

This report is the second in a year-long series that provides a comprehensive, current-day analysis of the direct care workforce and its critical role in the long-term care system in the United States. Caring for the Future: The Power and Potential of America's Direct Care Workforce—which will be released throughout 2020 in four parts, and in its entirety in early 2021—includes a detailed profile of these workers; a segmented look at the long-term care industry; a discussion on the evolving role of the direct care worker; a proposed framework for creating quality jobs in direct care; and a look forward at where this workforce and industry are heading. The report also offers concrete recommendations for policy and practice, and features stories of direct care workers from around the country, sharing their wisdom and ideas. In releasing this report, our goal is to strengthen the national dialogue on the direct care workforce, including what needs to change in policy and in practice.



PHI would like to thank the **W.K. Kellogg Foundation** and the **Woodcock Foundation** for their generous support of this report.



Table of Contents

- 2 Executive Summary
- 3 Terminology
- 4 Introduction
- 7 Shortfalls in Long-Term Care Financing
- 12 The Shifting Long-Term Care Landscape
- 17 Who Shapes Direct Care Job Quality?
- 20 Conclusion and Implications
- 22 Notes
- 24 Appendix 1: Data Sources and Methods
- 25 Appendix 2: Long-Term Care Industries by the Numbers

Executive Summary

PHI's 'Caring for the Future' Timeline

Part 1 - January 2020

Part 2 - Spring 2020

Part 3 - Summer 2020

Part 4 - Fall 2020

Full report with policy and practice recommendations - January 2021

Why does the occupation with the most projected job growth in the country have such poor job quality? Part of the answer is that our system is set up for failure. Our long-term services and supports (LTSS) system does not adequately or equitably meet consumers' needs, nor does it sufficiently invest in direct care workers' job quality. Also, even as the long-term care system grows rapidly, workforce development is often insufficiently addressed in the policies that shape this system.

The good news is: we can do better.

This report is the second in a year-long series—culminating in a comprehensive final report in January 2021—that examines the importance and impact of the direct care workforce. Each report in the series provides original data, indepth analyses, and policy and practice recommendations, as well as featuring individual direct care workers from around the country. The final report will compile all four individual reports, synthesize the key issues, articulate future challenges and opportunities, and provide a full set of policy and practice recommendations.

This report, We Can Do Better: How Our Broken Long-Term Care System Undermines Care, begins by describing the many distinct ways that long-term care financing currently falls short. The U.S. approach to long-term care financing requires consumers to spend all their savings and assets paying for care out-of-pocket before they become eligible for Medicaid, the largest payer of LTSS. In theory, Medicaid serves as a safety net for those who qualify, but in practice, its services are limited by eligibility requirements, inadequate funding, and workforce shortages.

This report also explores how the longterm care industry, as it is currently structured, fails to ensure quality jobs for direct care workers. A key lesson from this section is that the home care industry, where demand is growing most quickly, is increasingly fragmented and weakly managed by states, which has significant implications for direct care workforce development.

Finally, the report identifies the various types of stakeholders who play a role in shaping job quality for direct care workers. Some influence the workforce at a high level—through laws and regulations—while others impact job quality through their direct interactions with workers. We describe the unique contributions that stakeholders at all levels can make toward realizing better jobs for direct care workers.

This second installment in the Caring for the Future: The Power and Potential of America's Direct Care Workforce series concludes with two strategies for transforming the long-term care industry-and direct care jobs. First, the LTSS financing system should be reformed so that its consumers are protected from poverty when accessing care, and its workforce is strengthened and sustained. Second, we need to rethink how the long-term care sector is organized and regulated, with a focus on aligning workforce-related policies and identifying new opportunities to raise workforce standards. These changescombined with the investments spelled out in other reports in this series—will unlock our ability to meaningfully and universally address direct care job quality.

AUTHORS' NOTE

Since we completed this report, the emergence of COVID-19 has tragically underscored and transformed how we think about direct care workers and the long-term care system. We will be integrating our lessons learned from COVID-19 into future reports in the Caring for the Future report series, as we gain greater insight about the immediate and lasting effects of the pandemic.

2 It's Time to Care

Terminology

ACTIVITIES OF DAILY LIVING (ADLS)

Essential activities performed every day, including bathing, dressing, eating, toilet care, and transferring/mobility.

CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)

A federal agency within the U.S. Department of Health and Human Services that administers Medicare and partners with state governments to administer Medicaid, among other responsibilities.

CONSUMER

An individual who receives paid LTSS due to physical, cognitive, developmental, and/or behavioral conditions. Also referred to as a client.

CONSUMER-DIRECTED SERVICES

Publicly funded service delivery model that enables consumers to manage their own LTSS, including by hiring, scheduling, supervising, and dismissing known as participant-directed or self-directed services.

DIRECT CARE WORKER

Assists older adults and people with disabilities with daily tasks and activities across LTSS settings (and in hospitals and other settings, though these other settings report). Direct care workers are formally classified as personal care aides, home health aides, and nursing assistants, but their specific job titles vary according to where they work and the populations they serve.

FEE-FOR-SERVICE

A payment system where providers receive payments directly from public payers based on the amount of service that they provide.

AND SUPPORTS (LTSS)
A range of health and social services provided to individuals who require assistance with ADLs and IADLs. Also described as long-term care.

INSTRUMENTAL ACTIVITIES

Tasks associated with living

preparing meals, shopping, housekeeping, managing

medications, and attending

OF DAILY LIVING (IADLS)

independently, such as

LONG-TERM SERVICES

MANAGED LONG-TERM **SERVICES AND SUPPORTS**

An alternative Medicaid payment model whereby private health insurance plans manage care services using monthly, per-capita payments from states.

MATCHING SERVICE

REGISTRIESOnline job boards that
1) enable consumers to preferences and potential workers' availability and 2) help home care workers sustainable work schedules.



Introduction



of all revenue for longterm services and supports is provided by Medicaid In the previous report in this series (It's Time to Care: A Detailed Profile of America's Direct Care Workforce), we discussed a paradox in the long-term care field: direct care workers are in extremely high demand, but their job quality is poor. They are often overlooked, underutilized, and poorly compensated—and as a result, the field struggles to meet the growing need for their services. We suggested that this status quo could be disrupted through significant and immediate investments in two areas (among others): improving compensation and building career pipelines into direct care jobs.

But where do we start? A bewildering array of systemic barriers stand in the way of transforming job quality for direct care workers. First, long-term services and supports (LTSS) are expensive—typically ranging from \$50,000 to \$90,000 per year¹—but consumers have limited options to cover these costs. Because many consumers impoverish themselves paying for long-term care, Medicaid has become the primary payer for these services—accounting for 52 percent of all LTSS revenue²—but Medicaid programs are often underfunded and fragmented by various regulations and eligibility requirements.

"Fragmented" also aptly describes the expanding and evolving landscape of long-term care industries. Most notably, from 2007 to 2017, the home care industry added over 22,000 new establishments to meet rising demand.³ Compared to nursing homes, home care establishments employ fewer workers, are less likely to be part of chains, and are rarely licensed by states.⁴ This decentralization makes it very difficult to effect widespread improvements in job quality.

Given these systemic challenges, successful direct care workforce development efforts will require concerted effort by a range of stakeholders in the field. For example, at the highest level, state and federal governments can take steps to improve job quality through legislation and regulations. Individual consumers and businesses (whether small and local or large and national) that directly employ direct care workers can also play a role in empowering and supporting workers.

In this report, we examine the structural drivers of direct care job quality from three vantage points: financing, the business landscape, and the key actors that shape long-term care. By providing this macro-level analysis of our industry, we provide critical context for the subsequent reports in this series, which will address job quality factors on the ground.



Venecia Bradley

CARE PARTNER AT VILLAS OF KILLEARN LAKES (THE VILLAS) IN TALLAHASSEE, FL 6 YEARS AS A DIRECT CARE WORKER

ON WHY SHE DECIDED TO BECOME A RESIDENTIAL CARE AIDE:

"I do this work because of the love that I have for the Elders (residents of the Villas). My mom, who always taught me to respect my elders, actually got me started working in this field. She has done this work for years, and sometimes I would go with her to help out with her clients, and I just grew to love it. So I can't stop doing it. I won't stop doing it. I want to go further in this career because I have a lot of love for my Elders."

ON WHAT SHE FINDS MOST CHALLENGING IN HER ROLE:

"I enjoy my job, but some days the work can be very difficult. For example, bathing Elders is a challenge. Some Elders, the first thing they will do is tense up or even attack you. It can be hard, but you just have to know how to redirect them and help them understand that they are okay. You also need to be confident, because the Elders read off of you and if you're not okay, then they're not going to be okay either. Before I felt comfortable giving a bath or shower by myself, I would ask someone to assist me because the most important thing is to make sure there are no falls and that everyone stays safe."

ON WHAT SHE ENJOYS MOST ABOUT HER JOB:

"Caregiving in general is a lovely thing. Caring for somebody feels amazing, and helping people really is the best way of giving back. I actually love showing up to work just to interact with my Elders and talk about the simple things: hearing about their lives, their likes and dislikes, and what their favorite colors are. We have freedom to engage with them, and every day is something new here.

At the Villas, we don't have supervisors; we have coaches. Coaches are there for us if we need any assistance or help with certain Elders. They listen and encourage us and give support. Even our head boss, he shows a lot of respect for us. Our opinions matter. I had literally never worked at a job before where our bosses are so understanding or take how we feel into consideration. Some days we might have mishaps,

but overall everyone

gets along. We are a

family at the Villas."

