

Humane and Resilient Long-Term Care

A Post-COVID-19 Vision

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I INTRODUCTION

Long-term care institutions were ground zero for the COVID-19 pandemic in the United States. The first reported outbreaks in the country were in long-term care institutions; such facilities continued to experience very high rates of infection and death during the first two years of infection, and substantial risk well into 2023.¹

Long-term care residents make up less than 1 percent of the US population. Yet, by January 2021, before the benefits of the COVID-19 vaccinations had been realized to any significant extent,² residents and staff of these institutions accounted for 38 percent of all US deaths from COVID-19,³ and nursing home residents alone accounted for about 25 percent of confirmed US deaths.⁴ A year later, residents and staff of long-term care facilities still represented a very disproportionate share of COVID-19 fatalities – as of January 2022, they accounted for at least 23 percent of all COVID-19 deaths in the United States.⁵ This chapter explains the underlying causes of this devastation and what can be learned from it to improve the future quality of long-term care. It shows how the patterns observed in long-term care facilities

¹ See Centers for Disease Prevention & Control, Nursing Home Covid-19 Data Dashboard, www.cdc.gov/nhsn/covid19/ltc-report-overview.html.

² See Priya Chidambaram & Rachel Garfield, COVID-19 Long-Term Care Deaths and Cases Are at an All-Time Low, Though a Rise in LTC Cases in a Few States May Be Cause for Concern, Kaiser Family Foundation (Apr. 22, 2021), www.kff.org/coronavirus-COVID-19/issue-brief/COVID-19-long-term-care-deaths-and-cases-are-at-an-all-time-low-though-a-rise-in-ltc-cases-in-a-few-states-may-be-cause-for-concern/ (documenting the link between vaccination rates and the decline in COVID-19 mortality among residents and staff of long-term care facilities).

³ More Than One-Third of U.S. Coronavirus Deaths are Linked to Nursing Homes, NY Times, Jan. 12, 2021, www.nytimes.com/interactive/2020/us/coronavirus-nursing-homes.html (reporting on deaths in long-term care, despite the misleading article title).

⁴ Center for Medicaid & Medicare Services, COVID-19 Nursing Home Data, <https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg/>.

⁵ See Priya Chidambaram, Over 200,000 Residents and Staff in Long-Term Care Facilities Have Died from COVID-19, Kaiser Family Foundation (Feb. 3, 2022), www.kff.org/policy-watch/over-200000-residents-and-staff-in-long-term-care-facilities-have-died-from-covid-19/ (noting the lack of data on the demographic breakdown of these deaths).

are the combined result of an inadequate public health response to the needs of long-term care residents, preexisting regulatory failures that rendered long-term care institutions infection tinderboxes, and policies that steered vulnerable adults into these institutions in the first place. It then suggests the regulatory and cultural shifts needed to create a more humane and resilient model of long-term care.

II THE CRISIS IN LONG-TERM CARE INSTITUTIONS

In the United States, long-term care facilities fall into two major categories. First, there are nursing homes, highly regulated institutions that provide skilled medical and custodial care to adults with substantial chronic-care needs. Second, there are assisted living facilities, which provide a varied combination of housing, meals, and health-related services to adults with a broader range of care needs.

Residents of both types of long-term institutions are highly susceptible to COVID-19, as they are to other infectious diseases. Living in a congregate care setting impedes social distancing, and the flow of staff and visitors in and out of facilities creates many potential vectors of contagion. In addition, residents' underlying health conditions make them highly vulnerable to the effects of infections, increasing the likelihood that they will experience serious illness and death if infected with COVID-19.

However, as detailed in this part, COVID-19's disastrous impact on residents of long-term care institutions cannot be explained simply by residents' susceptibility to infection. Rather, it also reflects an inadequate public health response to COVID-19 in these facilities, as well as a preexisting regulatory failure that left long-term care residents unreasonably vulnerable to pandemic conditions.

