



TOGETHER IN CARE[®]

Empowering Direct Care Workers and Family Caregivers to Meet Growing Demand for Care

A PHI and National Alliance for Caregiving Issue Brief

JUNE 2024



This initiative has been made possible by generous support from



The
John A. Hartford
Foundation

INTRODUCTION

Together, direct care workers and family caregivers help millions of older adults, people with disabilities, and people with chronic conditions to live independently in their homes and communities. They are an essential resource when individuals choose to rely on other care settings, such as assisted living communities and skilled nursing homes.

As the U.S. population ages, demand for care will continue to rise across the full spectrum of long-term services and supports (LTSS), including demand for home and community-based services (HCBS).

Yet, direct care workers and family caregivers remain deeply undervalued and are still often overlooked entirely, despite ongoing federal, state, and community-level calls for investment in the care economy. Direct care workers face poor job quality, with a lack of sufficient training, inadequate compensation and support, and limited opportunities for advancement.¹ Family caregivers face isolation, care coordination challenges, economic impacts, and their own health risks.²

In response to these ongoing challenges, PHI and the National Alliance for Caregiving (NAC) leveraged vital support from The John A. Hartford Foundation to launch the *Together in Care*[®] initiative in 2023. Together, we seek to elevate and empower the critical relationship between direct care workers and family caregivers, to strengthen home and community-based services and increase access to high-quality, affordable care and support overall.

Drawing from PHI's direct care workforce expertise and NAC's expertise in empowering family caregivers, we ground this initiative in the knowledge that — while family caregivers and direct care workers are essential to our nation's care infrastructure — their care partnership has received far too limited focus.

This *Together in Care* issue brief draws attention to emergent mutually beneficial opportunities to change the paradigm for direct care workers and family caregivers — and highlights the need for additional research and increased evidence that can inform critical policy and practice-based interventions. We draw on insights from direct care workers, family caregivers, and recognized leaders in caregiving, home care, aging and disability services, Medicare and Medicaid, and workforce development. We gathered these perspectives through a September 2023 national convening with more than ten experts, 13 additional individual subject matter expert interviews, and a robust literature review.

In this brief, PHI and NAC share joint recommendations to strengthen the partnership between direct care workers and family caregivers. We have prioritized improvements to direct care jobs, recognizing poor overall job quality and resulting challenges to recruitment and retention as the greatest barriers to an effective and impactful partnership between direct care workers and family caregivers.

We are all together in care, bound by shared responsibility and collective need. Direct care workers and family caregivers hold the key to bringing an effective system of person-and-family-centered care and support to reality.



DIRECT CARE WORKERS AND FAMILY CAREGIVERS: AN ESSENTIAL PARTNERSHIP

In this section of our issue brief, we provide a snapshot of who direct care workers and family caregivers are, and the value they bring to U.S. society. Better understanding and investing in the contributions and needs of these caregivers is vital to improving the care and support they provide for older adults, people with disabilities, and people with chronic conditions.

Who Are Direct Care Workers?

More than 4.8 million direct care workers — including personal care aides, home health aides, and nursing assistants— support older adults and people with disabilities in private homes, residential settings, nursing homes, and other care settings across the country.³ These workers assist individuals with daily personal care, help them maintain their optimal health and wellbeing, and support their social engagement. Because they spend more time with individuals receiving care and support than any other healthcare or social care provider, they also offer vital information and insight to inform care planning and delivery.⁴

Despite their critical importance and impact, direct care occupations are characterized by poor job quality. With a median pay rate of \$15.43 per hour and a prevalence of part-time hours, nearly half (46 percent) of this workforce relies on public assistance and more than a third (39 percent) live in or near poverty.⁵

Direct care workers struggle with limited access to health insurance and paid time off, insufficient training, lack of recognition and respect for the important work that they do, and limited advancement opportunities.⁶ These factors contribute to high turnover rates and a shortage of workers at a time of growing demand.⁷ Because industries such as fast food and retail pay higher wages— often with better schedules— direct care workforce recruitment and retention are significant challenges.⁸

From 2016 to 2060, the population of adults 65 and older in the U.S. is projected to nearly double from 49.2 million to 94.7 million. Between 2021 and 2031, the direct care workforce is projected to add more than 1 million new jobs, representing the largest growth of any job sector in the country. During the same timeframe, nearly 9.3 million total direct care jobs will need to be filled, reflecting both new jobs and vacancies created as existing workers leave the field or exit the labor force. Addressing direct care job quality will be essential to recruiting and retaining sufficient workers to meet demand.¹⁰

The U.S. Direct Care Workforce

Women	86%
People of Color	62%
Immigrants	27%
Median Hourly Wage	\$15.43
Living in or Near Poverty Level	39%
Rely on one or more forms of public assistance	46%

Who Are Family Caregivers?

According to a 2020 NAC/AARP report, more than 53 million family caregivers provide essential care and support for millions of people in the U.S. today.¹¹ Drawing from NAC/AARP’s 2020 report, *Caregiving in the U.S.*, our issue brief defines a family caregiver as “any adult who provides unpaid care or support to a family member or friend.”¹²

Individuals take on family caregiving roles at every adult age. Approximately one in four caregivers (24 percent) are aged 18-34, and nearly half (47 percent) are under 50. More than one in three (35 percent) are aged 50-64, and one in five (19 percent) are 65 or older.¹³ The majority of family caregivers (61 percent) are women.

Family caregivers face both economic and health challenges as a direct result of caregiving. In total, 45 percent of family caregivers have experienced at least one adverse economic impact from caregiving, and nearly two-thirds (61 percent) have experienced employment impacts. Many report physical or emotional strain: approximately one in four report difficulty taking care of their own health, with a similar proportion seeing their own health decline. Two in ten family caregivers report feeling isolated or alone in their caregiving journey.¹⁴

Notably, one in four family caregivers (24 percent) care for multiple people, and an increasing number of family caregivers care for those with multiple conditions.

Family Caregivers in the U.S.

People of Color	39%
Women	61%
Men	39%
Experienced an adverse economic impact from caregiving	45%
Experienced an employment impact from caregiving	61%
Difficulty taking care of their own health	23%



Interconnected Roles

Care provided by direct care workers and family caregivers is inextricably linked. Nearly a third (31 percent) of family caregivers report that the family member for whom they provide care also receives paid home care from a direct care worker.¹⁵ Research shows that each member of this caregiving dyad often sets the stage for the other's success in providing care and support for essential daily tasks and activities, referred to as activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs).¹⁶ Family caregivers often provide new home care workers with critical information about an individual's specific needs and preferences and orient them to the home.¹⁷ Direct care workers are an essential support to family caregivers, helping them to balance care with other personal or professional responsibilities.

