

Douglas A. Singh

Effective Management of

# Long-Term Care Facilities

Fourth Edition





# **Effective Management of Long-Term Care Facilities**

FOURTH EDITION



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FOURTH EDITION

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I continue to dedicate this book to all those who serve the noble profession of long-term care as caregivers or leaders in the field and to the educators who are preparing the next generation of these caregivers and leaders.





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# New to This Edition

Every effort has been made to bring this fourth edition up to date with current materials, research findings, regulatory standards, reimbursement systems, and contemporary management practices. Tables and figures have been updated with the latest available data. Numerous exhibits have been added to summarize the main federal regulations—with cross-referenced F-Tags—that govern the delivery of the various services that skilled care nursing facilities must comply with. The theme of person-centered (resident-centered) care is interwoven throughout the text.

Chapter 4 Aging and Long-Term Care is new to this edition. This chapter has been added to consolidate in one place the various perspectives on aging and age-related issues associated with long-term care delivery. Hence, the book has 19 chapters. To keep the reading load within reason, certain nonessentials and materials that did not add value were deleted throughout the book, but without compromising quality.

*Note: All chapter references herein are for this fourth edition.*

Following is a list of the main revisions to aid in transitioning from the third edition:

- **Chapter 1 Overview of Long-Term Care**
  - New section on current mindsets and vocabulary
  - Association between age, gender, multimorbidity, and ADL/IADL limitations
  - Moved to Chapter 4: Aging and HIV/AIDS
- **Chapter 2 Long-Term Care Policy: Past, Present, and Future**
  - Impact of 1915(c) waivers and the Money Follows the Person program
  - Introduction to Medicare's value-based purchasing program. Details are covered in Chapter 7.
  - Introduction to the Quality Assurance Performance Improvement (QAPI) program and the role of quality improvement organizations. Details on QAPI are covered in Chapters 6 and 19.
  - Future implications of financing, program innovations, lifestyles, national wealth, and workforce planning for long-term care policy
- **Chapter 3 The Long-Term Care Profession**
  - Two main components of home health services: clinically oriented care and human services
  - Decline in utilization of Intermediate Care Facilities for Individuals with Intellectual Disabilities
  - New section: Facilitating technology
- **Chapter 4 (New) Aging and Long-Term Care**
  - Health status of racial and ethnic minorities
  - Moved from Chapter 9: Understanding aging; theories of aging; ageism and infantilization; diversity; and cultural accommodations

## **xx New to This Edition**

- Moved from Chapter 10: Mental and cognitive disorders
- Moved from Chapter 1: Aging and HIV/AIDS
- New section: Aging Among the Veterans
- New section: End-of-Life Issues
- New short case: Why Too Few Minorities?
- **Chapter 5 Legal Environment**
  - Exhibit 5-2 (New): Federal regulations and F-Tags pertaining to resident rights
  - Exhibit 5-3 (New): Federal regulations and F-Tags pertaining to abuse, neglect, and exploitation
- **Chapter 6 Regulation and Enforcement**
  - Revised Exhibit 6-1: Requirements of Participation and F-Tags for Nursing Homes (summary of all nursing home regulations)
  - The current survey process, QAPI, quality assessment and assurance (QAA) review, and role of the Certification and Survey Provider Enhanced Reporting System (CASPER)
  - New section: Achieving Continuous Compliance
- **Chapter 7 Financing and Reimbursement**
  - Table 7-1 (New): National Daily Median Costs of Long-Term Care Services, 2019
  - Medicare reimbursement under the Patient Driven Payment Model
  - How facilities have fared under the value-based purchasing program
  - Managed care contracts under Medicare Advantage and Institutional Special Needs Plans (I-SNPs)
  - Current examples of prosecutions under the False Claims Act
- **Chapter 8 Organization, Environment, and Culture Change**
  - Clinical outcomes and cost-effectiveness of homelike models
  - Updates on creating environments for residents with dementia
- **Chapter 9 Social Services, Admission, and Discharge**
  - Moved to Chapter 4: Sections on Knowledge of Aging and the Elderly and Diversity and Cultural Competence
  - New Section: Regulations governing transfers and discharges
  - New Section: Regulations pertaining to grievances
- **Chapter 10 Medical Care, Nursing, and Rehabilitation**
  - Exhibit 10-1 (New): Federal regulations and F-Tags pertaining to physician services
  - Role of nurse practitioners and physician assistants in the delivery of medical care
  - Role of evidence-based practices in medical care
  - Exhibit 10-2 (New): Federal regulations and F-Tags pertaining to nursing services and nurse aide training
  - Exhibit 10-3 (New): Federal regulations and F-Tags pertaining to resident assessment and care planning
  - Exhibit 10-4 (New): Federal regulations and F-Tags pertaining to infection prevention and control
  - New section: The Case of COVID-19
  - New section: Antibiotic Stewardship
  - Moved to Chapter 4: Section on Mental and Cognitive Disorders
  - Exhibit 10-6 (New): Federal regulations and F-Tags pertaining to pharmacy services
  - Calculation of medication error rate

- **Chapter 11 Recreation and Activities**
  - Exhibit 11-1 (New): Federal regulations and F-Tags pertaining to activities
  - Updates on qualifications and certifications of activities professionals
  - New section: Cognitive Stimulation
  - Updates on activities for residents with dementia
- **Chapter 12 Dietary Services**
  - Exhibit 12-1 (New): Federal regulations and F-Tags for dietary services
  - New section: Subcutaneous Infusion
  - Table 12-1 (New): Cost-Benefit Analysis for Decentralized Food Service
- **Chapter 13 Plant and Environmental Services**
  - Relevant F-Tags are referenced
  - Introduction to annual facility assessment (F838)
  - Table 13-1 (New): Minimum Testing and Servicing Requirements for Emergency Systems
  - Table 13-2 (New): Cost-Benefit Analysis for Installing Security Surveillance Equipment
- **Chapter 14 Administrative and Information Systems**
  - Relevant F-Tags are referenced
- **Chapter 15 Effective Governance, Leadership, and Management**
  - Behaviors most characteristic of highly rated leadership in nursing homes
- **Chapter 16 Effective Human Resource Management**
  - Correlations between staffing and survey deficiencies
  - Tables 16-1 and 16-2 (New): Staffing levels recommended by the Centers for Medicare and Medicaid Services
  - The issues of presenteeism versus absenteeism
  - Updates on medical exams and mandatory vaccinations
- **Chapter 17 Effective Marketing Management**
  - Key customers and the implications of Medicare's Hospital Readmissions Reduction Program for nursing home marketing
  - New Section: Assessment and Creation of Value
  - Implications of mass-market approach, regulatory constraints, and Medicaid
  - New section on online channels for promoting the facility
- **Chapter 18 Effective Financial Management**
  - Updated Exhibits 18-4 (Labor Hour Report) and 18-5 (Labor Cost Report)
- **Chapter 19 Effective Quality and Productivity Management**
  - New Section: The QAPI Program
  - Exhibit 19-1 (New): Federal regulations and F-Tags pertaining to quality assurance and improvement



# Preface

This *Fourth Edition* marks 18 years in furnishing comprehensive knowledge to prepare the next generation of long-term care administrators. It also puts into the hands of practicing administrators, corporate officers, and governing board members an in-depth reference source. From its inception, this book has been included in the list of recommended resources to prepare for the national nursing home administrator licensure exam administered by the National Association of Long-Term Care Administrator Boards (NAB). *Note: The American College of Health Care Administrators (ACHCA) no longer offers the certification exam for which this book was also recommended.*

This is the only book on the market that covers in one volume (1) what long-term care is and why it is an integral part of the larger health care delivery system; (2) the legal and regulatory parameters, and payment constraints within which long-term care facilities must be managed; (3) details on each of the main functional departments that administrators must understand and oversee (after all, how can someone effectively manage a nursing facility without having a detailed understanding of what services it provides, how those services are provided, and what regulations govern their delivery?); (4) effective governance and leadership, management of human resources, marketing, financial management, and quality and productivity, much of which is quite unique to nursing home administration and must be learned within that context; and, finally, (5) case studies to simulate situations that the administrator is likely to encounter in actual

practice. Like no other book, it also furnishes easy-to-understand summaries of the federal regulations referenced by their F-Tags.

Within the institutional long-term care continuum, similar skills are employed to effectively manage different types of operations. If a person can learn how to manage a skilled nursing facility, he or she can easily make the transition into managing other, less complex and less challenging, environments such as assisted living facilities or residential facilities.

