknown, as nursing home financing is marked by a significant lack of transparency. Although nursing homes report low operating margins, with potential negative impacts on patient care and quality, there are reports of nursing homes using third-party transactions or unrelated business entities to hide profits.²¹ This lack of transparency makes it difficult to rigorously compare the costs of care to payment rates. However, the fact remains that reliance on Medicaid is associated with lower quality of care. And even if Medicaid payment rates are sufficient to cover the costs of care as currently provided, this may not be the level of quality that is desired.

Relative to nursing homes, much less research has focused on the quality of HCBS, in part because the quality of that care is much less consistently regulated than in nursing homes. The research that exists casts doubt on the average level of HCBS quality under Medicaid, showing higher rates of hospital admission from HCBS than from nursing homes.^{22–24}

Barriers to Equity

In addition to concerns about average levels of quality, LTC in the United States is marked by inequities in nursing home quality correlated with payment source. Blacks and Latinx are more likely than Whites to reside in nursing homes that are understaffed, perform poorly on standard quality measures, and have high hospitalization rates. These nursing homes are also more reliant on Medicaid's low reimbursement rates, leaving little slack to invest in quality improvement.^{25,26} Older adults who need nursing home care and are reliant on Medicaid have limited choice of nursing homes and are often denied access to the highest-quality homes.^{27–29}

Even within Medicaid, outcomes of HCBS are also disparate by race, with Black individuals more likely to use HCBS than their White counterparts, and also more likely to have poor outcomes conditional on HCBS use.²²

Because racial and ethnic minorities are disproportionately represented among those relying on Medicaid for LTC, these longstanding disparities in access to high-quality LTC are inextricably linked to the way we finance and pay for care. Nursing home segregation reflects residential segregation, and most disparities in quality stem from across-facility differences in where people get care rather than within-facility discrimination.¹⁷ The dominance of Medicaid as a payor of last resort reinforces those differences across communities, requiring impoverishment of those who need LTC and relegating the poorest communities to the lowest quality care.³⁰

Barriers to Efficient Allocation of Resources

The current system of payment for LTC is plagued by fragmentation. Because Medicare does not pay for LTC, providers of acute, post-acute, and LTC services have little incentive to coordinate care across settings, despite the fact that these 2 types of needs often intersect. This lack of coordination is associated with inefficiencies in allocation across services as well as administrative burden for care recipients and their families. In addition to inefficiencies, the fragmentation across types of care often has indirect adverse consequences and creates perverse incentives. For example, it is well known that nursing homes have a financial incentive to hospitalize their long-stay residents on Medicaid even if a problem could be handled without transfer, as Medicare pays for the hospitalization and the hospitalization may trigger a lucrative post-acute care stay on return to the nursing home.^{31,32} These transfers are financially beneficial to the nursing home but potentially burdensome and harmful to nursing home residents. The problem of fragmentation is not limited to those between Medicaid and Medicare. Medicaid enrollees with access to both nursing home care and HCBS face a fragmented system of payment across institutional and home-based services, where choice of setting may be determined more by administrative rules and constraints than need.

The Case for a New, Federal LTC Benefit

As became painfully obvious during the COVID-19 pandemic, the problems of access, quality, equity, and efficiency in the US LTC system stem from structural problems with no easy solutions. Incremental changes have been attempted for decades: tweaks to reimbursement methods and rates, public reporting of quality, pay for performance programs, increased regulation and oversight, and a multitude of quality improvement initiatives. Unsurprisingly, these incremental changes have led to, at best, incremental improvements. No one—economists, policy makers, nursing home residents, or families and caregivers—would have designed the LTC payment system that exists today. Simply tweaking a bad system will not address the challenges and barriers to having a high-quality high-functioning LTC system.

Meaningful changes in access, quality, equity, and efficiency must start with fundamental coverage and payment reform.

We reimagine US LTC financing as a new federal benefit. A federal benefit could take several forms, from a Medicare-based benefit to a federalized Medicaid benefit or a new, separate program. But the federal nature of the benefit is essential, as it eliminates the current state-to-state variation in coverage of services and in payment rates that leads to substantial inequities in access and quality. Extending Medicare to cover LTC for older adults (ie, 65 years and older) may be the most sensible approach to a federal benefit, as it would avoid the current approach to covering LTC by qualifying for Medicaid after spending down assets, an implicit tax of the entirety of one's wealth that is imposed on only those people who need LTC. It would instead spread the risk across all beneficiaries. The alternative of a federalized Medicaid benefit for LTC could be more complicated and perhaps less effective in accomplishing the goal of supporting fundamental change in LTC, as it may be less feasible to extend to all older Americans and would not take advantage of the same administrative structure as other Medicare benefits.

By standardizing the benefit across populations and across states, a federal benefit has the most potential to (1) increase access to LTC services and reduce unmet need; (2) reduce arbitrary barriers between sites of care; (3) reduce inequities in access to care; (4) reduce differences in resources across nursing homes; and (5) guarantee that payment rates are adequate to cover the expected level of quality. Indeed, although the Medicare program has its own problems and challenges, Medicare enrollment at the age of 65 years is associated with substantial improvements in access to health care and reductions in inequities among older adults.³³

Several other features of a new LTC benefit are essential. First, like other Medicare components, and building on lessons learned from the failed Community Living Assistance and Supports (CLASS) Act, the new benefit would likely require taxpayer subsidies in conjunction with beneficiary premiums and cost-sharing. The federal LTC insurance scheme CLASS was passed as part of the Affordable Care Act with the stipulations that it be voluntary, self-sustaining without taxpayer subsidies, and incorporate only minimal controls for adverse selection. It was never implemented and eventually repealed after policy makers found there was no way to adhere to those stipulations simultaneously. A new long-term benefit will need to be built along the lines of other Medicare components incorporating some degree of taxpayer subsidization.

