AMA Journal of Ethics®
September 2022, Volume 24, Number 9: E822-829

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

What Do Organizations and Clinicians of Status Owe Their Patients' Home Health Aides?

Eileen Boris, PhD and Jennifer Klein, PhD

Abstract

This commentary on a case offers a historical perspective on how home health work became separate from other sites and means of professional caregiving, exacerbating poor continuity of care in the US health care system. Categorizing home health work as domestic work continues to racialize and marginalize workers. Poor public policy responding to market pressures to keep home health work cheap also perpetuates home health workers' classification as independent contractors, their lack of training, and low wages. This commentary suggests an alternative model for the future of home health work in the United States.

Case

Mr G, who is 77 years old and lives alone, has mild cognitive impairment, type 2 diabetes mellitus, and chronic kidney disease and currently has a suprapubic catheter due to urinary incontinence. His 2 adult children hire Ms S through a home care agency to help bathe Mr G, prepare his meals, clean as needed, organize (and often administer) his medications, and spend time with Mr G.

Ms S sought asylum in the United States 10 years ago and first began working for a cleaning service and then also for the home care agency as a home health aide. Ms S is 46 years old and most proud of her role in health care, which she considers her primary job and for which she received no formal training. The agency hires its employees as independent contractors and does not sponsor benefits (ie, health or dental insurance, paid leave, retirement contributions, or employee assistance counseling services). Ms S works full time at minimum wage, and, though she pays federal and state income taxes, her annual income falls below the federal poverty level and has been and remains insufficient for her to accrue savings. Ms S and her children currently qualify for Medicaid, are currently enrolled in their state's supplemental nutrition program, and visit a food pantry for groceries.

Mr G is currently Ms S's sole patient. Ms S is grieving the loss of a patient for whom she cared for 3 years until his transfer to home hospice and subsequent death. Ms S hopes her agency will assign another patient to her soon, as she needs the income, and is

considering taking on a third job. To make her typical morning arrival time of 6:30 am, Ms S makes 3 bus transfers from her apartment in the city to Mr G's suburban home. When Ms S arrives, Mr G is in his bathroom. She checks on him there, verifies that he is safe, and then returns to the kitchen to clean up milk on the floor that appears to have been spilled after she left yesterday. She then prepares Mr G's breakfast and medications. Mr G has spent more time with Ms S than any other person during the past 2 years and regularly calls her at home for companionship, comfort, and reassurance.

Ms S prepares a Center for Medicare and Medicaid Services Home Health Certification and Plan of Care (CMS-485) form online, which must be signed by Dr P, Mr G's physician. She was also asked to document prescription medication modifications ordered by Dr P, following Mr G's primary care appointment earlier this week. Ms S makes the changes but is unsure about how to implement a change to Mr G's insulin and is unsure whether one of Mr G's new prescriptions, just received by mail, contains the correct number and kind of pills, as the shapes and colors of and numbers on the capsules do not match those in a photograph she references online. Ms S calls Dr P's office to confirm; a member of Dr P's staff returns her call the next day but confirms only the name and dose of the medication. Ms S remains unsure what to do, so she also contacts Mr G's son. He is unfamiliar with the prescription changes and advises, "Just fill the boxes in the pill container for each day of the month as best you can. Dad will know which ones to take."

Still unsure what to do, Ms S leaves out the capsules that don't look right to her as she fills Mr G's pill box slots. She attaches an electronic sticky note in the online CMS-485 form, hoping Dr P will see it and clarify the prescription. Dr P does not see the electronic sticky note, signs the CMS-485 form, and moves to the next electronic health record document requiring review and sign off.

