

Chapter 1

HEALTH CARE DELIVERY SYSTEM

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Children's access to health care, the content and quality of services provided, and the outcomes of care all occur within the context of the health care delivery system. Understanding how health services can improve child health should begin with examining the structure of children's health care and the processes that occur once health professionals and patients interact. Findings from the relatively new scientific field of child health services research provide the pediatric care physician with a more accurate and complete picture of how health care affects child health.¹

This chapter uses a structure-process-outcome framework to describe the health care delivery system and to analyze its effects on children.² Structure refers to financial and organizational arrangements of the delivery system that are present before health professionals and patients interact. Structural elements include the pediatric workforce, child health care delivery sites, financing of services, and the medical home. Assessing the process of care includes investigating the scope of pediatric practice, the content of visits, pediatricians' referrals to specialists, and the quantity of different types of services delivered to children. The chapter concludes with an examination of the connections between pediatric services and child health outcomes.

HEALTH CARE DELIVERY SYSTEM: AN OVERVIEW

Health care is purchased by government, by employers with contributions from workers, and by individual consumers. Nearly one half of all health care is financed by the federal, state, and local governments. The organization of services—that is, the arrangement of providers and suppliers within the system—is strongly determined by how they are paid. Financing is a primary driver of organization. Changes occurred in the early 1980s when the prospective payment system was instituted by the federal government in the Medicare program. Hospital payment shifted from a

cost basis (payment for each service billed by the hospital) to a fixed fee that was based on the principal problem managed during the hospitalization (known as the diagnosis-related group [DRG]). This DRG-based payment system paid hospitals the same amount of money for all patients with appendicitis, regardless of how long they stayed or what services were provided. DRGs provided financial incentives to shorten lengths of stay and to shift services to the outpatient sector. The introduction of the DRG-based hospital payment system stimulated the proliferation of large outpatient specialty and surgical centers, with less emphasis on inpatient hospital bed growth. Today the United States has one of the lowest hospital admission rates throughout all developed nations, which is one of the legacies of the prospective payment system.

The delivery, or process of care, occurs when patients come into contact with providers or suppliers. The number and content of visits (utilization), the costs of these services, and the volume and types of surgical procedures are all examples of processes of care.

The degree to which health care is consistent with the best available medical evidence and linked to positive and desired health outcomes determines the level of quality of care. The end results of the health care delivery process are patient outcome, that is, changes in health, functional status, and patient well being.

STRUCTURE OF THE DELIVERY SYSTEM

Pediatric Workforce

Pediatrics and children's health care are not synonymous. A pluralistic mix of internal medicine, family medicine, pediatric specialties, and non-physician clinicians provides services to the nation's children.³ Individuals 17 years and younger make 23% of primary care visits to family physicians, whereas adolescents make more visits to specialists without pediatric training than to those with pediatric training. Nonetheless, pediatrics is widely viewed as the principal specialty responsible for setting child health care policy and ensuring the health of the nation's children.

Over the last several years, the increasing use of health care among older adults has been associated with pediatricians assuming responsibility

for a larger share of primary care visits made by children, whereas the number of child visits to family physicians has decreased. Key trends in the pediatric workforce that discussed in this chapter are (1) sustained interest in the field among graduating medical students, (2) more rapid growth in pediatricians than the population of children in the United States, (3) the dominance of women in the field, (4) the importance of international medical graduates to the pediatric workforce, especially the subspecialty workforce, and (5) a geographic maldistribution of providers.

By 2004 the total number of licensed physicians in the United States was approximately 870,000, with 8% (nearly 70,000) self-designating as pediatricians. The number of physicians has been growing steadily and at a faster rate than overall population growth. Approximately 70% of self-designated pediatricians obtain board certification from the American Board of Pediatrics (ABP), and 43,000 pediatricians are currently board certified in general pediatrics. Among certified general pediatricians, 1 in 5 obtains an additional certificate in a pediatric subspecialty.^{4,5} Although hospitals and health plans use board certification as a measure of clinical competence and expertise, the benefits of board certification on the quality and outcomes of patient care are not well established. The lack of this evidence may be a result of too few research studies devoted to this topic, inadequate measures of quality of care, health metrics that are poorly sensitive to change among children, or a problem with board certification itself in that it does not truly differentiate clinical competence among practitioners.

Across all medical specialties, women constitute 27% of all physicians but a much larger share for pediatrics. Currently, 69% of pediatric trainees are women, which contrasts with only 30% in 1975.⁴ The rise in the number of female pediatricians is one of the more impressive and important trends shaping the pediatric workforce. Women are more likely than men to work part time, and they spend fewer hours in direct patient care over their work lives. To maintain the same number of full-time equivalent physicians, more pediatricians may need to be trained each year in the future if the proportion of women in pediatrics remains as high as it is now or even increases.^{4,5}

In 2005, 202 accredited general pediatric residency training programs existed in the United

States and another 16 in Canada,⁴ and 10,190 pediatricians were enrolled in the US programs. When compared with 1991 figures, this growth is a 37% increase in the absolute number of pediatric residents, a rate of growth that far exceeds the proportional increase in the number of children in the country.⁶ Interest in pediatrics as a career choice continues to be strong. Approximately 14% of medical school seniors select a pediatric training program.

In 1967 the ABP and the American Board of Internal Medicine agreed that individuals who had 2 years of general internal medicine and 2 years of general pediatrics were eligible for board certification in both specialties.⁴ In 2005, over 90 combined med-peds residency programs in the United States offered 388 1st-year positions. However, the number of med-peds positions has been declining since 1997 when 459 1st-year slots were available. The percentage of women enrolled is less than in categorical pediatrics and has been stable over the last few years at approximately 50%. In rural communities or small towns, med-peds physicians may play a role as a consultant in the care of high-risk newborns and children who have a chronic illness or as a hospitalist for children and adults. In more competitive environments, internal medicine and pediatric practices can use the med-peds physician to attract new patients, especially adolescents and families desiring health care for everyone in the same practice. Because med-peds physicians can alter their practice according to patient demand, the amount of pediatric care that these health professionals will provide will likely decrease with the aging of the population.

Only 11% of pediatricians in the United States practice in rural communities to care for the 29% of the childhood population that live therein. By contrast, 37% of the children who live in large metropolitan areas are cared for by almost 59% of practicing pediatricians. The remaining 30% of practicing pediatricians live and practice in suburbia, serving 34% of the nation's children. Growth over the last decade in the number of child health physicians has not remedied the geographic disparities in their distribution. Except for pediatricians practicing in sparsely populated areas, which have limited hospital and technical support services and few pediatric specialists, pediatricians generally practice similarly throughout the United States. These professionals, as those in

other specialties, tend to settle in areas that have a high per capita income.

On average, 1 certified general pediatrician can be found for every 1700 children throughout the United States.⁴ This ratio is generally deemed to be an adequate supply of pediatricians, particularly given the higher growth in the number of pediatricians compared with the rate of growth of children. However, the statistic does not reflect important regional variation in the supply of pediatricians, with many rural and inner-city areas experiencing child health professional shortages. Approximately 1 in 10 children live in an area without a pediatrician. The location where residents complete their training is important determinant of job residence: States with fewer residency-training slots have lower pediatrician-to-child ratios. Interestingly, most geographic variation observed in the United States is not due to shortages of physicians, but results from substantial oversupply in particular locations.

