Effective Management of Long-Term Care Facilities

Third Edition

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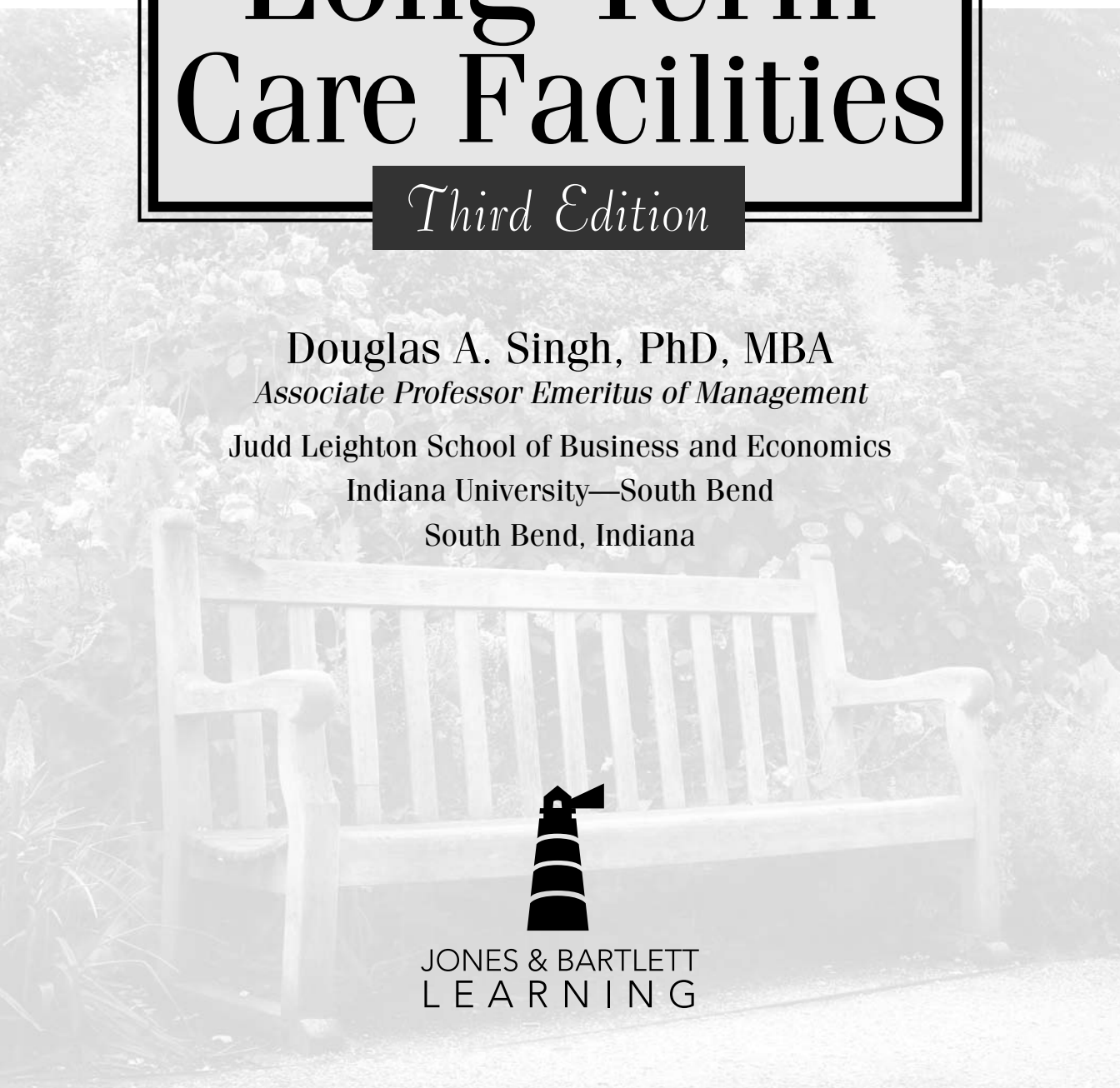

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Dedication

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.

Contents

New to This Edition

About 18 new cases have been added to this new edition. Most of these are short cases included at the end of various chapters, and are suitable for class discussion or short assignments. A new section, Terminology for Review, appears at the end of each chapter. The book has been updated with current research findings and data. The Affordable Care Act (ACA), as it pertains to long-term care, is discussed or referenced in several chapters.

This new edition contains 18 chapters. Chapter 4 found in the *Second Edition* has been deleted, and the pertinent materials have been incorporated in other chapters as deemed appropriate. Following is a list of the main revisions and additions:

- Chapter 2
  - Implications of the ACA for health policy, including long-term care
- Chapter 3
  - New section on cohousing
  - *Audiologist* added to rehabilitation professionals
- Chapter 4
  - A new section explains the differences between ordinary negligence and medical malpractice
  - New section on the Elder Justice Act under the ACA
  - Expansion of HIPAA in conjunction with the HITECH law
- Chapter 5
  - A new section explains the Interpretive Guidelines and their use. An example is furnished
  - New section on the Quality Indicator Survey
  - New table: National Scorecard on Selected Deficiency Citations
  - A new section covers Nursing Home Compare and five-star ratings
- Chapter 6
  - Productivity-based adjustment to PPS as mandated by the ACA
  - New section on Medicare value-based purchasing
  - New RUG-IV classification system
  - Opportunities under the ACA to post-acute providers for collaboration with hospitals
  - Fraud and abuse prevention under the ACA
- Chapter 7
  - A definition of culture change added
  - A new section on how to bring about culture change
  - New section on noise reduction
- Chapter 9
  - New section on adaptive rehabilitation
- Chapter 11
  - New section on eating issues with dementia patients

- Chapter 12
  - New section on the security of electronic data
- Chapter 13
  - Distinction between *de minimis* tasks and those regarded as "integral and indispensable" for the purpose of compensation
- Chapter 14
  - ACA requirements for corporate compliance
- Chapter 16
  - New section: Alcohol and Drug Testing and Medical Exams
- Chapter 18
  - The ACA's requirement for Quality Assurance Performance Improvement program
  - Update on measuring quality of life
  - New section on CMS's quality initiative and its effects on quality

Preface

To My Readers

This *Third Edition* continues to furnish up-to-date knowledge and skills 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.

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 care facilities.

This book differentiates itself from others on the market by giving you the most comprehensive, yet concise, understanding of how to effectively manage a long-term care organization. In one easy-to-understand volume, it explores laws, regulations, and financing; enlightens you on what is needed for creating a person-centered environment and how to adapt an existing nursing facility to the growing demands of culture change; details the organization and delivery of services; and furnishes essential skills necessary to manage it all. In real life, long-term care administrators must have a keen understanding of how organizational resources and delivery of services must be managed in an evolving healthcare landscape. The materials in this book are discussed in that context.

To apply what you learn, almost all chapters contain a short case (in some chapters there are two cases). Part V of the book contains 12 case studies that mostly span topics covered in more than one chapter. Also listed at the end of each chapter is key technical vocabulary, and Web-based resources for further learning.