A residential care aide who found her calling caring for older adults, Venecia's favorite part of working in a "small house" and neighborhood setting is forming bonds with residents and giving them the freedom to make choices about their days.*





Farah Germain

HOME HEALTH AIDE AT JASA IN BROOKLYN, NY 15 YEARS AS A DIRECT CARE WORKER

ON WHY SHE DECIDED TO BECOME A HOME HEALTH AIDE:

"I grew up taking care of sick family members. First my aunt, who was very sick when I came to this country from Haiti. Then it was my grandmother, and then my dad. I really like taking care of people.

When I first finished up school, I got a job in a clothing store, but it wasn't me. So I took a class to become a home health aide and started doing this work in 2005, and right away I loved it. But then, about five years ago, I decided to go to school for hotel management and was working as a housekeeping manager at a hotel. The job was good and the pay was okay, but I didn't like it. It just didn't feel like me. Everybody said I was crazy to throw away a job that paid twenty-something dollars an hour and make half as much money going back to home care. I told them, 'Yeah, I know, but they say don't do a job because of the money, do it because you love it.' You really have to have the heart for this job to stay in it."

ON WHAT SHE FINDS MOST CHALLENGING IN HER ROLE:

"I'm a single parent working six days a week, and I don't spend enough time with my kid. As home health aides, we work too hard, we're dealing with too much stress with the client, and we also have to deal with family members, and we're not getting paid for how hard we work. That's the problem. You have to pay your bills. You have to take care of your family. And if you are working hard six to seven days a week and you still can't cover your bills, then why are you working?"

ON HER RELATIONSHIP WITH HER CLIENTS:

"Some clients will make you hate this job, but others will make you love it because they appreciate you helping them. I've never had a problem with clients. I'm with been with him for almost three years now. I'm a very caring and patient person, but it is especially easy with him. If you don't know him well you might not expect that, because he doesn't always get along with what he doesn't like. He likes to get his food at a certain time, and to make sure everything is on time. He doesn't like to ringing. He doesn't like for a lot of people to talk to him, but me and him, we have conversations all the time. We watch TV together and talk about it, and he tells me about his childhood when he was a kid. He tells me everything."

With the natural inclination to care for and connect with others, Farah remains committed to supporting older adults as a home health aide, a job she loves despite the long hours and limited wages that can put a strain on her family.



Shortfalls in Long-Term Care Financing

The long-term services and supports (LTSS) financing system in the United States is overcomplicated and inadequate. Median annual costs for LTSS range from about \$50,000 for home care services and residential care to over \$90,000 dollars for nursing home care⁵—yet the average household only has around \$9,000 in savings,6 and more than half of Americans aged 18 to 64 have nothing saved for retirement.⁷ Further, only 11 percent of adults aged 65 and older hold private long-term care insurance policies (according to 2014 data), which carry high premiums and often limit or deny coverage for those with preexisting conditions.8 Due to high costs, limited savings, and few private insurance options, the path to poverty is short for many LTSS consumers.

Thus, the bulk of LTSS financing falls on Medicaid-a state and federal social assistance program for people who live in poverty. In 2015, the most recent year of data available, Medicaid payments constituted 52 percent of all long-term care spending.⁹ No other payer came close: out-of-pocket payments accounted for 16 percent, private insurance was just 11 percent, and the remaining 20 percent came from a variety of other public sources. This final category includes the Department of Veterans Affairs, the Older Americans Act, other non-Medicaid state programs, and Medicare Advantage plans. Traditional Medicare does not cover longterm care, although it does cover shortterm, post-acute services that are often provided in nursing homes or home and community-based settings.

Notably, the balance of Medicaid spending on LTSS varies across settings. Upwards of 80 percent of non-medical home care revenue comes from Medicaid, ¹⁰ while at the other end of the spectrum, assisted living and continuing care retirement communities receive just nine percent of their revenue from Medicaid (and 49 percent through out-of-pocket payments from consumers). ¹¹

In between these two endpoints, Medicaid payments constitute 41 percent of nursing home revenue and 18 percent of home health care revenue. These two industries balance their revenue somewhat by billing Medicare and private insurers for short-term, post-acute care services.

UNDERSTANDING MEDICAID LTSS PROGRAMS

While Medicaid is the largest payer of LTSS overall, there is considerable variation and complexity in Medicaid-funded LTSS programs across the country. In this section, we describe this complexity before drawing out the main implications for consumers and direct care workers.

While state Medicaid programs look very different (as discussed below), federal regulations require that all Medicaid programs share some common characteristics. According to the Centers for Medicare & Medicaid Services (CMS), states must cover a range of acute and post-acute care benefits for all Medicaid-eligible individuals. Covered services and eligibility requirements must be laid out in a "state plan" that CMS approves. Importantly, nursing home care is one of the services that must be included in state plans, but home care is not.

Despite this inbuilt "institutional bias" in federal Medicaid regulations—as described in the previous report in this series—states have gradually shifted the balance of Medicaid spending for LTSS to home and community-based settings in recent decades. Consumers overwhelmingly prefer to receive services at home, a preference that has been supported by decades of disability rights advocacy, court decisions, and policy changes.¹² Also, since home care is less expensive in most cases, states can save money by helping consumers delay or avoid nursing home admission.

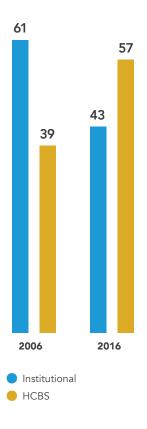
LTSS SPENDING BY PAYER, 2018



- Medicaid **52%**
- Other Public and Private 20%
- Out of Pocket 16%
- Private Insurance 11%

Source: Musumeci, MaryBeth, Priya Chidambaram, and Molly O'Malley Watts. 2019. *Medicaid Home and Community-Based Services Enrollment and Spending*. Washington, D.C.: Kaiser Family Foundation. https://www.kff.org/report-section/medicaid-home-and-community-based-services-enrollment-and-spending-issue-brief/.

MEDICAID HCBS AND INSTITUTIONAL LTSS EXPENDITURES AS A PERCENTAGE OF TOTAL MEDICAID LTSS EXPENDITURES, 2006 TO 2016 (In Percentages)



The majority of Medicaid funding for home and community-based services (HCBS) comes through 1915(c) waiver programs (which are authorized by section 1915(c) of the Social Security Act of 1935).13 In nearly every state (except Arizona, Rhode Island, and Vermont), these waiver programs serve people in the community who require an institutional level of care-meaning they meet eligibility criteria for the costlier mandatory nursing home care benefit. Even though they are the primary vehicle for funding HCBS, many 1915(c) waiver programs still have long waiting lists (because waivers allow states to cap enrollment for otherwise eligible consumers). In 2017, 707,000 people were on waiting lists for 1915(c) waiver services in 40 states, up from 332,000 in 2007.14

As well as 1915(c) waivers, states may also choose from a wide range of other program options—each with their own stipulations for consumers and the workforce. Thirty-five states offer personal care to certain consumers through amendments to their state plans—the same plans that cover mandatory acute and post-acute care services. 15 Among these 35 states, 17 have caps on services—which means that the level of services provided might not be sufficient, especially for people with more severe needs. States may also choose the 1915(i) authority under the Social Security Act to tailor state-plan personal care benefits *only* to a population with specific conditions or care needs. Finally, another option is the 1915(k) authority, which allows states to introduce a self-directed option for consumers under their state plans (a model that we discuss later in this report). Often, regulations under these programs overlap or conflict, adding to the complexity in Medicaid home and community-based servicesand complicating workforce development efforts.

PAYMENT MODELS IN MEDICAID

In addition to variation in service design and eligibility requirements, Medicaid programs vary across and within states by payment model. In the past, all states reimbursed LTSS providers through fee-for-service arrangements, whereby providers received direct payments for each hour of service for consumers. In recent years, however, states have adopted alternative payment models with the goal of making LTSS more efficient and effective.

Most notably, 24 states have shifted from a fee-for-service model to a managed long-term services and supports (MLTSS) model.¹⁶ MLTSS programs are authorized under four authorities (namely, sections 1932(a), 1915(a), 1915(b), and 1115 of the Social Security Act), each with its own goals, structure, and eligibility requirements. Under MLTSS, private insurance companies, called managed long-term care plans, receive monthly, per-capita payments that they use to coordinate services for their members. These programs are intended to financially motivate plans to meet consumers' needs and improve care outcomes at a lower cost. Proponents of MLTSS argue that these goals are not necessarily aligned in fee-for-service systems.

Another payment trend in Medicaidfunded LTSS is value-based payment, whereby payers deliver financial rewards or impose penalties based on outcomes related to cost and care quality. These arrangements are more common in acute care settings and nursing homes than in home care.17 This is partly because quality measurement in home care is underdeveloped—a 2016 study from the National Quality Forum (NQF), a nonprofit organization focused on health care improvement, uncovered 261 different quality measures for HCBS, reflecting a lack of consensus on the most important aspects of quality in this field.18

Source: Wenzlow, Audra, Steve Eiken, and Kate Sredl. 2016. Improving the Balance: The Evolution of Medicaid Expenditures for Long-Term Services and Supports (LTSS), FY 1981-2014. Washington, D.C.: Centers for Medicare and Medicaid Services (CMS). https://www.medicaid.gov/sites/default/files/2019-12/evolution-ltss-expenditures.pdf; Eiken, Steve, Kate Sredl, Brian Burwell, and Angie Amos. 2018. Medicaid Expenditures for Long-Term Services and Supports in FY 2016. Washington, D.C.: CMS. https://www.medicaid.gov/sites/default/files/2019-12/ltssexpenditures2016.pdf.

