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OPPORTUNITIES FOR STRENGTHENING THE DIRECT CARE WORKFORCE

ROGER C. LIPITZ CENTER FOR INTEGRATED HEALTH CARE ISSUE BRIEF - WINTER 2024

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Introduction

Millions of Americans manage basic health and functioning needs with help. Direct care workers are personal care, home health, and nursing aides who are paid to provide help with essential day-to-day activities such as bathing, dressing, mobility, toileting, and eating, as well as housekeeping and social activities. Direct care workers may also perform clinical tasks such as wound care and medication administration under the supervision of a licensed professional.

The estimated 5 million direct care workers in the United States are about evenly divided across home and community settings versus residential care and facility settings such as assisted living, nursing homes, and hospitals. Direct care workers are often employed by agencies and reimbursed by state Medicaid programs – but they may also be hired by individuals and families who pay out of pocket. Although direct care is the fastest growing occupation in the U.S., this critical workforce is generally undervalued and underpaid. It is overrepresented by racial and ethnic minoritized groups, women, and immigrants who receive minimal training and low pay – and because of limited career ladders and difficult working conditions, worker turnover is high.



The availability and adequacy of support from direct care workers has important consequences for quality of life, services use, care quality, and costs for those who rely on their help. However, information about the role, capacity, and workplace of direct care workers and strategies to better support them is limited relative to other health care professionals whose time is more commonly reimbursed by health care insurers. Faculty at the [Roger C. Lipitz Center for Integrated Health Care](#), based in the Department of Health Policy and Management at the [Johns Hopkins Bloomberg School of Public Health](#), are leading initiatives to better understand the composition and role of direct care workers, and to strengthen training and support. These initiatives involve contributing new knowledge, informing policy, and developing and testing models of care to better support the direct care workforce.

Contributing New Knowledge

[Dr. Chanee Fabius](#) has long been committed to a career directed at better support of care workers, motivated by personal caregiving and professional experiences as a care manager within Connecticut's Medicaid Home and Community-Based Services program. Since arriving at Johns Hopkins in 2018, Fabius has made important contributions to our understanding of the direct care workforce and identifying strategies to better support them.

Fabius has conducted a series of studies that shed light on the circumstances driving use of paid care among older adults nationally, and within the context of Medicaid-funded home and community-based care. Drawing on the National Health and Aging Trends Study (NHATS) she has documented profound disparities in caregiving and the high degree to which direct care and family and other unpaid caregivers' work is interwoven. Fabius has demonstrated that Black family caregivers are disproportionately more likely to provide [high-intensity care](#) of more than 40 hours per week to older adults with high care needs and limited financial resources, while being less apt to access [respite care](#). Her work demonstrates exceedingly [high rates of adverse consequences due to unmet care needs](#) among older adults dually enrolled in both Medicare and Medicaid with dementia, despite heavy reliance on [direct care](#). Importantly, an analysis recently published in the *Milbank Quarterly* found [direct care worker wages were inversely associated with clients' experiences of participation restrictions](#) – further reinforcing the relationship between care quality and worker compensation and supporting the argument for increased pay for care work.

Because direct care worker experiences and supports vary across the agencies that employ them, Fabius recently partnered with the [Hilltop Institute](#) to understand the organizational context and attributes of the more than 1,000 Maryland residential service agencies providing home-based care (e.g., skilled nursing, personal care, durable medical equipment) to older adults enrolled in [Maryland Medicaid](#). Study findings, published in the *Journal of Applied Gerontology*, indicate high rates of dementia among older adults receiving Medicaid-funded home and community-based support - and that despite most agencies reporting difficulty managing dementia behaviors, fewer than 1 in 5 had implemented dementia-specific training requirements for direct care workers.





Center members are leading research to understand effects of the supply and distribution of direct care workers. Newly appointed core faculty, Dr. Katherine Miller recently led a paper published in the *Journal of the American Geriatrics Society* that elucidates growing geographic disparities in use of paid care, with disproportionately exclusive reliance on family care in rural areas. Health economist and core faculty Dr. Karen Shen has investigated nursing home staffing during the COVID-19 outbreak in a series of studies, finding low rates of vaccination among nursing assistants, relative to residents, and notable gaps in direct care staffing in areas highly affected by COVID-19. A recent paper published in *JAMA Internal Medicine* establishes associations between within-facility staff turnover and lower care quality. Center trainee, Andrew Jopson, recently led a paper in the *Journal of the American Medical Directors Association* that demonstrates the growing reach of Managed LTSS (MLTSS) in many states' home and community-based service delivery environment.

Supporting Direct Care Workers through Embedded Pragmatic Clinical Trials (ePCTS).

The integration of direct care workers in team-based care is foundational to enacting safe, efficient, high-quality care. In the past several years, state efforts to rebalance Medicaid financing from institutions to community settings have led to higher acuity among people receiving help in the community. As a result, direct care workers carry new responsibilities that necessitate additional technical and interpersonal competencies. Center affiliates are leading applied interventional initiatives to contribute knowledge regarding scalable models of care and organizational initiatives to set the stage for broader diffusion across care delivery settings and health care systems.

