

CHAPTER

1

Embedding Advocacy in the U.S. Health System

I discuss a bottom-up approach to reforming the American health system in this book, which is to be used in tandem with top-down approaches such as those enacted by the Patient Protection and Affordable Care Act of 2010 as amended by Congress. Health professionals and consumers ultimately decide who gets served and with what benefits and services, even if high-level policies shape these choices—and they must take the initiative to correct ill-advised healthcare choices and policies through the use of advocacy.

I argue in this book that health professionals and consumers often must engage in advocacy to increase the odds that consumers will receive quality services, as well as preventive services, protection of their ethical rights, access to services, culturally-competent services, attention to stress and mental-health issues, and linkages to community resources. I cite extensive research that documents that millions of Americans don't receive these services and benefits.

Advocacy has received insufficient attention in existing health literature, whether the literature of physicians, social workers, psychologists, public health staff, nurses, occupational therapists, or physical therapists. I argue that these professionals have an ethical duty to advocate for specific patients or consumers when they don't receive needed services and access to care—or to provide patients or consumers with the skills and knowledge to advocate for themselves.

I argue that case management and navigation services, while important, do not give sufficient attention to advocacy. They focus on coordinating care and helping patients and consumers navigate the health maze, but they do not usually provide advocacy.

Many health professionals and consumers won't engage in advocacy, however, if they don't learn how to provide it. It requires them to develop specific advocacy skills. This book provides the first framework that links advocacy for individual patients or consumers (case or patient advocacy) with advocacy for groups of patients or consumers (policy advocacy). It identifies specific skills needed by advocates in sufficient detail that they can develop a practice of advocacy in their work.

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I link these advocacy practice skills to specific situations or scenarios that many advocates confront in their actual work. I identify and discuss 118 scenarios that often call out for advocacy when patients or consumers don't receive ethical or quality care, when they don't receive culturally competent care, when they can't afford their health services, when specific mental or substance-abuse problems are unaddressed, and when their care is not linked to their communities. I provide many vignettes in this book that demonstrate how health professionals and consumers provide effective advocacy in specific situations.

Health professionals need to create work environments that encourage advocacy. I argue in this chapter, as well as in Chapter 13, that advocacy is often an underground activity that is not encouraged in many hospitals and clinics. Health professionals need to engage in advocacy to create institutions that promote advocacy to improve healthcare in their settings.

Health professionals and consumers, too, need to change high-level policies in clinics, hospitals, communities, or the government that are inimical to quality healthcare. They shouldn't be content to delegate policy advocacy to public officials or to interest groups, but should actively participate in making them.

I hope this book fills a gap in existing health literature. I hope it encourages health educators and health professionals to provide courses and workshops on advocacy. I hope it encourages health professionals and consumers to engage in advocacy whenever they believe that it improves healthcare.

SEVEN PROBLEMS COMMONLY ENCOUNTERED BY HEALTHCARE CONSUMERS

Millions of people encounter seven problems when seeking help from their healthcare providers:

1. They often cannot finance their medical care, including millions of Americans who lack health insurance, persons who are underinsured, persons whose insurance claims are denied—problems that will be alleviated but not eliminated by the health legislation enacted by the Congress and President Barack Obama in March 2010.
2. They often receive medical care that does not meet widely accepted standards, such as the roughly 50% of consumers who do not receive evidence-based medicine for specific health conditions like depression, asthma, and early-stage chronic diseases.
3. They often experience violations of ethical rights, such as insufficient or inaccurate information to allow consumers to make informed choices about their care and breeches of confidentiality.
4. They often receive medical care that is not culturally relevant to them, including services not consonant with their culture, lack of adequate translation services, and lack of sufficient representation of ethnic and racial groups on medical staffs.

5. They often receive insufficient preventive care for specific health conditions, including chronic diseases or ones linked to environmental factors.
6. They often possess excessive levels of anxiety, depression, and other mental conditions that remain unaddressed.
7. Their healthcare often fails to link them with health-related programs and services in their communities.

