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Special Article

Essential but Excluded: Building Disaster Preparedness Capacity for Home Health Care Workers and Home Care Agencies

Emily Franzosa DrPH [a,b,*], Tamar Wyte-Lake DPT [c], Emma Tsui PhD [d], Jennifer Reckrey MD [a,e], Madeline R. Sterling MD, MPH, MS [f]

[a] Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York, NY, USA
[b] Geriatrics Research, Education, and Clinical Center (GRECC), James J. Peters VA Medical Center, Bronx, NY, USA
[c] Veterans Emergency Management Evaluation Center, Department of Veterans Affairs, North Hills, CA, USA
[d] Graduate School of Public Health and Health Policy, City University of New York, New York, NY, USA
[e] Department of Medicine, Icahn School of Medicine at Mount Sinai, New York, NY, USA
[f] Department of Medicine, Weil Cornell Medicine, New York, NY, USA

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ABSTRACT

COVID-19 has demonstrated the essential role of home care services in supporting community-dwelling older and disabled individuals through a public health emergency. As the pandemic overwhelmed hospitals and nursing homes, home care helped individuals remain in the community and recover from COVID-19 at home. Yet unlike many institutional providers, home care agencies were often disconnected from broader public health disaster planning efforts and struggled to access basic resources, jeopardizing the workers who provide this care and the medically complex and often marginalized patients they support. The exclusion of home care from the broader COVID-19 emergency response underscores how the home care industry operates apart from the traditional health care infrastructure, even as its workers provide essential long-term care services. This special article (1) describes the experiences of home health care workers and their agencies during COVID-19 by summarizing existing empiric research; (2) reflects on how these experiences were shaped and exacerbated by longstanding challenges in the home care industry; and (3) identifies implications for future disaster preparedness policies and practice to better serve this workforce, the home care industry, and those for whom they care.

COVID-19 has undeniably emphasized the importance of the long-term care industry, as well as the challenges it faces. But while media and research have understandably focused on the nursing home sector's struggles to manage the pandemic,[1–4] less attention has been paid to the often-invisible home health care workforce that maintained care for older adults living in the community during this uniquely challenging time. Care provided by home health care workers (HHCWs) (including home health aides, home care attendants, personal care aides, and homemakers), supports older, often disabled or homebound adults, allows them to remain at home, and potentially decreases hospitalization and emergency department use.[5] Community-dwelling older adults are especially at-risk during public health emergencies, and during the pandemic faced both multiple risk factors for the disease and disruptions in their medical and caregiving networks.[6] As the pandemic overwhelmed hospitals and nursing homes, many HHCWs continued providing hands-on care, helping patients remain safely in their homes.[7] Home care also provided a way for less symptomatic patients with COVID-19 to receive care at home and for discharged patients to regain function.[8]

The home care industry is extensive. More than 9 million individuals in the United States receive home care either through an agency or direct hiring, often paid through Medicare (for medical-related services) or Medicaid (primarily for nonmedical personal care services).[9] Conservative estimates suggest 2.6 million HHCWs provide this care, but the number is likely much higher given variations in state-level data, the number of individuals paying privately for care, and the informal "gray market"[9] (Figure 1). Yet during the pandemic, many home care agencies employing HHCWs found themselves disconnected from broader public health emergency

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* Address correspondence to Emily Franzosa DrPH, Geriatrics Research, Education, and Clinical Center (GRECC), James J. Peters VA Medical Center, Bronx, NY.
E-mail address: Emily.franzosa@va.gov (E. Franzosa).