Camran Hayes

HOME CARE SPECIALIST AND PERSONAL CARE WORKER AT COMMUNITY LIVING ALLIANCE IN MADISON, WI 1.5 YEARS AS A DIRECT CARE WORKER

ON WHY HE DECIDED TO BECOME A HOME CARE WORKER:

"When I was a teenager, my first job was at a nursing home as a dietary aide. I would pass out the milk, coffee, and food. And I was always so intrigued by the CNAs (certified nursing assistants) and the nurses. People would tell me, 'You should become a caregiver. You have that type of personality.' Never would I have ever thought that I could actually do this job. But then I guess I've always loved working with people.

My family is Iranian, and Persians take care of their elders. So I had some experience helping out with my grandparents, but nothing to the extent of nurse-delegated tasks. I never had any experience with that. Originally, I planned for this to be a 10 hours-aweek gig while I went to school and then maybe even worked another parttime job. But then I just started getting more clients, and they were giving good feedback, and eventually I started working full time. And then I just kept at it. I fell in love with it. I'm constantly growing and feeling challenged. Nothing feels more natural.'

ON WHAT HE FINDS MOST CHALLENGING IN HIS ROLE:

"Many CNAs do not get paid enough. With home care, you don't have coworkers. When I first got this job, I kind of felt like I was on my own for the longest time. I felt so lost and scared. And all the time I would think, 'Oh man, did I do something wrong?' When I started working on-call, the person who trained me became a caregiver role model for me, and that's when I started feeling more supported.

There's too much work to get done and not enough people doing the work. And I know that a lot of that has to do with pay. You could probably make more money working at QuikTrip, to be honest. And then you also have to take care of people's bodies and do toilet care. You have to be a certain kind of person to be able to do that kind of work."

ON SERVING RURAL AREAS:

"Transportation can definitely be an issue for caregivers. A lot of people at Community Living Alliance use the bus route to get to their clients' homes. I have a car so I can go anywhere in the Dane County area, but a lot of people just can't travel out to the outskirts or more rural areas. As upsetting as that sounds, at the end of the day, there's a lack of resources that prevents caregivers from going to homes out there."

Providing care to older adults and people with disabilities in their homes, Camran helps his clients live independently, a job he says gives his life a deeper purpose.



State Policy Spotlight

Tennessee has a wellestablished value-based payment program in nursing homes, but recent efforts to introduce a similar approach in HCBS were stymied by severe workforce challenges. Providers could not improve workforce recruitment and retention to meet consumer satisfaction targets without some up-front assistance from the state. To address these challenges and enable home care providers to participate in value-based payment arrangements, the state has developed a new workforce training program, and has made direct grants to providers to improve data collection and strengthen recruitment and retention.

Also, many existing measures have been carried over from acute and skilled nursing care settings and miss elements of home care quality that matter most to consumers, like quality of life and community integration, as two examples. Based on its research, NQF developed recommendations for assessing quality, but some are not yet tested and the field still lacks a robust, standardized home care quality framework. In short, before payers can reward quality in home care on a widespread basis, further work is needed to effectively measure quality.

MLTSS and value-based payment arrangements come with costs and benefits. On one hand, these payment systems present new opportunities for states, plans, providers, and other key stakeholders to collaborate in efforts to improve job quality and care quality. However, as noted above, introducing private payers and intricate payment incentives into public service delivery creates new complexity in an already fractured system.

MEDICAID IS NOT THE ANSWER

Various Medicaid program options have made HCBS services widely available and, in many states, have led to the successful diversion of consumers away from nursing homes. ¹⁹ However, there are three major drawbacks to relying on Medicaid as the primary mechanism for financing LTSS overall.

First, because it is only a safety net program, Medicaid requires consumers to fall far into poverty before it catches them—and even as a safety net, it does not always offer a sufficient level of support for eligible consumers. Many Medicaideligible consumers still fall through the gaps because they are placed on a waiting list, because their needs exceed service limits, or because they do not meet the specific eligibility requirements for waiver programs.



The second, and closely related, problem is that Medicaid systematically underfunds long-term care. Wage trends in recent years illustrate this point. In the previous report in this series, we showed that wages for direct care workers have hardly changed in the past decade-from \$12.24 in 2008 to \$12.27 in 2018—leaving direct care workers facing persistent economic instability.²⁰ By comparison, over the same period employers in other industries, like fast food and retail, have raised wages to stay competitive. Even in the face of close competition for workers—and rising demand for LTSS—only about half of states committed to increasing direct care worker wages in 2019 and 2020 through Medicaid reimbursement rate changes.²¹ Also, among those states that did raise reimbursement rates, the increases tended to be marginal and some did not keep up with inflation year to year. This limited investment in workers' wages, as an indicator of inadequate financing for Medicaid-funded LTSS, has been a key contributor to direct care workforce shortages nationwide.

Why this systematic underfunding? One of the main reasons is that, as a means-tested social assistance program, Medicaid is funded through general tax revenues rather than through universal payroll contributions. Therefore, Medicaid programs must always compete with other state budget items, like transportation and education—leaving far too many consumers without enough support and hindering vital job quality improvements.

The third challenge with relying on Medicaid as the primary payer of LTSS pertains directly to workforce development. Most states offer a multitude of LTSS programs targeting certain populations with specific services, and each program is often regulated separately—including with regards to workforce requirements. As a result, workforce development efforts often necessarily focus on a specific segment of the workforce, such as direct care workers in a particular Medicaid program, without addressing the big-picture challenges that are endemic in the field.

For these reasons, efforts to improve our long-term care financing system—and direct care jobs—will likely need to extend well beyond Medicaid.

THE FUTURE OF LTSS FINANCING

In fact, policymakers have recently begun to develop proposals for radically transforming the publicly financed LTSS system in the United States, in order to overcome the challenges described above and bring our nation in line with much of the industrialized world.²²

A key step toward reform came when the federal government attempted to create a new long-term care benefit through the Community Living Assistance Services and Supports (CLASS) Plan. Passed as part of the Affordable Care Act, the program would have provided a \$50 daily benefit to people in need of long-term care. However, the program was repealed before it was implemented due to concerns around financial sustainability.²³

Despite this setback at the federal level, innovative ideas have continued percolating in individual states. As a leading example, Washington State has established a Long-Term Care Trust that, beginning in 2025 will provide a daily benefit of \$100 (up to a lifetime benefit of \$36,500) to people who require assistance with three or more activities of daily living.²⁴ Although many consumers will have lifetime expenditures that exceed this amount, this program will be the nation's first universal long-term care benefit and could mark a significant turning point in LTSS financing.

Other states might soon follow the lead of Washington State. Stakeholders in Maine put forward a ballot initiative that would have established a universal long-term care benefit, and this new system would have funded direct care workforce development.²⁵ Other states have also begun legislatively exploring long-term care social insurance program options. Michigan, for example, recently commissioned a study to explore the feasibility of a universal long-term care insurance program, including workforce considerations.26 These cases illustrate the growing recognition that our current Medicaid-centric system cannot be sustained.

Medicaid programs must always compete with other state budget items, like transportation and education—leaving far too many consumers without enough support and hindering vital job quality improvements.

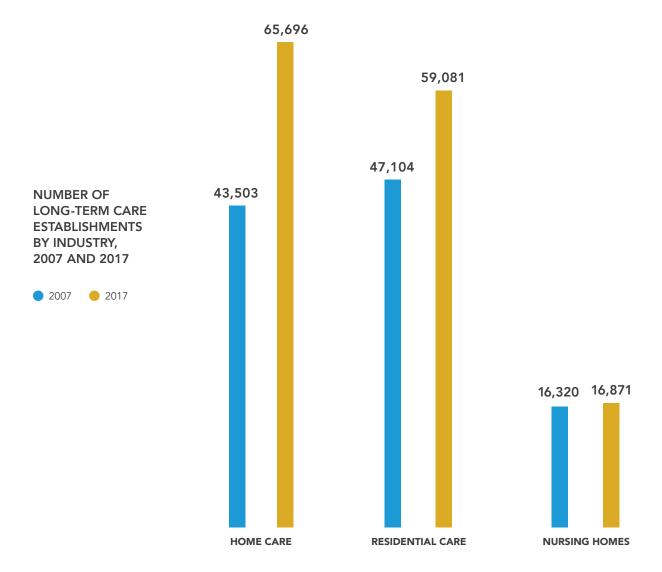
The Shifting Long-Term Care Landscape



Most new LTSS establishments (22,200, or 64 percent) have been in home care.

Notwithstanding the financing challenges discussed above, the LTSS industry continues to expand rapidly to meet growing demand for services. According to PHI's analysis of Economic Census data, long-term care added 34,700 new establishments from 2007 to 2017.²⁷ (Establishments are individual business units that may be sole proprietorships, franchise members, or branches of a corporate chain.) Most of those new

establishments (22,200, or 64 percent) were in home care. Residential care added 12,000 new establishments—including 7,600 new communities for people with intellectual and developmental disabilities and 4,700 new assisted living communities. (The residential care industry also lost 400 continuing care retirement communities.) Nursing homes added just 600 establishments.