Organization of This Book

The book is divided into five main parts. Each part covers chapters associated with a major theme. The five themes begin with an introduction to long-term care (Part I); progress to an explanation of legal, regulatory, and financing requisites (Part II); continue to organization and delivery of services (Part III); discuss the essentials of management in the areas of governance and leadership, human resource, marketing, finance, and quality improvement (Part IV), and conclude with cases (Part V) that call for the application of knowledge and skills learned in previous chapters.

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). The book is also recommended for the professional

certification exam of the American College of Health Care Administrators (ACHCA).

Part I: Introduction to Long-Term Care

This section furnishes the necessary foundation. Chapter 1 helps readers understand why long-term care is needed, who needs it, which key principles must drive the delivery of long-term care, and how the subsystems of long-term care fulfill a variety of needs.

In Chapter 2, you will go back in history to the beginnings of long-term care in the United States. After a discussion of what policy is and what purpose it serves, it is easy to understand that policy has been a main driving force behind the evolution of long-term care services. The future will be shaped by both government policy and private innovation, but policy will continue to play a dominant role. For example, the Affordable Care Act, which is referenced in several chapters, has important implications for long-term care delivery as it does for the rest of the health care delivery system.

Chapter 3 is based on the premise that efficient delivery of services to a nation's population necessitates a long-term care industry. The industry is made up of a variety of providers; private and public insurers; professionals who have the necessary qualifications; and an ancillary sector that includes case management agencies, long-term care pharmacies, and technology.

Part II: Laws, Regulations, and Financing

Unrelenting litigation against long-term care providers is here to stay. But, does the long-term care administrator have the basic knowledge about negligence, medical malpractice, misconduct, contracts, personal versus corporate liability, patient rights, and privacy-related legal mandates? You will find these and other issues discussed in Chapter 4.

Regulatory oversight will keep its unyielding pace. The Requirements of Participation are being enforced through the new Quality Indicator Survey. The well-prepared nursing home administrator not only must understand the survey and enforcement procedures but also comply with the *Life Safety Code*®, the Americans with Disabilities Act, and the Occupational Safety and Health Act. Chapter 5 focuses on how to achieve regulatory compliance.

No health care administrator can survive without an understanding of financing and reimbursement from various payers, of which the government is the largest. Chapter 6 simplifies the complexities of both public and private sources of financing for long-term care services.

Part III: Organization and Services

Chapter 7 discusses the organization of a nursing home and the evolution of care delivery according to the principles of person-centered care; enhanced environments that promote healing of the body, mind, and spirit; modern architectural designs; and the growing movement of culture change. These evolutionary changes are setting the standards for nursing homes of the future. Their adoption requires administrators to embrace new mindsets.

Social services within a facility must enable the residents to cope and adapt to major changes and conflicts in their lives. An understanding of aging is necessary for all who are associated with providing services to the elderly, and that includes the administrators. In addition, issues of cultural diversity, resident and family empowerment, planning for admission and discharge, and family support when death and terminal illness occur are all covered in Chapter 8.

Most administrators do not have background or training in clinical care. Yet, the primary reason that patients utilize

a long-term care facility is to have their medical, nursing, and rehabilitation needs addressed. Along with other chronic and comorbid conditions, residents commonly suffer from depression, delirium, and dementia. An understanding of these and other areas requiring special attention are discussed in Chapter 9.

In Chapter 10, you will discover that activity programming is not simply a matter of putting together a recreational agenda to comply with regulatory requirements. Meaningful activities call for a great deal of skill and resourcefulness.

Chapter 11 explains that dietary services must be designed to meet individual nutritional needs, sensory gratification, and social interaction. Menu planning, ordering and receiving, food production, cost control, emergency plans, and close attention to sanitation and food temperatures all play an important role in achieving the main objectives.

Maintenance and repairs, housekeeping, laundry, linen supplies and inventory control, building security, fire and disaster planning, waste disposal, and environmental safety are the main topics found in Chapter 12.

In Chapter 13, you will learn that business office functions go beyond basic reception and bookkeeping. Payroll and compensation practices, handling of the patient trust fund, and medical records are all governed by laws and regulations. Information systems are essential for effective management.

Part IV: Essentials of Effective Management

The five chapters in this section furnish the essential skills necessary for success, even for those who may have already taken academic courses in the areas covered in this section. More importantly, the chapters in this section apply management principles in the context of nursing home administration. Governance, corporate compliance, and leadership are addressed in Chapter 14. Because most facilities do not have separate positions of human resource manager, financial officer, marketing director, and quality control manager, Chapters 15–18 furnish the essential skills in these areas.

Part V: Case Studies

After studying the first three chapters, you should be able to address Case 1, in which an elderly immigrant couple needs long-term care services. The next three cases deal with legal and ethical issues in which patient rights must play an important role. Case 5 presents a novel scenario that an administrator may be quite unprepared to handle. Case 6 is about medical malpractice. Case 7 deals with both strategy and logistics that will often be necessary for implementing culture change. Evacuation of a facility (Case 8) is not common, but the administrator must be thoroughly prepared to take action during emergencies. In Case 9, you will find that leadership styles and actions can create conflicts that effective administrators must learn to prevent, but they must also address the conflict when it has already occurred. Corporate compliance is the theme in Case 10. There are many facilities today in which staff-related problems appear insurmountable. Case 11 challenges you to apply your ingenuity. Some administrators will face the challenge of opening new facilities. See if you are up to the challenges presented in Case 12.

Tools That Will Enhance Learning

- Read the brief overview at the beginning of each of the five parts of the book.
- Go through the What You Will Learn summaries at the beginning of each chapter.
- Study the chapters, keeping in mind the main themes that divide each chapter.
- Use the Glossary when you encounter an unfamiliar technical term.
- Stop and review the numerous illustrations (figures, tables, exhibits, etc.) you will find throughout the book.
- Review the terminology at the end of each chapter.
- Think through the For Further Thought assignments at the end of each chapter.
- Apply your learning to the case(s) furnished at the end of most chapters.
- Pick some area of interest to build on what you have learned by using the Internet resources in the For Further Learning sections.

Throughout the text, certain terms have been used interchangeably. Examples include nursing home, nursing facility, facility, and long-term care facility; patient, resident, and elder; and employee, associate, staff member, and worker. All these terms are found in the research literature and used by professionals in the field.

For Instructors

Please contact your Jones & Bartlett Learning account representative to get access to the complete Instructor's Manual, PowerPoint slides, Test Bank, and Excel materials. Also, if you would like to share your thoughts, I would be delighted to hear from you.

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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.

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.