Unfortunately, a lack of sufficient investment or support infrastructure pressurizes the working partnership between direct care workers and family caregivers. The shortage of direct care workers — representative of both high turnover as a result of poor job quality, as well as significant new demand — can make it challenging for families to find workers. When workers are available, family caregivers and consumers can struggle to connect with the right match and navigate the long-term care system to find publicly funded or financially sustainable private pay care options.

Once the consumer, family caregiver, and direct care worker are connected, maximizing effective communication and collaboration between them at the point of care is crucial.¹⁸

Interventions to address challenges for direct care workers or family caregivers have very often been one-sided—focused only on the experience of one group or the other. Yet addressing the pressures of family caregiving, workforce turnover, and expanding overall demand for direct care workers will require innovative, multi-faceted systemic solutions, and recognition that neither direct care workers nor family caregivers operate in a silo.

By strengthening the working partnership between family caregivers and direct care workers, we can make meaningful change to benefit millions of Americans who receive care—and millions who provide it.

A Call to Invest In Caregivers

Recognizing direct care workers as essential partners to family caregivers, the 2022 National Strategy to Support Family Caregivers¹⁹ (the 2022 National Strategy) made key recommendations for investment in this workforce.

The 2022 National Strategy called for the formation of a federal interagency task force to develop a direct care workforce development plan. **Congress** should pass legislation to establish this task force focused on multiple areas – including many identified in the National Strategy:

- Empower direct care workers to collaborate more effectively with consumers and family caregivers.
- Increase direct care workforce wages at the federal level, and incentivize state legislators, state agencies, and managed care plans to increase workforce wages and expand benefits.
- Incorporate “other issues that impact the workforce such as immigration reform, and student federal loan forgiveness programs.”

On April 18, 2023, President Biden signed an Executive Order that included more than 50 executive actions to enhance care in America. This historic executive action recognizes the dual importance and interdependence of paid and unpaid caregivers and calls upon executive agencies to advance a care agenda that elevates the crucial roles of direct care workers and family caregivers.²⁰

ISSUE BRIEF

RECOMMENDATIONS

Drawing on the input of a broad range of experts our complementary experience, PHI and NAC have identified recommendations in four areas to strengthen the partnership between direct care workers and family caregivers:

1. Promoting Care Team Integration

We recommend specific policies to support the full integration of both direct care workers and family caregivers into interdisciplinary care teams, including through training, technology, and regulatory change. We also recommend practices that strengthen direct care worker and family caregiver communication, collaborative problem-solving, and shared decision-making.

2. Expand Access to Self-Direction

We recommend policies that expand awareness, access to, and engagement in self-direction programs, particularly those with greater flexibility with regard to the inclusion of family members as paid caregivers. Such policies can address some of the economic challenges for family caregivers, help to meet the rapidly growing demand for direct care workers, and capitalize on family members' strong understanding of an individual's needs and preferences. Recognizing the significant demand for direct care workers, we also recommend that states assess and pursue development of targeted training and support for family caregivers who seek pathways to longer-term employment in direct care and other LTSS roles.

3. Strengthen Matching Services Registries

We recommend policies to improve the evidence base and fund the creation and maintenance of matching service registries—online platforms that can facilitate robust connections between individuals, families, and direct care workers.²¹ Currently, 20 matching service registries cover 12 states, allowing consumers and family members to search for direct care workers according to a range of criteria such as location, gender, availability, means of transportation, training credentials, and experience. Expanding the number of states with matching service registries and incorporating additional matching criteria for both direct care workers and consumers can significantly expand the impact of these resources.

4. Invest in Research and Evaluation

Finally, we recommend research and evaluation efforts focused on the collaborative relationship between direct care workers and family caregivers, to support the development of evidence-based and innovative practices that empower both direct care workers and family caregivers to strengthen person-and-family-centered care.

As noted above, our recommendations prioritize improvements to the quality of direct care jobs, recognizing that poor job quality presents the greatest barrier to an effective and impactful partnership between direct care workers and family caregivers.

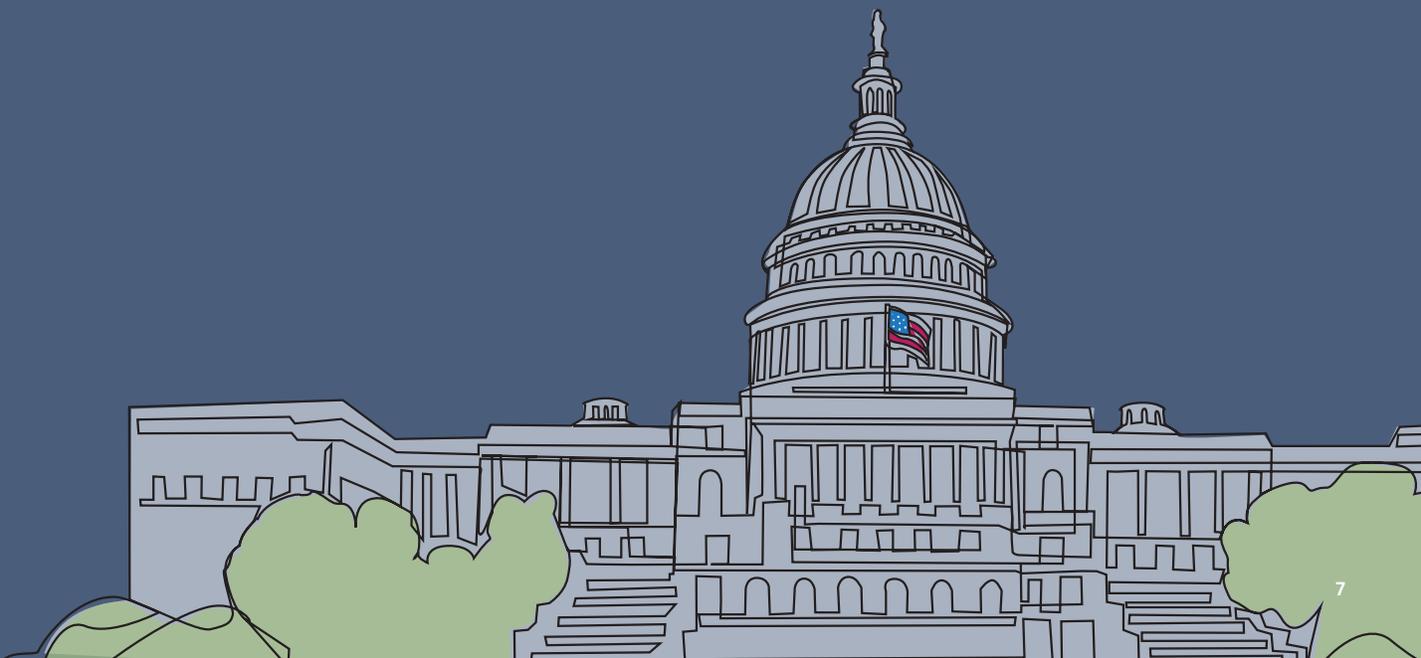
A Pivotal Moment for Caregivers

We are publishing this issue brief at a time of significant political division in the U.S., with national, state, and local election results that have and will continue to shape the conversation around our care economy for years to come.