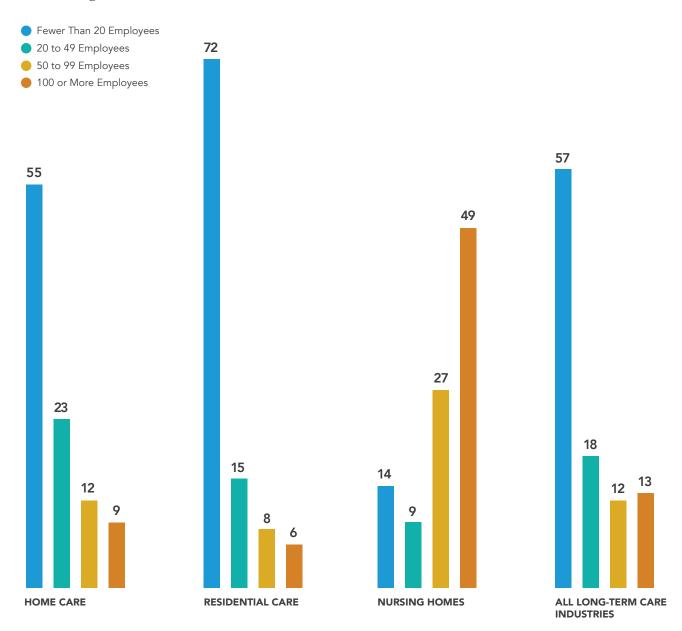
Source: U.S. Census Bureau. 2010. Health Care and Social Assistance: Geographic Area Series: Summary Statistics: 2007. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2007_US/62A1/0100000US; Economic Census of the United States U.S. Census Bureau. 2020. Health Care and Social Assistance: Summary Statistics for the U.S., States, and Selected Geographies: 2017. https://www.census.gov/data/tables/2017/econ/economic-census/naics-sector-62.html; analysis by PHI (December 2019).

While the home care industry (and to a lesser extent, residential care) is growing much more rapidly than the nursing home industry, rate of growth is not the only distinguishing factor among long-term care providers. There are also systematic differences in employment patterns, chain ownership,

and concentration of ownership across the home care, residential care, and nursing home industries. To explore these differences, we rely on data from the 2012 Economic Census. (While dated, this survey provides the most robust picture of each industry.)

EMPLOYMENT LEVELS IN LONG-TERM CARE ESTABLISHMENTS BY INDUSTRY, 2012

(In Percentages)



Source: U.S. Census Bureau. 2016. Health Care and Social Assistance: Subject Series - Estab & Firm Size: Employment Size of Establishments for the U.S.: 2012. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2012_US/62SSSZ2/0100000US; analysis by PHI (December 11, 2019).



of home care providers employ fewer than 50 employees. According to our analysis:

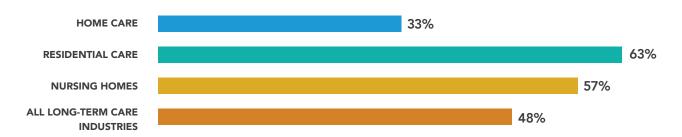
- Over three quarters of home care establishments employ fewer than 50 total employees (including direct care workers, licensed professionals, and other staff), whereas only one quarter of nursing homes have fewer than 50 employees.²⁸ Of note, 87 percent of residential care providers also employ fewer than 50 employees.
- Thirty-three percent of home care providers are owned by chains, compared to 57 percent of nursing homes and 63 percent of residential care providers.²⁹
- The 50 largest firms in the home care industry control just 26 percent of total industry revenue, versus 31 percent in nursing homes and 33 percent in residential care.³⁰

Taken together, these data demonstrate that the home care industry—while growing quickly—is also particularly fragmented and decentralized.

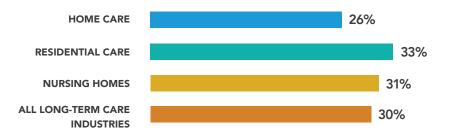
NEW PLAYERS IN THE HOME CARE INDUSTRY

The home care industry is becoming more like the nursing home sector in at least one area: for-profit ownership. From 2007 to 2017, the proportion of for-profit home care agencies increased from 67 percent to 76 percent.³¹ The greatest change was among non-medical home care providers (a subset of the home care industry), where for-profit ownership jumped from 45 percent to 60 percent.





INDUSTRY REVENUE CONCENTRATED AMONG THE 50 LARGEST FIRMS BY LONG-TERM CARE INDUSTRY, 2012



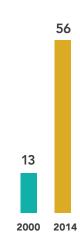
Sources: U.S. Census Bureau. 2016. Health Care and Social Assistance: Subject Series: Estab & Firm Size: Summary Statistics for Single Unit and Multiunit Firms for the U.S.: 2012. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2012_US/62SSSZ3/0100000US; U.S. Census Bureau. 2016. Health Care and Social Assistance: Subject Series: Estab & Firm Size: Summary Statistics by Concentration of Largest Firms for the U.S.: 2012. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2012_US/62SSSZ6/0100000US; analysis by PHI (December 11, 2019).

For-profit ownership is on the rise in home care for at least three reasons. First, the home care industry is increasingly attracting new franchise brands and aspiring franchise owners. From 2000 to 2014, the number of home care franchise brands jumped from 13 to 56,32 and in 2019, like previous years, three home care brands topped the Forbes list of "Best Franchises to Buy."33 Franchising is an attractive option because it offers a high growth opportunity paired with a low initial investment—but it presents both opportunities and risks for the sector. On one hand, franchising might allow small home care businesses to access the benefits of a larger organization, such as training curricula, marketing materials, and operational supports. On the other hand, franchisees might enter the market seeking a lucrative investment without a firm understanding of the industry's complexity—a naiveté that could put consumers and workers at risk.

Like franchise owners, private equity investors are also seeing an opportunity to invest in the home care industry.³⁴ (Private equity investors directly invest in private companies that are not publicly

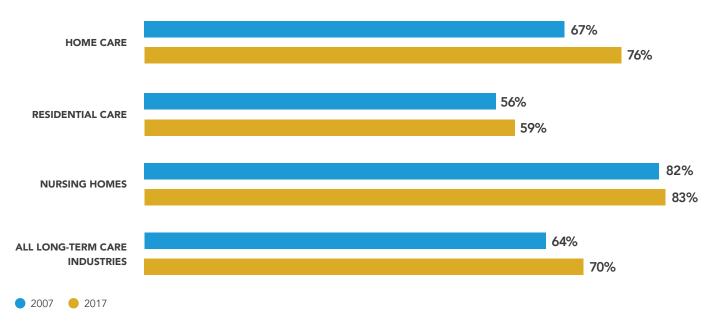
traded.) The boost of capital from these investors can help home care agencies build the infrastructure that they need to grow and thrive in a competitive market, including marketing programs and customer relationship managements systems, among other infrastructure elements. At the same time, the investors' expectations of financial return might lead providers to cut corners in pursuit of profit, again to the detriment of care quality or job quality.

Finally, venture capital investors are interested in home care, too. Unlike private equity investors—who aim to shore up the existing home care industry—venture capital investors seek to disrupt the home care sector, primarily by investing in innovative start-up companies.³⁵ In home care, most venture capital funds support start-ups that compete directly with existing home care agencies using technology-driven platforms. However, recent moves by three major home care start-ups indicate that these companies have reassessed their initial assumptions about the home care industry.



The number of franchise brands in home care increased in recent years.

FOR-PROFIT OWNERSHIP BY LONG-TERM CARE INDUSTRY, 2007 AND 2017



Sources: U.S. Census Bureau. 2010. Health Care and Social Assistance: Geographic Area Series: Summary Statistics: 2007. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2007_US/62A1/0100000US; Economic Census of the United States U.S. Census Bureau. 2020. Health Care and Social Assistance: Summary Statistics for the U.S., States, and Selected Geographies: 2017. https://www.census.gov/data/tables/2017/econ/economic-census/naics-sector-62.html; analysis by PHI (December 2019).

A Closer Look at Data Collection

The true size of the home care workforce—including workers hired directly by consumers—is difficult to count. First, states may include Medicaid-funded consumer-directed home care workers in their labor market data, but they are not required to do so (and it is difficult to ascertain which ones do). Moreover, workers employed through the gray market are almost impossible to identify because they are often paid off the books by consumers. Even though gathering data from individual households requires a significant investment, this may be what is needed to obtain a more accurate estimate of workforce volume, and to gain a better understanding of the role and impact of this workforce.

- Honor (with \$115 million in venture capital funds) began by offering services through an entirely online platform.³⁶ However, the company recently changed course and launched a partnership program, where they provide their services through existing agencies.³⁷
- Vesta Healthcare (with over \$40 million in venture capital funds) recently shifted its focus away from tech-enabled home care services toward Medicaid care management.³⁸
- Finally, HomeHero (which received \$23 million in venture capital funds) ceased operations because, according to founder and CEO Kyle Hill, they had begun with unrealistic assumptions about the industry, including an underestimation of the technological expertise of existing home care agencies.³⁹

It is not yet clear how these different types of for-profit companies will change the home care sector in the long term. While added capital and better infrastructure may improve access to care and job quality, investors and franchisees may also negatively impact the field—if they prioritize profits over care quality for consumers and job quality for workers.