Many persons possess a combination of two or more of these seven problems. Consider, for example, a woman who fails to receive preventive care (problem #1) because she cannot afford it (problem #2) or an immigrant who lacks sufficient information to give informed consent to a treatment (problem #1) because he lacks adequate translation services (problem #2). Both of them could suffer adverse health consequences if their multiple problems are not addressed. I discuss throughout this book how the Patient Protection and Affordable Care Act of 2010 as amended by the Congress will address many of these seven problems, but its effect will be considerably delayed because many of its provisions are not implemented until 2014 and subsequent years. It is historic legislation that has the potential to improve healthcare for tens of millions of consumers, but only if its provisions are implemented effectively when they take effect from 2010 to 2021. I argue that consumers will need to engage in advocacy, often with the help of specific healthcare professionals, *even* when this legislation is fully implemented because of deep-seated problems in the American healthcare system.

ADVOCACY

Healthcare patients or consumers often need help in addressing these seven problems. Some of them can advocate for themselves, such as persons who seek second opinions, contest adverse decisions by insurance companies, or request preventive services. Many other persons need assistance, however, from healthcare professionals because these people lack sufficient knowledge about the health system, are intimidated by it, lack time to seek redress, fear retaliation, or lack encouragement from family members and friends.

Healthcare professionals need a hands-on framework to help them provide advocacy on two levels. They need to help specific consumers obtain services and rights that would (likely) not otherwise be given to them and that would advance their personal well-being. I call this "case advocacy." Also, they need this advocacy framework to help healthcare professionals change dysfunctional policies in their institutions, communities, and the broader society that often create the need for case advocacy in the first place (I call this "policy advocacy.") I argue that healthcare professionals and consumers can't provide advocacy effectively if they don't develop competencies in specific skills needed for effective advocacy. I identify and discuss these skills with extensive use of vignettes provided by health advocates.

This book provides a framework called the Consumer Advocacy and Navigational Model (CAN), which links four levels or kinds of services provided by healthcare professionals: traditional services, navigation and case-management services, case (or

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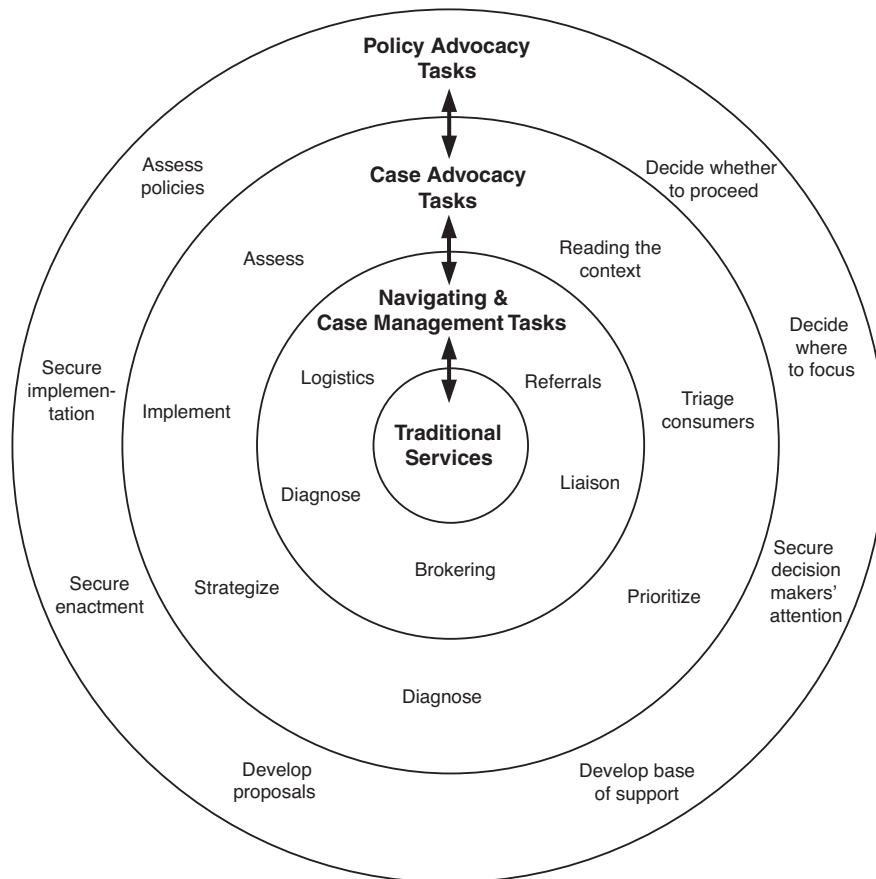


