

What's Needed?

Bob and Dan, brothers in their sixties, live full and active lives in their community despite progressive, lifelong functional limitations from muscular dystrophy. They have quick, intelligent minds; Dan is renowned for excelling at the quiz show *Jeopardy*. Both have severe mobility disability. Bob can move his hand sufficiently to operate his power wheelchair's manual joystick, but Dan must use a chin-operated miniature trackball joystick to direct his power wheelchair. The brothers need assistance with all activities of daily living (ADLs)—bathing, toileting, dressing, feeding, and basic mobility—and various instrumental ADLs (IADLs), such as meal preparation, shopping, and housework. They also periodically need suctioning of mucous secretions to keep them comfortable and reduce risks of aspiration.

The brothers live in their family home, where they have made many modifications over the years to improve accessibility. Bob can be transferred safely using a standard Hoyer lift, but Dan cannot because his neck is unstable. To accommodate his transfers, Dan devised an ingenious pulley system secured to ceiling beams and operated by a single personal assistant (PA). This pulley apparatus functioned well until Dan started feeling unsafe. Now Dan needs two—or sometimes three—PAs to lift and transfer him safely.

Their mother had been the primary caregiver for Bob and Dan for most of their sixty-plus years. She is now in her late eighties and has dementia, requiring assistance with her own ADLs and IADLs. A complex team currently supports Bob, Dan, and their mother in their home. One man has provided personal assistance services (PAS) for the brothers for almost 15 years, working nearly 80 hours per week. Lifting Dan, after he abandoned his jerry-rigged

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pulley contraption, requires concerted strength. Devoted to Bob and Dan, this male PA feels he cannot cut back his hours because he has the greatest physical strength of all the PAs and is therefore needed frequently.

Mona, in her early fifties, organizes the multimember PAS team that provides round-the-clock, in-home support for the brothers and their mother. She began her career as a certified nursing assistant in hospitals, but about a dozen years ago, she decided to move into home-based direct care providing PAS. Mona worked for a home care agency until Bob and Dan recruited her to work under their direction. She views herself as “case managing for the whole house. . . . I provide personal care, medicine, reminders, house cleaning, of course, shopping, you name it.” She works hard but finds meaning in her work. As Mona explained about Bob and Dan,

Even though they’re disabled, and they can’t do very much for themselves, they still want to be a part of the world. . . . I want to be able to help them achieve their goals of being a part of society. . . . The caregivers who work in the house, we all feel like *we are part of making their days happen*. And at the end of the day, when I come home or the other caregivers leave, we heave a sigh of relief. . . . It’s not a sigh of relief like we’re glad the job is done. We heave a sigh of relief that we’ve completed the task for them. . . . It makes me feel like I’m doing something. I’m being of service.

Americans overwhelmingly want to live in their homes and communities, even when they have significant disability. Only 4% of Americans prefer to enter a nursing home if they become unable to care for themselves.¹ However, like brothers Bob and Dan and their mother, people with substantial disability often require daily assistance with ADLs, their most intimate physical needs. Without basic ADL supports, people with significant disability cannot live safely, comfortably, and with dignity in their homes, maximizing their overall health, general well-being, quality of life, and hope for the future.

Over three-quarters of Americans who need in-home ADL supports receive this assistance from family members or friends, a vast unpaid workforce.² As a shorthand, unpaid family members or friends are often called informal caregivers, although the word *informal* fails to “capture the complexity of what family caregivers do or their connection to the older adults they are helping.”³ In 2020 an estimated 53.0 million adults in the United States—21% of adult Americans—reported being an informal caregiver to an adult or child in the prior year, with 24% of these caregivers saying they assisted two or more people.⁴ On average, informal caregivers were 49 years old, 61% were

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female, about 61% were non-Hispanic White, 17% were Hispanic, 14% were non-Hispanic Black, and 5% were Asian American or Pacific Islander.⁵ The racial and ethnic distributions of informal caregivers thus reflected the U.S. population overall in 2020—and the family members and friends that these caregivers served. Most informal caregivers (89%) took care of a relative, 50% cared for a parent or parent-in-law, and 12% assisted their spouse or partner.⁶