CONSUMERS AS EMPLOYERS IN HOME CARE

Another key feature of the shifting landscape of LTSS is the growing role of consumer direction in home care. Under the traditional agency-based model, consumers access the services they need through home care agencies, which handle all aspects of employment for home care workers. In contrast, the consumer-directed model positions consumers as the locus of control over their services, with responsibility over most aspects of home care worker employment. Every state and the District of Columbia offers Medicaid-funded consumer-directed options and, as of 2016, over one million consumers directed their own services under these public programs.40 (The total number of consumers who direct their care is actually much larger, given that many consumers privately hire and pay their own workers through the "gray market.")

There are two types of publicly funded consumer-directed programs.⁴¹ Under the "budget authority" model, consumers receive a flexible budget from the state to purchase the goods and services that they need. Under the "employer authority" model, consumers do not control their own budgets, but they still manage most aspects of the employment process, including recruiting, hiring, training, supervising, and firing workers. All states offer the employer authority option in at least one program and 33 grant consumers more control over their individual budgets.⁴²

Between the agency-based and consumer-directed models, there is a third model known as "agency with choice." In this model, the home care agency and the consumer share employer responsibilities: the consumer maintains nearly the same level of control as in a consumer-directed model, but the agency is the employer for tax purposes. As Also, unlike in the consumer-direction model, both consumers and workers can turn to the agency for additional support, such as for training and continuing education.

To note, although this section has focused on consumer direction in home care, principles of choice and autonomy can be integrated into residential settings as well. Since the 1980s, proponents of "culture change" have advocated for a more person-centered approach in nursing homes and residential care communitiesprioritizing individual choice and preference over standardized care.44 Within the culture change movement, providers strive to create more homelike environments in which residents are encouraged to determine their own daily lives, maintain their independence, and retain their individuality. In these homes and communities, direct care workers often have an elevated role, working in partnership with residents, nurses, and other members of the care team to deliver person-centered care. The culture change model has been shown to improve resident satisfaction and outcomes, and components of culture change have been codified in regulation.45 For example, a recent CMS rule requires nursing assistants to be directly involved in the care-planning process, recognizing their unique understanding of residents' needs and preferences.46

Who Shapes Direct Care Job Quality?

To this point, we have discussed the LTSS system in terms of financing mechanisms and industry characteristics. We now turn to the stakeholders within the system who shape direct care job quality. Our purpose is to identify the various levers that are available to improve these jobs, as well as to underline the importance of strong collaboration and commitment to job quality at every level.

Starting at the highest tier, the federal government plays a role in shaping direct care jobs through Medicare policy and regulations. The federal government has used this role to mandate minimum training requirements for home health aides and nursing assistants who work for Medicare-certified home health and nursing home providers (which constitute the majority of those providers). Since these workers likely also assist consumers who are enrolled in Medicaid and/or other public programs, such federal training requirements have an impact far beyond Medicare.

The federal government also has a role in directing Medicaid policy. While states have broad discretion over Medicaid program design, they must follow certain federal rules and guidelines. For example, through CMS, the federal government sets rules for various settings, from home care to nursing homes; approves or denies waiver applications, imposing limits on what states can and cannot do; and establishes regulations for implementing relevant legislation.

Compared to the federal government, however, states hold more power in shaping the direct care workforce. Nearly all nursing homes and many residential care communities are certified or licensed by states, 47 and these requirements often include some stipulations about staff qualifications. In home care, licensure is less common—just 26 states license non-medical home care agencies⁴⁸—but states can still regulate the home care workforce through Medicaid regulations, for example by requiring agencies to meet certain workforce requirements to receive Medicaid dollars. Further, states can improve job quality through Medicaid

reimbursement policy by, for example, stipulating a percentage of payments to providers that must be spent on workers' wages and benefits. Also, when states contract with managed care plans, they can set baseline rates that managed care organizations must pay providers (accounting for comprehensive labor costs) or allocate additional funding to plans that contract with high-road employers. To develop these policies, states sometimes gather input from state-sponsored workgroups-advisory bodies comprised of diverse stakeholders who are charged with producing recommendations to improve the direct care workforce.49

Finally, given their direct access to longterm care providers, states are wellpositioned to improve data collection on the direct care workforce. As noted in our previous report, the data that are most critically needed relate to the size, stability, and compensation of this workforce. States can use these workforce data to inform and evaluate the success (or shortcomings) of policies designed to support and strengthen the workforce.

As noted in the section on LTSS financing, managed long-term care plans also have a role in shaping direct care jobs. First, plans determine their own reimbursement rates for providers (similar to states with fee-for-service systems) and can therefore influence job quality.⁵² Second, managed care plans are responsible for ensuring that consumers receive the services to which they are entitled, and an adequate workforce is key to meeting this requirement because workforce shortages can cause service gaps and delays. In certain states (most notably, Arizona and Tennessee), managed care plans have taken innovative steps to strengthen provider networks by partnering with local trainers, improving the workforce pipeline, and offering innovation and capacity grants to providers, among other workforce development efforts.53

State Policy Spotlight

The **Texas** Health and Human Services Commission (HHSC) recognized in a 2018 report that the state was unable to adequately measure the scope of direct care workforce challenges without improved data collection.⁵⁰ To address this barrier, the HHSC added new questions about worker turnover, retention, and compensation to their existing provider surveys.⁵¹ These insights will help guide Medicaid policymaking and workforce planning in the state.

Industry Feature

Managed long-term care plans in Arizona are required to assist providers in their networks with direct care workforce development.54 In response to this requirement, Mercy Care, a managed long-term care plan in southern Arizona, committed to invest \$2,000,000 from 2018 to 2022 to strengthen the workforce. These funds are supporting a range of activities, including a marketing campaign, free training for workers, and an innovation fund that providers can access to launch recruitment and retention projects.

Similar to state and federal policymakers and managed care plans, employers—including organizations and individual consumers—play a direct role in shaping direct care job quality. Indeed, regardless of their state's policies and reimbursement levels, some employers excel in supporting direct care workers while others fall behind.

Home care cooperatives exemplify the important role that employers can play in improving direct care jobs. In the coop model, workers can own a portion of their employing agencies and access a range of benefits, including paid dividends in profitable years. Worker-owners also exercise real power in their workplaces and organizations, including by electing board members and participating in key decisions. This model appears to make a difference: on average, cooperatives pay \$.54 more per hour than other home care agencies in their states, and turnover at these organizations is 38 percent (versus 82 percent nationally).55 Currently, there are just 11 home care cooperatives nationwide that collectively employ 2,470 home care workers, but many elements of their worker-centered approach are transferable to other home care agencies. These cooperatives demonstrate that worker-centered practices can lead to strong outcomes, even in challenging business and policy environments.

Individual consumers shape job quality for workers as well. Under consumerdirected programs, consumers have control over most elements of employment, although they are only able to set workers' wages in the budget authority model. Also, most states delegate training to individual consumers, meaning workers receive all their training directly from their consumer-employers, and this training is neither standardized nor transferable to other employers. Therefore, the responsibility of ensuring that each worker is equipped with the necessary competencies to succeed in their role falls to each consumeremployer.

Self-directing consumers are often supported by specialized entities, which also therefore play a role in shaping job quality for direct care workers. Under Medicaid consumer-directed programs, fiscal management service (FMS) providers primarily assist with technical aspects of employment, like payroll and tax withholdings. One example of how the responsibilities of FMS providers can be expanded, however, comes from Washington State, which recently contracted with a single agency to serve as the "employer of record" for all 35,000 workers employed under the state's Medicaid consumer-directed programs.⁵⁶ Unlike typical FMS providers, this agency will also have important workforce development responsibilities, for example related to recruitment, compensation, supervision, and more. Although still in development, Washington's approach could serve as a model for other states to replicate in their own consumer-directed programs.

Consumer-led nonprofit organizations called Centers for Independent Living (CILs) also support consumers and their workers with employment-related issues. In some cases, CILs also directly recruit workers or operate full home care agencies. Some CILs and state agencies also operate matching service registries—online job boards that help consumers and workers find each other and establish employment relationships. These registries, which are active in 14 states, can also connect workers and consumers with other resources, including training and background checks.⁵⁷

There are also several similar online job boards for consumers and workers in the gray market. As a notable example, Care.com is an international, subscription-based platform that assists consumers with finding care for their loved ones, including older adults. The platform allows consumers to search for workers based on their needs, preferences, and location in the same way as nonprofit matching service registries. Care.com recently received \$157 million in venture capital investments to expand their services for individual consumers.⁵⁸

Finally, unions also have a role in shaping job quality in some cases. Unions that represent direct care workers collectively bargain with states around wages, training, and other elements of job quality. According to PHI's analysis of Current Population Survey (CPS) data, unionized direct care workers earn a median wage of \$13.00 per hour, compared to \$11.66 for non-unionized workers.⁵⁹ Unions also connect workers to resources and supports, including affordable unionsponsored health insurance. Over half (51 percent) of unionized workers have insurance through their employer or union; by comparison, less than a third (31 percent) of non-unionized direct care workers have health insurance through their employers. (The CPS data include consumer-directed workers who report they are employed by government entities but not those who are self-employed. As a result, these data cannot be used to estimate the overall unionization rate in the direct care workforce, and the analyses described here likely underestimate the impact of unionization in long-term care.)

