LONG-TERM CARE
IN AN AGING SOCIETY
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LONG-TERM CARE
IN AN AGING SOCIETY
THEORY AND PRACTICE

GRAHAM D. ROWLES, PHD
PAMELA B. TEASTER, PHD
Editors
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Preface

PAMELA B. TEASTER
GRAHAM D. ROWLES

Difficulties are what makes it honorable and interesting to be alive.

—Florida Scott-Maxwell, The Measure of My Days

To begin, we state the obvious: Our society is an aging one. Though many of its members will remain healthy and able to care for themselves for the majority of their lives, many others will cycle in and out of various types of long-term care arrangements. Although not all persons requiring long-term care will be old, all are indisputably aging. Because the topic of long-term care is critical for younger and more mature scholars and practitioners alike, we solicited a cadre of exceptionally insightful and prominent scholars to contribute to a comprehensive volume addressing long-term care within an aging society.

Our book, which begins and ends with a focus on the individual intersecting with others on micro to macro levels and is framed against a backdrop of changing landscapes and understandings, contains chapters with theoretical grounding and empirical research that meld with current practice in order to provide readers with a cutting-edge and comprehensive understanding of long-term care. We asked our contributors to consider five key themes and, where appropriate, to weave these themes within their chapters in order to embrace diverse aspects of the ever-changing landscape of long-term care. Specifically, we asked that they consider complex relationships among independence, dependence, and interdependence. Second, we asked that they recognize the fluidity of the long-term care continuum and the reality of constant change as a feature of each person’s long-term care experience. Third, we requested that they be particularly sensitive to the critical role of decision making in long-term care, considering both the individual recipient’s trajectory of care and decisions affecting the evolution of the long-term care system. Fourth, in drafting their chapters, we requested that our contributors pay special attention to the myriad ethical issues that pervade all levels of long-term care and that are especially important given the vulnerability of recipients of long-term care as well as the pressures that confront many caregivers. Finally, we emphasized that our contributors should not lose sight of the lived experience of long-term care and stressed that ultimately,
the purpose of the entire enterprise is to ensure the best possible quality of life for people at a time when they are likely to be most vulnerable.

Organized to progress along the long-term continuum from community-based care through supportive housing to institutional care, we include new approaches and perspectives. We suggest that the development of age-friendly communities and adaptive residential design are components of long-term care that delay entry of individuals into the formal care system. Emphasis is placed on the interface of technology and long-term care, not only a direction of immense promise but also the source of critical questions with respect to the desires of care recipients and the level of social and interpersonal contact that is maintained within our model of long-term care. Throughout the book, we seek to stress the importance of recognizing cultural diversity and the dangers of assuming that any one type of intervention appropriately fills every person's need. A critical issue to which our contributors devote attention is the complex relationship between voluntary and paid services. In a society in which family members are likely to be interacting from a distance and competing professional obligations place increased stress on traditional caregivers, this issue is of vital concern. Finally, emphasis throughout the contemporary long-term care continuum on person-centered care is featured prominently.

"Long-Term Care in an Aging Society" is organized in five parts: Part I: The Context of Long-Term Care, Part II: Community-Based Long-Term Care, Part III: Transitional Long-Term Care, Part IV: Facility-Based Long-Term Care, and Part V: Contemporary Issues in Long-Term Care. In Part I: The Context of Long-Term Care, we (Rowles and Teaster, Chapter 1) present case studies as exemplars of three very different long-term care situations: a fairly typical family-supported trajectory of community-based care, the care of a person with Down syndrome, and the story of an increasingly common scenario of caregiving from a distance. The three vignettes provide a context for defining long-term care, explanation of the demographic processes that have resulted in the current situation of demand for long-term care, and description of the general characteristics of persons requiring long-term care and those who care for them. Major themes that recur throughout the volume are then considered, including the role of family, friends, and acquaintances in providing informal care and the emergence over the past 50 years of an elaborate system of formal long-term care. We introduce new residential alternatives that have emerged to address the situation when aging in place in a familiar residence is no longer a viable alternative. The chapter concludes with consideration of the societal context of contemporary long-term care and a brief introductory discussion of new directions: moving beyond merely quality of care to quality of life, the role of age-friendly neighborhoods as part of an expanded view of long-term care, the growing importance of environmental design interventions and new technologies, and the culture change movement exemplified by emphasis on person-centered care.

In Chapter 2, Carol Haber provides a historical backdrop chronicling the development of long-term care in the American colonies and the United States from the 17th to the 21st century. Haber explains how economic, demographic,
political, and cultural changes have influenced attitudes and practices shaping long-term care and highlights the impact of historical ideas and institutions on care provision. She discusses such topics as how the English philosophy of care shaped early colonial policy, why almshouses were established and their impact on support of the poor and aged, the role and impact of religious beliefs on 19th-century institutional care, foundations of old-age homes in 19th-century America, beliefs about older adults in the first half of the 20th century, the effect of Social Security on institutional care, and the influence of legislative and judicial rulings in the second half of the 20th century on long-term care.

Part II: Community-Based Long-Term Care, begins with Whitlatch and Noelker’s interpretation of the role of the family in long-term care. The authors discuss the family-caregiving experience for older relatives caring for elderly and chronically ill elders. The prevalence of family care is described, as well as its estimated cost and value. Factors that affect the provision and consequences of caregiving, relevant theoretical paradigms, interventions to ameliorate negative effects and strengthen positive aspects of care provision, and public policies developed to meet the needs of and challenges faced by an increasing number of family caregivers provide the focus for the remainder of the chapter.

In many ways a companion to Chapter 3, Jackson and Gaugler focus on aspects of informal care in the community (Chapter 4). Their primary concern is with family caregiving of a relative with dementia. They consider various types of family involvement and the role(s) of family members in alternative types of residential long-term care-including assisted living and nursing facilities. The chapter also includes interpretation of philosophies guiding the culture change movement in nursing home environments and implications of this transition for family involvement. They round out the chapter by describing interventions for family involvement in residential settings and their limitations.

Chapter 5 (Hughes and Desai) adds another piece to the mosaic that is community-based long-term care in its exploration of the development of home care in the United States. This chapter includes a description of payment and regulatory policies influencing the present complex array of home care services. Elucidating the varied sectors of the home care industry, they discuss challenges for maximizing the positive impact of 21st-century home care. In particular, they explain the population, services, funding sources, and quality assurance mechanisms used for private home care and high-tech home care. They conclude with consideration of the potential of the Patient Protection and Affordable Care Act to improve coordination of care and care outcomes for persons with chronic conditions served by home care programs.

The place of geriatric rehabilitation in the continuum of long-term care is considered in Chapter 6. Sheets focuses on rehabilitation in postacute care settings: long-term acute-care hospitals, inpatient rehabilitation facilities, skilled nursing facilities, and home health agencies. Her chapter presents two conceptual models for disability, shows how each informs an understanding of rehabilitation, and illustrates how members of a rehabilitation team establish
rehabilitation goals and coordinate care. In addition, the chapter includes consideration of inpatient and outpatient rehabilitation settings for postacute care, rehabilitation interventions and modalities, and explains how Medicare funds rehabilitation services.

In the final chapter of Part II, Dabelko-Schoeny, Anderson, and Park (Chapter 7) introduce the growing phenomenon of adult day services (ADS). These contributors present the history and development of ADS, demographic characteristics of the ADS population, its organizational and operational structure, services offered, and how ADS are funded. Also considered is the influence of research on the impact and effectiveness of ADS for participants, family members, and society as well as future directions and contributions of ADS in meeting the growing need and desire for home- and community-based services.

In Part III: Transitional Long-Term Care, our focus is on the ambiguous and often highly stressful portion of the long-term care continuum during which the primary goal for many older and disabled adults is remaining in the community for as long as possible or utilizing a growing array of transitional environments that provide options short of highly “medicalized” institutional long-term care settings. Chapters are included on the environmental design and the use of technologies that may prevent or delay movement along the continuum toward a higher level of dependency, on the role of age-specific housing, and on rapidly proliferating assisted living alternatives.

Employing a transactional ecological perspective, Brown, Rowles, and McIlwain (Chapter 8) expand traditional conceptualizations of long-term care by emphasizing the importance of nurturing age-friendly community environments that provide supportive settings that can delay the need for forms of long-term care intervention that are more costly for the individual. The authors describe the importance of the built environment, and the role of age-sensitive environmental design and a growing array of assistive technologies used in contemporary long-term care. Embedded within the chapter are discussions of the principles of universal design and smart-home technologies and the potential for emergent and future assistive technologies to transform the long-term care landscape. The chapter concludes with observations on practical and ethical dilemmas associated with environmental design interventions and assistive technologies and the potential social and emotional costs in becoming reliant on technological interventions.