A The Role of Public Health Response Failures

COVID-19's impact on long-term care residents reflects a slow and inadequate public health response to the heightened risk the virus posed to residents. Testing of nursing home residents and staff was not mandated by the Centers for Medicaid and Medicare Services (CMS), the federal agency that regulates such homes, until September 2020, six months after the start of the pandemic in the United States.⁶ Nursing homes were provided with limited personal protective equipment (PPE) by the federal government. However, the Federal Emergency Management Agency (FEMA), which was tasked with provision, provided woefully insufficient amounts of PPE, much of which was simply unusable (e.g., faulty masks, gowns with no arm-holes) or clearly inappropriate (e.g., condoms as PPE);⁷ FEMA never provided the

⁶ Joe Eaton, *Who's to Blame for the 100,000 Covid Dead in Long-Term Care?*, AARP (Dec. 3, 2020), www.aarp.org/caregiving/health/info-2020/covid-19-nursing-homes-who-is-to-blame.html.

⁷ *Id.*

N95 masks that workers needed to avoid infecting residents.⁸ Of course, testing deficiencies and PPE shortages also occurred in hospital settings, but nursing homes were generally given lower priority than hospitals for testing and PPE allocation, despite their highly vulnerable populations.

The public health response to the needs of assisted living residents was even slower and more haphazard than that to nursing home residents. The Centers for Disease Control and Prevention prioritized all long-term care facilities for the administration of vaccines, and states largely followed this advice. Nevertheless, the rollout to assisted living facilities was slower and bumpier than in nursing homes, in part because the facilities are less equipped to facilitate medical care.⁹ Similarly, the federal government provided support to nursing homes in general but provided support only to assisted living communities serving Medicaid-eligible residents (some 16 percent of assisted living facilities).¹⁰

B *The Role of Regulatory Failure*

The degree of danger that COVID-19 has posed to long-term care residents reflects long-standing problems in how these facilities are operated. The extent of the operational failures, in turn, is shaped by two types of regulatory failure: (1) a failure to mandate certain practices essential to ensuring safe and humane care; and (2) a failure to enforce existing regulations designed to protect residents.

1 Inadequate Regulatory Requirements

The extent to which long-term care institutions are subject to regulations designed to protect residents varies by type of long-term care facility. Nursing homes are highly regulated. Since the adoption of the federal Nursing Home Reform Act as part of the Omnibus Reconciliation Act of 1987, nursing homes certified to receive Medicaid or Medicare funding must have a comprehensive resident assessment and care planning system, meet federal standards related to quality of care and resident safety, and respect and support a litany of residents' rights. By contrast, assisted living facilities, which are home to approximately one million Americans, are regulated almost exclusively at the state level (with significant variation from state to state) and are subject to far fewer regulatory requirements than nursing homes.¹¹ This difference in

⁸ *Id.*

⁹ Cf. Kaiser Family Foundation, January 14 Web Event: A Shot in the Arm for Long-Term Care Facilities? Early Lessons from the COVID-19 Vaccine Rollout to High Priority Populations (Jan. 14, 2021), www.kff.org/medicaid/event/january-14-web-event-a-shot-in-the-arm-for-long-term-care-facilities-early-lessons-from-the-covid-19-vaccine-rollout-to-high-priority-populations/.

¹⁰ See Helena Temkin-Greener et al., COVID-19 Pandemic in Assisted Living Communities: Results from Seven States, 68 *J. Am. Geriatrics Soc'y* 2727 (2020).

¹¹ See Alison M. Trinkoff et al., Comparing Residential Long-Term Care Regulations Between Nursing Homes and Assisted Living Facilities, 68 *Nursing Home Outlook* 113 (2019).

regulation can be attributed to several factors, including that: (1) assisted living was developed, at least ostensibly, as a nonmedical model of care; (2) the primary source of funding for assisted living facilities is private payment (unlike nursing homes); and (3) the 1987 Act was enacted prior to the ascendance of the assisted living industry.

Under-regulation of assisted living facilities is a serious concern. Such facilities increasingly take high-needs patients who might otherwise require nursing home care.