Also, under some collective bargaining agreements, unions serve as the primary trainer for the direct care workforce in their states. The most notable example of this is the SEIU 775 Benefits Group in Washington State, which provides the required 75 hours of training to consumer-directed workers, as well as offering extensive continuing education options for workers.⁶⁰

Recent court cases and policy changes may weaken the power of unions to collect dues and collectively bargain.61 First, in Harris v. Quinn, the Supreme Court ruled that consumer-directed home care workers are not fully public employees and therefore, non-union members cannot be compelled to pay union dues, even if they benefit from statewide collective bargaining agreements.⁶² Also, the federal government recently prevented Medicaid programs from paying union dues on behalf of workers, making it more difficult for unions to collect dues from their members.⁶³ To date, these rulings have not fundamentally altered the union landscape—unions report minimal membership losses and stable or rising funding levels—but their long-term impact remains to be seen.64

Industry Feature

In California, four Centers for Independent Living (CILs) offer a QuickMatch matching service registry. This registry platform includes features for consumers and workers, including the option for workers to record short messages for prospective employers. CIL staff maintain the registries by fielding questions from users, advertising their services, and, in some cases, recruiting workers to use the registries.

MEDIAN WAGES AMONG UNIONIZED AND NON-UNIONIZED DIRECT CARE WORKERS BY INDUSTRY, 2018



Sources: Flood, Sarah, Miriam King, Renae Rodgers, Steven Ruggles and J. Robert Warren. 2019. IPUMS, Current Population Survey: Version 6.0. Minneapolis, MN: IPUMS, University of Minnesota. https://doi.org/10.18128/D010.V9.0; analysis by PHI (February 7, 2020).

Conclusion and Implications

In Focus: PHI's **Policy Approach**

In 2019, the National Academy of Social Insurance released a report promoting "universal family care," a social insurance model designed to support care needs from early childhood through LTSS. Complementing this publication, PHI partnered with Caring Across Generations to release a report on the nine key considerations to strengthen the direct care workforce through

This report has examined how the LTSS system impacts direct care jobs from three vantage points. First, we have shown how our strained LTSS financing system underinvests in workers' job quality (and in consumers' care). Second, we have discussed how the changing industry landscape (that is characterized by rapid growth in home care and the increased dominance of for-profit companies) presents opportunities and challenges for strengthening the direct care workforce. And third, we have described the various stakeholders who shape direct care jobs, from the federal government to individual employers, and more. Based on these observations, we conclude with two systems-level ideas for strengthening the direct care workforce.

REFORMING LONG-TERM CARE FINANCING

The current approach to long-term care financing falls short. It does not protect consumers from financial ruin, nor does it ensure a living wage for the direct care workforce (or other elements of a quality iob). Because few consumers can afford to pay privately for LTSS, Medicaid has taken on a dominant role in long-term care financing, including increasingly in the home care sector. But Medicaid is not a universal benefit-which would be funded through widespread payroll contributions—so it must compete with many other budget priorities in state policymaking. This often leaves the system underfunded. Moreover, Medicaid programs are often developed in a piecemeal fashion and are immensely hard to navigate for consumers. This complexity also leads to fragmented or siloed workforce development efforts.

There is a clear need for a new approach to LTSS financing that addresses the overlapping interests of consumers and workers-with state-based universal the most promise. Such programs could provide consumers with the services they need without impoverishing them, older adults in meeting medical costs.



New long-term care insurance programs should also consider the needs of workers—including with regards to compensation, training, supervision, and other elements of job quality.

A more immediate, emergent opportunity to strengthen the direct care workforce and consumers' access to care is through Medicare Advantage. The federal government recently allowed Medicare Advantage plans, which are managed care plans for Medicare enrollees, to cover non-medical home care as an optional benefit, just like dental coverage or gym memberships. This expansion of coverage could be leveraged to support the workforce in a number of ways. For one, under-resourced Medicaidreliant home care agencies could secure a new revenue stream by providing services to Medicare Advantage enrollees—generating additional funds to invest in the direct care workforce. Relatedly, payers and providers could create new roles for direct care workers that focus on improving consumer outcomes and generating value for Medicare Advantage plans.

As states and the federal government continue to consider new funding mechanisms for long-term care, workforce considerations must be front and center. After all, a key challenge in the current system is that workforce shortages undermine access to care for all consumers, regardless of their method of paying for care.

ORGANIZING LONG-TERM CARE TO IMPROVE JOB QUALITY

The home care industry (and its direct care workforce) is growing rapidly. But home care is more diffuse and less regulated than the nursing home and (to a lesser extent) residential care industries, which makes it difficult to universally enact and enforce workforce policies and protections—or care quality standards. Also, workforce policies and reimbursement rates often vary across and within Medicaid programs.

A good start toward standardizing workforce policy across long-term industries would be to license home care agencies and fill in licensing gaps in residential care. Enacting workforce policy through licensure regulations can create consistency across providers, regardless of whether they are predominately publicly or privately financed. This approach is not only a consumer protection, but a critical lever for improving job quality.

In establishing and revamping licensure requirements, states could work to better align workforce regulations to create a more coherent regulatory framework across payers. For example, establishing portable, stackable training requirements through licensure requirements would allow direct care workers to work across settings without repeating their training. (As we will discuss in the next report in this series, current training requirements in different settings are often duplicative and nontransferable.)

Future reports in this series will explore the job quality improvements that are critically needed to boost recruitment, reduce turnover, and improve consumers' access to services, now and in the future. However, transforming direct care jobs will require restructuring our long-term care financing system and better aligning workforce policies (especially in the home care industry)—to ensure adequate funding and strengthen recruitment and retention across sectors. These goals will only be attained through coordinated and concerted effort among stakeholders at all levels of the long-term care system.

In Focus: PHI's Workforce Innovations

In 2015, PHI partnered with a managed care plan and three home care providers to create a salaried advanced role for home care workerscalled a Care Connections Senior Aide. These workers are trained to provide coaching and support for home care workers and family caregivers and serve as a resource to the interdisciplinary care team, strengthening ongoing knowledge and communication about clients' conditions. Pilottesting of the new role showed a reduction in caregiver strain and an 8 percent drop in emergency department visits (compared to the previous year).

Notes

- 1. Genworth. "Cost of Care Survey 2019." Last modified January 18, 2020. https://www.genworth.com/aging-and-you/finances/cost-of-care.html. The annual cost of home care assumes 44 hours of service over 52 weeks.
- 2. Musumeci, MaryBeth, Priya Chidambaram, and Molly O'Malley Watts. 2019. Medicaid Home and Community-Based Services Enrollment and Spending. Washington, D.C.: Kaiser Family Foundation. https://www.kff.org/report-section/medicaid-home-and-community-based-services-enrollment-and-spending-issue-brief/.
- 3. U.S. Census Bureau. 2010. Health Care and Social Assistance: Geographic Area Series: Summary Statistics: 2007. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2007_US/62A1/010000US; Economic Census of the United States U.S. Census Bureau. 2020. Health Care and Social Assistance: Summary Statistics for the U.S., States, and Selected Geographies: 2017. https://www.census.gov/data/tables/2017/econ/economic-census/naicssector-62.html; analysis by PHI (December 2019).
- 4. U.S. Census Bureau. 2016a. Health Care and Social Assistance: Subject Series Estab & Firm Size: Employment Size of Establishments for the U.S.: 2012. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2012_US/62SSSZ2/0100000US; U.S. Census Bureau. 2016b. Health Care and Social Assistance: Subject Series: Estab & Firm Size: Summary Statistics for Single Unit and Multiunit Firms for the U.S.: 2012. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2012_US/62SSSZ3/0100000US; analysis by PHI (December 11, 2019); National Center for Assisted Living (NCAL). 2019. 2019 Assisted Living State Regulatory Review State Regulatory Review. Washington, D.C.: NCAL. https://www.ahcancal.org/ncal/advocacy/regs/Documents/2019_reg_review.pdf; PHI. "Personal Care Aide Training Requirements." Last modified August 10, 2019. https://phinational.org/advocacy/personal-care-aide-training-requirements/.
- 5. Genworth, 2020.
- **6.** Garcia, Adrian. 2018. "This Is the Average Amount in Savings Accounts How Does Your Cash Stack Up?" Bankrate, December 3. https://www.bankrate.com/personal-finance/savings-account-average-balance/
- 7. Oakley, Diane, Jennifer Erin Brown, and Joelle Saad-Lessler. 2018. Retirement in America: Out of Reach for Most Americans? Washington, D.C.: National Institute on Retirement Security. https://www.nirsonline.org/reports/retirement-in-america-out-of-reach-for-most-americans/.
- **8.** Johnson, Richard. 2016. Who is Covered by Long-Term Care Insurance? Washington, D.C.: Urban Institute. https://www.urban.org/sites/default/files/publication/83146/2000881-Who-Is-Covered-by-Private-Long-Term-Care-Insurance.pdf.
- 9. Musumeci et al., 2019.
- 10. U.S. Census Bureau. 2016. Health Care and Social Assistance: Subject Series Misc Subjects: Receipts/Revenue by Type of Social Assistance for the U.S.: 2012. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2012_US/62SXSB6/0100000US; analysis by PHI (December 11, 2019).
- **11.** U.S. Census Bureau. 2019. *Table 4: Estimated Sources of Revenue for Employer Firms: 2013 through 2018.* https://www.census.gov/data/tables/2018/econ/services/sas-naics.html.
- **12.** Scales, Kezia. 2019. Envisioning the Future of Home Care: Trends and Opportunities in Workforce Policy and Practice. Bronx, NY: PHI. https://phinational.org/resource/envisioning-the-future-of-home-care-trends-and-opportunities-in-workforce-policy-and-practice/.
- 13. Musumeci, MaryBeth, Molly O'Malley Watts, and Priya Chidambaram. 2020. Key State Policy Choices About Medicaid Home and Community-Based Services. Washington, D.C.: Kaiser Family Foundation. https://www.kff.org/report-section/key-state-policy-choices-about-medicaid-home-and-community-based-services-issue-brief/.
- **14.** Musumeci, MaryBeth, Priya Chidambaram, and Molly O'Malley Watts. 2019. *Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists.* Washington, D.C.: Kaiser Family Foundation. https://www.kff.org/medicaid/issue-brief/key-questions-about-medicaid-home-and-community-based-services-waiver-waiting-lists/.
- 15. Musumeci, Watts, and Chidambaram, 2020.