The recommendations reflected below are intended to be non-partisan. The need for access to high-quality, person-and-family-centered care for all those who need it should be a unifying issue that generates bipartisan agreement, drawing from the commonality of our collective experience.

Bipartisan awareness of the importance of the care economy has grown exponentially in recent years. Policies and priorities to better support direct care workers and family caregivers, which were advanced in previous administrations, have gained critical momentum in the Biden Administration.

However, much work remains. American voters can play a critical role in electing candidates that prioritize the needs of consumers, family caregivers, and direct care workers. Investing in care is a social and economic priority that should span the political spectrum. Leaders on both sides of the aisle can lead the way in implementing the types of policies recommended in this issue brief. Building a care infrastructure that can benefit millions of individuals and families can be a source of hope and a demonstration of American values.



1. Care Team Integration

Policymakers, provider employers, and researchers should explore and test ways to support the integration of both direct care workers and family caregivers into care teams in ways that meet the preferences of consumers.

Direct care workers and family caregivers spend by far the most time with the individuals they support on a day-to-day basis, and therefore have essential knowledge of their experiences and needs. However, both direct care workers and family caregivers are too often excluded from care teams and care planning, which can lead to fragmentation, miscommunication, and information gaps.

Care team integration refers to the integration of family members and direct care workers into the interdisciplinary care team. Together, these essential caregivers can help to inform care planning and assessment, strengthen coordination, report changes in an individual's health status or Social Determinants of Health, and improve care quality, outcomes, and efficiency.

The imperative for care team integration for caregivers has deep roots. More than a decade ago, the Centers for Medicare & Medicaid Services (CMS) released a report highlighting the need for inclusion of both direct care workers and family caregivers in care teams to foster care coordination and promote person-centered care.²² The report clearly recognized the need for both training and funding to realize this goal. The 2016 resource *Families Caring for an Aging America*, produced by The National Academies of Sciences, Engineering and Medicine's Committee on Family Caregiving for Older Adults, clearly articulates how consumers often prefer or require involvement from family members or trusted friends in every aspect of care, including gaining access to support, care coordination, and support with ADLs.²³

One of the only evidence-based interventions to support care team integration for direct care workers was led by the California Long-Term Care Education Center (now called the Center for Caregiver Advancement). Supported by a CMS Health Care Innovation Award,²⁴ an intervention led by the California Long-Term Care Education Center²⁵ provided 60.5 hours of training for In-Home Supportive Services (IHSS) workers providing care to Medicaid-eligible consumers in California, to prepare these workers to take on more responsibility in the home in support of consumers. Each of the 17 training modules contained an "integration activity" that allowed participants to practice identifying problems and communicating with other members of the care team.

An impact study showed that participating IHSS workers felt that they were delivering better care, and that consumers agreed with this assessment. IHSS workers also reported that the training enhanced their confidence and communication with primary care providers, even for those who were already integrated on care teams. In turn, consumers were more satisfied with their IHSS workers, and felt confident that their IHSS workers would communicate well with their care teams. The study also showed that consumers experienced reduced emergency room visits and rehospitalizations two years after the training. Future efforts should assess the impact of providing family caregivers with comparable training, in tandem with direct care workers, an effort likely to be beneficial for their collaboration, the resulting quality of care for consumers, potentially further reducing emergency room visits and rehospitalizations.

With funding from New York State's Balancing Incentive Program, a 2015-2016 PHI initiative provided an advanced Care Connections Senior Aide role for home care workers predicated on care team integration. Conducted in collaboration with the managed care provider Independence Care System and multiple home health agencies, the Care Connections Senior Aide provided coaching and support to both home care workers and family caregivers, and a telehealth component to the project complemented this effort

by facilitating communication between home care workers and their supervisors about changes in a consumer client's condition (as well as a timely response from supervisors). Implementing this role led to an 8 percent reduction in emergency room visits for involved consumers, decreased family caregiver strain, improved relationships with consumer clients and families, improved direct care workforce communication with clinical managers, and increased job satisfaction for participating home care workers.²⁶

PHI has now developed curriculum and a model for experienced home care workers known as the Care Integration Senior Aide,²⁷ a model based on the

Care Connections Senior Aide. The newly developed CISA role places a greater focus on social determinants of health (SDOH) as well as clinical care. CISAs are trained to "observe, record, and report" on consumers' health conditions and SDOH, and communicate the necessary information to consumers' care teams, as well as liaise with the consumers and their family caregivers so everyone involved in the consumer's care is informed. The CISA's support can help to deepen communication between entry-level direct care workers, family caregivers, and consumers around health conditions and SDOH, ensuring that these perspectives more strongly inform the care team.

RECOMMENDATIONS and CONSIDERATIONS

- The **Health Resources and Services Administration (HRSA)** should fund additional pilot and demonstration projects, evaluating practice approaches to strengthening direct care worker, family caregiver, and consumer communication and collaborative problem-solving, and then develop policy guidance informed by the findings.
- Leveraging the knowledge generated through Geriatrics Workforce Enhancement Programs (GWEPs) and other initiatives, **states** should identify, disseminate, and consider funding training programs that support proactive communication and collaborative problem-solving between consumers, family caregivers, and direct care workers. **Provider organizations** should incorporate training in these areas for all staff, including direct care workers.
- To enhance the support provided to caregivers and improve overall care outcomes in the home health setting, we recommend that **policymakers, managed care plans, and employer providers** ensure that direct care workers receive enhanced training to better meet the care and support needs of consumers. Providers should receive reimbursement for enhanced observation skills to inform interdisciplinary care team discussions. Data should be collected on the impact of this practice on care outcomes and care team integration and support. By systematically embedding caregiver observations, care teams can gain valuable insights into the specific needs of clients and tailor training resources for caregivers accordingly. By equipping direct care workers with the skills to

observe changes in condition and working with home health care providers to operationalize communication internally, they can proactively address the diverse needs of caregivers and ultimately enhance the quality of care provided in the home.

