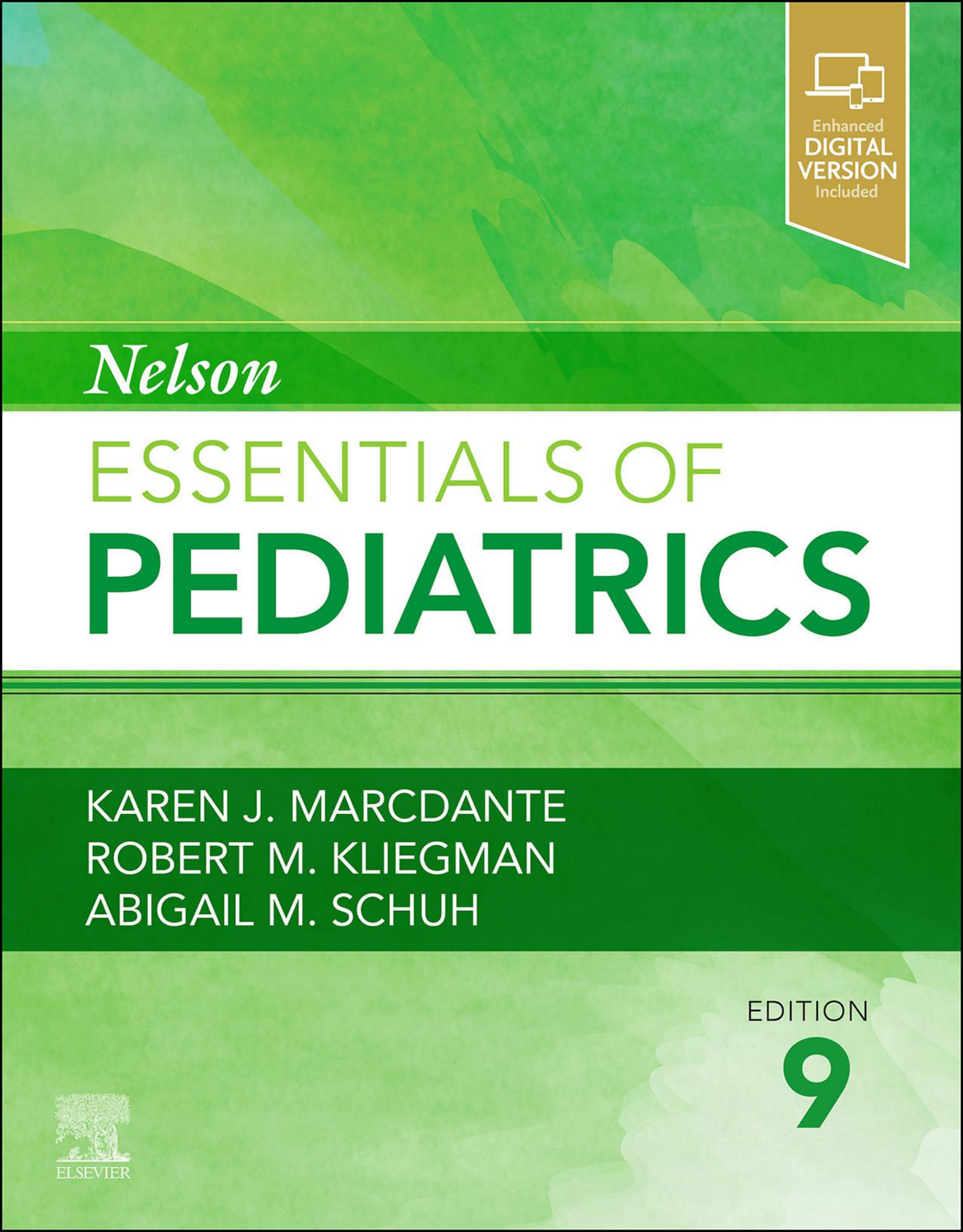
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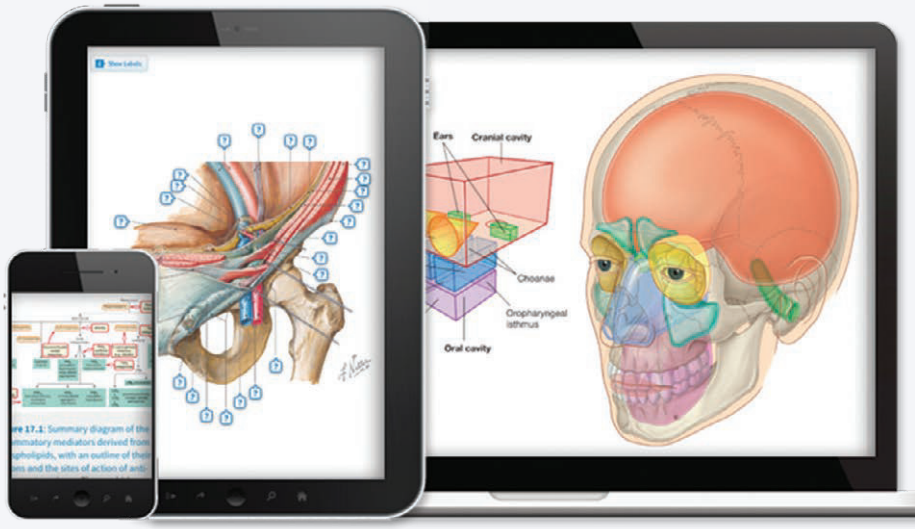

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This book is dedicated to our patients, who inspire us to learn more;
our mentors; and, now more than ever, our colleagues,
the dedicated medical professionals whose curiosity and focus
on providing excellent care and who, even in the face of recent adversity,
spur the advancement of our medical practice.