Nevertheless, state requirements for staffing – both in terms of the number and qualifications of personnel – are often minimal; assisted living facilities in some states are not even required to have staff present throughout the entire day.¹² A 2016 study found that although the majority of assisted living facilities admit residents who require nursing care, most did not have a licensed care provider on staff; rather, such facilities were staffed primarily by patient care aides, who, on average, were required to have fewer than seventy-five hours of training before they began providing care to residents, and who, in some facilities, were not required to have any formal training before providing resident care.¹³ This lack of skilled staffing is often attributed to the use by assisted living facilities of a “social model” of care instead of a “medical model,” but it raises serious concerns, by both patient advocates and medical providers,¹⁴ about the ability of assisted living facilities to meet residents’ basic needs, even during normal, non-pandemic conditions.¹⁵

Of particular relevance during the COVID-19 pandemic, infection-control requirements for assisted living facilities are also meager, despite the known risk of infectious disease outbreaks in such facilities.¹⁶ Only approximately one quarter of the states impose specific infection-control requirements on assisted living facilities, and over a third do not even require facilities to have infection-control plans.¹⁷ The result is a lack of proper planning and preparation for preventing transmission of disease. The lack of federal engagement is also a barrier to national-level planning and intervention. For example, assisted living facilities do not report COVID-19 infections and fatalities directly to the federal government,¹⁸ making it more difficult to understand and address the overall risk COVID-19 has posed to their residents.

¹² Id.

¹³ Kihye Han et al., Variation Across U.S. Assisted Living Facilities: Admissions, Resident Care Needs, and Staffing, *J. Nursing Scholarship* (2016); see also Anne S. Beeber et al., Licensed Nursing Staffing and Health Service Availability in Residential Care and Assisted Living, *62 J. Am. Geriatrics Soc’y* 805 (2014).

¹⁴ Sheryl Zimmerman et al., The Need to Include Assisted Living in Responding to the COVID-19 Pandemic, *21 J. Am. Med. Dir. Ass’n* 572 (2020); Phillip D. Sloane et al., Physical Perspectives on Medical Care Delivery in Assisted Living, *J. Am. Geriatrics Soc’y* 59 (2011).

¹⁵ Accord Andrew Vipperman, Sheryl Zimmerman & Philip D. Sloane, COVID-19 Recommendations for Assisted Living: Implications for the Future, *22 J. Am. Med. Dir. Ass’n* 933 (2021).

¹⁶ Rachel Kossover et al., Infection Prevention and Control Standards in Assisted Living Facilities: Are Residents Needs Being Met?, *15 J. Am. Med. Dir. Ass’n* 47 (2014).

¹⁷ Debra Dobbs, Lindsay Peterson & Kathryn Hyer, The Unique Challenges Faced by Assisted Living Communities to Meet Federal Guidelines for COVID-19, *32 J. Aging Soc. Pol’y* 334 (2020).

¹⁸ Sarah H. Yi et al., Characterization of COVID-19 in Assisted Living Facilities – 39 States, October 2020, *69 Morbidity and Mortality Weekly Report, Ctrs. for Disease Control & Prevention* 1730 (Nov. 2020),

While nursing homes are much more highly regulated than assisted living facilities, regulatory gaps still exist. Most importantly, federal regulations governing nursing homes fail to impose minimum staffing ratios. This failure had been identified as a major risk long before COVID-19 hit. It was well recognized that nursing home quality of care was undermined because nursing homes tend to be chronically under-staffed and to over-rely on part-time staff and staff who lack sick leave benefits (and thus are more likely to come to work when ill). There was also widespread agreement among experts that a minimum of 4.1 hours of direct-care staff per resident per day is needed on average to avoid systemic neglect,¹⁹ although most nursing homes provide less.²⁰ Recent evidence from the COVID-19 pandemic further underscores the danger of this gap by demonstrating the close relationship between staff time and resident well-being. Studies are finding that higher staffing levels (especially nurse staffing levels) are associated with reduced presence of COVID-19 in long-term care facilities,²¹ and with increased ability to contain outbreaks when they do occur.²² In addition, studies have linked over-reliance on part-time and agency staff, as well as lack of paid sick leave, to the spread of COVID-19 both within and among long-term care facilities.