Complementing Chapter 8, Cicero and Pynoos (Chapter 9) review the housing situation of the aging population as a component of the long-term care continuum. They focus on where, how, and why older adults strive to age in place; how home modification programs allow people with functional decline to adapt to their environment; and investigate innovative models that allow for long-term care to be delivered in the home, through shared housing and shared community experiences. They also discuss public program and service options that contribute to the long-term care continuum by providing alternatives to assisted living and skilled nursing facilities. A discussion of zoning, neighborhood design, and
housing design for an aging-friendly built environment reinforces the need for broader consideration of environmental aspects of long-term care.

Golant and Hyde (Chapter 10) examine assisted living, a relatively new addition to the long-term care continuum. They define assisted living and sources of knowledge about this alternative, chronicle the historical development of assisted living, and describe the range of assisted living residences in the United States that have resulted from this history. A typology of contemporary assisted living models is provided together with an explanation of the ways in which assisted living differs from other housing-care options. Golant and Hyde explain the demographics, health status, and impairment profiles of residents, and detail the occupancy costs of assisted living. Their discussion also incorporates an examination of the regulatory environment of assisted living; commentary on the challenges of achieving both a good quality of life and a good quality of care; explanation of the role of Medicaid in making assisted living affordable; and consideration of the future prospects of assisted living as a long-term care alternative.

Part IV: Facility-Based Long-Term Care takes us into the world of institutionally based long-term care and the end of life. Despite the proliferation of alternatives and efforts to enable older and disabled adults to remain in community settings for as long as possible, a significant proportion of older Americans spend time, often at the end of their lives, in a nursing facility. Dornin, Ferguson-Rome, and Castle (Chapter 11) provide a brief history of the development and growth of nursing homes as a feature of the long-term care system. They review the contemporary operation of nursing homes and describe the characteristics of residents. Their discussion includes consideration of the culture change movement, particularly resident-centered care, as well as new options that are creating homelike environments for residents, such as the Greenhouse Movement and the Eden Alternative. The authors conclude by considering future challenges and opportunities for the nursing home industry and a variety of trends in Medicare and Medicaid reimbursement.

In Chapter 12, on hospice and palliative care, Westcott, Hurley, and Hirschman consider ways in which end-of-life care is provided by hospice and palliative care options. Their chapter is concerned with how we can best integrate high-quality end-of-life care into existing long-term care services and supports. The discussion is framed in relation to an account of the history and development of hospice and palliative care. After describing the various contemporary settings that deliver hospice and palliative care, the authors discuss benefits and challenges in ensuring the sensitive and effective delivery of hospice and palliative care.

Having described many of the components of the complex array of elements that comprise the long-term care continuum, in Part V: Contemporary Issues in Long-Term Care, the final section of this book, concern shifts to a set of contemporary topics pertaining to the entire system of long-term care or representing special situations that do not fit neatly into the continuum. Many subpopulations who receive long-term care have special needs. One such subpopulation is
persons with mental illness. As Zanjani and Hosier explain (Chapter 13), in late life, mental illness can contribute to increased morbidity, disability, and even mortality. Persons with mental illness are to be found in virtually every long-term care environment. These authors point out the importance of addressing mental health of older adults, consider areas within the existing system that need improvement in order to enhance mental health management, and explore future areas of inquiry and intervention, including fostering a better understanding of managing severe mental illness and psychiatric comorbidities in late life in both community and long-term care facility settings.

In Chapter 14, Holstein explores another critical cross-cutting issue of relevance to all stages of the long-term care continuum—the ethics of care and being cared for on a long-term basis. This theme is apparent in many of the chapters, but here it is highlighted in Holstein’s discussion of what it means to be a practitioner, a resident, or both in long-term care settings; how such notions influence conceptions of autonomy; and how a different way of understanding autonomy, as well as the ethical principles of beneficence, nonmaleficence, and justice, broaden the scope of justifiable action in long-term care. Holstein stresses how injustices fester and are reinforced in long-term care policy and critiques the standard paradigm for analyzing ethical problems in long-term care. She elucidates general ethical concepts, applies ethical concepts to long-term care situations, and provides examples of ethical conundrums faced by long-term care facilities.

The litany of ethical dilemmas in long-term care is paralleled by an array of legal principles and issues considered in Chapter 15 in which Kapp considers long-term care and the law. Kapp outlines the most salient aspects of interaction between the legal system and various participants involved in the provision and receipt of long-term care. He helps us appreciate the roles of the law and lawyers in shaping the long-term care environment. He also evaluates the practical impact of the legal system on the professional and personal lives of the various participants in the long-term care system. The chapter concludes with discussion of the process of working within legal parameters to improve both quality of care and quality of life for long-term care consumers. The issue becomes one of reconciling effective legal risk management with ethically and clinically appropriate long-term care.

Perhaps the most daunting challenge facing long-term care in the 21st century is the issue of financing. With a huge anticipated increase in demand along the entire continuum, a projected shortage of caregivers, and low levels of remuneration for many workers in the long-term care sector of the economy, and the inability of many families to pay for the services they need, there is cause for anxiety. Although funding of the entire long-term care system is problematic, on a human level fiscal problems become manifest in the inability of individuals to afford the costs of long-term care. Applebaum and Robbins (Chapter 16) provide important insight into these issues. They discuss financial aspects of the provision of long-term services and supports to individuals who experience disability, how services are provided, and the costs and mechanisms of funding for
such services. As they note, of particular concern are the implications for consumers who are without coverage for ongoing long-term services and supports. Ultimately, the fate of long-term care and those who rely on the many options discussed in this book to receive decent care and maintain a good quality of life depends on the value that society places on providing long-term care and the way in which this becomes translated into policy. In the final chapter (Chapter 17), Fortinsky and Shugrue share insights into the politics and processes of public policy. They present a framework for understanding long-term care policy development by describing the political process by which long-term care policy decisions are made and the interrelationships among major types of long-term care policies, types and levels of decision makers in the long-term care arena, and interest groups that influence the formation of policy. Major historical milestones and current policy directions and dilemmas in policy making are outlined. The authors conclude with a description of major consensus trends in long-term care policy making: the impact of public policy decisions on persons needing long-term care, types of public policies affecting long-term care, the influence of various levels of governmental and nongovernmental policy makers, and the plethora of interest group political constituencies influencing long-term care policy decisions.

As additional aids for qualified instructors, both an Instructors’ Manual and a complete PowerPoint presentation are available by request to textbook@springerpub.com.

Acknowledging the outstanding credentials of our contributors, we emphasize that we, the editors, compiled this text because of an abiding and long-standing personal and professional interest in long-term care and our awareness of the need for a comprehensive textbook that considers the state of long-term care and incorporates a full integration of theory and practice. We hope and anticipate that this text will provide a useful resource for anyone with an interest in long-term care—a topic of relevance to every person reading these words.

As we move further into the 21st century, the issue of long-term care will become an increasingly important part of our national discourse as the baby boom population ages and requires an expanding proportion of long-term care economic and human resources. There is no doubt that the current system of long-term care is inadequate to meet future needs. Change is imperative. It is our hope that this change will be guided by full awareness of the current status of long-term care and informed discussion regarding optimal ways in which to proceed. In the pages that follow, our intent is to introduce readers to information and ideas that will enable a clear understanding of the changing face of contemporary long-term care and facilitate future, critical, and informed contributions to this highly important debate.
Acknowledgments

Since its initial conceptualization several years ago, this volume has been through many phases in its progress toward the reader’s desk. To our outstanding assemblage of authors we extend our deep appreciation for their tolerance and for sticking with us through a long and sometimes arduous process in developing this text, a process that involved a series of unforeseen challenges.

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Perhaps most important is the need to thank the many people who endeavor to improve long-term care: Many of you are among those who will read these words. You provide care, you direct care, you advocate for care, and many of
you are the recipients of care. You are on the front lines of innovation and your investment is essential for sustaining the quality of care. Your influence is apparent along the entire long-term care continuum. As our contributors frequently acknowledge in their chapters, it is you who ensure that care and caring remain at the heart of long-term care.

Finally, as editors, we offer thanks to the people close to us who nurture us. Pam wishes to thank her loving family members, Gerald, Evan, and Hadley, and to acknowledge their patience with all the late nights, early mornings, and stalled or foregone weekend plans that made completion of this book possible. Graham thanks Ruth for similar forbearance. In supporting our work, you provide the ultimate expression of long-term caring.
The Context of Long-Term Care
The Long-Term Care Continuum in an Aging Society

GRAHAM D. ROWLES
PAMELA B. TEASTER

CHAPTER OVERVIEW

This chapter provides an introduction to contemporary long-term care. We consider concepts of care and caring and provide expanded definitions of long-term care and the long-term care continuum. Demographic processes that have resulted in rapidly increasing demand for long-term care are described and the characteristics of populations in need of such care are outlined. The chapter then considers informal sources of long-term care, primarily the family, and describes the formal system of long-term care services support that has developed in the United States to enable individuals to age in place. Acknowledging that eventually community-based care may no longer be an option, the chapter introduces an array of residential options that provide progressively higher levels of social and medical support. We then explore recent trends in long-term care, including the culture change movement and the emergence of alternatives oriented toward more person-centered long-term care in both community and institutional settings. The chapter concludes with observations on some of the persistent issues confronting long-term care, including debates regarding the appropriateness of community living versus age-segregated care environments, dilemmas in financing long-term care and generating an adequately trained workforce, and the moral and ethical challenges we face, both as individuals and as a society, in providing the highest possible level of caring and practical support to those in need.