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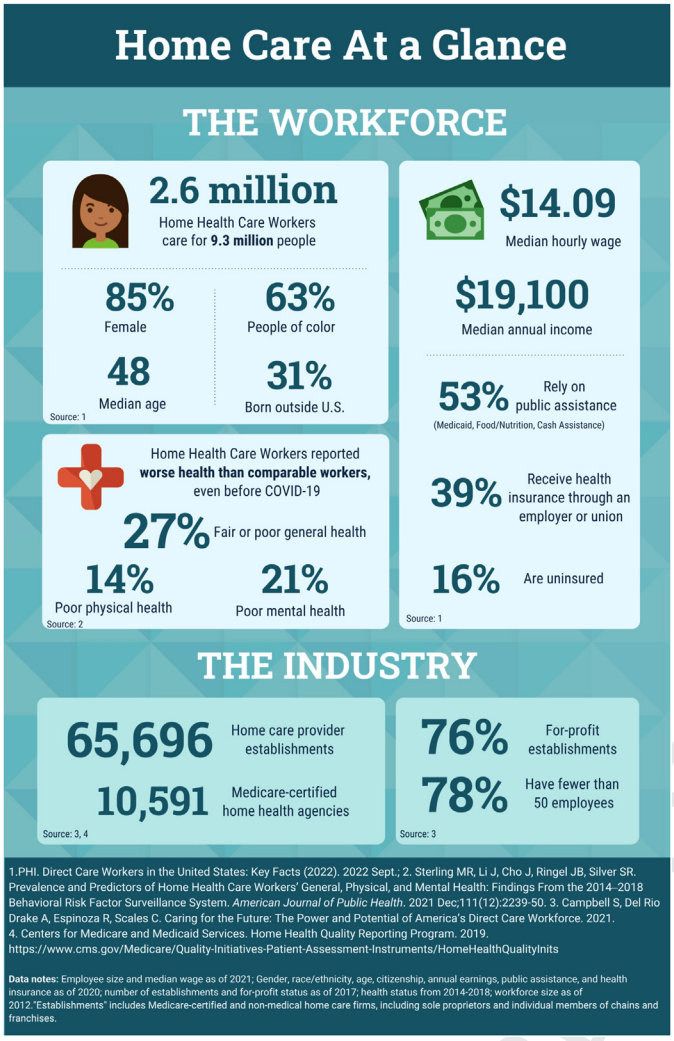

Fig. 1. Home care at a glance.
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planning efforts and struggled to provide workers with basic resources, including personal protective equipment (PPE), supplies, technical assistance, testing, and infection prevention guidance.[10,11] Unlike many nursing homes and large health care systems that could draw on institutional resources, the home care industry is fragmented and decentralized, and relies on a largely part-time, low-paid, and precarious workforce. The exclusion of home care from the broader COVID-19 emergency response underscores how the home care industry operates apart from the traditional health care infrastructure, even as HHCWs act as essential health workers. The marginalization of this industry puts HHCWs who are already at risk in further jeopardy and harms the medically complex patients they support.[12] Home care providers can and should be valuable partners in managing emergencies, and as long-term care increasingly shifts to the community, disaster preparedness efforts must explicitly include them.

In this article, we spotlight the challenges faced by HHCWs and home care agencies during the COVID-19 pandemic. We focus on HHCWs because while other home care providers (eg, nurses and physical therapists) were able to shift to less frequent home visits or remote work, HHCWs could not.[7] We aimed to (1) describe the experiences of HHCWs and their agencies during COVID-19 by summarizing existing empiric research; (2) reflect on how these experiences were shaped and exacerbated by longstanding challenges in the home care industry; and (3) highlight implications for future disaster preparedness policy and practice which could better serve this workforce, the home care industry, and the people they support.

Experiences of HHCWs and Home Care Agencies during COVID-19

A growing number of studies have examined the experiences of HHCWs and their agencies providing frontline care during the COVID-19 pandemic. These findings can be summarized by the following key themes (Figure 2).

Fear of Contracting and Transmitting COVID-19

HHCWs were fearful of contracting the virus on the job and worried about transmitting it to their patients or their own families, should they get sick. One of the first studies to show this was a qualitative study of 33 HHCWs employed by 23 different agencies in New York, NY.[13] HHCWs reported that their job did not allow for any social distancing, which inherently put them at high risk. This risk was worsened by a heavy reliance on public transportation, alongside a lack of PPE. These findings were corroborated in several following studies, including a qualitative study of HHCWs and agency leaders in Western New York and Southeast Michigan. In this study, HHCWs reported taking on extra duties in the home, such as sanitizing surfaces and grocery shopping at off-peak hours, to minimize risk of contracting COVID-19.[10,14] In addition, to prevent transmission, HHCWs monitored their own symptoms and remained vigilant for symptoms among their patients, including the completion of pre-work screening questionnaires.[15]