2 Under-Enforcement of Existing Regulations

Whereas the primary regulatory failure in the assisted living context is a failure to mandate necessary practices, the primary failure in the nursing home context is under-enforcement of existing regulations. Under federal law, US nursing homes that accept Medicare or Medicaid funds – virtually all US nursing homes – are required to meet extensive quality-of-care requirements.²³ For example, nursing homes must ensure that their residents receive individualized care in accordance with professional standards of practice and do not experience avoidable harm or avoidable reductions in functional abilities.²⁴ If such requirements were enforced, the fact that nursing homes are not directly required to use the inputs

www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6946a3-H.pdf (describing the lack of data on assisted living infections); Staff Report on COVID-19 in Assisted Living Facilities (July 2020), www.warren.senate.gov/imo/media/doc/Assisted%20Living%20Facilities%20Staff%20Report.pdf.

¹⁹ Charlene Harrington et al., The Need for Higher Minimum Staffing Standards in U.S. Nursing Homes, 9 *Health Servs. Insights* 13 (2016).

²⁰ Id.; see also Maggie Flynn, Registered Nurse Staffing Falls Short in Most Nursing Homes, Skilled Nursing News (Mar. 15, 2018), <https://skillednursingnews.com/2018/03/registered-nurse-staffing-falls-short-nursing-homes/>.

²¹ Charlene Harrington, Leslie Ross & Susan Chapman, Nurse Staffing & Coronavirus Infections in California Nursing Homes, *Pol'y, Pol., & Nursing Prac.* (2020); Rebecca J. Gorges & R. Tamara Konetzka, Staffing Levels and COVID-19 Cases & Outbreaks in U.S. Nursing Homes, 68 *J. Am. Geriatrics Soc'y* 2462 (2020).

²² Gorges & Konetzka, *supra* note 20.

²³ See Ctrs. for Medicare & Medicaid Servs., Nursing Home Data Compendium 2015 edition 1, 10 fig.1.2. (2015).

²⁴ See 42 C.F.R. §§ 483.21, 483.24–25 (2021).

they need to achieve those outcomes (such as sufficient staffing levels) would be of little practical consequence. However, that is not the case: nursing homes are rarely held to account for their failure to comply with regulations designed to protect residents.

This under-enforcement of regulations designed to protect nursing home residents is the combined result of two failures. The first is a failure of state inspectors to identify and accurately assess violations. As the Government Accountability Office has found, state inspectors systematically underreport serious deficiencies, including ones that pose immediate threats to residents' health and safety.²⁵ Similarly, the Government Accountability Office has criticized regulators for failing to collect the information necessary to protect residents from identified abuse and neglect.²⁶

The second type of under-enforcement failure is a failure to correct and penalize identified violations. Regulators have statutory authority to impose significant penalties on facilities – including holds on new admissions or payment, as well as monetary fines. However, CMS has instead taken an approach that imposes no financial consequences for most regulatory violations. When violations are found – even serious violations – facilities are typically simply directed to make corrections and regulators may never assess whether those corrections are actually made.²⁷ Fines are rare and are reserved for certain categories of violation; they are also typically too small to deter bad behavior.

These problems became more acute during the Trump Administration,²⁸ in part because the Administration moved away from assessing fines for violations on a per-day basis in favor of assessing them on a per-instance basis.²⁹ Moreover, the Trump Administration severely curtailed enforcement efforts during the COVID-19 pandemic as CMS suspended a broad array of enforcement actions and waived key regulatory requirements for nursing homes,³⁰ often as part of broader efforts to ease burdens on

²⁵ See US Gov't Accountability Off., *Nursing Homes: Despite Increased Oversight, Challenges Remain in Ensuring High-Quality Care and Resident Safety* (2006).

²⁶ See US Gov't Accountability Off., *Improved Oversight Needed to Better Protect Residents from Abuse* (2019).

²⁷ Off. of the Inspector Gen., Dep't of Health & Human Servs., *CMS Guidance to State Survey Agencies on Verifying Correction of Deficiencies Needs to Be Improved to Help Ensure the Health and Safety of Nursing Home Residents* (2019).

²⁸ See, generally, Joran Rao, *Nursing Home Fines Drop as Trump Administration Heeds Industry Complaints*, Kaiser Health Network (Mar. 15, 2019), www.aarp.org/caregiving/health/info-2020/nursing-home-covid-federal-aid-transparency.html.