International medical graduates (IMGs) constitute an important share of the pediatric workforce. The most common countries of citizenship for IMGs are (in rank order) the United States (ie, US citizens trained abroad), India, and Pakistan. In 1991, 33% of all 1st-year pediatric residents were IMGs, but this proportion dropped to 24% by 2005. IMGs account for a larger share of the subspecialist workforce. Nearly 1 in 3 board-certified pediatric subspecialists are IMGs. The subspecialties with the greatest proportions of IMG board-certified physicians are nephrology (41%), neonatology (40%), endocrinology (33%), and gastroenterology (33%). These data suggest that, for the foreseeable future, the pediatric workforce will require a large number of IMGs to work as both general and subspecialist pediatricians.⁷

Medical Training, Licensure, and Certification

Consumers and providers of health services differ in the priorities they place on the 3 main challenges of the health care delivery system: (1) ensuring access to care, (2) controlling costs, and (3) improving the quality of care. Costs of and access to medical care are of prime importance to consumers, who tend to assume that quality of care will always be good. In contrast, neither access nor cost is an important component of medical school training, which focuses almost exclusively on how to make a diagnosis; how to

support this diagnosis with appropriate information from the history, physical examination, and laboratory findings; and how to institute treatment that is appropriate to the diagnosis. The nature of most educational settings (university based, research oriented, with generally a highly specialized faculty) is responsible for a medical educational process that focuses largely on the biological bases of disease. In contrast, relatively little attention is devoted to understanding the social, occupational, and environmental causes of ill health, although issues such as these are major determinants of disease and dysfunction or patients' subjective assessment of their own health. Obtaining reliable and valid children's reports of their health is now possible in research settings. Application of these methods in clinical settings is a likely direction for clinical care and will enhance the ability of health care delivery systems to monitor their effectiveness.

The medical profession has always assumed responsibility for regulating entry into its ranks and for assessing the quality of care provided. Although state boards have the legal authority to dispense licenses to practice, all states delegate this responsibility to the profession, which nominates candidates, whom the state then licenses. Individuals merely must demonstrate that they graduated from medical school and can achieve a passing grade on a cognitive examination developed by the profession itself, either in the state (state licensing examinations) or nationally (the National Board of Medical Examiners or the Federation of State Licensing Boards, ie, Flex examinations).

The ABP requires certification renewal every 7 years for pediatricians certified after 1987. This renewal entails successful completion of the Program for Renewal of Certification in Pediatrics (PRCP), which includes a structured home study curriculum and a supervised, open-book written, or computer-based examination. Diplomates certified before 1988 may choose to renew their certification by completing the PRCP voluntarily.

Most health care provider organizations use certification and recertification data as one means of ensuring quality of care, requiring their pediatricians to be either board certified (having passed the written examination) or board eligible (having completed 3 years of pediatric residency training in an accredited program) with certification within 5 years of completion of residency

training. Pediatricians are not required to demonstrate competence under the conditions of actual practice, either when they enter practice or at any time afterward.

Although all practitioners must demonstrate at least a minimal amount of theoretic knowledge as a condition of licensure before they enter practice, the relationship between performance in tests and subsequent quality of practice has not been consistently demonstrated. Even the procedure by which physicians become certified as specialists provides dubious assurance of high quality. Board certification, apart from its relationship to longer lengths of postgraduate training, appears to have no relationship to practice quality. Continuing education requirements and periodic recertification procedures imposed by professional organizations are unlikely to improve the situation unless the model of quality of care on which the original educational and certification procedures are based is broadened to encompass assessment of the effect of services on health status.

Pediatric Specialization

In addition to general pediatrics, 16 areas of pediatric subspecialization are certifiable by the ABP (Table 1-1). A growing number of pediatricians appear to be selecting a career as a specialist. The absolute number of subspecialty trainees increased by 46% between 1996 and 2003. In 2005, 66% of 1st-time general pediatrics diplomates selected a career as a general pediatrician, 29% a career in a pediatric subspecialty, and 5% in another nonpediatric specialty. The top 5 career choices among pediatric subspecialty fields are neonatal-perinatal medicine, critical care medicine, hematology-oncology, cardiology, and emergency medicine. Women graduating from medical schools more recently are more likely than their older female counterparts to choose a subspecialty career, although male physicians still predominate within most subspecialties, particularly those that are procedure oriented (eg, cardiology, gastroenterology).

Only 59% of the certified pediatric subspecialists' time is spent in direct patient care. The remainder is spent in administration, research, and teaching, because 60% practice in academic health centers, which contrasts with fewer than 33% of internal medicine subspecialists who do so. For individuals who are not in academia,

almost 50% of endocrinologists and gastroenterologists do part-time work in general pediatrics, as do 73% of those entering nephrology.

Hospitalists

The traditional American system of care in which primary care physicians have cared for their hospitalized patients is undergoing a revolutionary change in many urban and suburban areas. A recent alternative allows primary care physicians to relinquish the care of their hospitalized patients voluntarily to a new group of inpatient generalists called *hospitalists*. Estimates suggest that 8000 US physicians function as hospitalists, just 600 of whom in 2002 were pediatricians. In 2003, 40% of pediatricians were affiliated with a hospital that employed a hospitalist. This proportion is expected to grow over the next several years.⁸

Hospitalists are physicians whose main responsibility is the general medical care of hospitalized patients and whose responsibilities may also include teaching, research, and hospital care management. Patients are referred by their primary care physicians and are referred back at the time of hospital discharge. Strong emphasis is placed on communication between the 2 physicians during the patient's hospital stay. The disadvantages of this arrangement include a loss of continuity of care between the primary care physician and the patient and a decreased scope of practice among general pediatricians.

On the other hand, the use of hospitalists allows for increased productivity by the office-based pediatrician. During office hours, leaving the office with waiting patients to see a hospitalized patient is difficult for a practitioner. Other reported advantages of hospitalists include their competency in technical skills (skills easily lost to the physician who visits the hospital only occasionally), shorter patient hospital stays because of constant in-hospital supervision, and the immediate availability of urgent care. (See Chapter 21, Hospital Care, and Chapter 20, Hospitalist Medicine: Communicating With Patients and Families.)

Nonphysician Clinicians

A large body of research evidence indicates that nonphysician clinicians—nurse practitioners and physician assistants—provide health care for many health conditions that is of equal quality to physicians. Because they can be trained at lower costs to society and their salaries are lower than

Table 1-1 Number of Board-Certified Pediatric Subspecialists Through 2005

PEDIATRIC SUBSPECIALTY	NUMBER CERTIFIED
Adolescent medicine (1994)*	505
Cardiology (1961)	1870
Critical care medicine (1987)	1287
Developmental-behavioral Pediatrics (2002)	427
Emergency medicine (1992)	1291
Endocrinology (1978)	1055
Gastroenterology (1990)	872
Hematology-oncology (1974)	1874
Infectious diseases (1994)	992
Medical toxicology (1994)	30
Neonatology-perinatal medicine (1975)	4421
Nephrology (1974)	668
Neurodevelopmental disabilities (2001)	241
Pulmonology (1986)	767
Rheumatology (1992)	215
Sports medicine (1993)	108

*Year in parentheses indicates when subspecialty board was established.

Source: American Board of Pediatrics. Workforce Data: The American Board of Pediatrics, 2005-2006. Available at: www.abp.org/ABPWebSite/stats/wrkfrc/workforce05.pdf.

those of physicians, many physician organizations and health maintenance organizations employ these professionals as primary care physicians and physician extenders in specialty settings. States are giving more independence to nonphysician clinicians, a tendency that has also stimulated their growth.

Pediatric nurse practitioners (PNPs) are usually prepared at the master's degree level. They are trained in the discipline of nursing, which has a strong emphasis on patient education and methods for coping with illness. Approximately 90% practice in primary care settings. A small share may be certified in a specialty. PNPs conduct physical examinations, track medical histories, make diagnoses, treat minor illnesses and injuries, monitor chronic disease maintenance therapy, and provide an array of counseling and educational services. In many states, PNPs prescribe medications independently, admit patients to hospitals, and make hospital rounds.