## Organization of This Book

The book is logically organized into five main parts. Each part covers chapters associated with a major theme. The five major themes begin with an introduction to long-term care; past, current, and future policy; components of the profession; and understanding the dimensions of aging (Part I). The next three chapters progress to an explanation of legal, regulatory, and financing requisites (Part II). The seven chapters in organization and delivery of services come next (Part III); the last five chapters cover governance and leadership, human resource, marketing, finance, and quality improvement (Part IV). The book concludes with case studies (Part V) that call for the application of knowledge and skills learned in previous chapters.

## Tools To Enhance Learning

- What You Will Learn summaries at the beginning of each chapter.
- Figures, tables, and exhibits to illustrate discussions in the text.



- List of terminology (highlighted in the text) at the end of each chapter.
- For Further Thought assignments at the end of each chapter.
- Short cases at the end of most chapters.
- Short lists of internet resources at the end of chapters for further learning.
- A Glossary is furnished as an easy reference to technical terms encountered in the text.

## **For Instructors**

Please contact your Jones & Bartlett Learning account representative to get access to the complete Instructor's Manual, slides in PowerPoint format, Test Bank, and Excel materials.

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# Acknowledgments

Several experts in long-term care either contributed cases written specifically for this book or provided valuable assistance in

developing cases. Where appropriate, their names and affiliations appear with their contributions.

# List of Abbreviations

## A

|       |  |
|-------|--|
| AARP  | Formerly known as the American Association of Retired Persons  |
| ACA   | Affordable Care Act (2010)                                     |
| ACHCA | American College of Health Care Administrators                 |
| ACO   | Accountable care organization                                  |
| ADA   | Americans with Disabilities Act; American Dietetic Association |
| ADEA  | Age Discrimination in Employment Act (1967)                    |
| ADL   | Activities of daily living                                     |
| ADN   | Associate degree in nursing                                    |
| ADON  | Assistant director of nursing                                  |
| AFC   | Adult foster care home   |
| AHCA  | American Health Care Association                               |
| AHIMA | American Health Information Management Association             |
| AIDS  | Acquired immunodeficiency syndrome                             |
| AIT   | Administrator-in-training                                      |
| ALF   | Assisted Living Facility                                       |
| AMDA  | American Medical Directors Association                         |
| ASHA  | American Speech-Language-Hearing Association                   |

## B

|     |                                       |
|-----|---------------------------------------|
| BBA | Balanced Budget Act of 1997           |
| BSN | Bachelor of science degree in nursing |
| BSW | Bachelor's degree in social work      |

## C

|          |   |
|----------|---|
| CASPER   | Certification and Survey Provider Enhanced Reporting System |
| CBO      | Congressional Budget Office                                 |
| CCRC     | Continuing care retirement community                        |
| CDC      | Centers for Disease Control and Prevention                  |
| CDM      | Certified dietary manager                                   |
| CEO      | Chief executive officer                                     |
| CFO      | Chief financial officer                                     |
| CMS      | Centers for Medicare & Medicaid Services                    |
| CNA      | Certified nursing assistant                                 |
| CON      | Certificate of need   |
| COTA     | Certified occupational therapy assistant                    |
| COVID-19 | Coronavirus Disease 2019                                    |
| CQI      | Continuous quality improvement                              |
| CSA      | Controlled Substances Act (1970)                            |
| CTRS     | Certified therapeutic recreation specialist                 |

## D

|      |  |
|------|--|
| DD   | Developmentally disabled                     |
| DHHS | U.S. Department of Health and Human Services |
| DME  | Durable medical equipment                    |
| DNR  | Do-not-resuscitate (order)                   |
| DO   | Doctor of osteopathic medicine               |
| DON  | Director of nursing                          |
| DPT  | Doctor of physical therapy                   |
| DRI  | Dietary Reference Intake                     |
| DTR  | Dietetic Technician, Registered              |

**E**

|      |   |
|------|---|
| EEOC | Equal Employment Opportunity Commission |
| EHR  | Electronic health record                |
| EPA  | U.S. Environmental Protection Agency    |

**F**

|      |                                     |
|------|-------------------------------------|
| FCA  | False Claims Act (1863)             |
| FDA  | U.S. Food and Drug Administration   |
| FICA | Federal Insurance Contributions Act |
| FIFO | First-in first-out                  |
| FLSA | Fair Labor Standards Act            |
| FMLA | Family and Medical Leave Act (1993) |
| FUTA | Federal Unemployment Tax Act        |

**G**

|      |  |
|------|--|
| GAAP | Generally accepted accounting principles |
| GPO  | Group purchasing organization            |

**H**

|       |  |
|-------|--|
| HCBS  | Home and Community Based Services                          |
| HHA   | Home health agency   |
| HI    | Hospital Insurance (Part A of Medicare)                    |
| HIPAA | Health Insurance Portability and Accountability Act (1996) |
| HIV   | Human immunodeficiency virus                               |
| HMO   | Health maintenance organization                            |
| HUD   | U.S. Department of Housing and Urban Development           |

**I**

|         |   |
|---------|---|
| IADL    | Instrumental activities of daily living                                   |
| ICF/IID | Intermediate care facility for individuals with intellectual disabilities |
| ID      | Intellectual disability   |
| IDD     | Intellectually/developmentally disabled                                   |

|     |                                   |
|-----|-----------------------------------|
| IOM | Institute of Medicine             |
| IPC | Infection prevention and control  |
| IRF | Inpatient rehabilitation facility |
| IRS | Internal Revenue Service          |
| IS  | Information systems               |
| IT  | Information technology            |

**L**

|      |                           |
|------|---------------------------|
| LAN  | Local area network        |
| LPN  | Licensed practical nurse  |
| LSC  | <i>Life Safety Code</i> ® |
| LTC  | Long-term care            |
| LTCH | Long-term care hospital   |
| LVN  | Licensed vocational nurse |

**M**

|      |  |
|------|--|
| MA   | Medicare Advantage                                 |
| MBO  | Management by objectives                           |
| MCO  | Managed care organization                          |
| MD   | Doctor of medicine                                 |
| MDS  | Minimum data set                                   |
| MFP  | Money Follows the Person (Program)                 |
| MRSA | Methicillin-resistant <i>Staphylococcus aureus</i> |
| MSBT | Multisensory behavior therapy                      |
| MSE  | Multisensory environment                           |
| MSS  | Multisensory stimulation                           |
| MSW  | Master's degree in social work                     |

**N**

|       |  |
|-------|--|
| NAB   | National Association of Long-Term Care Administrator Boards      |
| NBCOT | National Board for Certification in Occupational Therapy         |
| NCCAP | National Certification Council for Activity Professionals        |
| NCTRC | National Council for Therapeutic Recreation Certification        |
| NF    | Nursing facility (referring to a federal certification category) |
| NFPA  | National Fire Protection Association                             |
| NHA   | Nursing home administrator                                       |

NLRA National Labor Relations Act (1935)  
 NLRB National Labor Relations Board  
 NP Nurse practitioner  
 NPP Nonphysician practitioner  
 NTA Nontherapy ancillaries

## O

OAA Old Age Assistance  
 OBRA-87 Omnibus Budget Reconciliation Act of 1987  
 OSHA Occupational Safety and Health Administration  
 OT Occupational therapist or occupational therapy  
 OTR Occupational Therapist, Registered

## P

P&L Profit and loss statement (Income statement)  
 PA Physician assistant  
 PACE Program of All-Inclusive Care for the Elderly  
 PASRR Preadmission Screening and Resident Review  
 PDSA Plan, do, study, act (cycle)  
 PHI Personal health information  
 PM Preventive maintenance  
 POA Power of attorney  
 POC Plan of correction  
 PPD Per patient day  
 PPE personal protective equipment  
 PPS Prospective payment system  
 PRD Per resident day  
 PT Physical therapist or physical therapy  
 PTA Physical therapy assistant

## Q

QAA Quality assurance and assessment  
 QAPI Quality assurance/performance improvement

QIS Quality Indicator Survey  
 QoL Quality of life

## R

RAI Resident Assessment Instrument  
 RC/AL Residential care/assisted living (administrator's license)  
 RD Registered dietitian  
 RHIA Registered health information administrator  
 RHIT Registered health information technician  
 RN Registered nurse

## S

SARS-CoV-2 Severe Acute Respiratory Syndrome Coronavirus 2  
 SLP Speech/language pathologist  
 SMI Supplementary Medical Insurance (Part B of Medicare)  
 SMWT Self-managed work team  
 SNF Skilled nursing facility (referring to a federal certification category)  
 SPs Standard precautions  
 SSI Supplemental Security Income

## T

TB Tuberculosis  
 TCU Transitional care unit  
 TPN Total parenteral nutrition

## U

USDA U.S. Department of Agriculture

## V

VHA Veterans Health Administration  
 VRE Vancomycin-resistant *enterococci*



# About the Author

Dr. Douglas Singh retired from teaching graduate and undergraduate courses in health care delivery, policy, finance, and management in the School of Business and Economics and in the Department of Political Science at Indiana University–South Bend. He has authored/coauthored five books and has been published in several peer-reviewed journals.