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PREFACE

This edition was created in the midst of several pandemics, one caused by a virus and one focused on advancing social justice to overcome structural and personal racism. The many challenges highlighted by these pandemics are resulting in acceleration of necessary changes in medical education. These changes must be built on a foundation of evidence-based knowledge and heightened awareness. Our goal as the editors and authors of this textbook is not only to provide the classic, foundational knowledge we use every day, but also to include recent advances in a readable, searchable, and concise text for medical learners at all levels. Mastering this knowledge, when combined with mindful experiences in the rapidly changing world of medicine, will allow our readers to develop the practical wisdom needed to serve our patients and their families.

We hope that this text will help you investigate the common and classic pediatric disorders in a time-honored, logical format, helping you to both acquire and apply knowledge needed to provide high value care. We are honored to be part of the journey of the thousands of learners who rotate through pediatrics, those who will become new providers of pediatric care in the years to come, and those who continue to build on their knowledge.

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THE PROFESSION OF PEDIATRICS

Ahmeneh Ghavam | *Karen J. Marcdante*

CHAPTER 1

Population and Culture: The Care of Children in Society

CARE OF CHILDREN IN SOCIETY

Health care professionals need to appreciate the interactions between medical conditions and social, economic, and environmental influences associated with the provision of pediatric care. New technologies and treatments improve morbidity, mortality, and the quality of life for children and their families, but the costs may exacerbate disparities in medical care. The challenge for pediatricians is to deliver care that is socially equitable; integrates psychosocial, cultural, and ethical issues into practice; and ensures that health care is available to all children.

CURRENT CHALLENGES

Challenges that affect children's health outcomes include access to health care; health disparities; supporting their social, cognitive, and emotional lives in the context of families and communities; and addressing environmental factors, especially poverty. Early experiences and environmental stresses interact with the genetic predisposition of every child and, ultimately, may lead to the development of diseases seen in adulthood. Pediatricians have the unique opportunity to address not only acute and chronic illnesses but also environmental and toxic stressors to promote wellness and health maintenance in children.

Many scientific advances have an impact on the growing role of pediatricians. Newer genetic technologies allow the diagnosis of diseases at the molecular level, aid in the selection of medications and therapies, and may provide information on prognosis. Prenatal diagnosis and newborn screening improve the accuracy of early diagnosis and treatment, even when a cure is impossible. Functional magnetic resonance imaging allows a greater understanding of psychiatric and neurologic problems.

Challenges persist due to the increasing incidence and prevalence of chronic illness. Chronic illness is now the most common reason for hospital admissions among children (excluding trauma and newborn admissions). In older children, mental illness is the main non–childbirth-related reason for hospitalization. Pediatricians must also address the increasing concern about environmental toxins and the prevalence of physical, emotional, and sexual abuse, and violence. World unrest, terrorism, and a global pandemic have caused an increased level of anxiety and fear for many families and children.

To address these ongoing challenges, many pediatricians now practice as part of a health care team that includes psychiatrists, psychologists, nurses, and social workers. This **patient-centered medical home model** of care is designed to provide continuous and coordinated care to maximize health outcomes. Other models, such as school-based health and retail medical facilities, may improve access but may not support continuity and coordination of care.

Childhood antecedents of adult health conditions, such as alcoholism, depression, obesity, hypertension, and hyperlipidemias, are increasingly recognized. Infants who are relatively underweight at birth due to maternal malnutrition are at higher risk of developing certain health conditions later in life, including diabetes, heart disease, hypertension, metabolic syndrome, and obesity. Improved neonatal care results in greater survival of preterm, low birthweight, or very low birthweight newborns, increasing the number of children with chronic medical conditions and developmental delays with their lifelong implications. Childhood exposure to adverse experiences such as abuse, divorce, and violence increases the risk of diabetes, cardiovascular disease, and mental health disorders in adults.

LANDSCAPE OF HEALTH CARE FOR CHILDREN IN THE UNITED STATES

Complex health, economic, and psychosocial challenges greatly influence the well-being and health outcomes of children. National reports from the Centers for Disease Control and Prevention (CDC) (e.g., https://www.cdc.gov/nchs/data/hus/hus18.pdf) provide information about many of these issues. Some of the key issues include the following:

- **Health insurance coverage**. Because of programs like Medicaid and the State Children's Health Insurance Program, children are more likely than adults to have health insurance coverage. For example, in 2018, 36% of children were covered by Medicaid. The continued decline in uninsured children nationally over the past decade left 5.2% of U.S. children lacking insurance in 2018.
- **Prenatal and perinatal care**. Nearly 75% of women begin prenatal care in the first trimester with lower rates noted in Hispanic and Black populations. Less than 1 in 10 women had delayed or no prenatal care.
- **Preterm births**. The incidence of preterm births (<37 weeks) has been rising since 2014 after an initial decrease in the rate from 2007 to 2014. In 2018, the preterm birth rate was 10% with continued racial and ethnic disparities. However, the rates of low birthweight infants (≤2,500 g [8.3% of all

births]) and very low birthweight infants (≤1,500 g [1.4% of all births]) are essentially unchanged since 2006.

