



# Reforming Long-Term Care with Lessons from the COVID-19 Pandemic

## Proceedings of an Urban Institute Roundtable

*Howard Gleckman and Melissa M. Favreault*

*February 2021*

**On October 5, 2020, the Urban Institute hosted some of the nation’s leading long-term care experts for a roundtable to explore reforms in how the United States cares for older adults in the wake of the COVID-19 pandemic. Participants highlighted several key areas for reform and identified potential improvements in the system.**

## Context

The COVID-19 pandemic has exposed and amplified the structural weaknesses of the US system of care for older adults living with physical and cognitive limitations. The COVID Tracking Project at the Atlantic estimates that as of February 18, 2021, more than 170,600 residents of long-term care facilities had died from COVID-19, representing about 35 percent of all COVID-19-related deaths in the United States while making up less than 1 percent of the population.<sup>1</sup> Evidence suggests that some states underestimated COVID-19-related nursing home deaths.<sup>2</sup> The Centers for Disease Control and Prevention (CDC) estimates that adults age 65 and older living in all settings accounted for about 80 percent of the nation’s COVID-19-related deaths while making up only about 14 percent of COVID-19 cases.<sup>3</sup>

On October 5, 2020, the Urban Institute brought together 31 experts in long-term care, including researchers, policy analysts, and participants representing senior living communities, family caregivers, direct care workers, and managed care plans. The roundtable was supported by a generous grant from The John A. Hartford Foundation. Participants are listed at the end of this brief.<sup>4</sup>

The roundtable began with a brief discussion of what we know about COVID-19 and nursing homes from the rapidly growing empirical literature. Participants discussed how COVID-19 presents a

perfect storm for long-term care facilities and people who need long-term services and supports, or LTSS (Ouslander and Grabowski 2020). Because the virus is airborne, asymptomatic people often spread it, its features were poorly understood at the outset, and infection control practices were inadequate in many facilities even before the pandemic; challenges were enormous.

Researchers are still exploring why some facilities are more likely than others to have outbreaks. Early studies highlight the prevalence of the virus in the community as a key factor in facility outbreaks (Abrams et al. 2020; Gorges and Konetzka 2020, 2021; Rowan et al. 2020; White et al. 2020). Several studies also highlighted facility size, with larger facilities more likely to have outbreaks (Abrams et al. 2020; Spurlock et al. 2020; White et al. 2020; Zimmerman et al. 2021). Some research points to the potential importance of off-site treatment, such as cancer care and dialysis, where patients could have contracted the virus (Rowan et al. 2020). Residents in nursing homes with higher shares of Black residents and other residents of color are especially susceptible to both illness and death (Abrams et al. 2020; Chidambaram, Neuman, and Garfield 2020; Gorges and Konetzka 2021; Konetzka 2020; Li, Cen, et al. 2020; Li, Temkin Greener, et al. 2020; Spurlock et al. 2020). Research has also documented increased depression among residents due to isolation (Rowan et al. 2020). On an individual basis among people living in nursing homes diagnosed with COVID-19, age, sex and level of physical and cognitive impairment are all associated with mortality (Panagiotou et al. 2021).

One participant noted that we can expect more deaths among LTSS beneficiaries given that the underlying challenges have not been resolved. As Konetzka and Gorges (2021) note in a recently released article, “Despite best practices having emerged, these practices are either not being fully implemented or are inadequate to control the virus.” Other participants noted that in many European countries, nursing home residents also account for a large share of COVID-19 deaths, so the challenges are not unique to the United States (Comas-Herrera et al. 2020).

## Issues Identified

With their wide range of perspectives, the roundtable participants identified several issues that should be addressed in any reform of the nation’s system of delivering LTSS.

Most importantly, they broadly agreed that reform is necessary and urgent, especially considering the serious impact of the COVID-19 pandemic on frail older adults. The pandemic has highlighted the need for a better system of caring for those with chronic conditions and functional and/or cognitive limitations. Several participants argued for the importance of leveraging this unique moment to advocate for fundamental reforms.

The attendees agreed that reforms should focus on several domains:

- Redesigning Medicaid
- Creating a strong foundation for home- and community-based services (HCBS)
- Integrating medical care and LTSS

- Enhancing pay, benefits, and training for direct-care workers
- Focusing on the quality of life for frail older adults and younger people with severe disabilities, not just medical treatment or service delivery
- Reimagining nursing homes
- Supporting adults with disabilities along the full continuum of care
- Recognizing profound disparities in need for and access to high-quality care
- Improving data collection

It also is important to note that, although the roundtable focused on delivery issues, participants broadly agreed that fundamental reforms could not occur without major changes in LTSS financing. As one participant said, “the chewing-gum-and-duct-tape approach we have for financing is not working for us.” Changes are needed in both the amount of funding available for LTSS and in the way funding is allocated. The group generally agreed that many of the failures of the existing system are due to the misdirected incentives created by Medicare and Medicaid. Several called for more neutral payment approaches among care settings, and many called for greater federal support for Medicaid LTSS.

Below are brief summaries of the issues raised by the participants in each of these domains.

