

Caregiving in America

The Schmieding Center for Senior Health and Education of Northwest Arkansas (SCSHE),

located in Springdale, Arkansas, provides older adults and their families with education, healthcare, information resources and other services for more positive aging. Education services include unique in-home caregiver training programs, public programs on positive aging, and professional programs to improve the geriatric expertise of healthcare professionals and students. Healthcare services include comprehensive clinical care and rehabilitation by an interdisciplinary team of geriatric professionals. The Schmieding Center is a partnership of the University of Arkansas for Medical Sciences Donald W. Reynolds Institute on Aging, the Area Health Education Center-Northwest, and Northwest Health System.

The International Longevity Center-USA

(ILC-USA) is a not-for-profit, nonpartisan research, education, and policy organization whose mission is to help individuals and societies address longevity and population aging in positive and productive ways, and to highlight older people's productivity and contributions to their families and society as a whole. The organization is part of a multinational research and education consortium, which includes centers in the United States, Japan, Great Britain, France, the Dominican Republic, India, Sub-Saharan Africa, and Argentina. These centers work both autonomously and collaboratively to study how greater life expectancy and increased proportions of older people impact nations around the world.

“At
home
there’s
always
hope.”

Lawrence Schmieding

This report was developed under the auspices
of the Caregiving Project for Older Americans

This report was made possible
by the generous support of

MetLife Foundation

and the

Schmieding Foundation

ILC-SCSHE TASKFORCE



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ILC-SCSHE TASKFORCE
THE CAREGIVING PROJECT FOR OLDER AMERICANS



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This report was made possible through the generous support of
MetLife Foundation and the Schmieding Foundation, Inc.

MetLife Foundation

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ACKNOWLEDGMENTS

Both this report and the Caregiving Project for Older Americans have benefited greatly from interviews and ongoing conversations with leading caregiving experts. Former First Lady Rosalynn Carter, who is president of the Rosalynn Carter Institute for Caregiving; Jeremy Boal, director of the Mount Sinai Visiting Doctors Program; Steve Dawson, Steven Edelstein, and Carol Rodat of the Paraprofessional Healthcare Institute; Val Halamandaris, president of the National Association for Home Care and Hospice; Gail Gibson Hunt, president and CEO of the National Alliance for Caregiving; Carol Levine, director of the Families and Health Care Project at the United Hospital Fund; and Carol Raphael, president and CEO of the Visiting Nurse Service of New York—we extend our sincere thanks to everyone involved for sharing their insights and experiences.

We also are indebted to ILC board member Jackson Stephens, Jr., whose original educational grant launched the International Longevity Center's Arkansas Aging Project, which eventually led to the collaboration between the ILC and the Schmieding Center for Senior Health and Education on the Caregiving Project for Older Americans.

For their continued encouragement, inspiration, and friendship, we also thank Dr. David Lipschitz and Dr. Claudia Beverly at the Donald W. Reynolds Institute on Aging in Little Rock, Arkansas.

For its vision and generosity in supporting the Caregiving Project for Older Americans, we are indebted to the Schmieding Foundation. We also gratefully acknowledge the MetLife Foundation for its generous support of this publication.

Finally, this project would not have been possible without the generous support of Lawrence Schmieding.

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Figure 1.

A Letter from the Project Directors

To the Readers of This Report:

As geriatricians long concerned with caregiving, we are grateful for the opportunity for our two organizations to work together, connecting what we know—and what we have learned—with the growing gap between trained caregivers for older Americans and the accelerating need for them. In doing so, we recognize that caregiving is about individuals—those being served, those providing the service, and others who help organize the effort. It is about caring people helping others who need assistance to accomplish the most basic of daily tasks, and at the same time it is a looming national crisis that threatens to undermine the health of older persons even in the face of modern medical treatment, social services, and various technologies.

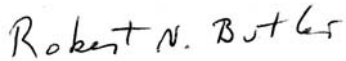
At a time when we know more about the health needs of older persons and treatment solutions that advance both physical and cognitive health, much of that knowledge is not reaching those who need it most. The knowledge found in our leading medical, nursing, and social work schools, for example, does not always trickle down to the people who spend the greatest amounts of time with older people in the last years of their lives. Those caregivers go by many names, with some working in institutions such as hospitals, nursing homes, and assisted-living facilities, while others are engaged in home care. Some are paid, others are volunteers, and many are family members.

We were brought together in 2004 and 2005 by a project assessing the far-reaching Arkansas Aging Initiative of community centers that was carried out by the International Longevity Center-USA in 2005 with the assistance of the leadership of the Donald W. Reynolds Institute on Aging at the University of Arkansas for Medical Sciences. A portion of the resulting report, *Arkansas: A Good Place to Grow Old?* (New York: ILC-USA, 2005), focused on caregiving at the Schmieding Center for Senior Health and Education in Springdale, Arkansas. Subsequently in connection with the 2005 White House Conference on Aging, we cooperated on two conferences—one on caregiving, the other on home care—carried out at the Schmieding Center. Concurrently, we discussed how a national caregiving project, drawing on the diverse but complementary capabilities of our two organizations, might be developed. With assistance from our staff and associates in New York and Springdale, the Caregiving Project for Older Americans was proposed.

Thanks to the generosity of Lawrence Schmieding and the Schmieding Foundation, a challenge grant of \$1 million was provided and thus launched the project, of which this report is the first public presentation. This report is designed both to map the territory and introduce our specific project initiatives, and to offer a context for what has already been done and what still needs to be accomplished in the caregiving field. The report will be used as a background paper for a national conference and will be disseminated widely to all 50 states where various caregiving initiatives are proposed or already under way. The Schmieding Foundation grant is the lead gift for a \$4.2 million, three-year effort to extend this project across the nation. We are eagerly seeking additional support and hope that this report will serve as a call to arms for those who might join this effort.

We invite readers to make comments and suggestions, since solving the caregiving crisis will only be possible with a vast cooperative effort among people who care about good health across the life course from early childhood through adulthood and into older age. Aging is about everyone, and everyone is affected by it. Clearly, caregiving is a systemic matter whose impact is multifaceted and cuts across the generations. Please contact us at caregivingproject@ilcusa.org.

Finally, we salute Lawrence Schmieding, a true champion of caregiving for older people in America, whose steadfast leadership and support have enabled this project to proceed.



Robert N. Butler, M.D.
President and CEO
ILC-USA



Larry Wright, M.D.
Director
Schmieding Center for Senior Health and
Education

Foreword

Unraveling the Caregiving Conundrum

“At home, there’s always hope,” Lawrence Schmieding has remarked with more than casual concern, growing out of personal experience. This remarkable agri-business leader and philanthropist encountered difficulty arranging caregiving services for his older brother some years ago. The up-close and highly personal experience caused him to ask, “If people of means are hard-pressed to find caregiving solutions for older family members and relatives, what about others who lack resources?”

Driven by his concern for the caregiving needs of family, friends, neighbors, and other citizens in his hometown of Springdale, Arkansas, Mr. Schmieding was inspired to provide funding for a multifaceted outpatient center with caregiving services and education at the core of its mission. The Schmieding Center for Senior Health and Education and several satellite centers provide services to older people and their families throughout northwest Arkansas. We asked Mr. Schmieding to consider supporting a caregiving project that would build on the Arkansas experience by launching a national project to improve and elevate paid caregiving in the home.

With a special interest in developing national curricula, standards of care, a career ladder for caregivers and possibly even an organization to work on behalf of these undervalued workers, we wanted to begin a process that appreciates the considerable work on caregiving done by various national, regional, and local organizations in the nonprofit, private, and public sectors but still addresses the vital national need for appropriately trained individuals.

That there is a current and looming crisis in caregiving is not in dispute. Although this report focuses on the caregiving needs of older Americans, the crisis affects younger adults and children with disabilities, too. With a growing population of older persons constituting a larger percentage of the adult public, the inevitable need for caregiving services in the home, whether provided by paid caregivers, family members or both, is striking. In the face of this situation, the recruitment, training, and retention of caregivers who are paid a living wage is critical, yet there is no comprehensive plan to make this happen. Thus, the Caregiving Project for Older Americans was born with a generous \$1 million challenge grant from the Schmieding Foundation and with a goal of ultimately raising an additional \$3.2 million over a three-year period.

This project, and the report presented here, represent a cooperative effort between our two organizations, the International Longevity Center-USA, an affiliate of Mount Sinai School of Medicine in New York City, and the Schmieding Center, which is a program of the Donald W. Reynolds Institute on Aging of the University of Arkansas for Medical Sciences in Little Rock. The Schmieding Center offers direct patient services, education, and caregiver training, while the ILC-USA focuses its energies on research, education, and advocacy to advance healthy aging and productive engagement of older people and to combat ageism.

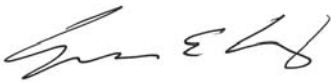
Caregiving in America offers a context for caregiving and an overview of the caregiving field, providing an inventory of work done over the years by various academic, professional, and service organizations. This background study is a prelude to our own project and acknowledges the considerable achievements and contributions of others. At the same time much needs to be done — the training, standard setting, and organization and delivery of caregiving. We believe we have much to do to address the challenges that lie ahead.

The continuing caregiving crisis is a condition that began so incrementally that few were initially aware of it. Now millions face its challenges in daily life. We ask both what we know about caregiving and who actually cares about caregiving. We consider the several major surveys aimed at understanding and monitoring the caregiving crisis. We take a detailed look at family caregivers and construct a profile of the direct care worker. We try defining the crisis and suggesting pathways for coping with it. We look at research that must be continued and developed to monitor and evaluate the experiences of families, regulators, paid caregivers, and others as the basis for policy recommendations, and, finally, we offer an agenda for action, including public policy and ideas for all sectors involved in the caregiving task.

We hope to engage caregiving experts and civic-minded individuals who can help in the process of fully understanding the dimensions of this challenge, and in providing greater awareness by the public, professionals, and policymakers.

This report owes its existence to many conversations between the principals and staff of the ILC-USA and the Schmieding Center. Its lead author is Dr. Ken Knapp, an economist and senior research analyst at the ILC, who worked closely with Vivienne Lorijn de Usandivaras, policy analyst and researcher. The entire ILC-SCSHE caregiving team listed at the end of this report made contributions. The report was edited by Judith Estrine, executive editor, and the cover was designed by Herbert Reade.

We marshal the shared interests of two organizations deeply committed to caregiving and join it with the national conversation on the topic, one often blocked by economic and social barriers.



Everette E. Dennis, Ph.D.
Executive Director
ILC-USA

Executive Summary

The United States is in the midst of a significant and growing caregiving crisis. About 1.4 million older Americans live in nursing homes, nearly 6 million receive care at home, and significant numbers go completely without the help they need. And the growing disparity between the demand and supply of caregiving services will only worsen with the aging of baby boomers in this country.

Other countries are confronted with the same demographic and social trends that are putting pressure on the caregiving industry in the United States. But in contrast to Japan, Germany, Austria, and some Scandinavian countries that reach large shares of their older populations through universal systems of long-term care, the United States arguably has no caregiving system at all, with its reliance upon Medicaid, a means-tested program whose benefits vary greatly from state to state.

An underlying combination of ageism and sexism explains in part why the caregiving crisis is receiving far less attention than it warrants. Older care recipients are deemed disposable and without value, and women continue to be the primary caregivers of family members. Like other unpaid work, their contribution to society is not included in national income accounts.

This report is the first product of the newly launched Caregiving Project for Older Americans, a multiyear, joint project of the International Longevity Center-USA (ILC) and the Schmieding Center for Senior Health and Education (SCSHE). The Caregiving Project for Older Americans was established through a \$1 million challenge grant from the Schmieding Foundation, and will work toward developing solutions to the growing caregiving crisis in the United States, through the initiatives described in Section 8.

This report and the Caregiving Project for Older Americans share the goal of comprehensively integrating what is known about both the paid and the family caregiving worlds. While our report focuses on the needs of older people, we recognize that disabled younger adults and children also have a large stake in the improvement of caregiving in America.

Caregiving in America documents the growing caregiving crisis in our country — the fact that, increasingly, there are too few caregivers, both paid and unpaid, and too many people needing care. Among the major topics covered are:

- What is the caregiving crisis, and why is it growing?
- Who provides care, and where?
- Who needs care? How many who need care go without it?
- Who are the major governmental agencies, nonprofit organizations, philanthropic foundations, businesses, and other major stakeholders in the caregiving field?
- The burden on family caregivers, who provide care to a great majority of those receiving home-based care
- The severe shortage of paid caregivers—especially of those in home-based settings

- Barriers to affordable, quality care including regulatory obstacles, the financing of long-term care (or lack of it), and the need for better communication among medical practitioners, caregivers, and care recipients
- Major public and private efforts to address the caregiving crisis, such as improving wages and benefits for direct care workers, enhanced training initiatives, and creating career ladders.

An important objective of the ILC-SCSHE Caregiving Project for Older Americans is to ensure that stakeholder organizations both inform the project and benefit from the results. The insights of representatives from government agencies, corporations, health care providers, and nonprofits in the fields of health care, gerontology, policymaking, academia, and business all will influence our work. Ongoing work of the Caregiving Project for Older Americans involves:

- Assembling a national advisory committee and expert panel
- Convening a national caregiving summit and
- Conducting a series of national caregiving surveys comparing the perspectives of paid home caregivers to those of other stakeholders, such as care recipients of state Medicaid directors.

The findings of our national caregiving surveys will inform the later stages of our work in the Caregiving Project for Older Americans. The development of our project also will be guided by the ideas and feedback generated by our national advisory committee and expert panel, and through our national caregiving summit. The core components of our future work include: (1) developing a curricula for professional and family caregivers with special modules on dementia, congestive heart failure, and other conditions; (2) working to create an accreditation and national certification program; (3) working to establish a career ladder initiative, and (4) efforts to found a national association for home caregivers.

Improving the availability of affordable, quality care for those who need it is the shared goal of the public and private organizations reviewed in this report. With the launching of the Caregiving Project for Older Americans, we join their efforts. And along with them, we recognize that when it comes to solving the growing caregiving crisis, there is still more work to be done.

INTRODUCTION

The United States is in the midst of a significant and growing caregiving crisis. About 1.4 million Americans aged 65 and over live in nursing homes, four times as many receive care at home, and significant numbers of frail older people go completely without the help they need. These numbers will only increase with the aging of baby boomers, exacerbating the “care gap” in this country. Simply put, there is a growing disparity between the demand for and supply of caregiving services.

On the supply side, long-term care providers are reporting unprecedented turnover and vacancy rates of paid direct care workers. The available workforce of caregiving paraprofessionals is often poorly trained and underpaid. This shortage is reflective of a wider national phenomenon—the emerging shortage of nurses, primary care doctors, and other health care professionals, which is partly the result of the maturation and impending retirement of the baby boom generation—that jeopardizes affordable, quality care.¹ Meanwhile, social and demographic trends, such as more women entering the labor force, more dual-earner households, and families having fewer children, have diminished the supply of family caregivers, who are by far the greatest source of care to impaired older adults. Especially hard-hit by these trends is the so-called sandwich generation, those with the dual responsibility of rearing children and caring for aging parents. Since many of these family caregivers work full-time, there is in fact a triple responsibility.

Caregiving is a global issue

Many nations are confronted with an aging population, more women entering the labor force, and smaller and more geographically dispersed families. In the United States these demographic trends are putting pressure on the caregiving industry by increasing demand at the same time as the supply of both paid and family caregivers² is decreasing. Some countries are responding somewhat better than others to this pressure. Japan, Germany, Austria, and some Scandinavian nations reach large shares of their older populations (and younger persons with disabilities) through universal systems of long-term care.³ The United States, on the other hand, “[a]rguably. . . has no system at all,” with its reliance upon Medicaid, with its availability limited by means-testing, interstate differences in benefits, and its bias toward nursing home care as opposed to home-based care.⁴ Private long-term care insurance policies cover a small percent of the population.

To date, little cross-national long-term care research has been conducted, although the respected Organisation for Economic Cooperation and Development (OECD), the World Health Organization, and other international organizations have begun such studies. Although cultural, institutional, and other differences would make it difficult for the United States to implement the long-term care system of another nation, U.S. policymakers and other stakeholders would do well to adopt an international perspective on long-term care to develop solutions to the growing caregiver crisis.⁵

Other dimensions of the caregiving crisis

An underlying combination of ageism and sexism explains in part why the caregiving crisis receives less attention than it warrants. Older people receiving care are deemed disposable and without value.⁶ As demonstrated by the recent scandal involving the wealthy socialite Brooke Astor—now the subject of a legal battle among family members about whether she needs more care—ageism cuts across class boundaries.⁷ Sexism, too, may prevent some from giving proper weight to the importance of improving the quality and availability of caregiving in America. Women continue to be the primary caregivers of family members, and like other unpaid workers, their contribution to society is not included in national income accounts.

Recent research has found that improvements in worker skill levels explain a significant portion of the growth in labor productivity over the past several decades in the United States.⁸ In addition to higher education levels, the increasing experience of the workforce has contributed to this growth in the quality of human capital. Baby boomers represent a sizeable number of this experienced resource, and as their older members fast approach typical retirement age, employers would do well to consider ways to attract or retain them. Disruptions and absenteeism due to employees' caregiving duties cost U.S. employers up to \$33.6 billion per year.⁹ One way for employers to attract or retain older workers would be through greater recognition of the caregiving issues faced by many older workers and to develop appropriate programs and services that address them.¹⁰

Market forces alone have been unable to develop adequate solutions to the growing caregiving crisis. Just as the private sector's inability to provide adequate health care to older people led to the creation of Medicare, a significant governmental role is needed in the caregiving field. For example, high turnover rates are often assumed to be the result of the low wages of paid caregivers. And yet, many people cannot afford to pay for even paid caregiving services. If industry wages rise, the number of paid caregivers might increase, but the demand will decrease because even fewer people will be able to afford to pay for them. This dilemma suggests that there might be a place for governmental wage subsidies or other public policy initiatives.

Family care, paid care—two separate worlds?

As will be discussed in Section 3, several major nonprofit organizations have been established to improve the caregiving system in the United States, partly by advocating for changes in public policy. These organizations fall under two categories: those whose primary interest is family caregivers, such as the National Alliance for Caregiving (NAC) and the Family Caregiver Alliance (FCA), and those that focus on paid caregivers, such as the Paraprofessional Healthcare Institute (PHI). Typically, family and paid caregiving are “treated as two separate worlds” by advocates, lobbyists, and policymakers, even though, empirically, “it is rare for these two caregiving systems not to interface in some way.”¹¹

Some initiatives, such as the Rosalynn Carter Institute for Caregiving's “Caring for You, Caring for Me” program, bring family and paid caregivers together to share experiences and perspectives, with a view to improving care. For example, as discussed in Section 6, families and paid caregivers often have quite different expectations about the appropriate role and responsibilities of the caregiver. But public policy is largely unreflective of these shared perspectives. Dr. Robyn Stone, Institute for the Future of

Aging Services (IFAS), who has done extensive research on both family and paid caregivers, stresses that these two groups lack the political unity necessary in order to encourage mutually beneficial public policy initiatives.¹² Gail Hunt, president and CEO of the NAC, strongly agrees that there is a vital need for a more holistic, integrated approach by advocates and policymakers from the family and paid caregiver fields.¹³

The fact that the NAC, which is one of the preeminent nonprofit organizations interested primarily in support for *family* caregivers, and the IFAS and PHI,¹⁴ who together, may have done more than any other nonprofit organization to further the cause of *paid* caregivers, are advocating a more integrated, comprehensive approach to addressing the growing caregiving crisis may be an indication that it is just a matter of time before the “false dichotomy”¹⁵ is dissolved.

