

Article

Always Essential: Valuing Direct Care Workers in Long-Term Care

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In the United States and worldwide, the coronavirus disease 2019 (COVID-19) pandemic has disproportionately impacted the long-term services and supports (LTSS) sector, which serves those individuals who are most at risk of morbidity and mortality from the disease. Although devastating, the crisis also, importantly, heightened the visibility of the direct care workforce—thanks to increased attention on the LTSS sector and extensive news coverage of the responsibilities and risks shouldered by these workers (Almendrala, 2020; Lyons, 2020; Quinton, 2020; Woods, 2020)—and catalyzed action to improve direct care job quality. This new momentum to improve direct care jobs builds on decades of efforts to reinvent the financing mechanisms, laws and policies, and regulatory processes that have historically marginalized this workforce. However, with the largest payer for LTSS in the United States being Medicaid, a means-tested public assistance program, past efforts to improve LTSS and elevate direct care jobs have tended to achieve incremental progress at best, and more often have ended in political gridlock or inertia (Lepore, 2019). Drawing on empirical data and historical and theoretical analyses of direct care work in the United States, this article examines how efforts to improve direct care jobs have historically been stymied by the incongruence between the moral value and material value attributed to this work (Lepore, 2008). We argue that this incongruity of values has not been sufficiently emphasized in past LTSS reform efforts, and recommend an approach for aligning these values in the post-COVID-19 era.

Direct Care is Essential Work

As the bulwark of paid long-term care services, direct care workers provide critical supports for older adults and people with disabilities across diverse settings. The U.S. direct care workforce comprises nearly 4.6 million workers, including almost 2.4 million home care workers (supporting individuals in their own homes and communities); approximately 735,000 residential care aides (working in congregate settings, such as assisted living); 566,000 nursing assistants working in skilled nursing homes; and nearly 900,000 workers in other settings (including hospitals; PHI, 2020).

In broad strokes, direct care workers assist individuals with activities of daily living and help them maintain their health, functional abilities, and quality of life to the extent possible (Hewko et al., 2015). Their work requires a mix of technical caregiving skills; health-related knowledge; infection prevention and control expertise; emotional intelligence and relational skills; and problem-solving and decision-making abilities, among other competencies. Nonetheless, despite these required competencies and their centrality to the health-care and LTSS system, direct care workers tend to be characterized as "unskilled" or "low-skilled" workers, along with entry-level workers in other sectors; this characterization is informed by and justifies their low pay, minimal training, and overall lack of recognition (Drake, 2020), as described further below.

During the COVID-19 pandemic, direct care workers—so often overlooked—were explicitly identified as "essential" for the first time. The needs of the direct care

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workforce were incorporated (albeit slowly) into emergency responses (for example, through the deployment of "strike teams" to fill staffing shortages; Comas-Herrera, 2020); some U.S. states, such as Arkansas (Arkansas Governor's Office, 2020) implemented hazard pay for direct care workers (as did other countries; Comas-Herrera et al., 2020); changes were made in regulation and practice to facilitate entry into direct care jobs (Scales & Grant, 2020); direct care workers were included in public-recognition campaigns (Thompson & Salerno, 2020); and more.

This attention on direct care is critically needed as demand for these workers escalates due to the aging of our population, which is exacerbating long-standing workforce and recruitment concerns (e.g., Stone & Weiner, 2001), particularly in home- and community-based settings, where the balance of LTSS is now provided. It is important to recognize, however, that demand for direct care is also evolving, as individuals live longer with complex health conditions (Scales, 2020). As one example, more than 50 million people worldwide are currently living with dementia, and this number is expected to increase to 152 million by 2050 (Alzheimer's Disease International, 2019). As it is estimated that threequarters of individuals living with dementia require personal assistance (Kasper et al., 2014), demand for direct care workers to provide this assistance is growing in absolute terms, but so too is the need for a direct care workforce that is capable of meeting the diverse needs of this population. Accordingly, direct care workers must be knowledgeable about cognitive impairment, skilled in managing care to avoid or address behavioral and psychological symptoms, prepared to recognize and report changes in health status that may require clinical intervention, adept at communicating with individuals with cognitive impairment and their unpaid caregivers and interdisciplinary care teams, and more, in addition to having the core competencies mentioned above.