Unfortunately, fear did translate into illness. Nearly one-quarter of the 300 home care agencies surveyed in New York State reported 1 or more HHCWs had tested positive for COVID-19 in March of 2020.[16] In addition, 45% reported HHCWs had been exposed at work. Another survey of 94 home care agency managers in Massachusetts in June of 2020 found that 59.6% had HHCWs who provided care to patients who tested positive or had COVID-19 symptoms.[11] Roughly three-quarters of managers reported that aides at their agencies had tested positive for COVID-19 or had symptoms which required them to quarantine. Although the data were cross-sectional and cannot be used to generate prevalence estimates, they are striking.

Limited Resources, Including PPE, Testing, and Information

Nearly all studies found that HHCWs lacked necessary PPE, especially early in the pandemic. Even when agencies did provide PPE, HHCWs often had to use public transportation to travel to their agencies' headquarters to pick it up, potentially exposing them to the virus.[10,13,14] Inadequate PPE was seen at the agency and state level as well. In a national survey of 1204 home care agencies in the initial weeks of the pandemic, 78% reported having insufficient PPE.[17] Of 300 home care agencies in New York State surveyed in March 2020, 67% did not have enough PPE and 1 out of 3 had difficulty obtaining it from the Office of Emergency Management.[16] Data from Massachusetts were similar; of 94 home care agency managers surveyed, 1 out of 3 were unable to purchase N95 masks for HHCWs during the first COVID-19 wave. Notably, 52.1% of agency leaders in this study