He spent more than 15 years as a licensed long-term care administrator in four

states. He also held the positions of regional manager, vice president, and consultant and supervised both skilled nursing care and independent living operations. His doctoral work at the School of Public Health, University of South Carolina, broke new ground in understanding nursing home performance on certification surveys, for which he was awarded the Long-Term Care Research award in 1995 by the Foundation of the American College of Health Care Administrators.

## PART I

# Introduction to Long-Term Care

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As a major component of the health care delivery system, long-term care (LTC) has received much attention in both developed and developing countries. LTC is closely associated with disabilities emanating from chronic conditions that are mostly related to human aging. Developed countries have seen a steep rise in chronic conditions, and the trend will continue. Thanks to better sanitation, nutrition, and medical care, longevity is also increasing in developing countries. A rise in chronic conditions and functional limitations is an unfortunate adjunct of longevity. Moreover, the social environment in developing countries is changing. Both men and women have been drawn into the workforce to improve their standards

of living, which leaves little time to address the needs of elderly parents and relatives. Hence, demand for LTC services is growing in the developing world as well.

A broad understanding of LTC as a distinct segment of the health care delivery system, LTC clients and services, policy perspectives, and industry perspectives lay the foundation for managing any LTC organization. The four chapters in this section address these areas:

- Chapter 1 explains what LTC is, why it is needed, what type of health care and social services constitute LTC, who needs LTC, and how LTC should interface with the broader health care system.

## **2**      **Part I** Introduction to Long-Term Care

- Chapter 2 focuses on policy as the driving force behind the evolution of LTC services. Financing, quality, and access to community-based services have shaped some of the recent developments. The future remains challenging and requires a number of policy initiatives to address lingering issues.
- Chapter 3 furnishes details of the LTC industry, which is necessary for the efficient delivery of services. The chapter covers community-based and institutional providers, insurers, LTC professionals, case management agencies, LTC pharmacies, and various categories of LTC technology.
- Chapter 4 addresses aging and the theories that undergird the delivery of person-centered care. The issues associated with stereotyping, cognitive function, and HIV/AIDS are discussed. The chapter addresses diversity and cultural accommodation. It concludes with the handling of death and dying.





## CHAPTER 1

# Overview of Long-Term Care

### WHAT YOU WILL LEARN

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- Appropriate vocabulary is used to complement changing mindsets in the delivery of long-term care.
- Physical and/or mental deficits that limit a person's ability to do regular daily tasks create the need for long-term care. Continuity of care after hospitalization may also suggest a need for long-term care.
- Long-term care is complex. It is founded on 10 main dimensions that can also be viewed as fundamental principles that should guide the delivery of long-term care.
- Not all seniors need long-term care. However, chronic ailments, comorbidity, disability, and dependency are progressive steps indicating the need for long-term care.
- The three broad sectors through which long-term care is delivered are informal care, home- and community-based care, and institutional care.
- Non-long-term care services must complement long-term care to meet a person's total care needs.

### Introduction

---

Long-term care (LTC) is associated with physical and/or mental deficits that limit a person's ability to do regular daily tasks that most humans take for granted. There can be numerous causes for functional limitations. Examples include complications arising from prolonged heart disease, onset of partial or full paralysis after a severe stroke, severe head injury from a motorcycle or industrial

accident, loss of physical capacity by a young adult from a crippling disease such as multiple sclerosis, a child born with severe autism, or gradual loss of memory in an aged person. LTC services are needed mostly by senior citizens, generally referred to as the elderly in health care literature—people older than 65 years—hence, most LTC services have been designed with seniors in mind.

LTC is a broad and complex system. Diverse LTC services—sometimes referred to as long-term services and supports (LTSS)—

are provided in a variety of community-based settings. Also, family members and surrogates provide most of the care that is unseen to outsiders and generally unpaid. Nursing homes and other LTC institutions play a critical role in delivering advanced levels of LTC services that cannot be provided effectively and efficiently in community or home settings. Moving to a nursing home often results from various losses, multiple and complex illnesses, impaired functioning, fewer social relationships, and a poorer quality of life than the general elderly population (Rinnan et al., 2018). In 2016, 65,600 LTC providers served approximately 8.3 million people in the United States (Harris-Kojetin et al., 2019). Americans receive LTC from a variety of formal sources, such as adult day care centers, home health agencies, hospices, nursing homes, and residential care communities.

## Mindsets and Vocabulary

---

In a general sense, those who receive medical services are referred to as “patients” in hospitals, doctors’, dentists’, and optometrists’ offices, and other medically oriented settings. LTC institutions, however, over the years have made an effort to limit the use of vocabulary prevalent in the medical model of health care delivery. The emphasis has shifted to a home/residential model of care delivery. No longer are the elderly referred to as “older folks.” Even the term “elders” has been suggested to replace the term “elderly.” In general use, “seniors” or “senior citizens” is also common. The patients residing in LTC institutions are referred to as “residents.” This change marked a distinction between emerging nursing homes and earlier poorhouses and mental asylums in which people were

commonly referred to as “inmates,” a term that was viewed as dehumanizing.

Improvements in vocabulary are being introduced with the intent of changing both administrative and caregiver mindsets that would be reflected in treating people receiving care in LTC institutions with compassion, respect, and dignity. The change in vocabulary is also viewed as a component of a broad movement called “culture change,” which emphasizes living and thriving in an environment in which each person is made to feel as a useful human being, who may still, in many cases, be able to make meaningful contributions to help others. **Person-centered care** delivery emphasizes the centrality of the recipient of care, whereas previously, economic efficiencies of the organization were given a higher priority. Delivery of health care services work around a person’s values and preferences. “Person-centered” appropriately applies to all venues of LTC care delivery; in institutional settings, use of the term “resident-centered” is also in use. Although the terms “institution” and “facility” are difficult to avoid in broad discussions, philosophically, the institution must be viewed as a person’s home. Hence, efforts are made to create a home-like, as opposed to the sterile, institutional environment of yesteryears. The leaders and managers in LTC have a responsibility to ensure that these guiding principles permeate the entire living and caregiving environment.

Regardless of the setting, whether it is institutional or community-based, use of the term “senile” is anathema; such individuals are referred to as “people with dementia.” **Dementia** is a general term for progressive and irreversible decline in cognition, thinking, and memory emanating from brain cells that have become damaged or destroyed. Also, the term “mental retardation” has been replaced with “intellectual disability” (ID).

## Why the Need for Long-Term Care

---

Broadly speaking, LTC services are needed under three main circumstances:

1. **Need for assistance in doing tasks of daily living.** Functional limitations arise because of physical and/or mental disability or severe illness. Both physical disability and cognitive impairment can trigger the need for LTC. **Cognitive impairment** is a mental disorder that is indicated by a person having difficulty remembering, learning new things, concentrating, or making decisions that affect the individual's everyday life. Even mild cognitive impairment is associated with greater physical decline compared to older people considered cognitively normal (Taylor et al., 2019). The severity of a person's dependency—ranging from partial to total—created by functional limitations determines whether low-level informal care or community-based services can meet the person's needs or whether high-level institutional services are necessary.

Two standard measures are available to assess a person's level of dependency. The first, the **activities of daily living (ADL)** scale, is used to determine whether an individual needs assistance in performing six basic activities: eating, bathing, dressing, using the toilet, maintaining continence, and transferring into or out of a bed or chair. Grooming and walking a distance of eight feet are sometimes added to evaluate self-care and mobility. Limitations in lower level ADLs, such as bathing, dressing, grooming, and walking without assistance generally do not require a person to be in an institution. Limitations in higher level ADLs, such as

eating, toileting, maintaining continence, and transferring, generally indicate the need for assistance in an LTC facility. Limitations in ADLs are about the same among users of home health services and nursing homes, except that nursing home residents have a greater need for assistance with toileting (Harris-Kojetin et al., 2019).

