



# TOGETHER IN CARE<sup>®</sup>

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

Issue Brief Executive Summary

PHI/National Alliance for Caregiving, June 2024



This initiative has been made possible by generous support from



The John A. Hartford Foundation

**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, and they are an essential resource when individuals choose to rely on other care settings as well. As the U.S. population ages, demand for care will continue to rise across the full spectrum of long-term services and supports, including demand for home and community-based services.

Yet, direct care workers and family caregivers remain deeply undervalued and are still often overlooked entirely. Direct care workers face poor job quality, with a lack of sufficient training, inadequate compensation and support, and limited opportunities for advancement. Family caregivers face isolation, care coordination challenges, economic impacts, and their own health risks.

In response, PHI and the National Alliance for Caregiving (NAC) leveraged vital support from The John A. Hartford Foundation to launch the *Together in Care*<sup>®</sup> 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.

This executive summary and our Together in Care issue brief as a whole draw attention to emergent mutually beneficial opportunities to change the paradigm for direct care workers and family caregivers. 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 more than ten experts, 13 additional individual subject matter expert interviews, and a robust literature review.



# ISSUE BRIEF

## RECOMMENDATIONS

Together, PHI and NAC have identified recommendations in four areas to strengthen the partnership between direct care workers and family caregivers. We share a full listing of these recommendations and considerations in our issue brief. Throughout, 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.

**1. 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.**

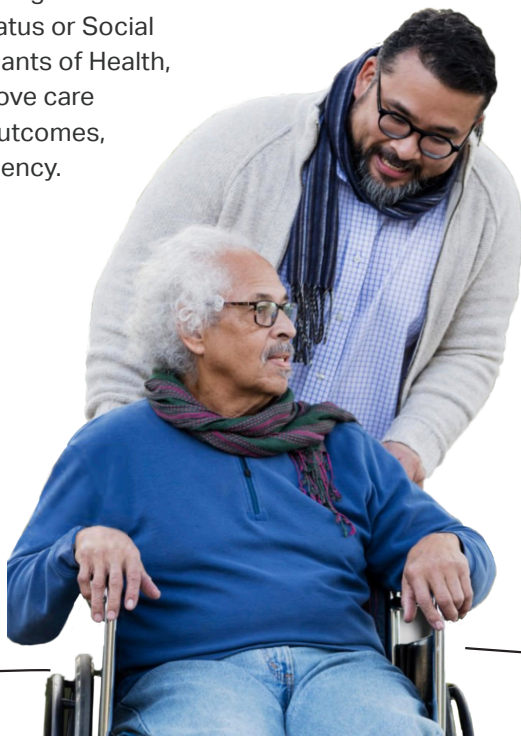
Direct care workers and family caregivers spend by far the most time with the individuals they support on a day-to-day basis, and therefore have essential knowledge of their experiences and needs. However, both direct care workers and family caregivers are too often excluded from care teams and care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

Together, direct care workers and family 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.

**2. 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. 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.

Self-direction programs, particularly those with greater flexibility with regard to the inclusion of family members as paid caregivers, can help to address some 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 consider pursuing development of targeted training and support for family caregivers who seek pathways to longer-term employment in direct care and other LTSS roles.



**3. 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 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.

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, incorporating additional matching criteria for both direct care workers and consumers, expanding language accessibility, and promoting wider enrollment can significantly expand the impact of these resources.

**4. 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.**

Research and evaluation efforts focused on the collaborative relationship between direct care workers and family caregivers can support the development of evidence-based and innovative practices that strengthen person-and-family-centered care.

Building evidence by capturing the experiences of and outcomes for direct care workers, family caregivers, and consumers, as well as quality and cost factors—can 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. Research in the home care setting also highlights the importance and impact of effective communication between family caregivers and direct care workers.

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.



## CONCLUSION

We are all together in care, bound by shared responsibility and shared collective need. The partnership between direct care workers and family caregivers is vital to bringing an effective system of person-and-family-centered care and support to reality. As our work to advance much needed dialogue moves forward, PHI and NAC welcome your collaboration in empowering direct care workers and family caregivers to support people and families across the country.



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