- **Birthrate in adolescents**. The national birthrate among adolescents has been steadily dropping since 1990, reaching its lowest rate (17.4 births per 1,000) for 15- to 19-year-old adolescents in 2018.
- **Adolescent abortions**. The rate of abortions among adolescents has been decreasing since its peak in 1988 and is now at its lowest rate since abortion was legalized in 1973. In 2015, adolescents aged 15–19 years accounted for 9.8% of all reported abortions, with an abortion rate of 6.7 abortions per 1,000 adolescents that age.
- **Infant mortality**. In 2017, the overall infant mortality rate in the United States was 5.8 deaths per 1,000 live births demonstrating a continued slow, downward trend since 1995. However, disparity remains among ethnic groups. Infant mortality among non-Hispanic Black women is nearly double the national average. U.S. geographic variability persists with highest mortality rates in the South.
- **Initiation and maintenance of breast-feeding**. In 2015, 83.2% of newborn infants started breast-feeding after birth. That same year, rates of breast-feeding at 6 and 12 months were 57.6% and 35.9%. Breast-feeding rates vary by ethnicity (higher rates in non-Hispanic White and Hispanic mothers) and education (highest in women with a bachelor's degree or higher).
- **Cause of death in U.S. children**. The overall causes of death in all children (1–24 years of age) in the United States in 2018, in order of frequency, were unintentional injuries, congenital anomalies, suicide, homicide, and malignant neoplasms (Table 1.1). Death rates from all causes continue to slowly decline.
- **Hospital admissions for children and adolescents**. In 2018, 7% of children were admitted to a hospital at least once. Respiratory illnesses are the predominant cause of hospitalization for children 1–9 years of age, while mental illness is the most common cause of admission for adolescents.

TABLE 1.1 Causes of Death by Age in the United States, 2018

AGE GROUP (YEAR)	CAUSES OF DEATH IN ORDER OF FREQUENCY
1–4	Unintentional injuries (accidents) Congenital anomalies Homicide Malignant neoplasms Influenza/pneumonia Heart disease
5–14	Unintentional injuries (accidents) Malignant neoplasms Suicide Congenital anomalies Homicide Heart disease
15–24	Unintentional injuries (accidents) Suicide Homicide Malignant neoplasms Heart disease

From National Center for Health Statistics (US). Health, United States, 2018. https://www.cdc.gov/injury/images/lc-charts/leading_causes_of_death_by_age_group_2018_1100w850h.jpg.

- **Significant adolescent health challenges: substance use and abuse**. There is increasing substance use and abuse among U.S. adolescents. Fourteen percent of high school students report using some illicit or injection drugs, and 14% report using non-prescription opioids, both placing youth at risk for overdose and HIV infection. In 2017, 30% of surveyed high school students drank alcohol, 14% binge drank, and 17% rode in the car with someone who had been drinking. Tobacco cigarette use has declined among teens over the past decade, but the rate of e-cigarette use (or vaping) has increased from 1.5% in 2011 to 27.5% in 2019. Vaping has been proven to pose significant health risks to both users and nonusers.
- **Children in foster care**. In 2018, 437,000 children were in the foster care system and of those children 56% were reunited with families and 25% were adopted. Children leaving foster care often lack the emotional or financial support necessary to succeed in life and experience homelessness and/or joblessness and will not graduate from high school.

OTHER HEALTH ISSUES THAT AFFECT CHILDREN IN THE UNITED STATES

- **Obesity**. Obesity is the second leading cause of death in the United States (estimated 300,000 deaths annually). Rates of childhood obesity continue to rise. The prevalence of obesity among children aged 2–19 years was 18.5% in 2018. Obesity rates among Hispanic and Black populations were well above 20%.
- **Sedentary lifestyle**. With advancing technology, children spend more time in front of a screen (television, videogames, computer, etc.); some spend more than 7.5 hours for entertainment per day. This does not include additional time spent on a computer for educational purposes.
- **Motor vehicle accidents and injuries**. In 2017, 675 children 12 years of age or younger died in motor vehicle crashes, and more than 116,000 were injured. Thirty-five percent of those killed were not appropriately restrained. In 2017, 2,364 teens, aged 16–19, were killed in motor vehicle crashes. Drivers aged 16–19 are nearly three times more likely than drivers over age 20 to be involved in a fatal crash.
- **Child maltreatment**. In 2018, nearly 1,770 children died of abuse and neglect in the United States, with at least 1 in 7 children having experienced child abuse and/or neglect in the past year. Reportedly, 1 in 4 girls and 1 in 13 boys has experienced child sexual abuse at some point in their lifetime leading to both short- and long-term physical and mental health complications.
- **Toxic stress in childhood leading to adult health challenges**. The growing understanding of the interrelationship between biologic and developmental stresses, environmental exposure, and the genetic potential of patients is helping us recognize the adverse impact of toxic stressors on health and well-being. Screening for and acting upon factors that promote or hinder early development provides the best opportunity for long-term health. The field of epigenetics is demonstrating that exposure to environmental stress impacts genetic expression and can result in long-term effects on development, health, and behaviors.

- **Military deployment and children**. Current armed conflicts and political unrest affect millions of adults and their children. Active duty and National Guard/Reserve servicemen and servicewomen are parents to more than a million children. One third of troops returning from armed conflicts have a mental health condition (alcoholism, depression, and post-traumatic stress disorder) or have experienced a traumatic brain injury. Their children are affected by these morbidities as well as by the psychologic impact of deployment. Child maltreatment is more prevalent in families of U.S.-enlisted soldiers during combat deployment than in non-deployed soldiers.

HEALTH DISPARITIES IN HEALTH CARE FOR CHILDREN

Health disparities are the differences that remain after accounting for patients' needs, preferences, and the availability of health care. Social conditions and inequity, discrimination, social stress, language barriers, and poverty are antecedents to and associated causes of health disparities. Disparities in infant mortality relate to poor access to prenatal care and the lack of access to appropriate health services for women.