The second commonly used measure is called **instrumental activities of daily living (IADL)**. This measure focuses on activities that support everyday functioning within the home and community and are necessary for independent living. These activities generally entail more complex interactions than those used in ADLs (American Occupational Therapy Association, 2017). Examples of IADLs include doing housework, cooking, doing laundry, grocery shopping, taking medication, using the telephone, and managing money (Gontijo et al., 2020). Deficits in IADLs can generally enable a person to live independently with some support and assistance. The IADL measure is also helpful when a nursing home resident is being discharged for community-based LTC or independent living. It helps in assessing how well the individual is likely to adapt to living independently and what type of support services may be most appropriate to ensure that the person can live independently.

2. **Need for continuity of care after hospitalization.** As an example, people recovering from accidents or orthopedic surgery, such as hip and knee replacements, require postacute rehabilitation. Other individuals, who are still subject to complications while in recovery, may require what is called **subacute care**, which also includes clinically complex care, such as wound care, tube feedings, or intravenous therapy.

3. **Need for care in specialized environments.** People with severe dementia need a supportive environment that is designed to reduce stress and provide a moderate amount of stimulation to the senses. Many children and adolescents need care in specialized pediatric environments because of physical and/or mental disabilities. Many children suffer from birth-related disorders that include cerebral palsy, severe autism, spina bifida, and epilepsy. The term **developmental disability** describes the general physical incapacity such children may face at a very early age. Those who acquire such dysfunctions are referred to as developmentally disabled, or DD. **Intellectual disability (ID)**, refers to below-average intellectual functioning, which also leads to DD in most cases. Down syndrome is the most common cause of ID in America. The close association between DD and ID is reflected in the term intellectually/developmentally disabled (IDD). Those with severe ID and/or DD are also likely to have disturbing behavioral issues and usually require institutional care in specialized facilities that provide special programming and services for children. For example, these facilities may have services and training for children to help them cope with musculoskeletal deformities by using customized braces, splints, and wheelchairs.

## Dimensions and Principles of Long-Term Care

---

No simple definition fully captures the nature of LTC. This is because a broad range of clients and services are involved. Yet, certain

dimensions form a common core of what LTC is. Besides furnishing a definition, the explanations covered in this section provide fundamental principles that must undergird the delivery of LTC.

**Long-term care** can be defined as a variety of individualized and well-coordinated total care services that promote the maximum possible independence for people with functional limitations and that are provided over an extended period of time, using appropriate current technology and available evidence-based protocols, in accordance with a holistic approach while maximizing both the quality of clinical care and the individual's quality of life. This comprehensive definition emphasizes 10 essential dimensions that should govern an ideal LTC system.

## Variety of Services

LTC encompasses a variety of services for three main reasons: (1) to fit the needs of different individuals, (2) to address changing needs over time, and (3) to suit people's personal preferences. Needs vary greatly from one individual to another. Even the elders, who are the predominant users of LTC services, are not a homogeneous group. For example, some people just require supportive housing, whereas others require intensive treatments. The type of services an individual requires is determined by the nature and degree of his or her functional disability and the presence of any other medical conditions and emotional needs that the individual may have.

Even for the same individual, the need for the various types of services can change over time. The change is not necessarily progressive, from lighter to more intensive levels of care. An individual may shift back and forth among the various levels and types of LTC services. For example, after hip surgery, a person may require extensive rehabilitation

therapy in a nursing facility for 2 or 3 weeks before returning home, where he or she receives continuing care from a home health care agency. After that, the individual may continue to live independently but require a daily meal from Meals on Wheels, a home-delivered meals service. Later, this same person may suffer a stroke and, after hospitalization, may have to stay indefinitely in a LTC facility. Hospice care may become necessary at the end of a person's life.

LTC services are an amalgam of five distinct types of services that are integrated into one total package of care:

- Medical care, nursing, and rehabilitation
- Mental health services and dementia care
- Social support
- Supportive housing
- Hospice services

### **Medical Care, Nursing, and Rehabilitation**

These services focus on three main areas:

1. Continuity of care after hospitalization. Post-acute LTC often consists of **skilled nursing care**, which is physician-directed care provided by licensed nurses and therapists.
2. Clinical management of chronic conditions and comorbidity. **Chronic conditions**—such as heart disease, cancer, chronic lower respiratory diseases, stroke, and diabetes—persist over time and are generally irreversible but must be kept under control to prevent health complications. **Comorbidity**, that is, coexisting multiple health problems, often becomes the leading cause of an individual's disability and erode that person's ability to live without assistance. Without LTC intervention in this situation, the risk of further morbidity and mortality greatly increases. Preventing complications from

chronic conditions—**tertiary prevention**—is an important aspect of LTC.

3. Restoration or maintenance of physical function. Rehabilitation involves short-term therapy treatments to help a person regain or improve physical function. Examples of cases requiring rehabilitation include orthopedic surgery, stroke, limb amputation, and prolonged illness.

### **Mental Health Services and Dementia Care**

Mental illnesses are conditions that affect a person's thinking, feeling, mood, or behavior, such as depression, anxiety, bipolar disorder, or schizophrenia. Such conditions may be occasional or long lasting (chronic). Depressive symptoms, comorbidity, and cognitive impairment often coexist and affect functional status (Marengoni et al., 2004). Mental health services are generally delivered by specialized providers in both outpatient and inpatient facilities. LTC staff, however, must be trained to recognize the need for mental health care among the residents.

In the United States, among those age 65 years and over, an estimated 5 million adults had dementia in 2014, and the number is projected to be nearly 14 million by 2060 (Centers for Disease Control and Prevention, 2019). With the growing prevalence of dementia in the United States and around the world, care for persons with dementia has become a major focus in LTC. Almost all people with dementia will develop at least one behavioral or psychological symptom over a 5-year period, which includes agitation, aggression, depression, etc. These symptoms generally predict the need for nursing home placement (Wang et al., 2020). Consequently, among the various LTC services providers, dementias are most prevalent among nursing home residents (48% in 2016) (Harris-Kojetin et al., 2019).

The most common form of dementia is **Alzheimer's disease**—a progressive degenerative disease of the brain, producing memory loss, confusion, irritability, and severe functional decline. Alzheimer's disease is also the sixth leading cause of death in the United States, often matching and surpassing many forms of cancers (Alzheimer's Association, 2019).

## **Social Support**

**Social support** refers to a variety of assistive and counseling services to help people cope with situations that may cause stress, conflict, grief, or other emotional imbalances. The goal is to help people make adjustments to changing life events.

Various stressors commonly accompany the aging process itself and create such adverse effects as frailty, pain, increased medical needs, and the inability to do common things for oneself, such as obtaining needed information or running errands. Other stressors are event driven. Events that force an unexpected change in a person's lifestyle or emotional balance—such as moving to an institution or loss of a loved one—require coping with stress or grief. Even the thought of change brings on anxiety. Many people go through a period of “grieving” when coming to terms with change. Grieving may manifest in reactions such as anger, denial, confusion, fear, despondency, and depression. Social support is needed to help buffer these undesirable emotions that may trigger latent mental illness or become manifested in aggressive behavior.

Social support is also needed when problems and issues arise in the interactions among people within social systems. For example, conflicts may arise between what a person wants for himself or herself and what the family may think is best. Conflicts can also arise between residents and caregivers or between two residents.

The level of social support depends on the severity of adverse events a person may go through (Fernandez-Alcantara et al., 2016). Social support includes both concrete and emotional assistance provided by families, friends, neighbors, volunteers, staff members within an institution, organizations such as religious establishments, and professional agencies. For people residing in LTC facilities, remaining connected with the community and the outside world is also an important aspect of social support.

## **Supportive Housing**

**Supportive housing** is a key component of LTC because certain functional and safety features must be incorporated to compensate for people's disabilities in order to promote independence. Some simple examples include access ramps that enable people to go outdoors, wide doorways and corridors that allow adequate room to navigate wheelchairs, railings in hallways to promote independent mobility, extra-large bathrooms that facilitate wheelchair negotiation, grab bars in bathrooms to prevent falls and promote unassisted toileting, raised toilets to make it easier to sit down and get up, and pull-cords in the living quarters to summon help in case of an emergency.

Congregate housing—multiunit housing with support services—is an option for seniors and disabled adults. **Support services** are basic assistive services, which may include meals, transportation, housekeeping, building security, social activities, and outings. However, not all housing arrangements provide all of these services.

## **Hospice Services**

Hospice services, also called **end-of-life care**, are regarded as a component of LTC. **Hospice** incorporates a cluster of special services for



terminally ill persons with a life expectancy of 6 months or less. It blends medical, spiritual, legal, financial, and family counseling services. However, the emphasis is on comfort, palliative care, and social support over medical treatment. **Palliation** refers to medical care that is focused on relieving unpleasant symptoms such as pain, discomfort, and nausea.