Physician assistants (PAs) are health personnel who are typically trained in 2 or 3 years to render basic health services that are also performed by physicians. PAs are health care professionals licensed to practice medicine with physician supervision. Similar to nurse practitioners, PAs

conduct physical examinations, diagnose and treat illnesses, order and interpret tests, and counsel on preventive health care; they may also assist in surgery and in other procedures. In 49 states, PAs can write prescriptions. Because of the close working relationship the PAs have with physicians, PAs are educated in the medical model designed to complement physician training. The demand is huge for PNPs (approximately 10,000 in the United States) and for PAs, (approximately 6000 in pediatric activity). Estimates indicate that 33% of PNPs practice in hospital clinics, 23% in private pediatric practices, 13% in community and public health settings, and 30% in schools and health maintenance organizations. In some underserved and rural areas, PNPs are the only source of primary pediatric care.

Child Health Care Delivery Sites

Children receive health care services in a large variety of inpatient and outpatient settings. Although home visits and home-based care were once commonplace in the United States, the vast majority of pediatric professionals no longer make house calls. In other countries, however, nurse home visitation, particularly for families of

newborn and infant children, is a routine part of pediatric care.

Inpatient Care Facilities

Hospitals have changed dramatically over the last 20 years in response to financial pressures to reduce lengths of stay and rates of admission. Many hospitals now offer a wide range of services, including inpatient care, outpatient diagnostic procedures, surgery, and outpatient physician visits. Whereas all inpatient care occurs in hospitals, hospital care can no longer be equated with inpatient care.

Approximately 5000 hospitals exist in the United States, and 250 (5%) of these are considered children's hospitals. Children's hospitals can be categorized as free-standing (approximately 20%) children's hospitals within larger general hospitals (approximately 45%) and other specialty, orthopedic, rehabilitative, and psychiatric hospitals (approximately 35%).⁹ Approximately 3 million children are hospitalized each year, and children's hospitals account for a third of these admissions. Thus the majority of children are treated in general hospitals with pediatric inpatient care units.

According to data from the Agency for Healthcare Research and Quality, 7% of Americans are hospitalized annually, but only 3% of children and adolescents have a hospital stay (8% of children younger than 6 years enter the hospital at least once per year, whereas only 2% of those 6 to 17 years of age are hospitalized during the course of a year).¹⁰ Children residing in low-income communities are more likely to be admitted to the hospital via the emergency department compared with those from higher-income residences. This difference may be a result of poorer access to primary care physicians in low-income communities and thus greater reliance on emergency departments. The average number of days a child remains in the hospital ranges from 3 to 4, but great variation exists in length of stay according to reason for hospitalization, type of health insurance, and, to a smaller degree, the type of hospital.

Only 15% of hospitals have a for-profit tax status, whereas 58% are nonprofit, 22% are owned by state and local governments, and 5% are owned by the federal government. The not-for-profit tax status allows these institutions to forgo paying taxes to the government and to borrow

money in the tax-exempt bond market. In return for these benefits, nonprofit hospitals are expected to provide services to the community, perhaps by accepting all patients regardless of ability to pay or by mounting community health programs.

Twenty percent of hospitals are teaching hospitals, which means that they are affiliated with one of the nation's 130 medical schools. Nearly one half of all US hospitals are located in rural areas, where the vast majority are small institutions with fewer than 100 beds total. In 2004, slightly less than 1 hospital bed for every 1000 children existed in the United States. Children's access to inpatient services in the United States is excellent.

Outpatient Care Facilities

Outpatient visits for children occur in a large variety of publicly and privately owned facilities, the most important of which are physician's offices, community health centers, hospital-based outpatient clinics, school-based health centers, emergency departments, urgent-care centers, and, most recently, retail-based clinics located in drug stores and stores such as Wal-Mart and Target.¹¹ Unfortunately, services that occur for the same patient in these varied settings are poorly coordinated and devoid of a centralized locus of information, needs assessment, or outcome evaluation. Some authors have called the child health care delivery system **a non-system of care as result** of this lack of integration.

ACCESS TO OUTPATIENT SERVICES. Approximately 70% of children have at least 1 visit to a physician's office each year, 6% visit physicians in a hospital clinic, and 12% have 1 or more emergency department visits.¹⁰ Many studies have documented that children make fewer than the number of visits recommended by the American Academy of Pediatrics (AAP). Barriers to accessing outpatient services are a chief cause of this underuse. The most important barrier to accessing care is financial. For example, use of dentists in the United States remains low, with just 42% of children seeing a dentist annually, a consequence of lack of insurance financing for these services. For other types of services, children's insurance may not fully cover the office visit. (Lack of coverage among insured persons for needed services is a problem that has been labeled *underinsurance*.) Additional access barriers to seeking outpatient care include geographic access problems

(lack of child health care practitioners in the community or difficulty traveling to the practice site) and organizational access problems (for nonnative English speakers a lack of interpreters, limited after hours care, or long appointment waits).

One-parent families and those with 2 working parents now make up the majority of families in the United States.¹² To maintain access to services, practices have been forced to extend their office hours to provide coverage during evenings and on weekends, in addition to on-call coverage at night. This trend is a radical departure from the office hours that pediatricians traditionally provided. After-hours coverage is provided in settings that are convenient, such as using the pediatrician's own office or an examination suite at the local community hospital. Many pediatricians join with their colleagues in sharing after-hours or weekend coverage. They take turns covering the telephone and meeting patients' needs, with prompt referral back to the patient's designated physician. This approach provides efficient off-hours medical care and affords each practitioner more time for rest, relaxation, and the pursuit of personal interests. To improve geographic access, pediatricians also have embraced the concept of the satellite office as a response to the movement of young families to the suburbs. These offices offer the same complete pediatric care available in the main office but are more accessible to suburban dwellers. Satellite offices often outgrow the main office as communities change in character or demographics and establish an identity of their own.

PHYSICIAN ORGANIZATIONS. Pediatric physician organizations can be categorized into solo practice, group practice (single-specialty practices with general pediatricians only and multi-specialty groups, which include general pediatrics and other types of specialties), health maintenance organizations, hospital-based practices, and free-standing emergency departments. The practice locations for office-based pediatricians in 2000 are shown in Table 1-2.¹³

Once common, solo practice is now clearly in decline. One in 10 physicians works in solo practice, but only 1 in 25 new physicians entering the workforce are choosing solo practice. Staffing an office with a single physician provides better continuity of care for patients and requires autonomous decision making on the business aspects of health care. This autonomy has been

appealing to some physicians. On the other hand, physicians in solo practice have a more difficult time arranging for after-hours, weekend, and vacation coverage than their group practice peers. Pediatricians entering the medical marketplace are increasingly concerned not only with their incomes, but also with such quality of life factors as time spent in the office, vacation, and coverage flexibility. Other benefits of group practice include administrative economies of scale, more stable cash flow, stronger negotiating position with health plans, greater financial reserves, which may facilitate investments in practice improvements such as health information technology, and the possibility of physicians developing areas of special expertise, which is useful for both primary care and specialty practices. Most medical groups in this country have fewer than 10 physicians.

Community health centers are 1 component of the federal government's consolidated Health Center Program that also includes homeless health centers, centers in public housing, and migrant health centers. For over 30 years, the Bureau of Primary Health Care within the US Department of Health and Human Services, the Health Resources and Services Administration, has provided federal support for health center programs.¹⁴ These resources are used to fund services for medically underserved populations, particularly uninsured children and their families, immigrant and seasonal farm workers and their families, homeless persons, public housing residents, and those needing school-based health care. Community health centers focus on providing comprehensive primary health care to persons in medically underserved areas. Approximately 4% of all primary care visits among children in the United States occur at community health centers, 8% in hospital primary care clinics, and the rest (88%) occur in physicians' offices.¹⁵ The proportions of visits made to community health clinics and hospital clinics are much higher for the uninsured and minority racial and ethnic groups because of poorer access to physician practices for these groups.

