COVID-19: The Time for Collaboration Between Long-Term Services and Supports, Health Care Systems, and Public Health Is Now

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Policy Points:

- To address systemic problems amplified by COVID-19, we need to restructure US long-term services and supports (LTSS) as they relate to both the health care systems and public health systems. We present both near-term and long-term policy solutions.
- Seven near-term policy recommendations include requiring the uniform public reporting of COVID-19 cases in all LTSS settings; identifying and supporting unpaid caregivers; bolstering protections for the direct care workforce; increasing coordination between public health departments and LTSS agencies and providers; enhancing collaboration and communication across health, LTSS, and public health systems; further reducing barriers to telehealth in LTSS; and providing incentives to care for vulnerable populations.
- Long-term reform should focus on comprehensive workforce development, comprehensive LTSS financing reform, and the creation of an age-friendly public health system.
**Context:** The heavy toll of COVID-19 brings the failings of the long-term services and supports (LTSS) system in the United States into sharp focus. Although these are not new problems, the pandemic has exacerbated and amplified their impact to a point that they are impossible to ignore. The primary blame for the high rates of COVID-19 infections and deaths has been assigned to formal LTSS care settings, specifically nursing homes. Yet other systemic problems have been unearthed during this pandemic: the failure to coordinate the US public health system at the federal level and the effects of long-term disinvestment and neglect of state- and local-level public health programs. Together these failures have contributed to an inability to coordinate with the LTSS system and to act early to protect residents and staff in the LTSS care settings that are hotspots for infection, spread, and serious negative health outcomes.

**Methods:** We analyze several impacts of the COVID-19 pandemic on the US LTSS system and policy arrangements. The economic toll on state budgets has been multifaceted, and the pandemic has had a direct impact on Medicaid, the primary funder of LTSS, which in turn has further exacerbated the states’ fiscal problems. Both the inequalities across race, ethnicity, and socioeconomic status as well as the increased burden on unpaid caregivers are clear. So too is the need to better integrate LTSS with the health, social care, and public health systems.

**Findings:** We propose seven near-term actions that US policymakers could take: implementing a uniform public reporting of COVID-19 cases in LTSS settings; identifying and supporting unpaid caregivers; bolstering support for the direct care workforce; increasing coordination between public health departments and LTSS agencies and providers; enhancing collaboration and communication across health, LTSS, and public health systems; further reducing the barriers to telehealth in LTSS; and providing incentives to care for our most vulnerable populations. Our analysis also demonstrates that our nation requires comprehensive reform to build the LTSS system we need through comprehensive workforce development, universal coverage through comprehensive financing reform, and the creation of an age-friendly public health system.

**Conclusions:** COVID-19 has exposed the many deficits of the US LTSS system and made clear the interdependence of LTSS with public health. Policymakers have an opportunity to address these failings through a substantive reform of the LTSS system and increased collaboration with public health agencies and leaders. The opportunity for reform is now.

**Keywords:** long-term care, public health, health policy, COVID-19, social insurance, Medicaid, aging.
It is widely accepted that the long-term service and supports (LTSS) financing and delivery system in the United States is broken.\textsuperscript{1,2} LTSS encompasses a broad range of paid and unpaid health-related and personal care assistance that people may need—for several weeks, months, or years—when they experience difficulty completing self-care tasks as a result of chronic illness or disability. LTSS provides assistance with the activities of daily living (such as eating, bathing, and dressing) and the instrumental activities of daily living (such as preparing meals, managing medication, and housekeeping) and are delivered in a range of settings, including nursing homes, assisted living and other residential care facilities, adult day centers, and private homes.

Despite several attempts at reform over the past 30 years and a growing population of older adults living with multiple, chronic health conditions who will need some form of LTSS during their lifetime, a patchwork system has prevailed. Federal-level attempts at LTSS financing reform have either ended in failure or produced incremental changes to the financing arrangements. More recently, individual states, such as Hawaii and Washington, have pursued their own financing reform initiatives.\textsuperscript{4,5} Nonetheless, substantial national reform—the kind that is needed to truly support those in need of LTSS—has remained elusive.

The heavy toll of COVID-19 on LTSS has brought the system’s failings into clear focus. The population served in LTSS settings like nursing homes, skilled nursing facilities (post-acute care), assisted living, and other residential care settings is an older, medically fragile population with multiple chronic conditions and a high proportion living with dementia. Accordingly, these individuals have the highest risk of complications, hospitalization, and death. Nursing homes now account for approximately 40\% of all COVID-19 deaths nationwide, although the impact on other LTSS settings is not being publicly documented uniformly.\textsuperscript{6,7} This loss of life is staggering. Moreover, COVID-19 has disproportionately affected certain populations, including African Americans, Latinos, and Native Americans, as well as individuals with low socioeconomic status (SES).\textsuperscript{8} A growing body of evidence clearly shows that the cases and deaths from COVID-19 in US nursing homes are disproportionately African Americans.\textsuperscript{9,10} This is due in part to the high community spread in areas with a high proportion
of African Americans; reliance on direct care workers in LTSS who are low-income women of color and are themselves at high-risk of contracting COVID-19, as well as the persistent historical and systemic inequalities and racism that have been exposed and exacerbated by the pandemic.