Assisting family members or friends offers rewards, including the intangible but deeply meaningful satisfaction of serving a loved one: 51% of informal caregivers find personal meaning or purpose in this role.⁷ Nonetheless, informal caregiving can exact a heavy toll. Many informal caregivers feel they have no option but to serve. When other informal help is unavailable, 66% of those caring for a spouse or partner feel they have no choice about becoming caregivers, as do 61% supporting a parent or parent-in-law, 45% assisting other relatives, and 21% serving friends or neighbors.⁸ Among informal caregivers providing high-intensity care, 32% report worse personal health because of their caregiving activities,⁹ 29% experience high physical strain,¹⁰ 49% admit high emotional stress,¹¹ and 29% describe financial problems because of caregiving.¹²

In contrast to the unpaid informal caregiver workforce, paid PAS workers provide approximately 16% of the total hours of in-home ADL support to Americans nationwide.¹³ For consumers with limited social networks and more complex needs, paid PAS is a lifeline.¹⁴ The percentage of paid PAS—so-called formal caregivers—will likely rise in coming decades. According to a 2016 report, “While the need for caregiving is rapidly increasing, the pool of potential family caregivers is shrinking. Families have fewer children, older adults are more likely to have never married or to be divorced, and adult children often live far from their parents or may be caring for more than one older adult or their own children.”¹⁵ Even if family members are around, they often have competing demands on their time and cannot fully support their relative needing assistance.

Paid PAs, like Mona and the staff providing 24/7 support for Bob, Dan, and their mother, increasingly assist Americans with severe disability living in their homes and communities. In 2018 approximately 1.55 million workers provided paid in-home PAS, an increase of 242% over the approximately 452,000 paid PAS workers in 2008 (Figure 1.1).¹⁶ Formal PAS providers look different from informal caregivers. The vast majority (almost 90%) are women, 60% are people of color, and roughly one in four is an immigrant.¹⁷ Paid PAs also supplement the efforts of informal caregivers: about 31% of informal caregivers report assistance from paid workers—aides, housekeepers, or others—in caring for their family members or friends in the prior year.¹⁸

Despite rising demand for their services, paid PAs earn low wages. In 2018 in-home PAS workers earned an average of \$11.40 per hour, an increase

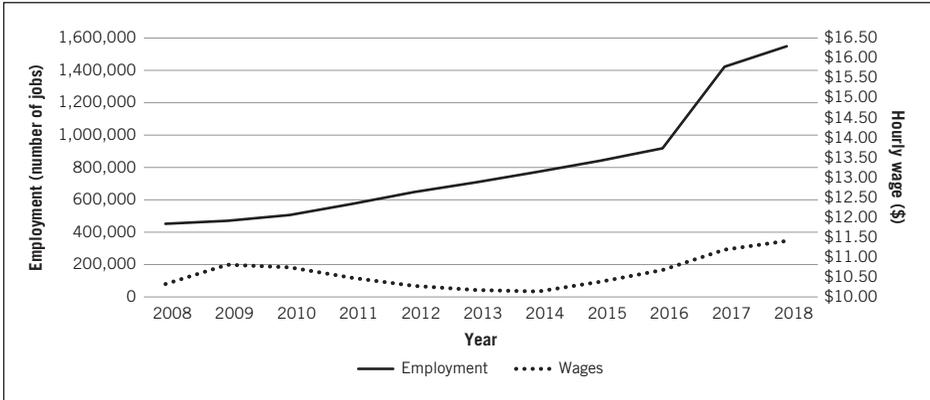


Figure 1.1 Personal Care Aides: Number of Jobs and Average Hourly Wages, 2008–2018

Source: U.S. Bureau of Labor Statistics, Division of Occupational Employment Statistics (OES). 2019. May 2008 to May 2018 national industry-specific occupational employment and wage estimates. <https://www.bls.gov/oes/current/oesrci.htm>; analysis by PHI (July 2, 2019). In 2018, the U.S. living wage was \$16.14/hour (Massachusetts Institute of Technology Living Wage Calculator: <https://livingwage.mit.edu/articles/37-new-data-up-calculation-of-the-living-wage>).