Several other public-sector *safety-net* provider systems offer health care services for uninsured and underinsured pediatric patients. These entities include local public health departments, community and migrant health centers, public

TYPE OF PRACTICE SETTING	PERCENTAGE OF PRACTICE TYPE
Self-employed solo practice	10
Two-physician group	6
Pediatrics group	26
Multiple-specialty group	12
Health maintenance organization (staff model)	5
Academic medical center	15
Nongovernment hospital	11
Government hospital or clinic	6
Other (eg, free-standing emergency department, community health center, etc)	11

Source: American Academy of Pediatrics. Socio-economic Survey of Pediatricians. Available at: www.aap.org/research/periodicsurvey/ps43soci.htm.

hospital systems, and school-based clinic systems. In addition, many not-for-profit organizations assist in meeting the health care needs of uninsured and underinsured children.

MEDICAL HOME. Over 90% of children identify a single practice as the place they usually go for their preventive and illness-related care. Children with a usual source of care use fewer emergency department services, are more satisfied with their care, and have shorter hospital stays than counterparts who lack such a place. Recent parlance has substituted the medical home for usual source of care, and a growing amount of policy development and quality improvement activities have addressed this concept.

Even for children who have a regular source of care, this source does not always provide all the required services, nor does it always integrate the services that the child has received elsewhere. Many children who have a physician whom they identify as their usual source of care go to other physicians when they need medical services. Primary care physicians may not be aware of these other visits, even though they may significantly influence the patient's response to subsequent care. Patients are often required to change their primary care physician when their parents' employer changes its managed health care contract.

This fragmented, uncoordinated care presents a major challenge to the profession's health care goals. If practitioners, health programs, and health institutions continue to function separately, without coordination, and if individuals continue to seek care from several sources, then

duplication of services will result, with an ever-increasing cost of care without commensurate gains. In fact, effectiveness is likely to diminish because different practitioners often give patients conflicting advice and treatment. The medical home concept is an approach for rectifying these problems. Desirable attributes of the medical home have been promulgated by the AAP.¹⁶

The pediatric primary care medical home is important for all children, not simply those who have long-term special health care needs. In addition to providing routine preventive services, anticipatory guidance, and acute care, the medical home adds several components to the conventional examination room-based model of primary care: registries of patients with specific diseases to better facilitate ongoing chronic care management; care coordination process that link children and families to appropriate medical, social, and community services; active and integrated comanagement between primary and specialty care; and patient education, particularly for patients with chronic and psychological disorders. The medical home should be easily accessible for patients, promote continuity of care, provide a wide range of services to meet most of the needs of children, and coordinate care received in all locations. These functions—access, continuity, comprehensiveness, and coordination—are the core attributes of primary care as defined by the Institute of Medicine.¹⁷ Research evidence demonstrates that when these functions are attained at a high level, children are less likely to be hospitalized for health problems that might be managed in outpatient settings,

families report greater satisfaction with care, and health care costs are reduced.¹⁸ (For a comprehensive discussion regarding the medical home, see **Chapter 8, Medical Home Collaborative Care.**)

PATIENT-CALL CENTERS OR AFTER-HOUR PROGRAMS. Pediatric call centers or after-hours programs (AHPs) have been established in all areas of the United States. Patients greatly value ready access to medical advice outside of office hours, a trend that has grown with the rise of 2 parents in the workforce because pediatricians' obligations to their patients do not cease when the office closes and because many calls are for non-urgent matters.

AHPs are staffed by trained personnel on nights, weekends, and holidays. They give advice for symptomatic care and appropriate prescription refills, make referrals to an emergency facility or to an after-hours pediatric office, or advise seeing the patient's own pediatrician during office hours. AHPs operate under professional oversight, using standardized protocols provided by pediatricians who use their services. In many instances, health care systems subsidize AHPs on behalf of their network of pediatricians because of the efficiency and cost savings attributed to them.

In a large, multicenter study, 65% of parents reported no preference about speaking with a physician or nonphysician for after-hours care, but 28% indicated a preference to speak with a physician.¹⁹ Over 80% of parents follow through with recommendations made by the call center professionals.

PROCESSES OF HEALTH CARE

The process of health care is composed of the interactions between patients and professionals. From the physician's perspective, key processes include identification of and screening for new problems; patient education; matching appropriate services to a patient's needs; diagnosis using cognitive processes, laboratory testing, and imaging studies; treatment with watchful waiting, information giving and guidance, prescribing, and therapeutic procedures; follow-up of ongoing problems; referral to specialists and community resources; and admission to hospital. From the patient and family's perspectives, the key process of health care are seeking health care and choosing to use services, disclosing health-related information and asking questions, self-

management for ongoing problems, participating in the recommended care plan, and assessing treatment effectiveness.

Scope of Pediatric Practice

The time a pediatrician spends in office practice remains challenging and interesting, although it is channeled differently than it was in the past. Through much of the early and middle 20th century, the practicing general pediatrician was the daily expert, always on call in the office for families in need or making frequent house calls and hospital rounds. The practitioner provided care to premature infants, to well and sick newborns, and to well and sick children in and out of the hospital. General pediatricians diagnosed and treated rheumatic fever, glomerulonephritis, all forms of infectious illnesses, and most forms of cardiac, neurologic, and allergic diseases. In short, general pediatricians dealt with all minor and most major illnesses. Subspecialists were few, usually found only in academic medical centers. Concepts such as *primary* and *tertiary* care were unknown, and pediatric intensivists, neonatologists, and other subspecialists did not exist in community hospitals. Time for parental health education was reduced because the pediatrician had to provide definitive care in the office, the home, and the hospital for virtually all diseases affecting their patients.

Today, the office-based, primary care pediatrician deals with illnesses that are only potentially serious and spends a good bit of time promoting health and well being. The patient is almost always seen in the office, rarely in the hospital, and almost never in the home. The variety of illnesses treated by the primary care pediatrician today does not even remotely resemble those of the past. Upper respiratory tract infections, moderate lower respiratory tract problems, feeding problems, gastrointestinal upsets, and minor trauma account for 75% to 85% of illness care. A large portion of practice time is now spent giving well-child care, dealing with family dynamics, and managing the new morbidities of mental illness, obesity, and school failure. The new scope of contemporary pediatric primary care is summarized in **Box 1-1.**

Changes in how acute infections are managed or prevented will have important and perhaps even dramatic effects on the future scope of pediatric practice. National policy recommendations

BOX 1-1 Scope of Pediatric Primary Care Practice

- Prenatal counseling to families preparing for the birth of their child
- Immunization for all age groups in the practice, with prior educational advice as to the benefit, risk, and alternatives, if any
- Acute illness management, including watchful waiting, appropriate prescribing, education, and follow-up
- Injury prevention by giving advice about seat belts, smoke alarms, water safety, home safety, poison control, and bicycle helmets
- Minor injury treatment
- Coordinating services for children with complex medical needs
- Structuring the practice consistent with the principles of the medical home
- Collaborating with families to support the achievement of educational goals from infancy through adolescence
- Becoming an expert on violence prevention and abuse avoidance
- Advice and support during divorce, marital crises, or other the loss of a family member
- Counseling families on lifestyle goals, such as the need for family time and for an understanding of work-related time constraints and stresses and how the family copes with them
- Promoting good health habits through advice about a prudent diet and nutrition, exercise, and dental hygiene
- Promoting avoidance of bad health habits such as sedentary activity, excessive television watching and video game playing, and parental smoking
- Identification and management of developmental and psychosocial problems, which is composed of screening, talk therapy, medication management, referral and comanagement with behavioral health specialists, and linkage with appropriate community resources
- Encouraging community activism through knowledge and use of common resources and involvement with school boards, religious groups, school athletic programs, and community facilities
- Care of adolescents and young adults, with the twin goals of providing guidance and anticipating problems in areas such as sexuality, sexually transmitted disease avoidance, drug and alcohol abuse and teenage pregnancy prevention, and education and career goals advice
- Supporting families to ensure that all children become flourishing adults

to decrease use of antibiotics for viral illnesses and otitis media have led to fewer prescriptions and visits for these conditions. New vaccines will further reduce the burden of acute illnesses in pediatric practice and will free pediatricians to provide more comprehensive services to enhance child health and development; promote healthy transitions into school, adolescence, and adulthood; reduce the suffering associated with psychosocial problems; and collaborate with families to maximize the chances that all children become flourishing adults.