One key systemic challenge preventing an effective response to the COVID-19 pandemic is the structure of US financing arrangements for LTSS, which determine the reimbursement, regulatory framework, and design of the benefits and services delivered. These financing arrangements have hobbled the LTSS system’s ability to respond adequately to the pandemic. These arrangements disperse responsibility and accountability across systems, thereby limiting which entities have enough resources to respond in the midst of crises as well as those that did have resources to invest in infection control training and other preparations before the pandemic began.

A mix of public and private funding sources pay for LTSS. These arrangements are in part a product of the incremental development of the US health care system over time. While the individual and family have historically played prominent roles in both paying for and providing long-term care, linking health care coverage to a benefit of employment in the post–World War II years and the establishment of the Medicare and Medicaid programs in 1965 have helped solidify the current arrangements. The Medicare program covers medical care—acute, primary, and postacute care—for older adults and certain categories of younger people with disabilities. Medicaid provides medical care for low-income younger people with disabilities and provides an entitlement to nursing home coverage for older low-income adults and younger people living with disabilities who meet certain financial and health eligibility requirements. Since the early 1980s, state Medicaid programs have expanded optional coverage for home care and personal care services through state plans or waivers approved by the Centers for Medicare & Medicaid (CMS). These services, however, are not an entitlement, and the main options for those individuals not eligible for Medicaid-covered LTSS are to rely on private insurance (only 15% of persons 65 and older have this coverage) or to pay their expenses out-of-pocket. Because of this complex and disjointed history, individual states and the federal government have overlapping and often conflicting responsibility for funding and regulating LTSS. Differences in how medical care and LTSS are paid for and the ownership of health care organizations (e.g., hospitals) compared
with LTSS entities impede the coordination of services across both sectors and seriously minimize opportunities for creating a seamless care delivery system.

Of note, whereas Medicare plays a large role in nursing home revenue streams, Medicare does not cover LTSS per se. Instead, it covers a narrow set of primarily medical-related services for individuals requiring skilled postacute care for a limited duration of time (i.e., 100 days following a hospital stay) and for home-bound individuals. The LTSS and health care sectors also are not integrated at the governmental and health systems levels, which prevents the coordination of care and targeting of outcomes for vulnerable older adults or adults living with disabilities, that is, those most likely to be at-risk for COVID-19 infection and who could benefit most from integrated care delivery in the home and residential settings.

Social media accounts and advocacy efforts have assigned the primary blame for the high rates of COVID-19 cases and deaths to nursing homes. Other systemic problems, however, have been unearthed during this pandemic: the lack of federal-level investment in and the coordination of the US public health system,\textsuperscript{14} as well as the cumulative effects of underfunding state and local public health programs.\textsuperscript{15} Taken together, this has prevented state and local public health departments from developing coherent and consistent strategies for coordinating early on with the LTSS system—particularly in residential care settings—to mitigate its role as hotspots for infection, its spread, and serious negative health outcomes.

Furthermore, public health systems—from the federal Centers for Disease Control and Prevention (CDC) to the state and local public health departments that are responsible for surveillance and population-based health interventions—typically do not pay as much attention to the older adult population as they do to other groups such as children, families, or unhoused persons.\textsuperscript{16,17} In the wake of COVID-19, this lack of attention coincided with a lack of adequate resources like personal protection equipment (PPE), testing, and contact tracing to target LTSS facilities and to help contain and mitigate the spread of infection early in the pandemic. Likely the best way to protect staff is to protect the communities surrounding nursing homes and other residential care facilities. That is, high rates of community spread are drivers of institutional staff infection and resident infection. Public health agencies should have been better positioned to pivot and respond based on the emerging evidence, but they were unable to make this pivot effectively
without adequate funding, support, or federal leadership. Targeted approaches to mitigating infection are a basic public health tenet.

A crisis often presents an opportunity to enact a major policy reform.\textsuperscript{18} The United States made seismic policy shifts after the economic devastation of the Great Depression (e.g., the passage of the Social Security Act of 1935) and in the wake of the Great Recession (e.g., the Affordable Care Act in 2010). The devastation brought about by COVID-19 suggests that once again, seismic systemic shifts of our culture, economy, and social policy arrangements are likely. The challenges confronting the US LTSS system suggest that both a near-term and a long-term response are needed to mitigate the impact of COVID-19 on the approximately 13 million Americans who require LTSS, both in the community and in institutions.\textsuperscript{19}

The recently assembled National Academy of Medicine’s Nursing Home Study Committee and the CMS-convened Coronavirus Commission on Safety and Quality in Nursing Homes have focused on just that.\textsuperscript{20,21} The report by the September 2020 commission details the challenges and profound effect of COVID-19 on nursing home care and highlights the opportunities for improving access to testing, tracing, and personal protective equipment (PPE), as well as the need for workforce enhancements, quality improvement, and other forms of technical assistance.\textsuperscript{21} The analysis and policy recommendations provided here reflect many of this report’s priorities but, notably, push for better integration of LTSS, public health, and health care systems.

We offer seven recommendations that national policymakers can immediately implement to shore up the LTSS system. To truly address the system’s long-standing failings, however, policymakers must tackle comprehensive reform. We therefore also offer three recommendations that would constitute comprehensive reform of the US LTSS system and its integration with the public health and health care systems.