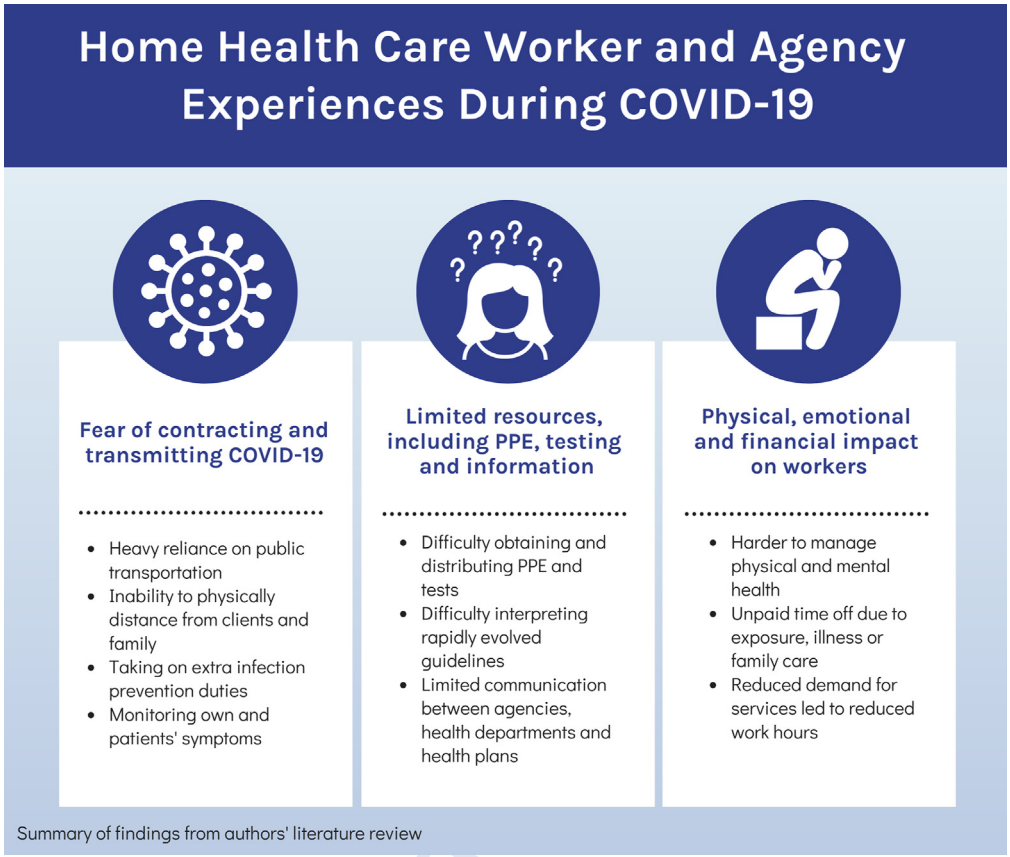

Fig. 2. Home health care worker and agency experiences during COVID-19.

reported difficulty interpreting rapidly evolving COVID-19 guidelines for their staff and the patients they served. A report commissioned by the US Department of Health and Human Services found that in addition to PPE, many agencies struggled to obtain COVID-19 tests.[18]

As the pandemic progressed, access to PPE improved. A survey of 256 unionized HHCWs in the summer-fall of 2020 found that the majority of HHCWs had PPE, however, 75% reported paying for it (out of pocket) at some point during the pandemic. In addition, studies found that as the months went on, implementing infection control practices, sourcing adequate PPE, and offering COVID-19 training to HHCWs and other staff became a top priority for home care agencies.

Physical, Emotional, and Financial Impact on HHCWs and Agencies

Recent studies have examined the COVID-19 impact on HHCWs' health and financial security. This is important because studies of HHCWs before COVID-19 found them to have poor physical and mental health compared with other similar frontline low-wage workers not working in the home environment.[19–21] A survey of 256 unionized and agency-employed HHCWs in New York found that 60% percent felt the pandemic made it harder to manage their physical and mental health, nearly one-half reported feeling emotionally drained, and 1 out of 5 worked fewer hours.[19] Many reported taking unpaid time off due to testing positive, being ill, or caring for loved ones. Forty-three percent of workers said the pandemic made it harder to pay for food, housing, and other basic needs.

Using the US Current Population Survey, a recent national study found that home care was one of the hardest hit industries during COVID-19 with respect to unemployment.[22] At the agency level, this was seen in Massachusetts; leaders reported that demand for services declined rapidly, reflecting patient and family member concerns about infection and/or HHCWs being unavailable to work.[11] Two national surveys conducted in March and April 2020 separately found patient census declined at over 60% of agencies, with one finding rural agencies were less affected than urban agencies.[23] In addition, agencies reported staffing shortages because of fear of infection, illness, quarantine, family responsibilities and confusion about federal and state stay-at-home orders, which made staffing cases challenging.[17] More recent data suggest that demand for home care services have since increased, with the National Association of Home Care and Hospice reporting a 125% increase in demand for HHCWs in 2021. However, formal research studies are lacking.

COVID-19 Exacerbated Longstanding Home Care Industry Challenges

The challenges faced by HHCWs, home care agencies, and the home care industry in general highlight longstanding problems in the way that home care services in the US are perceived, structured, and delivered.

Overlooked and Undervalued

The personal care that HHCWs provide has historically been undervalued and considered separately from medical care.[24] This stems from several, interrelated issues: This work is largely invisible, performed in private homes; it is often viewed as companionship rather than health care[25,26]; and it is disproportionately performed by minority and immigrant women.[9] These issues are reflected in racist and discriminatory labor policies that until recently excluded HHCWs from basic labor protections and occupational safety rules[27] and inadequate payment models that reimburse HHCW services at low

rates or exclude them altogether. Medicare, for instance, only covers personal care when it supports skilled nursing or therapy services. During COVID-19, these perceptions contributed to the exclusion of home care agencies from large health care coalitions. By not having a seat at the table, agencies and workers lacked clarity around which COVID-19 emergency guidelines and regulations applied to home care and were excluded from or lacked knowledge of resources available to health care providers.[23,28] Delays and inconsistency in designating HHCWs as "essential workers" delayed their access to PPE, COVID-19 testing, and vaccinations.[29,30]