Figure 1.1 Consumer Advocacy and Navigational (CAN) Model

patient) advocacy, and policy advocacy (see Figure 1.1). (See case advocacy and policy advocacy frameworks, respectively, in Chapters 3 and 12).

The innermost circle of Figure 1.1 depicts services that healthcare professionals have traditionally emphasized. Physicians provide care for specific health conditions with diagnostic tests, treatments, and medications. Social workers and nurses devote considerable time, for example, to discharge planning and bedside implementation of physicians' prescribed treatments—even though many leaders in both fields have expanded their roles significantly. Occupational therapists and physical therapists provide services to help patients engage in daily and occupational tasks. Speech and language pathologists help patients regain speech in the wake of strokes and other neurological injuries. Psychologists and social workers engage in counseling. Residents provide general and specialized kinds of medical care.

The next circle in Figure 1.1 depicts tasks commonly associated with patient navigation and case management that respectively help consumers navigate the health system and plan, as well as orchestrate, their services. Although theorists who have developed these models of care sometimes discuss advocacy as part of them, they usually

give case advocacy and policy advocacy secondary attention—or ignore them altogether. (See discussion of the marginalized status of case and policy advocacy in the online document at the end of this chapter.) The tasks commonly associated with case-management or navigational models *are* important and need to be undertaken, but they do not sufficiently discuss advocacy interventions.

I often use the word “consumers” throughout this book rather than the words “patients” or “clients” to emphasize that case advocates and policy advocates often possess different perspectives than healthcare professionals who operate in the two innermost circles of Figure 1.1. They focus *not* on planning and implementing treatment plans, but in helping people obtain services and rights not likely to be given to them—or in reforming dysfunctional policies in specific institutions and communities, as well as the broader society. Advocates sometimes help people obtain services and benefits to which they are legally entitled under existing statutes and regulations. They sometimes help people obtain ethical rights that many ethicists contend should be honored. They initiate or participate in efforts to reform existing statutes, regulations, and programs. If the term “patients” is widely used to describe persons who are diagnosed and treated for specific illnesses, the term “consumers” describes persons who exercise their rights or choices in a health system that sometimes denies or withholds them—whether through self-advocacy or with the help of healthcare professionals. It builds on the consumer-rights movement that has helped persons secure quality products at affordable prices for the past several decades. It builds upon publications that use the word “consumers,” such as Dean Halverson's book *Healthcare Tsunami: The Wave of Consumerism that Will Change U.S. Business* (2008). It is consonant with the movement toward patient-oriented care that currently exists in many hospitals and clinics as is discussed in Chapter 13. Readers who prefer the terms *patients*, *persons*, *clients*, or other terms need only substitute those terms for *consumers* throughout this book, while understanding why I use the word *consumers*. Nomenclature also differs among fields. Nursing literature often discusses “patient advocacy,” for example, rather than using the term “case advocacy.”

I sometimes use the generic term, “healthcare professionals,” to describe persons who can and should provide case and policy-advocacy interventions, that is, *any* professional who works in the healthcare system. I sometimes use the term “frontline staff” because these people are well situated to provide advocacy. They see consumers when they enter and use health systems, as well as when they are discharged from these systems or in their community settings. Social workers, nurses, psychologists, public health staff, speech and language pathologists, occupational therapists, and physical therapists fall within this rubric. I place residents in the ranks of frontline staff because they, too, see consumers for longer and more frequent times than do many physicians. Frontline staff is uniquely positioned to provide advocacy even as I contend that physicians, hospital administrators, and other hospital staff should also engage in case and policy advocacy.