Between 1993 and 2000 the proportion of pediatricians working part time increased from 11% to 20%. On average, however, the way in which pediatricians spent their time was constant between these years (Figure 1-1). Office-based pediatricians work 52 hours per week, spending approximately 40 of these hours in

direct patient care. Direct patient care occurs predominantly in office settings, but pediatricians also spend approximately 5 hours per week in hospitals, several hours on the telephone talking with parents, and small portions of time in the emergency department and delivery room. Full-time pediatricians work approximately 55 hours per week, whereas part-time workers spend 35 hours per week.

Referrals: Linking Primary Care With Specialty Care

Physicians providing primary pediatric health care assume responsibility for a broad spectrum of preventive and curative care and for coordinating the care their patients receive from other physicians. When primary care physicians need assistance in diagnosing and managing difficult cases,

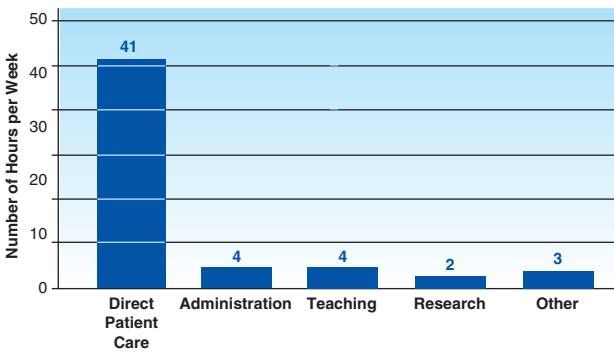


Figure 1-1 Hours per week spent in direct patient care, administration outside the practice, medical teaching, clinical or health services research, and other activities (eg, volunteer work) among pediatricians who have completed postgraduate training. (Source: American Academy of Pediatrics. *Socio-economic Survey of Pediatricians*. Available at: www.aap.org/research/periodicsurvey/ps43soci.htm.)

desire a specialized test or procedure (eg, endoscopy or surgery), or believe that management of their patients' health problems falls outside their scope-of-practice, they seek consultation and referral. (See Chapter 19, Art of Referral, Consultation, and Collaborative Management.) Approximately 2% of all general pediatric visits lead to a referral, and pediatricians make approximately 1 referral a day.²⁰ Referrals are also made in telephone conversations with parents, which account for 25% of all referrals. For 75% of referrals, pediatricians anticipate sharing care with, not delegating care entirely to, the specialist; unfortunately, this practice is not often achieved.

The 15 most common health problems that general pediatricians refer to specialists and the types of specialists referred to for each problem are shown in Table 1-3. Approximately 1 in 10 referrals are made for management of otitis media. Most referrals are not for chronic diseases or for children with special health care needs but are made for time-limited musculoskeletal, skin, eye, or ear, nose, and throat problems. An important caveat is the large share of referrals comprised by psychosocial and developmental problems, which, if combined, would be the most common reason for referral. Many specialties have overlapping scopes of practice, which is reflected in Table 1-3; for example, pediatricians send patients with hernias and hydroceles to both general surgeons and urologists. Why 1 type of specialist is selected rather than another is related

to a pediatrician's personal preference and the relationships the primary care physician may have with specialist colleagues.

Visits to Pediatricians

The National Center for Health Statistics reported that, in 2004, 910 million visits were made to office-based physicians, 13% of these were to pediatricians. The annual number of visits made by children and adolescents is highly related to age: 6.7 visits per person for children younger than 1 year, 2.8 visits per person for 1 to 4 year olds, and 1.9 visits per person for those between 5 and 14 years of age.

In 1993, pediatricians reported an average of 103 visits per week, whereas by 2000 the figure had decreased to 94, or approximately 19 patients per day. An average visit lasts 15 minutes, although duration of visits varies substantially according to content of the visit. Appointments made for comprehensive preventive care visits are much longer, for example, than others made for illness follow-up.

The primary reasons for pediatric visit are summarized in Table 1-4. Approximately one third of visits are for well-child care or prevention, another third is for diagnosis and treatment of physical problems, and the rest are for a variety of additional reasons. With the changing scope of pediatric practice, the share of visits devoted to acute management of physical health problems (currently approximately 30% of visits) is expected to decrease, whereas follow-up and management of psychosocial problems should increase.

Among young children, an equal proportion of visits are made to pediatric subspecialists and nonpediatric-trained specialists. By adolescence, however, a greater share of visits occurs with specialists who are not trained as pediatricians. Pediatric societies have championed the notion that the specialty care of children and adolescents should be provided by pediatric-trained medical and surgical specialists. For example, the Surgical Advisory Panel of the AAP in 2002 asserted that all children 5 years or younger who require surgical care should be referred to a pediatric surgeon.²¹

Physician Disciplining and Medical Liability

One of the most common methods used to address poor quality is through physician

Table 1-3 The 15 Most Common Health Problems General Pediatricians Refer to Specialists and Nonphysician Clinicians With Specialized Skills.

HEALTH PROBLEM REFERRED	PERCENTAGE OF ALL REFERRALS MADE BY GENERAL PEDIATRICIANS	TWO MOST COMMON TYPES OF SPECIALISTS REFERRED TO (PERCENTAGE OF TOTAL)
Otitis media	9.2	Otolaryngologist (95.3) Audiologist (3.5)
Refractive errors	5.6	Ophthalmologist (67.3) Optometrist (32.7)
Musculoskeletal signs and symptoms	5.0	Orthopedic surgeon (71.0) Physical therapist (11.8)
Benign skin lesions	4.5	Dermatologist (80.7) Plastic surgeon (10.8)
Behavioral problems	3.5	Psychologist (58.5) Psychiatrist (18.5)
Fractures (excluding digits and hips)	2.9	Orthopedic surgeon (92.5) Otolaryngologist (7.5)
Joint disorders, trauma related	2.7	Orthopedic surgeon (87.8) Physical therapist (12.2)
Developmental delay	2.6	Neurologist (20.8) Orthopedic surgeon (12.5)
Hearing loss	2.5	Audiologist (71.3) Otolaryngologist (28.3)
Strabismus, amblyopia	2.5	Ophthalmologist (97.8) Optometrist (2.2)
Viral warts and molluscum contagiosum	2.5	Dermatologist (87.0) Podiatrist (8.7)
External abdominal hernia and hydrocele	2.3	Pediatric or general surgeon (90.7) Urologist (9.3)
Depression and anxiety	2.3	Psychiatrist (52.4) Psychologist (40.4)
Allergies	2.1	Allergist (89.5) Ophthalmologist (5.3)
Chronic pharyngitis and tonsillitis	2.0	Otolaryngologist (94.6) Speech therapist (2.7)

Source: Forrest CB, Glade GB, Baker A, et al. The pediatric primary-specialty care interface: how pediatricians refer children and adolescents to specialty care. *Arch Pediatr Adolesc Med.* 1999;153:705-714.

disciplining programs and the medical malpractice system, even though the overall effect on quality of children's health care is low. In some countries, government agencies deal with patients' dissatisfaction and complaints. The consequences of these deliberations may be to exonerate the physician or recommend sanctions (usually financial) against the physician. The medical profession in the United States has been

impotent in meaningfully disciplining its members because no way has been found to impose sanctions short of revoking a license, which is rarely done. To date, both professional and legislative bodies have failed to come to grips with this issue.