- **States and provider employers** should explore ways in which experienced direct care workers can take on advanced roles—within their scope of practice—to support care team integration and empower consumers and family caregivers. By providing opportunities for career growth, such practices can also support improved recruitment and retention.
- Despite more than three million Medicare beneficiaries receiving home health services,²⁸ the current Home Health Benefit structure often falls short in meeting the complex needs of people with multiple chronic conditions.²⁹ Many family caregivers, unaware of the benefit, miss out on valuable support from home health providers. This gap not only jeopardizes individual well-being but also creates financial strain and hardship for the family caregiver. To address this, it is crucial to better engage family caregivers in the utilization of the Medicare Home Health Benefit.

This starts with ensuring Medicare beneficiaries and their family caregivers fully understand the home health benefit's limitations and eligibility criteria, which covers a range of home health services and in targeted instances (for individuals receiving skilled nursing care) can include part-time or intermittent home health aide care.³⁰

Expanding Training for Direct Care Workers: The Bigger Picture

This issue brief speaks to the importance of training to maximize the partnership between direct care workers and family caregivers.

A crucial step in these efforts, and in improving job quality for direct care workers overall, is defining core competencies for direct care occupations, to serve as a baseline and a foundation for training and credentialing.

States should explore ways to enable trained workers to move across settings with recognized credentials (making them universal within the state, and providing momentum for a federal credential), as a way to increase job opportunities and professionalize the field. Setting-specific and other specialty training could be aligned to the core competencies, creating pathways to advanced roles and other career advancement opportunities.

States should consider creating training modules that align with consumer and family caregiver needs, ultimately increasing workforce competencies and retention, and improving the quality of direct care jobs, making them more attractive to job seekers.

States should look to examples such as Wisconsin's Certified Direct Care Professional (CDCP).³⁴ The CDCP is a credential based on direct care worker core competencies that are required across long-term care settings. This credential rationalizes the training infrastructure for direct care workers by providing a set of recognized core competencies upon which specialty or setting-specific training can be stacked. This expands worker mobility and job opportunities. Legislation under consideration in the U.S. Senate calls for the establishment of a national training standards commission, which would advance the concept nationally.³⁵

CMS should implement a comprehensive education campaign aimed at certifying providers, beneficiaries, and family caregivers to ensure they are fully informed about Medicare's home health coverage parameters and the full range of available services. Further, CMS should enforce the family caregiver preparedness requirements that are included in current home health agency conditions of participation.

- State-level regulations and employer practices often limit access to health information for direct care workers. Yet, early indications from research efforts suggest that home care workers find access to health information helpful in their work with consumers,³¹ and there is potential to deepen care team integration should such access be expanded. **CMS and states** should explore pilot programs that test ways to increase access to health information for family caregivers and direct care workers, to build the case for evidence-based and evidence-informed interventions that improve care coordination. Practice approaches should center the consumer's perspective and permission. Key considerations include digital literacy, training needs, language accessibility, regulatory/scope of practice questions, and effective use of technology.³²
- As the Hospital at Home (HaH) Program expands and possibly becomes permanent,³³ **Congress** should direct CMS to establish metrics for evaluating the experiences and impacts of family caregivers in the program. **CMS** should develop comprehensive guidelines for supporting family caregivers engaged in HaH, including provisions for care coordination, planning, and training in partnership with direct care workers and other healthcare providers.
- In order to help realize additional potential for care team integration, **Congress** should advance legislation to permanently extend telehealth flexibilities for Medicare beneficiaries.
- **State Medicaid programs** should explore allowing flexibility for family caregivers to operate telehealth for care recipients. At the same time, states should explore the benefits of direct care workers having the ability to use telehealth technology in collaboration with family caregivers and consumers, to open additional lines of communication and information sharing essential to effective care team integration.

2. Expanding Access to Self-Direction

States and consumer advocates should explore opportunities to expand self-directed care programs in every state, to assess how new programs and expanding opportunities for self-direction can support more consumers and family caregivers and strengthen the pipeline of direct care workers.

Self-direction— also known in some contexts as consumer-direction —refers to the ability of care recipients, or their legally appointed representatives, to recruit, hire, train, and supervise their own direct care workers, often known as independent providers in this model. In some states and in specific circumstances, self-direction programs allow family caregivers to become paid caregivers for a family member. If family caregivers themselves do not wish to (or are not permitted to) serve as the paid caregiver, they can play a critical role in supporting the care recipient in hiring a direct care worker.

There are decades of evidence for the effectiveness of consumer-directed models. Findings from the “Cash & Counseling” demonstration project (1996-2009) were very positive. Compared to a control group, the Medicaid-eligible consumers participating felt like their care needs were better met, were more satisfied with their care, and reported better quality of life outcomes. Workers were also more satisfied, and family caregivers of participants reported better quality of life and less physical, emotional, and financial stress. Under this self-direction model, participants were no more likely to experience adverse events or health problems; some health problems showed a reduced incidence.³⁶

Further investment came in the form of the Money Follows the Person demonstration, a federal initiative to rebalance the emphasis of Medicaid-funded care from institutional to home and community-based settings, through which some states expanded access to self-direction.³⁷

The Affordable Care Act’s Community First Choice Option further expanded the ability of states to provide self-direction programs.³⁸ Today, per reporting from the National Academy for State Health Policy (NASHP) and Applied Self Direction, the national authority on consumer direction, all 50 states and Washington, D.C. currently have at least one self-directed option for LTSS.³⁹

The 2022 National Strategy to Support Family Caregivers calls for “Medicaid programs, programs offered by the VA, and Medicare Advantage programs to expand community-based long-term care options, including expanding self-directed opportunities to allow for the hiring of family caregivers, while also funding LTC services at rates that attract and retain a skilled direct care workforce.”



RECOMMENDATIONS and CONSIDERATIONS

- **States** should continue to examine Medicaid program models that allow family caregivers to be paid as a means of addressing direct care worker shortages and promoting consumer choice. Self-directed models can allow beneficiaries to select and pay for direct care workers—including family caregivers—to provide personal care, especially in rural areas and those with limited provider options. In the case of paying legally responsible family caregivers, these models should ensure protection of the individual's autonomy and prioritize community integration.
- **State Medicaid programs** should consider making training and supports available to family caregivers who take on the responsibility of providing paid care, implementing caregiver assessments to ensure caregiver needs are identified and addressed as part of consumer direction programs. Offering peer mentorship and access to healthcare for paid family caregivers may help offset the challenges and potential burnout associated with family caregiving.⁴⁰ States should also assess and pursue developing targeted training and support for family caregivers who, after taking on paid roles caring for a family member, seek pathways to longer-term employment in direct care and other LTSS roles.