**Background**

The United States has a highly fragmented LTSS financing system, with no single public long-term care insurance program. In 2018, the annual direct costs of LTSS were estimated to be $379 billion for both public and private payers.\textsuperscript{22} But the true costs are almost certainly higher, as most care is provided by unpaid caregivers. The indirect cost of
unpaid family and friend care, that is, the cost if all unpaid caregivers were paid at a home health aide worker's wage rate, is estimated to be as high as $522 billion annually, with between 18 million and 38 million Americans acting as unpaid caregivers for older adults and adults living with disabilities.\textsuperscript{20,23,24} Caregiving “costs” are disproportionately incurred by women, individuals with low socioeconomic status, and Black, Indigenous, and people of color (BIPOC), who often rely on, as well as provide, unpaid care.\textsuperscript{25} Taken together, the annual direct and indirect costs of LTSS are more than $900 billion. But this amount does not consider labor market losses and tax revenue losses that arise when caregivers leave the workforce or retire early,\textsuperscript{26,27} so it is far below LTSS’s total societal cost.

Private long-term care insurance (LTCI) has long been touted as a way to address the gap in coverage for LTSS, particularly for individuals who are not Medicaid eligible or likely to become Medicaid eligible with spend-down. Only an estimated 7.4 million Americans own a private LTCI policy, or around 15% of persons 65 and older.\textsuperscript{28} A multitude of arguments have been posited for why private LTCI utilization is not more widespread, but a major limiting factor is cost, with premiums of $6,000 to $8,000 a year.\textsuperscript{29} Thus, aside from LTCI and out-of-pocket financing of LTSS by individuals, most publicly funded LTSS is paid through the Medicaid program, which establishes coverage based on the criteria of age, disability status, and whether an individual has limited income and assets. Nonetheless, state Medicaid programs are afforded some flexibility in establishing their own eligibility requirements, which vary according to service level need and the types of programs offered by states.\textsuperscript{30}

Under federal law, Medicaid is required to cover care in institutional settings, whereas home- and community-based care is largely optional. The major variation in funding for home- and community-based services (HCBS) is at the state level, including the variation in state funding for Medicaid home- and community-based waivers, which cover medical and nonmedical care and assistance in the home for older adults living with disabilities and other special populations (e.g., fragile children).\textsuperscript{31}

Many states have strongly embraced HCBS through the use of Medicaid waivers and provisions within the Affordable Care Act (ACA) that prioritize rebalancing Medicaid LTSS away from institutional settings. Even though an overall majority of Medicaid LTSS funding (57% as of 2016) is now spent on HCBS, only 45% of the Medicaid LTSS dollars specifically spent on the care of older adults and people living with
disabilities went to HCBS as of 2016. Rebalancing the spending mix to HCBS and away from institutional-based care is consistent with preferences to remain at home but also places additional demands on unpaid caregivers. Furthermore, whereas more than half of states allow for self-directed Medicaid funds to be used to pay family caregivers—which helps compensate them for their role—family caregivers typically provide care that is unpaid and unsupported through social services or local and state public health agencies.

Despite these well-documented challenges, as well as attempts to address LTSS financing as part of the ACA (e.g., the CLASS Act), LTSS were ultimately largely omitted from US health care reform efforts. At a systems level, little has changed in the way that LTSS have been delivered over the past decade since the ACA’s passage. Twenty-seven states now use managed care for Medicaid LTSS. Furthermore, LTSS-covered services under Medicare Advantage (MA) are expanding, for example, through the use of pilot tests of home-delivered meals coverage of assisted living under some MA plans, and also transportation costs and personal care.

The exact benefits offered remain at the discretion of individual insurance plans. Medicaid expansion under the ACA also expanded access to LTSS for low-income adults not already covered by Medicare and Medicaid, and the ACA contained measures to support increased access to HCBS. For example, those states that adopt the Community-First Choice 1915 K Waiver receive an additional 6% match in Medicaid funds. A new study found that compared to similar persons living in Medicaid nonexpansion states, low-income non-Medicare-covered adults in Medicaid expansion states had increased use of both formally provided home care (medical professional visits or aides providing assistance with activities of daily living) and nursing home care—evidence that those most likely to gain coverage through health reform had increased their use of LTSS. Despite these advances in access for small portions of the population, the generosity of Medicaid LTSS benefits overall has not risen substantially in the past decade.

Policy supports for unpaid caregivers is one area of LTSS undergoing some reforms at a national level. These reforms have largely been limited to agenda setting, aside from the long-standing Administration on Community Living’s (ACL) National Family Caregiver Support Program (FCSP) and in the Veteran Health Administration’s (VHA) system
of care, which was mandated by law since 2010 to include comprehensive caregiver supports in its core mission. The National Academy of Sciences, Engineering, and Medicine urged building a national caregiver policy\textsuperscript{38} and in 2018, the RAISE Family Care Act was signed into law, requiring the convening of a Family Caregiving Advisory Council to advise, provide recommendations, and identify best practices on recognizing and supporting unpaid caregivers.\textsuperscript{39}

The development and implementation of caregiver supports remain largely up to state policymakers. Several state-level policies and programs have been initiated to support caregivers,\textsuperscript{40} and some states have additional (non-Medicaid) caregiver support programs (e.g., Hawaii).\textsuperscript{41} In addition, a handful of states now offer modest tax credits for caregivers, and up to ten states are implementing paid family leave in the near future, which can cover caregiving duties for up to 12 weeks. Some in this population are eligible for unpaid family leave.\textsuperscript{42} Other state-level supports are family caregiver training and respite services, including those funded through the ACL-administered FCSP.