Plan of this report

Consistent with aims of the Caregiving Project for Older Americans,¹⁶ this report focuses on the integration of what is known about both the paid and the family caregiving worlds into a comprehensive whole. While our report focuses on the needs of older people, we recognize that disabled younger adults and children also have a large stake in the improvement of caregiving in America.

Section 1 provides an overview of the factors contributing to the growing caregiving crisis, including demographic and social trends, while Section 6 offers a more detailed discussion of such barriers, including inadequate financing of long-term care (LTC) and a critical shortage of direct care workers (DCW). Section 1 also provides descriptions of institutional versus home- and community-based care, and other features of the caregiving environment.

More than 12 million people in the United States, about half of whom are over age 65, need some kind of long-term care. Section 2 presents a profile of older care recipients: gender, age, ethnicity, marital status, wealth and income, health status, and other characteristics. Section 3 describes the major stakeholders concerned about caregiving.

Family and friends are the exclusive caregivers for the great majority of adults who receive long-term care at home. In Section 4, demographic and other characteristics of these caregivers are provided: age, gender, ethnicity, socioeconomic status, physical and mental health risks, financial burdens, and so on.

A major barrier to affordable, quality care for older Americans is the severe shortage of paid caregivers—direct care workers—an issue discussed in Section 5. Section 5 also reviews job titles and workplace environment, socioeconomic profile, and the causes of high turnover rates among paid caregivers.

Most Americans who need long-term care prefer home-based care to nursing homes and other institutional settings, and since the 1980s there has been a change in emphasis toward home- and community-based care among policymakers, providers, and consumers.¹⁷ The 1999 Supreme Court *Olmstead* decision, which found that, under title II of the Americans with Disabilities Act (ADA), states must provide caregiving and other services in the most integrated setting appropriate to the needs of qualified individuals and disabilities, has reinforced the movement toward home-based care.¹⁸ Section 5

gives most attention to those paid caregivers who work in home- and community-based settings, although we touch upon direct care workers in institutional settings.

Other barriers to affordable, quality care in the United States are discussed in Section 6, including inadequate financing of long-term care; communication barriers among medical practitioners, caregivers, and care recipients; the need for more effective, locally based, caregiving deliver systems; and regulatory restrictions governing permissible caregiver duties.

Relevant public and private initiatives to overcome these barriers are reviewed in Section 7, including wage pass-throughs, enhanced training initiatives, consumer-directed care, and development of career ladders.

THE GROWING CAREGIVING CRISIS

Basically, the caregiving crisis is occurring because there are too few caregivers, both paid and unpaid, and too many people needing care. Demographic and social trends are reducing the available pool of family caregivers at the same time that the number of older people needing care is rising. The caregiving industry, meanwhile, is experiencing a severe, and worsening, shortage of paid paraprofessionals. Affordable, quality care is increasingly difficult—if not altogether impossible—to find.

What is caregiving?

There is no universally agreed-upon definition of caregiving, either in the literature¹⁹ or in practice. Generally, the term refers to services that are provided to people who are unable to care for themselves due to a disability or functional limitation, usually defined in terms of *activities of daily living* (ADLs) or *instrumental activities of daily living* (IADLs).²⁰ ADLs refer to basic self-care functions, such as bathing, dressing, using the toilet, getting in and out of beds and chairs, and eating. IADLs include functions related to maintaining independence, such as shopping, preparing meals, managing money, and performing housekeeping duties.

Measures of ADLs and IADLs are widely used by researchers and policymakers to analyze caregiving activities and to assess the level of care required of caregivers. But as Carol Levine, of the United Hospital Fund, has argued these measures of care recipients' limitations “do not convey the full spectrum or degree of complexity of the family caregiver’s responsibility.”²¹ Missed in the ADL and IADL measures are such significant caregiver activities as behavior supervision, pain management, and advocacy on behalf of the care recipient within the health care system.²²

Following the generally accepted usage in the caregiving literature, in this document the term *caregiving* denotes supportive, nonmedical, mostly low-tech services (such as help with bathing or eating) and some medical services (such as administering oral and intravenous medications and attending to wounds). Caregivers may be divided into two groups—formal caregivers, also called paid direct care workers, and informal or family caregivers. Both *informal caregiver* and *family caregiver* are problematic terms. The word *informal* has the unintentional connotation of laxity; and the term *family caregiver* usually refers not just to care by family members, but also to care by friends, neighbors, and volunteers. Even the term *caregiver* is not without controversy, since some observers prefer to use it exclusively to mean informal (family) help. Throughout this report, *formal* or *paid* caregivers are sometimes called *direct care workers* or *paraprofessionals*; and this group is distinct from *family*, *unpaid*, or *informal* caregivers. When the term *caregiver* stands alone, both formal and informal caregivers are meant.

Table 1.1. Job Description of Direct Care Workers

Nursing aides, also known as nursing assistants, certified nursing assistants, geriatrics aides, unlicensed assistive personnel, orderlies, or hospital attendants, perform routine tasks under the supervision of nursing and medical staff. They answer patients' call lights, deliver messages, serve meals, make beds, and help patients to eat, dress, and bathe. Aides may also provide skin care to patients, take their temperature, pulse rate, respiration rate, and blood pressure, and help them get into and out of bed and walk. They also may escort patients to operating and examining rooms, keep patients' rooms neat, set up equipment, store and move supplies, and assist with some procedures. Aides observe patients' physical, mental, and emotional conditions and report any change to the nursing or medical staff. Nursing aides employed in nursing care facilities often are the principal caregivers, having far more contact with residents than do other staff members. Because some residents may stay in a nursing care facility for months or even years, aides develop ongoing relationships with them and interact with them in a positive, caring way.

Home health aides help aged, convalescent, or disabled persons live in their own homes instead of in a health care facility. Under the direction of nursing or medical staff, they provide health-related services, such as administering oral medications. Like nursing aides, home health aides may check patients' pulse rate, temperature, and respiration rate, help with simple prescribed exercises, keep patients' rooms neat, and help to move patients from bed. They may help patients bathe, dress, and groom. Occasionally, they change nonsterile dressings, give massages and alcohol rubs, or assist with braces and artificial limbs. Experienced home health aides also may assist with medical equipment such as ventilators, which help patients breathe.

Psychiatric aides are also known as mental health assistants or psychiatric nursing assistants, who care for mentally impaired or emotionally disturbed individuals. They work under a team that may include psychiatrists, psychologists, psychiatric nurses, social workers, and therapists. In addition to helping patients to dress, bathe, groom themselves, and eat, psychiatric aides socialize with patients and lead them in educational and recreational activities. Psychiatric aides may play games such as cards with the patients, watch television with them, or participate in group activities, such as sports or field trips. They observe patients and report any physical or behavioral signs that might be necessary for the professional staff to know. They accompany patients to and from examinations and treatment. Because they have such close contact with patients, psychiatric aides can have a great deal of influence on their patients' outlook and treatment.

Personal care and home care aides generally provide unskilled, nonmedical caregiving to the aged, physically and/or mentally disabled and ill who live in their own homes or in residential care facilities instead of in health facilities. Most personal and home care aides work with aged or physically or mentally disabled clients who need more extensive personal and home care than family or friends can provide. Some aides work with families in which a parent is incapacitated and small children need care. Others help discharged hospital patients with relatively short-term needs.

Source: Bureau of Labor Statistics, U.S. Department of Labor (2006). Most text verbatim from source.

Perhaps the best way to define caregiving is to consider the list of tasks performed by caregivers. While Table 1.1 refers to the tasks of paid caregivers, also referred to as *paraprofessionals* and *direct care workers* (DCW), unpaid family caregivers also perform these tasks. Four categories of paid caregivers defined by the Bureau of Labor Statistics are listed in Table 1.1: nursing aides, home health aides, psychiatric aides, and personal care aides (also called home care aides). A wide variety of both medical (or quasi-medical) and nonmedical tasks are listed, including helping with eating, bathing, and dressing, taking temperature and pulse rate, changing nonsterile dressings, providing opportunities for socialization, and offering companionship. It is worth repeating that even the long list of activities in Table 1.1 may miss important caregiver activities.

Who provides caregiving, and where?

Caregiving is provided in both home-based and institutional settings (Table 1.2). Self-employed caregivers who do not work through agencies represent an important group that is not reflected in Table 1.2. It has been estimated that 29 percent of home care workers are self-employed.²³ Nor are informal (family) caregivers represented in Table 1.2.

TABLE 1.2. PROVIDERS OF LONG-TERM CARE IN THE U.S., 1998

TYPE OF PROVIDER	NUMBER
Nursing facilities	17,458
Intermediate care facilities	6,553
Residential facilities for adults/aged	51,227
Residential facilities for non-aged	13,277
Adult day care centers	3,590
Home health care agencies (certified or licensed)	23,263
Hospice organizations (certified or licensed)	4,336
TOTAL	119,704

Source: U.S. Department of Health and Human Services, Health Resources and Services Administration (2004).

About 80 percent of care recipients age 65 or older live in home- or community-based settings, the remainder in nursing facilities.²⁴ In addition to private homes and institutional nursing facilities, care is provided in group settings such as assisted-living facilities, congregate housing, residential care facilities, and adult day care centers. Although often included within the term *home-based care*, often these services are more institutional in character and resemble traditional nursing homes. There is considerable variation in terminology across states and among caregiving experts, and the distinction among these different types of group settings, and between them and institutional settings for care, is often cloudy.²⁵

Caregiving advocate Lawrence Schmieding says, “At home, there’s always hope.” But when it comes to group housing, the line becomes blurred. What is a *home*, and what is an institution? Arriving at a clear-cut answer to this question is problematic even among caregiving and housing experts. As the Visiting Nurse Service of New York’s Center for Home Care Policy and Research points out, “Confusion over terminology impedes the collaborative thinking and clear communication necessary for joint housing-LTC policy development” by disparate decision makers.²⁶

As suggested in Table 1.1, various titles are used for paid direct care workers (DCWs). For example, nursing aides are also referred to as nursing assistants, certified nursing assistants, geriatrics aides, unlicensed assistive personnel, orderlies, patient care assistants, resident assistants, and—simply—caregivers.²⁷ The term caregiver also is used as a synonym for home health aide (HHA), a job title classified by the Bureau of Labor Statistics that has many alternatives: residential counselor, home health provider, rehabilitation training specialist, direct support person, personal care attendant, and so on.²⁸

Nearly 80 percent of adults who receive care at home rely exclusively on unpaid help from family and friends. Only 8 percent of consumers of home-based care receive all of their care solely from paid workers, and 14 percent rely on both paid and unpaid workers. This means that family and friends provide support to well over 90 percent of people receiving care at home.²⁹

What is the caregiving crisis, and why is it growing?

Increasingly, there are too few caregivers, both paid and unpaid, and too many people needing care. Growing numbers of people are finding it increasingly difficult to obtain affordable, quality care. At the same time as the available pool of family caregivers is shrinking, the caregiving industry is experiencing a severe, and worsening, shortage of paid paraprofessionals. Meanwhile, as the baby boom generation grows older, the number of older people needing care will continue to rise. And the “blessing” of increasing life expectancy in the United States means not only that more people live to advanced age, but also that more of them will need care for a period of years or even decades.³⁰

The most significant cause of increasing demand for caregiving services in the future will be the aging of the baby boomers,³¹ and the U.S. population will continue to become old for several decades (Table 1.3). In 2005, about 17 percent of the population was age 60 or older; by 2050, this is projected to have increased to more than 26 percent. Most of this change in the population’s age composition will be due to the growth of the older age groups—ages 70–84 and ages 85 or older. They are more likely than younger members of the 60-and-over set to have chronic conditions that require care.

TABLE 1.3. POPULATION AGING IN THE UNITED STATES, 2005 TO 2050

	2005	2015	2025	2050
60 - 65	4.4%	5.8%	6.0%	5.3%
65 - 69	3.4%	4.8%	5.6%	4.9%
70 - 84	7.3%	7.5%	10.3%	10.9%
85+	1.7%	2.1%	2.3%	5.0%

Source: U.S. Census Bureau (2004).

Over the past several decades, although increasing numbers of women of all ages have entered the labor force, the majority of family caregivers are still women. Frequently, women carry a joint burden of paid employment and unpaid caregiving at home. Others are compelled to exit the labor force altogether to care for a family member, often a spouse. (See Section 4.)

Trends in family and living arrangements are also influencing the supply of family caregivers. Families are having fewer children. Over the past several decades the number of men and women who live alone has been steadily increasing.³² It is an unfortunate irony that while women have traditionally served as their family’s primary caregiver, when they reach advanced age and need care themselves, fewer family members are around to help. Two-thirds of women ages 75 or older live alone, compared to 29 percent of men the same age.³³

Trends in migration patterns also have an impact on the role of family caregivers. Traditionally, it was customary for a majority of people age 60 or older to eventually move from their homes to another location, usually a short distance away.³⁴ In recent years, “a new phenomenon” has been observed, “a discernible dispersal of retirement migration” away from the traditional destination states—Florida,

California, Arizona, and Texas—to “newly favored” destinations such as Cape Cod, Massachusetts, the Jersey shore, and the Ozarks of Missouri and Arkansas.³⁵ These demographic trends will increase demand for paid caregivers in some regions while decreasing demand in others, and change the interface between family and paid caregivers.

By itself, this anticipated increase in the demand for care and decreasing supply of family caregivers would represent a significant challenge to policymakers and others concerned about ensuring the availability of affordable, quality care. But these trends are only part of the story, for the increasing pressure on family caregivers, and on those needing care, is exacerbated by a severe shortage of direct care workers.³⁶

WHO NEEDS CARE?

Many who need care go without it

More than 12 million people in the United States, about 80 percent of whom are age 50 or older and about half of whom are age 65 or older, need some kind of long-term care.³⁷ Among those who are 50+ years of age, the average age is 75; the average age of all care recipients is 66.³⁸ Nearly two-thirds of care recipients are female.³⁹ Many of those in need of care simply go without it—about 20 percent of adults needing assistance are unable to find someone to help, either paid or voluntary.⁴⁰

ADLs and IADLs

Cancer, diabetes, and heart disease are the most commonly reported diseases among people age 50 or older who receive help from family or friends (Table 2.1). Although Table 2.1 shows that only 8 percent of family caregivers report Alzheimer's disease among care recipients age 50 or older, a follow-up question in the survey from which the data were obtained indicates that the incidence is much higher. The statistics in Table 2.1 are from an open-ended question about the main problems and illnesses of care recipients. In the follow-up question, the National Alliance for Caregiving and AARP specifically asked respondents who did not report Alzheimer's in the open-ended question whether the people for whom they provide care suffered from Alzheimer's or other mental confusion. An additional 17 percent said yes—which means that about one in four family caregivers faces the significant stress of caring for someone with Alzheimer's or other mental confusion.⁴¹

TABLE 2.1 PERCENT OF FAMILY CAREGIVERS REPORTING SPECIFIED PROBLEMS AND ILLNESSES AMONG CARE RECIPIENTS

	Recipient 18-49 Years Old	Recipient 50+
Old age	0%	15%
Cancer	4%	9%
Diabetes	4%	9%
Mental illness	23%	3%
Heart disease	1%	9%
Alzheimer's	0%	8%
Stroke	3%	6%
Mobility limitation	3%	6%
Arthritis	0%	5%
Blindness/vision	2%	3%

Base: 1,247 caregivers in the U.S.

Source: National Alliance for Caregiving and AARP (2004).

ADLs and IADLs are commonly used to assess the level of care required (Tables 2.2 and 2.3). While these measures are imperfect indicators of a caregiver’s level of responsibility because they ignore the incidence of disease among care recipients and miss significant responsibilities such as behavior supervision and pain management,⁴² responsibility grows as the care recipient requires more help with ADLs and IADLs.

TABLE 2.2. PERCENT OF FAMILY CAREGIVERS HELPING WITH IADLS

	% Saying Yes
Transportation	82%
Grocery shopping	75%
Housework	69%
Managing finances	64%
Preparing meals	59%
Helping with medication	41%
Managing services	30%

Base: 1,247 caregivers in the U.S.

Source: National Alliance for Caregiving and AARP (2004).

TABLE 2.3. PERCENT OF FAMILY CAREGIVERS HELPING WITH ADLS

	% Saying Yes
Getting in and out of beds and chairs	36%
Getting dressed	29%
Helping bathe or shower	26%
Getting to and from the toilet	23%
Feeding care recipient	18%
Dealing with incontinence diapers	16%

Base: 1,247 caregivers in the U.S.

Source: National Alliance for Caregiving and AARP (2004).

Family caregivers most commonly provide help with the following ADLs: getting to and from the toilet, bathing or showering, getting dressed, and getting in and out of beds and chairs (Table 2.3). Regarding IADLs (Table 2.2), the vast majority of caregivers help with transportation (82 percent), grocery shopping (75 percent), and housework (69 percent). Fifty percent of family caregivers help with one or more ADLs, and 80 percent help with three or more IADLs.⁴³

Living arrangements

About 55 percent of all care recipients live in their own homes, 24 percent in a caregiver's home, and 8 percent in someone else's home (Table 2.4). Only 5 percent of all care recipients reside in nursing homes, much lower than the 20 percent of recipients age 65 or older who do.

TABLE 2.4. LIVING ARRANGEMENTS OF CARE RECIPIENTS

	% Saying Yes
Own home	55%
In caregiver's household	24%
Someone else's home	8%
Nursing home	5%
Assisted-living	4%
Independent living/retirement	3%

Base: 1,247 caregivers in the U.S.

Source: National Alliance for Caregiving and AARP (2004).

Underscoring the need for advocacy and research

Significant numbers of frail older people go entirely without the help they need. Unfortunately, among those who find help, appropriate care is not always provided—even by intimate family members. For example, one study found that among physically disabled people age 65 or older who were being cared for by a spouse, nearly 40 percent reported emotional distress from receiving the assistance, 50 percent reported being helped with activities “unnecessarily,” and 28 percent reported not receiving help that they needed. This study was limited to care of people with physical limitations. Since caring for people with Alzheimer's disease and other cognitive impairments is usually more challenging,^{44,45} the authors note that the incidence of inadvertently inappropriate care by family caregivers probably is higher than reported in the study, as its authors point out.⁴⁶ Less than one-fifth of family caregivers receive formal caregiver training,⁴⁷ and 28 percent reported not receiving help that they needed.^{48,49}

This is not to discount the significant contribution of family caregivers but rather to underscore the importance of the work being done by the National Alliance for Caregiving, the Family Caregiver Alliance, the Rosalynn Carter Institute for Caregiving, and other organizations that advocate on behalf of family caregivers, as well as provide information and conduct research in this area.