²⁹ These changes are the subject of a lawsuit filed by AARP Foundation and Constantine Cannon LLP on behalf of the California Advocates for Nursing Home Reform and the National Consumer Voice for Quality Long-Term Care. See *Complaint for Declaratory & Injunctive Relief, Nat'l Consumer Voice for Quality Long-Term Care v. Azar* (filed Jan. 18, 2021) (No. 21-162), www.aarp.org/content/dam/aarp/aarp_foundation/litigation/2021/nat-consumer-voice-v-us-dept-hhs-complaint.pdf.

³⁰ Nina A. Kohn, *Addressing the Crisis in Long-Term Care Facilities*, The Hill, (Apr. 23, 2020), <https://thehill.com/opinion/civil-rights/494337-addressing-the-crisis-in-long-term-care-facilities>.

health care providers.³¹ In addition, in response to the pandemic, nearly half of the states granted nursing homes (as well as other health care providers, such as hospitals) new immunity from civil liability, either by executive order or by statute.³² This was despite the much weaker justification for immunity in the nursing home context. As Jessica Roberts and I observed in spring 2020: “Hospitals justify their push for immunity on the grounds that courts should not second-guess the ethically charged resource allocation decisions made rapidly in response to a crush of COVID-19 patients. By contrast, the primary concern for nursing homes is that they will be held liable for inadequate infection control – a problem that typically reflects more deliberative choices over time.”³³

The result is that regulations designed to ensure that nursing homes provide adequate care are treated more like aspirational standards than enforced rules. It should not be surprising, then, that preventable suffering plagues nursing home residents. For example, roughly 20 percent of Medicare beneficiaries in skilled nursing facilities suffered avoidable harm during their stays,³⁴ and most nursing homes had documented infection-control problems.

III A PATH FORWARD

The problems made visible by COVID-19 suggest the need to improve the regulatory framework governing long-term care facilities.³⁵ This section outlines regulatory changes that could better align financial incentives with quality of care and advocacy strategies that could help pave the way for such reforms.

A Align Financial Incentives for Institutions with Quality Indicators

Improving the overall quality of nursing home care in the United States will require adjusting the regulatory environment to create a much stronger economic incentive for nursing homes to deliver humane, high-quality care.

Economic incentives could take several forms. First, regulators could pursue enforcement approaches that include economically meaningful consequences for

³¹ See, for example, Dep’t of Health & Human Servs., Exceptions and Extensions for Quality Reporting Requirements (Mar. 27, 2020), www.cms.gov/files/document/guidance-memo-exceptions-and-extensions-quality-reporting-and-value-based-purchasing-programs.pdf (waiving certain reporting requirements for a range of health care institutions, including nursing homes).

³² See Nina A. Kohn & Jessica L. Roberts, Nursing Homes Need Increased Staffing, Not Legal Immunity, *The Hill* (May 23, 2020), <https://thehill.com/opinion/healthcare/499286-nursing-homes-need-increased-staffing-not-legal-immunity>.

³³ *Id.*

³⁴ Off. of the Inspector Gen., Dep’t of Health & Human Servs., Adverse Events in Skilled Nursing Facilities: National Incidence Among Medicare Beneficiaries (Feb. 2014), <https://oig.hhs.gov/oei/reports/oei-06-11-00370.pdf>.

³⁵ For further discussion of changing the regulatory framework for nursing homes, see Nina A. Kohn, Nursing Homes, COVID-19, and the Consequences of Regulatory Failure, 110 *Geo. L. J.* 1 (2021).

falling below acceptable standards. This would require making a broader range of violations fineable events and withholding new admissions and payments to facilities that are not in compliance with regulatory requirements. One way to do this would be to substantially expand the Special Focus Facility Program, which puts facilities with consistently high deficiencies on a more frequent inspection cycle and on a path to possible decertification, as legislation introduced in the US Senate in 2021 would do.³⁶ A more comprehensive approach would be to apply a broader and more robust range of penalties to all facilities – not merely those previously identified as particularly problematic.

Additionally, the Secretary of Health and Human Services might create real consequences for owners or operators with a track record of deficient care by refusing to certify the facilities that they own for participation in Medicare and Medicaid programs,³⁷ thereby cutting off primary sources of revenue.³⁸ Given that many facilities are part of large chains, and that chain ownership has been linked to lower quality care,³⁹ this could have substantial impacts.