Healthcare professionals wear, in effect, two hats. They plan and implement traditional services when terms like “patients” or “clients” are often used. When they switch into advocacy mode, whether at case or policy levels, they view the persons with whom

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they work as persons with rights, entitlements, and needs that should be honored. They help them obtain services, resources, ethical care, quality of care, preventive care, culturally competent care, and noninsular care *that they might not otherwise obtain*. They stand beside them. They help them question or challenge existing arrangements. They sometimes take risks as they help consumers—such as encountering anger from other professionals, administrators, or healthcare staff. They often help consumers obtain skills to advocate for themselves, but realize that some consumers need help from healthcare professionals to engage in advocacy, such as people who are traumatized or incapacitated by their medical conditions, those intimidated by the health system or specific professionals, or those who lack sufficient information.

Consumers, too, wear these two hats. They sometimes obtain diagnostic information, select treatment strategies, obtain preventive services, and adhere to physicians' recommendations. This "hat" conforms to what is normally described as the "patient role" although many experts prefer to use the term "consumer" even for this role because it is, they think, more empowering and less restrictive. Consumers wear another hat when they question the health system. They may wish to obtain further information to allow them to have informed consent. They may want second opinions. They may want to insist on specific entitlements, such as translation services if they have limited English proficiency (LEP). They may want to delay specific procedures. They may wish to consider using different medications. They may wish to change medical providers. They may want to consult the Internet to gain further knowledge about a specific health condition.

Frontline people do not actually prescribe medical treatments and medications to consumers, but they often observe their consequences on the consumer's well-being, psychology, family relationships, and finances. They sometimes find them to be confused or disturbed by their medical care. They sometimes discover that they have unanswered questions or doubts about their medical care. They sometimes find that their medical care has deviated from existing rules and regulations. They have an ethical duty to engage in advocacy in these circumstances, such as by helping consumers obtain information and ask questions.

SCENARIOS AND VIGNETTES

Healthcare professionals and consumers experience specific issues and problems as they give and receive services—which I call "scenarios." They describe situations where consumers confront unresolved ethical issues, wonder if they are receiving evidence-based care, believe they do not receive culturally competent services, fail to receive preventive services, cannot afford their care, possess mental distress that is not addressed by their care, and receive healthcare that is not linked to their communities. Each scenario provides a narrative that describes an issue or is confronted by consumers as they encounter one of the seven problems described earlier. Each scenario is often linked to specific policies, regulations, and protocols in health institutions and the broader

society. These scenarios serve as alerts for healthcare professionals to provide case advocacy when consumers' needs, entitlements, and ethical rights are not met by the health system. I provide 118 of these scenarios in Chapters 5 through 14, whether in the book (95 of them) or its online component (23 of them). (I discuss at the end of each chapter how to access the scenarios.) Some examples of these scenarios drawn from Chapters 5 through 14 include:

- Scenario 5.1: Advocacy to Enhance Consumers' Informed Consent (Chapter 5 which discusses consumers' ethical rights)
- Scenario 6.1: Advocacy to Help Consumers Learn About Evidence-Based Care Relevant to Their Healthcare (Chapter 6 which discusses consumers' right to quality services)
- Scenario 7.2: Advocacy to Help Consumers Obtain Translation Services (Chapter 7 which discusses consumers' right to culturally competent care)
- Scenario 8.1: Advocacy to Help Consumers Identify Personal At-Risk Factors (Chapter 8 which discusses consumers' right to preventive services)
- Scenario 9.3: Advocacy to Help Uninsured Consumers Obtain Coverage (Chapter 9 which discusses consumers' right to affordable services)
- Scenario 10.10: Advocacy to Help Consumers Manage Stress That Accompanies Physical Illness (Chapter 10 which discusses consumers' right to mental-health services)
- Scenario 11.1: Advocacy for Consumers Needing Community Referrals (Chapter 11 which discusses consumers' right to receive healthcare linked to their communities)

This book also presents vignettes contributed by healthcare professionals to illustrate how they provide advocacy. They describe advocacy interventions that are used by many healthcare professionals.