Before moving on to a discussion of family caregivers and the significant burden they face, we will review in Section 3 some of the major nonprofits and other caregiving stakeholders devoted to improving caregiving in the United States. Our discussion covers both those organizations primarily concerned with family caregivers and those with paid paraprofessionals.

WHO CARES ABOUT CAREGIVING?

Family caregivers obviously have a big stake in the growing caregiving crisis, as do paid paraprofessionals. (See Sections 4 and 5.) As discussed in Section 1, caregiving agencies, too, such as home care agencies and nursing homes, have an obvious interest in the care of older Americans.

In this section, we review some of the other major stakeholders in the caregiving field, such as governmental agencies, nonprofit organizations, philanthropic foundations, businesses and trade associations, and unions. (Also see Appendix A, which includes many more organizations than those discussed here.)

Administration on Aging

The National Family Caregiver Support Program (NFCSP), developed by the U.S. Administration on Aging (AoA), was established through enactment of the amendments to the Older Americans Act (OAA) in 2000.⁵⁰ The NFCSP “was the first federal law to explicitly acknowledge the service needs of families of older people in their caregiving role.”⁵¹ More than a third of all states provide support to the caregivers of older people through the NFCSP, the total of which amounted to \$155.2 million in fiscal year 2003.⁵² The relatively limited NFCSP funding available to states leaves gaps in caregiver support services, which vary considerably from state to state.⁵³

The NFCSP offers several direct services for caregivers, including assistance in gaining access to supportive services; counseling, support groups, and training; and respite care. Eligible populations for these services are family caregivers of older adults and grandparents, as well as other family members who are caregivers of children.

Another initiative of the AoA is the Eldercare Locator. Older people and their caregivers throughout the country can contact Eldercare Locator, by telephone or by Internet, to get contact information for state and local area agencies on aging and community-based organizations in their localities. The National Association of Area Agencies on Aging and the National Association of State Units on Aging work in partnership with the Eldercare Locator. The overall goal of the Eldercare Locator is to “help older persons live independently and safely in their homes and communities for as long as possible.”⁵⁴

Nonprofit organizations

Many nonprofit organizations are devoted to addressing caregiving issues in the United States through advocacy, education, original research, and other efforts. Generally, these nonprofits tend to focus either on family caregivers or on paid caregivers.

Family caregiving: Among the several major nonprofits in the United States concerned primarily with family caregivers are the National Alliance for Caregiving (NAC), the Family Caregiver Alliance (FCA), the Rosalynn Carter Institute for Caregiving (RCI), and the National Association of Professional Geriatric Care Managers (GCM).

The NAC is a coalition of national organizations that perform policy research, develop national programs and increase public awareness regarding family caregiving issues. Among the members are grass-roots organizations, professional associations, and corporations. A major initiative of the NAC is its National Caregiver Survey, last conducted in 2004 (jointly with AARP).⁵⁵ This survey has gathered information about family caregivers and the people for whom they care. Another program of the NAC is the Family Care Resource Connection, which reviews and rates caregiver resources. The NAC has also established a national grass-roots advocacy movement, *Toward a National Caregiving Agenda: Empowering Family Caregivers in America*, and several other programs that support and inform family caregivers.⁵⁶

The Family Caregiver Alliance is a major informational, research, and educational resource for family caregivers and those interested in the topic. Among the numerous FCA publications is the *National Consensus Report on Caregiver Assessment*, which has helped to document and to raise awareness of the needs of family caregivers, especially of their health and long-term care needs. An important initiative of the FCA is the National Center on Caregiving (NCC), a gateway for information on caregiving throughout the country. The NCC's services include Caregiver Alerts/State and National Policy Initiatives, which tracks and reports state and national legislation on issues of relevance to caregivers, policymakers, and other stakeholders. The NCC also has developed training and education programs and regularly organizes caregiving conferences and seminars.⁵⁷

The Rosalynn Carter Institute for Caregiving provides research, education, and training resources for paid and volunteer or family caregivers. It has formed partnerships with a variety of groups and organizations to improve the state of caregiving in diverse communities. The organization has several initiatives to promote caregiving for older persons.⁵⁸ These initiatives include the West Central Georgia Caregivers' Network, South Georgia Caregivers' Network, National Quality Caregiving, Rosalynn Carter Caregiving Award, Pope Fellowship/Scholarship Program, and the Johnson & Johnson/Rosalynn Carter Institute Caregivers Program.

The National Quality Caregiving Coalition of the RCI advocates for caregiving over the lifespan.⁵⁹ Its members include various associations, groups, and individuals. The Johnson & Johnson RCI Caregivers Program provides cash rewards to initiatives that aim to improve the well-being of caregivers who work with chronically ill, disabled, or aging family members or friends.⁶⁰

An important resource for older people needing care and their families is the National Association of Professional Geriatric Care Managers (GCM). GCM is a nonprofit association of gerontologists, nurses, social workers, and psychologists who specialize in aging and elder care issues. Members serve as geriatric care managers who help older adults and their families create a plan of care appropriate to the needs of the older adult. GCM provides advice about when a geriatric care manager might be appropriate for a family, serves as a link to care managers, and provides an online resource for locating professional care managers throughout the country.

Paid caregiving: The Paraprofessional Healthcare Institute's (PHI) declared goals are to improve the recruitment, retention, and training of direct care workers. PHI has engaged in substantive policy research in this area. Its National Clearinghouse on the Direct Care Workforce is perhaps the most exhaustive, detailed library of information about direct care workers available on the Internet or

anywhere else. Another influential body created by PHI is the Direct Care Alliance, a national advocacy group that represents consumers, workers, and providers in long-term care (LTC) and that promotes quality jobs and quality care.

PHI has also developed training programs, such as Cooperative Home Care Associates, an employee-owned home care agency in the South Bronx; Home Care Associates, an employee-owned home care agency in Philadelphia; and Independence Care System, an LTC program for people with physical disabilities living in New York City.⁶¹

There are several training programs throughout the country. For example, the Schmieding Center for Senior Health and Education (SCSHE) provides education and health care services for older adults and their families and health professionals. The SCSHE established the ElderStay@home Certified Home Caregiver Training program and a training program for family caregivers who care for a relative or friend.⁶²

The Institute for the Future of Aging Services (IFAS) is another nonprofit organization devoted to improving the paid caregiving workforce. The IFAS is a research institute within the American Association of Homes and Services for the Aging (AAHSA). The AAHSA is itself a very influential policy-driven coalition of nonprofits that provide services to older people: adult day services, home health, community services, senior housing, assisted-living residences, continuing-care retirement communities, and nursing homes.⁶³

A major goal of the IFAS is to build up the long-term care workforce by conducting objective research and finding best practices and evidence-based models of care that can be used by other organizations dedicated to issues regarding aging in the United States. As discussed in the next subsection, the four-year, \$15.5 million research and demonstration project, Better Jobs Better Care (BJBC) is an initiative of IFAS.⁶⁴

In addition to advocacy agencies, there are also numerous national and state-level associations of care providers throughout the country. Among these are the National Association for Home Care and Hospice (NAHC) and the American Health Care Association (AHCA).

The NAHC is a nonprofit trade association composed of home care agencies. Its other members include hospices, home care aide organizations, and medical equipment suppliers. The NAHC provides its members with regular policy updates on home care legislation and new approaches and methods on home care programs. It also publishes a variety of trade magazines of interest to the home care and hospice community, such as the *NAHC Report*, *Caring Magazine*, and *Home Care & Hospice News*.

The AHCA is a nonprofit association that represents both for-profit and nonprofit institutions, including nursing home agencies, care providers, and assisted-living facilities. Among its initiatives to improve the quality of care, the AHCA has a Health Services Research and Evaluation group, which supports the need to develop standardized quantitative measures of quality care.

Foundations and businesses

Numerous foundations and businesses are dedicated to improving the state of caregiving in the United States. Amgen, Johnson & Johnson, MetLife, and Pfizer are some of the many corporations in the United States that have taken proactive measures to address caregiving issues. Among the philanthropic foundations that support caregiving research, education, and outreach projects are the Robert Wood Johnson Foundation (RWJF), Atlantic Philanthropies, Johnson & Johnson (J&J), the MetLife Foundation, and the Donald W. Reynolds Foundation.

The RWJF has provided funding for caregiving initiatives, including PHI's Cooperative Home Care Associates project, and interfaith volunteer caregiving programs.⁶⁵ Among the many programs it has sponsored, Atlantic Philanthropies, together with RWJF, provided \$15.5 million for the Future of Aging Services' Better Jobs Better Care initiative, a four-year research and demonstration project. BJBC, in partnership with PHI, promotes the development of health care employment by providing technical assistance, training, and consultation to providers. BJBC also organizes national meetings and workshops, and publishes technical manuals, issue briefs, and newsletters relating to direct care workers and the caregiving field.

Atlantic Philanthropies has also funded PHI's capacity building, including support for PHI's Direct Care Alliance. Atlantic Philanthropies has funded the Visiting Nurse Associations of America's *Curricula for Homecare Advances in Management and Practice*, a program that focuses on improving care for older people by strengthening the geriatric capacity of home health care managers and their field nurses.⁶⁶

J&J has created and funded the Caregiver Initiative, the Johnson & Johnson/Rosalynn Carter Institute Caregivers Program, and a national survey about *Attitudes and Beliefs About Caregiving in the U.S.*⁶⁷ The MetLife Foundation has supported many caregiving studies and surveys, many by the NAC, through its MetLife Mature Market Institute (MMI). MMI has supported numerous publications on family caregivers, including several relating to the difficulties family members have balancing their time between work and caregiving responsibilities.⁶⁸

A primary interest of the Donald W. Reynolds Foundation is improving the quality of life for older people. One way the foundation advances this goal is through its Aging and Quality of Life program, which offers support for geriatrics training and education initiatives. The first grant awarded under this program established the Donald W. Reynolds Center on Aging and the Donald W. Reynolds Department of Geriatrics at the University of Arkansas for Medical Sciences (UAMS) in Little Rock. UAMS hospital is consistently cited as one of America's best, with its geriatrics clinical care program receiving extremely high marks. The John A. Hartford Foundation selected UAMS as a site for one of its prestigious Hartford Centers of Geriatric Nursing Excellence, which works to advance the cause of preparing academic geriatric nurses across the state and region.⁶⁹

Many other institutions have received funding under the Reynolds Foundation's geriatrics initiative, including Johns Hopkins University, New York's Mount Sinai School of Medicine, the University of Oklahoma, Cornell, Yale, and Boston universities. Donald W. Reynolds has also established an online clearinghouse, POGOe, or Portal of Geriatric Online Education, that provides geriatrics educational materials for clinicians.

The New York Business Group on Health (NYBGH), a subsidiary of the National Business Coalition on Health, is an example of how the business sector is addressing the caregiving issue. NYBGH is a coalition of employers and health-related agencies throughout the United States concerned with employer health benefits in the New York metropolitan area. The NYBGH established an *Eldercare Task Force*, which brings together different businesses, organizations, and government institutions that have workplace programs for employee caregivers. The task force's goal is to encourage employers to address the needs of employees with elder caregiving obligations.⁷⁰

Amgen, Eli Lilly and Company, GlaxoSmithKline, Johnson & Johnson Health Care Systems, Merck & Company, Inc., MetLife, Pfizer Inc, and the United Hospital Fund are among NYBGH's 150 members. Many of these firms have implemented workplace policies for employees with caregiving obligations. Amgen and Eli Lilly offer leave-of-absence benefits in case of family illness and flexible time schedules to accommodate employees with family responsibilities. In addition, the Amgen Foundation gives grants to initiatives that promote the quality of care and patient access to health care services.⁷¹

J&J Health Care Systems' emphasis is on decreasing costs and improving quality of care, in part by providing consulting and management service capabilities for acute care and ambulatory provider settings, and health and fitness services for employers. MetLife offers a variety of elder care programs as well as employee assistance programs in order to help them deal with the obligations of taking care of an older person at home.⁷²

Pfizer offers a variety of elder care initiatives, which include a Family Resource and Referral Program to help employees make decisions on issues that include caring for an older person, and educational resources. The company also offers flexible schedules for employees and full family benefits for many part-time employees.⁷³

Many of these corporate programs go beyond the 1993 Family and Medical Leave Act, which mandates, for companies with at least 50 employees, up to 12 weeks of *unpaid* medical leave for employees, and also requires that leave be allowed for employees to care for a sick child, parent, or spouse.⁷⁴

Service Employees International Union

The Service Employees International Union (SEIU) has a major influence on the caregiving industry. The union's membership includes 1.8 million working people and 50,000 retirees in the United States, Canada, and Puerto Rico. The SEIU is primarily active in four areas: hospital systems, long-term care, property services, and public services. It is the largest health care union on the continent, with 900,000 members—nearly 400,000 of whom are home care workers.⁷⁵

The SEIU strongly advocates for improvements in wages, health care and pension benefits, and working conditions as a way of addressing the shortage of direct care workers. For example, the SEIU Local 250 was active in establishing a comprehensive health insurance package and other benefits for direct care workers in San Francisco, which has had some success in attracting quality direct care workers.⁷⁶ A disproportionate share of direct care workers are immigrants, and some groups, such as the American Health Care Association and the National Association for Home Care, are lobbying Congress to revise immigration laws so that more low-skilled workers could enter the country. Others oppose such

measures as obstacles to higher wages and improved benefits necessary to attract more native-born workers.⁷⁷ The SEIU is a powerful advocate for immigrant workers, including those in the caregiving industry.

In addition to working toward the development of a stable, proficient direct care workforce—especially of home care workers—the SEIU works together with consumers, advocates, and others to improve the quality of both in-home and nursing home care.⁷⁸

All agencies and organizations discussed here and listed in Appendix A play a major role in shaping policy and guiding research on caregiving issues in the United States. Many have sponsored and conducted national caregiving surveys that provide important information about caregivers and care recipients.

For example, earlier in 2006 J&J commissioned a general public survey, *Attitudes and Beliefs About Caregiving in the U.S.* Much of the information provided in Sections 2 and 4 of this report comes from the findings of the NAC's national caregiver survey. Last conducted in 2004, in partnership with AARP, this survey was funded by the MetLife Foundation. PHI, in collaboration with the Direct Care Workers Association of North Carolina, has conducted a series of surveys of state Medicaid agencies and state Units on Aging.⁷⁹ In addition, both the Robert Wood Johnson Foundation and Pfizer have been involved with the National Council on the Aging's recent surveys of employees on health and supportive service providers.⁸⁰

Several federal government agencies, the Centers for Medicare and Medicaid, the Bureau of Labor Statistics, and the Assistant Secretary for Planning and Evaluation at the Department of Health and Human Services have been involved in the design, data collection, analysis, and funding for the National Long-term Care Survey, a longitudinal, nationally representative sample of older people in both institutions and at home.

These organizations share a purpose: to improve the availability of affordable, quality care for those who need it. And, notwithstanding their significant contributions, in the midst of their ongoing work they share an understanding that more work needs to be done.

CARRYING THE LOAD—FAMILY CAREGIVERS

Eight in ten adults who receive long-term care at home receive their care exclusively from family, friends, and volunteers, and among those who pay for a caregiver, two-thirds also receive informal (unpaid) help. Even without taking into account the wages and benefits that are sacrificed when people quit their jobs or reduce their hours in order to care for family members, the economic value of this unpaid contribution to American society is in the hundreds of billions of dollars *annually*, amounting to more than twice the amount spent on paid care in the United States.⁸¹

The NAC estimates that 21 percent of all adults in the United States provide some level of informal caregiving every year to those age 18 or older (Table 4.1).

TABLE 4.1. PERCENT OF ADULTS* WHO PROVIDE UNPAID CARE TO THOSE AGE 18 AND OLDER, U.S. TOTAL AND BY RACE AND ETHNICITY

	U.S. total	White	Black	Hispanic	Asian
All recipients of informal care	21%	21%	21%	16%	18%
Care recipients age 50+	16%	17%	15%	12%	15%
Care recipients age 18–49	5%	4%	6%	4%	3%

*People age 18 or older.

Source: National Alliance for Caregiving and AARP 2004.

Excluding recipients under the age of 18, about 75 percent of informal care is provided to people age 50 and over. Most informal caregivers are married or living with a partner (Table 4.2). More than 60 percent are female, and 42 percent are age 50 or older.⁸²

TABLE 4.2. MARITAL STATUS OF FAMILY CAREGIVERS

Widowed	6%
Divorced or separated	14%
Single	18%
Married/living with partner	62%

Base: 1,247 caregivers in the U.S.

Source: National Alliance for Caregiving and AARP (2004).

Juggling act—work and family responsibilities

The median income of caregiver households is below the national median. For example, in 2003 the median among caregivers was \$37,312, compared to \$43,564 for all households.⁸³ About one in four caregiver households earned less than \$30,000 in 2003 (Table 4.3).

TABLE 4.3. TOTAL ANNUAL HOUSEHOLD INCOME BEFORE TAXES OF FAMILY CAREGIVERS

Less than \$30K	24%
\$30–49K	26%
\$50–99K	27%
\$100K+	15%

Base: 1,247 caregivers in the U.S.

Source: National Alliance for Caregiving and AARP (2004).

Excluding those who care for a spouse, half of all informal caregivers contribute financially to the care of their recipients, an average of \$200 monthly.⁸⁴ Six in ten caregivers are employed (Table 4.4). To accommodate their caregiving role, most employed adults are forced to make adjustments at work.

TABLE 4.4. PERCENT OF FAMILY CAREGIVERS WHO ARE EMPLOYED, BY SEX, RACE, AND AGE, AND BY SELECTED CHARACTERISTICS OF CARE RECIPEINTS

Total	59%
Male	66%
Female	55%
White	61%
African American	58%
Hispanic	53%
Asian American	52%
18–34	65%
35–49	74%
50–64	58%
65 or older	12%
Recipient age 18–49	66%
Recipient age 50+	57%
Recipient lives in household	49%
Less than one hour away	61%
One hour or more away	69%
Level 1 caregivers	63%
Level 5 caregivers	43%

*Level of burden of caregiving duties, based upon the amount of time per week caregiver takes care of recipient and number and types of activities performed. Level 1 indicates the lowest caregiving intensity, and level 5 indicates the highest.

Base: 1,247 caregivers in the U.S.

Source: National Alliance for Caregiving and AARP (2004).