The hospice philosophy also includes the family as part of the unit of care with the resident. The option to use hospice means that temporary measures to prolong life will be suspended. The emphasis is on maintaining the quality of life and letting the person die with dignity. Psychological services focus on relieving mental anguish. Social and legal services help with arranging final affairs. Counseling and spiritual support are provided to help the individual deal with his or her death. After the individual's death, bereavement counseling is offered to the family or surrogates.

Hospice services are generally brought to the individual, although the option of residing in a freestanding hospice center may also be available. Hospice care can be directed from a hospital, home health agency, nursing home, or freestanding hospice.

## Individualized Services

LTC services are tailored to the needs of the individual. Those needs are determined by an assessment of the individual's current physical, mental, and emotional condition.

The philosophy of **resident-centered care** (or person-centered care) is founded on the principles of inclusivity, empowerment, and respect for each individual and his or her right to self-determination (Matthews et al., 2018). The resident's choices and preferences are incorporated into care decisions (Janowski, 2019). An individualized plan of care (or care plan, for short) is then developed to include customized interventions to

address the resident's needs in a comprehensive manner.

Past history of the individual's medical and psychosocial conditions; a social history of family relationships, former occupation, community involvement, and leisure activities; and cultural factors such as racial or ethnic background, language, and religion can all be incorporated to individualize the plan of care. The flow of individualization and delivery of care is illustrated in **Figure 1-1**.

## Well-Coordinated Total Care

LTC providers are responsible for managing the total health care needs of each resident. **Total care** means that any health care need is recognized, evaluated, and addressed by appropriate clinical professionals. Coordination of care with various medical providers such as the attending physicians, dentists, optometrists, podiatrists, dermatologists, or audiologists is often necessary



**Figure 1-1** Individualization and delivery of care

for prevention as well as the onset of health issues. Hence, LTC must interface with non-LTC services to address a person's total care needs.

## Promotion of Functional Independence

The goal of LTC is to enable the individual to maintain functional independence to the maximum level practicable. Restoration of function may be possible to some extent through appropriate rehabilitation therapy, but in most cases, a full restoration of normal function is an unrealistic expectation. The individual may have to be taught to use adaptive equipment, such as wheelchairs, walkers, special eating utensils, or portable oxygen devices. Ongoing maintenance therapy—such as assisted walking, range of motion exercises, bowel and bladder training, and cognitive reality orientation—is necessary to prevent progressive decline, although, over time, some loss of function is to be expected. Caregivers must motivate the person to do as much as possible for him- or herself to prevent further decline. Caregivers then “fill in” for all functions that can no longer be carried out independently. A comatose person who is totally confined to bed, for instance, presents an extreme case in which full assistance from caregivers becomes necessary.

## Extended Period of Care

Compared to acute care services that generally last only for a few days, the delivery of LTC extends over a relatively long period. Certain types of LTC services—such as rehabilitation therapies, postacute convalescence, or stabilization—may be needed

for a relatively short duration, generally less than 90 days. In other instances, because of severe health and disablement issues, LTC may be needed for years, perhaps indefinitely. It is estimated that 69% of LTC users will use some type of LTC for a period of 3 years (Arias, 2019). Examples include people with severe dementia, incontinence of bowel and bladder, severe psychiatric or behavioral issues, unstable postacute conditions, or those in a comatose/vegetative state. In nursing homes, in 2016, 43% of the residents were short stay, and 57% were long stay (Harris-Kojetin et al., 2019). People receiving community-based LTC services generally need them for a long duration to prevent institutionalization.

## Use of Current Technology

LTC providers must keep pace with and adopt new technology when it would facilitate care delivery, improve safety and quality, and promote operational efficiencies. Technologies that promote self-care and independence can enable people to stay in the community.

## Use of Evidence-Based Protocols

**Evidence-based care** relies on the use of best practices that have been established through clinical research. Clinical processes that have been proven to deliver improved therapies have been standardized into **clinical practice guidelines**. These guidelines become evidence-based protocols that are indicated for the treatment of specific health conditions or clinical circumstances. Numerous guidelines have been developed for use in nursing homes, which may also be adapted



for use in other LTC settings such as home health and assisted living.

## Holistic Approach

The **holistic approach** to health care delivery focuses on every aspect of what makes a person whole and complete. In this approach, a person's physical, mental, social, and spiritual needs and preferences are incorporated into medical care delivery and all aspects of daily living.

By its very nature, effective LTC is holistic. The following are brief descriptions of the four main aspects of holistic caregiving:

1. *Physical.* This refers to the technical aspects of care, such as medical examinations, nursing care, medications, diet, rehabilitation treatments, etc. It also includes comfort factors such as appropriate temperature, cozy furnishings, cleanliness, and safety in both home and institutional environments.
2. *Mental.* The emphasis is on the total mental and emotional well-being of an individual. Environmental and social support that reduce stress and anxiety can be instrumental in promoting mental and emotional well-being.
3. *Social.* Almost everyone enjoys warm friendships and social relationships. Visits from family, friends, or volunteers provide numerous opportunities for socializing. The social aspects of health care include companionship, information, counseling, and recreation.
4. *Spiritual.* The spiritual dimension includes personal beliefs, values, and commitments in a religious and faith context. Spirituality and spiritual pursuits are very personal matters, but for most people, they also require continuing interaction with other members of the faith community.

## Maximizing Quality of Care

Because of the multifaceted nature of LTC, quality of care can be achieved only with a multidisciplinary approach to caregiving. **Quality of care** is maximized when desirable clinical- and person-related outcomes have been achieved. Maximization of quality is an ongoing pursuit. Even though it is never fully achieved, the goal is to instill a culture of continuous improvement by focusing on the other nine dimensions of LTC discussed in this section. To improve quality, regulatory standards as well as evidence-based protocols must be implemented. Quality must be evaluated or measured to discover areas needing improvement, and processes should be changed as necessary. This becomes an ongoing effort.

## Maximizing Quality of Life

**Quality of life** refers to the total living experience, which results in overall satisfaction with one's life. Quality of life is related to cognitive functioning (Zimmermann et al., 2015); it also affects the behavioral and psychological symptoms associated with dementia among elderly individuals in LTC facilities (Suzuki et al., 2017). Quality of life is a multifaceted concept that recognizes at least five factors: lifestyle pursuits, living environment, clinical palliation, human factors, and personal choices. Hence, quality of life is enhanced by integrating these five factors into the delivery of care.

1. Lifestyle factors are associated with personal enrichment and making one's life meaningful through activities one enjoys. For example, many residents in institutional settings may still enjoy pursuing

their former leisure activities, such as woodworking, crocheting, knitting, gardening, etc. Many residents would like to engage in spiritual pursuits or spend some time alone. Even those whose functioning has decreased to a vegetative or comatose state can be creatively engaged in something that promotes sensory awakening through visual, auditory, and tactile stimulation.

2. The living environment should be one in which the person feels the most at home.
3. Palliation should be available for relief from unpleasant symptoms such as pain or nausea.
4. Human factors refer to caregiver attitudes and practices that emphasize caring, compassion, respect, and human dignity in the delivery of care. Residents in institutions generally find it disconcerting to have lost their autonomy and independence. Quality of life is enhanced when residents can govern their own lives and are given appropriate privacy.
5. LTC institutions should make every effort to accommodate the residents' personal choices. For example, food is often the primary area of discontentment, which can be addressed by offering a selective menu. Many elders resent being awakened early in the morning when nursing home staff begin their responsibilities to care for residents'

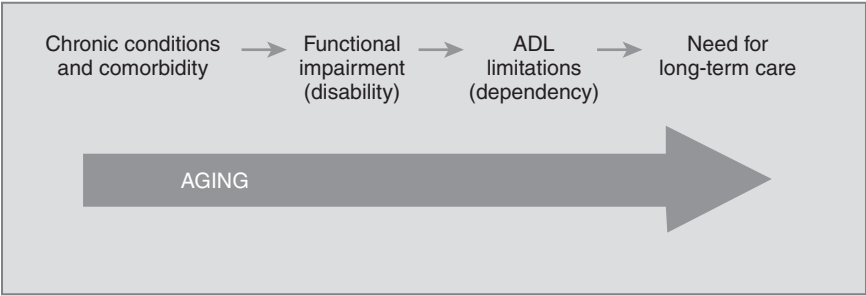
hygiene, bathing, and grooming. Flexible schedules should be implemented to accommodate personal preferences.