The scenarios and vignettes are embedded in the "policy and regulatory thicket" that envelops the U.S. health system, which is highly regulated by myriad statutes and regulations in federal, state, and local jurisdictions, accrediting authorities, and courts, as well as rules and procedures of specific health organizations. Healthcare professionals can provide effective advocacy only if they possess knowledge of this thicket, which is described as it is relevant to the seven problems of consumers in Chapters 5 through 11.

Health professionals and consumers should often engage in policy advocacy when they observe recurring scenarios or ones that are particularly harmful to consumers. Assume, for example, that a healthcare professional observed that homeless persons were frequently discharged from her hospital even when their underlying medical conditions had not been stabilized and even when a receiving agency or service had not been located. She might engage in policy advocacy by bringing this recurring scenario to the attention of hospital administrators, as well as other health professionals.

RESURGENCE OF INTEREST IN CASE AND POLICY ADVOCACY

Case advocacy and policy advocacy have often been discussed by theorists and practitioners in the literature of healthcare professions in preceding historical eras. (For fuller discussion, see online materials described at the end of this chapter.) Professionals have often been urged to provide these interventions to persons using the health system or to change defective policies that impede or prevent consumers from receiving needed services and resources.

Curiously, however, these theorists and practitioners have failed to provide specific frameworks to help healthcare professionals provide advocacy. I found no framework, for example, that discussed how professionals engage in case advocacy in existing literature—and the author pioneered a policy advocacy framework in prior books (Jansson, 1984, 2011). This book uniquely links the case- and policy-advocacy frameworks by discussing how healthcare professionals, as well as consumers, can use both kinds of advocacy singly and in tandem. This book fills this vacuum in existing literature by providing hands-on advocacy frameworks, as well as scenarios and vignettes that illustrate advocacy interventions.

A resurgence of case advocacy and policy advocacy is underway. Some writers have viewed case advocacy through the lenses of empowerment, seeing it not primarily as a managerial function, but as a way to help persons obtain services and rights that might otherwise be denied them by an unresponsive health system (Klein & Cnaan, 1995; Seal, 2007). Smith and Mason (1995) proposed a formal advocacy structure for the Caribbean American population in New York City to provide them with information about services and to help them gain access to them. Cox (2007) views advocacy as needed in bureaucratic systems to create policy and system-level changes. She desires, as well, a strengths-based perspective, including support groups, to help grandparent-headed families obtain services. Although still marginalizing its role, Hepworth, Rooney, and Larsen (2002) briefly discusses case advocacy as one of many tasks that social workers undertake in direct services—and links it to policy advocacy.

Some leaders in nursing view link health advocacy as necessary to uphold patient rights (Thacker, 2008). Nurse educators, such as A. Davis and Konishi (2007) seek greater nurse advocacy with physicians and other professional personnel. Earp, French, and Gilkey (2008) contend that U.S. nurses increasingly use case advocacy but call it "patient advocacy." They link it to protecting consumers' self-determination, educating and advising them that they can take part in decision making, and "interceding" for patients with others, including family members and physicians, so that patients' wishes are honored (Gilkey, Earp, & French, 2008, p. 6).

Case and policy advocacy have been widely supported among healthcare personnel and advocates who work in end-of-life and palliative care areas. Patients often need help in obtaining fuller communication with health providers about their preferences, the "spiritual and cultural dimensions" of their care, and adequate pain management (Institute of Medicine [IOM], 2003).

Partly following leadership of AIDS activists in the late 1980s and 1990s, a resurgence of advocacy has occurred with respect to specific diseases, such as breast cancer and diabetes (Gilkey et al., 2008.). Case and policy advocates want greater public education, communication of care options, financing of care, and research for these and other diseases (Davenport-Ennis, Cover, Ades, & Stovall, 2002).