\textbf{What Has COVID-19 Unveiled?}

COVID-19 has uncovered stark societal inequalities, namely, through its disproportionate impact on communities of color and low-income individuals. This impact has fallen on older residents and clients as well as the frontline certified nursing assistants and home health and personal care aides who provide most of the hands-on care in LTSS settings.\textsuperscript{9} These direct care providers are typically women who are Black, Indigenous, or otherwise people of color, earning low wages.\textsuperscript{43} One in four are foreign born.\textsuperscript{44} Nursing home aides earn an average hourly wage of $13.38, while home health and personal care aides earn even less, an average of $11.52 per hour.\textsuperscript{45} An average of 44\% live below 200\% of the federal poverty level, and 42\% receive some type of public assistance. In addition, the evidence suggests that not only do these workers spend more time working—including one in six who hold a second job—they also spend more time on housework, unpaid caregiving, and commuting than do other health care workers.\textsuperscript{46,47}

Given the poor compensation and other job-related and external challenges, it is not surprising that nursing home and home care providers were experiencing significant recruitment and retention problems
before the pandemic. Although we currently have no data documenting the extent of COVID-19–related turnover among aides and how the pandemic has affected the pipeline for these jobs, anecdotal evidence suggests that retention and recruitment have indeed suffered.

In addition to concerns about their personal safety and the potential of becoming infected and spreading the virus within their households, individual facility and home care agency policies are discouraging aides from working at multiple locations in order to reduce the risk of infection. These policies create a significant economic hardship for low-wage aides across all LTSS settings. Even if these workers do not continue working at multiple LTSS facilities, they may continue going to their second jobs in other sectors of the service economy, where they still will interact with coworkers and clients. Thus, these policies may not reduce risks but only penalize workers through reduced earnings.

The Families First Coronavirus Response Act (FFCRA) requires employers with fewer than 500 employees to provide up to two weeks of paid sick leave for certain COVID-19 reasons and up to 12 weeks of family medical leave for employees who are unable to work (or telework) because their minor child’s school or child care service is closed due to COVID-19. However, nursing home and home care aides are not protected by this legislation and can be excluded from the paid sick leave and expanded family and medical leave offered by their employer.

Approximately 24 states have temporarily increased Medicaid payments to nursing homes to support the continuation of care during the pandemic. Even though 18 states have increased Medicaid reimbursement for all providers, some types of LTSS providers are not receiving the same funding increases. Only a few states, such as Tennessee, are specifically using these payments for LTSS frontline worker hazard pay, whereas Arkansas, Texas, and New Jersey have tied funding increases to direct worker pay.

The longer-term impact of COVID-19 on Medicaid and LTSS funding is likely to be dire. States share overlapping responsibility with the federal government for funding Medicaid. In 2018, 39% of all Medicaid spending on LTSS was made by states, and Medicaid accounted for more than 29% of all state-level spending, constituting the single largest expenditure made by state governments.

Some states have already begun to consider cuts to Medicaid and other health services including LTSS—primarily HCBS—owing to the pandemic’s economic impact on revenue. The reversal of trends to more
community-based care instead of nursing home care (e.g., rebalancing), therefore, may be threatened by such budget cuts, which is bad for patient preferences and infection risk mitigation, given the congregate living arrangements of nursing homes. The extent of these cuts and if and how they are applied remain unclear. California lawmakers, for example, blocked proposed budget cuts, including a cut of 7% to the state’s In-Home Supportive Services Program. More such cuts are likely as the pandemic and the resulting economic fallout and budgetary impacts continue. This puts individual recipients of publicly financed LTSS at risk of losing their coverage and access to care when they need it most or relegating them to higher-risk nursing home care.

Unpaid caregivers are under increased pressure and strain to provide care during the pandemic. Many of these individuals have lost their job as result of COVID-19’s economic fallout, and many unpaid caregivers have also prohibited formal home care providers from entering their home, for fear of the care recipient’s being exposed to the virus. What happens when a caregiver contracts COVID-19 and is unable to provide care? We have very little information about care recipients’ unmet needs during the pandemic, as well as a firm understanding of the magnitude of the changes in received unpaid and paid caregiving.

We do, though, have evidence that many small-scale caregiver support programs have adapted during the pandemic, including moving their services to virtual support calls and trying to help those caring for institutionalized loved ones connect with their family members through video calls. Even though only a small fraction of unpaid caregivers in the United States receive support from programs, two consequences of these shifts in training could arise from the pandemic. First, we may see more unmet needs caused by the pandemic if existing programs are strained and cannot accommodate the additional needs, and second, the shift to virtual platforms may enhance caregivers’ ability to participate in supportive services, since it often is difficult for them to leave the house to participate in in-person training and support groups.