Second, public funding for long-term care facilities could be much more closely tied to outcomes. Specifically, a robust pay-for-performance scheme could vary payments to facilities based on metrics of resident well-being. Such an approach would be a significant departure from the status quo. Most nursing home residents in the United States have their care paid for by the Medicaid program. Yet the Medicaid program provides little incentive for nursing homes to provide high-quality care. The precise formulas by which state Medicaid programs reimburse nursing homes for care can be complicated and are largely based on a per-resident, per-day approach, with increases common for patient mix and some limited increases for certain factors related to quality. Nursing homes that provide a high level of personalized care can therefore expect to receive similar levels of compensation as homes that provide woefully substandard care. The result is an insufficient incentive to provide high-quality care and an opportunity for unscrupulous providers to profit at the expense of their residents' well-being.

The United States has never seriously tried a pay-for-performance system. Some states have offered small bonuses for certain improvements – but often these

³⁶ Sen. 4866, 116th Cong. (2021), [www.congress.gov/bills/116th-congress/senate-bill/4866](http://www.congress.gov/bills/116/congress/senate/bills/4866).

³⁷ See 42 U.S.C. § 1395i-3(d)(1)(A) (“[A] skilled nursing facility must be administered in a manner that enables it to use its resources effectively and efficiently to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident (consistent with requirements established under subsection (f)(5))”); 42

U.S.C. § 1395i-3(d)(1)(A) and § 1395i-3(f)(5) (2021) (requiring the Secretary of Health and Human Services to establish criteria for assessing a skilled nursing facility’s compliance with the requirement of subsection (d)(1) with respect to, among other things, “its governing body and management”).

³⁸ See Nina A. Kohn et al., *Using What We Have: How Existing Legal Authorities Can Help Fix America’s Nursing Home Crisis*, 65 *William Mary L. Rev.* (forthcoming 2023–2024) (explaining how this would be consistent with the Secretary’s statutory authority).

³⁹ See David C. Grabowski et al., *Low-Quality Nursing Homes Were More Likely Than Other Nursing Homes to be Bought or Sold by Chains in 1993–2010*, 35 *Health Affairs* (May 2016).

payments are too small to make those improvements economically attractive. Even amid the pandemic, as massive federal relief flowed to nursing homes, this windfall was almost entirely devoid of conditions,⁴⁰ and much of it may have never gone to patient care.⁴¹ Indeed, although the Trump Administration offered what it termed a “pay-for-performance” scheme in fall 2020, that scheme created no new requirements or meaningful new incentives. Rather, it simply offered bonus payments to facilities that kept new COVID-19 infections below a certain threshold – something the pay-per-resident model already incentivized. (Even without the payments, especially given shrinking admissions, nursing homes had an incentive to retain existing patients by avoiding lethal infections.)

The pandemic has exposed the need to consider moving to a robust pay-for-performance mechanism for long-term care facilities. Such an approach would encourage such facilities to improve performance and give facilities that make good choices for residents a stronger competitive advantage.

Third, public funding for long-term care facilities could be tied to inputs that research indicates predict quality of care and quality of life. That is, funding could be tied to use of inputs that are proxy measures of performance instead of (or in addition to) tying funding to direct measures of performance, as one would in a traditional pay-for-performance model. For example, funding – or at least increases in funding – should be tied to nursing homes meeting direct-care staffing minimums – including the 4.1 hours of direct-care staffing per day, which experts agree is critical to avoid systemic neglect.

Another way to prompt investment in critical inputs would be to adopt a “medical loss ratio” approach in which providers would be required to use at least a certain percentage of revenue to provide resident care. Much as the Affordable Care Act requires insurance providers to spend at least 80 or 85 percent of premium dollars on providing medical care, the federal government could require long-term care providers that accept Medicaid or Medicare funds to spend a minimum percentage of those funds on direct resident care (and not on administrative costs and profit).

Several states – spurred by concerns exposed by the COVID-19 pandemic – have begun to experiment with this type of spending requirement. In September 2020, Massachusetts announced that nursing homes in the state would be required to spend 75 percent of their revenue on direct-care staffing costs.⁴² The following month, New Jersey adopted legislation requiring that its nursing homes spend 90 percent of annual aggregate revenue on direct resident care, potentially broadly

⁴⁰ Eaton, *supra* note 5.