Advocacy to help patients gain access to alternative medicine has increased in recent decades. Advocates have sought greater communication among physicians, nurses, and patients about alternative-care options like acupuncture, medication, yoga, and use of herbs. They have fought to allow practitioners of alternative medicine to practice in hospitals. They have sought financing for it by private insurance plans, HMOs, and government programs. They have sought greater federal financing for research on the efficacy of alternative medicine.

The federal government has belatedly shown greater interest in financing research on case advocacy partly spurred by an IOM report (2000) that documented the sheer amount of medical error in the U.S. health system—possibly leading to between 44,000 and 98,000 unnecessary deaths each year. These astonishing figures are more than the number of persons killed during the Vietnam War or from annual deaths from automobile accidents. They make the ethical case for case and policy advocacy even more persuasive. Hospitals and clinics not only need case advocates to come to the aid of specific consumers to prevent medical errors and to help its victims and their families, but to establish safer systems of healthcare. The IOM (2000) contended that between 380,000 and 450,000 preventable adverse drug events take place in hospitals each year. Other scientific research questions overmedication of children and adolescents, the elderly, and persons with such chronic diseases as obesity.

Some graduate-level courses are devoted to advocacy—and even some specialized advocacy programs such as the Health Advocacy Program at Sarah Lawrence College, the Center for Patient Partnerships at the University of Wisconsin-Madison, and the Patient Advocacy Program at Stanford University (Hurst, Gaines, Grob, Weil, & Davis, 2008).

Some hospitals have implemented advocacy programs. Some of them hire "patient representatives" who are assigned to patients to help them use services and to attend to their complaints (Gilkey et al., 2008). Some hire health advocates. Some hire case or care managers who include advocacy in their work. Most hospitals have compliance officers, as well as risk-management departments whose officials sometimes engage in case- and policy-advocacy.

Interest in advocacy has been stimulated as well by background policy developments. As many employers curtail or limit health insurance for their employees because of the recession that began in 2008, the inequities of the U.S. health system become even more apparent, such as the lack of insurance for roughly 47 million Americans and the roughly 40 million Americans who are underinsured. Many insurance companies have capriciously denied coverage for specific health conditions of consumers. These problems will be partly corrected by federal legislation enacted by the Patient Protection and

Affordable Care Act passed by Congress as amended by the Healthcare and Education Reconciliation Act in March 2010 even though it will take years to become fully implemented. (Chapters 2, 5, 6, 8, 9, 10, 11 and 14 discuss this legislation more fully and refer to it by the first title for brevity in these various chapters.)

An increasing body of outcomes-based research has led to renewed interest in evidence-based medicine (EBM) during the past decade. Researchers have discovered that roughly 50% of Americans do not receive evidence-based medicine for such common ailments as asthma and depression. Millions of Americans do not receive state-of-art care for chronic diseases. (IOM, 2008; McGlynn et al., 2003).

Americans have become increasingly aware that the rights of many consumers have been violated by health providers. Some managed-care plans, for example, issued "gag orders" to their physicians to impede referrals to specialists. Some physicians routed patients to facilities that they owned or chose treatments that increased their profits—allowing conflicts of interest to influence their medical decisions.

Advocacy from attorneys and community-based advocacy organizations can be helpful to consumers, but it is not a substitute for advocacy from healthcare professionals, consumers, and consumers working in tandem with healthcare professionals. It is often limited to health-coverage or technical violations of statutes and regulations by providers—rather than the full range of seven problems that consumers often confront.

The enactment of the Patient Protection and Affordable Care Act in March 2010 as amended by Congress illustrates the resurgence of health advocacy. Many smaller health initiatives were enacted in preceding decades, but none equaled the magnitude of this Act, which will cover roughly 32 million uninsured persons, fund a wide array of health-prevention programs, and prohibit insurance companies from withdrawing or withholding coverage to consumers with preexisting conditions. It will greatly increase the size of the Medicaid program. Many health advocates contributed to its enactment. Many health advocates will need to be certain that its provisions are implemented in a timely and effective way during the coming decade.

