

# **CONTENTS** 2 About PHI 4 Wages and Benefits 6 Training and Advanced Roles 10 Expanding Access and Cultural 12 A Note on Family Caregiving 14 Appendix A: Highlights of PHI's Record of Bipartisan Federal Policy Action 16 Endnotes PHI would like to thank Daniel Wilson, Brian Lindberg, and David Schulke for their research and analysis on this report.

### Introduction

Across the country, direct care workers provide the majority of paid, hands-on care for millions of older people and people with disabilities. They represent a critical segment of a long-term care sector that must expand dramatically in the years ahead to meet the rapid growth in older adults. Unfortunately, this necessary expansion is jeopardized by low wages, thin benefits, and limited career advancement opportunities, yielding high turnover rates and a growing workforce shortage in paid caregivers. Our families increasingly rely on home health aides, personal care aides, and nursing assistants for support, but the supply of workers simply isn't meeting demand.

Strengthening this workforce would address three major concerns. First, a federal investment in this workforce is an investment in economic development. Direct care will create more jobs than any other occupation in the next 10 years. Second, direct care workers can ease the severe financial and psychological burdens of more than 40 million family caregivers, especially in rural areas. Finally, quality care depends on the quality of jobs for people providing that care. This has been the premise of PHI's work since our inception: the nation must improve the wages, benefits, training, and career opportunities for these workers if we are to recruit and retain a skilled. compassionate workforce.

This report provides analysis and recommendations across five areas critical to the stability of the direct care workforce. We advocate higher wages and benefits to ensure workers aren't forced into poverty or leave older Americans and those with disabilities

unserved because of low pay. We call for better training standards, competency requirements, and programmatic interventions so that clients can receive the skilled support they need and prefer. We argue for ongoing, reliable data on this workforce to effectively monitor the state of the workforce, inform public policy and workforce initiatives, and promote the highest quality of care.

## 5.2 million

### Number of direct care workers needed by 2024 across all settings

Source: PHI, 2017

We also propose solutions to expand access and promote cultural competence in long-term services and supports—all Americans should have equal access to care. Finally, we ask for more attention on the relationship between family caregivers and paid caregivers, joining the call for a national strategy on family caregiving.

PHI has worked successfully on bipartisan policy initiatives for decades (see Appendix A). We trust this collaboration will continue, and we welcome the conversation—America's older people, people with disabilities, and our families depend on it.

### **About PHI**

We believe that caring, committed relationships between direct care workers and their clients are at the heart of quality care. Those relationships work best when direct care workers receive high quality training, living wages, and respect for the central role they play.

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.

Drawing on 25 years of experience working side-by-side with direct care workers and their clients in cities, suburbs, and small towns across America, PHI offers all the tools necessary to create quality jobs and provide quality care. PHI's trainers, researchers, and policy experts work together to:

- Learn what works—and what doesn't—in meeting the needs of direct care workers and their clients, in a variety of longterm care settings;
- Implement best practices through hands-on coaching, training, and consulting, to help long-term care providers deliver highquality care; and
- Support policymakers and advocates in crafting evidencebased policies to advance quality care.





### Wages and Benefits

Low wages, part-time work, and a reliance on public benefits shape the economic realities of most direct care workers. The median hourly wage for home care workers in the U.S. is \$10.11—an inflation-adjusted wage that has remained virtually stagnant for the last 10 years. In turn, the median annual income for home care workers, most of whom work part-time or part of the year, is \$13,300. Most home care workers report wanting to work full-time, but for various reasons they're unable to obtain full-time hours; these reasons include cost savings for employers who can avoid

\$10.11

Median hourly wage for home care workers in 2015

Source: PHI, 2016

paying benefits, erratic scheduling to meet the short-term needs of clients, and clients whose needs for care cycle up and down, among other reasons. Because of low wages and unreliable work schedules, 24 percent of home care workers live in households below the federal poverty line, compared to 9 percent of U.S. workers. Similarly, nursing assistants working in nursing homes struggle with high poverty rates despite earning marginally higher incomes than home care workers.