Pediatricians practice in an environment marked by skyrocketing professional liability claims, and, in some communities, insurance

Table 1-4 Reasons for Pediatric Visits

REASON FOR VISIT	PERCENTAGE
Well-child care or prevention	37
Physical health problems: diagnosis, treatment, or both	30
Referral or consultation	2
Follow-up for a specific health problem	15
Psychosocial health problems: diagnosis, treatment, or both	8
Ambiguous or unclear problems	6
Other	2

Sources: American Academy of Pediatrics. Socio-economic Survey of Pediatricians. Available at: www.aap.org/research/periodicsurvey/ps43soci.htm; Forrest CB, Glade GB, Baker A, et al. The pediatric primary-specialty care interface: how pediatricians refer children and adolescents to specialty care. *Arch Pediatr Adolesc Med* 1999;153:705-714.

carriers have stopped underwriting pediatric malpractice policies.²² Some physicians pay annual premiums as high as \$25,000, which constitutes a significant percentage of physicians' gross income. Although pediatricians are less likely than other physicians to be sued, claims paid by insurers for pediatricians are among the highest of any specialty. Approximately one half of all claims are paid for young (younger than 45 years) pediatricians. Common reasons for malpractice lawsuits against pediatricians include problems with medical record documentation, failure to diagnose meningitis or sepsis, delay in diagnosing congenital dislocation of the hip or congenital hypothyroidism, mismanagement of croup and epiglottitis, and medication errors. Because of the variability among states in statutes of limitation for filing malpractice claims on behalf of minors, and because of failure to set monetary limits for malpractice awards, pediatricians are at risk not only for high awards, but also for settlement many years after the alleged malpractice occurred.

The 2001 periodic survey by the AAP revealed that, overall, no change in the frequency or nature of pediatricians' experiences had occurred with malpractice suits over the prior 15 years. On average, a pediatrician is sued 1.7 times. Approximately one third of claims are dropped by the plaintiff, and another third are settled out of court. Pediatricians are 3 times as likely as plaintiffs to win a case if it goes to court. Patients seen when covering another pediatrician's practice and hospitalized patients are most likely to generate malpractice suits.

To avoid malpractice suits, pediatricians should make prudent referrals, test appropriately, maintain good records, spend adequate time with patients, listen carefully to and address their concerns thoroughly, and use other techniques as listed in **Box 1-2**. However, no evidence has been found that either adopting these approaches or attending risk-management educational programs in reducing medical malpractice suits is effective. Defensive medicine has had an economic effect by increasing medical care expenditures. The best estimates are that it increases total health care costs in the United States by approximately 0.5% to 4%. Some of these practice changes may improve medical care; others may be unnecessary or even harmful. Because of a perceived change in physician-patient relationships resulting from the threat of liability, the pleasure of practice has lessened. Changes that are fair and equitable to both the public and the medical profession depend on societal attention to this difficult problem.

OUTCOMES OF CARE

The purpose of health care is not merely to build delivery systems or produce services. Citizens have child health care delivery systems to improve children's health, functioning, and well being. Thus the most important measures of pediatric health care effectiveness are related to the impact of services on child health, functioning, and well being.

The claim *children are healthy* is a myth with origins in the anachronistic notion of children as little adults. The key issue is the definition of

BOX 1-2 Ways to Avoid Malpractice Suits

STANDARDS

Meet normative standards of health care delivery (ie, according to expert opinion as found in medical textbooks, articles in scientific journals, or evidence-based medicine reviews) and empirical standards (ie, according to local medical practice).

COMMUNICATION

- Use positive methods in communicating with patients and parents, showing respect, understanding, concern, and compassion.
- Train staff members to be sensitive to a patient's needs at all times.
- Train staff members to manage patient telephone calls properly and to log all incoming and outgoing telephone calls, including patient problems and instructions given.

DOCUMENTATION

- Document the care process as completely as possible.
 1. Record on the 1st page of a patient's chart drug allergies and problem list.
 2. Record for each visit the history, findings on physical examination (including pertinent negative findings), diagnostic tests ordered (including their results), and treatment prescribed in sufficient detail for purposes of recall.
 3. Record all immunizations given and all screening test results.
 4. Record all telephone calls during which medical information about the patient was received or advice given; include date and time.
- Document using an electronic health record or write as legibly as possible.
- Place in the patient's chart discharge summaries of hospitalizations and referral letters to and responses from consultants.
- Never alter a chart in response to a claim. If a change in the meaning of a note is warranted as a result of newer findings or recollections, then write and date a new note referring to the previous note, leaving the original untouched.

healthy. If children are considered *little adults*, then their lower disease burden is certainly an indicator of better health. Only 10% of children have one of the long-term disorders—diabetes, cardiovascular disease, or asthma—that are typically included in disease-specific studies. The low prevalence of medical disorders calls into question the appropriateness for children of the conventional disease-oriented model of health. Certainly, a focus on children with chronic conditions merits continued attention. However, if improvement in the health of all children is the goal, then pediatric care physicians need to expand the conceptualization of child outcomes to capture the variability of health within the general population.

The dynamic developmental trajectories of childhood and the importance of the family to child outcomes are additional reasons why a child-specific outcomes framework is needed. Perspectives of health that incorporate a time

dimension and the need to consider factors that threaten and promote future health are now recognized to encompass commonly accepted definitions of health. Using this comprehensive concept of health, more than 50% of children have a significant need in terms of their well being and self-esteem, symptom burden, risk behaviors, or psychosocial resilience.

The time dimension of health suggests the need to focus attention on risks—health states and behaviors that are precursors to future morbidity, injury, and illness. Although the consequences of risks may not manifest themselves until adulthood, antecedents to risk behaviors and states are molded during childhood, and many risk behaviors make their debut in adolescence. The weight-activity-nutrition complex illustrates this life-course perspective. In childhood, the antecedents to obesity—eating and activity behaviors—are formed. By late middle childhood and early adolescence, approximately

1 in 6 individuals is overweight, with a heightened risk for future disease. For most individuals, the consequences of obesity—diabetes, asthma, low back pain, hypertension, and heart disease—do not become a problem until adulthood, although they occasionally appear in adolescence and even in childhood.

Promoting child health has intrinsic merit and has benefits for adulthood. Viewing health across the life span has been called the *life course model of health*. The model suggests that health is produced across the life span, but childhood is a critical period. Unique person-environment interactions exist at each stage of development, some of which can have profound effects on future health.

In summary, a framework for assessing the effects of health delivery systems on child outcomes must be specific to the unique needs and experiences of children, developmentally sensitive, incorporate a time dimension, and rooted in a life-course model of health production. Table 1-5 provides such a framework, showing the key child outcome concepts and examples of specific metrics. Each of the 8 child outcome domains from Table 1-5 is discussed here, with special emphasis given to linkages with medical services.

Survival

The significant declines in mortality over the last century can be attributed more to improvements in public health than to specific technological advances applied to individual patients. The discovery of antibiotics is the only scientific advance applied to individual patients who are ill that has had a major impact in improving length of life. The marked improvement in life expectancy over the last century has resulted primarily from lowered infant mortality. Infant mortality began to decline long before specific medical interventions were imposed, and the decline resulted from general improvements in sanitation, maternal nutrition, hygiene, and infant feeding. Immunizations are an important, although not primary, determinant of this decline. After infancy, deaths in childhood are so relatively infrequent that they are an insensitive indicator of the value of medical interventions. Some researchers have argued that disease-specific mortality statistics, such as 5-year cancer survival, are the most compelling mortality statistics to use to assess system effectiveness because they are directly related to the adequacy of treatment.