of only \$1.07 over the hourly wage in 2008 of \$10.33.¹⁹ Approximately one-fifth of in-home PAS workers have incomes below the federal poverty level.²⁰ Nonetheless, home-based supportive care is one of the fastest growing jobs in the United States today. According to the U.S. Department of Labor Bureau of Labor Statistics, demand for home-based PAS jobs will rise an estimated 36% from 2018 to 2028, much higher growth than for most other occupations in the United States.²¹ The Bureau of Labor Statistics lists personal care aides as the occupation with the highest projected numeric growth in its workforce, expected to have added 881,000 jobs from 2018 to 2028.²² In many regions across the United States, however, too few people are available or willing to take paid PAS jobs; thus the demand for paid PAs far outstrips the supply. Without this essential in-home support, individuals with disability who lack informal caregivers face the risk of institutionalization.

The Impending Crisis in Home-Based Paid Personal Assistance Services

For more than 40 years, health care professionals, policy makers, and advocates for consumers and formal caregivers have warned of this impending PAS crisis, with widening gaps between the available workforce and rising numbers of Americans needing in-home ADL supports. Confluent demo-

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graphic and workforce trends have generated an almost perfect storm, and projections of insufficient numbers of qualified workers to meet home-based PAS needs are increasingly troubling. On the consumer side, demographic forces include the following:

- The U.S. population is aging. Not only are individuals from the World War II generation reaching very advanced ages, but also the 78-million-person baby-boom generation, individuals born between 1946 and 1964, began turning 65 in 2011. Baby boomers have fewer family members available to become informal caregivers than prior generations did.
- The World War II generation had substantially better health and functional status than their parents' and grandparents' generations, thus reducing their need for home-based PAS until very late in life. But the baby boomers are reversing those favorable trends. Despite their lower smoking rates, baby boomers have higher rates of obesity, less frequent exercise, and other risk factors that increase disability rates.²³
- With medical advances, people born with significant disability now survive into middle and older ages; similarly, people who develop a disability in early adulthood are also living longer. Of 8.4 million people currently receiving long-term services and supports, 37% are younger than 65.²⁴ This population of younger adults requiring home-based PAS is growing.
- Racial and demographic population trends might also increase demand for home-based PAS. The rapidly growing Hispanic and Asian populations typically use more home and community-based supports and less institutional long-term care than do White or Black populations.²⁵

For paid PAS providers, factors contributing to widening gaps between consumers' in-home support needs and the available workforce include the following:

- Women comprise nearly 90% of the paid PAS workforce; by 2024, however, the number of women 24–64 years old in the United States will grow by only 1.9 million.²⁶ This pool of potential PAS job candidates will be too small to meet the growth in demand.
- Paid PAs typically earn low incomes. Between 2009 and 2019, median hourly wages, adjusted for inflation, for home care workers rose from \$11.21 to \$12.12, only by 8%. In 2018, nearly half (47%)

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of home care workers earned less than 200% of the federal poverty level, with median annual incomes of \$17,200.²⁷

- From 40% to 60% of paid PAs quit after less than one year on the job, largely because of low wages compounded by meager benefits, heavy workloads, poor supervision, little upward career mobility, and high transportation costs.²⁸
- Some regions have worse PAS workforce shortages than others, primarily because of entrenched structural factors. With their aging populations, sparsely inhabited rural areas are especially vulnerable to PAS workforce shortfalls. Greater travel distances between PAS clients and lack of public transportation also cause problems in rural regions. Nearly a quarter of PAS workers are foreign-born, but 96% of them live in cities.²⁹

Thus, powerful demographic and societal trends suggest that paid PAS consumers and providers may look very different in the future. The changes have critical implications for long-term care delivery systems, public and private health and long-term care insurance, housing and other community policies, and society more broadly. As a 2008 Institute of Medicine report summarized,

The future elderly population will be different from today's older adults in a number of ways. The demographic characteristics of older Americans will differ from [those of] previous generations in terms of their race, family structure, socioeconomic status, education, geographic distribution, and openness regarding their sexual orientation. All of these factors can affect health status and utilization of services. Trends in illness and disability will influence the need for services among the future older adult population. . . . Finally, older adults in the future may simply have different preferences for care than their predecessors.³⁰