List of Abbreviations

A

AAHSA American Association of Homes and Services for the Aging
AARP Formerly known as the American Association of Retired Persons
ACEND Accreditation Council for Education in Nutrition and Dietetics
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
ALFA Assisted Living Federation of America
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

CAPS Certified aging-in-place specialist
CARF Commission on Accreditation of Rehabilitation Facilities
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
CPOE Computerized provider order entry (system)
CQI Continuous quality improvement
CSA Controlled Substances Act (1970)
CSRA Community Spouse Resource Allowance
CTRS Certified therapeutic recreation specialist

D

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

E

EEOC Equal Employment Opportunity Commission
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)
FSES Fire Safety Evaluation System
FUTA Federal Unemployment Tax Act

G

GAAP Generally accepted accounting principles
GNP Geriatric nurse practitioner
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)
HIT Health information technology
HITECH Health Information Technology for Economic and Clinical Health Act
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 Intermediate care facility
ICF/IID Intermediate care facility for individuals with intellectual disabilities
ICF/MR Intermediate care facility for the mentally retarded
ICP Infection control practitioner
ID Intellectual disability
IDD Intellectually/developmentally disabled
IOM Institute of Medicine
IRF Inpatient rehabilitation facility
IRS Internal Revenue Service
IT Information technology

L

LAN Local area network
LPN Licensed practical nurse
LSC *Life Safety Code®*
LTC Long-term care
LTCH Long-term care hospital
LVN Licensed vocational nurse

M

MBO Management by objectives
MCCA Medicare Catastrophic Coverage Act (1988)
MCO Managed care organization
MD Doctor of medicine
MDRO Multidrug resistant organism
MDS Minimum data set

MIA (Community Spouse) Monthly Income Allowance
MMA Medicare Prescription Drug, Improvement, and Modernization Act (2003)
MR/DD Mentally retarded/ developmentally disabled
MRSA Methicillin-resistant *Staphylococcus aureus*
MSBT Multisensory behavior therapy
MSD Musculoskeletal disorder
MSE Multisensory environment
MSS Multisensory stimulation
MSW Master's degree in social work

N

NAB National Association of Long Term Care Administrator Boards
NASPAC National Association of Subacute/Post Acute Care
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

O

OAA Old Age Assistance
OBRA-87 Omnibus Budget Reconciliation Act of 1987
OSCAR Online Survey Certification and Reporting (system)
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)
PERS Personal emergency response systems
PHI Protected health information
POA Power of attorney
POC Plan of correction
PPD Per-patient-day
PPS Prospective payment system
PT Physical therapist or physical therapy
PTA Physical therapy assistant

Q

QAPI Quality assurance performance improvement
QIS Quality Indicator Survey
QM/QI Quality measure/quality indicator (report)
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
RUG Resource utilization group

S

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
TQM Total quality management

U

USDA U.S. Department of Agriculture

V

VHA Veterans Health Administration
VRE Vancomycin-resistant *enterococci*

PART I

Introduction to Long-Term Care

As a major component of the health care delivery system, long-term care (LTC) has been receiving increasing 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 increasing in developing countries. A rise in chronic conditions and functional limitations is an unfortunate adjunct of longevity. The social environment in developing countries is also changing. Both men and women are increasingly being drawn into the workforce to improve their standards of living. Hence, there is a growing demand for LTC services in the developing world as well.

A broad understanding of long-term care 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 three chapters in this section address these areas:

- Chapter 1 explains what long-term care is, why it is needed, what type of health care and social services constitute LTC, who are the clients served by long-term care, and how LTC should interface with the broader health care system.
- 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 meet the challenges.
- Chapter 3 furnishes details of the long-term care industry, which is necessary for the efficient delivery of services. The chapter covers community-based and institutional providers, insurers, LTC professionals, case management agencies, long-term care pharmacies, and seven categories of LTC technology.

Chapter 1

Overview of Long-Term Care

What You Will Learn

- Physical and/or mental deficits that limit a person's ability to do regular daily tasks create the need for long-term care. Activities of daily living (ADL) and instrumental activities of daily living (IADL) are two common measures used to evaluate functional status.
- In addition to assistance needed to perform daily living tasks, long-term care may also be needed for continuity of care after hospitalization and when specialized environments of care are necessary.
- 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 elderly need long-term care, but an aging and culturally diverse population, coupled with social changes, will create ongoing challenges. People with HIV/AIDS present complex needs and they are also entering old age.
- Those who need assistance obtain long-term care services through three subsystems of care: informal, community based, and institutional.
- Informal care is the largest of the three systems of long-term care. Community-based services have four main objectives and can be classified into two groups: intramural and extramural. The institutional system forms its own continuum of care to accommodate clients whose clinical needs vary from simple to complex.
- Non–long-term care services are needed to complement long-term care. Care coordination between the two systems—long-term care and non–long-term care—is often necessary to meet a patient'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 a person's 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 autism, or gradual loss of memory in an aged person. LTC services are needed mostly by the ***elderly***—people age 65 and over—hence, most LTC services have been designed with the elderly client in mind.

Long-term care is a complex system with broad boundaries (Prince et al., 2013). 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 long-term 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. In 2012, almost 8.4 million Americans received LTC from a variety of formal sources such as adult day care centers, home health agencies, hospices, nursing homes, and residential care communities (Harris-Kojetin et al., 2013).

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**. As just mentioned, limitations arise because of physical and/or mental disability or severe illness. Besides physical disability, cognitive impairment also increases 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. Cognitive impairment with or without dementia contributes to neuropsychiatric symptoms and increased disability (Tabert et al., 2002). The level of a person's dependency—ranging from partial to total—created by functional limitations determines the type of LTC service needed.

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 a long-term care facility.

The second commonly used measure is called ***instrumental activities of daily living (IADL)***. This measure focuses on a variety of activities that are necessary for independent living. Examples of IADLs include doing housework, cooking, doing laundry,

grocery shopping, taking medication, using the telephone, managing money, and moving around outside the home (Lawton & Brody, 1969). 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 patient 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.** The term ***subacute care*** is often used for services needed by people who need ongoing care after hospitalization because of a severe illness, injury, or surgical episode. These patients may be recovering but are still subject to complications while in recovery. Others may need clinically complex care, such as wound care, tube feedings, or intravenous therapy. Patients recovering from accidents or orthopedic surgery, such as hip and knee replacements, generally need intensive rehabilitation.
3. **Need for care in specialized environments.** 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, 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. Mental retardation (MR), now more commonly referred to as ***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 terms mentally retarded/developmentally disabled (MR/DD) or intellectually/developmentally disabled (IDD). Approximately 14% of children in the age group 3–17 are developmentally disabled; boys are almost twice as likely as girls to have DD (Boyle et al., 2011). 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.

Patients with severe dementia, such as Alzheimer's disease, also need tailored programming in specialized environments. For example, special therapies are used to address cognitive function and behavioral issues. A supportive environment is designed to reduce stress and provide a moderate amount of stimulation to the senses.

Dimensions and Principles of Long-Term Care

No simple definition fully captures the nature of long-term care. 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 long-term care.

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 practices, 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 apply to both institutional and noninstitutional long-term care. An ideal LTC system will incorporate these 10 dimensions.