Recommendations

It is essential to tackle the perennial problems in LTSS delivery using both near-term and longer-term measures (see Box). All the measures are intrinsically rooted in an overhaul of financing because the financing
arrangements drive delivery and access and have spillover effects on private-sector rates. Our proposed reforms to the US LTSS system will incur costs. Funds will need to be identified in order to pay for the changes to expand coverage and benefits. One potential source of funding is savings from reductions in Medicaid utilization as a result of the wider LTSS coverage we propose. A second funding source would be establishing a new financing mechanism for LTSS. Mandatory participation in this financing mechanism, which raises revenue specifically for the new coverage, is also needed, as experience with the design of the CLASS Act has demonstrated. Indeed, America needs to re-envision how to pay for LTSS, and any moves made to this end must reflect what those being cared for need and want.

Box. Recommendations for Reform

Near-Term Measures
- Require uniform public reporting of COVID-19 cases in all LTSS settings.
- Identify and support unpaid caregivers.
- Bolster protections for the direct care workforce.
- Increase coordination between public health departments and LTSS agencies and providers.
- Enhance collaboration and coordination across health, LTSS, and public health systems.
- Reduce further barriers to telehealth in LTSS.
- Provide incentives to care for our most vulnerable populations.

Long-Term Reforms
- Disseminate comprehensive workforce development.
- Achieve universal coverage through comprehensive financing reform.
- Create an age-friendly public health system.

Near-Term Measures

There continues to be a glaring lack of publicly available information about COVID-19 infections among LTSS users and the workforce. Similar to the federal government’s requirement that nursing homes report
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weekly COVID-19 infections and deaths, other settings in the LTSS continuum—home health care, assisted living, and other residential care settings—should be regularly reported and made public. The critical differences between the general population’s COVID-19 case data and the LTSS data should be made clear. The initial challenges with the nursing home data have been well documented and may be avoided with a careful approach to implementing in other LTSS settings. The use of uniform reporting requirements would help but would require far greater collaboration between the states and the federal government. Such collaboration is a distinct challenge given the blend of state and federal oversight across facility types and the definitions of assisted living and residential care across states. Specifically, CMS does not regulate most assisted-living facilities, but states do. Data from the full LTSS spectrum of services must be reported in order to enable real-time, tailored, evidence-based strategies. Public health agencies could lead this charge, directly addressing identified gaps in infection control resources across the LTSS spectrum.

Identifying and Supporting Unpaid Caregivers. Unpaid caregivers are critical to the care needs of older adults with LTSS needs; in fact, they are usually the primary providers of care. Even the most integrated and sophisticated health care systems desperately need a way to reliably identify caregivers. This is even more important in the midst of the COVID-19 pandemic. Identifying who may not have a family caregiver or what support a caregiver may have is essential. Adding an indicator of functional impairment to Medicare administrative data would offer a tangible, low-cost approach to identifying individuals and their caregivers that could be implemented nearly immediately.

The “Welcome to Medicare” visit and Medicare Annual Wellness Visit (AWV) are two opportunities to identify caregivers and document them in administrative data. While most individuals are likely to be functionally independent when enrolling in Medicare, the AWV offers an opportunity to address their needs on a regular basis allowing these data to be updated when a caregiver is needed. However, the AWV is not yet well utilized, as fewer than 25% of all Medicare beneficiaries receive an AWV each year and is even less well utilized by beneficiaries who are Black, Indigenous, or other people of color. Public health departments could promote wider utilization of the AWV to older adults and health care providers, ensuring that this is a support option for caregivers.
New policies that immediately allow caregivers of COVID-19 patients to be paid at the rate of home health aides would offer much needed financial support. Countries such as South Korea have adopted this approach at the municipal level. Currently, efforts to pay caregivers are generally limited to Medicaid. There is acute economic strain given massive layoffs. In just a few short months, more than 25 million Americans have lost their jobs and although the unemployment rate has declined from a peak in April 2020, it remained high at 8.6% in August 2020, thus disproportionately affecting low-income workers. Caregivers who are still able to work need to be paid if they are going to take time off from work. This is especially important for low-income caregivers without access to sick leave. Paying both working and nonworking caregivers would reduce the need for multiple caregivers and would enable them to remain in one place while the care recipient recovers from COVID-19. Adding COVID-19 recovery to a caregiver’s duties places an added burden on them, especially since they also need to be trained and their qualifications assessed. There are multiple evidence-based trainings for caregivers such as safety and injury prevention training that is not specific to COVID-19. Adapting COVID-19–specific CMS training for frontline workers could provide accessible rapid training for unpaid caregivers to mitigate transmission risk. Assessment protocols could draw from Medicaid programs that require assessment of those caring for beneficiaries using home- and community-based services. For example, the Rhode Island Personal Choice Program training model that requires assessment by a medical professional could be adapted.