## Medicaid

Participants generally agreed that Medicaid LTSS should be better funded and shift its focus from nursing home care to HCBS. Currently, nursing homes are the default settings for Medicaid LTSS, and they are the only settings where Medicaid pays for room and board. The mix of HCBS and nursing homes varies significantly across states. Although every state provides HCBS, those programs often are underfunded, making it difficult for those living at home with physical or functional limitations to obtain sufficient assistance. Even before the pandemic, the lack of adequate HCBS funding resulted in inadequate services. For example, 41 states have waiting lists for HCBS (Musumeci, Chidambaram, and Watts 2019).

Although the participants felt that HCBS should become the default option for Medicaid LTSS, opinions differed on whether and how this could be achieved. Several cautioned against using Medicaid as the tool to address the broad spectrum of social supports that beneficiaries often require. For example, some suggested that housing subsidies should be provided through state and local housing agencies rather than through Medicaid. One participant said, “Medicaid is not the chassis [on which] to build everything.”

At the same time, participants recognized the practical delivery and financial challenges that result when government provides a wide range of social supports through siloed departments and agencies, all with their own rules and budgets. Some felt that state and local governments must develop a more holistic cross-agency focus on meeting the needs of older adults. They noted California is attempting to create such a model by developing a [Master Plan for Aging](#).<sup>5</sup>

The roundtable also questioned whether Medicaid should be providing LTSS at all. Many participants felt government-funded LTSS should be addressed at the federal level through Medicare. But others felt this step is politically unrealistic, especially given Medicare’s budgetary problems, and said policymakers should focus on improving and sufficiently funding Medicaid LTSS. Many participants pointed to low Medicaid payment rates as a root cause of challenges in maintaining a safe environment for people using LTSS. Many participants also highlighted the importance of increasing the federal government’s share of Medicaid costs given state budget pressures. Others pointed out that Medicaid eligibility standards did not adequately account for geographic variation in living and care costs.

---

*States that rebalance are not always innovative.*

*—Roundtable participant*

---

## **The Need for a Strong HCBS Foundation**

Participants felt that HCBS could not fully succeed without a robust care infrastructure. That foundation may include family caregiver training and pay. Participants in the roundtable noted the extraordinary contributions of family caregivers to HCBS and how the pandemic stretched many to the breaking point. As one participant said, “the pandemic has afforded us the ability to focus on the role of family caregivers. If not for the unsung heroes, imagine how bad the situation would be.”

The pandemic has increased burdens on family caregivers. Women’s labor force participation has plummeted for many reasons, including the need to increase care for adults with disabilities as well as children, who often have been unable to attend in-person school. Without respite support, family caregivers often must choose between taking time to shop for food and other necessities and staying home to care for loved ones. These challenges have been especially severe during the pandemic, when shopping itself carries risks and there have been shortages of goods that family caregivers need (e.g., personal protective equipment, incontinence supplies, and bleach wipes). Participants noted that it is critical to view people with LTSS needs in their family contexts.

---

*The pandemic has afforded us the ability to focus on the role of family caregivers. If not for the unsung heroes, imagine how bad the situation would be.*

*—Roundtable participant*

---

A strong HCBS foundation may also include qualified and well-paid home care workers and personal care aides, reliable nutrition and transportation services, and enhanced telehealth. Several participants highlighted the importance of greater programmatic flexibility in Medicaid. The group also broadly endorsed enhanced options for housing with services, including models where low-income senior housing is combined with social supports and preventive nursing care. According to one participant, “states that rebalance are not always innovative.” As noted, states have had only limited success building out the necessary infrastructure to make HCBS truly successful.

Participants also discussed the importance of taking a functional approach to improve quality of life for people with LTSS needs in the community. Interdisciplinary teams could play a critical role. Several participants noted how relatively small changes in the home can make a big difference in a person’s ability to safely age in place. In one model, the Community Aging in Place—Advancing Better Living for Elders (CAPABLE) program,<sup>6</sup> a nurse, occupational therapist, and person skilled at home repairs and modifications work together to improve safety, motivation, and function; reduce depression; and increase independence by evaluating and modifying the home environment. Programs of All-Inclusive Care for the Elderly (PACE),<sup>7</sup> jointly funded by Medicare and Medicaid, similarly rely on interdisciplinary teams to improve the well-being of participants.

## **Integrating Medical Care with LTSS**

This concept was widely supported by participants, though many different models are possible. Many at the roundtable believe that functional and physical limitations should be considered public health issues and thus fully integrated into the nation’s public health system. However, some worry that such a model risks medicalizing supports and services.

Several participants suggested that integrated care for older adults should include benefits such as wellness care, behavioral health care, and case management.

Others focused on the value of expanding supports and services through Medicare managed care, including Medicare Advantage (MA) plans and Special Needs Plans (SNPs). For the past two years, MA plans have gradually been adding supportive services—such as home-delivered meals, transportation, and adult day services—for members with chronic conditions (ATI Advisory 2021; Long-Term Quality Alliance and ATI Advisory 2021). While transformation has been accelerating, uptake among plans remains limited. Some at the roundtable suggested payment and other regulatory reforms to accelerate adoption of these benefits by MA plans. For example, where individual MA plans do not have the necessary critical mass of members to provide services, multiple plans could pool resources.