- **16.** Jessee, Gary. 2019. "Managed Long-term Services and Supports (MLTSS)." PowerPoint slide deck presented at the ADvancing States Home and Community-Based Services Conference, Baltimore, Maryland, August 26. http://www.advancingstates.org/sites/nasuad/files/2019_Medicaid101_MASTER_DECK_8212019%20%28002%29.pdf.
- 17. Cook, Allison. 2019. Value-Based Payment and the Home Care Workforce: What New York Can Teach Other States. Bronx, NY: PHI. https://phinational.org/resource/value-based-payment-and-the-home-careworkforce-what-new-york-can-teach-other-states/.
- 18. National Quality Forum (NQF). 2016. Quality in Home and Community-Based Services to Support Community Living: Addressing Gaps in Performance Measurement. Washington, D.C.: NQF. http://www.qualityforum.org/Publications/2016/09/Quality_in_Home_and_Community-Based_Services_to_Support_Community_Living_Addressing_Gaps_in_Performance_Measurement.aspx.
- **19.** Ryan, Jennifer and Barbara Coulter Edwards. 2015. *Rebalancing Medicaid Long-Term Services and Supports*. Bethesda, MD: HealthAffairs. https://www.healthaffairs.org/do/10.1377/hpb20150917.439553/full/
- **20.** Scales, Kezia. 2020. It's Time to Care: A Detailed Profile of America's Direct Care Workforce. Bronx, NY: PHI. https://phinational.org/caringforthefuture/itstimetocare/.
- 21. Kathleen Gifford, Eileen Ellis, Aimee Lashbrook, Mike Nardone, Elizabeth Hinton, Robin Rudowitz, Maria Diaz, and Marina Tian. 2019. A View from the States: Key Medicaid Policy Changes: Results from a 50-State Medicaid Budget Survey for State Fiscal Years 2019 and 2020. Washington, D.C.: Kaiser Family Foundation. https://www.kff.org/report-section/a-view-from-the-states-key-medicaid-policy-changes-introduction/; PHI. "Workforce Data Center." Last modified August 30, 2019. https://phinational.org/policy-research/workforce-data-center/.
- 22. Veghte, Benjamin, Alexandra Bradley, Marc Cohen, and Heidi Hartmann. 2019. Designing Universal Family Care: State-Based Social Insurance Programs for Early Child Care and Education, Paid Family and Medical Leave, and Long-Term Services and Supports. Washington, D.C.: National Academy of Social Insurance. https://www.nasi.org/research/2019/designing-universal-family-care-state-based-social-insurance. To name a few examples, Germany and the Netherlands both offer universal benefits for people with disabilities of all ages, and Japan and France provide universal benefits for older adults (although benefits in France are tied to income).
- **23.** Appleby, Julie and Mary Agnes Carey. 2011. "CLASS Dismissed: Obama Administration Pulls Plug on Long-Term Care Program." *Kaiser Health News*, October 11. https://khn.org/news/class-act-implementation-halted-by-obama-administration/.
- **24.** Long-Term Care Trust Act. 2019. HB 1087. http://lawfilesext.leg.wa.gov/biennium/2019-20/Pdf/Bills/House%20Passed%20Legislature/1087-S2.PL.pdf.
- **25.** An Act to Establish Universal Home Care for Seniors and Persons with Disabilities. 2018. LD 1864. https://legislature.maine.gov/legis/bills/bills_128th/billtexts/IB000301.asp
- **26.** Slocum, Sarah. 2019. "Help Wanted: Better-Paid, Better-Trained, Caring Workers to Provide Long Term Supports and Service!" *MediCaring.org*, April 30. https://medicaring.org/2019/04/30/help-wanted/?fbclid=lwAR19iLZ4GRjs yO64kSpshfLbVwQnYquv345BPNKw9O4J6nYzAk7-17dybMU.
- 27. U.S. Census Bureau. 2010. Health Care and Social Assistance: Geographic Area Series: Summary Statistics: 2007. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2007_US/62A1/0100000US; Economic Census of the United States U.S. Census Bureau. 2020. Health Care and Social Assistance: Summary Statistics for the U.S., States, and Selected Geographies: 2017. https://www.census.gov/data/tables/2017/econ/economic-census/naics-sector-62.html; analysis by PHI (December 2019).
- 28. U.S. Census Bureau, 2016a.
- 29. U.S. Census Bureau, 2016b.
- **30.** U.S. Census Bureau. 2016. Health Care and Social Assistance: Subject Series: Estab & Firm Size: Summary Statistics by Concentration of Largest Firms for the U.S.: 2012. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2012_US/62SSSZ6/0100000US; analysis by PHI (December 11, 2019).

- **31.** U.S. Census Bureau. 2010. Health Care and Social Assistance: Geographic Area Series: Summary Statistics: 2007. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2007_US/62A1/0100000US; Economic Census of the United States U.S. Census Bureau. 2020. Health Care and Social Assistance: Summary Statistics for the U.S., States, and Selected Geographies: 2017. https://www.census.gov/data/tables/2017/econ/economic-census/naics-sector-62.html; analysis by PHI (December 2019).
- **32.** Tice, Carol. 2014. "Best Franchises to Own: Why Home Healthcare Is Hot." Forbes, May 27. https://www.forbes.com/sites/caroltice/2014/05/27/best-franchises-home-healthcare-is-hot/#4fceaf9249cd.
- **33.** Strauss, Karsten. 2019. "Meet the New Burger Kings—and the Rest of America's Best (And Worst) Franchises to Buy in 2019." Forbes, June 19. https://www.forbes.com/sites/karstenstrauss/2019/06/19/best-worst-franchises-buy-own/#39f734c7d79d.
- **34.** Holly, Robert. 2018. "Skeptics Raise Concerns as Private Equity Investment in Home Health Industry Rises." *Home Health Care News*, June 15. https://homehealthcarenews.com/2018/06/skeptics-raise-concerns-as-private-equity-investment-in-home-health-industry-rises/.
- **35.** Glasner, Joanna. 2016. "Why Venture Capitalists Are Caring More About Home Care." *Forbes*, November 21. https://www.forbes.com/sites/valleyvoices/2016/11/21/why-vcs-care-more-about-home-care/#3d36295655db.
- **36.** Crunchbase. "Honor." Last modified August 2, 2020. https://www.crunchbase.com/organization/honor-2.
- **37.** Holly, Robert. 2018. "Honor Faces Scrutiny Over Growing Partnership Model." *Home Health Care News*, December 9. https://homehealthcarenews.com/2018/12/honor-faces-scrutiny-over-growing-partnership-model/.
- **38.** Mullaney, Tim. 2018. "Hometeam CEO to Step Down as Company Goes All-In on Medicaid." *Home Health Care News*, April 15. https://homehealthcarenews.com/2018/04/hometeam-ceo-to-step-down-ascompany-goes-all-in-on-medicaid/; Schleifer, Theodore. 2018. "Both Hometeam's CEO and President are Leaving their Roles in a Shake-up as the Senior Care Startup Switches Directions." *Recode*, April 12. https://www.vox.com/2018/4/12/17231710/ceo-president-hometeam-seniorcare-josh-bruno-matt-marcotte-departures.
- **39.** Hill, Kyle. 2017. "There's No Magic in Venture-Backed Home Care." *Medium*, February 17. https://medium.com/@kaleazy/theres-no-magic-inventure-backed-home-care-8f5389528279#.cro8u5a03.
- **40.** Applied Self-Direction. "Self-Direction Programs." Last modified February 17, 2019. http://www.appliedselfdirection.com/self-direction-programs; Edwards-Orr, Merle and Kathleen Ujvari. 2018. *Taking it to the Next Level: Using Innovative Strategies to Expand Options for Self-Direction.* Washington, DC: AARP Foundation, The Commonwealth Fund, and The Scan Foundation. https://www.aarp.org/content/dam/aarp/ppi/2018/04/taking-it-to-the-next-level.pdf.
- **41.** Centers for Medicare and Medicaid Services. "Self-Directed Services." Last modified December 30, 2019. https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html.
- 42. Musumeci, Watts, and Chidambaram, 2020.
- 43. Scales, 2019.
- **44.** Mary Jane Koren. 2010. Person-Centered Care for Nursing Home Residents: The Culture-Change Movement. Bethesda, MD: HealthAffairs. https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2009.0966.
- **45.** Zimmerman, Sheryl et al. 2016. "New Evidence on the Green House Model of Nursing Home Care: Synthesis of Findings and Implications for Policy, Practice, and Research." *Health Services Research* 51 Suppl 1:475-96. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5338207/; Grabowski, David, A. James O'Malley, Christopher Afendulis, Daryl Caudry, Amy Elliot, and Sheryl Zimmerman. 2014. "Culture Change and Nursing Home Quality of Care." *The Gerontologist* 54(1): S35-S45. https://academic.oup.com/gerontologist/article/54/Suppl_1/S35/687612; Hermer, Linda, Natasha Bryant, Madeline Pucciarello, Carolina Mlynarczyk, and Bridget Zhong. 2017. "Does Comprehensive Culture Change Adoption via the Household Model Enhance Nursing Home Residents' Psychosocial Well-being?" *Innovation in Aging* 1(2). https://academic.oup.com/innovateage/article/1/2/igx033/4781448.
- **46.** Comprehensive Person-Centered Care Planning. 2016. 42 CFR §483.21. https://www.ecfr.gov/cgi-bin/text-idx?SID=8e85acce0f204b6f320fb7f9ebf6f33 e&mc=true&node=pt42.5.483&rgn=div5.