Injury and Disease

Even though pediatricians may not be able to prevent the occurrence of most disorders, they should be expert at recognizing these problems when they occur. The application of diagnostic or therapeutic strategies requires first that problems, or potential problems, be recognized. Evidence indicates that the existence of many types of health problems is often overlooked. For example, physicians are consistently poorer at recognizing the existence of behavior problems and social factors related to illness than they are at recognizing problems that have obvious biophysiological or anatomic manifestations. However, even organic problems may be neglected. Many children, and adults as well, have health conditions that their physicians fail to identify even when information about these conditions is available. Failure to recognize the problems that patients bring to physicians is a serious shortcoming in the provision of health services.

Problem recognition also extends to prevention of disease. One type of prevention, *primary prevention*, is traditional to pediatricians. It consists of recognizing susceptibility to disease and applying interventions to prevent disease from occurring. Although immunizations are the most obvious example of primary prevention, prevention goes far beyond this measure. In some instances, only certain people are at risk of acquiring disease later in life; pediatricians must direct efforts at discovering who these people are, at keeping them under surveillance, and at trying to eliminate the situations that allow the illness to develop. This approach is known as *secondary prevention*. As social, occupational, environmental, and behavioral factors become recognized as important antecedents of many chronic illnesses, pediatricians will become more involved in activities directed toward preventing them.

Up to now, secondary prevention has not been a common feature of pediatric practice, and children who are at risk have generally been identified at the initiative of government and social agencies. Examples of such efforts include hearing and vision screening in schools, special screening programs for specific disease in special populations (sickle cell anemia, Tay-Sachs disease), and state-mandated neonatal screening for inherited metabolic disorders (eg, phenylketonuria). A major challenge for pediatricians is

Table 1-5 Child Outcomes Framework for Assessing the Effects of Health Care Delivery Systems, Organized by 8 Domains

OUTCOME	MEASURES (EXAMPLES)
SURVIVAL	
Survival	<ul style="list-style-type: none"> • Infant mortality rate: number of children who die before their 1st birthday per 1000 live-born children • Life expectancy: number of years that a newborn child can expect to live • Five-year survival rates for specific diseases, such as cancer • Cause-specific mortality rate, such as mortality caused by asthma
INJURY AND DISEASE	
Injury	<ul style="list-style-type: none"> • Unintentional injuries • Intentional injuries • Child abuse and neglect rates • Suicide rates among youth
Development of disease	<ul style="list-style-type: none"> • Vaccine-preventable infections, such as measles, hepatitis B, pertussis • New cases of specific disorders, such as asthma, depression, attention deficit disorder, type 2 diabetes, seizure disorder, allergies, acne, metabolic syndrome, anxiety
Disease complications	<ul style="list-style-type: none"> • Severe dehydration • Suicide associated with depression • Iatrogenic complications associated with surgical interventions • Iatrogenic complications associated with medications • Consequences of untreated or inadequately treated infections, such as poststreptococcal glomerulonephritis, Lyme arthritis, pelvic inflammatory disease • School days lost resulting from illness
Disease severity	<ul style="list-style-type: none"> • Among patients with diabetes, glycated hemoglobin level • Among patients with asthma, forced expiratory volume in 1 second • Among children with hypertension, systolic and diastolic blood pressure levels • Cancer stage at diagnosis
GROWTH	
Growth	<ul style="list-style-type: none"> • Birth weight: low birth weight (<2500 g) and very low birth weight (<1500 g) • Underweight and failure to thrive: sex-specific weight for age is less than or equal to the 5th percentile • Overweight: sex-specific weight for age is greater than or equal to the 95th percentile
FUNCTIONING AND DEVELOPMENT	
Mobility	<ul style="list-style-type: none"> • Attainment of age-appropriate mobility developmental milestones (eg, age child walked) • Days of restricted activity • Amount and frequency of physical activity
Self-management	<ul style="list-style-type: none"> • Attainment of age-appropriate self care developmental milestones (eg, getting dressed independently) • Sleep habits • Nutritional intake behaviors • Dental hygiene • Adherence to medication regimens
Communication	<ul style="list-style-type: none"> • Attainment of age-specific receptive language capacities • Attainment of age-specific expressive language capacities

Table 1-5 Child Outcomes Framework for Assessing the Effects of Health Care Delivery Systems, Organized by 8 Domains—cont’d

OUTCOME	MEASURES (EXAMPLES)
Interpersonal interactions	<ul style="list-style-type: none"> • Developing satisfying and fulfilling friendships
Intellectual performance	<ul style="list-style-type: none"> • For youth and young adults, developing intimate relationships
FAMILY	
Family impact	<ul style="list-style-type: none"> • School readiness • Academic performance, such as grades and grade completion • Graduation from secondary school
Family connectedness	<ul style="list-style-type: none"> • Parental work days lost resulting from a child’s illness • Parental worry about child’s health
RISKS	
Risk behaviors	<ul style="list-style-type: none"> • Parental time spent with children in activities such as play, recreation, meals • Quality and frequency of child-parent discussions about the child’s life • Parental monitoring of children’s activities within and outside the home
RISKS	
Risk behaviors	<ul style="list-style-type: none"> • Tobacco smoking • Alcohol use • Drug use • Early sexual debut • Not wearing a seat belt while riding in a motor vehicle • Not using a helmet while riding a bicycle
SYMPTOMS AND COMFORT	
Symptoms	<ul style="list-style-type: none"> • Physically experienced sensations, feelings, and perceptions that are the result of a disease process • Emotionally experienced sensations, feelings, and perceptions that are the result of a disease process
Comfort	<ul style="list-style-type: none"> • Physically experienced body sensations, feelings, and perceptions that are not associated with a known disease process • Emotionally experienced body sensations, feelings, and perceptions that are not associated with a known disease process
WELL BEING	
Well Being	<ul style="list-style-type: none"> • Happiness • Self-worth • Life satisfaction • Flourishing: attaining a meaningful life

recognizing and dealing with occupational hazards that result in parents unknowingly exposing their children to toxic materials invisibly carried home from the workplace.

Much of health care is devoted to minimizing the effect of diseases on health. Reducing the impact of injury by limiting the duration of disability is an outcome that health care delivery systems can affect, although the provision of health services is not the only determinant of functional recovery. Similarly, health care

attempts to prevent or mitigate the effects of disease complications and to stabilize the disease itself so as to reduce its severity. Because managing the complexity, stability, and complications of disease are common and effective parts of pediatric practice, indicators of the adequacy of disease control are obvious candidates for outcomes for which the health care delivery system should be accountable.

The fact that many commonly applied therapeutic maneuvers are of unproved usefulness

and may even be dangerous is well known. For example, several studies demonstrate that surgical rates in the United States are much higher than those in other developed countries, without any demonstrable difference in the need for surgery as defined by prevalence of disease or illness. Even within the United States, the number of hospital admissions, the length of stay in the hospital, and the rate of surgical procedures vary markedly from area to area, unrelated to differences in medical need. This potential overuse of specialized services might actually result in poorer outcomes, with more patients than necessary experiencing iatrogenic complications of interventions. Another problem is the misuse of drug therapy. For many physicians, drug manufacturers' representatives and advertisements are the primary sources of information on new drugs. Several surveys have shown a widespread lack of appreciation by physicians of the dangers of many drugs and much unwarranted use of drugs. Outcomes data will be helpful in determining the usefulness of various therapeutic maneuvers and will guide the appropriate usage of drugs.