A family caregiver can sacrifice hundreds of thousands of dollars in lost wages, benefits, and Social Security over a work life in order to care for loved ones.⁸⁵ Perhaps not surprisingly, the greater the burden of caregiving duties, the greater the probability of adverse work-related adjustments (Table 4.5). Among employed adults whose caregiving burdens are greatest, more than 80 percent go in later to work or leave earlier than scheduled; nearly four in ten go from full-time to part-time jobs, which is often a transitional step before leaving the labor force altogether.⁸⁶

TABLE 4.5. WORK-RELATED ADJUSTMENTS BY LEVEL OF BURDEN

	TOTAL	Level 1	Level 2	Level 3	Level 4	Level 5*
Go in late, leave early, etc.	57%	40%	51%	63%	75%	83%
Take leave of absence	17%	8%	17%	14%	22%	41%
Go from full-time to part-time	10%	3%	7%	9%	15%	37%
Give up work entirely	6%	1%	3%	4%	4%	35%
Lose any job benefits	5%	2%	2%	5%	9%	15%
Turn down promotion	4%	2%	3%	5%	6%	14%
Choose early retirement	3%	1%	1%	2%	3%	12%
None of the above	38%	57%	44%	31%	21%	8%

*Level of burden of caregiving duties, based upon the amount of time per week caregiver takes care of recipient and number and types of activities performed. Level 1 indicates the lowest caregiving intensity, and level 5 indicates the highest.

Base: 935 caregivers employed while caregiving.

Source: National Alliance for Caregiving and AARP (2004).

All work and no play

Finding time for oneself is the most frequently reported unmet need of family caregivers,⁸⁷ and caregiving duties have a considerable impact on leisure activities (Table 4.6). Fifty percent of family caregivers report having less time for family and friends, and nearly the same proportion give up vacations, hobbies, or social activities.

Over 25 percent report exercising less than before they started their caregiving activities. Members of the so-called sandwich generation, those with the dual responsibility of rearing children and caring for aging parents, and with the additional responsibility of working full-time, very likely have little time to themselves.

Table 4.6. Impact of Caregiving on Family and Leisure Activities

	% Saying Yes
Less time for friends or family	51%
Give up vacations, hobbies, social activities	44%
Get less exercise than before	26%

Base: 1,247 caregivers in the U.S.

Source: National Alliance for Caregiving and AARP (2004).

Emotional stress and health risks

Family caregivers face significant physical and mental health risks, including depression, anxiety, insomnia, increased chances of developing chronic illnesses, and slower healing of wounds.⁸⁸ Caregiving is associated with high levels of emotional stress, especially among caregivers who report they had no choice but to provide care, and among those who provide the most hours of care and who help with several ADLs.⁸⁹ On average, family caregivers provide care for more than four years,⁹⁰ and of these about a third provide care for five years or longer (Table 4.7).

TABLE 4.7. ESTIMATED LENGTH OF CARE PROVIDED TO RECIPIENTS

Occasionally	5%
Less than 1 year	34%
1-4 years	31%
5+ years	29%

Base: 1,247 caregivers in the U.S.

Source: National Alliance for Caregiving and AARP (2004).

Nearly four in ten informal caregivers report that no other family member or friend helped to provide that care, and six in ten say that no paid help was obtained.⁹¹ The shortage of direct care workers has only worsened the financial, social, emotional, and health burdens carried by family caregivers.

FRAGILITY ON THE FRONT LINES— DIRECT CARE WORKERS

As our population continues to grow older and the pool of family caregivers grows smaller, who will care for us? In their seminal study of the shortage of direct care workers in the United States, Drs. Robyn Stone and Joshua Wiener ask just that question.⁹² If nothing further is done to resolve the critical shortage of direct care workers in this country, then, unfortunately, our answer will be the same as it already is for many older people—no one.

There are a number of factors affecting the supply and quality of direct care workers (DCWs). First, a demographic profile of DCWs is provided, followed by a description of the variety of paraprofessionals—nursing assistants, home care aides, personal care workers, and others—and their work environment.

Women on the front lines

About 90 percent of both nursing home aides and home care aides are women, which is an even higher percent of paid paraprofessionals than of family caregivers (Table 5.1). Hospital aides, who provide some caregiver services but who work in hospital settings, are about 80 percent female.

About 70 percent of DCWs are white, which is considerably lower than the national rate (82 percent). The proportion of DCWs who are black (25 percent) is nearly twice that of the national population (13 percent).^{93,94} Although the proportion who are not U.S. citizens is about the same as is true for the whole population (7 percent in 2000⁹⁵) among nursing home aides and hospital aides, it is much higher (16.2 percent) among home care aides (Table 5.1). However, these statistics exclude undocumented workers, who are likely to work off the books.

Educational attainment is considerably lower among DCWs than of the whole U.S. population. About a quarter of the U.S. population has completed at least four years of college,⁹⁶ compared to only 4.2 percent of nursing home aides and 6.5 percent of home care aides (Table 5.1). The percent of nursing home aides (22.6) and home care aides (31.5) who have not graduated from high school is considerably higher than the national average of about 16 percent.⁹⁷ However, high school graduation is actually more prevalent among hospital aides than among the entire population.

Many direct care workers are employed part-time, and some of them probably take other jobs to supplement their caregiving work.⁹⁸ Only 55 percent of nursing home aides and 46 percent of home care aides work full-time all year round.⁹⁹ Another 16 percent of nursing home aides and 12 percent of home care aides work full-time for part of the year, and the remainder work only part-time, either year round or part of the year.¹⁰⁰

TABLE 5.1. DEMOGRAPHIC CHARACTERISTICS OF NURSING HOME AIDES, HOME CARE AIDES, AND HOSPITAL AIDES, 1997–1999

Characteristics	Nursing Home Aides (%) N = 1,254	Home Care Aides (%) N = 216	Hospital Aides (%) N = 761
Age*			
Less than 25			
25–34	23.4	10.2	16
35–44	24.9	20.4	26.3
45–54	24.6	25	27.6
55–64	9.3	9.3	11.2
65+	2	8.3	1.4
Mean age*	36.4	42.8	38
% Female	90.1	88.4	81.1
Race			
White	70.6	70.4	69
Black	25	25.9	26.1
Other	4.4	3.7	4.9
Marital Status*			
Married	42.8	42.1	48.9
Widowed/divorced/separated	21.9	29.2	20.9
Never married	35.3	28.7	30.2
Education*			
<High School	22.6	31.5	10.2
High school graduate	49.9	39.4	42.3
Some college	23.3	22.7	40.5
4+ years of college	4.2	6.5	7
% with children under 18*	52.2	40.3	45.7
Citizenship*			
Native-born U.S.	85.4	74.5	85.3
Native-born U.S. outlying area	1.6	2.8	0.9
Native-born abroad U.S. parent	0.8	0.9	1.3
Foreign born (naturalized)	4	5.6	6
Not a U.S. citizen	8.2	16.2	6.4

*p < 0.01

Source: Yamada 2002.

Job titles, work settings

Job descriptions of four categories of DCWs were provided in Section 1 (Table 1.1): nursing aides, home health aides, psychiatric aides, and personal and home health aides. Within the caregiving industry job titles are used interchangeably. Table 5.2 illustrates the absence of standardization in the industry.

TABLE 5.2. ALTERNATIVE TITLES OF WORKERS**NURSING AIDE**

Type of Facility	Job Title Often Used
Skilled nursing facilities	Nurse aide Nursing assistant
Assisted-living facilities	Health aide Medication aide
Residential home care	Health aide Medication aide
Personal residences	Home health aide Residential medication aide
Intermediate care.....	Health aide
Hospitals	Health aide Patient care attendant
Rehabilitation facilities.....	Physical therapy aide Occupational therapy aide
Hospice facilities	Nursing aide
Psychiatric hospitals	Psychiatric aide

PERSONAL CARE AIDE

Type of Facility	Job Title Often Used
Personal residences	Personal care attendant Developmental disability aide Residential habilitation specialist Home care attendant Housekeeper Respite worker Homemaker Companion dietary aide
Residential home care	Service aide
Intermediate care.....	Developmental disability aide Residential habilitation specialist Behavioral assistant
Hospice facilities	Hospice worker Respite worker
Hospitals	Orderlies

Source: U.S. Department of Health and Human Services, Health Resources and Services Administration (2004).

Job titles sometimes depend on the setting of care, for example, whether the position is in a skilled nursing facility, group residence, or personal home. But Table 5.2 is only one table of titles from one source (the U.S. Department of Health and Human Services). There is no universally accepted job title for a particular position, and one cannot definitively know from the job title applied to a DCW whether the person works in a home or institutional setting. For example, the Bureau of Labor Statistics' O*NET database, which lists the characteristics of all jobs in the United States, lists “certified nursing assistant” as a job title for both home health aides and for nursing aides.

Help wanted—the critical shortage of paid caregivers

Low wages, few fringe benefits, unpleasant working conditions, low job satisfaction, the emotional and physical burdens of the job, and the lack of a real possibility for career development all contribute to the critical shortage of paid caregivers in the United States.¹⁰¹

Although work surroundings vary among both home-based and institutionally based direct care workers, in general, unpleasant working conditions and work tasks contribute to the high turnover rates among DCWs. Caregivers spend much of their time standing or walking. Hazards from minor infections and major diseases are often part of the job, as are the physical burdens of lifting and moving clients, and unpleasant duties such as emptying bedpans and changing linens. Clients may be irritable, abusive, depressed, angry, or otherwise difficult, although many are cooperative and pleasant. Home-based caregivers may work in residences that are dirty or messy.¹⁰²

TABLE 5.3. FRINGE BENEFITS OF NURSING HOME AIDES, HOME CARE AIDES, AND HOSPITAL AIDES, 1997–1999

Benefits	Nursing Home Aides (%)	Home Care Aides (%)	Hospital Aides (%)
Health insurance			
Medicare*	2.4	8.3	1.2
Medicaid*	11.3	15.7	4.7
VA/Military/CHAMPUS	3	1.9	2.8
Current employer/union*	41.8	25.5	62.3
None	N/A	N/A	N/A
Health insurance premium**			
Employer pays all	23.9	30.9	21.3
Employer pays part	67.4	60	74.1
Employer pays none	8.8	9.1	4.6
Pension plan			
Provided by employer*	43.5	24.1	71.5
Participate in plan if provided*	53.8	65.4	66.9

Notes: CHAMPUS = Civilian Health and Medical Program Uniformed Service.

*Percentages are statistically significant at 1%.

**Percentages are statistically significant at 5%.

Source: Yamada (2002)

Low wages and few fringe benefits are barriers to the recruitment and retention of DCWs.¹⁰³ The lack of health insurance coverage for many paid caregivers is a primary example (Tables 5.3). Caregiver wages are among the lowest among U.S. occupations—the median hourly wage in 2004 was just over \$10 among nursing aides, under \$9 among home health aides, and about \$8 among personal care and home care aides (Table 5.4). (The national median in 2004 was about \$14 per hour).¹⁰⁴

TABLE 5.4. MEDIAN WAGES, TOTAL EMPLOYMENT, AND PROJECTED NEED OF DIRECT CARE WORKERS, 2004–2014

Trends	Nursing Aides	Home Health Aides	Personal Care and Home Care Aides	Psychiatric Aides
Median Wages (2004)				
\$\$ per hour	10.20	8.92	8.18	10.99
\$\$ per year	21,220	18,550	17,020	22,860
Employment (2004)				
# of employees	1,455,000	624,000	701,000	59,000
% of Projected Growth (2004-2014)	22.3	56.0	41.0	2.3

Source: O*NET Online, <http://online.onetcenter.org>, accessed May 2006; Hecker (2005).

A lack of respect from management also adversely affects the supply of paid caregivers. Supervision even in nursing homes, not to mention in home-based settings, is sometimes nonexistent, and although nursing aides, home-care aides, and other paraprofessionals may have the best direct knowledge of a client's condition, they are often ignored.¹⁰⁵

The absence of uniformity of standards for paid home caregivers and of a national consensus about the information, understanding, and training required of caregivers are among the other impediments to ensuring an adequate supply of quality care in the United States. At present, there is no universally accepted curriculum for either paid or unpaid caregivers. The development of uniform, acceptable national standards of care and caregiver curriculum would enhance the value and reward of caregiver occupations and help alleviate the worker shortage. High national standards of performance and curricula could help change society's negative perception of DCW occupations and would have a positive impact on the value society places upon both paid and unpaid caregivers.¹⁰⁶

About 1.5 million nursing aides were employed in the United States in 2004 (Table 5.4); there were 624,000 home health aides and 701,000 personal care and home care aides. Because of the difficulty in obtaining reliable counts of self-employed caregivers, many of whom work off the books, the number of paid direct care workers in the United States is probably higher than reflected in Table 5.3.¹⁰⁷

The fastest growing occupation in the United States is home health aides,¹⁰⁸ with the number needed expected to increase 56 percent over the next decade (Table 5.4).¹⁰⁹ An additional 41 percent of personal and home care aides will be needed over the next decade, making it the tenth fastest growing occupation.¹¹⁰ Not only is demand leading to more job openings for these and other direct care workers, but also replacement needs due to high turnover rates among paraprofessionals are creating even more job openings.

The gap between demand and supply for paid caregivers continues to widen. In Section 6 we will discuss major barriers to affordable, quality care, followed in Section 7 by a discussion of the public and private initiatives that have been implemented to address the worker shortage.

OTHER BARRIERS TO AFFORDABLE, QUALITY CARE

Regulatory obstacles

With the aging of the baby boom generation, demand for home- and community-based care will continue to grow. The Visiting Nurse Service of New York argues that “[t]he intersection of housing and LTC services is the next critical arena for addressing the needs and preferences of older adults,” but that federal and state regulations are an impediment to the development of linkages between housing and caregiving services.¹¹¹ Regulatory restrictions prohibit paid caregivers “from doing what they think is right,” and create “disparities between what they’re allowed to do as certified and licensed paraprofessionals . . . and what they’re allowed to do as ordinary citizens, relatives, and friends.”¹¹²

Families wishing to provide caregiving at home for older adults are allowed to do so, including the hiring of in-home caregivers who are independent contractors. These individuals are often untrained and have no supervision or accountability.

However, if families or individuals want to hire in-home caregivers through a reputable home caregiving agency that trains, supervises, and helps manage the caregiving process, they often find that such help is not available because of regulatory restrictions. While the majority of older adults need only nonmedical caregiving, Medicare/Medicaid regulations do not clearly differentiate between nonmedical “caregiving” and medically necessary caregiving as a part of “health care.” In practice, this means that Medicare/Medicaid and the majority of state regulations restrict any paid in-home caregiving to home *health* agencies, thereby excluding home *caregiving* agencies from providing even nonmedical caregiving services.

Several federal policies favor nursing homes over home-based care. For example, although eligible persons under Medicaid cannot be denied nursing home services due to state budgetary shortfalls, the same entitlement protection status is not extended to home- and community-based waiver services. (Waivers are discussed in the next subsection.) Another example is that in order to qualify for Medicaid spending, states must have a statewide nursing home program, whereas home- and community-based services (HCBS) programs are optional. Higher income eligibility thresholds under Medicaid also are allowed for nursing home than for HCBS coverage in many states, and several other federal and state policies relating to eligibility for and coverage of long-term care services under Medicaid favor institutional over home-based care.¹¹³

Medicaid is the largest source of public funds for long-term care in the United States. Although it has been shown that most people would prefer to be cared for in their own homes,¹¹⁴ the institutional bias of Medicaid, the result both of the federal structure of the system and of differences in how states interact with that system, is a significant regulatory obstacle to home care. However, during her testimony at the 2005 White House Conference on Aging, Dr. Beth Vaughan-Wrobel urged the elimination of “outdated regulations” under Medicaid that hinder development and delivery of geriatrics care management services that would help family members plan for and provide care for older adults in a home-based setting and that are symptomatic of this institutional bias.¹¹⁵

Notwithstanding the fact that state legislatures, fearful of a “woodwork effect”—that is, that more people will claim benefits that can be handled by state finances—have limited Medicaid coverage of home- and community-based services,¹¹⁶ there has been progress away from this institutional bias, as more and more states are developing strategies to keep consumers of care out of nursing homes and other institutions in favor of residential settings. Partly this has been achieved through the Medicaid 1915(c) Home and Community-Based Waiver Services. The number of Medicaid beneficiaries receiving long-term care in group residential settings outside nursing homes has grown rapidly in recent years, from 40,000 beneficiaries in 1998 to 102,000 in 2002.¹¹⁷ Unlike the open-ended personal care option under Medicaid (discussed below), the 1915(c) waiver program is limited to beneficiaries who would otherwise need to be institutionalized.¹¹⁸

TABLE 6.1. MANDATORY AND OPTIONAL LONG-TERM CARE BENEFITS OF MEDICAID

“Mandatory” Items and Services	“Optional” Items and Services
<i>Institutional Services</i>	<i>Institutional Services</i>
<ul style="list-style-type: none"> • Nursing facility (NF) services for individuals 21 or older Noninstitutional services	<ul style="list-style-type: none"> • Inpatient/nursing facility services for individuals 65 and over in an institution for mental diseases (MD) • Intermediate care facility for people with mental retardation (ICF/MR) • Inpatient psychiatric hospital services for individuals under age 21
<i>Noninstitutional Services</i>	<i>Noninstitutional Services</i>
<ul style="list-style-type: none"> • Home health care services (for individuals entitled to nursing facility care) 	<ul style="list-style-type: none"> • Home health care services • Case management services • Prescription drugs • Respiratory care services for ventilator-dependent individuals • Personal care services • Private duty nursing services • Hospice services • Services furnished under a Program for All Inclusive Care for the Elderly (PACE) • Home- and community-based services

Source: O’Brien and Elias (2004).

States apply for the 1915(c) waiver at their own discretion. Another way Medicaid influences how care is provided is through its mandatory and optional services (Table 6.1). States are required to offer the mandatory services, but many do not offer optional care. Only about half of the states have implemented Medicaid's personal care option (Table 6.2). Thus, state-directed Medicaid programs have great influence about the kinds of tasks paid paraprofessionals are allowed to perform, which is discussed further in the next subsection.

TABLE 6.2. MEDICAID LONG-TERM CARE SERVICES

	Mandatory or Optional?	Financial Eligibility	Benefits	Statewide Coverage
Nursing Home Care	Mandatory for individuals 21 and over	Must be eligible for Medicaid.	Provides skilled nursing care and rehabilitation services in a facility that meets federal requirements.	Yes
Intermediate Care Facilities for Individuals with Developmental Disabilities	State option (50 states)	Must be eligible for Medicaid.	Provides ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services to help each individual function at his/her greatest ability in a protected residential setting.	Yes
Home Health Care	Mandatory for individuals 21 and over who would otherwise be entitled to institutional care	Must be eligible for Medicaid.	May provide nursing therapy, home health aides, medical supplies, and equipment. Limits on services allowed.	Yes
Personal Care	State option (27 states)	Must be eligible for Medicaid.	Usually includes assistance with activities of daily living and homemaker/chore services. In some states includes cuing/supervisory services, and nursing care. Limits on services allowed.	Yes
Home-and Community-Based Services Waivers	State may seek a waiver from the secretary of HHS. Waivers must be "cost effective": the cost of caring for an individual under the waiver must be less than or equal to the cost of institutional care.	Under Medicaid, individuals "at risk" of institutional care are eligible.	Case management, adult day care, home health aide, personal care habilitation, assisted-living services, and respite care. Limits on services allowed.	Not required. Can target certain geographical area and/or specific population groups.