## Seniors and Long-Term Care

Many older adults are in relatively good health. Nevertheless, as a person ages, chronic ailments, comorbidity or multimorbidity, disability, and dependency tend to follow each other. This progression is associated with increased probability that a person would need LTC (**Figure 1-2**).

The number of functional limitations in ADLs and IADLs rises with both age and multimorbidity (two or more health problems), as illustrated in **Table 1-1** and **Figure 1-3**. Secondly, given the number of chronic conditions, ADL/IADL limitations increase faster among women than among men. Hence, the users of LTC services are overwhelmingly women (Harris-Kojetin et al., 2019).

**Aging in place** is an old concept that refers to an individual's preference and ability to live in one's own home or familiar surroundings where the person's changing needs over time are accommodated. Hence, home- and community-based services (HCBS) are preferred by most seniors, and these services have grown more rapidly than



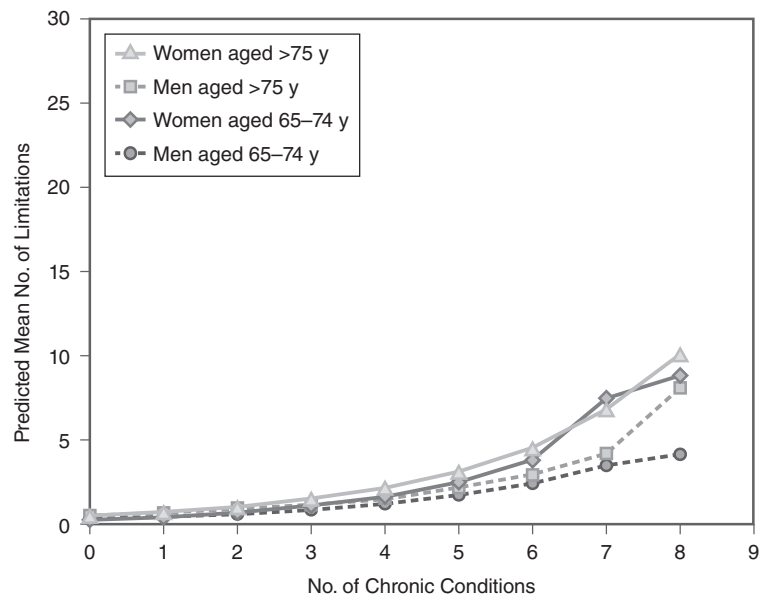
**Figure 1-2** Progressive steps toward the need for long-term care among seniors

**Table 1-1 Association Between Age, Gender, Multimorbidity, and ADL/IADL Limitations**

| No. of Chronic Conditions | Mean Number of ADL and IADL Limitations |       |         |       |
|---------------------------|---|-------|---------|-------|
|                           | Age 65–74                               |       | Age ≥75 |       |
|                           | Men                                     | Women | Men     | Women |
| 0                         | 0.3                                     | 0.3   | 0.5     | 0.5   |
| 1                         | 0.4                                     | 0.4   | 0.7     | 0.7   |
| 2                         | 0.6                                     | 0.7   | 0.9     | 1.0   |
| 3                         | 0.9                                     | 1.1   | 1.2     | 1.5   |
| 4                         | 1.2                                     | 1.6   | 1.6     | 2.2   |
| 5                         | 1.7                                     | 2.5   | 2.2     | 3.1   |
| 6                         | 2.4                                     | 3.8   | 2.9     | 4.6   |
| 7                         | 3.5                                     | 7.5   | 4.2     | 6.8   |
| 8                         | 4.2                                     | 8.8   | 8.1     | 10.1  |

Note: ADL/IADL figures have been rounded.

Data from Jindai, K., Nielson, C. M., Vorderstrasse, B. A., & Quiñones, A. R. (2016). *Multimorbidity and functional limitations among adults 65 or older, NHANES 2005–2012*. Atlanta, GA: Centers for Medicare and Medicaid Services. Retrieved from [https://www.cdc.gov/pcd/issues/2016/16\\_0174.htm#:~:text=Disease%2C%20functional%20limitation%2C%20and%20disability%20should%20not%20be,develop%20interventions%20for%20high-risk%20adults%2065%20or%20older.](https://www.cdc.gov/pcd/issues/2016/16_0174.htm#:~:text=Disease%2C%20functional%20limitation%2C%20and%20disability%20should%20not%20be,develop%20interventions%20for%20high-risk%20adults%2065%20or%20older.)



**Figure 1-3** Predicted mean number of ADL/IADL limitations by the number of chronic conditions, stratified by gender and age group

Data from Jindai, K., Nielson, C. M., Vorderstrasse, B. A., & Quiñones, A. R. (2016). *Multimorbidity and functional limitations among adults 65 or older, NHANES 2005–2012*. Atlanta, GA: Centers for Medicare and Medicaid Services. Retrieved from [https://www.cdc.gov/pcd/issues/2016/16\\_0174.htm#:~:text=Disease%2C%20functional%20limitation%2C%20and%20disability%20should%20not%20be,develop%20interventions%20for%20high-risk%20adults%2065%20or%20older.](https://www.cdc.gov/pcd/issues/2016/16_0174.htm#:~:text=Disease%2C%20functional%20limitation%2C%20and%20disability%20should%20not%20be,develop%20interventions%20for%20high-risk%20adults%2065%20or%20older.)

LTC institutions. Severe declines in health, however, necessitate institutional services, particularly for people who need care and monitoring around the clock. Also, short-term institutional services are needed for convalescence and rehabilitation.

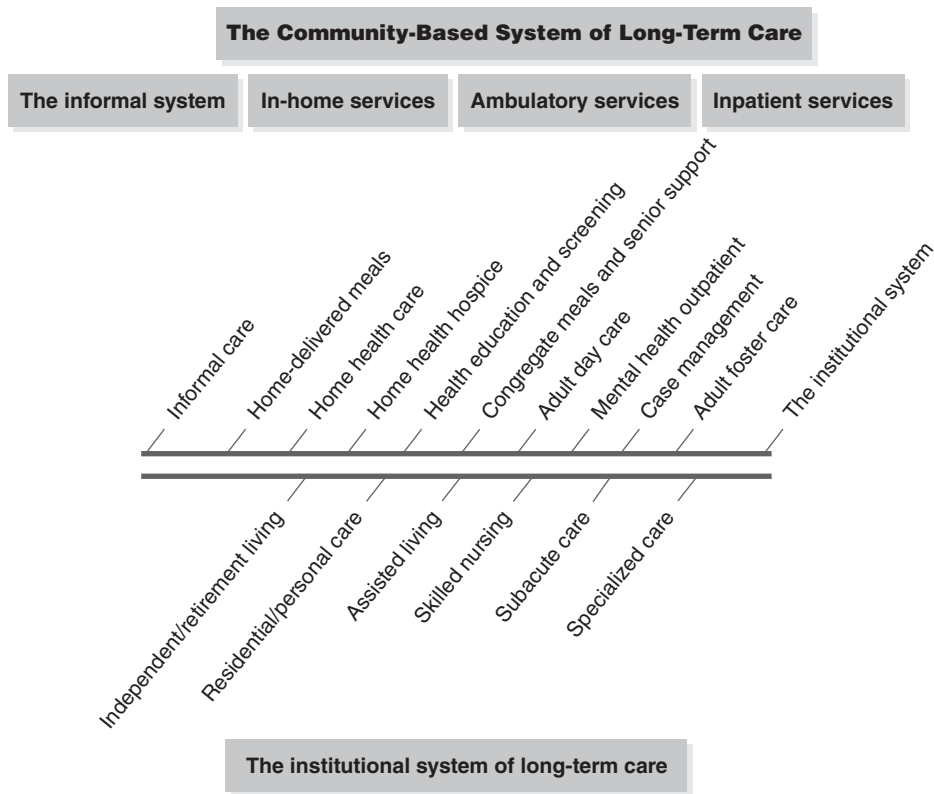
# The Continuum of Long-Term Care

**Continuum of long-term care** refers to the full range of LTC services that increase in the level of acuity and complexity from one end to the other—from informal and community-based services at one end of the continuum to the institutional system at the other end.

Hence, the LTC continuum has three major segments: informal care, HCBS, and the institutional system.

Although institutional management is the focus of this text, the other two segments, informal care and HCBS, also have important implications for administrators who manage LTC institutions. From an institutional perspective, the other two segments are viewed as competition.