1. Variety of services
2. Individualized services
3. Well-coordinated total care
4. Promotion of functional independence
5. Extended period of care
6. Use of current technology
7. Use of evidence-based practices
8. Holistic approach
9. Maximizing quality of care
10. Maximizing quality of life

Variety of Services

Long-term care 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 elderly, 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. Depending on the change in condition and functioning, the individual may shift back and forth among the various levels and types of LTC services. For example, after hip surgery, a patient 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. Depending on individual need, these services are integrated into the 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 treatment of acute episodes in hospitals. 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. If not controlled, serious complications can develop. The mere presence of chronic conditions, however, does not indicate a need for long-term care. When chronic conditions are compounded by the presence of ***comorbidity***—coexisting multiple health problems—they often become the leading cause of an individual's disability and erode that individual's ability to live without assistance. This is when LTC is needed. 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. It is provided immediately after the onset of a disability. Examples of cases requiring rehabilitation include orthopedic surgery, stroke, limb amputation, and prolonged illness.

Mental Health Services and Dementia Care

An estimated 25% of older adults have depression, anxiety disorders, or other significant psychiatric conditions. Moreover, mental health disorders are frequently comorbid in older adults, occurring with a number of common chronic illnesses such as diabetes, cardiac disease, and arthritis (Robinson, 2010). The risk of depression in the elderly also increases when ability to function becomes limited (National Institute of Mental Health, 2007). Mental health services are generally delivered by specialized providers in both outpatient and inpatient facilities. Caregivers need training to recognize the need for mental health care so the patient can be referred to qualified providers in the community.

With the growing prevalence of dementia in the United States and around the world, care for patients with dementia has become a major focus in LTC. ***Dementia*** is a general term for progressive and irreversible decline in cognition, thinking, and memory. It is a denerative condition with no known cure. The risk of dementia increases with age. Approximately 15% of people older than 70 years of age have dementia (Hurd et al., 2013); the majority have ***Alzheimer's disease***—a progressive degenerative disease of the brain, producing memory loss,

confusion, irritability, and severe functional decline. Although people with mild dementia may receive home-based care, almost 40% of people with dementia receive institutional LTC. Among institutionalized patients, almost 72% have a diagnosis of dementia, according to one study (Helmer et al., 2006).

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, which is a normal part of the transition process. Grieving may manifest in reactions such as anger, denial, confusion, fear, despondency, and depression (McLeod, 2002). 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 patient wants for himself or herself and what the family may think is best for the patient. Conflicts can also arise between patients and caregivers.

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 senior centers, or other private or public professional agencies. For people residing in LTC facilities, to remain connected with the community and the outside world is an important aspect of social support.

Supportive Housing

Supportive housing is a key component of LTC because certain functional and safety features must be carefully planned to compensate for people's disabilities in order to promote independence to the maximum extent possible. 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. They may include meals, transportation, housekeeping, building security, social activities, and outings. However, not all housing arrangements provide all of these services.

Adequate space, privacy, safety, comfort, and cleanliness are basic features that

must be present in all housing options. An institutional environment must feel home like; it must encourage social activities, promote recreational pursuits, and have a décor that is both pleasing and therapeutic.

Hospice Services

Hospice services, also called ***end-of-life care***, are regarded as a component of long-term care. The focus of hospice, however, differs considerably from other LTC services. ***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 support 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.

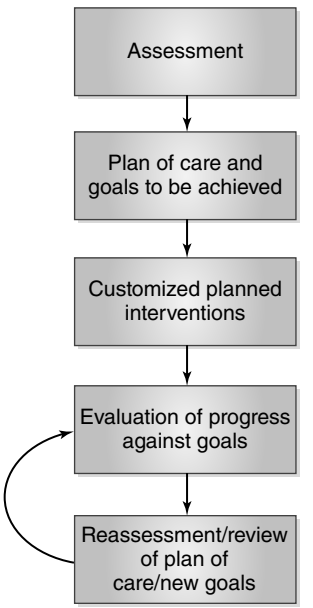
The hospice philosophy also regards the patient and family together as one unit of care. The option to use hospice means that temporary measures to prolong life will be suspended. The emphasis is on maintaining the quality of life and letting the patient die with dignity. Psychological services focus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

Hospice services are generally brought to the patient, although a patient may choose to go to a freestanding hospice center if one is available. Hospice care can be directed from a hospital, home health agency, nursing home, or freestanding hospice.

Individualized Services

Long-term care services are tailored to the needs of the individual patient. Those needs are determined by an assessment of the individual's current physical, mental, and emotional condition. Other factors used for this purpose include past history of the patient'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. Information from the assessment is used to develop an individualized plan of care that enables caregivers to deliver customized interventions to address the patient's needs in a comprehensive manner. The flow of individualization and delivery of care is illustrated in **Figure 1–1**.

Figure 1–1 Individualization and Delivery of Care



Well-Coordinated Total Care

Long-term care providers are responsible for managing the total health care needs of an individual client. ***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 for preventive services and to deal with the onset of impairments at an early stage. The need for total care coordination can also be triggered by changes in basic needs or occurrence of episodes. Transfer to an acute care hospital or treatment for mental or behavioral disorders may become necessary. Hence, long-term care must interface with non-LTC services.

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 must be taught to use adaptive equipment such as wheelchairs, walkers, special eating utensils, or portable oxygen devices. Caregivers should be trained to motivate the patients to do as much as possible for themselves to prevent further decline. Assistance is rendered when a patient is either unable to do things for him- or herself or absolutely refuses to do so. A patient may be unable to walk independently but may be able to take a few steps with the help of trained caregivers. Assistance with mobility helps maintain residual functioning. Ongoing maintenance therapy—such as assisted walking, range of motion exercises, bowel and bladder training, and cognitive reality orientation—is also necessary to prevent progressive functional decline. However, in spite of these efforts, it is reasonable to expect a gradual decline in an individual's functional ability over time. As this happens, services must be modified in accordance with the changing condition. In other words, LTC must "fill in" for all functions that can no longer be carried out independently. For instance, a comatose patient who is totally confined to bed 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 services—such as professional 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. 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. People receiving community-based LTC services generally need them for a long duration to prevent institutionalization.

Use of Current Technology

Use of appropriate technology can enable people to stay in the community. It can

also improve overall safety and quality of care. For example, a personal emergency response system (PERS) enables an at-risk elderly person living alone at home to summon help in an emergency at any time during day or night. A fall detector can be used at home or in an institution. Electronic medication dispensers are programmed to dispense pills and sound an alarm as reminders for a person to take prescribed medications. Remote monitoring technology can be used to monitor vital signs, blood pressure, and blood glucose levels using video technology. Recently, remote monitoring of cardiac implantable electronic devices, such as pacemakers and implantable cardioverter defibrillators, in the United States and Europe has been gaining acceptance. The technology has been found to be highly effective in managing clinical events, such as arrhythmias and cardiovascular disease progression. Examples of technology for institutional settings include GPS (global positioning systems) to monitor a patient who may wander away, sensor technology to prevent and heal pressure ulcers by detecting moisture levels and length of time spent in one position, use of robotic pets, and pedometers to measure daily activity levels (Morley, 2012).