While offering supports and services through MA plans is a relatively new concept, most states have transferred their Medicaid LTSS programs to managed-care plans. These initiatives have had some success integrating medical care with supports and services, but several roundtable participants said they still have not achieved their full promise. According to one participant, “Plans have done an OK job but they are not transformational. They are not stimulating innovation.”

---

*We can't solve the challenges of long-term care unless we address this workforce problem.*

*—Roundtable participant*

---

## **Workforce**

Nearly all participants agreed that few reforms would be achievable without improving pay and working conditions for direct care workers. The pandemic has highlighted already-severe shortcomings, including chronically low wages, poor training, few opportunities for advancement, and lack of paid sick leave and other benefits. According to one participant, “We can’t solve the challenges of long-term care unless we address this workforce problem.”

Participants noted that many nursing home COVID-19 outbreaks may have been caused by aides, often asymptomatic, bringing the virus into facilities. Underpaid aides frequently work multiple jobs (Van Houtven, DePasquale, and Coe 2020), which increases their chances of infection and the likelihood they will expose others to the virus. The ongoing lack of personal protective equipment and rapid and accurate testing resulted in asymptomatic aides spreading disease in facilities where they work. With no paid sick leave, some aides worked even when they were ill, further spreading the virus.

The long-term care industry faced a growing shortage of direct-care workers even before the pandemic (SteelFisher et al. 2021). That labor shortage has now become more severe despite temporary wage increases being offered by some facilities and home care agencies. A major challenge, according to some participants, is that increasing wages and benefits will put growing pressure on already-strained Medicaid budgets, with no obvious source of additional funding.

---

*We must first address the profound ageism and devaluation of our elders.*

*—Roundtable participant*

---

## **Quality of Life**

Many participants said that a lesson of the COVID-19 pandemic has been the lack of focus on quality of life for frail older adults. This has been highlighted by decisions to bar family access to residents of long-term care facilities to prevent COVID-19 outbreaks. Several attendees reported that the regulatory focus on infection control, with only limited awareness of the risks of social isolation, may be leading to high levels of physical and cognitive decline among residents.

Participants were interested in seeing better data on the degree to which social isolation has led to excess morbidity and mortality in senior living facilities. Others felt the unwillingness of government to respond to this issue was a result of ageism. And others felt the situation highlighted the need for more social workers in care facilities.

## Reimagining Nursing Homes

Some participants felt that nursing homes are obsolete and that postacute care and long-term care can be better provided in other settings. Others felt that nursing homes would continue to play a role. However, they felt the current nursing home model is likely to undergo substantial change as a result of the pandemic.

One issue the roundtable identified is that large facilities carry high levels of risk, but efficiencies of scale are not apparent. A system where long-stay residents and postacute patients share facilities is a function of the payment system that overpays for Medicare postacute care and underpays for Medicaid long-stay services. Housing these two groups together makes little clinical sense and increases the risk of disease transmission. Further, when postacute business declines (as it did during the pandemic), nursing home finances may become unsustainable.

One participant noted that assisted living has attracted many residents who can be cared for relatively easily, leaving nursing homes to care for those with the highest and costliest level of need with insufficient reimbursement. COVID-19 outbreaks in long-term care facilities, combined with lockdowns that have separated residents from their families for more than nine months, have also reduced consumer demand for nursing home care.<sup>8</sup>

Even as demand falls, costs are rising: labor costs are increasing, and facilities will require significant recapitalization to upgrade internal space for better infection control.

Participants suggested several solutions. Most agreed that many older adults with LTSS needs could remain at home for a longer period with enhanced HCBS. For those who require facility-based care, alternatives include expanding Green House and similar small-home models that are designed for 8 to 10 residents and use creative new staffing designs. Early evidence suggests that these models had far fewer COVID-19 cases and fatalities than other facilities (Zimmerman et al. 2021).

For those who require postacute skilled nursing care, one model could be a return to hospital-based extended care units. Another participant suggested that nursing homes focus on shorter but more intensive post-acute care, similar to what is now provided by hospital medical-surgical units. Under this model, stays would average two to five days, rather than one to two weeks.

## Continuum of Care

Many participants noted that frail older adults often move along a continuum as their care needs change. As a result, the participants suggested several alternatives, including housing with services, an option that can prevent acute clinical episodes and help residents maintain a stable quality of life. At

the same time, some group-home models can provide care for older adults with early-stage physical or cognitive limitations in a timely, comfortable, and cost-effective way.

Several participants stressed the importance of focusing these housing models on social supports rather than a medical model of care. Some participants suggested converting hotels and shuttered nursing homes into such environments.

However, advocates for all these reforms acknowledged that most changes in housing for frail seniors would require fundamental changes in payment models to attract investors who largely have avoided these innovative models so far. These might include enhanced housing subsidies for low-income older adults.

## **Reducing Disparities in Need for and Access to High-Quality Care**

A cross-cutting theme in the discussion was the critical role that racial inequities play in many of the LTSS inadequacies. A majority of direct care staff are Black people, Hispanic people, and immigrants of color (Campbell 2020). Many have been exposed to coronavirus disproportionately at home and work, and more than 1,000 direct care workers have died from the disease.