- Infant mortality increases as the mother's level of education decreases.
- Children from poor families are less likely to be immunized and receive dental care at 4 years of age.
- Children with Medicaid/public coverage are less likely to be in excellent health than children with private health insurance.
- Children of ethnic minorities and those from poor families are less likely to have physician office or hospital outpatient visits and more likely to have hospital emergency department visits and higher rate of hospital admission.

CHANGING MORBIDITY: SOCIAL/EMOTIONAL ASPECTS OF PEDIATRIC PRACTICE

- **Changing morbidity** reflects the relationship among environmental, social, emotional, and developmental issues; child health status; and outcome. These observations are based on significant interactions of **biopsychosocial** influences on health and illness, such as school problems, learning disabilities, and attention problems; child and adolescent mood and anxiety disorders; adolescent suicide and homicide; firearms in the home; school violence; effects of media violence, obesity, and sexual activity; and substance use and abuse by adolescents.
- An estimated 1 in 5 children, ages 13–18 years, has a mental health condition. Half of all lifetime cases of mental illness begin by age 14 years. The average delay between onset of symptoms and intervention is 8–10 years. Suicide is the second leading cause of death for children ages 10–24 years, making early recognition of mental illness paramount. Children from poor families are twice as likely to have psychosocial problems as children from higher-income families. Nationwide, there is a lack of adequate mental health services for children.

Important influences on children's health, in addition to poverty, include homelessness, single-parent families, parental divorce, domestic violence, both parents working, and inadequate child care. Related pediatric challenges include improving the quality of health care, social justice, equality in health care access, and improving the public health system. For adolescents, there are special concerns about sexuality, sexual orientation, pregnancy, substance use and abuse, violence, depression, and suicide.

CULTURE

The growing diversity of the United States requires that health care workers better understand the impact of health, illness, and treatment on the patient and family from their perspective. This requires open-ended questions, such as: "What *worries* you the most about your child's illness?" and "What do you *think* has caused your child's illness?" One must address concepts and beliefs about how patients/families interact with health professionals, as well as their spiritual and religious approach to health and health care from a cultural perspective, allowing incorporation of differences in perspectives, values, or beliefs into the care plan. Conflicts may arise because religious or cultural practices may lead to the possibility and/or perception of child abuse and neglect, which are required, by law, to be reported to social service authorities (see Chapter 22).

Complementary and alternative medicine (CAM) practices constitute a part of the broad cultural perspective. Therapeutic modalities for CAM include biochemical, lifestyle, biomechanical, and bioenergetic treatments, as well as homeopathy. It is estimated that 20–40% of healthy children and more than 60% of children with chronic illness use CAM and don't always reveal CAM use to their physician. Screening for CAM use can aid the pediatrician's counseling and minimize unintentional adverse interactions.

PEARLS FOR PRACTITIONERS

See Profession of Pediatrics: Pearls for Practitioners at the end of this section.

CHAPTER 2
Professionalism

CONCEPT OF PROFESSIONALISM

Society provides a profession with economic, political, and social rewards. Professions have specialized knowledge and responsibilities and exist as long as they fulfill responsibilities for the social good.

Today, the activities of medical professionals are subject to explicit public rules of accountability. Governmental and other authorities at city, state, and federal levels grant limited autonomy to professional organizations and their membership through regulations, licensing requirement, and standards of service (e.g., Medicare, Medicaid, and the Food and Drug Administration). The Department of Health and Human Services regulates physician behavior in conducting research with the goal of protecting human subjects. The National Practitioner Data Bank, created in 1986, contains information about physicians and other health care practitioners who have been disciplined by a state licensing board,

professional society, hospital, or health plan or named in medical malpractice judgments or settlements. Hospitals are required to review information in this data bank every 2 years as part of clinician re-credentialing. There are accrediting agencies for medical schools, such as the Liaison Committee on Medical Education (LCME), and postgraduate training, such as the Accreditation Council for Graduate Medical Education (ACGME).

Public trust in physicians is based on the physician's commitment to altruism, a cornerstone of the Hippocratic oath and an important rite of passage and part of medical school commencement ceremonies. The core of professionalism is embedded in the daily healing work of the physician and encompasses the patient-physician relationship. Professionalism includes an appreciation for the cultural and religious/spiritual health beliefs of the patient, incorporating the ethical and moral values of the profession (e.g., justice, courage, and wisdom) and the moral values of the patient. Professionalism also includes the understanding that dire circumstances may require physicians to provide care in uncertain situations, be it due to a natural disaster or a global pandemic. The ability of medical professionals to adapt in an ever-changing environment is a vital component of professionalism within medicine.