Use of Evidence-Based Practices

Evidence-based care relies on the use of best practices that have been established through clinical research. Increasingly, clinical processes that have been proven to deliver improved therapies are being standardized into ***clinical practice guidelines***. These guidelines become evidence-based protocols that are indicated for the treatment of specific health conditions. They have been developed to assist practitioners in delivering appropriate health care for specific clinical circumstances. An increasing number of standard guidelines have been developed for use in nursing homes. Some of these same guidelines can also be used in other LTC settings such as home health and assisted living.

Holistic Approach

The ***holistic approach*** to health care delivery focuses not merely on a person's physical and mental needs but also on every aspect of what makes a person whole and complete. In this approach, a patient's 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 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 satisfaction-related outcomes have been achieved. Maximization of quality is an ongoing pursuit and is never fully achieved. Hence, maximizing quality requires a culture of continuous improvement. It requires a focus on the other nine dimensions encompassing the nature of LTC discussed in this section. To improve quality, regulatory standards as well as evidence-based clinical practice guidelines 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 a multifaceted concept that recognizes at least five factors: lifestyle pursuits, living environment, clinical palliation, human factors, and personal choices. Hence, quality of life can be 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, and fishing. Many residents would like to engage in spiritual pursuits or spend some time alone. Even patients 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 must be comfortable, safe, and appealing to the senses. Cleanliness, décor, furnishings, and other aesthetic features are critical.
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, and preservation of human dignity in the delivery of care. Institutionalized patients generally find it disconcerting to have lost their autonomy and independence. Quality of life is enhanced when residents have some latitude to govern their own lives. Residents also desire an environment that promotes privacy.
5. LTC institutions should make every effort to accommodate patients'

personal choices. For example, food is often the primary area of discontentment, which can be addressed by offering a selective menu. Many elderly resent being awakened early in the morning when nursing home staff begin their responsibilities to care for patients' hygiene, bathing, and grooming. Flexible schedules can be implemented to accommodate individual choices.

The Elderly and Long-Term Care

The elderly, people 65 years of age or older, are the primary clients of long-term care. As previously stated, a person's age or the presence of chronic conditions by itself does not predict the need for long-term care. However, as a person ages, chronic ailments, comorbidity, disability, and dependency tend to follow each other. This progression is associated with increased probability that a person would need long-term care **(Figure 1–2)**.

The probability of having limitations in ADLs and IADLs increases significantly with age **(Figure 1–3)**. In a broad sense, approximately one-third of the elderly have functional limitations of one kind or another; among those age 85 and older, two-thirds have functional limitations (Congressional Budget Office [CBO], 2013). According to the U.S. government's website, http://www.longtermcare.gov, an estimated 70% of older Americans will eventually need some type of LTC, even though many may never leave their own homes. Surveys over time have shown that the vast majority of older Americans wish to stay in their own homes indefinitely. Hence, community-based services are preferred by most older people, and these services have grown more rapidly than LTC institutions. Severe declines in health, however, may necessitate institutional services, particularly for people who need care around the clock.

In 2012, 44% of noninstitutionalized older persons assessed their own health as excellent or very good, compared to 64% for persons aged 18–64 years (Administration on Aging, 2013). It is reasonable to assume that the segment of the elderly population in fair to poor overall health is likely to require LTC at some point. Even for those in good or excellent health, short-term LTC may become necessary after an accident, surgery, or acute illness.

Important differences in health exist according to population characteristics. Compared to whites, fewer elderly African-Americans, Hispanics, Asians, and American Indians/Alaska Natives rated their health as

Figure 1–2 Progressive Steps Toward the Need for Long-Term Care Among the Elderly

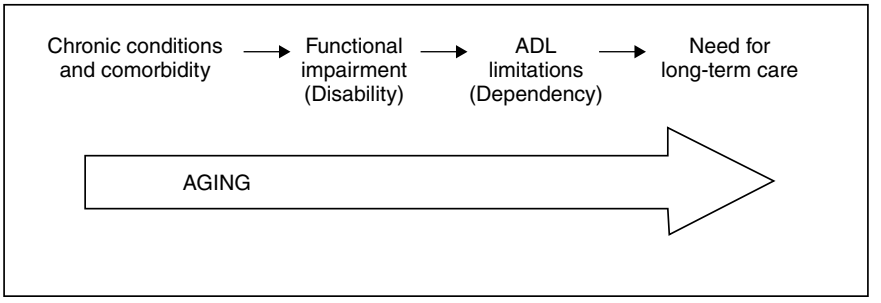
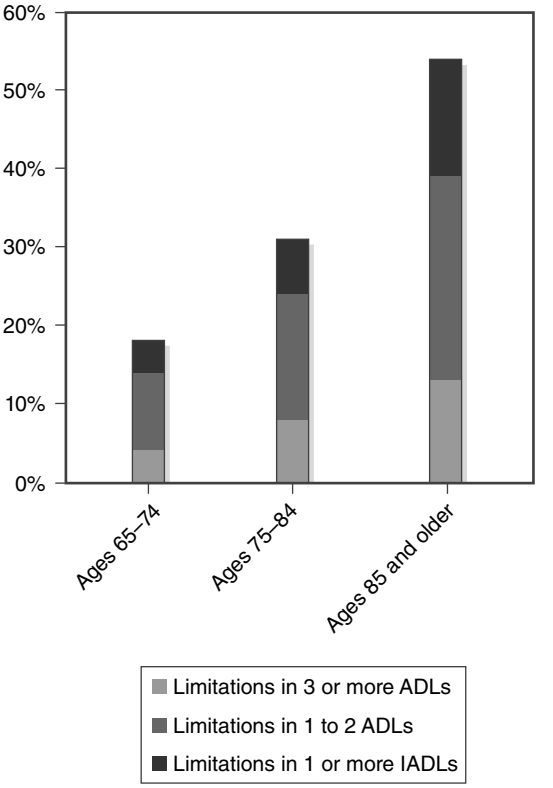


Figure 1–3 Limitations in ADLs and IADLs Among Community-Dwelling Elderly



Reproduced from Congressional Budget Office. 2013. *Rising demand for long-term services and supports for elderly people.* Washington, DC: Congressional Budget Office.

excellent or very good (Administration on Aging, 2013). Because the growing nonwhite elderly population is in poorer health, it is likely to face a greater need for LTC services later in life. Social and cultural factors important to each group will present new challenges in the delivery of LTC services.

By 2050, 20% of the U.S. population will be elderly, up from 12% in 2000. The number of people age 85 and older will grow the fastest (CBO, 2013). Growth of the elderly population will bring a corresponding surge in the number of elderly people with functional and cognitive limitations. Thus, the need for LTC will increase sharply in coming decades.

The rest of the developed world also faces aging-related problems and challenges in providing adequate LTC services very similar to those in the United States. Actually, the elderly population as a proportion of the total population in other developed countries, such as Japan, Germany, France, and Great Britain, is already higher than it is in the United States.