Source: O'Brien and Elias (2004).

State efforts to move away from institutional care and to strengthen components of their community-based care systems were given further impetus by the 1999 Supreme Court *Olmstead* decision. Provided that the care recipient does not oppose such placement, states are required under *Olmstead* to provide community-based services for persons with disabilities otherwise entitled to institutional care.¹¹⁹ Budgetary constraints in some states have had a dampening effect, but legislation passed in response to *Olmstead* by several other states has helped bolster their community-based care systems, such as through improved information and referral systems.¹²⁰

A promising area both for enabling older people to live more independently and for improving the quality of in-home care is the development and funding of assistive technologies. For example, Carnegie Mellon University and the University of Pittsburgh were recently awarded a five-year, \$15 million grant by the National Science Foundation to develop assistive technologies at the Quality of Life Technology Engineering Research Center. Devices to keep track of health status and activity levels of people living alone, mobility systems, improved wheelchairs, and systems that prolong the age at which older people may safely drive are among the many technologies being developed at the Center.¹²¹ Rapid progress is being made by scientists throughout the world in the development of artificial intelligence and robotics—automobiles that drive themselves, robotic lifeguards, robots that assemble IKEA furniture—which are increasingly changing daily life.¹²² Lynn Friss Feinberg, deputy director of the National Center on Caregiving at the Family Caregiving Alliance notes, advances in technology “are providing tools to help family caregivers that simply did not exist a decade ago.”¹²³

Financing long-term care

Economist Peter Arno estimated that the national economic value of informal caregiving was \$257 billion in 2000¹²⁴. This estimate is based on an hourly wage of \$8.81, which is midway between the prevailing minimum wage (\$5.15) and the average, national wage for home health aides (\$12.46). Opportunity costs to caregivers, such as wages and benefits that are forgone when people are forced to leave the labor force to care for their family members, are not considered in Arno’s estimate. The annual contribution by informal caregivers is more than twice the amount paid nationally for home health and nursing home care, which totaled \$126 billion in 2000 (\$31 billion of which went to home health care services and \$95 billion of which went to nursing home care).¹²⁵

Few Americans have private long-term care insurance—in 2001, only about 4 million people had private insurance plans that covered long-term care services¹²⁶. Despite the strong preference by consumers for home and community-based services, most public financing for long-term care is limited to nursing home services. Of the total Medicaid long-term care spending, only about one-third goes toward home and community-based services.¹²⁷ It has been argued that the problem is not that too few dollars go to LTC, but that too much is spent “in the wrong ways,” and that “[t]he home and community-based services infrastructure is grossly underdeveloped and starved for revenue.”¹²⁸

TABLE 6.3. LONG-TERM CARE: NATIONAL SPENDING, 2004.*

Other private	3.3 %
Private health insurance	9.0 %
Out-of-pocket	23.3 %
Medicare	20.5 %
Federal and state Medicaid	40.9 %
Other public	3.1 %

*Freestanding facilities only. Additional services are provided in hospital-based facilities but are not included here. Medical care provided in the home by private and public nonfacility-based home health agencies. Medical equipment sales or rentals not billed through home health agencies and nonmedical types of home care (e.g., Meals on Wheels, chore-worker services, friendly visits, or other custodial services) are excluded.

Source: Smith et al. (2006).

The percents of national long-term care expenditures that are paid for by Medicaid, Medicare, out-of-pocket by individuals, and otherwise are presented in Table 6.3. Table 6.4 presents percents of national spending on home health care; Table 6.5, on nursing home care.

TABLE 6.4. HOME HEALTH CARE: NATIONAL SPENDING, 2004.*

Other private	2.3 %
Private health insurance	12 %
Out-of-pocket	11.3 %
Medicare	38.0 %
Federal and state Medicaid	31.7 %
Other public	4.6 %

*Medical care provided in the home by private and public nonfacility-based home health agencies. Medical equipment sales or rentals not billed through home health agencies and nonmedical types of home care (e.g., Meals on Wheels, chore-worker services, friendly visits, or other custodial services) are excluded.

Source: Smith et al. (2006).

These tables must be interpreted with caution for several reasons. First, expenditures on *custodial care*—assistance with activities of daily living such as dressing and bathing—are excluded from the totals. This is an important exclusion to bear in mind, since most long-term care is for custodial care, as opposed to *skilled care*.¹²⁹ Medicare does not even reimburse for custodial care.

Another reason to be careful interpreting the tables is that the services reimbursed under Medicare are generally short-term in duration—notwithstanding the fact that they fall under the “long-term care” umbrella.¹³⁰ And lastly, only people working through agencies are included in the tables—self-employed direct care workers are excluded. For all these reasons, public financing of long-term care is exaggerated in the tables, and out-of-pocket financing is understated.

Allowing for these significant qualifications, it can be said that Medicaid accounts for about 41 percent of national spending on LTC in the United States, Medicare for about 21 percent (Table 6.3). Out-of-pocket expenditures represent more than a quarter of the total amount that is spent on nursing home care (Table 6.5), and about 11 percent of the total spent on home health care (Table 6.4). It bears repeating that these statistics do not include spending on either personal care services or self-employed paid direct care workers. Reliable numbers on self-employed workers, many of whom work off the books, are elusive.¹³¹

To veterans enrolled in its health care system, the U.S. Department of Veterans Affairs (VA) offers a variety of geriatric and long-term care services. Nearly all of the VA’s medical centers provide home- and community-based outpatient long-term care programs. The VA also provides inpatient long-term care to nearly 65,000 veterans, but its primary focus is on providing home care.¹³²

TABLE 6.5. NURSING HOME CARE: NATIONAL SPENDING, 2004*

Other private	3.7 %
Private health insurance	7.8 %
Out-of-pocket	27.7 %
Medicare	13.9 %
Federal and state Medicaid	44.4 %
Other public	2.5 %

*Freestanding facilities only. Additional services are provided in hospital-based facilities but are not included here.

Source: Smith et al. (2006).

Home care financing: Of the approximately \$139 billion spent on LTC in the United States in 2002, only one-fourth went for home-based care.¹³³

Medicare includes a small home care program. During the 1980s, Medicare expanded the delivery of both home health and personal care services, but the Balanced Budget Act (BBA) of 1997 created incentives for home health agencies to limit the volume of care, and spending dropped sharply.¹³⁴

Although states are required to cover home *health* services under the Medicaid program, providing *personal* care at home is optional (Table 6.2). Medicaid provides two options for home care coverage, the optional “personal care services” benefit and the (c) Home and Community-Based Services Waiver program. All 50 states provide at least one of these options.

Nursing home financing: About one-fifth of long-term care costs (Table 6.3) and only about 14 percent of nursing home costs (Table 6.5) are financed through Medicare. Medicare may cover a portion of the first 100 days in a nursing home if the visit follows a related hospital stay of three days or more and if other conditions are met. As mentioned, Medicare does not include custodial care as part of its benefit package.

Medicaid is a means-tested program to which only low-income individuals qualify. Still, it is the largest public funding source for nursing home services, accounting for close to half of the spending in the United States (Table 6.5). Although a significant percentage of older people who require nursing home services qualify for Medicaid, many must “spend down” their assets until they are eligible.¹³⁵ Despite concerns that many older people transfer assets to their children and other relatives in order to qualify for Medicaid LTC services, most studies suggest that this practice is not widespread.¹³⁶

The optional “personal care services” benefit was adopted in the mid-1970s. If a state provides this optional benefit, it must be made available to all state residents who are enrolled in the state’s Medicaid program and who meet the criteria for personal care.¹³⁷ There cannot be a waiting list. States may, however, set coverage limits, regardless of need, and they are not required to pay for all of the personal care services that a disabled Medicaid-eligible individual may need.

The Medicaid 1915(c) Home and Community-Based Services Waiver program has been available since 1981. The program requires states to submit a waiver to the Center for Medicare and Medicaid Services (CMS) specifying the scope of the program. States are allowed to provide a broader range of services than they offer under the personal care services option, but they may also place a cap on the number of unduplicated recipients that they will serve, so there may be a waiting list associated with this program. Indeed, they may not provide care to more recipients than the number of recipients approved in the waiver by CMS. States must meet a budget neutrality standard, so they may not spend more for these 1915(c) services than they would spend on institutional care. This means that states may not exceed the annual per capita Medicaid costs for individuals in nursing homes. If they do, the federal government could, in theory, deny its matching payments. To protect against this possibility, states often adopt stricter standards of budget neutrality than the federal government requires.

Let’s talk—the need for better communication among medical practitioners, caregivers, and care recipients

A key issue is the quality of communication between medical practitioners and both paid paraprofessionals and family caregivers.¹³⁸ Physicians and other medical practitioners often speak in “medicalese,” using terminology that is unfamiliar to caregivers. Medical practitioners sometimes are too rushed to take sufficient time to explain, educate, support, and motivate caregivers.

A lack of integration of eligibility and coverage standards across supportive, disability, and medical service programs adversely affects patients with chronic conditions, as does the professional culture among clinicians that emphasizes an episodic “day’s appointments” approach to services and treatment protocols.¹³⁹

Physicians receive little or no training in the area of home- and community-based care.¹⁴⁰ Commonly, medical practitioners possess a poor understanding of their patients' home environment or of their patients' physical and cognitive capabilities. Medical practitioners often have little knowledge regarding the entire caregiving spectrum—how to access care, the different levels of caregivers, their proficiencies and skills, and so on—yet are expected to write orders and/or sign off on specific issues directly related to such caregiving.

For their part, caregivers sometimes expect medical practitioners to prescribe help or care step-by-step, with an expectation of patient improvement. Some want forms filled out on the spot or call frequently for unnecessary reasons.

A communications problem, often stemming from differences in expectations, also exists between paid caregivers and care recipients and their families. Sometimes what a family expects of a paid caregiver is quite different from what the paid caregiver believes her role to be. This disconnect is sometimes laced with racial, class, cultural, and language undertones.

For example, the family may not understand why a caregiver will not clean dishes, vacuum, prepare food, do shopping—"not a big deal," thinks the family. There are differences in expectations between paid caregivers and the recipients' families about other aspects of care. For example, should a caregiver lift a patient who cannot bear her own weight, or transfer a heavy patient between a wheelchair and bed? Another example is whether the caregiver should take a patient outside every day for fresh air, rather than sitting inside watching television or talking on the phone and taking care of her own (caregiver) personal tasks. There is often a disconnect between family members and paid caregivers about the extent to which the caregiver should try to stimulate and actively engage the patient.

Families often assume that paid caregivers are fairly well paid and are unaware that a large share of their payments goes to the agency. And there is very often the expectation that the caregiver will make the patient "better." For their part (as discussed in Section 5), although many paid caregivers are highly motivated and effective, others may be poorly motivated, or even apathetic about their patients, because of low wages, little chance for career development, and other negative aspects of their jobs.

Caregiving delivery system

Anyone who has ever confronted the urgent need to find caregiving for an older adult knows how frustrating it can be. The learning curve is steep, there is no easy access point, and the process is fractured into many unconnected components. As essential as it is that we create more and better caregivers for older adults, it is equally necessary to make those caregiving resources easily available to those who need the services. There are important implications concerning the lack of a functional delivery system—a coordinated process for getting caregiving information and services to those who need them when they need them.

Locally based models are needed to facilitate the connection of the supply of caregiving information and services with the growing demand for them. The AoA's Eldercare Locator (discussed in Section 3) helps people obtain contact information for caregiving and other service providers in their areas, but

does not provide a network of actual personalized services and information for people at a local level. The Eldercare Locator program refers people to local Area Agencies on Aging (AAAs) or other government-related agencies. There is a great deal of variability from location to location in terms of the information and services available from AAAs—often they have lists of local agencies that accept Medicaid and other forms of public assistance, but not of agencies that would be more appropriate for people who do not qualify for Medicaid. The Eldercare Locator program is therefore biased toward the Medicare/Medicaid model and toward older people who qualify for those benefits. People who have to pay out-of-pocket for care often find they are on their own.

One locally based model of a caregiving delivery system, one that would serve private-pay families and older people who have heretofore had no real unified process to follow, is the Elderstay@home program developed by the SCSHE (Figure 1). Elderstay@home ties together all information, referral, consultation, medical, and caregiving services into a network that a family can access with a single phone call, and is sponsored by community and faith-based groups. While the primary goal of Elderstay@home is to serve private-pay families and older people, it accepts all calls and so also serves the Medicaid-eligible population. Further development of locally based caregiving delivery systems such as Elderstay@home's model would improve access to care for many older people, especially those who pay for care out-of-pocket—or who cannot find affordable care and so go without it.

Elephant in the room—public policy

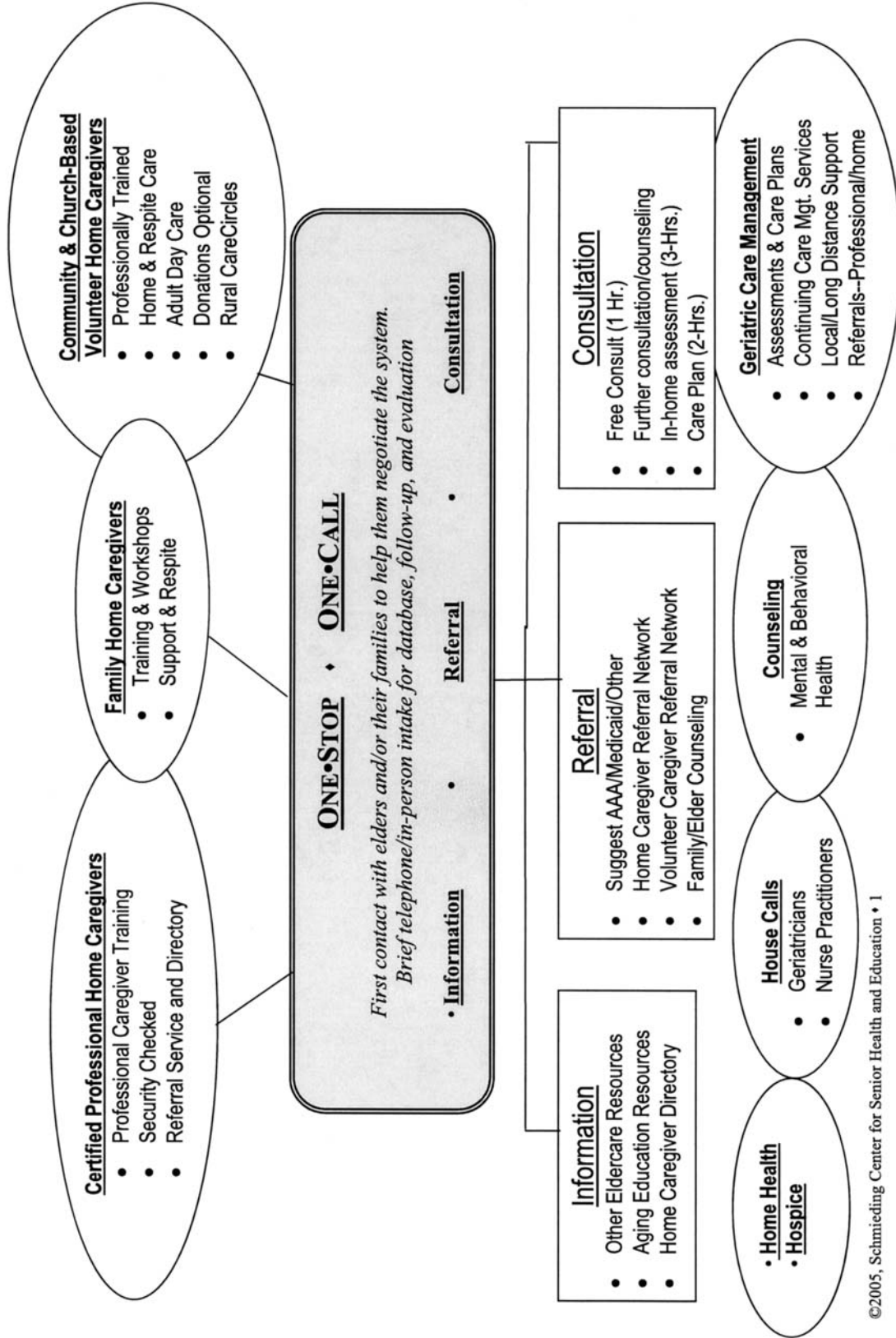
As discussed, Medicare and Medicaid rules have a major influence on the caregiving industry. Programs developed specifically to improve caregiving in the United States are not made in a vacuum but are done in the context of broader federal and state policies, some of which relate to caregiving directly, others of which are related indirectly.

Workforce development and educational policies can affect the supply of paid caregivers so that they channel funds to selected industries and occupations. For example, the Employment and Training Administration of the U.S. Department of Labor recently developed an apprenticeship program in partnership with employers for high school students interested in home care and other caregiving work.¹⁴¹ As noted in Section 5, a relatively high percent of home care aides and other DCWs are immigrants to the United States. As true of other occupations, the supply of labor in the caregiving industry is influenced by national immigration policy.¹⁴²

Within the broad public policy arena, several initiatives have been implemented to address the shortage of DCWs. Some of these are summarized next. We also discuss other programs, such as consumer-directed care, that are not directed toward the shortage of paid workers but that approach the caregiving crisis from a different angle.

FIGURE 1.

Elderstay@home: A Community & Faith-Based Home Care Delivery Model



DEVELOPING SOLUTIONS— PUBLIC AND PRIVATE EFFORTS TO ADDRESS THE CAREGIVING CRISIS

This section complements the review in Section 3 of the many governmental agencies, nonprofits, philanthropic foundations, and businesses whose activities have helped to improve caregiving in America. Just as a detailed discussion of the efforts of any one of these organizations is beyond the scope of this report, in the current section we can only summarize some of the most important public and private caregiving initiatives.

Section 3 includes a description of some of the resources that are available to family caregivers, such as the National Alliance for Caregiving, the Family Caregiver Alliance, the Rosalynn Carter Institute for Caregiving, and the publicly funded National Family Caregiver Support Program. In addition to these, there is a wide variety of stat-supported services for family caregivers.¹⁴³ These programs are extremely valuable in that they contribute to solving the caregiving crisis by offering assistance to the single greatest source of caregiving in the United States—family and friends.

This section focuses on paid direct care workers and on the public and private efforts to address the shortage of these workers. After all, one main reason family caregivers need supportive services is that they cannot find affordable, quality help, even on a part-time basis to provide them with respite! In other words, if every family had access to affordable, quality paraprofessionals, then the burden on family caregivers would be greatly alleviated.