PROFESSIONALISM FOR PEDIATRICIANS

The American Board of Pediatrics (ABP) adopted professional standards in 2000, and the American Academy of Pediatrics (AAP) updated the policy statement and technical report on Professionalism in 2007, as follows:

- **Honesty/integrity** is the consistent regard for the highest standards of behavior and the refusal to violate one's personal and professional codes. Maintaining integrity requires awareness of situations that may result in conflict of interest or that may result in personal gain at the expense of the best interest of the patient.
- **Reliability/responsibility** includes accountability to one's patients, their families, society, and the medical community to ensure that all needs are addressed. There also must be a willingness to accept responsibility for errors.
- **Respect for others** requires the pediatrician to treat all persons with respect and regard for their individual worth and dignity; be aware of emotional, personal, family, and cultural influences on a patient's well-being, rights, and choices of medical care; and respect appropriate patient confidentiality.
- **Compassion/empathy** requires the pediatrician to listen attentively, respond humanely to patient/family concerns, and provide appropriate empathy for and relief of pain, discomfort, and anxiety as part of daily practice.
- **Self-improvement** is the pursuit of and commitment to providing the highest quality of health care through lifelong learning and education. This includes learning from errors, aspiring to excellence through self-evaluation, and accepting the critiques of others.
- **Self-awareness/knowledge of limits** includes recognition of the need for guidance and supervision when faced with new or complex responsibilities, the impact of behavior on others, and establishing appropriate professional boundaries.
- **Communication/collaboration** is crucial to providing the best care for patients. Pediatricians must work cooperatively and communicate effectively with patients, their families, and all health care providers involved in the care of their patients.
- **Altruism/advocacy** refers to unselfish regard for and devotion to the welfare of others. It is a key element of professionalism. Self-interest or the interests of other parties should not interfere with the care of one's patients and their families.

PEARLS FOR PRACTITIONERS

See Profession of Pediatrics: Pearls for Practitioners at the end of this section.

CHAPTER 3
Ethics and Legal Issues

ETHICS IN HEALTH CARE

The ethics of health care and medical decision-making relies on **values**. Sometimes, ethical decision-making in medicine is a matter of choosing the least harmful option among many adverse alternatives. In the day-to-day practice of medicine, major ethical challenges are infrequent although always possible.

The legal system defines the minimal standards of behavior required of physicians and the rest of society through the legislative, regulatory, and judicial systems. Laws support the principle of **confidentiality** for teenagers who are competent to decide about medical issues. Using the concept of **limited confidentiality**, parents, teenagers, and the pediatrician may all agree to openly discuss serious health challenges, such as suicidal ideation and pregnancy. This reinforces the long-term goal of supporting the developing autonomy and identity of the teenager while encouraging appropriate conversations with parents.

Ethical problems usually derive from **value differences** among patients, families, and clinicians regarding choices and options in the provision of health care. Resolving these value differences involves several important ethical principles. **Autonomy**, based on the principle of **respect for persons**, means that competent adult patients can make choices about their health care after being appropriately informed about their health condition and the risks and benefits of alternative diagnostic tests and treatments. **Paternalism** challenges the principle of autonomy and involves the clinician deciding what is best for the patient. Under certain circumstances (e.g., when a patient has a life-threatening medical condition or a significant psychiatric disorder and is threatening self or others), paternalism is an accepted alternative to autonomy.

Other important ethical principles are those of **beneficence** (doing good), **nonmaleficence** (doing no harm or as little harm as possible), and **justice** (the values involved in the equal distribution of goods, services, benefits, and burdens to the individual, family, or society).

ETHICAL PRINCIPLES RELATED TO INFANTS, CHILDREN, AND ADOLESCENTS

Infants and young children do not have the capacity for making medical decisions, thus decision-making falls onto their parents. Parental decision-making should be guided by

what is in the best interest of the child. In certain older children, assent can be obtained for medical decision-making. Obtaining the **assent** of a child is the process in which the child is involved in decision-making with information appropriate to the child's capacity to understand. Most adolescents (<18 years of age) cannot legally provide informed consent for medical decisions; however, they can and should provide assent. Exceptions include medical decisions made by an adolescent for certain medical conditions, notably sexual and mental health. Emancipated minors are legally able to provide informed consent for medical decision-making.

The principle of shared medical decision-making is appropriate, but the process may be limited because of issues of confidentiality. A parent's concern about the side effects of immunization raises a conflict between the need to protect and support the health of the individual and of the public. Parental decisions that are clearly not in the child's best interest should be challenged.

LEGAL ISSUES

All competent patients of an age defined legally by each state (usually ≥18 years of age) are autonomous regarding their health decisions. To have decision-making capacity, patients must meet the following requirements:

- Understand the nature of the medical interventions and procedures, understand the risks and benefits of these interventions, and be able to communicate their decision.
- Reason, deliberate, and weigh the risks and benefits using their understanding about the implications of the decision on their own welfare.
- Apply a set of personal values to the decision-making process and show an awareness of the possible conflicts or differences in values as applied to the decisions to be made.

These requirements must be placed within the context of medical care and applied to each case with its unique characteristics. Most young children are not able to meet these requirements, hence parents serve as their legal surrogate decision-maker unless circumstances preclude them from making decisions in the child's best interest (e.g., abuse)

It is important to become familiar with state law as it, not federal law, determines when an adolescent can consent to medical care and when parents may access confidential adolescent medical information. In 2003, the Health Insurance Portability and Accountability Act (HIPAA) became effective, requiring a minimal standard of confidentiality protection. The law confers less confidentiality protection to minors than to adults. It is the pediatrician's responsibility to inform minors of their confidentiality rights and help them exercise these rights under the HIPAA regulations.