- In April 2024, **CMS** issued a comprehensive final rule on Medicaid-funded home and community-based services. Provisions included more stringent requirements for data collection and evaluation. CMS should support states to include specific metrics related to self-direction in their data collection and reporting.
- While self-direction has expanded, particularly since the COVID-19 pandemic, the extent to which individuals with disabilities have opportunities to self-direct is still quite limited. Many barriers exist within programs, and some either do not allow certain family members and legally responsible relatives to be hired, or place unnecessary restrictions. Restrictions on hiring legally responsible relatives were lifted during the Covid-19 public health emergency. However, hiring of legally responsible relatives remains entirely prohibited within the Medicaid state plan personal care option. **CMS** should eliminate this restriction, which limits the ability for states to streamline and align policies within their HCBS programs. Such a change could increase both the quality and efficiency of care in states and nationwide.
- Enrollment among consumers eligible for self-direction is limited to date; too few individuals know that this is an option. **CMS** should provide technical assistance to states to support outreach with regard to self-direction, with a focus on expanding reach with underserved communities.
- According to the Arch National Respite Network and Resource Center, a growing number of state, federal, and private sources provide options for respite for family caregivers.⁴¹ **States** should consider continuing to expand access to respite care for family caregivers, including respite care options within self-directed programs, and should expand options that allow family members to provide paid respite care services.⁴² **States and employer providers** should focus on ensuring that respite care assignments can help to support full-time employment for direct care workers. Employer providers should also ensure that direct care workers have training and support in relationship-building and communication with family members and consumers during the short-term engagements common to respite services.

The Power of Self-Direction Programs, and The Importance of Training

At age 18, Zchon Polon was supporting his grandfather as an unpaid family caregiver in a rural part of Washington state. Through a self-directed program, he became an Independent Provider to care for his mother throughout her cancer treatment, and to care for his brother, who has Down syndrome. Consumer-directed programs give families like Zchon's more control over their home care services by enabling them to hire their own IPs directly. While many family caregivers face challenges balancing unpaid caregiving with paid employment, Zchon receives compensation for providing care through the Consumer Direct Care Network Washington.

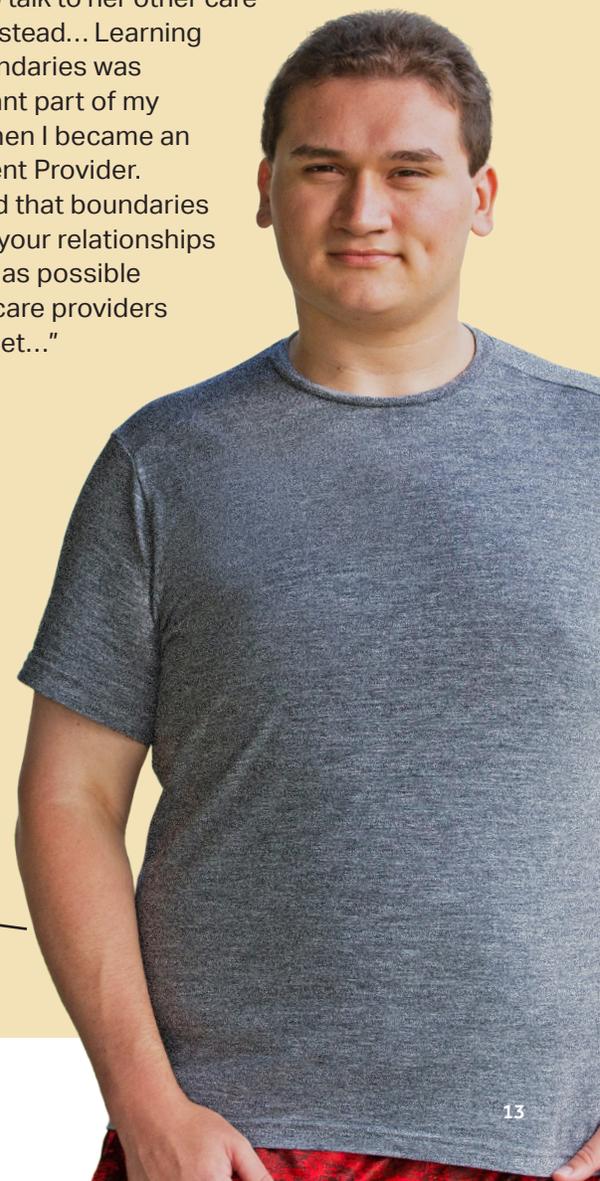
"I had already been helping out my grandfather with things around the house when he was diagnosed with ALS. As he started having more and more medical needs, much of the care fell to me. It's something I wanted to do initially—I enjoyed helping him and spending time with him—but it soon became something I did out of necessity for my family because no one else was able to step in and help."

Zchon's story underscores the importance of training for direct care workers and family caregivers alike, given the challenges caregiving roles can bring.

"Once I officially became an Independent Provider, I got access to resources and trainings I wish I had when I first cared for my grandfather. Now, my clients are my mom and my brother. This work is rewarding in its own right, and I like being able to support

individuals' needs and help them do things they can't do for themselves. But caring for someone as your job is a lot more demanding than people think."

"Burnout can happen in any job, but especially with providing care, and especially when that care is for family members. When it comes to caring for family, there needs to be role distinction and a separation so you're not 'on' all the time. Otherwise, that line can get blurred easily. When I have a day off, I tell my mom she can reach out if she really needs something from me, but otherwise, I ask her to talk to her other care provider instead... Learning about boundaries was an important part of my training when I became an Independent Provider. We learned that boundaries help keep your relationships as healthy as possible and allow care providers time to reset..."



3. Matching Service Registry Options

Policymakers, practitioners, and payors should collaborate to fund the creation and maintenance of—and evidence base for—matching service registries as effective vehicles for connecting individuals, families, and direct care workers.

Matching service registries are online portals where direct care workers can advertise the experience, credentials, and care services they provide, and consumers can create profiles that describe the care that they are seeking. These searchable portals enable workers and consumers, and in some cases family members, to directly connect with each other based on their complementary experiences, needs, and preferences. A well-designed, robust matching service registry therefore has potential to ensure that workforce expertise and consumer needs align. Moreover, matching service registries—by facilitating better matches between workers and consumers—can strengthen continuity of care, which is highly valued by family caregivers and associated with better care outcomes for consumers.⁴³

Despite their value in connecting workers and consumers and supporting family caregivers, there has been little sustained public investment in matching service registries to date. Presently only 12 states offer these registries (PHI, 2024).⁴⁴

A 2023 CMS Bulletin acknowledged the value of matching service registries, provided guidance on how states can establish them, and indicated that start-up and technology costs could be eligible for enhanced federal financing.⁴⁵ The bulletin also shared that American Rescue Plan Act (ARPA) funds from the COVID-19 pandemic could be put towards developing registries if coordinated through CMS. The window of opportunity is narrow as CMS expects states to expend such funds by March 31, 2025.⁴⁶