Wages and benefits

Some states have tried to make direct care jobs more attractive through wage increases. One mechanism for increasing wages is “a wage pass-through,” which basically earmarks a portion of Medicaid reimbursement increases (or of other funding sources) for increases in wages (or in benefits) of direct care workers.¹⁴⁴ Twenty-one states had implemented wage pass-through legislation as of 2003. There is a great deal of variation in the size of salary increases, what types of workers are targeted, whether provider participation is mandatory or optional, and other design features offered among the various state wage pass-through programs.¹⁴⁵

Several states have also tried to develop programs to increase health-insurance coverage among direct care workers, although budgetary restrictions have limited implementation of these programs, even when state legislation has authorized them.¹⁴⁶ Gail Hunt of the NAC, citing the success in San Francisco of the coalition of the Service Employees International Union (SEIU) Local 250, the Public Authority, and consumer groups to attract and retain quality direct care workers through a comprehensive health insurance package and other benefits, considers ideas for offering health insurance as having major policy implications.¹⁴⁷ Also beneficial would be programs offering reimbursements for commuting expenses to home health aides and personal care workers, as adopted in some states.¹⁴⁸

Enhanced training initiatives

Prior to starting their jobs, most direct care workers receive little or no formal training.¹⁴⁹ Aides working in Medicare- or Medicaid-certified nursing homes or home health agencies are required by federal law to receive a minimum level of training within a specified time.¹⁵⁰ But the mandated training under federal law is inadequate in the view of many industry experts,¹⁵¹ and there is evidence that some workers are not receiving training that will allow them to effectively serve their clients.¹⁵²

About half of the states require more than the minimum levels set by federal law.¹⁵³ And, as discussed in Section 3, several organizations have developed enhanced training programs throughout the country. Among these are PHI's Cooperative Home Care Associates, and the ElderStay@home Certified Home Caregiver Training program established by SCSHE. Some training programs target both formal and informal caregivers.

The American Red Cross's Family Caregiving Program, launched in 2004, serves as both an informational and training resource for family caregivers. The training program covers home safety, financial and legal issues, bathing, health maintenance, and other topics. Special modules of the program include general caregiving skills, assisting with personal care, caring for the caregivers, caregiving for a loved one with Alzheimer's or dementia, and caring for a loved one with HIV/AIDS. Training is provided through American Red Cross chapters throughout the country.¹⁵⁴

Creating career ladders

An important aspect of caregiver training is the creation of a career path with opportunities that establish caregiving as its own respected and valued profession in health care. There is little point in training and educating a cadre of caregivers who cannot afford to remain in the field because there are no opportunities for advancement.

The development of career ladders for direct care workers is being explored by several states.¹⁵⁵ Usually, these programs emphasize opportunities for advancement from aide to registered nurse or licensed practical nurse.¹⁵⁶ But moving up the career ladder to professional licensure in this way does not appeal to many of these workers, who would prefer instead developing skills that allowed them to move into positions of greater authority—and higher wages—in jobs more closely related to their current work. For example, New York City has experimented with creating a cadre of “field support liaisons” who visit care attendants in the field, identify problems, and provide peer support.¹⁵⁷

Consumer-directed care

One way states have tried to broaden the pool of potential workers is through consumer-directed care options. Essentially, through consumer-directed care, the care recipient has the final say regarding the planning and directing of his or her own care. Recipients of care may hire friends or family members and control the funding, although the programs vary from state to state.¹⁵⁸

A relatively new form of consumer-directed care is “cash and counseling,” whereby Medicaid benefits or Medicaid waiver benefits are “cashed out” in lieu of services and distributed directly to consumers of care.¹⁵⁹ In 1995, a national cash-and-counseling demonstration project was initiated, funded by the Department of Health and Human Service’s Office of Assistant Secretary for Planning and Evaluation and the Robert Wood Johnson Foundation. The four states that were awarded demonstration money were Arkansas, Florida, New Jersey, and New York. Operational difficulties prevented New York from adopting the program, so in the end there were only three demonstration states.¹⁶⁰ The demonstration was structured as a randomized, controlled experiment so that outcomes for cash-and-counseling clients could be compared to outcomes for clients of managed home care services.¹⁶¹ A 2005 evaluation of the demonstration found “overwhelmingly positive effects on the well-being of consumers and caregivers,” but higher resulting Medicaid costs that “may raise concerns for states that have tight budget constraints.”¹⁶² The program has subsequently been expanded to 12 other states, based upon the success of the demonstration.¹⁶³

Provider initiatives

Several nursing homes, home care agencies, and other caregiving providers have experimented with a variety of interventions to improve the recruitment and retention of direct care workers.¹⁶⁴ Both financial and nonfinancial incentives have been offered to workers, including special recognition and award programs, career ladders, referral bonuses, and reimbursement for child care or transportation. Few of these programs have been evaluated for their effectiveness.¹⁶⁵

Notwithstanding these public and private efforts to ameliorate the shortage of paid caregivers, the caregiving crisis continues to grow. Despite the major undertakings of government agencies, nonprofits, foundations, and businesses to improve the availability of affordable, quality care in America, family caregivers remain overburdened, and too frequently those who need care go without it. (See Section 3).

PLATFORM FOR ACTION: PRIORITIES FOR SOLVING THE CAREGIVING CRISIS

This report is part of the multiyear Caregiving Project for Older Americans, a joint initiative of the International Longevity Center-USA and the Schmieding Center for Senior Health and Education. One guiding principle of our project is to learn from both the formal and informal caregiving worlds, which typically are treated—withstanding their empirical interconnectedness—as separate and distinct by advocates, lobbyists, and policymakers. In developing solutions to the caregiving crisis, we take the approach urged by such caregiving experts as Robyn Stone and Gail Hunt—a comprehensive, integrated approach.

Ongoing work of The Caregiving Project for Older Americans involves:

- assembling a national advisory committee and expert panel,
- convening a national caregiving summit, and
- conducting a series of national caregiving surveys, comparing the perspectives of paid home caregivers to those of other stakeholders, such as care recipients or state Medicaid directors.

While numerous state- and local-level surveys of paid caregivers in the United States have been conducted and evaluated in recent years, most of these were of institutionally based caregivers as opposed to home-based workers.¹⁶⁶ There have been national-level surveys of nursing homes, home care agencies, and providers of health and supportive services for older people,¹⁶⁷ but no national survey of direct care workers themselves has been conducted. The difficulty of identifying a nationally representative sample of paid direct care workers, especially those in home-based settings, and even more so those who work independently of home health agencies, probably explains why this group has not been surveyed. A better understanding of how to develop a dependable, affordable, quality direct care workforce could be achieved if a way could be found to explore—through a national survey—this uncharted territory.

Also beneficial would be national surveys designed to document both the need for home care in the population and the need for home care workers with better training. Relatively little is known about (1) how many people hire paid caregivers; (2) how many pay out of pocket; and (3) how they find the paid caregivers, whether through an agency, word of mouth, or otherwise. How difficult was it for them to find a paid caregiver? A national survey of people who have paid for home-based caregiving would help answer these and other questions, and could include consumer assessments of the quality of care provided by the caregiver and her level of training.

The findings of our national caregiving surveys will inform the later stages of our work in *Caregiving in America*. The development of our project will also be guided by the ideas and feedback generated by our national advisory committee and expert panel, and through our national caregiving summit. The core components of our future work include: (1) developing a curricula for paid and family caregivers with special modules on dementia, congestive heart failure, and other conditions; (2) working to create an accreditation and national certification program; (3) working to establish a career ladder initiative, and (4) efforts to found a national association for professional caregivers. Following is a brief description of these four ideas.

Curricula for professional and family caregivers

In cooperation with caregiving organizations, professional societies, institutions of higher education (including community colleges), and other organizations, the ILC-SCSHE team will work to create national curricula for both paid and informal caregivers. The curricula development will be informed by experts in caregiving, geriatric medicine, nursing, health policy, and social work, as well as by curricula models throughout the country, including the model created in Arkansas by the SCSHE. We plan to develop special modules for congestive heart failure, Alzheimer’s disease and dementia, stroke, diabetes and other conditions within the curricula. In addition, we think it is important to foster literacy and numeracy among direct care workers, many of whom have modest educational backgrounds. Many paid caregivers are immigrants, and a well-defined curricula should address the language and cultural barriers that often exist. These barriers work both ways—communicating with patients with limited English proficiency is an increasingly common issue faced by physicians and other health care practitioners.¹⁶⁸

The project team will recruit an expert advisory committee composed of caregiving leaders and other appropriate stakeholders who will vet the final product. All aspects of the project will be widely communicated to the media to draw attention to the caregiving crisis and to provide suggested solutions.

Accreditation and national certification program

The ILC-SCSHE team will work to achieve a national accreditation process to train caregivers, a national certification/licensing process, and continuing education requirements to maintain certification. Family members that require in-home paid caregivers should have assurance that a certified caregiver has professional training in home caregiving skills, has been tested for competency, and that she continues to acquire knowledge in the field (this is currently not the case).

Career ladder initiative

Important in the education and training of caregivers is creating a career path with opportunities that establish caregiving as its own respected and valued profession in health care. There is little point in educating a cadre of caregivers who cannot afford to stay with this work. Finding a sustainable career model for professional caregivers is crucial, and our project will explore and make recommendations for developing such a model. One important consideration of this component of our project will be how to recruit more men into the caregiving profession, which often involves lifting and moving of care recipients.

National association for home caregivers

The career ladder, accreditation and national certification, and curricula initiatives of our project will serve as the basis for efforts to establish a National Association for Professional Home Caregivers. The primary functions of the association would include promoting the professional development of its members, establishing and maintaining professional standards of practice, advancing sound social policies, and providing services that protect its members and enhance their professional status.

CONCLUSION

An important objective of the ILC-SCSHE Caregiving Project for Older Americans is to ensure that various stakeholder organizations both inform and benefit from the results of our project. The insights of representatives from government agencies, corporations, health care providers, and nonprofits in the fields of health care, gerontology, policymaking, academia, and business all will influence our work. This project will fully involve leadership from these fields, in addition to incorporating the needs of stakeholders actually on the “ground floor” that are providing or receiving care. In that respect, the project has the advantage of the SCSHE, whose work in Arkansas with caregivers and care recipients will largely inform the work of the project.

Improving the availability of affordable, quality care for those who need it is the shared purpose of all of the public and private organizations reviewed in this report. With the launching of our Caregiving Project for Older Americans, we join their efforts. And along with them, we recognize that when it comes to solving the growing caregiving crisis, there is still more work to be done.

Caregiving in America is an important step on a larger journey for the Caregiving Project for Older Americans. In mapping the territory of caregiving, we have come to appreciate that it is at once simple and complex. In the face of a burgeoning older population that will only expand in the future, the need for competent caregivers who can assist those in need in their homes is a simple fact of life. It is simply a matter of supply and demand with the need for caregivers clearly outdistancing those available to do the work. Thus we need more caregivers to assist the older population at a time when more people (and a larger percentage of the population) live longer than at any time in human history. A close look tells us that the need for formally trained and certified caregivers who are paid a living wage is also profound—and here the issue becomes more complex.

How the necessary workforce will be recruited, how it will be trained and who will do it, how a career ladder can be established and how this cadre of home health care workers can be financed are all questions that must be explored and answered. At the same time, the caregiving crisis is not just a matter of mechanical formulation wherein ample portions of money and training can intervene and solve a growing national problem. Part of that “something more,” is making caregiving a respected occupation and a calling for those who choose this career route. Getting to that desirable goal is not an insoluble problem, but a matter for which there will be reasonable solutions over time. Some of those are mentioned specifically in this report, others require continued and creative work to be realized. It is to that challenge and the simple and complex aspects of caregiving to which this report is addressed.

The authors and all those who contributed to this report were greatly impressed by the massive amount of work that has been devoted to understanding and unraveling the caregiving crisis in America and elsewhere. Major organizations, leading professionals and scholars have spent years in this cause, and our own study is done humbly and with recognition of those who have been working diligently in this field. At the ILC-USA, caregiving is a central concern that connects efforts to promote healthy aging and productive engagement with a vigorous effort to combat ageism. This is done in the context of a

policy research center, eager to understand and solve problems. At the Schmieding Center caregiving and direct service to those needing caregiving is an essential portfolio. Thousands of clients and patients have benefited from these direct services. In going forward the ILC-USA and the Schmieding Center hope to join two kinds of knowledge: that gained in formal research and that gained by the dint of clinical experiences—with both parties contributing in both arenas—to the benefit of all of the stakeholders in the caregiving field. That includes those using and providing caregiving services at the individual and institutional level as well as all of the generations who need to know and understand caregiving—from young children and middle-aged adults to those in the last years of their lives. Caregiving for older persons is not confined solely to older people. The understanding, involvement, and creative cooperation of their children, grandchildren, and others are also essential to the challenges ahead.

ENDNOTES

1. Girion 2006.
2. Both *informal caregiver* and *family caregiver* are problematic terms. The word *informal* has the unintentional connotation of laxity; and the term *family caregiver* refers to care that is provided not just by family members but also by friends, neighbors, and volunteers. Even the term *caregiver* is not without controversy, since some observers prefer to use it exclusively to mean informal (family) help. Throughout this report, formal or paid caregivers are sometimes called direct care workers or paraprofessionals. This group is distinct from family, unpaid, or informal caregivers. When the term *caregiver* stands alone, both formal and informal caregivers are meant.
3. Gibson 2004.
4. Gibson 2004.
5. Gibson 2004.
6. Anti-Ageism Taskforce at the International Longevity Center 2006.
7. Silverman 2006.
8. Aaronson and Sullivan 2001.
9. MetLife Mature Market Institute and NAC 2006.
10. Flextime, telecommuting, and job-sharing are among the programs suggested by MetLife Mature Market Institute and NAC 2006. While the MetLife/NAC report did not limit itself to older caregivers, these same programs are likely to be attractive to older workers (Muller and Knapp 2003).
11. Seavey et al. 2005.
12. Seavey et al. 2005. Dr. Robyn Stone reviewed the cited article, which was published by the Institute for the Future of Aging Services (IFAS). The article argues for greater integration of paid and family caregiving into a more comprehensive system. Its primary author, Dorie Seavey, is national policy specialist for the Paraprofessional Healthcare Institute (PHI). IFAS and PHI often work in collaboration.
13. Interview with Gail Hunt, May 12, 2006.
14. Both IFAS and PHI were involved in the article cited in footnote 12, as noted therein.
15. Seavey et al. 2005.
16. As described in the foreword, this is a multiyear, joint project of the International Longevity Center-USA (ILC) and the Schmieding Center for Senior Health and Education (SCSHE).
17. Stone 2004.
18. Kaiser Commission on Medicaid and the Uninsured 2004.
19. Walker et al. 1995.
20. Definitions for these and many other terms are provided in the glossary.
21. Levine et al. 2004, p. 152. While the quotation refers to family caregivers, the same idea may be applied to paid caregivers.
22. Levine et al. 2004.
23. Leon and Franco 1998. The study was limited to caregivers of the Medicare population.
24. U.S. Department of Health and Human Services, HRSA 2004.
25. Feldman and Ahrens 2005.
26. Feldman and Ahrens 2005, p. 1.
27. O*NET Online, <http://online.onetcenter.org>, accessed May 2006.
28. O*NET Online, <http://online.onetcenter.org>, accessed May 2006.
29. O'Brien and Elias 2004.
30. NAC 2003.
31. U.S. Department of Health and Human Services et al. 2003.
32. U.S. Census Bureau 2000, Ch. 5.
33. U.S. Census Bureau 2000, Ch. 5.
34. Longino and Warnes 2005.
35. Longino and Warnes 2005, p. 539.
36. Stone 2004.
37. NAC and AARP 2004; Feder et al. 2000.
38. NAC and AARP 2004.
39. NAC and AARP 2004.
40. Feder et al. 2000.

41. NAC and AARP 2004.
42. As discussed in Section 1.
43. NAC and AARP 2004.
44. Newsom and Schulz 1998.
45. Wright 2006.
46. Newsom and Schulz 1998.
47. NAC and AARP 2004.
48. Newsom and Schulz 1998.
49. Wright 2006.
50. AoA, <http://www.aoa.gov>, accessed June 2006.
51. Feinberg 2006.
52. AoA <http://www.aoa.gov>, accessed July 2006.
53. Elderweb, <http://www.elderweb.com>, accessed June 2006.
54. AoA, <http://www.aoa.gov>, accessed June 2006.
55. As reported in NAC and AARP 2004.
56. NAC, <http://www.caregiving.org>, accessed June 2006.
57. FCA, www.caregiver.org, accessed August 2006.
58. RCI, <http://rci.gsw.edu>, accessed June 2006.
59. NQCC, <http://www.nqcc-rci.org>, accessed June 2006.
60. J&J/RCI, <http://www.rci.gsw.edu>, accessed June 2006.
61. PHI, <http://www.paraprofessional.org>, accessed July 2006.
62. SCSHE, <http://www.schmiedingcenter.org>, accessed July 2006.
63. AAHSA, <http://www.aahsa.org>, accessed August 2006.
64. IFAS, <http://www.futureofaging.org>, accessed July 2006.
65. RWJF, <http://www.rwjf.org>, accessed July 2006.
66. Atlantic Philanthropies, <http://www.atlanticphilanthropies.org>, accessed July 2006.
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68. MetLife, <http://www.metlife.com>, accessed July 2006.
69. Dennis et al. 2005.
70. NYBGH, <http://www.nybgh.org>, accessed July 2006.
71. Amgen and Eli Lilly, <http://www.amgen.com>, <http://www.lilly.com>, accessed July 2006.
72. Johnson & Johnson Healthcare Systems, <http://www.jjhcs.com>, accessed July 2006.
73. Pfizer, <http://www.pfizer.com>, accessed July 2006.
74. U.S. Code, Title 29, sec. 2601.
75. SEIU, <http://www.seiu.org>, accessed August 2006.
76. Private communication with Gail Hunt.
77. Newman 2006.
78. SEIU, <http://www.seiu.org>, accessed August 2006.
79. The findings of these surveys are reported in National Clearinghouse on the Direct Care Workforce and the Direct Care Workers Association of North Carolina 2005; PHI and North Carolina Department of Health and Human Services 2004 and 2002; and North Carolina Division of Facility Services 2001, 2000, and 1999.
80. NCOA and Pfizer 2003 and NCOA 2001.
81. Arno 2002. This is discussed further in Section 6.
82. NAC and AARP 2004.
83. The median for caregiver households is from NAC and AARP 2004; the national median is from U.S. Census Bureau 2006.
84. NAC and AARP 2004.
85. NAC and Brandeis University 1999.
86. NAC and AARP 2004.
87. NAC and AARP 2004.
88. Cannuscio et al. 2002; Kiecolt-Glaser et al. 1995; MacCallum et al. 2003; and Schulz and Beach 1999.
89. NAC and AARP 2004.
90. NAC and AARP 2004.
91. NAC and AARP 2004.
92. Stone and Wiener 2001.