A second essential feature of the payment system is the coverage of LTC across the settings and the range of LTC options of care, while also avoiding the administrative barriers to choosing the most appropriate and efficient setting of care. The current system prevents the efficient and appropriate use of services that best match an individual's needs. In some cases, given the complete lack of HCBS in some states and lack of adequate supply in others, people in need of LTC are admitted to nursing homes when they could have been better served at home. At the same time, states may encourage HCBS use for everyone because payment rates are lower, even when a nursing home level of care may be more appropriate or necessary. In other words, separate financing and payment systems for HCBS and nursing home care and misaligned incentives across them create a false dichotomy and present barriers to rational allocation of resources across settings. A federal benefit covering the range of LTC options would enable individuals, their families, and their care providers to choose the most appropriate setting without artificial and sometimes nonsensical barriers.

To promote the use of lower-cost options and increase efficiency, benefits can be structured to encourage home-based care while simultaneously supporting caregivers. Numerous models for this exist in other countries.⁴ Some countries structure benefits to encourage the use of family care, paying family caregivers and providing them with training and other supports; most cover a wide variety of HCBS;

and most structure benefits to discourage the use of nursing home care unless it is the only option. To avoid overuse, assessments can continue to be required to establish the level of severity, similar to existing requirements in Medicaid. The decisions about the appropriate setting of care can take into account an individual's preferences, appropriateness of the home environment, and availability of caregiver support as well as health-related needs.

A federal LTC benefit that covers care across settings is also a first step toward decreasing fragmentation in care. Not only would a federal benefit diminish the effect of arbitrary coverage rules driving decisions about location of care, it would also align the financial incentives to coordinate care across settings. Although a uniform payer alone will not be a panacea to care coordination, as evidenced by some prior attempts to integrate Medicare and Medicaid for complex populations, it does provide the opportunity for financing and payment to more effectively encourage coordination and accountability of care across settings of care. Prior experiments with these types of care coordination models, for example through the PACE program,³⁴ have shown some success. A federal LTC benefit provides the opportunity to implement these programs more broadly.

Other elements of the structure of the benefit are less fundamental and would be subject to rigorous analyses of the costs associated with each option. The cost tradeoffs in the context of private LTC insurance have been well described,³⁵ and some of the same arguments apply here. One such option is whether coverage would be limited to catastrophic coverage, requiring beneficiaries to pay out of pocket or through private insurance when LTC needs begin until a set period of time or spending has elapsed. Because catastrophic coverage would cost less than first-dollar coverage, it may be a reasonable option, although it would leave people with barriers to access during the waiting period. On the other hand, a limited upfront benefit that is capped would defeat the purpose of the reform, as those with more serious needs could still run out of resources and need a payor of last resort.

As with any major policy reform, there are some tradeoffs and challenges associated with a new federal benefit for LTC. The main tradeoff of moving to a federal benefit is the loss of state control over their LTC programs and spending; state control can lead to better tailoring of programs to the needs of each state's population. However, it is not clear that the differences from state to state in current coverage are a result of tailoring rather than inequities. Relatedly, state control can lead to important policy innovation, which would likely be diminished under a federal benefit. Despite these tradeoffs, we believe that the advantages of a federal benefit in terms of improved access, quality, equity, and efficiency far outweigh the benefits from state control. Tweaking the state-based system of Medicaid as a payer of last resort can only lead to incremental change and will not solve the more fundamental problems in the system. Ideally, the new federal benefit would eliminate the need for back-end Medicaid funding, not just wrap around it.

In terms of challenges, the obvious key challenge is political; however, over the years, other major reforms have somehow found success, and the problems of the LTC system have recently been prominent and visible. A related challenge is the cost of such a new benefit, but the costs of inaction are also high.

Implications for Policy and Practice

The responsibility for initiating and creating a new Medicare component lies squarely with the US Congress. Multiple proposals have been put forth over the past few decades for some type of federal LTC insurance, but all have failed to be implemented. A new LTC benefit is politically challenging, but this may be a moment of opportunity, or a moment of opportunity might appear in the near future. The Biden administration has recognized the need for

additional LTC funding, at least through Medicaid, and congressional representatives and senators across the political spectrum have expressed concern for the tragedy of COVID-19 in nursing homes. In summer 2021, legislation was introduced in the House for a catastrophic LTC benefit. Called the Well-Being Insurance for Seniors to be at Home (WISH) Act, it proposes a tax-financed LTC benefit that would start to pay benefits after a minimum of 1 year of eligibility, longer for those with higher incomes. The hope is that private insurance companies would offer complementary products to cover the waiting period. Although the details differ from what we propose here, such legislation underscores that the COVID-19 crisis may have created a window of opportunity for change.

Fundamental payment reform for LTC involves resources and risks. A new, federal LTC benefit, especially one that ensures adequate payment to LTC providers while also addressing unmet need, will require attention to many details that have not been spelled out here. It will also require an influx of resources. Some of the funding would be a shift from current Medicaid funding through the states, but a budget-neutral system is not feasible and new funding will undoubtedly be required. It will require addressing premiums, and their role in revenue for the program, eligibility criteria, and many implementation details. Additionally, a new federal benefit is politically challenging and entails the risks of administrative challenges and unintended consequences. However, retaining the status quo remains the far greater risk. Although there is much to work out, the problems of the current payment system in terms of inadequate access, substandard quality, inequity, and inefficient allocation of resources compel us to do so. These problems—that became only too obvious during the COVID-19 pandemic—will only be amplified as the US population ages and LTC needs grow, straining state Medicaid budgets and exhausting personal resources. The rational solution is to reform the payment system now.

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