Under special circumstances, non-autonomous adolescents are granted the legal right to consent under state law when they are considered mature or emancipated minors or because of certain public health considerations, as follows:

- **Mature minors**. Some states recognize adolescents who meet the cognitive criteria and emotional maturity for competence and provide them with legal decision-making capacity. The Supreme Court has decided that pregnant, mature minors have the constitutional right to make decisions about abortion without parental consent. Although many state legislatures require parental notification, pregnant adolescents wishing to have an abortion do not have to seek parental consent. The state must provide a judicial procedure to facilitate this decision-making for adolescents.
- **Emancipated minors**. Children who are legally emancipated from their parents may seek medical treatment without parental consent. The definition varies from state to state but generally includes children who have graduated from high school, are members of the armed forces, married, pregnant or have children, runaways, live apart from their parents, and are financially independent or declared emancipated by a court.
- **Interests of the state (public health)**. State legislatures have concluded that minors with certain medical conditions, such as sexually transmitted infections and other contagious diseases, pregnancy (including prevention through the use of birth control), certain mental illnesses, and drug and alcohol abuse, may seek treatment for these conditions autonomously. States have an interest in limiting the spread of disease that may endanger the public health and in eliminating barriers to access for the treatment of certain conditions.

ETHICAL ISSUES IN PRACTICE

Clinicians should engage children and adolescents based on their developmental capacity in discussions about medical plans so that the child has a good understanding of the nature of the treatments and alternatives, the side effects, and expected outcomes. There should be an assessment of the patient's understanding of the clinical situation, how the patient is responding, and the factors that may influence the patient's decisions. Pediatricians should always listen to and appreciate patients' requests for confidentiality and their hopes and wishes. The goal is to help nourish a child's capacity to become as autonomous as is appropriate to their developmental stage.

Confidentiality

Confidentiality is crucial to the provision of medical care and is an important part of the basis for a trusting patient-family-physician relationship. Confidentiality means that information about a patient should not be shared without consent. If confidentiality is broken, patients may experience great harm and may not seek needed medical care. See Chapter 67 for a discussion of confidentiality in the care of adolescents.

Ethical Issues in Genetic Testing and Screening in Children

The goal of **screening** is to identify diseases when there is no clinically identifiable risk factor for disease. Screening should take place only when there is a treatment available or when a diagnosis would benefit the child. **Testing** usually is performed when there is some clinically identifiable risk factor. Genetic testing and screening present special problems because test results have important implications. Some genetic screening (sickle cell anemia or cystic fibrosis) may reveal a carrier state, which may lead to choices about reproduction or create financial, psychosocial, and interpersonal problems (e.g., guilt, shame, social stigma, and discrimination in insurance and

jobs). Collaboration with, or referral to, a clinical geneticist is appropriate in helping the family with the complex issues of genetic counseling when a genetic disorder is detected or anticipated.

Newborn screening should not be used as a surrogate for parental testing. Examples of diseases that can be diagnosed by genetic screening, even though the manifestations of the disease process do not appear until later in life, are polycystic kidney disease; Huntington disease; certain cancers, such as breast cancer in some ethnic populations; and hemochromatosis. For their own purposes, parents may pressure the pediatrician to order genetic tests when the child is still young. Testing for these disorders should be delayed until the child has the capacity for informed consent or assent and is competent to make decisions, unless there is a direct benefit to the child at the time of testing.

Religious Issues and Ethics

The pediatrician is required to act in the best interests of the child, even when religious tenets may interfere with the health and well-being of the child. When an infant or child, whose parents have a religious prohibition against a blood transfusion, needs a transfusion to save the child's life, the courts always intervene to allow a transfusion. In contrast, parents with strong religious beliefs may refuse immunizations for their children. States may use the principle of **distributive justice** to require immunization of all during outbreaks or epidemics, including individuals who object on religious grounds.

Children as Human Subjects in Research

The goal of research is to develop new and generalized knowledge. Parents may give informed permission for children to participate in research under certain conditions. Children cannot give consent but may assent or dissent to research protocols, and these decisions should be respected. Special federal regulations have been developed to protect child and adolescent participants in human investigation. These regulations provide additional safeguards beyond those for adult participants while still providing the opportunity for children to benefit from the scientific advances of research.

Many parents with seriously ill children hope that the research protocol will have a direct benefit for their child. The researcher should be sensitive and compassionate in explaining to the parents that research does not guarantee a (better) treatment.

Ethical Issues Surrounding Scarce Resource Allocation

Medical resources are finite and under certain circumstances, notably a global pandemic, risk becoming a scarce resource. In such situations it is possible that allocation strategies need to be developed and implemented. The ethical principles of justice, beneficence, and nonmaleficence serve as guiding pillars to ensure that resources are allocated in a fair manner.

PEARLS FOR PRACTITIONERS

See Profession of Pediatrics: Pearls for Practitioners at the end of this section.

CHAPTER 4
Palliative Care and End-of-Life Issues

The death of a child is one of life's most difficult experiences. The **palliative care** approach is defined as patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. This approach should be instituted when medical diagnosis, intervention, and treatment cannot reasonably be expected to affect the imminence of death. Central to this approach is the willingness of clinicians to look beyond traditional medical goals of curing disease and preserving life and toward enhancing the life of the child with assistance from family members and close friends. High-quality palliative care is an expected standard at the end of life.

Palliative care in pediatrics is not simply end-of-life care. Children needing palliative care have been described as having conditions that fall into four basic groups based on the goal of treatment. These include conditions of the following scenarios:

- A cure is possible, but failure is not uncommon (e.g., cancer with a poor prognosis).
- Long-term treatment is provided with a goal of maintaining quality of life (e.g., cystic fibrosis).
- Treatment that is exclusively palliative after the diagnosis of a progressive condition is made (e.g., trisomy 13 syndrome).
- Treatments are available for severe, non-progressive disability in patients who are vulnerable to repeated health complications (e.g., severe spastic quadriparesis with difficulty in controlling symptoms).

These conditions present different timelines and different models of medical intervention while sharing the need to attend to concrete elements affecting the quality of a child's life and possible death and are mediated by medical, psychosocial, cultural, and spiritual concerns.