Without a living wage, direct care workers rely heavily on public benefits to survive. Fifty-one percent of home care workers and 38 percent of nursing assistants rely on some form of public assistance such as nutrition assistance, Medicaid, or cash assistance. Additionally, the nature of this work—low pay, irregular hours—makes it difficult for many direct care workers to access employer-based or individual health coverage. New research from PHI quantifies the beneficial effect of Medicaid expansion on health coverage for direct care workers: the uninsured rate among this workforce dropped by 26 percent between 2010 and 2014, helping half a million direct care workers afford health care despite their low wages.<sup>3</sup>

The proliferation of minimum wage initiatives around the country has drawn attention to the wage concerns of low-income workers. In 2013, the U.S. Department of Labor extended wage and overtime protections under the Fair Labor Standards Act (FLSA) to home care workers nationwide. Unfortunately, reports from the field show that this rule has not been effectively enforced. Further, since the rule went into effect in October 2015, advocates across the spectrum have signaled the importance of meeting these wage increases with appropriate levels of Medicaid funding rather than capping work hours, a response that further challenges older people and people with disabilities to find the caregivers they need.

#### WAGES AND BENEFITS

### RECOMMENDATIONS FOR FEDERAL POLICY ACTION

- Enforce the U.S. Department of Labor's Home Care Final Rule of 2013, which extended wage and overtime protections under the Fair Labor Standards Act to home care workers. This rule improves the well-being of 2 million U.S. home care workers, while reducing turnover, strengthening an economically vital sector, and making the occupation more attractive to new employees.
- Protect expanded Medicaid benefits and tax credits that allow direct care workers to obtain health insurance coverage. Affordable health coverage for direct care workers increases financial stability, which allows them to continue providing professional care to the people who rely on them.
- Expand and promote access to the Earned Income Tax Credit (EITC), a refundable tax credit for low- to moderate-income working people. The EITC, which can increase annual income by more than \$6,000, incentivizes work and increases economic stability for low-wage workers. Without this annual tax credit, many direct care workers could not afford to continue in their roles.
- Support family and medical leave and pregnant worker accommodation policies that are essential to this predominantly female workforce. These programs improve the health and economic stability of working parents and their children, while benefitting providers and the overall economy.



#### WHAT'S IN CONGRESS\*

The Pay Workers a Living Wage Act would raise the federal minimum wage to \$15 over 4 years.

The Family and Medical Insurance Leave Act would establish the Office of Paid Family and Medical Leave and entitle every individual to family and medical leave insurance (FMLI) benefits.

The Family and Medical Leave Act Protections for Part-time Workers Act of 2016 would extend FMLA benefits to workers with 12 or more months of employment, regardless of hours worked.

The Pregnant Workers
Fairness Act would
require employers
to make reasonable
accommodations to the
pregnancy, childbirth, or
related medical conditions
of job applicants and
employees.

Bills are from the 114th Congress

# Training and Advanced Roles

Quality training ensures that direct care workers have the skills and knowledge to deliver excellent person-centered care. Unfortunately, training standards are often inadequate, and they vary by occupation and state. For home health aides, less than onethird of states require more than the minimum federal standard of 75 hours and only six states meet the National Academy of Medicine's (formerly the Institute of Medicine) 2008 recommendation of 120 hours.<sup>4</sup> For personal care aides, there are no federal training standards, resulting in dramatic differences across states and, in many instances, only minimal requirements. Training standards for nursing assistants in most states also rarely meet the National Academy of Medicine's recommendation. Further, PHI's extensive experience in workforce development and curriculum design around the country shows that the existing curricula for direct care workers tends to be outdated, often failing to address the skills, competencies, and learning styles of this workforce.

Federal standards would create opportunities for direct care workers to advance when they improve their knowledge and skills. Direct care workers can offer an enhanced level of support to older people and people with disabilities, improving the quality of care and potentially reducing costs, if they handle new responsibilities such as assisting with clinical observation and reporting, educating clients on health promotion and medication adherence,

and supporting the care team with coordination across disciplines. These responsibilities are within the current scope of practice and do not require legislative action. Furthermore, these advanced roles would increase the value of the direct care worker within the health care system.