Fragmented and Decentralized

Home care agencies are frequently small, inadequately reimbursed through public funds, and reliant on a part-time workforce with a high turnover rate driven by low wages and a physically and emotionally demanding workload.[24] These challenges are exacerbated in rural areas, which often have limited providers, inadequate transportation options, heightened difficulty recruiting and retaining workers, and a heavier reliance on informal caregiving supports.[31–33]

Although home care agencies are required to have emergency preparedness protocols in place, many do not implement them in practice and struggle to develop procedures on an ad-hoc basis when an emergency does occur.[34] Prior to COVID-19, agencies frequently reported limited emergency response capacity, particularly rural agencies and those with less established relationships with local emergency response partners and health care providers.[35–37] Although some agencies provide services through contracts with local health and human service departments, health systems and managed long-term care plans, these partnerships rarely included systematic sharing of resources, information or support during COVID-19. In one panel on pandemic preparedness, agency leaders called for the need for better communication and support from health plans, as well as infrastructure to connect agencies to each other and state and local entities organizing supplies and testing.[28] Without these networks, many agencies were unable to access PPE, infection prevention guidance, and training resources. Workers had limited access to benefits and protections commonplace in large hospitals and health care systems such as paid sick leave and workplace safety standards. The lack of a centralized infrastructure and de-prioritizing of home care has also made it difficult for agencies to support worker vaccination, which is now mandated for many HHCWs. In addition, COVID-19-related costs such as PPE, infection prevention supplies and paid time off for workers alongside the decline in patient services combined with inadequate public funding threatens the viability of home care agencies.[17]

Absence of Technologic Infrastructure

Unlike institutional settings, individual home care agencies have to finance and implement their own technology, preventing them from connecting with each other and their patient health care systems. In pre-COVID times, this created challenges coordinating patient data to efficiently staff cases. Even those agencies contracted by managed long-term care plans and local health systems often do not have interoperable systems, and have difficulty sharing patient information.[38] Some agencies have utilized regional health information exchanges to identify patients who need to resume service or update care plans following a hospital or emergency department visit; however, these systems require patient consent, may not include all health care providers, and need dedicated staff to monitor and pull patient information.[39] During COVID-19, these issues were magnified. Forthcoming work by [blinded] found agencies were both expected to disseminate information on the pandemic in real time and quickly implement methods for screening HHCWs for COVID-19 symptoms and tracking staff but lacked the infrastructure to do so.

Early studies also demonstrated that the pandemic altered how HHCWs interact with technology on a daily basis. For example, prior to COVID-19, many HHCWs used telephonic punch codes to report patient symptoms or log working hours. Now, HHCWs frequently track their and their patient COVID-19 symptoms via a Smartphone or agency-sponsored app, and help patients access telehealth visits. In addition, annual training is now offered virtually. These advances often require aides to use their personal mobile devices and data plans,[40] and the effectiveness of new virtual trainings have yet to be systematically evaluated.

Lack of Workforce Data

Due to industry fragmentation, wide variation in payers and funding, and the substantial gray market, data on the home care workforce is sparse, localized, and disconnected from patient data,[41] making it difficult to understand the impact of COVID-19 on worker retention, turnover, and the quality of home care services. Although it is unclear how many HHCWs have permanently left the workforce, home care agencies and patients increasingly report urgent worker shortages, particularly in rural areas.[42] A lack of workforce surveillance data also makes it difficult to assess important geographic trends in the prevalence of COVID-19 or the percentage of vaccinated workers. Comprehensive information on the workforce, their attitudes, and worker and patient outcomes are critical to designing and enforcing worker safety standards and protections in the future.

Supporting Disaster Preparedness for HHCWs and Agencies: Implications for Policy and Practice

Providers across the long-term care sector felt undervalued and marginalized during the COVID-19 pandemic, and struggled to access the resources and information they needed to maintain services and keep their staff and clients safe.[43–45] However, home health care faced unique challenges in delivering one-on-one care in private homes while being largely disconnected from the broader health care and long-term care system and emergency resource networks. Improving the preparedness of the home care industry and its workforce to maintain care during the evolving COVID-19 pandemic and future emergencies calls for targeted, permanent, and inclusive changes that (1) recognize the home care industry and HHCWs as part of the larger health and long-term care system, (2) explicitly include HHCWs and agencies in emergency planning and resource allocation, and (3) strengthen worker protections while improving agency capacity to provide these protections. In Table 1, we summarize some of the pre-existing and COVID-related challenges described in this article at the HHCW, home care agency and home care industry levels and present key policy recommendations to address them. We also identify actors with the power to make these changes (eg, home care agencies, unions, professional associations, state and federal regulatory bodies.)