The three subsystems that form the LTC continuum are illustrated in **Figure 1-4**. Different levels of institutional settings also form their own institutional continuum. Apart from personal needs, client preferences, availability of community-based care, and ability to pay for services all play a role in determining which services are used.



**Figure 1-4** The continuum of long-term care

## Informal Care

Most LTC services in the United States are provided informally, without formal payment, by family, friends, and surrogates, such as neighbors and members from church or other community organizations. Informal care is also the predominant form of LTC in other industrialized countries (Kolodziej et al., 2018). For the most part, services rendered are of a basic nature, such as general supervision and monitoring, running errands, helping with medications, cooking meals, and, to a lesser extent, assistance with bathing, eating, grooming, and dressing. However, in some cases, informal caregivers must perform complex tasks for which they receive little preparation, hands-on training, or meaningful support (Reinhard et al., 2019).

It is estimated that 41 million family caregivers in the United States provided an estimated 34 billion hours of care to adults with limitations in daily activities. The estimated economic value of their unpaid contributions was approximately \$470 billion in 2017 (Reinhard et al., 2019), which exceeds the \$409 billion spent in 2018 from all formal paid sources combined (Colello, 2020).

The extent of informal care that an individual receives depends highly on the extent of the support network the individual has. People who can depend on a network of family and others can often continue to live independently much longer than those who have little or no social support.

The caregiving burden can vary. For some people, caregiving can instill confidence, provide meaning and purpose, enhance skills, and bring the caregiver closer to the older adult. For others, caregiving takes a significant toll in terms of emotional distress, depression, anxiety, or social isolation. Some caregivers also report being in poor physical

health themselves (National Academies of Sciences, Engineering, and Medicine, 2016).

The pool of informal caregivers, in relation to the growing senior population needing LTC, is expected to shrink rather dramatically in the future. Various reports suggest that the number of seniors who are divorced, unmarried, or without children has been on the rise. This trend portends that formal services will have to pick up the slack, but at a significant cost to society.

## The Home- and Community-Based System

Community-based LTC services can be categorized as intramural and extramural, and they have a fourfold objective:

1. To deliver LTC in the most economical and least restrictive setting whenever appropriate for the person's health care needs.
2. To supplement informal caregiving when more advanced skills are needed than what family members or surrogates can provide.
3. To provide temporary respite to family members from caregiving stress.
4. To delay or prevent institutionalization.

## Intramural Services

**Intramural services** are taken to people who live in their own homes, either alone or with family. The most common intramural services include home health care and Meals on Wheels. Limited support programs that provide services such as homemaker, chores and errands, and handyman assistance also exist, but the funding to pay for such services is not well established and varies from community to community. **Home health care** brings services such as nursing care and rehabilitation

therapies to home-based residents who do not need to be in an institution and yet are unable to leave their homes safely to get the care they need.

### ***Extramural Services***

**Extramural services** are community-based services that are delivered outside a person's own home. These services are available at a community-based location. Examples include services such as adult day care, mental health outpatient clinics, and congregate meals provided at senior centers.

**Adult day care** enables a person to live with family but receive professional services in a daytime program in which nursing care, rehabilitation therapies, supervision, and social activities are available. **Senior centers** are local community centers where seniors can congregate and socialize. Many centers offer a daily meal. Others sponsor wellness programs, health education, counseling services, information and referral, and some limited health care services. **Respite care** can include any formal LTC service (adult day care, home health, or temporary institutionalization) when it allows family caregivers to take time off while the individual's care is taken over by the respite care provider. It allows family members to get away for a vacation or deal with other personal situations.

## **The Institutional System**

Institutional LTC is more appropriate for people whose needs cannot be adequately met in a community-based setting. Facilities within the institutional continuum range from independent living facilities or retirement centers at one end to subacute care and specialized care facilities at the other end (see the lower section of Figure 1–4). On the basis of the level of services they provide, institutional LTC facilities may be classified under six distinct

categories (facilities in the first two categories may be referred to as quasi institutions): Independent or retirement housing, residential or personal care, assisted living, skilled nursing, subacute care, and specialized care.

For most people, the array of facilities, which often go by different names, can be remarkably confusing. This is particularly true as distinctions between some of them can be blurry because the services these facilities provide may overlap. For example, what is defined as board-and-care (i.e., residential and personal care) in one state may be called assisted living in another.

### ***Independent or Retirement Housing***

Independent housing units and retirement living centers are not LTC institutions in the true sense because they are meant for people who can manage their own care. These residences do not deliver clinical care but emphasize privacy, security, and independence. Their special features and amenities are designed to create a physically supportive environment, as described previously.

### ***Residential or Personal Care Homes***

In addition to providing a physically supportive environment, these facilities generally provide light assistive care, such as medication use management and assistance with bathing and grooming. Other basic services such as meals, housekeeping, laundry, and social and recreational activities are also generally included.

### ***Assisted Living Facilities***

An **assisted living facility** provides personal care, 24-hour supervision, social services, recreational activities, and some nursing and

rehabilitation services. These facilities are appropriate for people who cannot function independently but do not require skilled nursing care. To emphasize a residential environment, assisted living facilities generally have private accommodations, rather than semi-private rooms that are common in skilled nursing facilities.

### ***Skilled Nursing Facilities***

These are the typical nursing homes at the higher end of the institutional continuum. Compared with the types of residences discussed earlier, the environment in skilled nursing facilities is more institutionalized and clinical. Yet, many facilities have implemented creative ideas in layout and design to make their living environments as pleasant and homelike as practicable.

The facility must be adequately equipped to care for residents who require a high level of nursing services and medical oversight. Yet, the high level of clinical care must be balanced with adequate quality of life in a resident-centered environment.

### ***Subacute Care Facilities***

Subacute care, defined earlier, has become a substitute for services that were previously provided in acute care hospitals. It has grown because it is a cheaper alternative to a hospital stay. Medical technology has played a critical role in the development of subacute care outside of hospitals.

### ***Specialized Care Facilities***

Some nursing homes have opened specialized care units for residents requiring ventilator care, Alzheimer's and dementia care, intensive rehabilitation, or closed head trauma care. Other specialized facilities include intermediate care facilities for individuals with intellectual disabilities (ICFs/

IID). The key distinguishing feature of the latter institutions is specialized programming and care modules for residents suffering from intellectual disabilities and associated comorbidities.

## **Long-Term Care and Complementary Services**

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Services within the broader health care delivery system are also needed by LTC recipients. Hence, care coordination between the two systems—LTC and non-LTC—is necessary to meet a person's total care needs. As an example, a person living at home may undergo partial mastectomy for breast cancer, return home under the care of a home health agency, require hip surgery after a fall in the home, and subsequently be admitted to a skilled nursing facility for rehabilitation. This individual will need recuperation, physical therapy, chemotherapy, and follow-up visits to the oncologist. Once she is able to walk with assistance and her overall condition is stabilized, she may wish to be moved to an assisted living facility.

Following are the main non-LTC services that are complementary to LTC:

- **Primary care**, which is defined as medical care that is basic, routine, coordinated, and continuous over time. It is delivered mainly by community-based physicians. It can also be rendered by midlevel providers such as physician's assistants or nurse practitioners. Primary care is also brought to nursing home residents, whereas those residing in less institutionalized settings, such as retirement living communities or personal care homes, commonly visit the primary care physician's office.

- Mental health care is delivered by community-based mental-health outpatient clinics and psychiatric inpatient hospitals.
- Specialty care is delivered by community-based physicians in specialty medical practices, such as cardiology, ophthalmology, dermatology, or oncology. Certain services are also delivered by free-standing chemotherapy, radiation, and dialysis centers. Other services are provided by dentists, optometrists, opticians, podiatrists, chiropractors, and audiologists in community-based clinics or mobile units that can be brought to a LTC facility.
- Acute care is delivered by hospitals and outpatient surgery centers. Acute episodes in an LTC setting require transfer of the individual to a hospital by ambulance.
- Diagnostic and health screening services are offered by hospitals, community-based clinics, or mobile medical services. Some common types of services brought to LTC facilities include preventive dentistry, x-ray, and optometric care.



## Terminology for Review

activities of daily living  
adult day care  
aging in place  
Alzheimer's disease  
assisted living facility  
chronic condition  
clinical practice guideline  
cognitive impairment  
comorbidity  
continuum of long-term care  
dementia  
developmental disability  
end-of-life care  
evidence-based care  
extramural services  
holistic approach  
home health care  
hospice  
instrumental activities of daily living

intellectual disability  
intramural services  
long-term care  
palliation  
person-centered care  
primary care  
quality of care  
quality of life  
resident-centered care  
respite care  
senior center  
skilled nursing care  
social support  
subacute care  
support services  
supportive housing  
tertiary prevention  
total care

## For Further Thought

1. How does long-term care differ from other types of medical services?
2. For nursing home residents, dignity and privacy issues are often more important than

clinical quality. Identify some staff practices that will promote an individual's privacy and dignity. (Think about how you would like to be treated by caregivers.)