Commentary

How did we develop a system of home care that insufficiently sustains those who need assistance with the activities of daily life but also leaves personal attendants and aides in legal, economic, and social limbo, as neither nurses nor maids, within the labor market yet outside labor standards and regulations? We rely on the service ethos of female workers, predominantly immigrant and US-born women of color, when neither families nor professionals can care for frail elders and people with disabilities on a daily basis.[1] A historical perspective illuminates 3 conundrums highlighted by the case: (1) the separation of home aides and personal attendants from medical care, (2) their occupational categorization as domestic workers, and (3) the provision of home care on the cheap through racialized stigmatization of the work and workers' lack of training, low wages, and classification as independent contractors or "companions." In consequence of home aide standing outside of a medical team, continuity of care suffers. This situation was not inevitable but rather developed from historical choices and actions: public policies, responsibilities for services being divided between public and private agencies, and competing professionalization agendas of social work, nursing, public health, and medicine. In addition, the persistent association of hands-on care in domestic spaces with unpaid mother love and wifely duties continually lessened its value, regardless of the labor supply.

It is important to emphasize that we are talking about a job and not the uncompensated care that family members give to each other. The tasks might be similar, and the aide might be as attentive as—and even more experienced than—middle-class professionals

who, for example, leave their own jobs to tend to an incapacitated relative or friend. Aides may embrace caring as a calling and adhere to a service ethos but are not salaried employees. Thus, they can be economically exploited by working beyond assigned hours without proper payment and at the same time take pride in their labor.[2]

In what follows, we offer a historical perspective on how home health work became separate from other sites and means of professional caregiving, exacerbating poor continuity of care in the US health care system. We also suggest an alternative model for the future of home health work in the United States.

Home Care's New Deal Origins

The conflation of home care with domestic labor stems from more than alleged categorical equivalency. It's rooted in institutional arrangements, gender ideologies, occupational segregation by race (and gender), and deliberate labor policies. Home health care was defined as domestic service in part because home health care workers, hospital and nursing home workers, and household employees often have been the same people who have moved between work in low-wage labor markets and receipt of government assistance (commonly known as welfare).[3]

Home care developed as a distinct occupation during the Great Depression, when the New Deal was introduced to respond to the economic crisis. Under the Works Progress Administration (WPA), relief programs called homemaker or housekeeper services sent unemployed women into poor households where a mother was in the hospital, ill, or incapacitated; the WPA "homemaker" was assigned to perform labor such as cooking, cleaning, comforting, and caring for children.[4] These New Deal home care programs solved 2 problems: they provided African American women—who composed the majority of household workers in the Northeast, South, and Midwest—alternative income to day-labor street corner sites, in which would-be employers picked up women for a day's cleaning for pennies an hour.[4] WPA homemaker or housekeeper services additionally relieved strained public hospitals of the burden of maintaining patients with chronic illness by enabling such individuals to be tended to in their homes.[4]

At the same time, the new permanent social and economic security legislation under the New Deal excluded occupations in which African Americans predominated, in part to overcome Southern Dixiecrat opposition to expanding Black rights. Hence, the Social Security Act, the National Labor Relations Act, and the Fair Labor Standards Act (FLSA) drew poor Black women outside the boundaries of labor and social protection; the New Deal perpetuated a form of occupational Jim Crow.[5] It conflated paid labor in the home with family labor, which even New Dealers believed defied regulation. Occupations associated with women, and particularly with Black women, such as nurse companions, homemakers, and other in-home care workers, were thus excluded under old age insurance, unemployment benefits, and collective bargaining legislation, as well as from the national minimum wage, maximum hours, and right to overtime compensation provisions of the FLSA. Not until 3 decades later would employees of nonprofits come under the labor law, including most nurses and health aides.[4]

Public policy shaped the contours of home care, but New Dealers did not act alone. Nurses and physicians also left their mark on the shape of home care by limiting the housekeeper's repertoire of tasks. As *The Trained Nurse and Hospital Review* editorialized in 1939: "This care is not nursing, but the use of such workers, under the supervision of physicians and nurses, will free more technically prepared workers for the

medical care of such patients which is still in its infancy."[6] Seeking to carve out the professional competency of licensed nurses, leading voices, such as the New York State Nurses Association and the Board of Nurse Examiners, drew the line where "simple home care" ended and nursing care began. Home aides might make beds and help with daily personal care, including "giving bed pan and care of it, filling of hot water bottle … and helping patient to take simple medicine."[7] But they were not to give nasal or eye drops, apply bandages, or help "the patient apply a brace, hypodermic injection of insulin, and administration of enemata and douches"—procedures that registered nurses insisted were part of the repertoire of a practical nurse, not a housekeeper.[7] Thus 3 legacies emerged from the New Deal: filling home health care jobs with women on public assistance, excluding these jobs from labor standards, and separating them from the health care professions.[4]