**Bolstering Protections for the Direct Care Workforce.** This pandemic has demonstrated the important role of the direct care workforce in LTSS and the serious risks these workers face both on the job and in their communities. Policymakers must understand that emergency actions are essential, as subsequent waves of the virus are expected. LTSS is the lowest-priority sector among health care providers in receipt of PPE, as well as testing and contact tracing. LTSS providers should have access to the PPE they need to provide safe care to their clients. Furthermore, a system establishing backup workers to fill COVID-19–related staff vacancies is desperately needed, since LTSS has no backup workforce. Overall, more progressive labor policies beyond these modest measures arising in the first six months of the pandemic (e.g., living wages, paid sick leave, paid family leave) would be good LTSS policy and good health policy, with
the potential to improve the lives of direct care workers, to raise the quality of care, and to reduce the need to work multiple jobs.

Because they are related to the workforce, and even more closely related to residents’ health outcomes, infection control plans must be re-examined and empirical studies of the benefits of tight infection control must be carried out. Infection control is a basic function of any public health system and emergency response. Yet, it is doubtful that infection control has been adequate in response to the pandemic.

In 2019 the Centers for Medicare and Medicaid Services urged facilities to take an all-hazards approach in their emergency response planning, which covers both natural and human-made disasters. Media reports indicate, however, that many nursing home staff were not aware of this new plan and did not practice any new plan and that if a comprehensive plan did exist, the facility’s resources were quickly overwhelmed. Regulation has a role in addition to bolstering resources in order to support and be able to activate an infection control plan. Infection control is currently underregulated, with few inspections. Yet, lapses in infection control are among the most commonly cited deficiencies that inspectors find. These types of deficiencies can range from a lack of hand washing to a failure to use protective equipment. Better infection control is an important support from which all LTSS direct care workers would benefit, and it would also serve as a risk mitigation strategy that would benefit the recipients of their care.

To address these concerns, CMS recently rolled out its Targeted COVID-19 Training for Frontline Nursing Home Staff & Management, with five specific modules designed for frontline clinical staff and ten designed for nursing home management. Quality improvement organizations, funded by CMS to work with nursing homes, are required to build this training into their future action plans. It is too soon to assess the impact of this training program. A new National Nursing Home COVID Action Network worth as much as $237 million was created under an AHRQ contract and was funded through the 2020 Coronavirus Aid, Relief, and Economic Security (CARES) Act. This network—a partnership between AHRQ, the University of New Mexico’s ECHO Institute, and the Institute for Healthcare Improvement (IHI)—provides free training and mentorship to nursing homes across the country to increase the implementation of evidence-based infection prevention and safety practices to protect residents and staff. Similar training efforts have not been developed for home health and home care aides and
management, but they should be developed to better support the full spectrum of direct care workers.

Increasing Coordination Between Public Health Departments and LTSS Agencies and Providers. Greater collaboration between public health departments and LTSS agencies and providers—both institutional and home based—would help with infection control, including testing, contact tracing, and monitoring. Despite the great need, local investment in public health systems is haphazard and federal investment is insufficient. Although local and state public health departments have collaborated with LTSS agencies and providers in helping mitigate the effects of this pandemic, these partnerships have often developed too late and have varied across states and localities. All public health agencies could supply resources to nursing homes, home care agencies, and other community-based providers to help them implement their emergency plans during this pandemic as well as during future disasters. Public health teams at the local and state level should also work with LTSS providers to ensure better infection control and staffing—for example, earlier this year South Korea integrated public health agencies with LTSS to help recruit volunteers to fill direct care worker vacancies.62

An immediate focus should be nursing homes, assisted living, and home care agencies located in coronavirus hot spots or in potentially at-risk communities with a combination of testing, contact tracing, and comprehensive infection control support. Establishing high-functioning lines of communication within states is a basic step that could improve these partnerships and would enhance the ability of non-CMS–regulated facilities, such as assisted living, to implement recommended screening, testing, and other infection control measures.

Enhancing Collaboration and Communication Across Health, LTSS, and Public Health Systems. A system for communication between acute care facilities and LTSS facilities is lacking and transcends the ever-present challenges of shared electronic health records (EHR) in US health care, a challenge across all health care settings. Both the persistent organizational and cultural difference between acute care and LTSS and the lack of communication between these systems likely are compounded by societal-level and health care-level ageism and ableism.73,74

These ways of thinking include the idea that hospitals “fix” patients and have great value to society, whereas LTSS are for people whose outcomes are unlikely to improve. We saw it in the early days of the pandemic when physicians and nurses volunteered to work in hospitals’
intensive care units that were in great need nationally. But we heard little about those electing to work in nursing homes that also faced massive needs. The disparate ownership of acute care versus LTSS facilities complicates any hope of sharing information or collaborating. A complex mix of for-profit, private, and public ownership usually means that LTSS facilities and nearby hospitals are not part of the same vertically integrated system. Memoranda of understanding (MOUs) or formal contracts reflecting the now popular models of “patient-centered medical homes” or “accountable care organizations” may be a philosophical as well as a practical answer to such gaps in coordination.\(^7\)

Providers of long-term services and supports lag behind others in the US health system in the use of technology such as electronic health records (EHRs).\(^6\) Although advances have been made in promoting wider utilization, the impact of leaving LTSS providers out of the federal incentives to use EHR systems continues to discourage their adoption.\(^7\) The technological capacity of LTSS providers must be improved by investing in these systems to enable their linking with the acute care system.