Some challenges we describe have been partially addressed through COVID-19 relief legislation. For example, the Coronavirus Aid, Relief, and Economic Security Act provided funding to health care organizations to offset some financial burdens of the pandemic, including PPE costs and lost revenue. The American Rescue Plan increased federal matching funds to states for home and community-based services, which may be used to support COVID-19 related costs and worker recruitment, retention and support.[46,47] Some states also implemented emergency Medicaid waivers that increased payment rates and provided emergency sick leave to workers.[46] However, these funding sources are temporary and it is unclear whether and how home care agencies and HHCWs benefit. A recent study by the research and advocacy organization PHI found 26 states did not

Table 1
Recommendations for Improving Disaster Preparedness among Home Health Care Workers and Home Care Agencies

Challenges	Recommendations	Actors
HHCWs		
Inadequate PPE and protective supplies	• Include HHCWs in federal occupational health and safety standards • Create local government advisory boards to advise policymakers on worker safety and labor protections	Federal Occupational Safety and Health Administration; local/regional government agencies
Essential health care worker status is not uniform and varies across states	• Early inclusion of HHCWSs as essential workers • Designate HHCWs as medical workers in federal guidance	Department of Health and Human Services, Department of Labor, Centers for Medicare and Medicaid Services
Limited paid health and leave benefits	• Provide temporary increases in payment rates to home care agencies • Expand safety net for workers at high risk of infection including adequate pay, paid sick leave, childcare, and workplace safety standards.	Local, state, federal Departments of Labor; unions
Heavy reliance on public transportation	• Provide funding to temporarily support private transportation	Congress, Centers for Medicare and Medicaid Services, home care agencies
Limited avenues for technical support, information and assistance	• Increase bidirectional communication between agencies and HHCWs • Foster interworker support groups and communication • Create local public health councils to educate workers and employers about worker safety standards and rights • Provide communication tools (phones, tablets, data plans) to HHCWs	Home care agencies, unions, professional associations, local Departments of Health
Limited access to physical and mental health resources and services	• Include frontline workers in burnout prevention and emergency preparedness training • Co-design benefits and supports with HHCWs • Train supervisors to better support aides and/or supplement their efforts with dedicated support staff • Provide guaranteed hours and/or pay to stabilize wages during emergencies • Allow for flexible scheduling to accommodate family responsibilities	Home care agencies, unions, professional associations local, state and federal Departments of Health and Emergency Management
Home Care Agencies		
Lack of access to and resources to pay for PPE, testing and vaccinations	• Provide funding, supplies and technical assistance to manage pandemic related costs and logistics	Local, state and federal Departments of Health, Centers for Medicare and Medicaid Services
Lack of technological infrastructure	• Provide funding and technical assistance to develop interoperable patient record systems manage workforce scheduling and surveillance	Local, state and federal Departments of Health and Emergency Management, Centers for Medicare and Medicaid Services, US Department of Health and Human Services' Telehealth Resource Center
Financial pressures due to lower patient volume, fluctuations in staffing and pandemic-related costs	• Include home care agencies in provider relief funding • Provide guidance and technical assistance on accessing emergency relief funds	State and local Departments of Health and Emergency Management, Centers for Medicare and Medicaid Services
Home Care Industry		
Exclusion of home health from broader health care emergency planning efforts	• Develop standardized infection control protocols and infection prevention guidance for home care • Actively engage home health agencies in local health care coalitions and regional resource hubs	Centers for Disease Control and Prevention, State and local Departments of Health and Emergency Management, professional home care associations
COVID-related policy measures were temporary or did not explicitly cover home care	• Permanent regulations to support home care agencies and workers	Congress, with the Centers for Medicare and Medicaid Services, DHHS, and Department of Labor
Low reimbursement rates threaten recruitment and retention of staff, agency viability and high-quality care for home care clients	• Increase funding for home care services and HHCW wages and benefits	Congress, with the Centers for Medicare and Medicaid Services