To ensure that diagnostic procedures and instituted therapy are adequate and that problems are being resolved as expected, patients must be monitored; this approach is known as *outcomes assessment*. Medical textbooks and teaching rarely include information that helps the practitioner define appropriate intervals for reassessing particular health problems. Such information has to come from careful studies of the natural history of patients' problems, with and without intervention, and such studies are rare. Moreover, little is known about the extent to which practitioners follow up problems they treat. When the issue has been examined, research shows that failure to follow up on treated patients results in unresolved health problems; at the very least, it produces a highly inefficient health care system: Care is paid for, but no benefit is gained. At the most, outcomes assessment will ultimately lead to societal demands for greater accountability of the profession.

The likely scenario is that future physicians will be encouraged, and perhaps even required, to keep certain types of data about children in their practices. A data set for hospitals to use for each patient admitted and a similar set for ambulatory care have been accepted by the National Center for Health Statistics and recommended for wide

use. This information includes registration data (patient identification number, name, address, birth date, gender, race, and marital status) and encounter data (facility identification number, provider identification number, patient identification number, source of payment, date of encounter, patient's purpose for visit, physician's diagnosis, diagnostic and management procedures, and disposition). Adoption of this or a similar system for collecting and standardizing information will facilitate the understanding of health and disease processes and the role medical care plays in influencing them. (For more details, see [Chapter 6, Quality Improvement in Practice.](#))

Growth

Monitoring children's growth is one of the cornerstones of pediatric primary care. Assessing growth requires pediatricians to examine both tails of the distribution: underweight and overweight. The ability of pediatricians to identify growth problems is well established. Whether pediatric professionals have an important effect on preventing growth problems is less clear. Today, approximately 1 in 6 children is overweight. Interventions that pediatricians can apply to prevent the problem of being overweight are lacking. Problems with inadequate weight are more easily addressed by health care; however, the degree to which a health care delivery system can affect the healthy growth of an entire population remains to be demonstrated. (See [Chapter 299, Obesity and Metabolic Syndrome.](#))

Functioning and Development

Children's functional capacities in the areas of self-management, mobility, communication, interpersonal interactions, and intellectual capacity rapidly change and acquisition of new abilities characterizes stages of development; they are also targets of health services. Monitoring age-appropriate development of new capacities and intervening with children who have problems in each dimension is a fundamental part of well-child care.

Reducing the number of days of restricted activity, for example, due to acute illness or asthma is often a primary treatment outcome. When asked about the meaning of *being healthy*, children and youth talk about "being able to do what I want to do, play what I want to play, or see my friends." Similarly, children know that

healthful self-management habits are an important part of their health status, and counseling on these topics is part of virtually every routine health visit. One of the *new morbidities* with which pediatricians have become more concerned is learning and intellectual development. For young children, pediatricians counsel parents about the importance of reading to brain development, enjoyment, and for being prepared to learn once the child starts school. Programs such as Reach Out and Read (www.reachoutandread.org/) have been developed to provide office-based practitioners with tools for promoting early childhood literacy.

As children get older, pediatricians work with them and their families in setting educational goals, monitoring children's performance in school, and, with youth, setting goals for their young adult professional lives. Perhaps the single best indicator of the health of a population of children and youth is the rate of graduation from secondary school. Healthy children finish high school and successfully transition into adulthood.

Family

Children's health outcomes are inextricably bound with their family. The family and home life are the most important contexts in the production of children's health and for promoting their development. Parenting and family involvement in a child's life are especially critical. A variety of studies have shown that accumulated childhood exposures to different types of abuse or household dysfunction directly increase the risk of psychiatric disorder and several chronic diseases that emerge later in life. Abuse appears to alter the structures and functions of a child's brain and the body's reactivity to stress. Unstable (especially rejecting) parent-child relationships produce biological changes that interact with future environmental stimuli to produce adult disease.

Child health can affect the family by influencing parental emotions and mood (eg, excessive worry about a sick child, a depressed mood in a parent who devotes a large share of time to the care of a child with a special health care need) and parents' work productivity. These family outcomes can then affect children's health in a reciprocal dynamic relationship.

Risks

When a child or youth engages in high-risk behavior, the chances of future injury or disease

are increased. Not wearing a helmet while riding a bike enhances the likelihood that if the child is in a bike accident, a head injury will occur. Tobacco smoking in adolescence negatively affects pulmonary function and begins a cascade of negative effects on future cardiovascular and pulmonary structure and function. Early sexual debut heightens the chances for acquiring sexually transmitted diseases and teen pregnancy.

Routine health visits for adolescents should always address risk avoidance. Significant effects of these interventions, primarily information giving and counseling, on the incidence and frequency of risk behaviors have not been shown in research studies. This type of evidence is needed to guide risk avoidance interventions better. Until these data are made available, most professionals would not want to be held accountable for the levels of risk behavior in the population for whom they care.

Symptoms and Comfort

Feelings of discomfort can be experienced physically and emotionally, and they may or may not be linked to a disease. Almost one half of all office-based visits involve some degree of symptom management. Children who feel uncomfortable are less involved in desired activities, more likely to miss school, and more unhappy than others without the same feelings. Relieving the suffering associated with illness is a core function of health services delivery. **Thus the level of comfort a patient population or the symptom burden of a diseased subgroup is a clear outcome indicator that can be linked to health services.**

Well Being

Well being has 2 components. The 1st component, simply stated, is *happiness*—the degree to which life experiences match the individual's expectations. Health care delivery systems add to the happiness of children by ensuring that the risk of injury and disease is as low as possible and the impact of disorders when injury or disease occurs is minimized by preventing unwanted symptoms and ensuring the highest level of comfort possible, by promoting growth and development, by counseling on behavior (both ways to improve health directly and ways to avoid harm), and by supporting families in the care of their children.

The 2nd component is meaning, predictability, and flourishing. Healthy children see and plan for

their future. Children who have led healthy lives are more likely to become flourishing adults.

Outcomes and Health Services

Some of the outcomes in Table 1-5 are more **amenable** to services than others. The knowledge base linking services to outcomes is largest for the biological outcomes—survival, disease, and growth. Surprisingly, no consensus exists on the specific outcome metrics that the effectiveness of health care delivery systems on which should be evaluated. For which outcomes should health care delivery systems be held fully accountable, partially accountable, or not at all accountable? This question remains largely unanswered, which severely limits the profession's ability to use outcomes assessment to improve health care services. Future health care delivery systems for children must become more outcomes oriented. Deciding which outcomes on which to base these new delivery systems is an urgent task facing all child health care professionals and managers.

TOOLS FOR PRACTICE

Engaging Patients and Family

- *Learn More About Pediatric Subspecialists Fact Sheets* (fact sheets), American Academy of Pediatrics (www.aap.org/family/pedspecfactsheets.htm)

Medical Decision Support

- *American Board of Pediatrics* (Web page), American Board of Pediatrics (www.abp.org/abpwebsite/)
- *Subspecialty Workforce Data and Resources* (Web page), American Academy of Pediatrics (www.aap.org/workforce/copwssw.htm)
- *The Mapping Health Care Delivery for America's Children Project* (interactive tool), American Academy of Pediatrics and Dartmouth Medical School, Center for the Evaluative Clinical Sciences (www.aap.org/mapping/)
- *Women in Pediatrics* (Web page), American Academy of Pediatrics (www.aap.org/womenpeds/)

Practice Management and Care Coordination

- *Developing a Telephone Triage and Advice System for a Pediatric Office Practice* (book), American Academy of Pediatrics (www.aap.org/bst/showdetl.cfm?&did=15&product_id=2837&catid=133)
- *Pediatric Call Centers and the Practice of Telephone Triage and Advice: Critical Success Factors* (report), American Academy of Pediatrics (www.aap.org/sections/telecare/11_98.pdf)

- *Pediatric Telephone Protocols, Office Version, 11th ed* (book), American Academy of Pediatrics and Schmitt, BD (www.aap.org/bst/showdetl.cfm?&did=15&product_id=4179&catid=141)
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