Palliative care can make important contributions to the end-of-life and bereavement issues for families without time to prepare for an unexpected death. This may become complicated in circumstances where the cause of the death must be fully explored such as possible child abuse or neglect, as this subjects the family to intense scrutiny and may create guilt and anger directed at the medical team.

PALLIATIVE AND END-OF-LIFE CARE

Palliative treatment is directed toward the relief of symptoms as well as assistance with anticipated adaptations that may cause distress and diminish the quality of life of the dying child. Elements of palliative care include pain management; expertise with feeding and nutritional issues at the end of life; and management of symptoms, such as minimizing nausea and vomiting, bowel obstruction, labored breathing, and fatigue. Psychologic elements of palliative care have a profound importance and include sensitivity to bereavement, a developmental perspective of a child's understanding of death, clarification of the goals of care, and ethical issues. Palliative care is delivered through a multidisciplinary approach, giving a broad range of expertise to patients and families as well as providing a supportive network for the caregivers. Caregivers

involved may be pediatricians, nurses, mental health professionals, social workers, and pastors.

A model of integrated palliative care rests on the following principles:

- **Respect for the dignity of patients and families**. The clinician should respect and listen to patient and family goals, preferences, and choices. School-age children can articulate preferences about how they wish to be treated. Adolescents can engage in decision-making (see Section 12). **Advanced care** (advance directives) should be discussed with the child and parents to determine what they would like as treatment options as the end of life nears. Differences of opinion between the family and pediatrician should be addressed by identifying the multiple perspectives, reflecting on possible conflicts, and altruistically coming to agreements that validate the patient and family perspectives yet reflect sound practice. **Hospital ethics committees** and consultation services are important resources for the pediatrician and family members.
- **Access to comprehensive and compassionate palliative care**. The clinician should address the physical symptoms, comfort, and functional capacity, with special attention to pain and other symptoms associated with the dying process while also responding empathically to psychologic distress and human suffering, and provide treatment options. Respite should be available at any time during the illness to allow the family caregivers to rest and renew.
- **Use of interdisciplinary resources**. Because of the complexity of care, no one clinician can provide all needed services. The team members may include primary and subspecialty physicians, nurses in the hospital/facility or for home visits, the pain management team, psychologists, social workers, pastoral ministers, schoolteachers, friends of the family, and peers of the child. The child and family should decide who should know what during all phases of the illness process.
- **Acknowledgment and support provisions for caregivers**. The primary caregivers of the child, family, and friends need opportunities to address their own emotional concerns. Team meetings to address thoughts and feelings of team members are crucial. Institutional support may include time to attend funerals, counseling for the staff, opportunities for families to return to the hospital, and scheduled ceremonies to commemorate the death of the child.
- **Commitment to quality improvement of palliative care through research and education**. Hospitals should develop support systems and staff to monitor the quality of care continually, assess the need for appropriate resources, and evaluate the responses of the patient and family members to the treatment program.

Hospice care is a treatment program for the end of life that provides the range of palliative care services by an interdisciplinary team including specialists in the bereavement and end-of-life process. In 2010, legislation was passed allowing children covered under Medicaid or the Children's Health Insurance Program (CHIP) to receive access simultaneously to hospice care and curative care.

BEREAVEMENT

Bereavement refers to the process of psychologic and spiritual accommodation to death on the part of the child and the child's family. **Grief** has been defined as the emotional response caused by a loss which may include pain, distress, and physical and emotional suffering. It is a normal adaptive human response to death. Assessing the coping resources and vulnerabilities of the affected family before death occurs is central to the palliative care approach.

Parental grief is recognized as being more intense and sustained than other types of grief. Most parents work through their grief. Complicated grief, a pathologic manifestation of continued and disabling grief, is rare. Parents who share their problems with others during the child's illness, who have access to psychologic support during the last month of their child's life, and who have had closure sessions with the attending staff are more likely to resolve their grief. In the era of technology, some parents may find solace in connecting with other parents with similar experiences in an online forum.

A particularly difficult issue for parents is whether to talk with their child about the child's imminent death. Although evidence suggests that sharing accurate and truthful information with a dying child is beneficial, each individual case presents its own complexities based on the child's age, cognitive development, disease, timeline of disease, and parental psychologic state. Parents are more likely to regret not talking with their child about death than having done so.

COGNITIVE ISSUES IN CHILDREN AND ADOLESCENTS: UNDERSTANDING DEATH AND DYING

The pediatrician should communicate with children about what is happening to them while respecting the cultural and personal preferences of the family. A developmental understanding of children's concepts of health and illness helps frame the discussion and can help parents understand how their child is grappling with the situation. Piaget's theories of cognitive development, which help illustrate children's concepts of death and disease, are categorized as sensorimotor, preoperational, concrete operations, and formal operations.

For children up to 2 years of age (sensorimotor), death is seen as a separation without a specific concept of death. The associated behaviors in grieving children of this age usually include protesting and difficulty of attachment to other adults. The degree of difficulty depends on the availability of other nurturing people with whom the child has a good previous attachment.

Children from 3–5 years of age (preoperational; sometimes called *the magic years*) have trouble grasping the meaning of the illness and the permanence of the death. Their language skills at this age make understanding their moods and behavior difficult. Because of a developing sense of guilt, death may be viewed as punishment. If a child previously wished a sibling dead, the death may be seen psychologically as being caused by the child's wishful thinking. They can feel overwhelmed when confronted with the strong emotional reactions of their parents.