Fabius is leading a line of research directed at improved information sharing and communication between direct care workers and family caregivers of persons with dementia. With funding from the IMPACT Collaboratory she has undertaken qualitative work to understand information sharing in Medicaid-funded home and community-based care. Fabius interviewed residential service agency administrators, nurses, and direct care workers in Maryland, and found that agency information sharing processes involved the use of electronic management systems and patient portals to facilitate information sharing within agencies and with clinicians, variably timed assessments to gather information about participant preferences and routines, and collaboration with family caregivers. Findings emphasize the need to better coordinate information sharing between interdisciplinary care teams. This is particularly important for the care delivered to older adults living with dementia, who often rely on direct care workers navigating complex family dynamics as well as dementia-related behaviors (e.g., agitation, hallucinations).

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The direct care workforce is tremendously diverse and in high demand, but challenges that include low pay, minimal training, and reduced job quality must be addressed if we are to strengthen the workforce to accommodate the needs of a growing population of older adults with disability.

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A recent 5-year career development award from the National Institute on Aging will allow Fabius to expand her recent work and collaborate with state leaders and local home care providers to develop and evaluate strategies to address these challenges and strengthen relationships and communication between direct care workers and family caregivers of older adults living with dementia receiving Maryland Medicaid-funded supports.

A five-year, National Institute on Aging-funded leadership award to Center Director, Jennifer Wolff, has enabled the convening of an interdisciplinary group of social scientists and clinician-scientists from Johns Hopkins and external institutions to identify promising approaches for scaling consumer health information technology innovations to address the care needs of persons living with dementia. This work has primarily focused on understanding the landscape, use, and identity of users of the patient portal among older adults with dementia. Next steps will build on this work, following a broader set of activities that use codesign approaches to more effectively engage the broader care team, including shared care arrangements that involve direct care workers.

A Focus on Policy

Federal and State policy makers are developing strategies to systematically recognize and support the care workforce. Center faculty and affiliates are engaged in supporting and advancing these efforts through partnering, presenting, and program evaluation.

Chanee Fabius serves as a member of the Maryland Department of Health, Long-Term Services and Supports Community Options Advisory Council which advocates for LTSS equity and quality for the roughly 20,000 older adults and persons living with disabilities receiving Medicaid home and community-based supports in Maryland. The advisory council reviews and provides feedback on enrollment, procedures, and proposed changes to the program, which has grown by at least 40% in the past decade and doubled in expenditures, spending \$485 million in 2019. She is also a member of the Maryland Regional Direct Services Collaborative, a network of organizations and individuals who collaborate to build and sustain the direct care workforce in Maryland. Fabius recently served on the steering committee of the 2023 National Summit on Dementia Care and Services and is highly sought out for her expertise on care workers, having presented to the National Alzheimer’s Project Act (NAPA) Advisory Council on Alzheimer’s Research, Care, and Services, and a 2023 National Academies of Sciences, Engineering, and Medicine workshop on Aging in Place.

Jennifer Wolff was recently named to the RAISE Advisory Council, convened by the Administration for Community Living, and charged with providing recommendations to the Secretary of Health and Human Services on effective models of support to care workers, including both direct care workers and family

caregivers, as well as improving coordination across federal government programs. The 2022 National Strategy to Support Family Caregivers is the first of its kind and names specific actions to be undertaken by federal, state, and local government as well as private sector actors geared toward expanding access to and support for the care workforce.

Examples of recommendations include, for example, strengthening partnerships between family caregivers and direct care workers through federal, state, and local action that increase wages and benefits, improve training strategies, and support career advancement for the workforce.

The Veterans Administration has been a leader in developing and evaluating innovative community-based long-term services and support programs to support older Veterans, and actively supports self-direction (such as paying family members to provide personal care aid) and extensive caregiver support.

Kate Miller is involved in efforts to evaluate these programs. She has had a sustained interest in how Veterans Administration programs and policies affect workforce and economic issues (e.g., wages); the mechanisms by which patient care may be impacted (e.g., through worker turnover); and, ultimately, caregiver and patient outcomes. Her work demonstrates the profound emotional and financial effects of caregiving in the Veterans population, the exacerbation of distress imposed by the COVID-19 outbreak, and the costs and value associated with the Veterans Health Administration Program of Comprehensive Assistance to Family Caregivers.

In The Media

[A Journal of Applied Gerontology Special Issue Podcast: The Homecare Workforce Caring for Older Adults](#) episode features a discussion with Chanee Fabius, PhD and Jennifer Reckrey, MD, led by center affiliate Katherine Ornstein, PhD.

Work led by Fabius and colleagues was featured in a recent [Population Reference Bureau \(PRB\) report](#) describing the LTSS needs of vulnerable older adults, particularly those dually-enrolled in Medicare and Medicaid, and those living with dementia.

Shen and colleagues' research was highlighted in a [New York Times article](#) demonstrating disparate rates of COVID-19 vaccinations for nursing home aides. Work led by Shen was featured in a [Mother Jones article](#) showing linkages between state Medicaid LTSS commitment and adult daughters leaving the workforce to care for aging parents.



Select Publications

Fabius CD, Millar R, Geil E, et al. The Role of Dementia and Residential Service Agency Characteristics in the Care Experiences of Maryland Medicaid Home and Community-Based Service Participants and Family and Unpaid Caregivers. *Journal of Applied Gerontology*. 2022;0(0):1-12.

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Shen K, McGarry BE, Grabowski DC, Gruber J, Gandhi AD. Staffing Patterns in US Nursing Homes During COVID-19 Outbreaks. *JAMA Health Forum*. 2022 Jul 22;3(7):e222151. doi: 10.1001/jamahealthforum.2022.2151. PMID: 35977215; PMCID: PMC9308062.

Acknowledgements

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