Recent developments highlight the potential of quality training and advanced roles. A 2016 evaluation of the federally-funded Personal and Home Care Aide State Training (PHCAST) Demonstration found that this sixstate program led to low attrition rates and high levels of satisfaction among direct care aides who participated.<sup>5</sup> In New York City, an 18-month pilot program for advanced training among 1,100 home health aides found that clients served by aides with advanced training had 10 percent fewer visits to the emergency room than clients with aides who did not receive advanced training.6 Similarly, a multiyear training initiative in New York City led to increased retention and job satisfaction among home health aides who took part in the training program.<sup>7</sup> And in June 2016, New York passed a bill that creates an advanced role for home health aides, allowing them to perform tasks such as administering medication and injecting insulin upon completing training and demonstrating competency.8

#### ► TRAINING AND ADVANCED ROLES

### RECOMMENDATIONS FOR FEDERAL POLICY ACTION

- Adopt federal training standards and competency requirements for personal care aides and encourage states to meet the 120 hours of training for all direct care workers recommended by the National Academies of Sciences, Engineering, and Medicine.
- Provide federal funds for training home care workers, similar to how Medicaid supports the training of nursing assistants in institutional settings.
- Fund grants to support the training and advancement of home health aides and personal care aides, including demonstration grants that evaluate the impact of entry-level and advanced training on the overall stability of the workforce. New demonstrations should validate successful training models, standards, and curricula, as well as identify training programs that are accessible, and culturally and linguistically appropriate.
- Pilot training programs for direct care workers and family caregivers who support individuals with chronic conditions such as diabetes and Alzheimer's disease, among others.



#### WHAT'S IN CONGRESS\*

The Together We Care Act of 2015, which establishes a pilot program to fund both the training of public housing residents as home health aides and the provision of home care to public housing residents.

22

Number of states without training requirements for personal care aides across all programs

Source: PHI, 2017

\*Bills are from the 114th Congress.

# Data Collection and Quality

The increased attention on the capacity of the direct care workforce has highlighted the need for ongoing, reliable information about these workers. Neither state nor federal long-term care systems report the data necessary to inform public policy and workforce initiatives, set priorities for reforming the long-term care system, or compare state progress nationwide. Additionally, the home and community-based services field lacks an agreed-upon definition of "quality," as well as the measures needed to improve it, though recent federally-funded work by the National Quality Forum has begun filling that gap. Policymakers across the board are hampered by a general lack of data.

# 1.1 million

Number of direct care jobs to be created between 2014 and 2024. The demand for direct care workers will outpace the combined demand for fast food workers, retail salespeople, teachers, police, and firefighters.

Source: PHI, 2017

In a growing number of states, the shift to Medicaid managed long-term care has placed more responsibility on managed care plans to monitor the quality of those services. Unfortunately, without an agreed-upon quality framework, plans and states cannot measure it. Moreover, two areas where better funding and evaluation would improve quality and save dollars—chronic care delivery models and telehealth interventions—remain severely underfunded and understudied.

PHI has identified three essential areas for data collection on the direct care workforce.<sup>11</sup> "Workforce volume," which includes the number of full-time and part-time workers, measures the distribution of workers across settings and programs, and determines where resources should be allocated. "Workforce stability," which includes turnover rates and vacancy rates, assesses whether investments in the workforce reduce turnover and improve retention. "Worker compensation," which includes average hourly wages, annual income, and benefits such as health insurance and paid time-off, illustrates whether direct care jobs are competitively attractive with other occupations. These indicators provide a strong start for improving data and reporting on this workforce.

DATA COLLECTION AND QUALITY

### RECOMMENDATIONS FOR FEDERAL POLICY ACTION

- Work with states to gather and report data that measure workforce volume, workforce stability, and worker compensation, including staffing statistics, workforce turnover, vacancy rates, wages, annual income, and benefits in home and community-based services and across facilities.
- Incorporate direct care workforce quality measures into federally-funded long-term services and supports programs and demonstrations, based in part on the National Quality Forum final report of September 2016.
- Promote improved performance by managed care plans, including implementation of quality strategies, performance measures, improvement projects, and mechanisms to identify enrollees with high needs—all with a goal of producing quality ratings.
- Support programs focusing on integrated chronic care delivery models that promote accountability, manage care more effectively, and reduce costs.
- Promote and fund telehealth interventions and demonstration projects that provide greater support to home care workers delivering long-term services and supports—and save taxpayer dollars.