Among care recipients, research has found significantly higher COVID-19 prevalence and mortality in nursing homes that serve Black and brown communities (Abrams et al. 2020; Chidambaram, Neuman, and Garfield 2020, Konetzka 2020; Li, Cen, et al. 2020; Li, Temkin Greener, et al. 2020; Spurlock et al. 2020). This may be correlated with higher levels of infection in those communities (Gorges and Konetzka 2021; Khazanchi, Evans, and Marcelin 2020). In Khazanchi, Evans, and Marcelin's (2020) words, "studies suggest that fundamental causes of COVID-19 inequity include systemically racist policies, such as historic racial segregation and their inextricable downstream effects on the differential quality and distribution of housing, transportation, economic opportunity, education, food, air quality, health care, and beyond." For example, one roundtable participant mentioned in some communities of color, transportation is inadequate and some key services are limited or not available.

## **Data Collection**

Many participants raised the need for improved and more timely LTSS data. Some examples include data on Medicaid waiting lists, the effects of COVID-19 on frail older adults outside of nursing homes, the effects of social isolation on older adults, whether enhanced LTSS reduces medical costs, and the benefits of alternative care settings.

## **Conclusion**

The COVID-19 pandemic has amplified and highlighted the deep existing flaws in the long-term care system in the US. It has had devastating effects on people needing and providing LTSS, especially in



long-term care facilities. Residents and direct care workers have faced high rates of infection and death. Residents also have suffered from isolation due to long-term separation from their families and friends.

The effects of the pandemic should spur policymakers and providers to address long-standing problems in the way we care for people with disabilities. Participants in our roundtable highlighted the need to rethink many aspects of the current system, including the Medicaid program, nursing homes, and job conditions for direct-care workers. Change must aim to improve the quality of life of frail of older adults and younger people with severe disabilities. It must do so along the full continuum of care and recognize important disparities in access to high-quality care.

## Appendix: Roundtable Participants

- **Gretchen Alkema, PhD**, Vice President of Policy and Communication, SCAN Foundation
- **Donna Benton, PhD**, Research Associate Professor and Director of Family Caregiver Support Center, University of Southern California Leonard Davis School of Gerontology
- **Stuart Butler, PhD**, Senior Fellow, Economic Studies, Brookings Institution
- **Marc Cohen, PhD**, Clinical Professor, Department of Gerontology, University of Massachusetts Boston, Codirector, Leading Age LTSS Center
- **Robert Espinoza, MPA**, Vice President of Policy, PHI
- **Melissa Favreault, PhD**, Senior Fellow, Urban Institute
- **Lynn Friss Feinberg, MSW**, Senior Strategic Policy Advisor, AARP
- **Wendy Fox-Grage, MS, MPA**, Project Director, Chronic and Vulnerable Populations team, National Academy for State Health Policy
- **Terry Fulmer, PhD, RN, FAAN**, President, The John A. Hartford Foundation
- **Howard Gleckman**, Senior Fellow, Tax Policy Center, Urban Institute
- **Joseph Gaugler, PhD**, Professor and Robert L. Kane Endowed Chair in Long-Term Care and Aging, University of Minnesota
- **Mary Kashack**, Executive Director, Long-Term Quality Alliance
- **Ruth Katz, MEd**, Senior Vice President of Public Policy/Advocacy, Leading Age
- **Gavin Kennedy, MS**, Associate Deputy Assistant Secretary for Behavioral Health, Disability, and Aging Policy, Office of the Assistant Secretary for Planning and Evaluation, DHHS
- **Leslie Kernisan, MD, MPH**, Founder and Primary Author BetterHealthWhileAging.net, Clinical Instructor, University of California San Francisco
- **Robert Kramer, MDiv**, Founder and Fellow, Nexus Insights

- **R. Tamara Konetzka, PhD**, Louis Block Professor of Public Health Sciences and the College, University of Chicago
- **Jennifer Kowalski, MS**, Vice President, Public Policy Institute, Anthem, Inc.
- **William Marton, PhD**, Director, Division of Disability and Aging Policy, Office of the Assistant Secretary for Planning and Evaluation, DHHS
- **Anne Montgomery, MS**, Director, Eldercare Improvement, Altarum
- **Susan Ryan, MA**, Senior Director, Green House Project
- **Daniel Reingold, MSW, JD**, President and CEO, Riverspring Health (Hebrew Home at Riverdale)
- **Julie Robison, PhD**, Professor, Health Center on Aging, University of Connecticut
- **Emily Rosenoff, MPA**, Director, Division of Long-Term Services and Supports Policy, Office of the Assistant Secretary for Planning and Evaluation, DHHS
- **Lois Simon, MPH**, Executive Vice President, Policy and Programs, Seniorlink
- **Brenda Spillman, PhD**, Senior Fellow, Urban Institute
- **David Stevenson, PhD**, Professor of Health Policy, Vanderbilt University School of Medicine
- **Nora Super, MPA**, Senior Director, Center for the Future of Aging, Milken Institute
- **Sarah Szanton, PhD, MSN, RN**, Endowed Professor for Health Equity and Social Justice, Director, Center for Innovative Care in Aging, Johns Hopkins University
- **Anne Tumlinson, MA**, Founder and CEO, ATI Advisory/Daughterhood
- **Courtney Van Houtven, PhD**, Professor, Department of Population Health Science, Duke University School of Medicine

