

CHAPTER 1

Introduction

Many of us will need help when we get old—help with shopping, with getting dressed, with using the bathroom. Who will help us? Some people are born with developmental or physical disabilities, and others have accidents that render them unable to live a full life without assistance. Who will help those among us?

In 2015 nearly 19 million people under the age of sixty-five and nearly 14 million people over the age of sixty-five reported that they had difficulty taking care of themselves or living independently.¹ Although 33 million is a big number, it is nothing compared to what the number will be as the baby boom ages. The number of adults ages sixty-five and older who will need assistance is predicted to nearly double in the next twenty-five years (for detailed discussion of projections of future needs, see appendix D). Population growth in younger cohorts will also increase the demand for services for the non-elderly disabled.

Who will care for the aged and the younger disabled? It is beyond dispute that doctors, nurses, physical therapists, dietitians, and other professionals will be important, but we all know who does the care work on a day-to-day basis and who makes a huge difference for those who need care: unpaid family and friends, home care aides, and, in nursing homes, certified nursing assistants (CNAs).² Ask any adult child of an elderly parent or any parent of a younger disabled person about who is central to the quality of life and physical well-being of their loved one and they will point to these paraprofessionals.

I interviewed a social worker who told me this story about a home care aide working with an elderly woman:

Not only did she provide the hands-on care, she did something very interesting. She looked out for the patient's welfare beyond her job . . . because toward the end of her life [the patient] had split shifts, two twelve-hour care [shifts], seven days a week, [and] if there was a new home care aide who had to come in, or someone was on vacation on the days when she was off, she would call in and talk to them about the patient's needs. The patient was difficult . . . so she would call in on her days off and make sure people understood, and [she] explained to them how you could be most successful in working with her. She put herself out tremendously.

This story tells us much about the central role of the home care aide, who earned \$10 an hour, in shaping the quality of life of the patient who needed her help. But the story is also problematic in that it feeds into the belief that all that home care aides have to offer is a caring personality, warmth, and empathy. This book will argue, I hope convincingly, that home care aides can do much more and that expanding their role is the path to making the job better.

In 2007 then-senator Barack Obama spent a day “walking in their shoes” with America's employees, one of whom was a home care aide in California. The senator commented at length about how important the work was, how difficult it was, and how poorly it was compensated.³ Seven years later, the Obama administration reinterpreted the Fair Labor Standards Act (FLSA, the federal minimum wage law) to apply to home care aides, but this change had little practical effect. Fundamentally, not much has changed since 2007.

Understanding the situation of direct care workers also speaks to another important theme: addressing the size and persistence of a large low-wage workforce in the midst of a prosperous nation. Home care aides exemplify these workers, who work on average for less than \$10 an hour. Across-the-board solutions such as raising the minimum wage are certainly helpful, but to sustainably upgrade the quality of jobs, we need to understand the dynamics of each industry, the incentives of its key actors, and ways to upgrade workers' productivity so that they can earn more.

Table 1.1 The Demographics of Direct Care Workers, 2015

	CNA	Home Care Aide
Women	89.0%	88.0%
Immigrant	18.4	26.7
Under age thirty-five	44.8	28.1
Some college	49.8	46.3
Black	33.6	28.3
Hispanic	10.4	19.5

Source: 2015 American Community Survey (ACS).

CARE SETTINGS AND CARE WORKERS

Broadly speaking, caregivers fall into three groups: unpaid family members, home care aides, and CNAs. The largest group by far is made up of those unpaid family members who help their loved ones at home. I estimate that there are over 20 million such unpaid helpers (see appendix B).

Paid help at home is provided by home care aides.⁴ In 2015 there were 2.2 million home care aides working “above the table.” An additional unknown number worked in the so-called gray market, or “below the table.” In nursing homes across the country, 1.3 million CNAs provided the vast majority of day-to-day care.

Home care aides and CNAs are similar in many respects: about 90 percent are women, and they are disproportionately people of color; while many have only a high school education, almost half have some college education. But there are also some differences between them. CNAs tend to be younger than home care aides, and about 30 percent of home care aides are immigrants; roughly 20 percent of CNAs are immigrants (see table 1.1). Median annual earnings were \$15,019 in 2015 for home care aides and \$20,025 for CNAs.⁵ Both figures represent poverty-level earnings (for discussion of how I derived these figures, see appendix B).