Occupational Narrowing

After World War II, home care expanded, but attempts to make it a good job ran up against its low prestige and lack of professional standards. Some nonprofit family and child welfare agencies, many of them denominational, sought to improve conditions by targeting older women with career ladders, benefits, and decent wages. Along with public welfare departments, these agencies—led by women social workers and aided by the US Children's Bureau—established visiting homemaker programs to maintain the aged and people with disabilities in the community rather than in more expensive hospitals and nursing facilities. However, they managed to create only a few civil service positions before lack of funding stymied this effort.[4] At the same time, for-profit employment bureaus that provided domestic servants sent women into homes to assist the elderly.[4] Despite their different intentions, both for-profit and nonprofit private sector agencies joined government programs in funneling women into hands-on caring positions complementary to but distinct from hospital or clinic-based care, which required licensed professionals. For homemaker service, job training tended to consist of domestic tasks—laundry, making beds, cooking—the labor that poor women of color had so long been expected to do. Because these jobs went by the terms *homemaker*, *visiting housekeeper*, *home aide*, and *personal attendant*, the US Department of Labor soon classified them as domestic service in its *Dictionary of Occupational Titles*, further conflating the status and function of so-called housekeepers and domestic servants.[8]

Further separating medical professionals from home aides, hospitals began instituting their own home care programs in the 1950s. The home care unit run by Montefiore Hospital in New York City promised "continuity of care" for patients sent home by the hospital, touting the close attention of an integrated medical team. Yet because hospital officials treated home aides as casual workers whose presence didn't serve any medical need, they made little effort to consistently build this workforce.[4] The Hospital Council of Greater New York—an agency that bridged public and private institutions—more narrowly defined the home care team as "the physician, the nurse, and the social worker."[9] Hospitals offered a range of services but would contract out home nursing to independent visiting nurse agencies. When it came to home aides, a hospital social worker could hire "any individual she deemed suitable to perform housekeeping duties,"[9] including relatives and friends, thereby treating the labor as casual and marginal. State employment bureaus also kept lists of potential housekeepers.[9] Whereas welfare administrators repeatedly stressed the "professional" character and training of public homemakers,[4] the hospital programs operated under a different premise: "housekeeping service … did not involve professional personnel."[7] Indeed, a

survey of housekeeper duties found that cleaning consumed more hours than any other chore, with the bedridden requiring the most personal care.[9]

Although housekeepers' home visits were far more regular than those of nurses or physicians, their labor was mostly invisible—like other forms of domestic or care work—and precarious. The refusal to recognize the hands-on knowledge and emotional support of home aides deprived physicians of crucial information, impeding care. With hospitals viewing housekeeper services outside of their mission—indeed, beyond their understanding of care—nonprofit and later for-profit agencies supplied aides, especially once Medicaid funding became available, which has served as the de facto payment system for long-term care.[7]

Unionization?

By the 1970s, service sector unions were looking to organize household workers, but, unable to reach domestic workers hired by individuals, they found home care workers employed by agencies or directly paid by governments.[10] In 1974, private household workers gained protection under the FLSA; at the very same moment, however, the Department of Labor reclassified home aides as "elder companions," akin to casual babysitters, and excluded them from the FLSA's minimum wage and overtime provisions, even if they were employed by third-party agencies and hospitals.[4] Once again, home aides would be denied the legal status of "workers" and the rights that have accompanied that status. Treated as companions rather than breadwinners, thousands of New York home attendants experienced nonpayment of wages in the latter half the 1970s. They took to the streets to protest these conditions with signs reading, "Take Us Out of Slavery" and "I am Not A Slave."[10]

Law and public policy changes in the 1980s, combined with fiscal constraints and the emergence of a for-profit home care industry, facilitated the contracting out of home health care and the classification of home care workers as independent contractors.[10] By that time, recent immigrants had joined African Americans in the home care workforce.[4] Hence both public and private services could deny their responsibilities as employers, extending the disjunction between such jobs and professional health care by paying minimum wages without benefits or career ladders.[11]