## Notes

- <sup>1</sup> “The Long-Term Care COVID Tracker,” The COVID Tracking Project, accessed February 22, 2021, <https://covidtracking.com/nursing-homes-long-term-care-facilities>.
- <sup>2</sup> See “N.Y. Severely Undercounted Virus Deaths in Nursing Homes, Report Says,” January 28, 2021, <https://www.nytimes.com/2021/01/28/nyregion/nursing-home-deaths-cuomo.html>.
- <sup>3</sup> “Demographic Trends of COVID-19 Cases and Deaths in the US Reported to CDC,” CDC COVID data tracker, accessed February 22, 2021, <https://covid.cdc.gov/covid-data-tracker/#demographics>.
- <sup>4</sup> The meeting was conducted under Chatham House rules to promote openness, so we report comments without attribution.
- <sup>5</sup> “Master Plan for Aging,” California Health & Human Services Agency, accessed February 9, 2021, <https://www.chhs.ca.gov/home/master-plan-for-aging/>.
- <sup>6</sup> See “Community Aging in Place—Advancing Better Living for Elders (CAPABLE),” Johns Hopkins School of Nursing, accessed February 9, 2021, [https://nursing.jhu.edu/faculty\\_research/research/projects/capable/](https://nursing.jhu.edu/faculty_research/research/projects/capable/).

<sup>7</sup> See the “List of State Websites for Additional State Information on PACE” file hosted at “Programs of All-Inclusive Care for the Elderly for States,” Medicaid.gov, accessed February 9, 2021, <https://www.medicaid.gov/medicaid/long-term-services-supports/pace/programs-of-all-inclusive-care-for-elderly-for-states/index.html>.

<sup>8</sup> Anna Wilde Mathews and Tom McGinty, “Covid Spurs Families to Shun Nursing Homes, a Shift That Appears Long Lasting,” *Wall Street Journal*, December 2, 2020.

## References

- Abrams, Hannah R., Lacey Loomer, Ashvin Gandhi, and David C. Grabowski. 2020. “Characteristics of US Nursing Homes with COVID-19 Cases.” *Journal of the American Geriatrics Society* 68: 1653–56.
- ATI Advisory. 2021. “New, Non-Medical Supplemental Benefits in Medicare Advantage in 2021.” Washington, DC: ATI Advisory.
- Campbell, Stephen. 2017. “Racial and Gender Disparities Within the Direct Care Workforce: Five Key Findings.” Bronx, NY: PHI.
- Chidambaram, Priya, Tricia Neuman, and Rachel Garfield. 2020. *Racial and Ethnic Disparities in COVID-19 Cases and Deaths in Nursing Homes*. San Francisco: Kaiser Family Foundation.
- Comas-Herrera, Adelina, Joseba Zalakaín, Elizabeth Lemmon, David Henderson, Charles Litwin, Amy T. Hsu, Andrea E. Schmidt, Greg Arling and Jose-Luis Fernández. 2020. “Mortality Associated with COVID-19 in Care Homes: International Evidence.” London: London School of Economics and Political Science, International Long-Term Care Policy Network.
- Gorges, Rebecca J., and R. Tamara Konetzka. 2020. “Staffing Levels and COVID-19 Cases and Outbreaks in US Nursing Homes.” *Journal of the American Geriatrics Society* 68 (11): 2462–66.
- Gorges, Rebecca J., and Tamara Konetzka. 2021. “Factors Associated with Racial Differences in Deaths among Nursing Home Residents With COVID-19 Infection in the US.” *JAMA Network Open* 4 (2): e2037431. doi: 10.1001/jamanetworkopen.2020.37431.
- Khazanchi, Rohan A., Charlesnika T. Evans, Jasmine R. Marcelin. 2020. “Racism, Not Race, Drives Inequity Across the COVID-19 Continuum.” *JAMA Network Open* 3 (9).
- Konetzka, R. Tamara. 2020. Statement before the United States Senate Special Committee on Aging, Washington, DC, May 21.
- Konetzka, R. Tamara, and Rebecca J. Gorges. 2021. “Nothing Much Has Changed: COVID-19 Nursing Home Cases and Deaths Follow Surges.” *Journal of the American Geriatrics Society* 69 (1): 46–47.
- Li, Yue, Helena Temkin-Greener, Gao Shan, Xueya Cai. 2020. “COVID-19 Infections and Deaths among Connecticut Nursing Home Residents: Facility Correlates.” *Journal of the American Geriatrics Society* 68 (9): 1899–1906.
- Li, Yue, Xi Cen, Xueya Cai, and Helena Temkin-Greener. 2020. “Racial and Ethnic Disparities in COVID-19 Infections and Deaths Across U.S. Nursing Homes.” *Journal of the American Geriatrics Society* 68 (11): 2454–61.
- Long-Term Quality Alliance and ATI Advisory. 2021. *Data Insight: Special Supplemental Benefits for the Chronically Ill in Plan Year 2021*. Washington, DC: Long-Term Quality Alliance and ATI Advisory.
- Musumeci, MaryBeth, Priya Chidambaram, and Molly O’Malley Watts. 2019. “Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists.” San Francisco: Kaiser Family Foundation.
- Ouslander JG, and DC Grabowski. 2020. “COVID-19 in Nursing Homes: Calming the Perfect Storm.” *Journal of the American Geriatrics Society* 68: 2153–62.
- Panagiotou, Orestis A., Cyrus M. Kosar, Elizabeth M. White, Leonidas E. Bantis, Xiaofei Yang, Christopher M. Santostefano, Richard A. Feifer, Carolyn Blackman, James L. Rudolph, Stefan Gravenstein, Vincent Mor. 2021.