LEARNING OBJECTIVES

After completing this chapter, you should have an understanding of:

- The demographic context of contemporary long-term care
- The diversity and characteristics of populations needing long-term care
In the Context of Long-Term Care

Introduction

Family Stories

Grandma Brewster

It was easy to remember how old “Grandma Brewster” was because she was born in 1900. When she died in 1995, Margaret had lived a full life. After her husband’s death in 1973, she remained in the large two-story New England colonial-style Connecticut home on the five-acre lot where she and Albert had raised their twins, Samuel and Susan. Sam lived with his family (including four of Elizabeth’s grandchildren) in a ranch home, about half a mile away. Susan, her husband, and two of their three daughters lived on a dairy farm a little over a mile from Margaret. For several years, Margaret was able to remain in her home. She took up painting and devoted increasing amounts of time to her needlework. The matriarch of the family, she continued to host Thanksgiving dinner where close to 20 members of the extended family would dine beneath the Norman

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Rockwell “Freedom from Hunger” framed print that adorned the dining-room wall. Over the years, members of the family played an expanding role in preparing food and coordinating the celebration. Sam and Susan were frequent visitors, with Sam assuming progressively greater responsibility for home repair, garden maintenance, and providing assistance with her finances. Nonslip strips were placed on the wooden steps outside the kitchen door, and Sam installed a handrail to reduce the possibility of a fall when the steps were wet. A telephone with a large dial, modified ring-tone, and volume control was installed to compensate for Margaret’s declining hearing and vision. As climbing the stairs became more problematic, Sam moved her bed downstairs into the room adjacent to the dining room. Over the years, the locus of family events—with the notable exception of Thanksgiving (where family members pitched in more and more to help with preparation of the meal)—gradually shifted to Sam’s and Susan’s homes.

And then, one day, Margaret fell. She was hospitalized with a back injury. Returning directly to her home was not an option. And so, when she left the hospital, Margaret moved into Sam’s house for a period of recuperation. She stayed for several months. Because of a lack of space (three of Sam’s children were still living at home), staying with Sam was not a viable long-term option. As time passed, Margaret became increasingly anxious to go “home.” Sam, Susan, and the remainder of the family were concerned for her safety should she do this. Following extended discussions involving Margaret and different factions of the family, some of it quite tense, they all agreed that the best option for Margaret would be to move to a smaller residence. Consequently, Margaret gave up her home of 47 years and relocated to a four-room apartment in town. She lived in a modern apartment block that had begun to develop into a naturally occurring retirement community (NORC), as a progressively increasing proportion of residents were older adults. Margaret accommodated well. She kept her car and so was still able to attend her church and her painting classes and visit family and friends. The smaller residence was much easier to maintain and keep to the level of pristine cleanliness she had always valued. Although she was on the third floor, an elevator that opened close to her door made it easy to get around. She became close friends with new neighbors, including Mary Corson, a widow only 1 year younger, who lived in the next apartment and Audrey Septian who lived at the other end of the corridor. The three ladies would spend much time together. Margaret remained fully engaged with her family as Sam, Susan, or one of her grandchildren would always pick her up so that she could attend gatherings that might extend into the evening. Margaret had decided that she would no longer drive at night.

This arrangement worked well for more than 4 years; but when her friend Mary died and Audrey moved into a nursing facility, Margaret’s increasing isolation and growing frailty necessitated a move to a setting where she might receive regular onsite care. After some searching around and family discussion of various options, Sam, Margaret, and the rest of the family settled on Cavendish Place, a continuing care community that provided dining facilities, assistance with activities of daily living (ADLs), and a continuum of health care support options that would become increasingly available to Margaret as her
level of impairment increased. Once again, Margaret quickly settled into her new home, this time a room with an adjacent bathroom. She surrounded herself with photographs of Albert, her children and grandchildren, a few family heirlooms she had the space to accommodate, and her craft projects. Over the next few years, she was still picked up for family events, but as her health declined, this strategy became progressively less feasible. She became increasingly reluctant to leave the familiarity and comfort of her room although she still hosted family members, including her grandchildren and great-grandchildren, who loved to hear her stories and receive the candy she always kept next to her chair. She remained cognitively competent although she tired easily and dozed more often. Eventually, she needed to be on oxygen for part of each day. On May 4, 1995, Margaret, “Grandma Brewster” died in her sleep.

**Anders Swenson**

Anders Swenson is now 36 years old. He was born in Tennessee at a time when the median life expectancy of individuals born with Down syndrome was less than 25 years (Yang, Rasmussen, & Friedman, 2002). By 1997, this figure had increased to 49 years, and today the life expectancy of persons with Down syndrome is approximately 60 years.

When he was a child, Anders experienced many of the comorbidities associated with Down syndrome. He had a heart condition that required surgery and was subject to frequent respiratory infections. In the small town where he lived, resources for the care and support of persons with Down syndrome and their families were limited. Both of his parents, Gunnar and Joanna, were well educated. They quickly schooled themselves on Down syndrome and soon became conversant with the condition. They became fully engaged in the local community of parents with Down syndrome children, eventually assuming a leadership role. Anders received the best possible care, with both of his parents fully invested in his future and a family context in which both Gunnar and Joanna were fully aware of and committed to their unexpected long-term responsibility for his well-being. Both accepted that their lives would be reshaped as a result of their lifelong commitment to the long-term support of their son. Though they fully embraced their parental role, both worried about how he would fare when they were much older or no longer alive (Dillenburger & McKerr, 2010). As Anders grew into adulthood, his potential was maximized at every step. Following a move to Montana, Gunnar and Joanna made sure that he continued to receive the best possible education. Also, they prepared for his future. Gunnar worked with him to the point that he was able to develop a degree of independence and become part of a father and son craft business.

In 2014, Gunnar died after a lengthy battle with a chronic form of leukemia. While Joanna remains alive, Anders can count on her continuing committed and knowledgeable support. What about the thousands of other persons with disabilities being cared for by aging parents? Who will provide the appropriate level of informed long-term care when they are gone?
Mark A. Lincoln

Mark A. Lincoln was born in 1922, the youngest boy born to an Arkansas farm family of nine. He was raised as a member of the Church of the Brethren: the women wore long dresses and covered their hair with white bonnets; the men wore plain, dark clothes and broad-brimmed hats. Their faith, a cornerstone of their work and life, demanded strict adherence to its tenets. Their religion forbade education beyond the 8th grade, but Mark was so capable that he repeated the grade twice, helping the teacher of the one-room school during his “second year.” When Mark was 16, he left the farm to work in a sign business owned by his oldest brother. At age 18, he was called to fight in World War II. His goal was to be a fighter pilot, but World War II had already been won on a number of fronts, and so he ended up working on radios in the Philippines. Taking advantage of the GI Bill, he completed a degree in theater but soon realized that he could well starve before he was “discovered.” He acquired a secondary school teaching certificate, returned to live with his older brother, and became a high school teacher of English and theater. There he met Ellen, an English teacher at the same high school. They married and moved to a small comfortable home. Ellen became pregnant within two years of the marriage, and the couple had one child.

Shortly after the birth of their daughter, Kaylee, Mark began a career in banking that lasted the rest of his working life. Ellen continued teaching high school English for over 30 years. The three led a modest but warm and loving life together. After graduation from the local high school, Kaylee attended a nearby state university, earned a master’s degree in theater, and married an English teacher who worked at the same high school where her parents had first met. Immediately after the marriage, work opportunities led to Kaylee and her new husband moving 6 hours away. For 7 years, Kaylee taught high school English and theater while her husband also taught high school but later returned to school and completed a law degree. Upon graduation from law school, a career opportunity for Kaylee’s husband enabled the couple to move 4 hours closer to her parents. Kaylee then went back to school, earned a doctorate, and was hired by the university she had attended. About a year later, Mark (now 76) and Ellen (now 74) had their first grandchild, a curly-haired boy.

All her life, Ellen had been plagued by respiratory problems, having inherited them from her father. After many years of treatments, including steroids, prednisone, and inhalants, she died at the age of 77. In the spring prior to her mother’s death, Kaylee had accepted a new faculty position about a 6-hour drive from her parents’ home. She was concerned about leaving her father alone so soon after her mother’s death, although she knew he was surrounded by many friends (mostly around Mark’s age). For the first few years after Ellen’s death, Mark cooked for himself, volunteered at the church and local hospital, and visited back and forth with his daughter and her family.