93. U.S. Census Bureau 2001.
94. U.S. Census Bureau 2001, Tables 44 and 45.
95. U.S. Census Bureau 2001, Tables 44 and 45.
96. U.S. Census Bureau 2001.
97. U.S. Census Bureau 2001.
98. Stone 2004.
99. Yamada 2002.
100. Yamada 2002. This is a simplification—some direct care workers are classified by the source as “non-workers,” meaning that they are either unemployed or currently unavailable for work.
101. Stone and Wiener 2001; Stone 2004; Harris-Kojetin et al. 2004; U.S. Department of Health and Human Services et al. 2003.
102. U.S. Department of Labor, Bureau of Labor Statistics 2006.
103. Stone 2004.
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105. U.S. Department of Health and Human Services 2004.
106. Stone and Wiener 2001.
107. U.S. Department of Health and Human Services et al. 2003.
108. Hecker 2005.
109. Table 5.4 shows projected growth from 2004 to 2014.
110. Hecker 2005.
111. Feldman and Ahrens 2005, p. 8.
112. Stone 1999.
113. Kane et al. 1998, pp. 77–82.
114. Visiting Nurse Service of New York. <http://www.vnsny.org/research>.
115. Vaughan-Wrobel 2005.
116. Winchester and Frydman 2003.
117. Feldman and Ahrens 2005.
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119. Kaiser Commission on Medicaid and the Uninsured 2004.
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121. Watzman et al. 2006.
122. Markoff 2006.
123. Feinberg 2006.
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125. Smith et al. 2006. The Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group, periodically revises its estimates of numbers on national health expenditures. The tables presented in the text are from a more recent revision and so differ somewhat from those presented in Arno 2002.
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APPENDIX A. MAJOR CAREGIVING STAKEHOLDERS IN THE UNITED STATES

NONPROFITS	
Organization	About the Organization*
<p>AARP Family, Home, and Legal program http://www.aarp.org/families</p>	<p>AARP has a variety of programs that focus on enhancing quality of life for older people. by providing its members with information, advocacy, and service programs. Under its Family, Home, and Legal program, AARP has developed a caregiving initiative that provides caregivers with information on various issues in the field.</p>
<p>American Academy of Home Care Physicians http://www.aahcp.org/</p>	<p>AAHCP members include home care physicians, physicians who make house calls, care for homebound patients, act as home health agency medical directors, or who refer patients to home care agencies.</p>
<p>American Association for Homecare http://www.aahomecare.org</p>	<p>AAHomecare focuses on making health care in the home more accessible for all Americans. The organization provides home care services by a wide variety of nursing and home health aide professionals such as medical social workers, registered nurses/licensed practical nurses, family caregivers, home health aides, and physicians.</p>
<p>American Association of Homes and Services for the Aging http://www.aahsa.org/</p> <ul style="list-style-type: none"> • Institute for the Future of Aging Services • Better Jobs Better Care • Quality First 	<p>The members of AAHSA are organizations that provide services for older people ranging from home health to nursing homes. IFAS is a policy research institute housed within AAHSA. Its aim is to advance the development of quality health, housing, and supportive services for the aging population in the U.S., through policy practice and research. In affiliation with IFAS, Better Jobs Better Care is a three-year research and demonstration project. Quality First is a framework for quality care in aging services.</p>

NONPROFITS	
Organization	About the Organization*
<p>American Geriatrics Society http://www.americangeriatrics.org</p>	<p>The AGS is a nationwide association of geriatrics health care professionals, research scientists, and others dedicated to improving the health, independence, and quality of life of older people in the U.S. The AGS promotes high quality, comprehensive, and accessible care for older people, including those who are chronically ill and disabled. The organization provides leadership to health care professionals, policymakers, and the public by developing, implementing, and advocating programs in patient care, research, professional and public education, and public policy.</p>
<p>American Health Care Association http://www.ahca.org • National Center for Assisted Living http://www.ncal.org</p>	<p>AHCA is a federation of affiliated state health organizations, representing nonprofit and for-profit assisted-living, nursing facility, developmentally disabled, and subacute care providers for elderly and disabled individuals nationally. AHCA also serves as a source within the long-term care field, providing information, education, and administrative tools that enhance the quality of caregiving. NCAL represents nonprofit and for-profit assisted-living residences that are dedicated to professional care for the elderly and disabled.</p>
<p>Consumer Consortium on Assisted Living http://www.ccal.org</p>	<p>CCAL is an education and advocacy organization focused on the needs, rights, and protection of assisted-living consumers, their caregivers, and care receivers. CCAL educates consumers, trains professionals, and advocates for assisted-living issues.</p>
<p>Family Caregiver Alliance National Center on Caregiving http://www.caregiver.org</p>	<p>The Family Caregiver Alliance addresses the needs of family and friends who provide caregiving and long-term care services at home. It offers support services to caregivers nationwide, statewide, and locally. The NCC was established as a program of the Family Caregiver Alliance. Its aim is to develop cost-effective policies and programs for caregivers in every state of the U.S. NCC focuses on research and public policy and also serves as an informational resource on caregiving and long-term care issues for policymakers, providers, family caregivers, and media.</p>

NONPROFITS	
Organization	About the Organization*
<p>Mount Sinai Visiting Doctors http://www.mountsinai.org</p>	<p>Mount Sinai Visiting Doctors Program delivers primary care in the home to more than 400 homebound adults throughout Manhattan. The program is housed at Mount Sinai Hospital.</p>
<p>National Alliance for Caregiving http://www.caregiving.org</p>	<p>NAC is a coalition of national organizations that focus on issues of family caregiving. The main focus of the alliance is to conduct policy research, develop national programs, and increase public awareness on family caregiving issues.</p>
<p>National Association of Professional Geriatric Care Managers http://www.caremanager.org</p>	<p>GCM is a nonprofit association of professional practitioners whose purpose is the development, advancement, and promotion of humane and dignified social, psychological, and health care for the elderly and their families through counseling, treatment, and the delivery of concrete services by qualified, certified providers. GCM is committed to working toward the highest quality of care for the elderly and their families through education, advocacy, and high standards of professional practice.</p>
<p>National Association for Home Care and Hospice http://www.nahc.org</p>	<p>NAHC is a trade association representing the interests and concerns of home care agencies, hospices, home care aide organizations, and medical equipment suppliers. NAHC is dedicated to making the lives of home care and hospice providers easier. It offers professional development and policy updates related to home care and hospice.</p>
<p>National Association of Local Long-term Care Ombudsman Program http://www.nalltco.org</p>	<p>The National Association of Long-term Care Ombudsman Program focuses on advocating for the rights of long-term care facility residents with the aim of improving their quality of life and care.</p>

NONPROFITS	
Organization	About the Organization*
<p>National Family Caregivers Association http://www.thefamilycaregiver.org</p>	<p>NFCA advocates for family caregivers who care for a chronically ill, aged, or disabled person. They provide resources and education services such as <i>Communicating Effectively with Healthcare Professionals</i>, which helps caregivers interact with doctors and health care professionals. Together with NAC they have created an outreach program, <i>Family Caregiving: It's Not All Up to You</i>, that puts family caregivers in touch with information and services that can better their lives and the level of care they provide.</p>
<p>Paraprofessional Healthcare Institute http://www.paraprofessional.org</p> <ul style="list-style-type: none"> • Health Care for Health Care Workers • Cooperative Home Care Associates • Home Care Associates • Independence Care System • National Clearinghouse on the Direct Care Workforce • Direct Care Alliance 	<p>PHI is a leader in long-term care workforce policy. PHI focuses on developing new approaches to direct-workforce recruitment, retention, training, public policy research, and caregiving practices. HCHCW focuses on the lack of insurance for the direct care workforce. It develops policy solutions and creates awareness in order to bring about change. The National Clearinghouse on the Direct Care Workforce is an online library of information on the direct care workforce. The Direct Care Alliance is a national advocacy group that represents consumers, workers, and providers in long-term care and focuses on advocating for quality jobs and quality care.</p>
<p>Pioneer Network http://www.pioneernetwork.net</p>	<p>The Pioneer Network is a national network of individuals in the field of long-term care. The organization's mission is to advocate and facilitate changes in an aging population. It aims to change attitudes and beliefs toward aging. Pioneer Network does this by building support systems, promoting changes in public policy and research, and developing access to resources.</p>

NONPROFITS	
Organization	About the Organization*
<p>Rosalynn Carter Institute for Caregiving http://rci.gsw.edu</p> <ul style="list-style-type: none"> • National Quality Caregiving Coalition • Johnson & Johnson/Rosalynn Carter Institute Caregivers Program 	<p>RCI promotes effective caregiving practices, builds awareness of caregiving needs, and contributes to public policy that focuses on caregiving in the community. NQCC is a coalition of national associations, groups, and individuals that promote caregiving throughout the lifespan. The Johnson & Johnson RCI Caregivers Program focuses on programs that aim to improve the well-being and quality of life of caregivers.</p>
<p>United Hospital Fund http://www.uhnyc.org</p> <ul style="list-style-type: none"> • Families and Health Care Project 	<p>The United Hospital Fund focuses on improving health care in New York. This is accomplished by contributing to public policy research and analysis, developing support programs, and promoting accessible health care services. The Families and Health Care Project focuses on supporting family caregivers at home. Its aim is to create public and professional awareness of the role family caregivers play in the health care system. It also supports a variety of programs that target family caregivers' needs such as education and training.</p>
<p>Visiting Nurse Associations of America http://www.vnaa.org</p>	<p>VNAA is a national association for community-based home health organizations known as Visiting Nurse Associations (VNAs). VNAs created the profession of home health care, and today VNAs care for about 4 million people annually.</p>
<p>Visiting Nurse Service of New York http://www.vnsny.org</p> <ul style="list-style-type: none"> • Center for Home Care Policy and Research 	<p>VNSNY is a home health care agency. The Center for Home Care Policy and Research conducts research to promote the delivery of high quality, cost-effective care in the home and community. Its services include senior care, private care, hospice care, and after-hospital care.</p>

NONPROFITS	
Organization	About the Organization*
<p>The Atlantic Philanthropies http://www.atlanticphilanthropies.org <ul style="list-style-type: none"> • Ageing Programme </p>	<p>Atlantic seeks to bring about lasting improvements in the lives of older adults, transform how aging is viewed within society, and improve the way older persons are treated by society. It focuses on aging in Bermuda, Northern Ireland, the Republic of Ireland, and the United States.</p>
<p>Donald W. Reynolds Foundation http://www.dwreynolds.org</p>	<p>The Donald W. Reynolds Foundation's sponsorship of nonprofit organizations and institutions has four main goals: (1) meeting the needs of communities in Arkansas, Nevada, and Oklahoma, primarily through improved facilities for local nonprofits; (2) combating atherosclerosis and atherosclerotic heart disease through cutting-edge, translational research; (3) improving the quality of life of older people in the U.S. through better training of physicians in geriatrics; and (4) enhancing the quality and integrity of journalism, focusing particularly on better training of journalists who serve smaller communities and on business journalism.</p>
<p>Henry J. Kaiser Family Foundation http://www.kff.org <ul style="list-style-type: none"> • Health Policy </p>	<p>KFF provides information to policymakers, the media, and the public on the major health care issues facing the U.S. KFF is primarily an operating foundation that develops and runs its own research and communications programs, often in partnership with outside organizations.</p>
<p>John A. Hartford Foundation http://www.jhartfound.org</p>	<p>The Foundation's overall goal is to increase the nation's capacity to provide effective and affordable care to its rapidly increasing older population. Through its grant-making, the Foundation seeks specifically to (1) enhance and expand the training of doctors, nurses, social workers, and other health professionals who care for elders; and (2) promote innovations in the integration and delivery of services for all older people.</p>

NONPROFITS	
Organization	About the Organization*
<p>Johnson & Johnson Consumer Products Company http://www.strengthforcaring.com • The Caregiver Initiative “Strength for Caring”</p>	<p>Strength for Caring is an online resource and community for family caregivers. Strength for Caring helps family caregivers take care of their loved ones and themselves. Strength for Caring is part of the Caregiver Initiative created by Johnson & Johnson Consumer Products Company, Division of Johnson & Johnson Consumer Companies, Inc.</p>
<p>MetLife Foundation http://www.metlife.com • MetLife Mature Market Institute</p>	<p>The MetLife Mature Market Institute is the company’s information and policy resource center on issues related to aging, retirement, long-term care, and the 50+ marketplace. Staffed by gerontologists, the Institute provides research, training, education, consultation, and information to support MetLife, its corporate customers, and business partners.</p>
FOUNDATIONS & BUSINESS	
Organization	About the Organization*
<p>Pfizer Inc http://www.positiveprofiles.com • Pfizer Medical Humanities Initiative</p>	<p>PMHI is dedicated to understanding and enhancing the patient-physician relationship. PMHI works to foster a balance between humane care and scientific expertise in the health care field and promotes compassion, understanding, and partnership as core values in health care. To accomplish this mission, PMHI creates and supports fellowships, scholarships, physician and medical student leadership awards, and community health programs designed to bring physicians and patients closer together and strengthen the health care system.</p>
<p>Robert Wood Johnson Foundation http://www.rwjf.org</p>	<p>RWJF seeks to improve the health and health care of all Americans. It prioritizes grants into four goal areas: (1) access to quality health care at reasonable cost; (2) improve the quality of care and support for people with chronic health conditions; (3) promote healthy communities; and (4) reduce the personal, social, and economic harm caused by substance abuse.</p>

FOUNDATIONS & BUSINESS	
Organization	About the Organization*
<p>The Archstone Foundation http://www.archstone.org</p>	<p>The Archstone Foundation is a private grant-making organization whose mission is to contribute toward the preparation of society in meeting the needs of an aging population.</p>
<p>New York Business Group on Health, a subsidiary of the National Business Coalition on Health http://www.nybgh.org • Eldercare Task Force</p>	<p>NYBGH is a not-for-profit coalition of 150 businesses and is the only organization in the New York metropolitan area focused on employer health benefit issues. Members include employers and health-related organizations. The Eldercare Task Force brings together different businesses, organizations, and government institutions that have workplace programs for employee caregivers.</p>
SERVICES EMPLOYEES INTERNATIONAL UNION	
Organization	About the Organization*
<p>Service Employees International Union http://www.seiu.org</p>	<p>SEIU's membership includes 1.8 million working people and 50,000 retirees and is the fastest-growing union in North America. SEIU is primarily active in four areas: hospital systems, long-term care, property services, and public services. SEIU is the largest health care union, with 900,000 members in the field, including nurses, LPNs, doctors, lab technicians, nursing home workers, home care workers. It is also the largest property services union, with 225,000 members in the building cleaning and security industries, including janitors, door men and women. SEIU is the second largest public services union, with 850,000 local and state government workers, public school employees, bus drivers, and child care providers.</p>

GOVERNMENT	
Organization	About the Organization*
<p>Administration on Aging http://www.aoa.gov</p> <ul style="list-style-type: none"> • Aging and Disability Resource Center • DHHS National Family Caregiver Support Program • Eldercare Locator 	<p>The enactment of the Older Americans Act Amendments of 2000 established the National Family Caregiver Support Program. The program, developed by the Administration on Aging of the U.S. Department of Health and Human Service, is based on successful caregiving programs in states such as California, New Jersey, Wisconsin, and Pennsylvania, and on the needs expressed by family caregivers across the U.S. The Eldercare Locator is a public service initiative of the U.S. Administration on Aging. It connects older Americans and their caregivers with sources of information on senior services. Centers for Disease Control and Prevention</p>
<p>http://www.atpm.org</p> <ul style="list-style-type: none"> • Association for Prevention, Teaching, and Research 	<p>APTR is the national association supporting health promotion and disease prevention educators and researchers. APTR includes members of the Association of Preventive Medicine Residents. Individual members include physicians, nurses, public health professionals, and health services researchers. Institutional members include academic departments and programs, health agencies, and schools of public health. APTR develops vital curriculum and communication tools for educators, researchers, residents, and students, and promotes professional development.</p>
<p>Center for Medicare and Medicaid Services http://www.cms.hhs.gov</p>	<p>CMS's overall goal is to serve Medicare and Medicaid beneficiaries and improve the quality and efficiency of the U.S. health care system. It also aims to improve the quality of health and health outcomes of Medicare and Medicaid beneficiaries.</p>

GOVERNMENT	
Organization	About the Organization*
<p>Department of Labor</p> <ul style="list-style-type: none"> • Employment and Training Administration <p>http://www.dol.gov</p>	<p>In its role as an employer, the DOL has a variety of progressive programs to deal with the diverse issues and needs that confront working men and women. The DOL was one of the first federal agencies to negotiate a comprehensive menu of available alternative work schedules for their employees. Its WorkLife Center assists employees in managing their work and family responsibilities. The WorkLife Center clearinghouse offers referral services, websites, literature, and videos on family-friendly topics and personnel flexibilities such as dependent child and elder care, leave options, telework, and employee assistance programs. In promoting elder care programs, the DOL offers two support groups—an Alzheimer support group and the newly established Elder Care Support Group, both of which hold monthly meetings. The DOL sponsors annual elder care fairs with representatives from national and local adult dependent care organizations. In addition, the DOL holds brown bag seminars for those who care for aging parents or relatives.</p> <p>The DOL's Employment and Training Administration (ETA) administers federal government job training and worker dislocation programs, federal grants to states for public employment service programs, and unemployment insurance benefits. These services are primarily provided through state and local workforce development systems. The ETA oversees the High Growth Job Training Initiative, the primary purpose of which is to prepare workers for new and increasing job opportunities in high growth, high demand, and economically vital sectors of the American economy. Health care is one of the targeted industries—among others are aerospace, automotive, construction, information technology, and advanced manufacturing.</p>

GOVERNMENT	
Organization	About the Organization*
	<p>Locally based partnerships are the foundation of the initiative. Partnerships include governors, economic development leaders, business and industry, and educators, who work collaboratively to develop solutions to the workforce challenges and labor shortages facing these industries.</p>
<p>Office of Assistant Secretary for Planning and Evaluation http://aspe.hhs.gov</p>	<p>ASPE is the main advisor of the Secretary of the U.S. Department of Health and Human Services on policy development. It coordinates policy activities, research, evaluation, economic analysis, legislation development, and strategic planning.</p>

*Information about organizations was taken directly from their websites.

GLOSSARY ¹⁶⁹

Activities of daily living (ADLs). Basic self-care functions. Inability to perform ADLs is a common trigger for long-term care services and is measured through a variety of ADL scales. The most common ADLs measured are bathing, dressing, using the toilet, transferring in and out of beds and chairs, and eating.

Acute care. All diagnostic, preventive, or curative treatments of illnesses, including hospital services and physician services, whether delivered to inpatients or outpatients, and all primary care.

Administration on Aging (AoA). The federal agency created in 1965 to administer the Older Americans Act. As of 1992, Administration on Aging was elevated to a subcabinet level within the U.S. Department of Health and Human Services. It is directed by the assistant secretary for aging in that department.

Adult day care. Community-based group programs designed to meet the needs of functionally and/or cognitively impaired adults. Adult day centers provide a caring, home-like setting for individuals who, for their own safety and well-being, can no longer be left at home alone. Adult day centers offer protected settings that are normally open five days a week during business hours and include a mixture of health, social, and support services. Specialized programs for individuals with Alzheimer's disease or related disorders also exist.