Throughout the book, I take up the circumstances of all three groups of helpers—unpaid family caregivers, home care aides, and CNAs. That said, the focus does tilt toward home care aides, for two reasons. Home care aides have received relatively little attention compared to unpaid family caregivers or even CNAs. For example, an important recent Institute of Medicine (IOM) report focused on unpaid family caregivers; moreover, a large advocate

community works on their behalf.⁶ Similarly, and owing in part to persistent scandals and a heavier regulatory structure, there is considerably more research on CNAs than on home care aides.

A deeper explanation for my focus on home care aides—and one that points to the future—is that people prefer to stay at home and home care aides are central to making this possible. Seventy-eight percent of older people in an AARP survey strongly agreed with the statement that they wanted to stay in their home and avoid a nursing home as long as possible, and a survey by the Associated Press and the National Opinion Research Center (NORC) had exactly the same result.⁷

The younger disabled share this preference; indeed, their struggle to change society's perspective on their needs has very much the feel of a civil rights movement. A disabled woman with whom I spoke put it this way: "Younger folks want to be independent, want to live in their communities, want to do what other people do when they live their lives. They want to work, they want to go to school, whatever it is. They want to do what other people do. They're looking at as much flexibility as they can have."

A fundamental affirmation of this perspective came from the U.S. Supreme Court's ruling on the meaning of the Americans with Disabilities Act (ADA) of 1990. In the 1999 *Olmstead* decision, the Court held that institutionalization perpetuates "unwarranted assumptions" that the disabled are "incapable or unworthy of participating in community life" and "severely diminishes the everyday life activities of such individuals."⁸ The Court therefore held that policy, including the provision of long-term services and support, should to the maximum degree provide the opportunity for full community and home integration.

In response to these preferences, as well as to cost considerations, public policy over the last several decades has sought to rebalance long-term services and supports (LTSS) expenditures away from nursing homes and toward home care. Enabling people to stay at home will become more difficult, however, as the pool of family caregivers shrinks relative to need (for discussion of this point, see appendix D). And while there is some debate over this point, from a public policy perspective home care is generally more cost-effective than nursing home care.⁹ Of course, nursing homes will still be important when the need for care is extended and intensive, as it is for people with significant medical and self-care issues.

How Direct Care Workers Are Viewed

Direct care workers receive little respect. Decision-makers—doctors, hospitals, state regulators, state legislators, insurance companies, federal bureaucrats—typically do not think that home care aides can be real members of a care team. Home care aides are seen as unskilled companions, or glorified babysitters, with little education and little potential. Belief in them is scarce. The fact that home care aides are women and disproportionately racial minorities or immigrants does not help.

In the course of researching this book, I interviewed home care agency CEOs who made remarks like, “I totally believe the home care aides make the difference for patients, and they have not had the opportunity to show it.” Such high-minded sentiments are rarely acted upon, however, and the reality on the ground is different: the work of home care aides is viewed with contempt, lack of imagination, and ignorance.

One example of contempt surfaced when I met with an expert on reforming delivery systems who worked for a nonprofit public health organization. I was interested in discussing how to fix the Medicaid program and mentioned that I was eager to expand the scope of practice for home care aides. I described the silliness of the rule in some states that home care aides cannot administer eyedrops but can only guide the hand of the client. She replied, “Well, I’m not sure the limitation is a bad idea. What if they put in the cat’s eyedrops instead of the client’s?” This comment came from a reasonable woman, an expert in the field, who was neither racist nor sexist. She seemed to suggest that either home care aides cannot read or they do not care enough about their clients to pay attention. (Of course no one is perfect. Consider the doctors who operate on the wrong body parts.¹⁰ Also consider that there are no limitations on how family caregivers can administer care.)