About 2 years after Ellen’s death, Mark fell for the first time and had to be hospitalized: during his stay he was diagnosed with dementia and peripheral
neuropathy. Although he was discharged home, his fall was the first of many such incidents that followed. He also was involved in a number of minor car accidents. Over a 5-year period, Mark grew thin and pale. He became increasingly confused, and more and more often when she visited, Kaylee found remnants of old food and milk in his refrigerator but little else to eat in the house. She called her father daily and tried to visit as often as her work schedule and her own family responsibilities would allow. Her ability to provide daily support was severely limited by distance at a time when her work responsibilities were increasing and time available to take care of her father had decreased. And then Mark was diagnosed with four heart blockages requiring surgery. During the surgery, Kaylee was in constant contact with the surgeon. Shortly after the surgery, accompanied by Mark’s now 4-year-old grandson, Kaylee moved in with Mark where she spent several weeks helping her father convalesce and trying to fulfill her distant work commitments. Subsequently, when he could travel, Kaylee drove her father back to her house where he would stay for a few weeks. Kaylee’s husband helped when he could, but the location of his work meant that he was away for extended periods.

Though Mark regained strength and acuity and eventually returned home, it was not long before his confusion returned, he began to eat less and less, and he experienced several more falls and minor car accidents. He loved his daughter and her family and appreciated the dilemma posed by their living so far away, but he remained firm in his conviction to remain in the town where he had lived his entire adult life. Nine months later, after another car accident and a precipitous fall that again landed him in the hospital, Mark reluctantly agreed to sell the family home and move into an assisted living facility. He arranged the sale of most of the personal property accumulated over his lifetime with Ellen. Kaylee, her husband, and his grandson traveled to help him move out of the family home and into the facility. Mark fared well at Oakwood Hills for about a year and a half. Over time, he began to mix up his medications (Kaylee arranged for him to be assisted), became increasingly confused and depressed (he began to accuse Kaylee of trying to put him in a “home”), and was sometimes hostile to staff (Kaylee intervened with the facility administration and with Mark’s physician). His balance gradually worsened, but he refused to use a cane or a walker, even though Kaylee and others provided him with many varieties.

Kaylee had long wished for another child. After over 6 years of waiting, she traveled to China to adopt a little girl of 2½ years. Her husband and son remained in the United States because not only Mark but also Kaylee’s mother-in-law was failing and was too frail to be left with no close family member nearby. While walking to the telephone in his room to hear the first words of his new granddaughter and speak to his daughter, both in China, Mark fell again, this time slamming his head hard against a table and crashing to the floor. He had broken his neck. Despite the efforts of the medical team, his son-in-law, and Kaylee’s efforts to guide his care from a distance, Mark died 10 days after she returned to the United States.
DEFINING LONG-TERM CARE

The three stories introducing this chapter are modeled on actual situations; they are among the myriad possible scenarios of long-term care considered within this book. Dilemmas of aging in place versus relocation, emergent issues resulting from success in extending the longevity of persons born with disabilities, and difficulties in providing care from a distance are examples of an array of issues in providing long-term care in an aging society—a society in which the need for such care is increasing in the face of stable or declining human and capital resources. But what then, exactly, is long-term care?

The most often used definition is that of Kane and Kane (1987, p. 4), who defined long-term care as “a set of health, personal care and social services delivered over a sustained period of time to persons who have lost or never acquired some degree of functional capacity.” In this book we broaden this perspective. Fundamental to such elaboration is clear expression of what we mean by care and caring. The words care and caring can be viewed in many ways, but perhaps most important is to distinguish between the practice of care and the emotion behind caring—we care for our fellow humans and attempt to be caring individuals. We navigate the process, programs, or mechanisms through which this sentiment is manifest: the provision of care services and programs and the practical acts of serving the needs of those who have “lost or never acquired some degree of functional capacity.” Care or caring about the fate of others without administrative structures, services, and programs to provide this care in a practical way is noble but ineffective. On the other hand, provision of a full array of services and programs without an underlying and fully internalized ethic of care and caring results in a system that may be effective in providing practical support but lacking in meaning for all involved (Douglas, 2010; Tronto, 1993). The trick, of course, is to develop approaches to care and systems of care that are fully integrated expressions of a caring society that acknowledges the richness of human experience and is based on the desire to enable all people to function at their highest level of human potential. The ever-growing system of long-term care options in the United States has sometimes provided care without caring because it has strayed away from the ultimate purpose of not just providing services or support to improve function but also achieving the loftier goal of facilitating the highest possible quality of life for those being served.

A diversity of definitions of care and caring and the distinction between sentiment and service is woven throughout the chapters in this book. Rather than limiting each author within the rubric of standardized definitions, we encouraged the contributors to write from their own individual perspectives on long-term care. In this introductory chapter we provide four general definitions of long-term care, but we encouraged the authors of each chapter to expand on these definitions in the most appropriate manner for expressing different aspects of the long-term care enterprise.

As we have noted, much has been written on notions of care and caring (Bassett, 2002; Parr, 2003; Weaver, 2013). As Kittay, Jennings, and Wasunna (2005)
so eloquently articulated, “People do not spring up from the soil like mushrooms. People produce people. People need to be cared for and nurtured throughout their lives by other people, at some times more urgently and more completely than at other times” (p. 443). The need for an ethos of care and caring has been often expressed in fields such as nursing (Bassett, 2002; Dewar & Nolan, 2013).

Our definition of long-term care, the concrete manifestation of care and caring, blends the perspectives of Kane and Kane (1987) and Mosby’s Medical Dictionary (2009): health, personal care and social support delivered on a recurring or continuing basis to persons who have lost or never acquired some degree of functional capacity. This definition embraces all forms of long-term support, ranging from the informal care provided by family and friends to the full array of formal services provided by both public and private service delivery programs, organizations, and institutions. In recent decades, the diversity of options has increased; there are now a plethora of alternatives for providing different types of long-term support.

The proliferation of long-term care alternatives is not a random occurrence. It represents the progressive creation of new options as the landscape of needs has evolved (see Chapter 2). What has emerged as a long-term care system is a linked set of supports, services, and integrating mechanisms that guide and track the provision of both informal and formal physical and mental health and social services to persons in need of long-term care (adapted from Evashwick, 2005). This system is imperfect and dynamic. For example, a generation ago, Cavendish Place was not an option for Margaret; there was no need to confront the issue of Ander’s care in his 60s, as he would not be alive at that age, and Mark Lincoln’s daughter would likely have been living nearby, thus obviating the need for long-distance caregiving. It is also important to acknowledge the cultural diversity of long-term care systems. Nursing facilities, assisted living, special housing options, adult day care, and the full array of alternatives discussed in this book are distinct features of contemporary American society. They do not exist as options within societies that sustain alternative cultural models of long-term care; for example, the sustained and sometimes exclusive primacy of the family in the provision of long-term care.

As the current system of long-term care in the United States developed over the past century, it increasingly became framed within a continuum of care, one that continues to evolve in the present century. Recognition that the long-term care needs of individuals are constantly changing necessitates a system that allows for the flow of individuals within the system, often although not invariably, in the direction of increasing dependency. Margaret Brewster and Mark Lincoln both reflect this pattern. Their stories provide unique trajectories of movement along a continuum in which a variety of pathways are available. Formally defined, we can consider the continuum of care as an integrated form of long-term care provision that provides a comprehensive and linked set of supports and services focused on meeting the health, personal care, and social services needs of individuals as their capabilities and circumstances change (adapted from Evashwick, 2005). In adopting this definition, we emphasize the importance of avoiding the negative connotation of an invariant progression.
from independence to dependency and, instead, frame the continuum in the context of exchanges occurring throughout the life course. As part of the human condition, human beings are interdependent from birth to death (Silverstein, Conroy, Wang, Giarusso, & Bengtson, 2002). The physical dependency of infancy is reciprocated by the gift of a new life. The social contract of adulthood necessitates the manifestation of this reciprocity through care of both the young and old as part of the accumulation of social capital. In old age, we draw on this capital as we exchange the receipt of physical care in payment for the legacy we have created and that we will leave.

Throughout this volume, notions of care and caring, the design of long-term care services, and consideration of ways in which these are linked within a long-term care system are framed within a continuum of linked options that, ideally, are constantly transitioning toward maximizing quality of life.

THE DEMOGRAPHIC CONTEXT OF CONTEMPORARY LONG-TERM CARE

PATTERNS OF CHANGE

As societies move through the process of industrialization and development, they experience a **demographic transition** that results in increased longevity, a growing elderly population, and the survival of sub-population groups that formerly might not have survived through infancy (Figure 1.1). In the first phase of the transition, essentially agrarian societies are characterized by high birthrates and high but fluctuating death rates as a result of wars, famines, and epidemics. During this phase, the population remains small and young, with few individuals surviving to old age. With development and industrialization, improvements in sanitation, fewer epidemics, enhanced health care and better living conditions, infant mortality levels drop. But a cultural lag in recognizing that fewer births are needed to ensure the survival of a viable population means that the overall population begins to rise. This growth continues although at a gradually slowing pace as birthrates drop and death rates remain low. Eventually, a situation is reached where death rates are low and birthrates are also low (although sometimes fluctuating as a result of periodic “baby booms”). The overall population stabilizes at a high level. In some developed countries, it appears that the overall population may even be moving to a point below replacement level (where the number of births is lower than is needed to maintain the population size).