RECOMMENDATIONS and CONSIDERATIONS

- The **U.S. Department of Labor** should commission a feasibility study to assess the strengths, risks, logistics, and total costs of launching and promoting matching service registries in every state.
- The **U.S. Department of Labor and CMS** should also provide guidance on how matching registries can provide resources such as sample employment agreements to support the independent matching and contracting between consumers and service providers. DOL should collaborate with PHI and state-based organizations to strengthen the infrastructure for these efforts.
- Building on its 2023 bulletin, **CMS** should commission or fund an evaluation of matching service registries and sustain and expand its support to incentivize the development of effective models at the state level. Moreover, CMS should consider convening a learning collaborative and/or funding technical assistance to advance state efforts to establish and improve matching service registries.
- **State Medicaid programs** should consider designing matching service registries to empower consumer choice and support family caregiver needs, leveraging available federal resources and other funding sources. Designing these resources for language accessibility and promoting wide enrollment can significantly expand their impact.
- Matching service registries should be designed in collaboration with state-level Departments of Labor, Health, and Education, LTSS provider networks, community-based organizations, consumers, family caregivers, and direct care workers and other partners – to ensure that matching services registries create meaningful employment opportunities and provide robust access to care.



Impact for Women, People of Color, and U.S. Immigrants

Investment in the partnership between family caregivers and direct care workers has tremendous potential to benefit women, people of color, and U.S. immigrants.

From 2020 to 2060, the proportion of older adults of color will increase from 24 percent to 45 percent, and the proportion of older adults who are immigrants will increase from 14 percent to 23 percent.⁴⁷

As of 2020, three in five family caregivers (61 percent) are women. Four in ten are people of color, including 17 percent Hispanic or Latino, 14 percent non-Hispanic African American or Black, 5 percent Asian American and Pacific Islander, and 3 percent being another race/ethnicity, including multiracial.⁴⁸

Direct care workers are primarily women (86 percent) and people of color (62 percent).⁴⁹ While immigrants account for 17 percent of the overall U.S. labor force, they represent 32 percent of the home care workforce, 26 percent of the residential care aide workforce, and 21 percent of the nursing assistant workforce.⁵⁰

These statistics make clear that investing in direct care is imperative to addressing deep structural inequities related to gender, race and ethnicity, country of origin, and other intersecting identities. As one resource for additional consideration: A September 2023 PHI policy brief provides a strong overview of the role of immigrants within the direct care workforce and offers federal policy recommendations to better support these workers and improve care.⁵¹



4. Recommendations for Investment in Research and Evaluation

Federal and state policymakers, private philanthropy, and other payors should fund research and evaluation to inform policy and practices that strengthen the partnership between direct care workers, family caregivers, and the individuals they support.

A cross-cutting priority should be to build the evidence base on effective policy and practice interventions that strengthen and sustain the partnership between direct care workers and family caregivers. This evidence base—which should include the experiences of and outcomes for direct care workers, family caregivers, and consumers, as well as quality and cost factors—is critically needed to inform and compel future investment.

The existing research literature, although limited, offers promising insights to build upon. For example, research on family member and staff relationships in nursing homes has clearly shown associations between improved communication, family member and staff experiences, and resident outcomes.⁵² Research in the home care setting also highlights the importance and impact of effective communication between family caregivers and direct care workers.⁵³ In one study, family caregivers noted that caregiving tasks, such as symptom monitoring and interaction with medical providers, often require coordination with direct care workers.⁵⁴ They reported that good communication—including the clear

delineation of tasks—provides a roadmap for caring for a family member and helps reduce stress.

A clear message from across the current literature is that family caregivers, direct care workers, and consumers all benefit from training and support on communication and collaboration. But much more evidence is needed to support the scale and spread of training and support programs and other policy and practice interventions.



Recommendations and Considerations

- In 2019, Outcome and Assessment Information Set (OASIS-D) removed a question for clinicians about family caregiver training needs at the start of home health care, which had been the sole national source of such data. This removal has hindered the ability to systematically track family caregiver needs and identify opportunities to better inform direct care workers in supporting those needs. **CMS** should reinstate this item and leverage data to inform the optimization of family caregiver training needs by engaging and supporting health care providers and direct care workers.⁵⁵

- As recommended by the HCBS Forward workgroup that was convened by the Secretaries of Labor and Health and Human Services in 2023 through 2024, **federal funding** should be designated for a new national survey of services and supports for people under the age of 65 with disabilities and chronic conditions.⁵⁶ This study would complement existing studies on the caregiving needs of older adults, generate rich insight on caregiving across settings and programs (including consumer direction), and provide “a better understanding of the dynamics between paid and unpaid or informal care.”

- **The Secretaries of Labor and Health and Human Services** should fund a study of the gray market of unregulated private-pay home care. This study would help shed light on the nearly invisible experiences of direct care workers and family caregivers in this sector, as well as build better understanding of the true size and characteristics of the direct care workforce and LTSS system overall.

- **Federal and state agencies** should coordinate to fund and evaluate interventions and demonstration projects focused on strengthening communication and collaboration between direct care workers and family caregivers, improving care team integration (including through enhanced technology), supporting successful experiences in consumer direction programs, and other priority topics discussed in this brief. These evaluations should aim to assess outcomes for workers, family members, and consumers, as well as impacts on care delivery and cost, to make the case for deeper systemic investment in these areas.

- As a final research recommendation, **policymakers, employer providers, researchers,** and others should partner in building the evidence base on other areas of policy and practice that pertain to or impact direct care workers or family caregivers. As examples, more research is needed to:

1. Understand how family caregivers and direct care workers can be effectively engaged in care transitions, in order to help support care continuity and minimize the risk of rehospitalization and other adverse outcomes;
2. Examine how Family Councils can be structured to support stronger relationships between family members and staff in nursing homes;
3. Explore how family caregiver assessments can be leveraged by payers and employer providers to ensure that family members' needs are met and that they are empowered, together with direct care workers and consumers, as integral members of the care team; and
4. Examine how HIPAA-compliant dedicated messaging platforms can allow family caregivers, direct care workers and other members of the interdisciplinary care team to communicate directly and easily, among other topics.”





Team Kimmy: Providing Home Care for a Veteran

Karee and Jim White live just south of Raleigh in Apex, North Carolina. Both U.S. Army veterans (Karee a major; Jim a first lieutenant) the couple have nine children. Service is a family tradition: seven of Karee and Jim's adult children currently serve or have served in the military themselves.

Karee and Jim's oldest child, Kimmy Fix, served active duty in Afghanistan as an Army Medical Service Corps Officer. In 2014, at age 25, she suffered a traumatic brain injury in a car accident while stationed in Italy. In a severe coma, Kimmy wasn't expected to survive or emerge from her coma if she did.