This attitude is reflected in the policy and research communities. Consider the imbalance in research on improving nursing homes and research on improving paid home care. As mentioned earlier, the more extensive regulatory structure that governs nursing homes and the seemingly constant scandals associated with them have focused a great deal of attention on upgrading the quality of nursing homes to the point that there are now both federal and state standards and ratings. There have been systematic interventions and reform efforts, such as movements toward “culture change” and the Pioneer

Network of progressive nursing homes, which I describe later. There is simply nothing equivalent when it comes to paid home care or the role of home care aides.

In addition to contempt, there is also a great lack of imagination in understanding the role of home care aides. A doctor who runs a program aimed at expanding the role of home care aides described his vision of a home care aide as being like a “good grandmother” caring for a family. He had little sense of home care aides as real members of a care team.

Ignorance is another problematic component of the general view of home care aides. I interviewed senior administrators of the Centers for Medicare and Medicaid Services (CMS), the federal agency most responsible for funding and managing long-term care, and I also interviewed senior health care staff in the White House Office of Management and Budget (OMB). None of these senior officials had any idea about how home care is actually delivered; nor did they understand the role in long-term care of this massive workforce, which was essentially invisible to them.

Home care aides are deeply affected by these attitudes and the ignorance about their role. In a focus group, one home care aide said:

Most people, when they hear we're a home health home care aide, they look at us like we're the scum of the earth. We're stupid. We don't know anything. I don't have to tell them nothing. I don't have to talk to them. It's bad. I'll try to tell them certain things about the client, and they act like they didn't hear anything that I said and just go straight to the client and talk to them. And I just want to say, “Hello, I'm here, I am human. . . . Home care aide is a title.”

THE POSSIBLE FUTURE OF LONG-TERM CARE

Imagine that you are designing a system of care from scratch. Given people's preferences and needs, what are your goals? You know that people want to stay in their homes and remain connected to their communities, and you also know that home and community-based care is usually more affordable than institutional care. You also know that the people who spend the most time with the young and elderly disabled are home care aides. What would your system of care look like?

The most fundamental change is to reconceive long-term care as central to the quality of life of the millions of people who need it, rather than as the stepchild of the health care system, as it is seen today. This change would require raising the profile of the field within medicine and incorporating long-term care providers into health care teams. And to an important extent, the focus of medical care would have to be shifted away from a unitary interest in acute care and toward a more balanced interest in maintaining high quality of life for clients.

There are a number of concrete elements to this vision. Considering that the major source of support for people who need help is unpaid family members, you could find ways to make their lives easier and their caregiving more effective. Doing so would require thinking about broader social policies, such as paid family leave, and about more narrowly focused efforts, such as training. Most people want to stay at home, but nursing homes will continue to play an important role, and there is much room for quality improvement. Broadening access to small-group living arrangements is important. And of course, there is the challenge of financing. A great irony of our system is that the poor (via Medicaid) and the very rich have some degree of protection and insurance and the vast middle is left with nothing. As the numbers explode, this will become unacceptable.

Another part of your vision would be maximizing home care aides' contributions to the well-being of those for whom they care. As you think about ways to improve pay and working conditions for home care aides, you would look for strategies to improve their productivity and enable them to help reduce medical costs. These two objectives—ensuring that home care aides are as helpful and productive as possible and finding ways to economize on the cost of care—are complementary and point in the direction of new thinking about the delivery of care.

The central idea is to reconceive the role of home care aides. Although it is important to be realistic and not expect all aides to be interested in or capable of undertaking an expanded role, much of this book is devoted to making the case that many are in fact interested and capable. Aides could be trained in skills ranging from observation of health conditions to wound treatment to health coaching to physical therapy assistance. They could assist in clients' transitions from the hospital to the home rather than an institution. There would be regular communication between home care aides and doctors and

nurses. In other words, home care aides would be members of the health care team.

This vision of the role of home care aides is far from today's reality, but it is consistent with emerging ideas about how to deliver health care. In recent years, new approaches to delivering medical care have begun to percolate through the system and gain traction. The focus has been on three key pressure points: preventative care, treatment of chronic conditions, and transitions from acute care (in hospitals) to the home. The core idea is to manage these three needs utilizing nonphysicians who work to "the top of their license." Throughout the delivery system, long-standing occupations, such as medical assistant, are being upgraded and new occupations, such as community health worker and health coach, are being implemented. In all of these cases, clinical work is done by lower-level and (importantly) cheaper employees, and the evidence shows a payoff in terms of both the quality of care and the cost. I argue here that home care aides can be part of this transformation.