Aging of People with HIV/AIDS

With the increased use of highly active antiretroviral therapy (HAART), AIDS

(acquired immune deficiency syndrome) has evolved from an end-stage terminal illness into a chronic condition. With reduced mortality, the prevalence of HIV (human immunodeficiency virus) in the population has actually increased, including among the elderly. People over the age of 50 are not only aging with HIV infection, but also represent a high proportion of new HIV infections (Watkins & Treisman, 2012). For example, in 2007, almost 17% of new diagnoses of HIV were in individuals who were older than 50 years (Kearney et al., 2010). It is estimated that by 2015 half of all HIV-infected individuals in the United States will be over the age of 50 (Effros et al., 2008).

Care of HIV/AIDS patients presents special challenges because this population has characteristics that are quite dissimilar to the rest of the LTC population. As HIV/AIDS patients age, they become susceptible to multiple comorbidities and cognitive impairment. Liver disease and cardiovascular disease are both associated with long-term use of HAART. HIV/AIDS patients are also at a high risk of developing various types of cancers, depression, dementia, and Alzheimer's disease (Cahill & Valadéz, 2013), and have a significantly higher prevalence of weight loss and incontinence of bladder and bowel (Shin et al., 2002). Older people living with HIV report lower levels of physical ability and less independence compared with younger people (Pereira & Canavarro, 2011). These factors indicate a greater need of LTC services among people with HIV/AIDS. Many older adults living with HIV/AIDS are disconnected from traditional informal support networks and rely heavily on formal care providers (Shippey & Karpiak, 2005). HIV/AIDS patients have a variety of medical and social needs over time. Changing needs require transitions between community-based services, nursing homes, and hospitals.

The Long-Term Care Delivery System

The LTC system is sometimes referred to as the ***continuum of long-term care***, which means the full range of long-term care 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 long-term care continuum has three major subsystems:

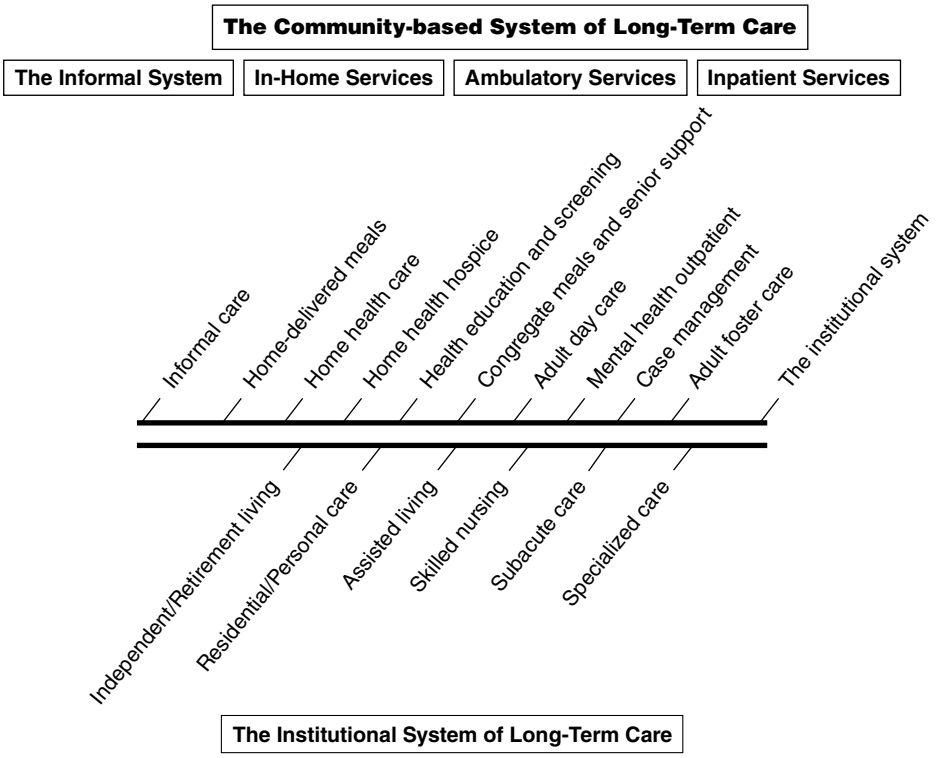
- The informal system
- The community-based system
- The institutional system

The first subsystem, informal care, is the largest, but it generally goes unrecognized. For the most part, it is not financed by insurance and public programs; it includes private-duty nursing arrangements between private individuals. The other two subsystems mostly have formalized payment mechanisms to pay for services.

Although institutional management is the focus of this text, the other two subsystems, informal care and community-based service, also have important implications for administrators who manage LTC institutions. The community-based services and informal systems compete with the institutional system in some ways but are also complementary.

The three subsystems that form the LTC continuum are illustrated in **Figure 1–4**.

Figure 1–4 The Continuum of Long-Term Care



There are also different levels of institutional settings forming their own institutional continuum.

Given the complexity of the LTC system, case management (also called care management) fills in a key role. ***Case management*** is a centralized coordinating function in which the special needs of LTC clients are identified and a trained professional determines which services would be most appropriate, determines eligibility for those services, makes referrals, arranges for financing, and coordinates and monitors delivery of care to ensure that clients are receiving the prescribed services. Case management helps link, manage, and coordinate services to meet the varied and changing health care needs, particularly for those who have complex medical issues, such as people with HIV/AIDS. Case management provides a single entry point for obtaining information about and accessing services. The extent of disability and personal needs primarily determine which services on the continuum may be best suited for an individual. However, client preferences, availability of community-based services, and ability to pay for services also play a significant role.

In recent years, numerous public and private health care organizations have proliferated—organizations that offer information to consumers on how to care for someone at home, how to find and pay for community-based services, and how to find an appropriate institutional setting.

The Informal System

Contrary to popular belief, most LTC services in the United States are provided informally by family, friends, and surrogates such as neighbors and members from church or other community organizations. For the most part, services rendered are of a basic nature, such as general supervision and monitoring, running errands, dispensing medications, cooking meals, assistance with eating, grooming and dressing, and, to a lesser extent, assistance with mobility and transfer.

It is estimated that 92% of community-dwelling residents receive unpaid help (Kaye et al., 2010), from approximately 42 million informal caregivers in the United States (Feinberg et al., 2011). Family members also play an important role in managing the often critical transitions between settings of care delivery, such as between hospital and nursing home (Levine et al., 2010). Unpaid care is also the largest source of financing LTC; its estimated economic value in 2009 was $450 billion, up from $375 billion in 2007 (Feinberg et al., 2011).

The extent of informal care that an individual receives is highly dependent on the extent of the support network the individual has. People with close family, friends, neighbors, or surrogates (such as members of a religious community) can often continue to live independently much longer than those who have little or no social support. Men, minorities, married individuals, and those with less education are more likely to receive care from family and friends and are less likely to receive care in a nursing facility (Alecxih, 2001).