Since the end of the 20th century, home care workers have fought to gain recognition as workers worthy of living wages. In urban areas such as Chicago and San Francisco, unions won inclusion in minimum wage protections.[4] They bargained for training programs that aides eagerly and often desperately sought, especially to protect themselves and their clients from injuries. Where they had sufficient leverage, as in New York, unions could incorporate training and safety programs into collective bargaining contracts.[12]

A surge in home care unionization in the late 1990s and early 2000s, however, faltered by the 2010s when some states negated prior agreements with care unions, governments restricted resources, and public sector workers suffered conservative backlash. Rulemaking put home care workers back in the FLSA in 2013, but the US Supreme Court ruled in *Harris v Quinn* (2014) that home care workers could not be considered public employees for collective bargaining purposes, which undermined home care unions' financial viability.[4] Since then, state governments and private agencies have sought to avoid paying overtime by cutting hours or rejecting pay for on-call sleep time during 24-hour shifts.[13]

Where unions were blocked, grassroots groups of workers began mobilizing outside of formal trade unions. In New York, for example, the Ain't I A Woman?! Campaign challenged the wage and time theft of 24-hour shifts, even as local unions accepted the state's rationale for underpaying workers for lack of funds and failed to demand full compensation.[14] Immigrant worker centers and ethnic associations under the National Domestic Workers Alliance pushed for inclusion of home care in state-level bills of rights as a mechanism to extend labor standards; since 2010, activists have won legislative passage of a domestic workers bill of rights in 10 states and 2 cities.[15] In the early 2020s, a feminist care network, including unions and domestic worker organizations, lobbied government to include home care as crucial human infrastructure.[16,17]

Conclusion

A recent finding that nursing associations and councils have "been a major impediment to the expansion of the aide role and inclusion of these aides in team-based care"[18] reminds us that the struggle of nurses to elevate their profession involved nurses moving out of the home and into the hospital and differentiating their tasks from those of workers with less training and authority. We recognize that it is difficult to think of those without professional certification as valuable members of the care team, and some readers of this commentary will bristle at the thought. And yet the order of things is not natural; it is made by public policy and all-too-human institutions. Providing "competency-based" training and living wages to the hands-on home attendant could improve client outcomes—but only if we truly value the observational knowledge of home aides. As the case shows, it was the aide—not the physician or family member—who was on the scene and noted changes and patient difficulties. While electronic monitoring and forms may be efficient, they rarely substitute for communication and coordination.

We are not talking about diversity, equity, and inclusion when we suggest taking seriously the knowledge of workers who happen to be predominantly women of color. We believe that the most ethical response is to acknowledge the value of this labor force. Is it ethical to generate jobs that fail to generate living wages? Will not our neglect produce worn-out and sicker future patients who have spent their lives tending to others but cannot afford the care they now require themselves? We ask readers to consider fixing a system that public policies have wrought by providing the infrastructure and funding for good jobs that allow workers a voice in the work they perform. We concur with the conclusion of a February 2022 Paraprofessional Health Institute study: leaders in the field of long-term care should address "discrimination based on race, gender, and immigration status … as well as their manifestations in … low wages due to the systemic undervaluing of care work."[1] Both clients and home care workers then could obtain the dignity and security they deserve.

References

1. McCall S, Scales K. Direct care worker disparities: key trends and challenges. PHI; 2022. Accessed July 20, 2022. http://www.phinational.org/wp-content/uploads/2022/02/Direct-Care-Worker-Disparities-2022-PHI.pdf
2. Zelizer VA. *The Purchase of Intimacy*. Princeton University Press; 2005.
3. Terlizzi LP; National Clearinghouse on Aging. Human resources issues in the field of aging: homemaker-home health aide services. AoA Occasional Papers in Gerontology 2. US Department of Health, Education, and Welfare; 1977.
4. Boris E, Klein J. *Caring for America: Home Health Workers in the Shadow of the Welfare State*. Oxford University Press; 2015.