- "Risk Factors Associated with All-Cause 30-Day Mortality in Nursing Home Residents With COVID-19." *JAMA Intern Medicine*. doi: 10.1001/jamainternmed.2020.7968.
- Rowan, Patricia, Reena Gupta, Rebecca Lester, Michael Levere, Kristie Liao, Jenna Libersky, Debra Lipson, Andrea Wysocki, Julie Robison, and Patricia A. Bowen. 2020. *A Study of the COVID-19 Outbreak and Response in Connecticut Long-Term Care Facilities*. Princeton, NJ: Mathematica.
- Spurlock, Bruce, Alex Stack, Charlene Harrington, Leslie Ross, Mahil Senathirajah, Frank Yoon, Parker Lewis, and Richele Benevent. 2020. *COVID-19 in California's Nursing Homes: Factors Associated with Cases and Deaths*. Oakland: California Health Care Foundation.
- SteelFisher, Gillian K., Arnold Epstein, David C. Grabowski, Karen Joynt Maddox, E. John Orav, and Michael L. Barnett. 2021. "Persistent Challenges of COVID-19 in Skilled Nursing Facilities: The Administrator Perspective." *Journal of the American Geriatrics Society*. doi: 10.1111/jgs.17062.
- Van Houtven, Courtney Harold, Nicole DePasquale, and Norma B. Coe. 2020. "Essential Long-Term Care Workers Commonly Hold Second Jobs and Double- or Triple-Duty Caregiving Roles." *Journal of the American Geriatrics Society* 68: 1657–60.
- White, Elizabeth M., Cyrus M. Kosar, Richard A. Feifer, Carolyn Blackman, Stefan Gravenstein, Joseph Ouslander, and Vincent Mor. 2020. "Variation in SARS-CoV-2 Prevalence in US Skilled Nursing Facilities." *Journal of the American Geriatrics Society* 68 (10): 2167–73.
- Zimmerman, Sheryl, Carol Dumond-Stryker, Meera Tandan, John S. Preisser, Christopher J. Wretman, Abigail Howell, and Susan Ryan. 2021. "Nontraditional Small House Nursing Homes Have Fewer COVID-19 Cases and Deaths." *Journal of the American Medical Directors Association*. <https://doi.org/10.1016/j.jamda.2021.01.069>.

## Other Selected Resources

- AARP Public Policy Institute. 2021. *AARP Nursing Home COVID-19 Dashboard*.
- Alkema, Gretchen. 2020. "Making Lemonade from a Very Sour Lemon: Capitalizing on Regulatory Flexibilities Born from the COVID-19 Public Health Emergency." Blog. SCAN Foundation.
- Blewett, Lynn A., and Robert Hest. 2020. "Emergency Flexibility for States to Increase and Maintain Medicaid Eligibility for LTSS under COVID-19." *Journal of Aging & Social Policy* 32: 4–5, 343–49. DOI: 10.1080/08959420.2020.1774312
- Butler, Stuart M. 2021. "Time to Rethink Nursing Homes." *JAMA Health Forum*.
- Cahan, Eli M., Terry Fulmer, and Nirav R. Shah. 2020. "Protecting Healthcare's Family Caregivers Amidst The COVID-19 Pandemic." *Health Affairs Blog*, April 24.
- Chidambaram, Priya, and Rachel Garfield. 2021. *Patterns in COVID-19 Cases and Deaths in Long-Term Care Facilities in 2020*. San Francisco: Kaiser Family Foundation.
- CMS. COVID-19. Nursing Home Data. <https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg/>.
- CMS, Center for Clinical Standards and Quality/Quality, Safety & Oversight Group. 2020. "COVID-19 Survey Activities, CARES Act Funding, Enhanced Enforcement for Infection Control Deficiencies, and Quality Improvement Activities in Nursing Homes." <https://www.cms.gov/files/document/qso-20-31-all.pdf>.
- Coronavirus Commission for Safety and Quality in Nursing Homes. 2020. *Commission Final Report, September 2020*. McLean, VA: MITRE Corporation.
- Dawson, Walter D. Nathan A. Boucher, Robyn Stone, and Courtney H. Van Houtven. 2021. "COVID-19: The Time for Collaboration Between Long-Term Services and Supports, Health Care Systems, and Public Health Is Now." *Milbank Quarterly*, February 16. <https://doi.org/10.1111/1468-0009.12500>.
- Denny-Brown, Noelle, Denise Stone, Burke Hays, Dayna Gallagher, Marie Squillace, Helen Lamont, Iara Oliveira, and Judith Dey. 2020. *COVID-19 Intensifies Nursing Home Workforce Challenges*. Princeton, NJ: Mathematica.