As societies move through the demographic transition, patterns of illness and death gradually change as a result of an **epidemiologic transition**. Researchers generally consider this transition as involving three phases. First, corresponding to the earliest phases of the demographic transition, is a stage of pestilence and famine characterized by high death rates from periods of chronic malnutrition, plague, and epidemics of infectious diseases such as smallpox and cholera. During a second stage, there is a gradual decline in deaths from epidemics and famine and a transition to infectious diseases such as tuberculosis, pneumonia,
and influenza as dominant causes of death. With improvements in medical care, these diseases become far less prevalent among younger people but become the scourges of old age. In the final phase of the epidemiologic transition, there is a shift from infectious diseases as the primary cause of death and disability to chronic illness as the major cause of morbidity and mortality. Today, the dominant chronic illnesses are coronary heart disease, hypertension, diabetes, arthritis, and cancers (Centers for Disease Control and Prevention, 2015).

One outcome of these processes is increasing survivorship rates as, over time, growing numbers of individuals are able to enjoy a ripe old age, albeit often experiencing the limitations of chronic disease. This process is illustrated in Figure 1.2, which portrays the progressive “rectangularization” of survivorship curves for the United States as higher percentages of individuals experience old age.
Overall, these trends have given rise to the increased importance of long-term care as a component of life in contemporary societies. This has been reinforced by a number of associated trends. First has been the geographical dispersion of the family resulting in transformation of the ways that long-term care is provided from an almost exclusive focus on geographically proximate family providing unpaid direct day-to-day care to increasing reliance on mechanisms of care from a distance (e.g., the daily calls that Mark Lincoln received from his daughter Kaylee and the manner in which she ran interference with his physicians and caregivers). Such geographical separation has provided added impetus to the development of paid formal services, including home care, home-delivered meals, visiting nurse services, and adult day services.

A second trend has been the compression of morbidity, a notion that has generated some controversy. The basic argument here is that with improved medicine and healthier lifestyles, the period of time that individuals are experiencing life-limiting effects of chronic illness gradually declines. It is suggested that this shortens the period of living with disability and hence the need for long-term care. This argument is reinforced by the emergence of a new phase of life in developed societies, often termed the third age, a period of active postretirement living during which individuals remain healthy and are able to engage in new pursuits and activities (e.g., the arts, second careers, volunteering) that were not available or possible to previous generations (Laslett, 1989; Weiss & Bass, 2002). This view is supported by evidence that each cohort of older adults tends to be healthier than the one that preceded it (Manton, Gu, & Lamb, 2006). On the other hand, there are those who suggest that increased longevity merely extends the length of time that individuals experience the most negative effects of chronic illness and extends the period of disability and need for long-term care.

A third trend that has accelerated in recent years has been the provision of long-term care in an array of new settings. During colonial times, the primary
locale of long-term care was the family; those without family were generally
cared for by almshouses (see Chapter 2). Since that time, the locations in which
long-term care is provided have multiplied. During the Great Depression of
the 1930s, the nursing home appeared as part of the long-term care landscape.
This alternative flourished, to the point that today, there are close to 1.5 million
nursing facilities in the United States. The long-term care continuum now
includes an array of special housing options, including federally supported
housing alternatives that developed from the 1960s through the early 1980s, self-
contained retirement communities, assisted living facilities, continuing care
communities, and comprehensive campus-like facilities providing support
for all levels of needed care. These alternatives are discussed in detail in later
chapters of this book.

Although there is debate about the effects of recent demographic and health
status trends, there is little doubt about the increasing need for an array of long-
term care options. This book is about this need and the many ways in which it
is being addressed.

LONG-TERM CARE POPULATIONS

A wide range of individuals require long-term care. First are those who experi-
ence chronic health conditions, variously defined by the U.S. National Center
for Health Statistics as lasting for at least 3 months and by other agencies and
researchers as at least 12 months. Such conditions include arthritis and other rheu-
matic conditions, hypertension, heart disease, lower respiratory disease, cancer,
diabetes, depression, and cerebrovascular disease. Data from 2005 show that 44%
of all Americans had at least one chronic condition, and 13% had three or more
(Paez, Zhao, & Hwang, 2009). The number of persons with chronic conditions is
anticipated to grow to 157 million in 2020 with 81 million having multiple condi-
tions (Wu & Green, 2000; Figure 1.3). The percentage of individuals with multiple
chronic conditions is also increasing, as revealed in Figure 1.4, which documents
increases in the percentage of people ages 45 to 64 and 65 and over with two or
more of nine selected chronic conditions: hypertension, heart disease, diabetes,
cancer, stroke, chronic bronchitis, emphysema, current asthma, and kidney dis-
ease (Fried, Bernstein, & Bush, 2012). As noted earlier, the prevalence of most
chronic conditions increases with age as these conditions tend to worsen with age.
This often necessitates higher levels of long-term care as impairment increases.

A second long-term care population consists of individuals living with
impairment resulting from a permanent, usually untreatable defect caused
by disease, injury (an amputated leg), cognitive limitation (Down syndrome—
Anders would be in this category), or a congenital malformation (blindness
since birth). Chronic illness and impairment result in disability, a reduction in
a person’s ability to perform self-care and complete regular functions of daily
living without assistance. Traditionally, disabilities are assessed through mea-
sures of functional status. These measures include tools that assess physical,
cognitive, emotional, and social dimensions of functional ability. For example,
FIGURE 1.3 Projected increase in numbers of persons with chronic conditions (in millions).

![Projected increase in numbers of persons with chronic conditions](image)


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FIGURE 1.4 Percentage of adults aged 45 to 64 and 65 and over with two or more of nine selected chronic conditions, 1999–2000 and 2009–2010.

![Percentage of adults with chronic conditions](image)

1Significantly different from 1999–2000, p < 0.05.

Note: Access data table at: http://www.cdc.gov/nchs/data/databriefs/db100_tables.pdf#1

Source: CDC/NCHS, National Health Interview Survey.
the most widely employed measure of physical function is assessment of **activities of daily living (ADLs)**, a measure initially developed during the 1960s that assesses self-care abilities with respect to eating, dressing, toileting, transferring, and continence. The measure is often employed using a four-point assessment scale: (1) totally independent, (2) requiring mechanical assistance only, (3) requiring assistance from another person, and (4) unable to perform activity (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963). This measure has been modified in a variety of different ways since its introduction, although most variants continue to use at least five of the initial measures. A second often-used measure moves beyond self-care and focuses on the ability of a person to function in ways conducive to maintaining independent living. The **instrumental activities of daily living (IADLs)**, first introduced by Lawton and Brody (1969), assesses abilities with respect to managing money, using the telephone, grocery shopping, personal shopping, using transportation, housekeeping, completing daily chores, and managing medications. Again, there are a variety of different manifestations of this measure.

As measures of functional status have become more sophisticated and all encompassing, they have expanded to embrace measures of mental health, social engagement, and environmental participation. Classic among these more recent models is the now widely employed International Classification of Functioning, Disability and Health (ICF) disablement model of the World Health Organization (WHO, 2001; Figure 1.5). Approved for use by the World Health Assembly in 2001, this measure is based on underlying principles of **universality** (applicable to all people irrespective of health condition and in all physical, social, and cultural contexts), **parity and etiological neutrality** (avoiding either explicit or implicit differentiation among health conditions (physical or mental) by making the

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**FIGURE 1.5** International classification of functioning, disability and health.
important shift from health status to functioning), neutrality (employing nonevaluative language wherever possible to include both positive and negative aspects of status), and environmental influence (recognizing the important role of physical environment factors, such as climate, terrain, and building design, as well as social factors such as attitudes, institutions, and laws, in determining functioning and disability). Since its introduction, there have been many different applications and adaptations of the ICF for use with specific populations and in specific situations. However, the model now provides a widely accepted framework for defining the situation of populations that tend to be in need of long-term care.

Regardless of the measures employed to assess levels of functional ability or disability, the population in need of long-term care is both diverse and growing. Indeed, the U.S. Department of Health and Human Services estimates that 70% of people turning age 65 can expect to use some form of long-term care during their lives (http://longtermcare.gov/the-basics/who-needs-care/, retrieved on January 4, 2015). The older a person grows, the more likely he or she is to need long-term care, especially women because they outlive men by about five years and consume more long-term care services. Also, persons with disability, including 69% of people aged 90 or older, are likely to consume significant long-term care resources. Persons with chronic illness and high blood pressure, many of whom are older adults, make heavy use of long-term care resources. Persons living alone (the proportion of older women living alone has risen to almost 50%) are more likely to need long-term care. Finally, the population in need of long-term care is influenced by heredity and by lifestyle factors (e.g., diet and exercise habits).