Adult day health care. A category of adult day care that provides comprehensive, professional support in a protected environment including on-site nurses, physical therapists, social workers, and/or other professionals for adults who experience a decrease in physical, mental, and social functioning and require tailored medical and/or psychiatric supervision. Such centers normally offer a wide range of therapeutic and rehabilitative activities as well as social activities, meals, and transportation.

Area Agency on Aging (AAA). The designated local program to administer the service functions of the Older Americans Act. The number of AAAs nationwide fluctuates around 660. Each is responsible for implementing the Title III services of the Older Americans Act and the other Older Americans Act objectives in its Planning and Service Area with budgets that flow from state units on aging. AAAs often have other sources of funding as well. In many states, the AAAs are the central point for long-term care case management and/or management of Medicaid waiver programs and other long-term care programs in the area.

Assistant Secretary for Planning and Evaluation (ASPE), Office of. A federal agency at the sub-cabinet level in the U.S. Department of Health and Human Services that is responsible for a planning and evaluation agenda for the whole department. The Division of Aging, Disability, and Long-term Care within ASPE has funded many long-term care studies.

Assistive equipment. Range of products and technology designed to help elders or people with disabilities lead more independent lives. Examples include special telephones for people with hearing impairments, walking aids, elevated toilet seats, communication devices, etc.

Assisted-living facilities (ALF). A residential apartment complex that caters to older adults by providing built-in care services and 24-hour on-call assistance. These residential settings maximize independence but do not provide skilled nursing care. Most ALFs do not accept public financing and rely on private pay from residents or their families.

Baby boomers. Persons born in the U.S. from 1946 to 1964.

Board and care home. A generic term for residential care facilities that are not licensed or certified as nursing homes and that typically provide a lighter level of care than nursing homes within a more residentially oriented environment. States use various terms, including *residential care facility*, in licensing such entities.

Caregiver. Either an *informal caregiver* or a *formal caregiver*.

Caregiving. There is no unambiguous, universally agreed-upon definition of caregiving in the literature or in practice. Generally the term refers to services that are provided to someone who is unable to care for him- or herself due to a disability or functional limitation, usually defined in terms of ADLs and IADLs, although these measures miss such relevant caregiver activities as behavior supervision, pain management, and advocating on behalf of the care recipient within the health care system. In this report, the term *caregiving* may denote either nonmedical caregiving—supportive, mostly low-tech personal care (such as help with bathing or eating) or medically necessary caregiving—providing health care (such as administering oral and intravenous medications and attending to wounds). We have attempted to distinguish between these two very different types of caregiving when it is important to be clear as to which type is being discussed.

Care manager. A professional who finds and coordinates appropriate social and medical services for elders or persons with a disability and their families. Sometimes referred to as a “case manager.” See *provider*.

Cash and Counseling. A demonstration project funded as a partnership of ASPE and the Robert Wood Johnson Foundation in 1995 to demonstrate the effectiveness of cash allocations in lieu of Medicaid or Medicaid waiver services for community-dwelling, long-term care consumers. The original program was structured as a randomized, controlled experiment in four states: Arkansas, Florida, New Jersey, and New York.

Center for Medicare and Medicaid Services (CMS). CMS administers the Medicare program and works in partnership with the states to administer Medicaid, the State Children’s Health Insurance Program (SCHIP), and health insurance portability standards.

Care management services. A service in which a professional, typically a nurse or social worker, assists in planning, arranging, monitoring, or coordinating long-term care services.

Certified nurse aide (CNA). A CNA has completed training as a nurse's aide (or assistant) and is certified to perform these duties under the direction of a registered nurse or appropriate therapist, i.e., personal care, assisting with ambulation. CNAs help nurses in nearly every aspect of nursing care in hospitals, clinics, home health, assisted-living, private homes, and doctor's offices. In hospitals, *nursing assistants* also provide daily care to patients, such as helping with meals, baths, exercises, and treatments.

Certified nursing assistant (CNA). See *certified nurse aide*.

Chronic care. Ongoing provision of medical, health, social, psychological, and spiritual care services that enable persons with serious and persistent conditions to optimize their functional independence and well-being. A disease or condition is one that lasts over a long period of time and typically cannot be cured, often associated with disability.

Community-based services. Services designed to help older and functionally impaired people stay independent and remain in their own homes (e.g., adult day care, senior centers, day respite programs).

Community support facility. Residential care facilities (rest homes) licensed to provide care to individuals with mental health problems.

Companionship services. Companions visit isolated and homebound elders for conversation, reading, and light errands. May also be termed "friendly visitor" services.

Consumer-directed care. Long-term care where the client (or consumer) has a strong role in planning and directing his or her own individual care. Consumer-directed care is sometimes contrasted to agency-directed care, though the distinction is not part of the definition. At its most pronounced, consumer-direction means that clients select, train, supervise, and fire their care attendants.

Continuing-care retirement community. A residential campus that provides a continuum of care—from private apartments to assisted-living to skilled nursing care—all in one location. The primary advantage of this model is that an individual or couple does not need to relocate if health care needs change over time.

Custodial care. Custodial care is the provision of services and supplies that can be given safely and reasonably by individuals who are neither skilled nor licensed medical personnel, including assistance with activities of daily living and related nonmedical care. Medicare specifically prohibits reimbursement for custodial care services in-home or in a nursing home. (Contrast with *skilled care*.)

Direct care worker (DCW). DCWs are known by many titles, including certified nursing assistant (CNA), nursing assistant, home health aide, home care aide, personal assistant, personal care attendant, and direct support professional. They provide an estimated 70 to 80 percent of the paid hands-on, long-term care and personal assistance received by Americans who are aged, chronically ill, or living with disabilities. DCWs work in many places, including nursing homes, clients' homes, adult day centers, assisted-living facilities, and other community settings.

Extended care facility. The original name for the long-term care facilities covered under Medicare that were viewed as having a rehabilitation capability.

Family caregiver. Someone who provides *informal care*.

Formal caregiver. See *formal care* and *caregiver*.

Formal care. Paid care provided by a home health aide or homemaker and arranged or supervised by a home care agency or provided by a nurse or therapist. It embraces all care delivered by care providers of in-home care or care in congregate settings.

Geriatrician. A medical specialist who is qualified to care for older people. In the United States, geriatricians are subspecialists of either internal medicine or family practice who have completed additional training and passed a specialty examination.

Health care. The prevention, treatment, and management of illness and the preservation of mental and physical well-being through the services offered by medical and health professionals. In the context of caregiving, health care refers to medically necessary services that must be provided by and/or supervised by medical professionals, such as RNs, as opposed to those nonmedical services provided by caregivers who give personal care but not health care.

Health care provider. A person trained and licensed to give *health care*. A health care provider is also a place licensed to provide health care. Examples include doctors, nurses, and nursing homes.

Home care. *Caregiving* provided in the home, including many group settings.

Home-based care. See *home care*. In this report, the term is often used as a shortcut for *home- and community-based care*.

Home- and community-based care. See *home-care*.

Home- and community-based services (HCBS). Supportive services to help people of all ages with disabilities to live in the community. Each state has a mix of programs and funding sources. The Medicaid program pays for many of these services in all states. There are also other federal, state, and local dollars that fund home- and community-based services, including the Social Services Block Grant, Older Americans Act, Education and Rehabilitation funds and State General funds. HCBS includes home health care, personal care, adult day care, respite care, and assisted-living facilities.

Home care agency. Generally, this refers to any agency that provides services to people in their own homes, including but not limited to those certified as vendors under Medicare. States vary on the kind of licensure they require for home care agencies—and on terminology. The term may be confusing because it is used in several ways in the literature and by those in the caregiving field: (1) as a general term for any agency that provides any services to people in their own homes; (2) as a synonym for *home health agency*; and (3) as a synonym for a *home caregiving agency* that provides only nonmedical care-

giving services. In this report, *home care agency* means any agency that provides either *both* personal and healthcare or that provides only personal care.

Home caregiving agency. Any organization providing nonmedical, in-home caregiving services. It is distinct from a *home health agency*. (See *home care agency*, which is a more generic term.) Home caregiving agencies do not accept Medicare/Medicaid reimbursement, and so only provide “medically necessary” caregiving under Medicare/Medicaid rules.

Home health agency. Ordinarily, an agency certified to receive reimbursement as a home health agency under Medicare. The rules for certified health agencies have changed over the years, but certified home health agencies must offer at least two of six specified services: nursing, physical therapy, occupational therapy, speech therapy, medical social work, and home health aides.

Home health aide (HHA). A person who has training in those supportive services that are required to provide personal care and emotional comfort and to assist the patient toward independent living in a safe environment. In home health, written instructions for patient care are prepared by a registered nurse or the appropriate therapist.

Home health care. Sometimes used in the literature to include only health-related services delivered at a person’s home, such as assistance with medications, wound care, and intravenous therapy. Just as commonly, this term is used in the literature to mean both health-related services and *personal care*. Because *home health agencies* also provide basic personal care as a part of their health care-related services, this term is often used in the literature to mean both health-related services and nonmedical caregiving services. In this report, a conscious effort is made to separate the two kinds of caregiving into either nonmedical caregiving or medically necessary caregiving.

Home help. See *home health care*.

Homemaker services. Services delivered at home that do not include hands-on care, such as shopping, laundry, light cleaning, meal preparation, and transportation assistance. Also referred to as home chore services.

Homeshare. A cost-effective living arrangement in which a group of older adults shares a house or apartment. Sometimes this is done with a person who functions as a light caregiver and who may also make some meals.

Independent-living centers. Community-based resource centers for individuals with disabilities of all types. Centers across the U.S. offer information about public benefits and local resources, support, and advocacy, with the goal of maximizing the ability of disabled persons to live independently.

Independent provider (IP). Home care workers and personal assistance workers who are some equivalent of “self-employed” as opposed to being employed by home care agencies. When IPs are covered under Medicaid, they are sometimes paid by the state (after the client authorizes the number of hours), sometimes by the client, and sometimes by agencies designated to act as fiscal intermediaries for the consumer-employers.

Informal caregiver. See *informal care* and *caregiver*.

Informal care. Unpaid care provided by a long-term care consumer's family members, friends, or volunteers. The term sometimes carries the connotation of an unlicensed caregiver whose services are not arranged and supervised by a home care agency.

Instrumental activities of daily living (IADLs). A measure of independent functioning often used as assessment. IADLs include the ability to shop, prepare meals, manage money, and perform housekeeping duties.

Licensed practical nurse (LPN). An LPN has completed training as a practical nurse and may perform selected nursing duties in accordance with the Illinois Nursing Act of 1997, including the administration of treatments and medications in caring for the ill, under the direction of a *registered nurse*.

Long-term care (LTC). Health, personal care, and related social services provided over a sustained period of time to people who have lost or never developed certain measurable functional abilities.

Medicaid. A state-operated and state-administered program that is financed jointly by the state government and the federal government according to a matching formula and that provides medical benefits for low-income people in need of health and medical care. States operate their Medicaid programs with substantial policy-setting discretion but under general federal guidelines. Medicaid was authorized in 1965 under Title 19 of the Social Security Act.

Medicare. A nationwide health insurance program for people 65 and over, for people eligible for social security disability payments for two years or more, and for certain workers and their dependents who need kidney transplantations or renal dialysis. The program was enacted in 1965 as Title 18 of the Social Security Act. Under Part A, it covers hospital care and limited nursing home care. Under Part B, it includes physician services, home health care, laboratory services, and medical equipment. Consumers contribute to the costs of Medicare through premiums, deductibles, and co-payments as specified under the law.

Nurse. A person trained to take care of the sick, injured, or disabled under the supervision of a doctor.

Nursing home. Also called *skilled nursing facility*. A residential care setting offering a protective, therapeutic environment for individuals who require rehabilitative care or can no longer live independently because of chronic physical or mental condition requiring round-the-clock skilled nursing care. Nursing homes are state-licensed and subject to certain state and federal regulations.

Older Americans Act (OAA). A statute enacted in 1965 and subsequently regularly amended. The OAA's major provisions include a bill of rights for older people (Title I), a federal responsibility to advocate and coordinate on behalf of the aged (Title II), a service capacity for nutritional and other services (including some long-term care services) through a national network of State Units on Aging and Area Agencies on Aging (Title III), training and research on aging (Title IV), employment for seniors (Title V), programs for Native American tribes (Title VI), and a variety of protective programs, including the LTC ombudsman program (Title VII).

Paraprofessional caregiver. Paraprofessional caregivers are home health aides, certified nursing assistants, personal attendants, and other frontline caregivers working in nursing homes, assisted-living facilities, adult care homes, group homes for the mentally and physically disabled, and individual clients' residences.

Paid caregiver. Someone who provides *formal care*.

Personal assistant services (PAS). Services to assist people with ADL deficiencies with their personal care. PAS may be provided, at state option, as part of the state Medicaid plan. Sometimes PAS are provided through independently employed care providers and are contrasted to care from home care agencies.

Personal care. The functions of a nonmedical caregiver, including assistance with activities of daily living, self-administration of medications, bathing, dressing, grooming, feeding, ambulation, changing position in bed, and other tasks.

Person-centered care or person-first. Honoring the person before the task. These practices provide the basis for creating a daily life worth living, striving to nurture the mind and the spirit, and promoting growth and development for all.

Post-acute care. Care that follows a hospital stay and is usually related to that stay. Medicare covers the following types of post-acute care: rehabilitation center care, skilled nursing home care, and home health care.

Primary care. Basic or general health and preventive care provided when a patient first seeks assistance from the medical care system. It is also defined as the entry point into the health care system and is generally provided in a physician's office or health care clinic setting.

Primary caregiver. The person (usually the spouse or adult child) that takes on the main or day-to-day responsibility of caring for the physical, psychological, and/or social needs of another person.

Provider. The term most commonly refers to institutions—such as hospitals, clinics, home caregiving agencies, nursing homes—that provide health care, caregiving, or related services. The term sometimes also refers to individuals who provide health care or caregiving.

Registered nurse (RN). A nurse who has completed extensive training and has passed a specific state qualifying examination in order to perform complete nursing services. RNs are licensed under state laws.

Residential care facility. A generic term for a group home, specialized apartment complex or other institution that provides care services where individuals live. The term is used to refer to a range of residential care options, including assisted-living facilities, board and care homes, and skilled nursing facilities.

Respite care. Temporary or intermittent care for individuals with disabilities, illnesses, dementia, or other health concerns to give relief to caregivers from the demands of ongoing care. Respite care can be provided at home, in the community (e.g., adult day care centers or special respite programs), or overnight in a facility.

Skilled care. The provision of services and supplies that can be given safely and effectively only by, or

under the supervision of, skilled or licensed medical personnel. Skilled care is medically necessary when provided to improve the quality of health care of patients or to maintain or slow the decompensation of a patient's condition, including palliative treatment. (Contrast with *custodial care*).

Skilled nursing facility (SNF). See *nursing home*.

Social adult day care. A category of adult day care that focuses on socialization and therapeutic recreation. There is typically no health monitoring or nursing oversight.

Social Security Disability Insurance (SSDI). An extension of Medicare coverage (effective 1973) to include disabled persons under 65 who qualify for Social Security cash disability benefits (for at least 12 consecutive months) or who require hemodialysis or kidney transplantation. The Medicare benefits so provided are the same as for persons age 65 and over. Beneficiaries must have worked under the Social Security Act five years out of the previous ten years before they were disabled.

Sub-acute care. Also called *transitional care*. Care of persons discharged from a hospital who still require active treatment, rehabilitation, or close monitoring. As hospital payment under Medicare was changed to a prospective payment regardless of length of stay, patients were discharged earlier. This care that was formerly provided under a hospital's aegis is now called sub-acute care. Sub-acute care can be provided in nursing homes with heavier nurse staffing or in converted facilities that represent former excess hospital capacity.

Supplemental Security Income (SSI). A federal government program that pays monthly benefits to low-income individuals with few assets. Beneficiaries must be age 65 or older or blind or disabled. A basic national payment level is established by the federal government annually.

Traditional nursing home. These facilities provide care to people who can't be cared for at home or in the community. Nursing homes provide a wide range of personal care and health services. For most people, this care generally is to assist people with support services such as dressing, bathing, and using the bathroom for people who are unable to take care of themselves due to physical, emotional, or mental problems.

Transferring. An activity of daily living—the ability to move in or out of a bed, chair, or wheelchair.

Transitional care. See *sub-acute care*.

Wage pass-through. A state designates some part of a reimbursement increase for one or more public funding sources for long-term care (typically Medicaid, but sources may also include Older Americans Act funds, state appropriations, etc.) and uses it specifically to increase wages and/or benefits for front-line workers.

Waivers. Any authorized exemption of a statutory program.

1915(c) waivers. Waiver under the Social Security Act that allows states that have successfully applied to federal authorities to use matching Medicaid funds with much more flexibility to cover home- and community-based services not ordinarily covered by Medicaid or to waive other Medicaid rules as long as the service recipients are nursing-home certifiable. Also known as 2176 waivers.

ABBREVIATIONS

AAA	Area Agency on Aging
AAHSA	American Association of Homes and Services for the Aging
ADA	Americans with Disabilities Act
ADLs	Activities of daily living
AGS	American Geriatrics Society
AHCA	American Health Care Association
ALF	Assisted-living facilities
AoA	Administration on Aging
ASPE	Office of Assistant Secretary for Planning and Evaluation
BBA	Balanced Budget Act
BJBC	Better Jobs Better Care
CCRC	Continuing-care retirement communities
CMS	Center for Medicare and Medicaid Services
CNA	Certified nurse aide (or assistant)
DCW	Direct care worker
DOL	Department of Labor
ETA	Employment and Training Administration
FCA	Family Caregiver Alliance
GCM	National Association of Professional Geriatric Care Managers
HCBS	Home- and community-based services
HHA	Home health aide
HHS	U.S. Department of Health and Human Services
IADLs	Instrumental activities of daily living
IFAS	Institute for the Future of Aging Services
ILC-USA	International Longevity Center-USA

IP	Independent provider
J&J	Johnson & Johnson
LCC	Life care communities
LPN	Licensed practical nurse
LTC	Long-term care
MMI	MetLife Mature Market Institute
MR/DD	Mental retardation/developmental disability
NAC	National Alliance for Caregiving
NAHC	National Association for Home Care and Hospice
NCC	National Center on Caregiving
NFCSP	National Family Caregiver Support Program
NQCC	National Quality Caregiving Coalition
NYBGH	New York Business Group on Health
OAA	Older Americans Act
OECD	Organisation for Economic Cooperation and Development
PAS	Personal assistant services
PHI	Paraprofessional Healthcare Institute
RCI	Rosalynn Carter Institute for Caregiving
RN	Registered nurse
RWJF	Robert Wood Johnson Foundation
SCHIP	State Children's Health Insurance Program
SCSHE	Schmieding Center for Senior Health and Education
SEIU	Service Employees International Union
SNF	Skilled nursing facility
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
VA	Veterans Affairs, U.S. Department of

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