- Espinoza, Robert. 2020. "The Emotional Cost of the Nursing Home Lockdown." Bronx, NY: PHI.
- Espinoza, Robert. 2020. *Would you Stay? Rethinking Direct Care Job Quality*. Bronx, NY: PHI.
- Feinstein, Karen Wolk. 2020. "What COVID-19 Exposed in Long-Term Care." *Health Affairs Blog*, November 5.
- Fulmer, T. T., C. F. Koller, and J. W. Rowe. 2020. "Reimagining Nursing Homes in the Wake of COVID-19." *National Academy of Medicine Perspectives*, September 21.
- Gleckman, Howard. 2021. "Pandemic Is a Tragedy, and a Chance to Rethink Long-Term Care." *Health Progress: Journal of the Catholic Health Association of the United States*, Winter.
- Gleckman, Howard. 2021. "Is the Shift of Medicaid Long-Term Care from Nursing Facilities to Home About to Accelerate?" *Forbes*, February 24.
- Grabowski, David C. 2020. "Strengthening Nursing Home Policy for the Postpandemic World: How Can We Improve Residents' Health Outcomes and Experiences?" New York: Commonwealth Fund.
- Grabowski, David C. 2021. "The Future of Long-term Care Requires Investment in Both Facility- and Home-Based Services." *Nature Aging* 1, 10–11. <https://doi.org/10.1038/s43587-020-00018-y>
- Grabowski, David C., and Vincent Mor. 2020. "Nursing Home Care in Crisis in the Wake of COVID-19." *JAMA* 324 (1): 23–24.
- Harrington, Charlene, Anne Montgomery, Terris King, David C. Grabowski, and Michael Wasserman. 2021. "These Administrative Actions Would Improve Nursing Home Ownership and Financial Transparency in the Post COVID-19 Period." *Health Affairs Blog*, February 10.
- Harrington, Charlene, Leslie Ross, Susan Chapman, Elizabeth Halifax, Bruce Spurlock, and Debra Bakerjian. 2020. "Nurse Staffing and Coronavirus Infections in California Nursing Homes." *Policy, Politics, & Nursing Practice* 21: 174–86.
- Kaushal, Ashish. 2021. "How the Pandemic Made the 'Last Acceptable Prejudice' Worse: Ageism has Colored the Response to COVID-19 and is Setting Everyone up for a More Difficult Economic Recovery." *Foreign Policy*, February 11.
- Khazanchi, Rohan, Evan R. Beiter, Suhas Gondi, Adam L. Beckman, Alyssa Bilinski, and Ishani Ganguli. 2020. "County-Level Association of Social Vulnerability with COVID-19 Cases and Deaths in the USA." *Journal of General Internal Medicine* 35 (9): 2784–87.
- Konetzka, R. Tamara. 2021. "Improving the Fate of Nursing Homes During the COVID-19 Pandemic: The Need for Policy." *American Journal of Public Health*, January 28.
- Lantsman, Jacqueline, Milena Berhane, and James Hernandez. 2021. "To Achieve Equitable Quality of Care in Nursing Homes, Address Key Workforce Challenges." *Health Affairs Blog*, February 17. DOI: 10.1377/HBLOG20210210.904101
- Lewis, Tanya. 2021. "Nursing Home Workers Had One of the Deadliest Jobs of 2020: An Analysis of Incomplete Data Shows They Had a Death Rate Higher than that of Loggers, and May have Rivalled Fishers for Most Perilous Profession." *Scientific American*, February 18.
- MACPAC (Medicaid and CHIP Payment and Access Commission). 2020. "State Management of Home- and Community-Based Services Waiver Waiting Lists." Washington, DC: MACPAC.
- Milken Institute Center for the Future of Aging. 2020. "Recommendations to Build a Dementia-Capable Workforce and System amid COVID-19." Santa Monica, CA: Milken Institute Center for the Future of Aging.
- Murray, Kate, Merle Edwards-Orr, Highsmith Rich, Molly Morris, and Kathleen Ujvari. 2021. "Paying Family Caregivers to Provide Care during the Pandemic—and Beyond." Washington, DC: AARP Public Policy Institute.
- PHI. 2020. "Competitive Disadvantage: Direct Care Wages Are Lagging Behind." Bronx, NY: PHI.
- Skufca, Laura. 2020. *Attitudes Toward Long-Term Care Amid COVID-19*. Washington, DC: AARP Research.
- Spanko, Alex. 2021. "Everyone is Right About What's Wrong with American Nursing Homes." *Skilled Nursing News*, February 24.