One message of the emerging thinking on managing chronic conditions is that improving the quality of life for the elderly and disabled does not require high-tech medicine but rather quality care and attention. Home care aides see their clients every day for hours. No one is in a better position to help with the challenges of chronic conditions than they are.

Is integrating home care aides more deeply into the medical care team, while improving their jobs in the process, a realistic goal? Are home care aides themselves interested in these changes? Do some simply lack the capacity to learn new skills and expand their work? If substantial enhancement of their role had an impact on clients, would payers have any interest in making the investment? All of these are reasonable questions that deserve careful answers, and they will be addressed in this book.

THE DIFFICULTY OF CHANGING THE ROLE OF HOME CARE AIDES

The vision just laid out holds real promise for offering better care and improving the quality of the jobs for those who do the work. But achieving this vision will be very hard. Part of the problem—indeed a central problem—is the low repute of direct care workers, as described earlier. Lack of confidence in

home care aides and respect for them is an important obstacle to expanding their role. But there are more concrete challenges. It will be no surprise to learn that a core challenge is money, on several levels. The primary funder of long-term care, not just for poor people but for some working people and middle-class people, is Medicaid.¹¹ Long-term care's reliance on Medicaid is a problem because Medicaid is widely seen as part of the welfare system; indeed, that is precisely where it originated. As a consequence, Medicaid funding, unlike Medicare funding, is constantly under attack and the program enjoys few powerful allies.

Medicaid is funded jointly by the federal government and the states, with the proportions varying by the wealth of the state. Thus, any effort to increase resources for the training and compensation of home care aides must go through state legislatures, which are struggling with demands on state budgets and must manage competing constituencies. This problem is not confined to "red" or "blue" states, but is a challenge that faces all states.

Compounding the problem are the incentive structures, which are not properly aligned. Most of the elderly whose long-term care is paid by Medicaid are also covered by Medicare, but the Medicaid system, being partly funded by states and subject to state policymaking, has no incentive to save Medicare costs (by, for example, enhancing the role of aides), since Medicare is entirely federally funded. It is essential that these incentives be fixed, and some efforts are being made to do so.

The third obstacle lies in politics, especially occupational politics. Scholars who study occupations have long noted the sharp elbows and jostling for position when two occupations seek to capture the same set of tasks. Lawyers and real estate agents, for instance, have fought over their spheres of control, as have plumbers and pipefitters. Any effort to expand the role of home care aides is quickly reminded that nurses are no friend of such an expansion. In most states the nurse practice act (NPA) sharply limits what home care aides can do, as illustrated later when I describe recent efforts to create an "advanced aide" title in New York State. This example even understates the problem, considering how modest the proposed upgrades were that would have qualified a home care aide as an advanced aide. There has been no serious effort to enact the vision laid out here, and certainly such an effort would raise substantial opposition.

The lack of alignment between the interests of the two main stakeholders, the elderly and the younger disabled, only compounds these political difficulties. The disability movement is best understood as a drive for civil rights, one strong theme of which has been an insistence by the disabled on controlling and managing their own care to the maximum extent possible and avoiding any whiff of “medicalization” or “doctor knows best.” A slogan of the movement, “nothing about us without us” captures this theme. The aversion of the disability rights movement to medicalization and expert control is understandable, but the movement’s implied opposition to policies aimed at expanding the role of home care aides and deepening their responsibilities and training works against the interests of the other stakeholder, the elderly. This potential fracture in a coalition of the elderly, the disabled, and home care aides weakens any movement to address the failings of the current system.

REASONS TO BE OPTIMISTIC

Although there are many challenges to improving long-term care and the role of home care aides, there are also reasons to think that progress is possible.