ADVOCACY FROM OUTSIDE THE HEALTH SYSTEM

Private attorneys have provided advocacy for healthcare consumers for many decades. They have initiated malpractice suits—or threatened suits on behalf of specific consumers. They have brought suits against, or threatened suits, against insurance companies. They have often been involved in suits that allege that providers infringed on their rights, such as withholding information, proceeding with surgical procedures without obtaining informed consent, or divulging confidential information.

Public interest attorneys have litigated extensively against local, state, and public governments on behalf of specific consumers or groups of consumers. In Los Angeles County, for example, attorneys from the Western Center on Poverty and Law, as well as the American Civil Liberties Union, have questioned decisions by Los Angeles County to curtail services, close facilities, privatize facilities, or raise consumer fees.

An array of not-for-profit and for-profit organizations have arisen during the past decade in many jurisdictions that provide advocacy to patients, particularly with respect to insurance claims. Some of them handle hundreds of thousands of inquiries, often brokering decisions among providers, consumers, and insurance companies with remarkable success in overturning denials of insurance claims.

Many states have departments that oversee facets of the health system, such as ones that have jurisdiction over insurance plans, managed-care plans, hospital services, and public systems of healthcare. These departments often have hotlines that consumers can access when they want information or want to complain about specific services or fees.

ADVOCACY AS AN UNDERGROUND ACTIVITY

Advocacy remains an underground activity in many healthcare settings. I discovered that many frontline staff provide advocacy on frequent occasions when I collected vignettes about advocacy with the assistance of doctoral student Jennifer Paek. I was surprised by the number and quality of vignettes that they provided. Frontline staff reported that they frequently engage in advocacy, such as a nurse who said: "I engage in case advocacy on a daily basis often on many occasions." I discuss data gathered in a survey in Chapter 13 that documents that social workers and nurses frequently engage in advocacy with respect to ethical issues of consumers (Jansson & Dodd, 2002; Dodd, Jansson, Brown-Saltzman, Shirk, & Wunch, 2004). They engage in it, I hypothesize, because they see so many consumers who possess one or more of the seven problems I have identified in this book—and realize that they might suffer harm if they did not receive assistance.

This book aims to bring case and policy advocacy into the daylight. I provide frameworks for engaging in them. I discuss why it is often needed by consumers for ethical and evidence-based reasons. I argue in Chapter 13 that it should be a recognized and respected activity in clinics and hospitals as is true in such health systems as the Mayo Clinic, the Geisinger Health System, City of Hope Hospital, and a national network of hospitals that use the Planetree model.

ADVOCACY AS AN ETHICAL IMPERATIVE

Healthcare professionals do not usually receive pay increases, promotions, or recognition from engaging in case or policy advocacy. Advocacy usually is not included in their job descriptions. Some of them are censored or punished for engaging in case advocacy *even when they only seek to improve the well-being of specific consumers through responsible actions*. The fear of being censored or punished for advocacy often deters frontline staff from engaging in it—even when this fear is not warranted.

Nor is it surprising that advocacy often ruffles feathers because advocates often question the status quo. Advocates who help consumers obtain second opinions regarding diagnostic tests or treatments may antagonize those physicians who view such advice as a criticism of their work. Policy advocates who seek to change existing

policies and protocols within their health organizations may be criticized by officials who support existing policies.

Other barriers exist. It takes time to engage in advocacy when frontline people are hard-pressed by their existing duties—particularly when advocates help persons with particularly difficult problems. Advocates often face adverse odds. They sometimes cannot help consumers for pragmatic reasons, such as when their insurance policies do not cover specific health problems that they possess. They sometimes lose races against the clock when they help people who are nearing death, such as help them make choices about their medical care, complete their wills, or meet with relatives and friends.