5. Palmer P. *Domesticity and Dirt: Housewives and Domestic Servants in the United States, 1920-1945*. Temple University Press; 1989.
6. Just a word with you. *Trained Nurse Hosp Rev*. 1939;102:303.
7. Fraenkel M. *Housekeeping Service for Chronic Patients*. Welfare Council of New York City; 1942.
8. Homemaker (dom. ser.) housekeeper, visiting, 677, domestic service occupations (2.00.00 through 2-09.99). In: Bureau of Employment Security, US Department of Labor. *Dictionary of Occupational Titles*, *Vol II: Occupational Classification and Industry Index*. 2nd ed. US Government Printing Office; 1949:59.
9. Hospital Council of Greater New York. *Organized Home Medical Care in New York City: A Study of Nineteen Programs*. Harvard University Press; 1956.
10. Boris E, Klein J. We were the invisible workforce: unionizing home care. In: Cobble DS, ed. *The Sex of Class: Women Transforming American Labor*. Cornell University Press/ILR Press; 2007:177-193.
11. Boris E, Klein J. Organizing home care: low-waged workers in the welfare state. *Polit Soc*. 2006;34(1):81-106.
12. Ducey A. *Never Good Enough: Health Care Workers and the False Promise of Job Training*. Cornell University Press/ILR Press; 2009.
13. Shotwell JL, Wool E, Kozikowski A, et al. "We just get paid for 12 hours a day, but we work 24": home health aide restrictions and work related stress. *BMC Health Serv Res*. 2019;19(1):907.
14. Ain't I A Woman?! Accessed September 23, 2021. https://www.aintiawoman.org/
15. Passed legislation: states and cities with a Domestic Workers Bill of Rights. National Domestic Workers Alliance. Accessed September 23, 2021. https://www.domesticworkers.org/programs-and-campaigns/developing-policy-solutions/bill-of-rights/passed-legislation/
16. Caregiving advocates look to Senate for quick passage of Build Back Better, expanded access to care and jumpstart economy. News release. Care in Action; November 11, 2021. Accessed May 31, 2022. https://careinaction.us/pressreleases/2021/11/19/caregiving-advocates-look-to-senate-for-quick-passage-of-build-back-better-expanded-access-to-care-and-jumpstart-economy
17. Heather McGee interviews Ai-jen Poo. *New York Times*. December 7, 2021. Accessed May 31, 2022. https://www.nytimes.com/2021/12/07/podcasts/transcript-ezra-klein-podcast-ai-jen-poo.html?fbclid=IwAR2mjkdt9P6pNDTC73GMyiZNbqJS8W68kP3NwWSJcmccAIPHSA0nXFAmkAw
18. Stone RI, Bryant NS. The future of the home care workforce: training and supporting aides as members of home-based care teams. *J Am Geriatr Soc*. 2019;67(suppl 2):S444-S448.

Eileen Boris, PhD is the Hull Professor and Distinguished Professor of Feminist Studies, History, Black Studies, and Global Studies at the University of California, Santa Barbara. Her books include *Home to Work: Motherhood and the Politics of Industrial Homework in the United States* (Cambridge University Press, 1994) and *Making the Woman Worker: Precarious Labor and the Fight for Global Standards* (Oxford University Press, 2019). Her public writings have appeared in the *New York Times, American Prospect, Time*, and *The Nation*, among other places.

Jennifer Klein, PhD is the Bradford Durfee Professor of History at Yale University in New Haven, Connecticut. She is the author of *For All These Rights: Business, Labor, and the Shaping of America's Public-Private Welfare State* (Princeton University Press, 2006) and co-author, with Eileen Boris, of *Caring for America: Home Health Workers in the Shadow of the Welfare State* (Oxford University Press, 2012). She also served as co-senior editor of the journal *International Labor and Working-Class History* from 2010-2015 and has been on its editorial board for 20 years.

Editor's Note

The case to which this commentary is a response was developed by the editorial staff.

Citation

AMA J Ethics. 2022;24(9):E822-829.

DOI

10.1001/amajethics.2022.822.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

ISSN 2376-6980