The pool of informal caregivers, in relation to the growing elderly population needing LTC, is going to shrink rather dramatically in the future. Various reports suggest that the number of older people who are divorced, unmarried, or without children has been on the rise. This trend has serious implications for the formal subsystems of LTC delivery.

The Community-Based System

Community-based LTC consists of formal services provided by various health care agencies. These services can be categorized as intramural and extramural. Community-based LTC services have a fourfold objective:

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

Intramural Services

Intramural services are taken to patients 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 patients in their own homes because such patients do not need to be in an institution yet and are generally 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 patient's home. They require that patients come and receive the services at a community-based location. This category mainly includes services such as adult day care, mental health outpatient clinics, and congregate meals provided at senior centers. Respite care is another type of service that can be classified as extramural.

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. Adult day care centers generally operate programs during normal business hours 5 days a week. Some programs also offer services in the evenings and on weekends. ***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 kind of LTC service (adult day care, home health, or temporary institutionalization) when it allows family caregivers to take time off while the patient'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 without neglecting the patient.

The Institutional System

Institutional LTC is more appropriate for patients whose needs cannot be adequately met in a community-based setting. Apart from a patient's clinical condition, factors such as inability to live alone or lack of social support may suggest a need to be in an institution. The institutional sector of LTC offers a continuum of services according to the patient's level of dependency for care. Facilities within the institutional continuum range from independent living facilities or retirement centers at one extreme to subacute care and specialized care facilities at the other extreme (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 living
- Residential or personal care
- Assisted living
- Skilled nursing
- Subacute care
- Specialized care

For most people, the array of facilities that often go by different names can be remarkably confusing. This is particularly true because distinctions between some of them can be blurry. 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. This is because services provided by these facilities can overlap. Brief descriptions of these facilities follow.

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 to promote an independent lifestyle. For example, the living quarters are equipped with emergency call systems. Bathrooms have safety grab bars. Rooms are furnished with kitchenettes. Congregate housing units have handrails in the hallways for stability while walking. Other housing units offer detached cottages with individual garages that allow residents to come and go as they please. ***Hotel services*** such as meals, housekeeping, and laundry may or may not be available.

Residential or Personal Care Homes

Facilities in this category go by different names such as domiciliary care facilities, adult care facilities, board-and-care homes, and foster 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. Because personal care homes are located in residential neighborhoods, they are sometimes regarded as a community-based rather than an institutional service.

Assisted Living Facilities

An assisted living facility (ALF) 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. However, ALFs are increasingly offering services for Alzheimer's/dementia care (Hoban, 2013). To emphasize a residential environment, ALFs generally have private accommodations, as opposed to semi-private, which is common in skilled nursing facilities.

The typical assisted living resident is female, 87 years old, mobile, but needing assistance with two to three ADLs. The majority of these residents transfer from their homes. Approximately, 59% eventually move into a skilled nursing facility and one-third pass away (National Center for Assisted Living, 2013).

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.

These facilities employ full-time administrators who must understand the varied concepts of clinical and social care and have been trained in management and leadership skills. The facility must be adequately equipped to care for patients who require a high level of nursing services and medical oversight, yet the quality of life must be maximized. A variety of disabilities—including problems with ambulation, incontinence, and behavioral episodes—often coexist among a relatively large number of patients. Compared with other types of facilities, nursing homes have a significant number of patients who are cognitively impaired, suffer from other mental ailments such as depression, and have physical disabilities and conditions that often require professional intervention. The social functioning of many of these patients has also severely declined. Hence, the nursing home setting presents quite a challenge to administrators in the integration of medical care, mental health services, and social support.

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. Early discharge from acute care hospitals has resulted in a population that has greater medical needs than what skilled care facilities were earlier able to provide.

Specialized Care Facilities

Some nursing homes have opened specialized care units for patients requiring ventilator care, treatment of Alzheimer's disease, intensive rehabilitation, or closed head trauma care. Other specialized facilities include intermediate care facilities for individuals with intellectual disabilities (ICFs/IID), previously known as intermediate care facilities for the mentally retarded (ICF/MR). The key distinguishing feature of the latter institutions is specialized programming and care modules for patients suffering from mental retardation and associated disabilities.

Long-Term Care and Complementary Services

Services within the broader health care delivery system are often needed by long-term care patients. Hence, care coordination between the two systems—long-term care and non–long-term care—is often necessary to meet a patient'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. Depending on the change in condition and functioning, the patient may move between the various levels and types of LTC services and may also need transferring between LTC and non-LTC services.

The following are the main non-LTC services that are complementary to long-term care:

- ***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 brought to the patients who reside in nursing homes, 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 delivered by community-based mental-health outpatient clinics and psychiatric inpatient hospitals.
- Specialty care delivered by community-based physicians in specialty practices, such as cardiology, ophthalmology, dermatology, or oncology. Certain services are also delivered by freestanding 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 long-term care facility.
- Acute care delivered by hospitals and outpatient surgery centers. Acute episodes in a LTC setting require transfer of the patient to a hospital by ambulance.
- Diagnostic and health screening services 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
Alzheimer's disease
case management
chronic conditions
clinical practice guidelines
cognitive impairment
comorbidity
continuum of long-term care
dementia
developmental disability
elderly
end-of-life care
evidence-based care
extramural services
holistic approach
home health care
hospice
hotel services
instrumental activities of daily living
intellectual disability
intramural services
long-term care
palliation
primary care
quality of care
quality of life
respite care
senior centers
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.)

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 homemaker appropriate? Why or why not? What do you suggest?

FOR FURTHER LEARNING

Administration on Aging: A federal agency established under the Older Americans Act.

http://www.aoa.gov/

Family Caregiver Alliance: A nonprofit organization set up to provide information and resources to address the needs of families and friends providing long-term care at home.

http://www.caregiver.org

The George Washington Institute for Spirituality and Health: Affiliated with the George Washington University, the Institute is a leading organization on educational and clinical issues related to spirituality and health.

http://smhs.gwu.edu/gwish

The Meals On Wheels Association of America: This organization represents those who provide congregate and home-delivered meal services to people in need.

http://www.mowaa.org

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

National Institute of Mental Health: A government agency under the U.S. Department of Health and Human Services. The agency engages in education and research in all aspects of mental health and mental illness.

http://www.nimh.nih.gov/index.shtml

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Chapter 2

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

What You Will Learn

- 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.
- Public policy can take many different forms. Policies can come from all three branches of government.
- In the United States, long-term care policy and general welfare have been closely intertwined. The Social Security Act of 1935 and the creation of Medicare and Medicaid in 1965 were landmark policies that indirectly started a nursing home industry that has remained mostly private. Regulation of the industry soon followed.
- Quality of care issues in nursing homes took center stage during the 1980s. The Nursing Home Reform Act of 1987 provides current nursing home regulations dealing with patient care, but the regulations also have some serious drawbacks.
- Most of the current activity in long-term care policy has been directed toward moving people out of nursing homes into the community.
- The complex interaction of financing, access, utilization, and expenditures is critical to current and future long-term care policy.
- Future policy initiatives are necessary in the areas of prevention, financing, workforce development, health information systems, mental health, and evidence-based practices.