Karee and Jim have been fierce advocates for Kimmy's care at every step, and they have made keeping her living at home where she can have the best quality of life possible their family's priority. Retrofitting a small cottage on their property for accessibility with help from friends, they set out to find sustainable care for her.

At first, coverage through the Department of Defense provided 24x7 care, but when Kimmy was retired from active duty, the family were left with just six hours per day of care for support. Through Karee's advocacy, the family were able to gain access to the VA's Veteran-Directed Care Program, a consumer-directed care program that empowers nursing home eligible veterans with a budget for home and community-based services.⁵⁷

This program, alongside other financial resources, makes it possible for the family to directly employ CNAs as caregivers to meet Kimmy's care and support needs.

"Living hour to hour became day to day, week to week, you know, and then finally, month to month is where we are now" Karee said.

While aphasia limits Kimmy's communication, she finds ways to make her preferences clear. Her dad, Jim, sees honoring those preferences as the most important thing the family can do. "I want to give her the most dignified life that she has left," he says.

Direct care workers are essential to that process, providing support for ADLs and building caring, trusted relationships with Kimmy to ensure that her care needs and preferences are honored. Kirstin Barbour, a CNA for Team Kimmy, says: "It's a really intimate job. You have to be intuitive... she can't always tell you what she wants or needs... I know at times she's trying to tell me something. A lot of the shift can be just trying to understand. It takes a lot of patience."

A nursing student, Kirstin speaks powerfully to finding meaning as a CNA caregiver for Team Kimmy. "This job chose me. That's the best way I can put it. I can leave work knowing I bettered their life in some small way."

Her hope for families like Kimmy's? "A change I would like to see," Kirstin says, "is [families] not having to advocate so much for themselves. There are so many resources that could help somebody, and if you don't know about it, you don't know to ask for it. There's a good chance you're not going to get it." Making such resources easier for individuals and families to access is vital to the future of care.

Jim speaks to wanting to ensure that Team Kimmy's direct care workers are well paid, acknowledging the economic burdens they face. As a nation, "it's a demographic reality that we need a lot of caregivers" Jim says. "If you don't want to pay them an extra \$5 an hour, you're missing the forest for the trees."

Despite challenges and significant limitations to what will be possible in her recovery, Kimmy continues to make progress. "I believe she understands 80 to 90 percent of the things I tell her," Karee says. Today, she is "the strongest she's been," she adds. "I don't know how much longer she's going to be around, but if her will is an element that's the most important in the mix...she'll be around a long time."

CONCLUSION

PHI and NAC welcome your responses to this brief. The recommendations and considerations shared are intended as the start to a national conversation about the interwoven roles and contributions of direct care workers and family caregivers.

We are all together in care – and we have the opportunity and responsibility to invest in our nation’s care infrastructure. We call on Congress, CMS, HRSA, the DOL, states and state agencies, managed care plans, provider employers, and advocates to invest further in the essential partnership between direct care workers and family caregivers.

These caregivers provide a lifeline for older adults, people with disabilities, and people living with chronic conditions. Empowering them in their roles will help to ensure high-quality, responsive care to meet the needs and preferences of millions of Americans, now and in the future.



NOTES

1. PHI, *Direct Care Workers in the United States: Key Facts 2023*
2. *Caregiving in the United States*, The National Alliance for Caregiving and AARP, 2020.
3. PHI. "Workforce Data Center." Last modified September 2023. <https://phinational.org/policy-research/workforce-data-center/>.
4. PHI. 2023. *Direct Care Workers in the United States: Key Facts*. Bronx, NY: PHI. <https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-2023/>.
5. PHI, 2023.
6. PHI, 2023.
7. Donlan, Andrew. 2023. "After 3-Year Dip, Home Care Turnover Soars To 77 percent." *Home Health Care News*, May 24, 2023. <https://homehealthcarenews.com/2023/05/after-dipping-for-three-years-home-care-turnover-rate-soared-to-77-in-2022/>; Gandhi, Ashvin, Huizi Yu, David Grabowski, 2021. "High Nursing Staff Turnover In Nursing Homes Offers Important Quality Information." *National Library of Medicine*, March 2021. <https://pubmed.ncbi.nlm.nih.gov/33646872/>
8. PHI. 2024. "Direct Care Workforce State Index." Last modified May 2024. <https://www.phinational.org/state-index-tool>.
9. PHI, 2023, *Direct Care Workers in the United States: Key Facts*.
10. PHI. "Workforce Data Center." Last modified September 2023. <https://phinational.org/policy-research/workforce-data-center/>.
11. NAC/AARP, 2020.
12. NAC/AARP, 2020.
13. NAC/AARP, 2020.
14. NAC/AARP, 2020.
15. *Caregiving in the United States*, 2020
16. The Administration for Community Living provides a range of examples of these activities, including ADLs and IADLs, here: <https://acl.gov/ltc/basic-needs/what-is-long-term-care>
17. Sims-Gould, Joanie, and Martin-Matthews, Anne, 2010. *We share the care: family caregivers' experiences of their older relative receiving home support services*. Health Soc Care Community. 2010 Jul;18(4):415-23.
18. Together In Care® Initiative Expert Panel, 2023.
19. CMS. Person-Centered Care | CMS.
19. The 2022 National Strategy was developed jointly by advisory councils created by the RAISE Family Caregiving Act and the Supporting Grandparents Raising Grandchildren Act. See Administration for Community Living, 2022. National Strategy to Support Family Caregivers, Washington, DC. <https://acl.gov/CaregiverStrategy>
20. See <https://www.whitehouse.gov/briefing-room/presidential-actions/2023/04/18/executive-order-on-increasing-access-to-high-quality-care-and-supporting-caregivers/>.
21. Source: PHI, 2023. See <https://www.phinational.org/advocacy/matching-service-registries/>.
22. National Direct Service Workforce Resource Center. 2011. *Common Goals and Policy Recommendations Emerging from the CMS Leadership Summit on the Direct Service Workforce and Family Caregivers*. Washington, DC. National Direct Service Workforce Resource Center. <https://www.medicaid.gov/sites/default/files/2019-12/cms-leadership-summit.pdf>
23. See <https://www.ncbi.nlm.nih.gov/books/NBK396396/>
24. <https://advancecaregivers.org/wp-content/uploads/2021/11/CLTCEC-Home-Care-Integration-Training-Project-Brief.pdf>
25. Today, the organization is known as the Center for Caregiver Advancement.
26. See https://www.phinational.org/impact_story/career-development-project-improved-clinical-outcomes/
27. PHI. <https://www.phinational.org/resource/implementing-the-care-integration-senior-aide-a-practical-guide-for-home-and-community-based-services-providers/>
28. CMS, 2021: See <https://www.cms.gov/medicare/quality/home-health>
29. Bipartisan Policy Center, 2024. https://bipartisanpolicy.org/download/?file=/wp-content/uploads/2022/04/Optimizing-the-Medicare-Home-Health_RO_Web-Ready.pdf
30. See <https://www.medicare.gov/coverage/home-health-services>
31. Fabius, Chanee. Personal interview. January 10, 2024.
32. Together In Care Experts Panel. September 2024.
33. AARP, 2022: <https://www.aarp.org/pri/topics/ltss/family-caregiving/family-caregiver-considerations-for-the-future.html>
34. WisCaregivers CDCP | Become a Certified Direct Care Professional (wiscaregivercdcp.com)
35. Casey, Colleagues Introduce Bill to Support Direct Care Workforce and Family Caregivers | Senator Bob Casey (senate.gov)
36. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1955329/>
37. <https://www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/index.html>
38. NASHP, 2021: <https://nashp.org/paying-family-caregivers-through-medicaid-consumer-directed-programs-state-opportunities-and-innovations/>
39. See these two references: <https://nashp.org/paying-family-caregivers-through-medicaid-consumer-directed-programs-state-opportunities-and-innovations/#:~:text=States%20are%20increasingly%20using%20consumer,one%20consumer%20direction%20LTSS%20option>
40. PHI and NAC Together In Care Experts Panel. September 2024.
41. See <https://archrespite.org/caregiver-resources/how-to-pay-for-respite/>.
42. NASHP, 2023: See <https://nashp.org/emerging-respite-care-strategies-in-medicaid-home-and-community-basedservices-waivers-for-older-adults-adults-with-physical-disabilities-and-their-family-caregivers/>