⁴¹ Andrew Soergel, *Nursing Homes Are Getting Billions in COVID Aid – Where Is It Going?*, AARP (Nov. 24, 2020), www.aarp.org/caregiving/health/info-2020/nursing-home-covid-federal-aid-transparency.html.

⁴² *Nursing Facility Accountability and Supports Package 2.0* (Sept. 10, 2020), www.mass.gov/doc/COVID-19-nursing-facility-accountability-and-supports-package-20/download.

defined.⁴³ New York followed suit in April 2021, when – as part of the state’s annual Budget Bill – it adopted a requirement that nursing homes spend at least 70 percent of their revenue on direct patient care.⁴⁴

Ultimately, the success of this type of approach, however, will depend on several factors.

These include how states categorize expenses. New York, for example, defines “direct patient care” to include expenses that arguably do not fit that description (such as “plant operation and management”) and thus would allow for less money to be spent on what the lay person might think of as “direct patient care” than the language of its requirement suggests. It will also depend on setting the threshold at the correct level (i.e., higher than the 70 percent New York requires), so that owners do not unreasonably profit at the expense of residents. In addition, it will require imposing transparency requirements that prevent nursing homes from hiding profits as expenses through transactions with related entities.

B Increase Support for Community-Based Care

The pandemic revealed the inherent danger posed by the current policy framework, which favors institutional care over community-based care. Currently, Medicaid – the primary funding source for long-term care services in the United States – steers older adults in need of long-term care into institutions by (1) requiring states to use Medicaid funds to cover nursing home care but allowing states to choose whether to pay for most home-based care; and (2) allowing states that cover home-based care services to cap the number of beneficiaries served. Thus, in some states older adults must wait years before they can get home-based care.⁴⁵ Even then, care recipients may receive less help than they need because nearly three quarters of states limit how many hours they can get.⁴⁶ Thus, Medicaid pushes individuals – especially those with a lower socioeconomic status – into institutions even when they could live healthier and more satisfying lives with in-home help.

This institutional bias cannot be justified on fiscal grounds as it is not clear that steering individuals into facilities reduces public costs; there is some evidence that it may actually increase care-associated costs.⁴⁷ Nor can it be squared with the integration

⁴³ See S.B. 4482, 2020–2021 Leg., Reg. Sess. (N.J. 2020) (spelling out New Jersey’s provisions, which give executive branch actors substantial discretion in defining “direct patient care”).

⁴⁴ S.B. 2507-C (NY 2021).

⁴⁵ Medicaid and CHIP Payment & Access Commission, State Management of Home- and Community-Based Services Waiver Waiting Lists (Aug. 2020), www.macpac.gov/wp-content/uploads/2020/08/State-Management-of-Home-and-Community-Based-Services-Waiver-Waiting-Lists.pdf.

⁴⁶ MaryBeth Musumeci, Molly O’Malley Watts & Priya Chidambaram, Key State Policy Choices About Medicaid Home and Community-Based Services (Feb. 2020), <http://files.kff.org/attachment/Issue-Brief-Key-State-Policy-Choices-About-Medicaid-Home-and-Community-Based-Services>.

⁴⁷ See, for example, Off. of Pol’y Dev. & Rsch., US Dep’t of Housing & Urban Dev., Measuring the Costs and Savings of Aging in Place (2013), www.huduser.gov/portal/periodicals/em/fall13/highlight2.html.

mandate of the Americans with Disabilities Act, which prohibits states from unreasonably requiring individuals with disabilities to receive services in a segregated setting when their needs could be reasonably accommodated in the community.⁴⁸

If the devastation that COVID-19 has wrought on residents of long-term care institutions has taught policymakers nothing else, it should teach them this: Medicaid's bias in favor of institutionalization is dangerous and must end. Where a Medicaid beneficiary's long-term care needs could be met in the community, and providing such care in a community-based setting would not be more expensive than providing care in an institutional setting, states should be required to provide coverage for community-based care on at least equal terms with institutional care. States should also be encouraged, even if not required, to cover care in community-based settings when doing so is not prohibitively expensive.