Although the aging of the population and other demographic processes are important determinants of an expanding demand for long-term care, rising demand is only a part of the problem. Equally important is consideration of the increasing demand for people, often family members, to provide long-term care in the face of multiple and competing demands. The other side of long-term care is the people whose lives are shaped and often transformed by the need to provide long-term care, both informal care (generally unpaid) received from family members, friends, and acquaintances and formal care (generally paid) provided by programs, services, and agencies.

**INFORMAL CARE: FAMILIES, FRIENDS, AND ACQUAINTANCES**

As former first lady Rosalynn Carter once expressed it, “There are only four kinds of people in the world—those who have been caregivers, those who currently are caregivers, those who will be caregivers and those who need caregivers” (Carter & Golant, 1994, p. 3). It is difficult to estimate the number of informal caregivers because definitions vary widely as to who a caregiver is and what informal care constitutes. Does bringing in the mail from a roadside mailbox for an elderly neighbor constitute care? How does such support equate with providing 24-hour assistance with ADLs and medical care for an aging parent? According to the National Center on Caregiving, 65.7 million caregivers (29% of
the U.S. Adult population) provide care to someone who is ill, disabled, or aged (Family Caregiver Alliance, 2012). Of these, 43.5 million adult caregivers care for someone 50 years of age or older and 14.9 million care for someone who has Alzheimer’s disease or another dementia. AARP reported that in 2009, about 42.1 million family caregivers in the United States provided care to an adult with limitations in daily activities at any given point in time, and about 61.6 million provided care at some time during the year. The estimated economic value of their unpaid contributions was approximately $450 billion in 2009, up from an estimated $375 billion in 2007. More detailed descriptions of the characteristics of these caregivers, the challenges they face, and the rewards they receive from caregiving are provided in Chapters 3 and 4. Here, we emphasize that informal care from families and friends is likely to remain the primary source of long-term care support for the foreseeable future. The majority of caregivers are women (66%), 34% of whom care for two or more people (Family Caregiver Alliance, 2012). The average age of caregivers is 48 years, an age that is rising steadily. Many caregivers are themselves growing older, with an average age of those caring for persons 65 and older being 63 years. Along with the rising age of caregivers, the average number of hours per week devoted to caregiving increases with age.

Providing care to a person in need is not without cost. There has been an ever-expanding literature on caregiver burden and the economic and social costs of providing long-term care. These costs include lost wages, reduced potential for professional advancement, impaired health, social isolation, clinical depression, and other manifestations of emotional distress (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). In the past decade there has been growing awareness that despite the stresses and strains, there are benefits to becoming a caregiver: an enhanced sense of purpose, feelings of competence in the role of caregiver, being glad to give back to the receiver, personal growth, and a sense of meaningfulness in life (Raschick & Ingersoll-Dayton, 2004; Savundranayagam, 2014). It is also increasingly recognized that the view of caregiving as a burden is culturally based: in some cultures, the provision of care is viewed as a normative aspect of life. Indeed, in their work with five reservation-dwelling tribes in the American Southwest, Hennessey and Johns (1996) discovered that caregivers were more concerned about their work and other commitments interfering with their caregiving rather than caregiving interfering with their work and other aspects of their lives.

**FORMAL CARE: THE RISE OF SERVICE SYSTEMS, THE AGING NETWORK, AND CORPORATE CARE**

Although the bulk of long-term care is provided by family members, the long-term care landscape has been supplemented by the development of formal (paid) long-term care. As the difficulties and stresses of family caregiving gradually increase with the deteriorating condition of the care recipient, the tendency for informal care to be supplemented by formal care resources also increases. Assistance
from family members with shopping, housekeeping, mowing the lawn, changing lightbulbs, and fixing the faucet gradually becomes supplemented by participation in Meals-on-Wheels programs, three visits a week from a home care worker to provide help with bathing, or support from an array of community-based services.

Development of systems of formal long-term care was very much a feature of 20th-century Western culture. Stimulated by the Social Security Act of 1935, which provided federal resources to facilitate the financial support of older adults and those in need, the situation in the United States paralleled the emergence in many developed nations of support systems for increasing populations of aging and disabled individuals. A major reinforcement was the passage of the Older Americans Act in 1965 and the creation of Medicare and Medicaid, programs providing funding for medical care. Amendments to the Older Americans Act in 1973 created a system of long-term care service delivery by forming Area Agencies on Aging and what has come to be known as the “Aging Network.” This involved the creation of 56 State Units on Aging and a nationwide system of 629 Area Agencies on Aging, 244 tribal organizations, and two native Hawaiian organizations. Under the aegis of these administrative units, the array of services and resources supporting long-term care has proliferated throughout the nation to include adult day care, adult protective services, family caregiver support, help for grandparents raising grandchildren, guardianship, health promotion, home care, legal services, nutrition, ombudsman programs, personal care attendants, and transportation. Many of these services are delivered in individual communities through local senior centers. An elaborate infrastructure and network of social services is now available to persons requiring long-term care support at home.

**RELOCATION AND THE EMERGENCE OF RESIDENTIAL ALTERNATIVES**

Many current programs and services reflect a priority that evolved during the 1980s on aging in place—enabling people to remain at home in a familiar setting (Rowles, 1993; Tilson, 1990; see Chapters 8, 9, and 10). Indeed, a priority on aging in place has evolved into a societal policy mantra even though there has been a dawning realization that this may not be the optimal situation for some older adults or persons with disabilities.

There comes a point when the combined efforts of families and community-based services are no longer sufficient (Robison, Shugrue, Porter, Fortinsky, & Curry, 2012). Often a tipping point occurs when the long-term care recipient becomes incontinent, his or her level of cognitive impairment is such that the care recipient becomes a danger to himself or herself, or the primary caregiver can no longer cope (Ryan & Scullion, 2000). At this point, and sometimes in anticipation of this point, it becomes necessary to consider alternative settings for the provision of care. In parallel with community-based options, a smorgasbord of residential and health care specialized environments has developed.
Gradually, over time, the **nursing home** emerged as an institutional alternative to family care, with the number of facilities in the United States rising from about 1,200 with 25,000 beds in 1939 to 15,465 nursing facilities with 1,646,302 beds in 2011 (Kaiser Foundation, 2015). Further impetus to this option was provided by the previously mentioned Older Americans Act and the introduction of Medicare and Medicaid. The result was expansion of the nursing home industry accompanied by increasing corporatization of this long-term care option.

In parallel with this trend, and partially in response to the abysmal circumstances of many older adults (in 1959 poverty among persons 65 and older was 35%), came a growing interest in *residential options for older adults*. Over the past few decades, alternatives between the extremes of living with family members and nursing home residence proliferated (Exhibit 1.1).

**EXHIBIT 1.1 Examples of the Growing Array of Residential Settings of Long-Term Care**

<table>
<thead>
<tr>
<th>Community-Based Housing</th>
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<tbody>
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<td>Basic Types</td>
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<td>Single-Family Residences</td>
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<td>Apartments and Condominiums</td>
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<td>Mobile Homes</td>
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<tr>
<td>Independent Planned Housing</td>
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<tr>
<td>Public Housing</td>
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<td>Section 202 Housing</td>
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<td>Section 8 Housing</td>
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<tr>
<td>Retirement Communities With Few Supportive Services</td>
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<tr>
<td>Alternative Options</td>
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<td>Single Room Occupancy Hotels (SR0s)</td>
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<td>Boarding Houses</td>
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<td>Community Housing (Section 236 Housing)</td>
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<td>Cooperative Housing</td>
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<td>Older Adult Communities</td>
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<td>Village Model Communities</td>
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<td>House Sharing</td>
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<td>Granny Flats (Australia)</td>
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<td>Elder Cottage Housing Options (ECHO)</td>
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<td>Home Care Suites</td>
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<th>Congregate Living</th>
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<td>Planned Housing With Meals in Common Dining Room and Some Supportive Services</td>
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<tr>
<td>Retirement Communities Offering Extensive Services</td>
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<tr>
<td>Assisted Living</td>
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<td>Continuing Care Retirement Communities (CCRCs)</td>
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<td>Family Board and Care Homes</td>
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<th>Health Care Facilities</th>
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<td>Life Care Facilities</td>
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<td>Nursing Facilities</td>
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<tr>
<td>Specialized Care Facilities (e.g., Dementia Care Units)</td>
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<tr>
<td>Hospitals</td>
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<td>Hospice</td>
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These options can be arrayed along a continuum addressing a progressively increasing need for service and health care assistance. From the 1950s through the 1970s, federally supported housing options were developed, including public housing, Department of Housing and Urban Development (HUD)-supported Section 8, Section 236, and Section 202 housing (often constructed by faith communities and nonprofit organizations that received low-interest loans (Figure 1.6). The focus was on providing affordable housing to older adults and persons with disabilities (see Chapter 9). Change in federal policy during the 1980s led to significant curtailment of funding for new construction of such housing. As the original residents aged in place in these settings and grew increasingly frail, a need arose for supportive services.