- Stevenson, David G. and Alice Bonner. 2020. "The Importance of Nursing Home Transparency and Oversight, Even in the Midst of a Pandemic." *Health Affairs Blog*, May 12.
- Swartz, Katherine, and Judith Feder. 2021. [Nursing Home Residents and Workers Need More than COVID-19 Vaccinations](https://doi.org/10.1599/mqop.2021.0205). *Milbank Quarterly Opinion*, February 5. <https://doi.org/10.1599/mqop.2021.0205>.
- Szanton, Sarah L., Qian-Li Hue, and Bruce Leff. 2019. "Effect of a Biobehavioral Environmental Approach on Disability Among Low-Income Older Adults: A Randomized Clinical Trial." *JAMA Internal Medicine* 179 (2): 204–11.
- Teshale, Salom, Paige Spradlin, Wendy Fox-Grage, and Kitty Purington. 2020. "States Use Appendix Ks to Provide Innovative Flexibilities for Medicaid Enrollees and Caregivers during COVID-19." Portland, ME: National Academy for State Health Policy.
- Van Houtven, Courtney, David Anderson, Mira Gill, Anna M. Zavodszky, Christina Silcox, and Mark McClellan. 2021. [Risk Assessment and Testing Considerations for SARS-CoV-2 Transmission in Congregate Care Facilities](#). New York: Rockefeller Foundation, and Washington, DC: Duke Margolis Center for Health Policy.
- Van Houtven, Courtney H., and Walter D. Dawson. 2021. [Long-Term Care Reforms Should Begin With Paid Home Care Providers](https://doi.org/10.1599/mqop.2021.0113). *Milbank Quarterly Opinion*, January 13. <https://doi.org/10.1599/mqop.2021.0113>.
- Weller, Christian, Beth Almeida, Marc A. Cohen, and Robyn I. Stone. 202. "Making Care Work Pay: How a Living Wage for LTSS Workers Benefits All." *Health Affairs Blog*, December 7.
- Wilde Mathews, Anna and Jon Camp. 2020. "Covid-19 Pandemic Hits Nursing-Home Finances: Genesis Healthcare, Others Lean on Federal Support as Costs Rise, Revenue Falls." *Wall Street Journal*, May 27.
- Wilde Mathews, Anna, Jon Camp, and Tom McGinty. 2021. "Covid-19 Cases Decline in Nursing Homes, Offering Hopeful Sign for Vaccines: Latest Drop-off May be an Early Signal that the Shots are Working, Say Industry Officials." *Wall Street Journal*, January 29.

## About the Authors

**Howard Gleckman** is a senior fellow in the Urban-Brookings Tax Policy Center at the Urban Institute, where he edits the fiscal policy blog *TaxVox* and the daily news summary the *Daily Deduction*. He is also affiliated with Urban's Program on Retirement Policy, where he works on long-term care issues. Before joining Urban, Gleckman was senior correspondent in the Washington bureau of *Business Week*, where he was a 2003 National Magazine Award finalist. He was a 2006–07 media fellow at the Kaiser Family Foundation and a visiting fellow at the Center for Retirement Research at Boston College from 2006 to 2008. Gleckman writes two regular columns for *Forbes.com*, on tax policy and elder care. He is author of the book *Caring for Our Parents* and speaks and writes frequently on long-term care issues.

**Melissa Favreault** is a senior fellow in the Income and Benefits Policy Center at the Urban Institute, where her work focuses on the economic well-being and health status of older Americans and individuals with disabilities. She studies social insurance and social assistance programs and has written extensively about Medicaid, Medicare, Social Security, and Supplemental Security Income. She evaluates how well these programs serve Americans today and how various policy changes and ongoing economic and demographic trends could alter outcomes for future generations. Favreault earned her BA in political science and Russian from Amherst College, and her MA and PhD in sociology from Cornell University.

# Acknowledgments

This brief was funded by The John A. Hartford Foundation. We are grateful to them and to all our funders, who make it possible for Urban to advance its mission.

The views expressed are those of the authors and should not be attributed to the Urban Institute, its trustees, or its funders or any of the roundtable participants or the organizations with which they are affiliated. Funders do not determine research findings or the insights and recommendations of Urban experts. Further information on the Urban Institute’s funding principles is available at [urban.org/fundingprinciples](https://urban.org/fundingprinciples).

We are grateful to the experts who gave so generously of their time to attend the roundtable. We give special thanks to Tamara Konetzka, Ruth Katz, and Dan Reingold, who gave level-setting introductory remarks, and to Gretchen Alkema and Anne Tumlinson, who served as breakout group facilitators. Michael Marazzi and Casey Simmons provided editorial assistance, and Casey served as the roundtable Zoom master. Richard Johnson provided helpful comments.



500 L'Enfant Plaza SW  
Washington, DC 20024

[www.urban.org](https://www.urban.org)

## ABOUT THE URBAN INSTITUTE

The nonprofit Urban Institute is a leading research organization dedicated to developing evidence-based insights that improve people’s lives and strengthen communities. For 50 years, Urban has been the trusted source for rigorous analysis of complex social and economic issues; strategic advice to policymakers, philanthropists, and practitioners; and new, promising ideas that expand opportunities for all. Our work inspires effective decisions that advance fairness and enhance the well-being of people and places.

Copyright © February 2021. Urban Institute. Permission is granted for reproduction of this file, with attribution to the Urban Institute.