C *Change the Narrative*

The lack of protection for long-term care residents indicates an underlying willingness on the part of policymakers to tolerate suffering and isolation among older adults. This tolerance, which was present long before the COVID-19 pandemic, has been revealed in stark terms by the crisis itself. Indeed, the pandemic has shown not only how policymakers allowed dangerous conditions and patterns to persist, but also that they are willing to accept unprecedented levels of isolation and suffering. For example, federal and state regulators have responded to the pandemic by barring residents from having family visitors, while doing nothing to reduce the number of staff entering facilities. Limits on family visitors – even those who were serving as caregivers – were accepted in the name of protection, even though it meant condemning residents to conditions akin to solitary confinement. At the same time, not a single state adopted a one-site rule limiting staff to working in one care facility during the pandemic, as Canadian provinces did.⁴⁹ Nor did regulators require facilities to make efforts to reduce reliance on part-time and agency staff, despite evidence suggesting that eliminating staff linkages could reduce COVID-19 infections in nursing homes by 44 percent.⁵⁰

This tolerance suggests that public outcry and advocacy for the good care and humane treatment of long-term care residents is not yet sufficiently aligned or effective to support reform. Particularly in the context of a strong nursing home industry lobby – which demonstrated its muscle last year by extracting billions of dollars in payouts, in addition to liability relief from the COVID-19 pandemic – a different narrative and more robust advocacy effort is likely to be needed to significantly change the status quo.

⁴⁸ See, generally, *Olmstead v. LC*, 527 US 581 (1999).

⁴⁹ See, for example, Ont. Ministry of Long-Term Care, COVID-19 Action Plan: Long-Term Care Homes (May 2020), www.ontario.ca/page/COVID-19-action-plan-long-term-care-homes.

⁵⁰ M. Keith Chen, Judith A. Chevalier & Elisa F. Long, Nursing Home Staff Networks & COVID-19 (Oct. 2020), www.pnas.org/content/118/1/e201545118.

It is instructive to compare policy and advocacy related to institutionalized older adults to that pertaining to children and disabled younger adults. A bias in favor of institutionalization persists for older adults even as it is eroded for younger ones. Although public funding continues to steer older adults into institutions, institutions for children and younger adults (e.g., orphanages, mental hospitals, and institutions for the developmentally and cognitively disabled) are increasingly shuttered, with the money diverted to community-based care. Ageism likely also shapes the willingness to tolerate regulatory violations in nursing homes. As noted above, nursing homes that violate regulations designed to protect residents from harm typically face a mere slap on the wrist. By comparison, childcare centers in violation of state regulations designed to protect children in their care commonly have their licenses revoked and their facilities closed.

Creating the momentum for reforming the status quo will therefore require concerted advocacy efforts to make it clear to policymakers that it is worthwhile to invest the political capital and resources necessary to transform long-term care – that the lives of those who need long-term care are worth it. This, in turn, will likely require creating a vocal, organized constituency for reforming long-term care systems. Advocates have long worked to improve regulations and policy interventions by working with regulators to improve the design and administration of long-term care policy. Little focus, by comparison, has been placed on creating public momentum or awareness of the issues, or on organizing stakeholders, such as family members, to advance reform.

With the consequences of the status quo laid bare by COVID-19, advocates should seize the moment to change the narrative about long-term care. Specifically, advocates must describe over-institutionalization of older adults, and the neglect they receive in facilities, not merely as a policy challenge, but as a civil rights issue of major moral consequence. By embracing a narrative that focuses on rights and morality, advocates may be able to capitalize on the moment to invigorate advocacy efforts and potentially foster a grassroots movement to push for a system of long-term care that is both humane in its approach and resilient to future disruptions.

IV CONCLUSION

The vulnerability of nursing homes and other long-term care facilities to COVID-19 both exposes the failures of current regulatory schemes designed to protect residents and points to what needs to happen to build a humane long-term care system that is resilient to public health disruptions. Fortunately, the policy changes needed to make long-term care resilient and humane are not radical; they would merely bring interventions that have been applied in other health care contexts into the long-term care space. However, making these changes will require confronting not only entrenched financial interests and institutions, but also the underlying attitudes that have enabled systems that normalize isolation and suffering.