**Reducing Further Barriers to Telehealth in LTSS.** Since March 2020, CMS has loosened its restrictions on the use of telehealth access and personal health information privacy in response to the pandemic, including at LTSS facilities.\(^8\) Until now, telehealth expansion has been slow because of questions about health care quality and patient privacy and its presumed dramatic shift from traditional, in-person patient care. Now, a majority of states have in some capacity increased HCBS provided through telehealth.\(^9\) We have a forced natural experiment to see whether this will work for patients and providers alike and whether it will reduce barriers to telehealth. Will these changes endure after the pandemic?

Specific to LTSS, US Senators Amy Klobuchar (D-MN) and Bob Casey (D-PA) introduced legislation in April 2020 to enhance telehealth support for older adults and increase access to technology, allowing “virtual visits” during this pandemic.\(^8\) Although the Advancing Connectivity during the Coronavirus to Ensure Support for Seniors (ACCESS) Act would help protect vulnerable LTSS populations, their providers, and their families, it remains in committee. This proposal includes $50 million for the US Department of Health and Human Services’ Telehealth Resource Center to assist nursing homes receiving funding through Medicare or Medicaid to expand their telehealth offerings.\(^8\) This
proposal is supported by the AARP, the Center for Medicare Advocacy, Justice in Aging, the Long Term Care Community Coalition, and the National Consumer Voice for Quality Long-Term Care. Currently, the bill has been referred to the Committee on Appropriations, in addition to the Committees on Energy and Commerce, Ways and Means, and the Budget, for a period to be subsequently determined by the Speaker.82

With anecdotal reports that hospice providers are being barred access to nursing homes, it is critical to fill gaps with telehealth options and accelerate the training of existing nursing force workers in pain management and person-centered principles in the hospice care model to address corresponding gaps in non-COVID-19 and COVID-19 end-of-life care needs. If federal efforts at allocating funds for telehealth do not succeed, the states may need to think creatively to bring telehealth to LTSS, in much the same way they did with Medicaid and HCBS, in which more than 47 states have advanced mental health provision via telehealth.51

Providing Incentives to Care for Our Most Vulnerable Populations. Poor programs result in poor outcomes. A more equitable system of providing and paying for care is desperately needed. Right now, we need to invest heavily in providers who serve low-income, medically fragile LTSS residents. Although this is a long-standing need, the current crisis has made it an urgent need. As seen with the challenges of rolling out the stimulus packages, the small businesses that need the resources the most are often the ones unable—owing to a lack of agency, access, or infrastructure—to apply for and secure funds essential to support their work.83 This is true for many independent long-term care providers and home care providers who often care for the most vulnerable and medically fragile and need resources for care that Medicaid reimbursements cannot fully cover. While raising Medicaid payments across the board would help the most at-risk LTSS residents as well as all LTSS recipients, a thorough realignment of the system to better provide and finance care is needed. Without this larger systemic reform of LTSS, the challenges that plague the current system will persist and intensify far beyond the current crisis. These changes need to occur at both the state and federal levels, given their shared responsibility of delivering Medicaid programs.
Long-Term Reforms

Comprehensive Workforce Development. The LTSS workforce is undervalued because the frontline staff are not viewed as professionals; they are often labeled as unskilled and, as noted earlier, are paid low wages. They thus have few opportunities to receive training to improve their clinical skills and to advance their careers. Yet these jobs are extremely demanding and increasingly complex because they care for individuals with complex physical, behavioral, and cognitive needs that require a range of skills and competencies. 48,60,84

In fact, a 2008 Institute of Medicine report called for significant investments in education and financial support for professionals caring for older adults in the United States, including frontline caregivers in LTSS settings. 85 Over a decade later, little progress has been made in this sector. Nursing homes, other residential care organizations, and home- and community-based providers face significant challenges in recruiting and retaining well-prepared, high-quality staff across the continuum of occupations, particularly frontline caregivers. Anecdotes from the field suggest that many certified nursing assistants and home care aides, as well as mid- and upper-level managers and clinicians, are leaving the LTSS sector as the pandemic has caused irreparable stress for those who have endured the risk of infection, the deaths of residents and staff, and bad publicity, particularly in nursing homes. The unfavorable social media coverage is likely to dissuade potential candidates from even considering seeking a frontline, clinical, or administrative job in this sector.

The CARES Act provided some financial relief for frontline caregivers to help them with wraparound services like access to food, childcare, and transportation. In addition, at least half of the states temporarily increased Medicaid reimbursement rates designed, in part, to encourage staff retention when peers called in sick or did not come to work. 86,87 Several states have specified pay increases for direct care workers in nursing homes and other non-institutional care settings. 51 Arkansas adopted temporary supplemental payments that increased direct care workers’ weekly pay by a base supplemental payment according to the number of hours worked and an additional tiered acuity payment for those working in facilities with COVID-19–positive patients. In Texas, the nursing home payment rate increase included pay raises for direct care workers and for supply and dietary costs. 51 The Heroes Act, passed by the US House of Representatives just at the time of writing, would provide significantly more resources to support direct care workers. 88
Policymakers could take this a step further and approach these challenges holistically. First, direct care workers should be fairly compensated and receive a living wage, regardless of the job-related risks of COVID-19. A new report exploring the economic impact of providing a living wage to direct care workers across LTSS settings indicates that this effort would help relieve staffing shortages by adding 330,000 direct care workers to the ranks of those already employed, or a roughly 9.1% boost to employment in 2022. By 2030, the economic impact of additional spending by workers is estimated to be $17 billion and $22 billion more than it would have been without this higher pay. Paying all direct care workers a living wage would also reduce their use of public assistance programs between $912 million and $1.6 billion per year. In order for all employers to pay a living wage, state Medicaid programs (the largest payer for LTSS), should raise their reimbursement rates and require that these increases be passed on directly to workers. Moreover, these changes should be sustained beyond the end of the pandemic. Otherwise, Medicaid-funded employers would struggle to cover new wage mandates, and workers would not necessarily receive the benefits.