9 in 10

Ratio of home care workers who are women

Source: U.S. Census Bureau, 2015

26%

Percentage of home care workers without health coverage

28%

Percentage of home care workers who are immigrants

24%

Percentage of home care workers living below the federal poverty line. In comparison, 9 percent of U.S. workers live below the FPL

Source: PHI, 2016

# Expanding Access and Cultural Competence

Millions of Americans rely on long-term services and supports (LTSS), yet access to these supports is hindered by tight eligibility requirements, a lack of available resources in one's geographic area, inadequate federal and state funding, and a dearth of resources that are culturally and linguistically appropriate. While 52 percent of people age 65 and older will require some form of long-term care in their lives, reports around the country routinely illustrate the challenges facing people who can neither afford nor access necessary services.<sup>12</sup>

# 88 million

Projected population of people age 65 and older in 2050. Between 2015 and 2050, this population will nearly double from 47.8 million to 88 million

Source: U.S. Census Bureau, 2014

For millions of Americans, access to LTSS is made possible through the Medicaid program. In fact, Medicaid serves as the country's primary payer for these services, with 34 percent of the Medicaid budget directed toward long-term care. As the current presidential administration, as well as various leaders in Congress, weigh major reforms to programs such as Medicaid and Medicare, it is important to consider the

impact on America's older adults and people with disabilities. Already, a growing number of reported workforce shortages among direct care workers signals a crisis in paid caregiving—one worsened by state Medicaid budgets that often don't account for the real costs associated with labor or beneficiaries with higher needs.

In addition to affordability, access to longterm services and supports is hampered by a lack of culturally and linguistically appropriate services. Nationwide, the population of elders in the U.S., as well as people with disabilities, continues to diversify. In 2010, 20 percent of people age 65 and older in the U.S. were people of color, a group that will more than double by 2050. Lesbian, gay, bisexual, and transgender (LGBT) people age 65 and older will grow to at least 3 million in the same time frame.<sup>13</sup> Despite the body of research demonstrating pronounced disparities in access to services and health outcomes among these populations, there is a lack of culturally and linguistically appropriate services aimed at these diverse communities, including a lack of trained caregivers versed in their realities. To help address this problem, in 2010 PHI developed the curriculum for SAGE's National Resource Center on LGBT Aging, a federallyfunded cultural competence program that trains aging professionals on the unique needs of LGBT older people.<sup>14</sup>

EXPANDING ACCESS AND CULTURAL COMPETENCE

# RECOMMENDATIONS FOR FEDERAL POLICY ACTION

- Strengthen and expand Medicaid, ensuring that direct care workers and the people they serve continue to obtain health coverage and access to long-term services and supports. In the current federal debate, this means not undermining Medicaid's financing structure through blocks grants or a per capita cap, which would force states to cut benefits, limit enrollment, and cut payments to providers.
- Regularly assess how to improve access to lowcost services and supports, including in rural areas, where health and LTSS resources are sparse.
- Expand special needs
   demonstration projects that
   enable people to remain in
   the community, secure their
   care preferences, and prevent
   the costly and repetitive use of
   hospitals and skilled nursing
   facilities.
- Promote and fund culturally and linguistically appropriate training and services that effectively reach communities of color and LGBT people.



### WHAT'S IN CONGRESS\*

The Community-Based Independence for Seniors Act of 2015, which would establish a Community-Based Institutional Special Needs Plan demonstration program to provide home and community-based care to eligible Medicare beneficiaries.

The Older Americans Community Access Revitalization and Education Act (CARE Act), which would create a demonstration project in which an intraprofessional team provides "wraparound" services to high-cost, high-need older people.

The Medicare Adult Day Services Act of 2015, which would expand Medicare coverage to include adult day care, including medical care, rehabilitation therapies, and a range of other services to older people and people with disabilities. The Senior Home Modification Assistance Initiation Act, which would amend the Older Americans Act to provide federal resources for home modifications for older people, enabling them to live independently and safely in their homes.

The Ruthie and Connie LGBT Elder Americans Act, which would amend the Older Americans Act to include LGBT older people, specifying them as a vulnerable population with greatest economic and social need as a result of a lifetime of discrimination.

### A Note on Family Caregiving

Home care workers and family caregivers often work together to support older people and people with disabilities in their homes and communities. The two systems complement each other; home care workers support older people, people with disabilities, and their families with caregiving needs, and when family caregivers aren't available, paid caregivers provide all of the care. A home care worker can also be a central part of the care team, working with clients and families to deliver the best care possible. Unfortunately, without paid assistance, family caregivers are increasingly strained to provide this care alone, incurring significant out-of-pocket costs and toiling with the physical and emotional pressures associated with caregiving.15 As one approach, PHI supports the federal effort to establish a national strategy for family caregivers through the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act. We also urge federal leaders to support training initiatives, research, and other innovations that promote a holistic approach to care management among home care workers, their clients, and family caregivers.