Introduction

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 intended to address current and potential issues that the government believes are in the best interest of the public. As with other types of decisions, policy is intended to accomplish certain defined purposes. When the intended goals of public policy pertain to health care, the government's decisions and actions are referred to as ***health policy***. Health policies affect groups or classes of individuals, such as physicians, the poor, the elderly, or children. They can also affect various types of organizations, such as medical schools, managed care organizations, hospitals, manufacturers of medical technology, or employers in the American industry. The Affordable Care Act (2010),[1] also known as Obamacare, is a prime example of a major health policy that also extends into the broader domain of public policy because of its tax consequences on individuals and businesses.

LTC policy is specifically crafted to address issues pertaining to access, financing, delivery, quality, and efficiency of LTC services. These policies particularly affect the recipients of services such as the elderly or disabled; provider organizations such as nursing homes, home health agencies, and senior centers; caregivers such as physicians and certified nursing assistants; managers such as nursing home administrators; and manufacturers and purveyors of technology and medical supplies.

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. States also establish guidelines that insurance companies must follow in the design and sale of LTC insurance. Local governments establish zoning laws specifying where LTC facilities may be built.

The term *policy* is also sometimes used in the context of private policy. More appropriately, however, private policies are strategic decisions that senior managers in private organizations make to better serve their markets. For example, the increased prevalence of dementia among the elderly has prompted the growth of specialized Alzheimer's care facilities in response to a rising market demand. In the health care sector, 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 strategic decisions.

Types of Policy

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

[1]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.

(CMS) or state health boards, interpret the legislation and formulate rules and regulations to implement the laws. Thus, in the process of interpretation and implementation of laws, administrative bodies also end up creating policy. The term ***policymakers*** is generally applied to legislators and decision makers in regulatory agencies who become actively involved in crafting laws and regulations to address health care issues. The two sources of policymaking 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. The president often plays an important role in policymaking by generating support of his agenda in Congress, by appealing to the American people as to why certain issues are important, and by proposing legislation for Congress to act on. 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.

Legislation contained in the Balanced Budget Act of 1997 required Medicare to develop a prospective payment system (PPS) to reimburse skilled nursing facilities. This legislative policy triggered several rounds of policymaking. First, the Health Care Financing Administration (now called Centers for Medicare and Medicaid Services) developed and implemented a new payment methodology in 1998. Subsequently, to address concerns from nursing home operators, Congress instituted a series of temporary payment increases through two pieces of legislation—the Balanced Budget Refinement Act of 1999 and the Medicare, Medicaid, and State Children's Health Insurance Program (SCHIP) Benefits Improvement and Protection Act of 2000 (MedPAC, 2002).

A 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 persons with developmental disabilities, persons with physical disabilities, persons with mental illness, and the elderly—when such services were determined to be appropriate by professionals responsible for rendering health care to these people. In 2012, the U.S. Supreme Court upheld part of the Affordable Care Act 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) and established the position of a National Health Information Technology Coordinator. 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***).

These examples illustrate that public policy can take many different forms that can have far-reaching consequences. When policies require that certain individuals or organizations perform or behave in a certain manner, the policies carry the force of law. Violations can result in various kinds of penalties that can include monetary fines, withholding of payments by the government, and prison terms for criminal offences.

Long-Term Care Policy: Historical Perspectives

Policy evolution in the United States did not progress according to some planned design. This follows the general pattern of American health policymaking. Health care policymaking has followed an ad hoc approach to incrementally address issues as they have cropped up.

LTC policies in the United States had three major effects:

1. The government became the largest payer for services provided by nursing homes. This encouraged the growth of a private nursing home industry.
2. The government implemented policies to regulate nursing homes.
3. For several decades, long-term care policy actually promoted institutionalization because there was little financial incentive to develop community-based services. As rising costs put strains on federal and state budgets, it was not until the 1980s that policies promoting 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 17th 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. These facilities admitted poor and needy persons of all kinds, including those released from prison and the ill who did not have family or relatives to take care of them. 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. The boards' efforts led to some improvement in living conditions and to separation of the insane from the sane and the dependent elderly from the able bodied (Stevenson, 2007). The 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. The elderly 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 elderly. Simultaneously, deplorable conditions fueled a reform movement

to move people out of poorhouses. 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 financial assistance to needy elderly persons. For the fiscal year that ended on June 30, 1936, Congress authorized the sum of $49,750,000 under Title I of the act in the form of matching grants, meaning the states participating in the program would share in the total cost of the program (Social Security Administration, n.d.). The new law purposely prohibited payments to anyone living in a public institution (i.e., a poorhouse), and was instrumental in putting an end to the poorhouse system (Wagner, 2005, pp. 132–133). An unintended side effect of this policy, however, was that it started a private for-profit nursing home industry in the United States because many elderly now were able to pay for services in privately run homes for the aged and boarding homes (Eustis et al., 1984, p. 17). Private nonprofit homes for the aged did not grow at the same rate as for-profit homes because the nonprofit facilities were established to care for members of particular religious, ethnic, or fraternal groups and thus restricted whom they would admit (Doty, 1996).

The Hospital Survey and Construction Act of 1946, commonly known as the Hill-Burton Act, provided federal funds to states for the construction of new hospital beds. An unplanned result of the Hill-Burton legislation was that many of the old hospitals that were being replaced were converted to nursing homes (Stevenson, 2007).

Policies during the 1950s provided federal funds for the construction of nursing homes while, at the same time, OAA payments were increased and a 1950 Social Security Amendment required payments for medical care to be made directly to nursing homes rather than to the recipients of care. By public policy, nursing homes now became recognized as institutions of medical care rather than social welfare. Nursing homes could now contract directly with the state governments and get reimbursed for services delivered to the elderly poor. Also, at this time, nursing homes were required to be licensed by the states. The legislation contained no specific standards for licensure; hence, each state set its own rules (Phillips, 1996). It is estimated that by 1960 there were over 10,000 nursing homes with 400,000 beds in the United States (Vladeck, 1980).

Financing and Growth of Nursing Homes

The creation of Medicare and Medicaid in 1965 as Title 18 and Title 19 amendments, respectively, to the Social Security Act brought about the most transforming changes in the American health care landscape. Medicare and Medicaid are two major public health insurance programs. ***Medicare*** covers health care services for the elderly, certain disabled people, and those who have end-stage renal disease (kidney failure). ***Medicaid*** covers health care services for the poor.

With the creation of Medicare and Medicaid, LTC became more fully integrated into the U.S. health care delivery system. Also, the federal and state governments became the largest payers for LTC services, and the politics of long-term nursing home care took root. Medicare and Medicaid funding for nursing homes also attracted Wall Street investors and real estate developers to a fast-growing nursing home industry dominated by chains—that is, multifacility systems that own and operate