Though Morally Valued, Direct Care is Devalued by the Market

Despite the heterogeneity of direct care job titles and roles, and the recent designation of these workers as essential, direct care workers share a common experience across settings and jurisdictions: a lack of formal recognition of their contributions. This structural devaluation is reflected in minimal training and advancement opportunities for direct care workers, strikingly low compensation, limited support and supervision on the job, and little professional or public esteem for direct care.

Direct care workers' devaluation is the product of historical processes—including the transition of caregiving from the unpaid (or very low-paid) domestic sphere to the marketplace (Held, 2002), and the division of labor by gender and race (Gurtler, 2005)—and perpetuated by

systemic underinvestment in the long-term care that these workers provide. This underinvestment in LTSS is premised on the neoliberal view that caregiving is a family responsibility rather than a societal one (Eckenwiler, 2011), and enabled by the implicit and explicit sexism and racism that inform the American labor market and class structure more broadly (Altonji & Blank, 1999; Rogers-Vaughn, 2016).

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As a result of these historical processes and the resulting political and societal reluctance to reform LTSS financing (Lepore, 2019), the direct care workforce struggles for recognition and compensation even as demand for their services grows rapidly. For this workforce of predominantly women (87%), people of color (59%), and immigrants (26%), wages remain persistently low (with median wages hovering around \$12 to \$13 per hour over the past decade); nearly half the workforce lives at or near the poverty level (45%); about 15% lack health insurance, while more than a third rely on Medicaid or other public coverage; and opportunities to advance professionally or economically are almost non-existent (PHI, 2020).

This devaluation of direct care jobs conflicts, however, with the higher moral value that direct care carries in contemporary American culture. Caregiving tends to be framed as a natural act of love (or duty), rather than skilled work deserving compensation; indeed, direct care workers themselves often report being intrinsically motivated by the desire to help others, give back, or fulfill a calling (Lepore, 2008; Scales, 2019a). The inconsistency between moral and market values was acutely evident during the COVID-19 pandemic, when direct care workers were often hailed as "heroes" but rarely protected or compensated accordingly (Reilly, 2020).

Although the direct care workforce in LTSS has been buttressed by a culture that assigns moral value to altruism and helping others, these values are insufficient to drive recruitment and retention or job quality improvements. Instead, systematic policy reform is needed to bring about meaningful, sustainable change in LTSS and the direct care jobs at its core. As argued nearly 20 years ago and still true today: "fundamental structural changes in social institutions and values are needed to accord greater societal recognition to the work of caring" (Hooyman et al., 2002, p. 12).

Aligning the Moral and Material Value of Direct Care

Changing our structures, institutions, policies, and culture to align with the moral value and economic value of direct care—as needed to resolve the enduring workforce crisis and ensure sustainable, high-quality LTSS in the years ahead—will require unprecedented levels of local, state, and national leadership, commitment, and collaboration. Here, drawing on lessons learned during the pandemic, we elaborate on what must be done to elevate this essential work and workforce.

As already suggested, the devastating impact of COVID-19 on the long-term care sector was neither surprising nor inevitable: rather, it was the underfunded, uncoordinated, and overlooked nature of the sector that mitigated against a timely response and contributed to the staggering infection and death rates among LTSS consumers and workers (Khimm & Strickler, 2020). With this glaring evidence, we face a window of opportunity to overcome longstanding political and societal barriers and truly overhaul LTSS financing and regulation: to create a coherent and sustainable system that can both withstand short-term shocks like COVID-19 and meet population needs over time. In the United States, efforts to achieve this type of transformation can build on momentum generated at the state level (Washington, for example, recently enacted the country's first social LTSS insurance program; Covert, 2019) and through the presidential campaign (which saw LTSS included in many candidates' policy platforms for the first time). Going forward, the challenge will be to ensure that budget concerns—which will be formidable in the aftermath of the pandemic, particularly at the state level, where most LTSS decisions are made—are not invoked as an absolute barrier to achieving the LTSS financing and delivery improvements that have become so clearly and immediately necessary. Budgetary decisions must advance a lasting alignment between the moral and material value of direct care, not only address the immediate economic impact of the pandemic.