Simple demographics will push us toward a solution. As the number of people who need care rises and the reservoir of family caregivers shrinks, rising pressures toward reforming the system are likely to be translated into politics. The structure of the long-term care industry is also changing. All states are moving their Medicaid long-term care into managed care insurance (and out of the traditional fee-for-service systems), and calls for integrating Medicaid and Medicare systems for the elderly are increasing. State budgets are under pressure, and states’ share of Medicaid long-term care costs is a big part of the problem. We can therefore hope that both insurance companies and the states will consider the feasibility of using the relatively cheap services of home care aides, once they are better trained and have a broader set of duties, to reduce the costs of chronic care in lieu of more expensive health care providers. In states where they are active, unions are pushing to expand the role of home care aides. Add all of this up and the potential is there to shake up a stagnant system, improve the options of those who need assistance, and make far better use of the human capital and potential of home care aides.

THE BROADER CONTEXT: ADDRESSING INCOME INEQUALITY AND THE COST OF CARE

Our country's ability to provide long-term care is faced with many challenges: it is expensive and beyond the means of most Americans; the delivery system is fragmented and very difficult to navigate; and families are under enormous stress and must often make considerable sacrifices to care for their loved ones. Fixing this system will bring us closer, however, to addressing two of the most important challenges our society faces: maintaining and indeed improving the quality of life for our soon-to-explode elderly and disabled populations, and addressing growing economic cleavages and the persistence of a large low-wage job economy.

Activists, researchers, and policymakers have noted and deplored the circumstances of direct care workers, both those in homes and those in nursing homes. What I add is a framework for thinking about the problem and some analysis and data to flesh it out; most importantly, I place this challenge in the context of our larger system of long-term care. I describe how the job market for aides functions; lay out the financing and industrial system that shapes the present system and constrains improvement; offer evidence that transforming the role of aides can improve the overall quality of long-term care and save money; address the economic and political challenges of making this happen, and offer a vision of a long-term care system that is both more humane and more effective. I argue that improvement is possible if we align our interest in improving the jobs of direct care workers with the goal of improving care for clients and helping payers and providers operate more efficiently and profitably. Moreover, this in-depth analysis of the industry and its economic and political context provides a model for thinking about how to improve the quality of low-wage jobs in other settings.

As a nation, we spend too much on health care, and those costs are not sustainable. One approach is to cut care and ration it, but most of us would agree that this is not the way to go. We need to find ways to deliver quality care for less money. One component of the solution is to increase productivity by reallocating tasks. As a recent *New England Journal of Medicine* article on the health care system argued:

Approaches that encourage delegation of tasks from physicians and nurses to other workers . . . provide opportunities for additional savings and increased productivity. . . . A large obstacle to such a wholesale redesign is the complexity of the federal and state reimbursement rules and requirements for scope of practice, licensure, and staffing ratios.¹²

This is precisely the argument developed in this book. By expanding the role of aides, not only do we improve their jobs and reduce the incidence of low-wage work in America, but we can also improve the delivery of care and save money while doing it.

This is not to say that the choices will be easy. Much of this reform effort will be conducted in the weeds of policy; appeals to fairness and decency, no matter how evocative, have to be matched by a deep understanding of the mechanics of the system and the incentives motivating all of the actors. At the same time, if we can demonstrate the path toward better practice in such a way as to motivate a powerful coalition of consumers and workers, then we will all be better off.

THE PLAN OF THE BOOK

To say that the challenges facing our provision of long-term care are complicated would be a radical understatement, and part I describes the present landscape in the depth we need in order to begin meeting those challenges. The next chapter provides an overview of that landscape, including the key institutions and the vocabulary of long-term and direct care. In chapter 3, I describe the world of direct care workers: who they are and the work they do. Chapter 4 takes up the labor market for aides, and chapter 5 discusses unpaid family caregivers and the important topic of the consumer-directed model, under which families receive support to hire their own home care aides, who are also typically family members.

In part II, I turn to the future. Chapter 6 briefly introduces the question of whether it is in fact reasonable to think that the role of aides can be expanded. Chapter 7 reviews the arguments for taking this path as well as the evidence that it can work. I believe that the material in this chapter is convincing and that a fair-minded reading supports the idea that a new approach

to the provision of long-term care is possible. But reason does not always win out: chapter 8 describes the obstacles, economic and political and cultural, to change. There are also reasons to be optimistic, however, and these are the topic of chapter 9. I conclude the book with a discussion of concrete steps for moving ahead.