The need to provide more services to aging populations in federally subsidized housing was complemented by the emergence of a new alternative funded by the private sector—assisted living (Golant & Hyde, 2008; Wilson, 2007; see also, Chapter 10). The idea of assisted living is based on maximizing independence but providing supportive services within a model of care in which residents have not only private and public space and maximum autonomy in controlling their daily lives and care but also ready access to both routine and specialized services. Unfortunately, although creative options abound, alternatives such as assisted living still remain prohibitively expensive for many people and are not available in many communities (Golant, 1992).
The long-term care needs of persons who are aging or living with disability or in other situations requiring assistance over an extended period are constantly evolving as their capabilities and circumstances change. Long-term care involves far more than a set of services or institutional settings and should be considered in the context of the life course. When we are born we become part of a convoy of individuals who nurture us (Antonucci & Akiyama, 1987; Antonucci, Berditt, & Akiyama, 2009). Initially, this convoy comprises our parents, siblings, and other relatives as well as our pediatrician, the people who support us in our faith community, and the friends we accumulate as we progress through childhood. The convoy tends to expand as we continue our education or pursue a career and as our lives become intertwined with an ever-broadening population of colleagues and associates. People also fall away from the convoy as our grandparents and eventually our parents die, as we change careers, as we relocate, and as we grow older. Interwoven throughout this book are ways the convoy changes, the processes involved in this change, and the ways in which our progress is supported at different times by different human resources and environmental contexts. Progress along the continuum is rarely completely unidirectional. Rehabilitation, introduction of a new medication that counters impairment, or a psychological intervention may reverse the course.

In developed societies, the aspiration is for a continuum of care that is maximally flexible, accommodates to changing circumstances, and provides for an optimum quality of life over an individual’s life course. Ideally, there should be no gaps—no circumstances in which an individual in need falls between the cracks of the long-term care system. In reality, the system is fragmented, constantly in transition, and, for many caregivers, remains extremely difficult to negotiate. Typically, each individual’s progress along the continuum involves phases of moving into and out of different types of both informal and formal long-term care.
still received “shockingly deficient” care. In the following year, Congress enacted the Omnibus Budget Reconciliation Act (OBRA ’87), also known as the Nursing Home Reform Act. Passage of this law heralded a gradual process of transition in nursing facility care, representing expansion from a primary concern with physical care to increasing emphasis on quality of life. Significant components of this legislation included requirements for comprehensive assessment of the condition of every person admitted and development of a written plan of care; annual assessment of ADLs for all residents; preadmission screening and annual resident reviews to detect mental illness or mental retardation; and mandated services (physician, nursing, rehabilitative, pharmaceutical, dietician, dental, and medically related social services). Increased emphasis was placed on resident rights. When admitted to a nursing home, residents were to be informed both in writing and verbally of their legal rights, which include the right to choose their own physician, be free from chemical and physical restraints, enjoy privacy and confidentiality of personal and medical records and protection of personal funds, voice grievances without fear of reprisal with prompt attention to resolution of those grievances, organize and participate in resident groups (with family members able to meet in family groups), and have access to federal or state surveys of the facility and to a local or state long-term care ombudsman. The OBRA ’87 legislation also provided for improved staffing and training by mandating at least one registered nurse (RN) on duty 8 hours a day, 7 days a week, and a licensed nurse on duty 24 hours a day, 7 days a week. Facilities with more than 120 beds were to employ at least one full-time social worker, and nurses’ aides were to undergo at least 75 hours of approved training and pass a competency evaluation. The legislation also introduced federal requirements for regular surveys and certification of facilities. Moreover, states were to conduct unannounced standard surveys of nursing homes at least once a year, which included an audit of a sample of resident assessments and interviews with residents to determine the quality of care they were receiving. Finally, the legislation introduced procedures for enforcement and sanctioning of noncompliant facilities.

This detailed example of a piece of long-term care–related legislation provides one historical illustration of the way in which the system of long-term care in the United States has evolved as the need for and scale of supportive intervention has grown. The emergent alternative of assisted living is seeing a similar transition from an initially unregulated option to an increasingly regulated component of the long-term care continuum. At this point, most states have developed their own definition of assisted living with distinct regulations with regard to the licensing and monitoring of such facilities. The result is a patchwork of guidelines shaping the form of this component of long-term care.

**WIDENING HORIZONS**

Recognition that an integrated and person-centered long-term care system must focus on maximizing quality of life for both care recipients and care providers at all points along the long-term care continuum has been an important stimulus
to evolitional change. **Person-centered care** is respectful of and responsive to each person’s needs, preferences, and values, and ensures that care recipients’ own values guide all decisions affecting their lives. This has involved both a rethinking of the underlying philosophy of care and a broader definition of what we mean by long-term care. As Kane (2001, p. 295) wrote: “Bluntly put, LTC [long-term care] policies and practices in the United States are flawed, particularly for those LTC consumers who are old.” In an indictment of the contemporary system at the turn of the century she noted that there was undue emphasis on nursing home and institutional care over community-based and home care alternatives. She noted particularly skimpy geographical availability of home care alternatives and services in many localities and rued the focus on quality of care rather than quality of life. In part, Kane argued, this stemmed from overemphasis on safety and health. At the core of her argument was advocacy for the need for a complete reorientation of the way in which long-term care is conceptualized:

One little-tested assumption is that safety—defined vaguely or not at all—is the be all and end all of LTC. Embedded in most of our rules and regulations is the idea that LTC should aspire to the best possible quality of life as is consistent with health and safety. But ordinary people may prefer the best health and safety outcomes possible that are consistent with a meaningful quality of life.

(Kane, 2001, p. 296)

During the early years of the 21st century, it appears that this voice is being increasingly heeded, as the cultures of most components of the long-term care continuum are evolving in new consumer-focused directions (e.g., person-centered care, supported decision making).

One direction is growing appreciation of the role that **age-friendly neighborhoods** and livable communities can play in creating environments supportive of individual’s ability to defer the need for long-term care. In 2007 the World Health Organization conducted focus group research in 33 cities in 22 countries around the world (including New York City and Portland, Oregon) to identify characteristics of communities that maximized their livability and the ability of people to actively participate in community activities regardless of age and level of functional ability. The result was *Global Age-Friendly Cities: A Guide* (WHO, 2007a) and development of a checklist identifying eight essential features of an age-friendly city that provided foci for maximizing the engagement of all residents (WHO, 2007b; Figure 1.7). In the United States, this initiative was picked up by AARP, which developed its own criteria for livable communities and established a growing network that currently embraces 41 cities, towns, and counties serving more than 28 million people (www.aarp.org/livable-communities/, accessed January 25, 2015). Both organizations developed a program whereby communities could work toward achieving recognition as an age-friendly community by developing programs of intervention and enrichment to enhance the livability of their community. Implications of the age-friendly community movement for long-term care are many because
residence in a supportive well-designed, well-serviced, and highly negotiable community is likely to enable vulnerable individuals to continue effective functioning in their community for longer than might otherwise be the case (Zur & Rudman, 2013). It will help to expand the long-term care continuum by delaying individuals’ need to harness family and community resources.

Comparable interventions on the scale of the immediate residence are also increasingly viewed as options for delaying entry into the formal long-term care system. Design interventions and new technologies are enabling persons in need of long-term care to remain at home far longer than in the past. Such technologies include home modification (Kim, Ahn, Steinhoff, & Lee, 2014), smart homes (Chan, Campo, Esteve, & Fourniols, 2009), universal design (Steinfeld & Maisel, 2012), and surveillance technologies that enable caregivers to monitor older adults and persons with disabilities from a distance while enabling them to age in place in a familiar residence (Sixsmith et al., 2007; see Chapter 8).

Beyond environmental change, there has been growing emphasis on lifestyle and self-care interventions that are conducive to maintaining independence and that serve to reduce the need for long-term care support at the beginning of the long-term care continuum and limit the need for assistance as a person’s capabilities decline (Clarke & Bennett, 2013; Jerant, von Friederichs-Fitzwater, & Moore, 2005; Kennedy et al., 2007). Close health monitoring with routine medical checkups and preventive screening, exercise programs, programs to reinforce good nutrition and hydration, and the development of local community self-help networks are important options for delaying the need for more costly forms
of long-term care. Indeed, the recent development of consumer-driven collaborative models for aging in place, including the “village” model, represent an ever-widening array of alternatives that are likely to reduce the need for formal long-term care programs as people in need of long-term care take increasing responsibility for their future (Scharlach, Graham, & Lehning, 2012).