Policy advocates sometimes fail to obtain reforms of protocols, budgets, and statutes because of opposition from specific officials, interest groups, and lobbyists. The challenges facing policy advocates were dramatically illustrated by the failure of the American Nurses Association, the National Association of Social Workers, and the American Public Health Association to obtain a "public option" in the Patient Protection and Affordable Care Act of 2010 because of opposition from insurance companies and others—a publicly financed and organized insurance plan that would have competed against private insurance plans and possibly lowered the cost of premiums.

Most advocates are willing to take risks and to devote time to case and policy advocacy even when they confront adverse odds and sometimes do not succeed.

A PHILOSOPHICAL PREMISE

Traditional models of healthcare emphasized its hierarchy extending from physicians at its apex and descending to an array of staff who assumed somewhat subordinate roles. The term *ancillary staff*, often applied to social workers, occupational therapy (OT) and physical therapy (PT) staff, and speech pathologists, describes this subordinate role. Even residents have often been placed in relatively subordinate roles in many hospitals, as have many nurses.

Alternatively, healthcare can be viewed as a partnership between many professions. In this view, consumers "belong" to a health team that includes members of many professions where no one is "ancillary." All members of the team need sophisticated knowledge of consumers' health needs to be able to be advocates for them. They need to know a lot about policies and institutions in the broader society. They need to be knowledgeable about such diverse topics as evidence-based medicine, second opinions, translation services, civil rights, health financing, medical errors, prevention, and court rulings.

It is the ethical obligation of healthcare professionals, in this view, to engage in case advocacy even when not specifically invited by other medical staff to participate. They are ethically obligated, as well, to engage in policy advocacy when they discover that many consumers need case advocacy because they encounter defective policies that are obstacles to the care that they need. They must engage in this work with diplomacy and with due respect to other medical staff, always making it clear by their demeanor, actions, and language that they want to advance the well-being of consumers.

AN OUTLINE OF THIS BOOK

I analyze the evolution of the U.S. health system in Chapter 2 to better understand why many of its consumers experience one or more of the seven problems. I provide a framework for case (or patient) advocacy in Chapter 3 that identifies eight tasks that advocates must undertake. It places advocacy in specific institutional, community, and policy contexts. It discusses how advocates identify contextual factors that assist their advocacies and that impede it.

I discuss four advocacy skills that frontline staff needs when engaging in case advocacy, including developing and using influence, engaging in ethical reasoning, using such interactional skills as communication, conflict management, and group skills; and using analytic skills in Chapter 4.

I emphasize case advocacy for consumers in Chapters 5 through 11 where I discuss policies and regulations germane to the seven problems, discuss some evidence-based research relevant to them, and present 118 scenarios that case advocates and consumers sometimes confront when they experience these seven problems. I provide some vignettes that illustrate the need for case advocacy, as well as the use of case advocacy by healthcare professionals or specific consumers.

I provide a policy-advocacy framework in Chapter 12 that describes eight tasks that advocates undertake when they seek to change specific policies in organizational, community, and government settings.

I discuss policy advocacy in organizational settings in Chapter 13. I relate evidence that frontline staff engages in case advocacy frequently with respect to one of the seven issues confronting healthcare consumers: protection of their ethical rights. This data suggests that case advocacy is integral to the work of many frontline staff even if it is often not sufficiently recognized and encouraged. I discovered, too, that frontline people want to do considerably more case advocacy with respect to consumers' ethical issues. I discuss strategies for embedding case advocacy in clinics and hospitals so that it becomes a recognized and integral part of the practice of healthcare professionals.

Policy advocacy in community and government settings is discussed in Chapter 14. I relate some promising reforms that policy advocates have achieved and are currently seeking to enact in local, state, and federal venues. Healthcare professionals can play an important role in troubleshooting the implementation of the Patient Protection and Affordable Care Act of 2010.

ONLINE MATERIALS RELEVANT TO THIS CHAPTER

Read an overview of the marginalized status of case advocacy in professional literature in social work, nursing, and medicine from 1940 to the present under the heading, "The Marginalizing of Case Advocacy in Professional Literature." Access these materials by going to the web site of John Wiley & Sons at www.wiley.com/go/jansson.