Nonetheless, one preference seems immutable: consumers' strong desire to remain home. "It amazes me that nobody's gotten this notion yet: the 'boomers' are coming," said a woman in her mid-fifties with multiple sclerosis (MS). "Despite MS and other diseases, they're going to live longer. We're not going to warehouse them in nursing homes. These 'boomers' simply won't do that. They're not going to go quietly into the night."³¹ A widow living alone, she was determined to remain at home despite severe mobility problems necessitating personal assistance with toileting, bathing, and dressing. She constantly struggled to find PAs but had recently identified a young woman, an immi-

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grant from eastern Europe, who seemed reliable and a good match. Communicating in English was challenging, but each seemed determined to make the situation work. Having an enduring, positive, supportive relationship would benefit both the woman with MS and her new PA—the reciprocity or win-win for both consumers and PAs that underlies long-term PAS success.

The growing mismatch between consumers' needs for paid PAS and the available PAS workforce has numerous implications, including those for population health, societal expectations about aging in America, health care and other social costs to governments and individuals, community-based social service agencies, and policy and regulatory systems that must respond to this looming threat. At the heart of this crisis are individual people with significant disability and their paid PAs, interacting generally daily—sometimes around the clock—in intimate ways in the privacy of consumers' homes. The interpersonal dynamics of PAS consumers and PAs are complex, complicated by wage and payment policies, job training and oversight, differences by gender, race, ethnicity, language, immigration status, culture, structural racism, and myriad other human factors. How consumers and PAs respond to the dynamics determines the durability of these consumer-PA dyads, with critical implications for the satisfaction and well-being of both.

The Goals of This Book

Finding sustainable solutions to the looming paid PAS crisis requires understanding the intertwined and complex policy, personal, and interpersonal factors affecting in-home ADL supports. This book therefore explores both the policy context of paid PAS and the experiences and attitudes of PAS consumers and PAs, real people. Policies and structural factors directly affect people's lives and well-being along multiple dimensions and largely determine whether people requiring ADL supports can continue living in their homes as they wish or need to enter a nursing home.

To examine how policies affect actual people, this book draws on narratives from paid PAS consumers and PAs, describing their lived experiences and perspectives about paid in-home PAS. Many publications have addressed PAS for people at very advanced ages. As the Institute of Medicine notes, however, “older adults in the future may simply have different preferences for care than their predecessors.”³²

Therefore, this book focuses on people in middle age or at the leading edge of the baby boom—people in their early seventies. In 2018 I interviewed 21 in-home, paid PAS consumers in these age ranges and 20 PAS workers; for Chapters 13 and 14, I later interviewed a 20-year old college student with a severe disability to introduce the perspective of someone who will need paid

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PAS well into the future. I audio-recorded all interviews, which were then transcribed verbatim. This book uses interviewees' own words, stories, and viewpoints to explore paid in-home PAS. I did not edit quotes for grammar or syntax in order to retain authenticity. With several exceptions, I refer to interviewees using pseudonyms and change small details to protect their confidentiality. With their permission, I use real names for Michael and Nelita, to whom I dedicate this book, as well as three new PAs introduced in the epilogue.

The novel coronavirus pandemic hit the United States in late February 2020, when I had written nearly half of this book, and it continues ablaze, killing thousands of Americans daily, as I review the final manuscript. The pandemic carries enormous and life-altering consequences for both consumers and PAs. Early in the pandemic, although home-based PAs were considered essential workers, their pay remained unchanged, they still often lacked health insurance benefits, and they generally worked without adequate personal protective equipment (PPE).³³ Nonetheless, in the upswelling, heartfelt emotions of those initial months, these PAs were called heroic—and in many cases they were. But understandably many left the PAS workforce. Just as the pandemic laid bare long-standing inequities within the U.S. health care system, it also heightened the impending crisis affecting home-based PAS.

Although all interviews long predated the tragic COVID-19 pandemic, throughout the book, I briefly suggest implications of COVID-19 and any future pandemics for PAS consumers and PAs. As elsewhere in U.S. society, the novel coronavirus pandemic will likely have long-term consequences for paid PAS that remain unforetold. The epilogue does tell one story from the frontlines of early COVID-19, about how three PAs saved the life of their consumer who became deathly ill, Michael.