Moving along the continuum, stimulated by the Administration for Community Living’s National Family Caregiver Support Program (NFCSP), which was established in 2000 to provide grants to states and territories, we have seen in many states the emergence of programs providing social and financial assistance for caregivers (Feinberg & Newman, 2004). These have included respite services, support groups, and psychoeducational interventions (Feinberg, 2014; Noelker & Browdie, 2012; Sorensen, Pinquart, Habil, & Duberstein, 2002). There is also a growing recognition of the need to provide long-term support for the increasing number of grandparents who are assuming full long-term responsibility for raising their grandchildren (Hayslip & Kaminski, 2005). A major source of respite for caregivers has been the proliferation of both social and medical care models of adult day service (Fields, Anderson, & Dabelko-Schoeny, 2014; see also, Chapter 7).

Underlying most of these innovations is a fundamental reorientation of thinking about long-term care. Increasingly, long-term care is guided by an emphasis on culture change, a movement that embraces a person-centered or person-directed approach in which (insofar as is possible) individuals are fully informed and engaged in decision making about their care. This philosophy involves acknowledging the personhood of each human being, knowing each care recipient in his or her biographical context, maximizing autonomy and choice, and nurturing relationships (Ekman et al., 2011; White, Newton-Curtis, & Lyons, 2008). At the home- and community-based services end of the continuum, implementation of this philosophy of care has encountered cultural and structural barriers, such as fragmentation of service delivery, restrictive regulation, and financing-related limitations, which provide an ongoing challenge (Hagenow, 2003; Ruggiano & Edvardsson, 2013).

Nowhere is the emphasis on humanizing and reframing care from a lived experience, humanistic perspective and the notion of person-centered care more important than at the institutional care end of the long-term care continuum, which is, for many, still the setting that provides the final terminus of life. We have begun to move beyond the tragedy of “double burial,” where relocation to a nursing facility symbolized a kind of societal death preceding a person’s corporeal demise. Efforts to delay nursing facility entry for as long as possible (for both social and financial reasons) are in some ways less pressing because the culture change movement is transforming the focus of institutional care from a custodial and palliative final phase of life to a less onerous phase of active life before death (Rahman & Schnelle, 2008). In addition to resident-centered care, this transformation involves the creation of a homelike atmosphere, the development of close relationships between residents and staff, empowerment of staff, collaborative decision making, and implementation of feedback strategies facilitating continuous quality improvement (Koren, 2010).
Development of the Eden Alternative by William Thomas during the 1990s provides an exemplar of this approach (Thomas, 1994). Thomas argued that the three plagues of loneliness, helplessness, and boredom account for the bulk of suffering among older adults. He advocated for the development of elder-centered communities that would replace the traditional nursing facility by creating a human habitat where life revolves around close and continuing contact with plants, animals, and children. His view was that such relationships provided young and old alike with a pathway to a life worth living (Exhibit 1.2).

For Thomas, an elder-centered long-term care community should create opportunities to give as well as receive (providing an antidote to helplessness). Such a community should imbue daily life with variety and spontaneity by creating an environment in which unexpected and unpredictable interactions and happenings could take place (providing an antidote to boredom). Meaningless social activity was to be replaced by meaningful activities that would counteract the corrosion of the human spirit that typified most nursing homes. Finally, echoing Kane’s (2001) sentiment, he envisaged a setting where medical treatment would be the servant of genuine human caring, rather than its master. Operationalizing these ideas entailed de-emphasizing top-down bureaucratic authority by placing maximum possible decision-making authority into the hands of residents or those closest to them. Thomas envisaged an environment in which the creation of community was a never-ending process nurtured by wise and engaged leadership in which human growth was never separated from human life.

Elements of Thomas’s ideas have been operationalized in a number of facilities and in many countries (Brownie, 2011; Otsuka, Hamahata, Komatsu, Suishu, & Osuka, 2010) and have evolved into a contemporary greenhouse model of institutional long-term care that has completely transformed both the design and organization of the traditional nursing home (Jenkens, Sult, Lessell, Hammer, & Ortigara, 2011; Rabig, Thomas, Kane, Cutler, & McAlilly, 2006). Greenhouse

**EXHIBIT 1.2 The Ten Principles of the Eden Alternative**

1. Loneliness, helplessness, and boredom are the plagues of the human spirit
2. Close and continuing contact with children, animals, and plants builds a human habitat
3. Loving companionship is the antidote to loneliness
4. Giving and receiving care are the antidotes to helplessness
5. Variety and spontaneity are the antidotes to boredom
6. Meaning is essential to human life
7. Medical treatment is a partner in care, not its master
8. Wisdom grows with honoring and respecting elders
9. Growth is not separate from life
10. Wise leadership is the lifeblood of thriving

*Source: Brownie (2011).*
facilities consist of small self-contained houses for 10 or fewer residents. They employ an array of smart home technologies. A central focus is on the development of relationships that maximize the identification of and respect for resident choices. In contrast to the traditional nursing facility, the household operates on no fixed schedule. Residents may have meals, receive personal care, sleep, rest, and engage in activities whenever they choose. The vision is that residents who are so inclined will participate with staff in household activities such as planning and preparing meals, gardening, caring for the household pets, cleaning and doing laundry. Residents and caregiving staff are expected to engage in direct personal relationships and eat together, talk together, make decisions together, and play together. An additional feature of a Green House facility is its open relationship with the community in which it is located. Visitors, including individuals from the surrounding community, are encouraged to engage informally with residents and staff. The transformation is even manifest in a new language designed to completely erase traditional administrative culture and hierarchical senior/junior staff and staff/resident relationships. Exemplifying the new order, residents are “elders,” the nursing assistant is now the “shahbaz” (plural “shahbazim”), the administrator is the “guide,” and volunteers from the community beyond the facility are known as “sages.” Even traditional activities are renamed. For example, a dining experience is referred to as a “convivium” (The Green House Project, 2014).

Emergent long-term care options take us further and further away from the time when long-term care alternatives were care at home or assignment to an almshouse. As the long-term care continuum continues to evolve with an ever-widening array of opportunities within a more comprehensive and differentiated long-term care system, it is important to remain mindful of significant challenges throughout the entire continuum. It is useful to conclude this opening chapter by noting some of these fundamental concerns.

**CHALLENGES OF LONG-TERM CARE**

Contemporary long-term care in the United States faces many challenges beyond the sheer numbers of people who may need assistance during the next few decades. Fundamental philosophical questions continue to focus ongoing debate. For more than 60 years since Mumford (1956) raised the issue in his seminal commentary on age-based residential segregation, there has been debate about the optimal living arrangements for older, frail, or disabled people. Should they be treated separately in segregated environments where their presumed needs can be most effectively addressed (Golant, 1985), or should they remain a part of the community and fully integrated within the stream of community life as is consistent with the 1999 *Olmstead v. L. C.* decision of the Supreme Court and the provisions of the 1990 Americans with Disabilities Act? What are the preferences of persons receiving care? Might they prefer to be among their peers? To what extent should we allow burgeoning long-term care technologies that facilitate monitoring and support from a distance to replace the intimacy of direct human contact? How will we go about funding long-term care programs...
and services in the face of rapidly increasing demand when the current long-term system is challenged to handle even the current level of need?

As we write this chapter, there are more than 20,000 people in Kentucky (where we both worked together for over a decade) who are eligible for services but are not receiving them because these services are not available. To what extent is the growing corporatization of long-term care compatible with the current emphasis on culture change and the humanization of care? With the dominant medical model of care under attack, how long will it remain viable? Does the pathway to the future mandate new models of care? In view of changing perceptions of the nature of care and increasing recognition of the potential for meaning in late life, can current models of care be maintained? Where will the long-term care workforce come from? Will it be able to cope with the projected increase in demand? How will the people providing long-term care be trained and by whom? Where will we find the resources to appropriately reimburse this labor force?

At the most fundamental level, these complex issues are all encapsulated within the question of both individual and societal moral responsibility toward those in our midst who are most vulnerable. On an individual level, at some time in our life, each of us is likely to be challenged to provide or secure support for a relative or friend in need of care. On a societal level, the question becomes one of communal moral responsibility and the values to which we choose to adhere. As Hubert Humphrey eloquently phrased this in 1977 “the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life—the sick, the needy and the handicapped.” The challenge is to come up with the very best system of long-term care, a system that provides appropriate support to those in need along the entire continuum of life. This is a tall order. One way to begin is to develop a deeper understanding of the complexities of contemporary long-term care in all its dimensions. This book is designed as a contribution to this effort. We begin, in Chapter 2, by learning from history and by considering how things came to be as they are today.

**DISCUSSION QUESTIONS**

1. How has the provision of long-term care changed over the past three decades, and how would you explain these changes?
2. Identify and discuss at least three major long-term care issues illustrated by the chapter-framing cases of Grandma Brewster, Anders Swenson, and Mark A. Lincoln.
3. Who needs long-term care and how is this population changing?
4. How is long-term care a continuum? What types of long-term care arrangements are part of the continuum? Is thinking in terms of a continuum the best way to frame discussions of long-term care? What are some alternatives?
5. At the outset of reading this book, and given your present level of understanding, explain your preferences should you need long-term care.
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