Direct care job quality must be central to these efforts. Without a stable and sufficient workforce to deliver services, no other systemic improvements to LTSS will be feasible. First and foremost, it is critical to ensure that direct care jobs offer a living wage and a pathway to economic self-sufficiency; otherwise, employers will continue to struggle with high rates of turnover, losing workers to other sectors that provide more competitive wages, better benefits, more stable schedules, less arduous (or dangerous) work, or other advantages (Scales, 2020). It became clear during the pandemic that essential workers who devote themselves to supporting the health and well-being of others—thanks to both altruistic motivations and financial necessity—should be recognized for the risks and sacrifices entailed. Corresponding efforts to temporarily increase their compensation—for example, through short-term hazard pay or "appreciation pay"-should be succeeded by long-term, widespread improvements to the pay scale

for this workforce, whether through Medicaid or more broadly through minimum wage increases (Lepore et al., 2020) or other policy levers.

Employer-sponsored benefits—such as health insurance, retirement plans, paid leave, and more—are another important component of compensation that help improve direct care jobs and reduce turnover (Kemper et al., 2008; Morris, 2009; Stearns & D'Arcy, 2008). Policy interventions to improve compensation could follow the example of New York's Home Care Worker Parity Law (2020), which mandates that home care workers in the New York City region receive a base wage plus an additional amount that can be paid in either wages, benefits, or a combination of both. As long as reimbursement rates cover such mandates, employers can make choices about how to structure their compensation packages to boost recruitment and incentivize worker retention.

Going beyond incremental improvements in wages and benefits, however, it is time to systematically recognize and maximize the complex skill set that direct care workers already bring to the job, and the material value as well as moral value of their contribution to care delivery and outcomes. In the context of the pandemic, for example, direct care workers played an essential role in reducing the burden on hospitals by caring for COVID-19-positive individuals in place or post-discharge. In general, as the often-quoted "eyes and ears" of the interdisciplinary care team (Stone & Bryant, 2019), direct care workers also help reduce avoidable hospitalizations—a common performance measure—and other adverse health outcomes by observing, recording, and reporting changes of condition that may require clinical attention (and in many cases, by directly performing or assisting with tasks that are necessary to manage individuals' health outside the hospital). With policymakers, payers, and health systems increasingly focused on improving service quality while reducing costs, it is becoming both feasible and necessary to quantify direct care workers' impact on hospitalization rates and other outcomes, and thereby to generate the political will to improve their jobs and elevate their role.

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There are a number of policy strategies that can be implemented to elevate the role of direct care workers, including creating a stackable and portable credentialing system to facilitate both lateral and vertical career mobility; upskilling

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the entire workforce through higher entry-level and ongoing training standards, to maximize their contribution to care quality and outcomes; developing advanced roles for more experienced workers; and providing additional support and compensation to reflect direct care workers' enhanced responsibilities (Drake, 2020). Through their funding and purchasing policies, policymakers and payers (including individual consumers) can also directly support high-road employers who are already pursuing such strategies—for example, employers that are committed to providing quality training and career advancement opportunities—and incentivize others to follow the same example.

There is also a particular opportunity to examine and extend direct care workers' use of technology to improve care quality and efficiency, and thereby to justify better investment in their training and compensation (Scales, 2019b). For example, pilot studies have shown that new technology-supported communication pathways can improve the exchange of information between home care workers and their clinical supervisors, facilitating timely responses and reducing the risk of more costly interventions (Scales, 2019a).

With the COVID-19 pandemic having challenged our complacency about long-term care in the United States, we may have reached a historic turning point for the sector and its workforce. Translating this moment of awareness and opportunity into action will require strong leadership and coordination among federal, state, and local agencies and actors to directly address the workforce issues raised here, as well as pursue complementary policy reforms, particularly addressing immigration policies that severely limit the workforce supply (LeadingAge, 2019). To ensure older adults and people with disabilities receive the services they need, where and when they need them, it is time to overturn the status quo and craft politically viable strategies to elevate the material status of this irrefutably moral work.

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