Notes on Language

In the United States, roles of PAS workers are evolving rapidly, as policy makers aim to shift long-term support services away from nursing homes and other facilities into homes and communities. Looking across institutional and home-based settings, workers who provide personal assistance are often grouped with other so-called direct care workers. According to the 2008 Institute of Medicine report,³⁴ direct care encompasses three categories of paraprofessionals:

1. **Nurse aides**, also known as certified nursing assistants (CNA), geriatric aides, orderlies, and hospital attendants, work primarily in institutions—hospitals, nursing homes, and residential care facilities. On-site nursing staff supervise nurse aides. Typical activi-

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- ties include answering patients' call lights; serving meals and helping patients eat; making beds; assisting patients with bathing and dressing; escorting patients to medical appointments; and taking vital signs, administering medications, and performing other supervised medical tasks (e.g., wound care, urinary catheter management).
2. **Home health aides** generally work for home health care agencies or residential care facilities. They assist clients with ADL needs in their homes and can also prepare meals and perform light housekeeping tasks. Supervision typically involves periodic checks with nurses, physical or occupational therapists, social workers, or case managers. Some state regulations allow home health aides to also perform clinical tasks under the supervision of a licensed professional.
 3. **Personal assistance services workers** are employed either by an agency or directly by consumers (or the consumer's family). They work in homes and assist with ADLs and IADLs. With some employers, PAS providers may have little or no supervision by a health care professional.

Today boundaries are blurring between home health aides, who perform tasks addressing consumers' health conditions among other duties, and PAS workers, who often cannot provide health-related services because of state regulations. Home- and community-based service (HCBS) initiatives increasingly bring PAS workers into interprofessional care teams, working alongside licensed health care professionals to keep consumers as healthy as possible and prevent hospitalization.

The language used to refer to both PAS consumers and workers varies substantially across and within regions. PAS consumers are sometimes called employers or supervisors when they directly hire and manage their in-home workers. Home care agencies that provide and oversee PAS workers sometime call consumers clients or use clinical terminology—"patients" or "cases"—language eschewed by many disability rights advocates wary of medicalizing their daily lives.

Terminology for PAS workers also varies widely, including PAS worker or PAS provider; home care worker or aide; personal care assistant, attendant, or aide (all with the acronym PCA); paid or formal caregiver; and other local, regional, or regulatory nomenclatures. In parallel, other words and phrases to describe PAS include attendant care or services, home care services, support services, or a *mélange* of these terms, such as home support services or PCA work. With evolving roles, some PAS workers now refer to themselves as home health aides (HHAs), although as noted above, this phrase historically

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applied only to workers with nurses or other health care professionals as supervisors.

Here, when referring to individual workers, I generally use personal assistant (PA), although in discussions of specific policies, I use terminology (e.g., PCA) employed by the relevant policy makers. The acronym PA is preferred by Natalie, a consumer in her early fifties with spinal muscular atrophy, who had eight PAs providing in-home ADL supports each week. Over her lifetime, Natalie estimates she has had over 100 PAs:

I'm using about 14 hours a day. . . . A lot of people [refer to these workers as a] PCA, personal care assistant. I'm not fond of the idea that they take care of me. I like the idea that they assist me in caring for myself. So, I tend to use personal assistant, or the older term, attendant. . . . My friend's in the UK. He uses the word "carer." . . . I have my personal preference, but I actually couldn't care less in the bigger picture, as long as people know what we're talking about.

Embedded within language are implicit assumptions about the value and merit of the work and the person receiving this support. Some observers avoid calling PAs workers, viewing the term as demeaning and disrespectful of the skills and effort required to perform PAS. Here, at the outset of this book, it is critical to emphasize that consumers with significant disability who lack informal caregivers could not survive in their homes and communities without the support of paid PAs. Often PAS work requires astute observation, quick thinking, unerring judgment, manual and physical dexterity, and understanding of health conditions and their complications. At all times, PAS demands skill in negotiating complex interpersonal relationships between people—consumers and their PAs.

In-home PAS has a valid claim to being lifesaving. This work is also essential for preserving the dignity, self-respect, and quality of life of consumers with disability who require ADL supports. Appreciating these complexities, this book celebrates both PAS work and PAs for supporting people with disability to live their lives as they wish in their homes and communities.