implement any hazard pay or sick leave policies, and most that did ended hazard pay after 3 months.[48] Other efforts aimed specifically at supporting frontline workers have had limited impact on HHCWs. For example, while the Families First Coronavirus Response Act and Coronavirus Aid, Relief, and Economic Security Act mandated paid leave for workers, health care employers were initially excluded. This likely disproportionately affected HHCWs, who are less likely to receive paid leave and whose employers often lacked resources to expand it. Similarly, although the Occupational Safety and Health Administration's temporary emergency standard for health care workers required employers to provide protections such as appropriate PPE, it did not provide funding to help meet these new requirements.[49]

Improving preparedness among HHCWs and employer agencies will require additional and more sustainable change. First, home care agencies and workers must be fully integrated into emergency public health planning. This should include designating HHCWs as medical workers in federal guidance, including home care agencies in broader emergency planning coalitions, and providing agencies with guidance, technical assistance, technology, and financial resources and supplies at the same level as institutional health care settings. There is a growing movement to recognize the role of home care, as evidenced in the explicit inclusion of home care in the 2017 Medicare and Medicaid revised CMS disaster preparedness guidelines.[50] However, home care's perceived role varies greatly, and has not been clearly defined at the local, regional, state, or federal level.[51] Consolidation in the home care market, driven by for-profit players like franchise operators and private equity firms could potentially centralize emergency resources. But given concerns over the impact of private equity ownership on quality and employment standards in nursing homes and hospice,[52–56] consolidation is not an easy answer. One study found that private-equity owned nursing homes were less likely to

have PPE during the COVID pandemic than other facilities.[57] Instead, strengthening natural avenues for individual agencies to share and receive information and resources (for instance, through professional associations, regional coalitions, resource hubs, and state and local health departments) may be a more effective way to support these diverse providers.

Second, HHCWs need additional protections and benefits to care for patients without risking their physical, mental or financial health. This includes PPE, supplies, safe transportation, and safety nets like paid sick leave and mental health support. Although these benefits would ideally be guaranteed at the federal level, some cities have put local regulations in place. For instance, New York City's Paid Sick Leave benefit was designed specifically to cover precarious and part-time workers, including HHCWs. Certain efforts may also need to be geographically tailored to address specific needs and inequitable access to resources; for instance, providing safe, low-cost transportation in rural areas or targeting supports to workers and agencies serving disadvantaged areas or higher proportions of racially minoritized clients.[58–60] Policies should also aim to reduce rather than exacerbate the precarity of this workforce, for instance, by implementing broad-based, universal worker protections like unemployment insurance that are available to undocumented immigrant workers, including HHCWs.[12] Finally, we recognize an urgent need for accurate, up-to-date guidance on HHCW protections during emergencies and recommend exploring new, worker-engaged models for community-based education around emergency occupational health and safety guidance. One promising opportunity is the creation of public health councils such as those developed by the Los Angeles Department of Health.[61] These worker-led groups in industries at high risk for COVID-19 educate coworkers about public health orders and ensure employers are meeting them. Including HHCWs in these groups would go a long way to ensure safety and improve information dissemination. Another worker-led initiative in Harris County, Texas established an Essential Workers Board, including home health care workers, to advise county officials and give frontline workers a more formal role in determining workplace health and safety policies in their region.[62]

The COVID-19 pandemic has magnified existing challenges for home care employers and workers and accelerated the transition of health care into the home. Lessons learned during the pandemic can be leveraged to better integrate home care into the broader health care sector, protecting workers and the patients for whom they care. Recognizing home care's unique contribution to supporting older and disabled adults while supporting this vital workforce can ensure the safe, effective, and equitable provision of urgently needed long-term care in the community during emergencies and beyond.

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