Finally, policymakers could also standardize training requirements for frontline caregivers across all LTSS settings. Barriers to aides’ career advancement should be dismantled by, for example, loosening state nurse delegation regulations. In addition, we must have support for job growth in LTSS occupations through apprenticeship programs and other educational initiatives, as well as efforts to develop clinical and managerial leadership in nursing homes, other residential settings, and home care.

**Universal Coverage Through Comprehensive Financing Reform.** The need for LTSS financing reform owing to COVID-19’s brutal impact on state budgets and Medicaid is urgent. A social insurance approach to financing LTSS that is based on individual care and support needs and that covers all Americans, regardless of their financial status, is necessary for adequate LTSS coverage. Importantly, this approach must provide coverage of living needs—and not just the care aspects—of LTSS. This approach would protect against financial catastrophe and end the current system that is based on the need to be financially destitute in order to access coverage via Medicaid. Such an approach would benefit both individuals and families and would also create a far more stable and more generous funding stream to providers.

Universal coverage is essential to achieving greater equity in access and coverage, but it is also essential to the fiscal viability of the
financing mechanism (e.g., everyone pays into the system). Although political concerns about a universal and therefore mandatory approach led to a voluntary program in the form of the CLASS Act, the failure to embrace the universal approach undermined the viability of CLASS. Policymakers cannot afford to make this same mistake again when addressing LTSS financing reform.

Creating an Age-Friendly Public Health System. More than 70% of care recipients are women, as women usually outlive men. True reform can thus result from a paradigm shift only in the way we think about and value our fellow human beings—women, minorities, older adults, and people living with disabilities. Specifically, the heightened infection rates and deaths observed among Black, Latino, and Native American communities nationally are reflected in LTSS facilities. This will require another call to action for these particularly disadvantaged groups, including older adults and people living with disabilities and minority status.

Public health departments must recognize the heightened health risks that the older adult population faces, particularly during public health emergencies. Over the long term, they must take strong action to prepare older adults for future public health emergencies while also monitoring their day-to-day health needs with an eye toward aggressively promoting wellness and preventing disease. The United States is now experiencing the tragic consequences of a health system that encourages medical personnel, public health professionals, and providers of social services to work in silos that rarely connect or coordinate.

The progress made in the acute health care sector to provide age-friendly health care has not extended substantially to the long-term care sector. First coined in 2002 by the World Health Organization and accelerated in 2017 by partnerships between the John A. Hartford Foundation, the Institute for Healthcare Improvement, and two health systems, the age-friendly health care movement has been primarily limited to the ambulatory care, emergency department, and inpatient settings. Inclusion of care in the home is a goal of the movement as well to more effectively engage with and support unpaid caregivers. The recommendation to expand supports for unpaid caregivers is particularly consistent with building a more age-friendly public health system. Nonetheless, the age-friendly care movement has not permeated public health agency approaches, nor has it spread to most home care and residential or nursing home care settings. The cornerstone of this movement is to train
providers in geriatric principles, appropriate assessment, and provision of care—all aligned with the four “Ms.” These are (1) what Matters, or the goals of the older adult; (2) Medication, ensuring that medication does not interfere with the other principles; (3) Mentation, preventing, identifying, treating, and managing dementia, depression, and delirium across settings of care; and (4) Mobility, promoting moving safely every day to allow older adults to live in a way that matters to them. The age-friendly care movement—inclusive of LTSS—must partner more closely with public health and health care delivery systems during this pandemic and beyond. Learning from exemplary hospitals and their successful partnerships with outside agencies would be helpful in making progress toward an age-friendly public health paradigm that addresses the full spectrum of LTSS.

Every sector of our health care system has an equally valuable role to play, especially during a pandemic. The three systems—LTSS, public health, and wider health care systems—must begin to work more collaboratively in a coordinated fashion to safeguard the health and safety of older adults and the people who care for them. In fact, public health agencies could lead the transformation of the LTSS sector to be an age-friendly system.

Conclusions

COVID-19 has exposed the many shortcomings of the US LTSS system. Although these are not new problems, this pandemic has exacerbated and amplified their impact to a point that they are impossible to ignore. Policymakers have an opportunity to act to address these failings through a substantive reform of the LTSS system and collaboration with public health. Indeed, the LTSS system has recently been shown to be a critical component of the public health response to COVID-19, and its important role should be amplified. The time for reform is now. We have a sobering opportunity to enact cross-sector change and must do so while the nation’s focus is trained on COVID-19 impacts.

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