### Conclusion

The typical home care worker makes \$10 an hour, works part-time and irregular hours, and relies on public benefits to manage her health and remain financially secure. She is part of a rapidly growing occupation in the country, spurred by an aging America. Yet despite the value of direct care and the growing demand for these workers, she will likely leave her job within a year, exacerbating the workforce shortage that looms heavy over older people, people with disabilities, and their families. In turn, millions of people are left without proper care. This is the all-too-common story of the more than 4.4 million direct care workers in this country and the millions of workers to come—unless we strengthen this workforce.

Federal reform can reverse these trends and change the lives of both workers and their clients. A federal investment in this workforce would promote better wages and benefits, enhance training and create advanced roles, collect regular data on the workforce and the quality of both jobs and care, expand access to services and supports, and thread the contributions of family caregivers with those of paid caregivers, ultimately creating a vibrant system of care. Millions of Americans are relying on our ingenuity and solutions. The time for federal reform is now.

### Appendix A:

Highlights of PHI's Record of Bipartisan Federal Policy Action

The U.S. Department of Health and Human Services (HHS) funds PHI, in partnership with the thennamed Future of Aging Services, to formulate a collection of papers exploring public policies and industry practices affecting the recruitment and retention of direct care workers.

PHI advises and authors a chapter in the Institute of Medicine's Retooling for an Aging America: Building the Health Care Workforce, a seminal federal report calling for increased attention on health care workers, including the direct care workforce.

Through a grant from the National Institute on Disability and Rehabilitation Research at the U.S. Department of Education, PHI begins sub-contracting with the now-named Community Living Policy Center at the University of California, San Francisco, to provide research and analysis on strengthening the personal care aide workforce nationwide. This essential work continues today.

2002 2005 2006 2008 2009

- As part of a multi-state research initiative, the Centers for Medicare and Medicaid Services (CMS) funds PHI to produce a series of publications to help state agencies, service providers, and individual consumers recruit, train, and retain home care workers.
- As one of the primary partners for the National Direct Service Workforce Resource Center established by CMS, PHI develops a range of online resources and provides technical assistance to state leaders to address the growing workforce shortage in direct care.
- CMS and the U.S. Department of Education fund PHI to provide guidance on the state of workforce data through its landmark report, The Need for Monitoring the Long-Term Care Direct Service Workforce and Recommendations for Data Collection.
- PHI co-founds the Eldercare
  Workforce Alliance, along
  with 25 national organizations
  committed to preparing the
  health and long-term care
  systems to support older
  Americans and their families.
  PHI is appointed a co-convener
  of this historic alliance.

The Office of Management and Budget adopts PHI's recommendations to redefine its occupational titles and definitions for direct care workers, which now includes home health aides, psychiatric aides, nursing assistants, and personal care aides.

To support the Personal and Home Care Aide State Training (PHCAST) Program, the Health Resources and Services Administration works with PHI to inform the curriculum design of six states' training initiatives. PHI works closely with the U.S. Department of Labor to inform its historic rule extending wage and overtime protections under the Fair Labor Standards Act to home care workers nationwide. After a court delay, and two years of advocacy, the rule goes into effect in October 2015. PHI provides more than 30 recommendations to CMS to modernize its regulations that govern Medicaid managed care and nearly 80 recommendations to help improve nursing home regulations.

PHI becomes a member of the Forum on Aging, Disability, and Independence at the National Academies of Sciences, Engineering, and Medicine.

2010 2013 2014 2015

PHI partners with SAGE to design a training curriculum for its National Resource Center on LGBT Aging, seeded by a historic grant from the U.S. Department of Health and Human Services. PHI joins a 20-member, national committee of experts at the Institute of Medicine (now the National Academies of Sciences, Engineering, and Medicine) to study the state of family caregiving, resulting in the 2016 report, Families Caring for an Aging America.

PHI has transformed the federal landscape for direct care workers—leading the research, analysis, and advocacy for this rapidly growing segment of the American workforce.

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