- 47. NCAL, 2019.
- 48. PHI. 2019.
- **49.** Cook, Allison. 2019. "State Workgroups Confront the Direct Care Workforce Crisis." PHI, October 29. https://phinational.org/news/stateworkgroups-confront-the-direct-care-workforce-crisis/.
- 50. Texas Health and Human Services Commission (HHSC). 2018. Community Attendant Recruitment and Retention Strategies. Austin, TX: HHSC. https://hhs.texas.gov/sites/default/files/documents/laws-regulations/reports-presentations/2018/rider-207-community-recruitment-retention-strategies-aug-2018.pdf
- **51.** HHSC. 2019. Community Attendant Recruitment and Retention Strategies. Austin, TX: HHSC. https://hhs.texas.gov/sites/default/files/documents/laws-regulations/reports-presentations/2019/community-attendant-recruitmt-retention-strat-aug-2019.pdf
- 52. Musumeci, Watts, and Chidambaram, 2020.
- **53.** Campbell, Stephen, Yonda Snyder, Patti Kilingsworth, Bill Kennard, and Sarah Hauck. 2019. "How Managed Care Plans Can Support Home Care Workforce Development." PowerPoint slides presented at the Advancing States Home and Community-Based Services Conferences, Baltimore, Maryland, August 28. http://www.advancingstates.org/sites/nasuad/files/hcbs/files/MLTSS%20and%20Workforce%20Development%20HCBS%202019. pdf.
- 54. Campbell et al., 2019.
- **55.** Kazda, Katrina. 2019. "Quantifying the Cooperative Difference in Home Care." PowerPoint slides presented at the Cooperative Development Foundation National Home Care Cooperative Conference, Dulles, Virginia, November 21. https://e0055355-4a1d-4b7e-9bc2-bf949532c037.filesusr.com/ugd/98a0e1_a0841cf40f6e4ea287d927e833aa4549.pdf
- **56.** Mullaney, Tim. 2018. "Controversial Home Care Overhaul Passes in Washington State." Home Health Care News, March 28. https://homehealthcarenews.com/2018/03/controversial-home-care-overhaul-passes-in-washington-state/; Washington State Aging and Long-Term Support Administration. "Consumer Directed Employer." Accessed December 29, 2019. https://www.dshs.wa.gov/altsa/stakeholders/consumer-directed-employer.
- **57.** PHI. "Matching Service Registries." Last modified November 19, 2019. https://phinational.org/advocacy/matching-service-registries/.
- 58. Glasner, 2016.
- **59.** Flood, Sarah, Miriam King, Renae Rodgers, Steven Ruggles and J. Robert Warren. 2019. *IPUMS, Current Population Survey: Version 6.0.* Minneapolis, MN: IPUMS, University of Minnesota. https://doi.org/10.18128/D010.V9.0; analysis by PHI (February 7, 2020).
- **60.** Choitz, Vickie, Matt Helmer, and Maureen Conway. 2015. *Improving Jobs to Improve Care*. Washington, D.C.: Aspen Institute. http://www.myseiubenefits.org/wp-content/uploads/2015/05/SEIU-CaseStudy.pdf.
- 61. Scales, 2019.
- **62.** Harris v. Quinn. Decided June 30, 2014. https://www.supremecourt.gov/opinions/13pdf/11-681_j426.pdf.
- **63.** CMS. 2019. Medicaid Program; Reassignment of Medicaid Provider Claims. 84 FR 19718: 19718-19728. https://www.federalregister.gov/documents/2019/05/06/2019-09118/medicaid-program-reassignment-ofmedicaid-provider-claims.
- **64.** Rainey, Rebecca and Ian Kullgren. 2019. "1 Year After Janus, Unions Are Flush." *Politico*, May 17. https://www.politico.com/story/2019/05/17/janus-unions-employment-1447266.
- **65.** PHI. 2019. Workforce Matters: The Direct Care Workforce and State-Based LTSS Social Insurance Programs. Bronx, NY: PHI. https://phinational.org/resource/workforce-mattrs/.
- **66.** Bureau of Labor Statistics (BLS). 2010. "Standard Occupational Classification." Accessed September 6, 2019. https://www.bls.gov/soc/2010/.
- **67.** U.S. Census Bureau. 2017. *North American Industry Classification System.* Washington, D.C.: U.S. Census Bureau. https://www.census.gov/eos/www/naics/2017NAICS/2017_NAICS_Manual.pdf

Appendix 1: Data Sources and Methods

The direct care workforce comprises three occupations as defined by the Standard Occupational Classification (SOC) system developed by the Bureau of Labor Statistics (BLS) at the U.S. Department of Labor (DOL): personal care aides, home health aides, and nursing assistants. ⁶⁶ Workers are classified based on their onthe-job responsibilities, skills, education, and training.

The industries that are described in this report are defined by the North American Industry Classification System (NAICS).⁶⁷ "Home Care" includes two industries: (1) Services for the Elderly and Persons with Disabilities and (2) Home Health Care Services. "Residential Care Homes" also comprises two industries: (1) Residential Intellectual and Developmental Disability Facilities

and (2) Continuing Care Retirement Communities and Assisted Living Facilities for the Elderly. "Nursing Homes" refers to the Nursing Care Facilities (Skilled Nursing Homes) industry.

Our analyses of industry trends were produced using data from the U.S. Economic Census. To produce trends in the number of long-term care establishments, we relied on 2007 and 2017 datasets, the most recent data years available for this purpose. However, because 2017 data were not available for analyses of long-term care establishment employment size, franchise membership, chain ownership, and concentration, 2012 data were used instead.

Appendix 2: Long-Term Care Industries by the Numbers

Setting	Home Care	Residential Care	Nursing Homes	All Long-Term Care Industries
Industry Trends				
Establishments in 2007	43,503	47,104	16,320	106,927
Establishments in 2017	65,696	59,081	16,871	141,648
Numeric Change	22,193	11,977	551	34,721
Percent Change	51%	25%	3%	32%
Trends in For-Profit Ownership				
Proportion of For-Profit Establishments in 2007	67%	56%	82%	64%
Proportion of For-Profit Establishments in 2017	76%	59%	83%	70%
Percentage Point Change	9%	4%	2%	5%
Percent Change	13%	7%	2%	9%
Chain Ownership and Franchise Establishments				
Chain Ownership	33%	63%	57%	48%
Chains with fewer than 5 establishments	11%	9%	11%	10%
Chains with 5 to 9 or more establishments	6%	6%	6%	6%
Chains with 10 or more establishments	15%	48%	40%	32%
Franchise Establishments	7%	_	_	_
Long-Term Care Establishment Employment Size				
Fewer than 20 employees	55%	72%	14%	57%
20 to 49 employees	23%	15%	9%	18%
50 to 99 employees	12%	8%	27%	12%
100 or more employees	9%	6%	49%	13%
Share of Revenue Controlled by Largest Firms				
4 largest firms	7%	13%	11%	10%
8 largest firms	12%	18%	16%	15%
20 largest firms	19%	25%	22%	21%
50 largest firms	26%	33%	31%	30%

Source: U.S. Census Bureau. 2010. Health Care and Social Assistance: Geographic Area Series: Summary Statistics: 2007. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2007_US/62A1/0100000US; Economic Census of the United States U.S. Census Bureau. 2020. Health Care and Social Assistance: Summary Statistics for the U.S., States, and Selected Geographies: 2017. https://www.census.gov/data/tables/2017/econ/economic-census/naics-sector-62.html; U.S. Census Bureau. 2016. Health Care and Social Assistance: Subject Series: Estab & Firm Size: Summary Statistics by Concentration of Largest Firms for the U.S.: 2012. https://factfinder.census.gov/bkmk/table/1.0/en/ECN/2012_US/62SSSZ6/0100000US; analysis by PHI (December 11, 2019).

About PHI

PHI works to transform eldercare and disability services. We foster dignity, respect, and independence for all who receive care, and all who provide it.

As the nation's leading authority on the direct care workforce, PHI promotes quality direct care jobs as the foundation for quality care.

PHInational.org

- Learn about our consulting services, policy research, advocacy, and public education campaigns
- Scroll through our multi-media library of research, analysis, and other resources
- Download state-by-state data on the direct care workforce
- Bookmark our newsroom for the latest news and opinion: PHInational.org/news/
- Subscribe to our monthly newsletter: PHInational.org/sign-up/





400 East Fordham Road, 11th Floor

Phone: 718.402.7766 Fax: 718.585.6852

Email: info@PHInational.org

PHInational.org

#CaringForTheFuture PHInational.org/CaringForTheFuture