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## CASE

### Can Mrs. Klausman Stay in Assisted Living?

Contributed by Katie Ehlman, PhD, CHES, HFA; Elizabeth Ramos, MS, RD, CD; Julie McCullough, PhD, RD; and Mary Kay Arvin, OTD, OTR, CHT, College of Nursing and Health Professions, University of Southern Indiana.

Mrs. Klausman is a 92-year-old resident in an assisted living facility. She has mild cognitive impairment and needs help with bathing and medication administration. Because of progressive arthritis, she is having difficulty eating. The silverware slips out of her hands and falls to the floor so that staff members must

keep replacing it. Mrs. Klausman becomes visibly frustrated and embarrassed. The food service manager and the administrator decide to meet with Mrs. Klausman's daughter and recommend that the family should hire a home care provider to assist Mrs. Klausman at mealtimes. The facility does not have staff resources to feed residents. The resident's daughter is thinking whether a skilled nursing facility would be more appropriate for her mother.

## Questions

1. Identify and evaluate Mrs. Klausman's deficit in self-feeding from different perspectives on what long-term care consists of.
2. Should Mrs. Klausman be transferred to a skilled nursing facility? Explain.
3. Is hiring a home care provider appropriate? Why or why not? What do you suggest?

## For Further Learning

Administration for Community Living. A federal agency established to promote the well-being of older individuals by providing services and programs designed to help them live independently in their homes and communities. <https://acl.gov>

National Council on Aging: A private, nonprofit organization providing information, training, technical assistance, advocacy, and leadership in all aspects of care for the elderly. <http://www.ncoa.org>

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## CHAPTER 2

# Long-Term Care Policy: Past, Present, and Future

### WHAT YOU WILL LEARN

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- Decisions made by the government in the form of policy can affect numerous groups and classes of individuals. Strategic decisions made in private organizations may also hinge on public policy.
- Health policy can take many different forms and can come from all three branches of government.
- Historically, long-term care policy in the United States has been closely intertwined with general welfare policies.
- The Nursing Home Reform Act of 1987 was instrumental in laying the foundation for current nursing home regulations.
- Cost concerns as well as people's preferences have led to the policy of moving people out of institutions into the community.
- The complex interaction of financing, access, utilization, and quality is critical to current and future long-term care policy.
- The demographic imperative poses several challenges for the future that policy must address.

### Introduction

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Long-term care (LTC) policy is a subset of broader health policies that fall within the domain of public policy. **Public policy** refers to decisions made and actions taken by the government that are believed to be in the public's best interest. Public policy that is directed at issues pertaining to health care

is referred to as **health policy**. Health policies affect groups or classes of individuals, such as physicians, the poor, seniors, and children. They can also affect various types of organizations, such as medical schools, managed care organizations, hospitals, nursing homes, and manufacturers of medical technology. The Affordable Care Act of 2010 (ACA),<sup>1</sup> also known as Obamacare, is a prime example of a major health policy that has affected

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<sup>1</sup> Affordable Care Act is the shortened name commonly used for the Patient Protection and Affordable Care Act of 2010 as amended by the Health Care and Education Reconciliation Act of 2010.

many aspects of health care delivery, such as health insurance, regulatory mandates, and payments to providers.

LTC policy is specifically crafted to address issues pertaining to access, financing, delivery, quality, and efficiency of LTC services. These policies have been aimed at helping people to receive better services.

Policy may be made at the national, state, or local level of government. For example, national building and fire safety codes govern the construction, design, and safety features for LTC facilities. State policies govern licensure of facilities and health care professionals and sale of insurance products. Local governments establish zoning laws specifying where LTC facilities may be built.

Public policy is often an important consideration when private organizations make strategic decisions. For example, a strategic decision by a skilled nursing facility to convert some of its beds to deliver subacute care may be driven by a public policy to increase reimbursement for subacute care. Hence, in addition to market demand factors, policy considerations can play a critical role in managerial decisions.

## Types of Policy

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Commonly, policy takes the form of laws passed by legislative bodies such as the U.S. Congress or state legislatures. Administrative bodies, such as the Centers for Medicare and Medicaid Services (CMS) or state health boards, interpret the legislation and formulate rules and regulations to implement the laws. For example, the massive set of regulations crafted by the CMS (contained in the *State Operations Manual: Guidance to Surveyors for Long-Term Care Facilities*) are designed to carry out the mandates of the Nursing Home Reform Act

(1987). Thus, administrative bodies also end up creating policy. The term **policy makers** is generally applied to legislators and decision makers in regulatory agencies. The two sources of policy making just mentioned are the most common. Less frequently, certain decisions rendered by the courts, and executive orders issued by the president of the United States or state governors, also become policy. Hence, all three branches of government—legislative, judicial, and executive—can make policy. The executive and legislative branches can establish health policies; the judicial branch can uphold, strike down, or modify existing laws affecting health care. Examples in all three areas follow.

Medicare's current methodology for paying skilled nursing facilities goes back to the Balanced Budget Act of 1997 which required Medicare to develop a prospective payment system (PPS). The Protecting Access to Medicare Act of 2014 required the CMS to implement value-based purchasing program that takes into account rehospitalization rates (American Health Care Association, 2020). In 2019, a new patient-driven payment model went into effect. It forced nursing homes across the nation, once again, to readjust their operational strategy. A landmark 1999 decision by the U.S. Supreme Court in *Olmstead v. L.C.* directed states to provide community-based services for persons with disabilities—including people with developmental disabilities, physical disabilities, or mental illness—when such services were deemed more appropriate than nursing facilities. In 2012, the U.S. Supreme Court upheld part of the ACA to be constitutional, but also ruled that the federal government could not coerce the states into expanding their existing Medicaid programs as required by the Act.

The 2004 Executive Order 13335 provided incentives for the use of health information technology (HIT). One of the

main objectives of this executive order was to develop a nationwide HIT infrastructure that would allow a patient's electronic health records to be portable and available to different health care providers (i.e., make electronic health records **interoperable**).

Policies carry the force of law. Violations can result in penalties that can include monetary fines, withholding of payments by the government, and prison terms for criminal offences.

## Long-Term Care Policy: Historical Perspectives

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Health care policy making in the United States has followed an ad hoc approach to incrementally address issues as they have cropped up. LTC policies had three major effects:

1. The government became the largest payer for services provided by nursing homes. This promoted the growth of a private nursing home industry.
2. The government implemented policies to regulate nursing homes and hold them accountable for complying with the regulatory standards.
3. For several decades, LTC policy promoted institutionalization. Rising costs put strains on federal and state budgets, but it was not until the 1980s that policies promoting home- and community-based services were crafted.

## Welfare Policies and Long-Term Care

The history of LTC policy in the United States goes back to the building of poorhouses in

the late seventeenth century. A **poorhouse** (or almshouse) was a government-operated institution during colonial and postcolonial times where the destitute of society, including the elderly, the homeless, the orphan, the ill, and the disabled, were given food and shelter, and conditions were often squalid. The first poorhouse in the United States is recorded to have opened in 1660 in Boston (Wagner, 2005, p. 10). The poorhouse program was adopted from the Elizabethan system of public charity based on English Poor Laws. In the United States, cities, counties, and states operated these facilities, which were often located on farms and, hence, also referred to as poor farms. The poorhouses were part of a very limited public relief system that was financed mainly by local governments. In response to the growing concerns about abuse and squalid living conditions, some states created state-run Boards of Charities in the mid-1800s to oversee and report on the local poorhouse operations.

Tireless efforts of Dorothea Lynde Dix (1802–1887), a social reformer, were particularly instrumental in convincing Massachusetts' legislature to pass laws that would put the mentally ill in separate facilities. Between 1894 and World War I, the State Care Acts were passed. Each state built its own mental asylum and took financial responsibility for the care of mentally ill patients. These reform efforts even spread abroad to Canada and Europe.

Passage of the Social Security Act in 1935 was a landmark piece of legislation. Senior citizens were particularly hard hit during the Great Depression as many of them saw their lifetime savings disappear. Hence, the federal government specifically addressed the needs of America's seniors. An Old Age Assistance (OAA) program was included in the Social Security Act. The OAA program made federal money available to the states to provide