NOTES

43. Reckrey, Jennifer M., David Russell, Mei-Chia Fong, Julia G. Burgdorf, Emily C. Franzosa, Jasmine L. Travers, and Katherine A. Ornstein. 2024. "Home Care Worker Continuity in Home-Based Long-Term Care: Associated Factors and Relationships with Client Health and Well-Being." *Innovation in Aging*. Shaw, Amy L., Catherine A. Riffin, Ariel Shalev, Harveen Kaur, and Madeline R. Sterling. 2021. "Family caregiver perspectives on benefits and challenges of caring for older adults with paid caregivers." *Journal of Applied Gerontology* 40(12): 1778-1785. 44. PHI and NAC Together In Care Experts Panel. September 2024.

44. PHI, 2024. See <https://www.phinational.org/advocacy/matching-service-registries/>

45. CMS, CMCS Informational Bulletin, December 2023. https://www.medicaid.gov/sites/default/files/2023-12/cib12122023_0.pdf

46. CMS, December 2023.

47. PHI, Direct Care Workers in the United States: Key Facts 2023.

48. NAC/AARP, 2020.

49. PHI, September 2023.

50. PHI, 2023.

51. PHI, 2023 : see <https://www.phinational.org/resource/bridging-the-gap-enhancing-support-for-immigrant-directcare-workers/>

52. Falzarano et al., 2022.; Haesler et al., 2010.

53. Reckrey et al., 2020.

54. Shaw et al., 2021

55. See <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8742751/>

56. <https://acl.gov/sites/default/files/Direct%20Care%20Workforce/improving-hcbs-workforce-data-issue-brief.pdf>. HCBS Forward stands for "Home and Community-Based Services Federal Opportunities Regarding Workforce and Research Data. This workgroup was convened in response to President Biden's Executive Order 14095: *Increasing Access to High-Quality Care and Supporting Caregivers*.

57. See https://www.va.gov/geriatrics/pages/Veteran-Directed_Care.asp

© PHI 2024

AUTHORS:

Amy Robins, Ben Freeman, Antoniette "Toni" Gingerelli, Mike Wittke

APPENDIX: Expert Panel List

PHI and NAC extend special thanks to our Together in Care Expert Panel, for sharing your time and expertise to inform this initiative:

Corinne Eldridge
President & CEO, Center for Caregiver Advancement

Lynn Friss Feinberg
Retired (formerly of AARP; independent consultant)

Debbi Harris
Family Caregiver

Christina Irving
LCSW, Director of Client Services, Family Caregiver Alliance

Nidhi Mirani
CEO, Carina

Lauren Pongan
formerly National Director, Diverse Elders Coalition

Mina Raj, PhD
Professor, Aging, Caregiving, and Technology Lab at University of Illinois at Urbana Champaign.

Kezia Scales, PhD
Vice President of Research and Evaluation, PHI

Jennifer Schiller
CEO Research Institute for Homecare (formerly Alliance for Home Health Quality and Innovation)

Regina Shih, PhD
Professor, Rollins School of Public Health, formerly Program Director at RAND

Zulma Torres
Direct Care Worker, Cooperative Home Care Associates

Design: RD Design

ACKNOWLEDGEMENTS

This issue brief is dedicated to the millions of direct care workers and family caregivers who provide essential care and support for so many people across the country. Know that the care you provide is seen, and deeply valued.

Thank you to **The John A. Hartford Foundation** for making this initiative possible.

Special thanks to our Expert Panel, and to all who provided interviews, bringing their additional expertise and perspective to this initiative:

Lindsey Althaus; Alison Applebaum; Jenny Chang; Tara English; Chanee Fabius, PhD; Stephanie Gibbs, JD; David Goldfarb; Lizzy Letter; Nidhi Mirani; Maggie Ornstein, PhD; Jen Powers Alge; and Peggy Welch.

Thank you to **Karee and Jim White, Kirstin Barbour, and Zchon Polon** for sharing your essential stories.

We are grateful for additional support and expertise from **Joseph Caldwell, PhD.**

Finally, thank you to **Autumn Campbell, Jason Resendez, Murray Devine, Kezia Scales** and **PHI's Research and Evaluation Team, and Jodi M. Sturgeon.**

About PHI

PHI is a national organization committed to strengthening the direct care workforce by producing robust research and analysis, leading federal and state advocacy initiatives, and designing groundbreaking workforce interventions and models.

For more than 30 years, we have brought a 360-degree perspective on long-term services and supports to our evidence-informed strategies.

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

About NAC

Established in 1996, the National Alliance for Caregiving (NAC) is a national membership coalition that brings together more than 50 national healthcare companies and nonprofits, care innovators, caregiving advocacy organizations, and financial services leaders to advance a common agenda of building health, wealth, and equity for America's 53 million family caregivers. From championing our nation's first-ever national caregiving strategy to releasing new insights on the realities of caregiving, NAC works tirelessly to make caregiving more sustainable and equitable through agenda-setting research, programming, and policy change.



261 Madison Avenue, Suite 913
New York, NY 10016
Phone: 718.402.7766
Email: info@PHInational.org