In children ages 6–11 years of age (late preoperational to concrete operational), the finality of death gradually comes to be understood. Magical thinking gives way to a need for detailed information to gain a sense of control. Older children in this range have a strong need to control their emotions by compartmentalizing and intellectualizing.

In adolescents older than 12 years of age (formal operations), death is a reality and seen as universal and irreversible.

Adolescents handle death issues at the abstract or philosophical level and can be realistic. They may also avoid emotional expression and information, instead relying on anger or disdain. Their wishes, hopes, and fears should be attended to and respected.

CULTURAL, RELIGIOUS, AND SPIRITUAL CONCERNS ABOUT PALLIATIVE CARE AND END-OF-LIFE DECISIONS

Understanding the family's religious/spiritual or cultural beliefs and values about death and dying can help the pediatrician work with the family to integrate these beliefs, values, and practices into the palliative care plan. Cultures vary regarding the roles family members have, the site of treatment for dying people, and the preparation of the body. Some ethnic groups expect the clinical team to speak with the oldest family member or only to the head of the family, outside of the patient's presence, while others involve the entire extended family in decision-making. For some families, dying at home can bring the family bad luck; others believe that the patient's spirit will become lost if the death occurs in the hospital. In some traditions, the health care team cleans and prepares the body, whereas in others, family members prefer to complete this ritual. Religious/spiritual or cultural practices may include prayer, anointing, laying on of the hands, an exorcism ceremony to undo a curse, amulets, and other religious objects placed on the child or at the bedside. Families differ in the idea of organ donation and the acceptance of autopsy. Decisions, rituals, and withholding of palliative or lifesaving procedures that could harm the child or are not in the best interests of the child should be addressed. Quality palliative care attends to this complexity and helps parents and families navigate the death of a child while honoring the familial, cultural, and spiritual values.

ETHICAL ISSUES IN END-OF-LIFE DECISION-MAKING

Before speaking with a child about death, the caregiver should assess the child's age, experience, and level of development; the child's understanding and involvement in end-of-life decision-making; the parents' emotional acceptance of death; their coping strategies; and their philosophical, spiritual, and cultural views of death. These may change over time. The use of open-ended questions to repeatedly assess these areas contributes to the end-of-life process. The care of a dying child can create **ethical dilemmas** involving **autonomy, beneficence** (doing good), **nonmaleficence** (doing no harm), truth telling, confidentiality, or the physician's duty. It is extremely difficult for parents to know when the burdens of continued medical care are no longer appropriate for their child and may, at times, rely on the medical team for guidance. The beliefs and values of what constitutes quality of life, when life ceases to be worth living, and religious/spiritual, cultural, and philosophical beliefs may differ between families and health care workers. The most important ethical principle is what is in the **best interest** of the child as determined through the process of **shared decision-making**, **informed consent** from the parents, and **assent** from the child. Sensitive and meaningful communication with the family, in their own terms, is essential. The physician, patient, and family must **negotiate** the goals of continued medical treatment while recognizing the burdens and benefits of the medical intervention plan. There is no ethical or legal difference between withholding treatment and withdrawing treatment, although many parents and physicians see the latter as more challenging. Family members and the patient should agree about what are appropriate **do not resuscitate** (also called **DNR**) orders. Foregoing some measures does not preclude other measures being implemented based on the needs and wishes of the patient and family. When there are serious differences among parents, children, and physicians on these matters, the physician may consult with the **hospital ethics committee** or, as a last resort, turn to the legal system by filing a report about potential abuse or neglect.

ORGAN DONATION IN PEDIATRICS

The gap between supply and demand of transplantable organs in children is widening as more patients need a transplant without a concomitant increase in the organ donor pool. Organ donation can occur one of two ways: after fulfilling criteria for neurologic (brain) death or through a process of donation after circulatory death (DCD). DCD has only recently gained acceptance in pediatrics. Organ procurement, donation, and transplantation are strictly regulated by governmental agencies to ensure proper and fair allocation of donated organs for transplantation. It is important that pediatric medical specialists and pediatricians be well acquainted with the strategies and methods of organ donation to help acquaint both the donor family and the recipient family with the process and address expectations. Areas of concern within pediatric organ donation include availability of and access to donor organs; oversight and control of the process; pediatric medical and surgical consultation and continued care throughout the transplantation process; ethical, social, financial, and follow-up; insurance coverage; and public awareness of the need for organ donors. Organ donation and organ transplantation can provide significant life-extending benefits to a child who has a failing organ and is awaiting transplant, while at the same time place a high emotional impact on the donor family after the loss of a child.

PEARLS FOR PRACTITIONERS

See Profession of Pediatrics: Pearls for Practitioners at the end of this section.

Suggested Readings

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PEARLS FOR PRACTITIONERS

CHAPTER 1

Population and Culture: The Care of Children in Society

- Pediatricians must continue to address major issues impacting children's health outcomes including access to care, health disparities, and environmental factors including toxic stressors such as poverty and violence.
- The significant increase in the number of children with a chronic medical condition (e.g., asthma, obesity, attention-deficit/hyperactivity disorder) affects both inpatient and outpatient care.
- Addressing the following as a part of routine health care allows pediatricians to impact health care outcomes:
  - Toxic stressors (e.g., maternal stress, poverty, exposure to violence)
  - The use of electronic nicotine delivery systems or e-cigarettes
  - The sedentary lifestyle as children spend an increased amount of time in front of a screen (television, video games, computers, cell phones)
  - Early recognition of mental illness (It is estimated that 1 in 5 adolescents has a mental health condition.)
  - Use of complementary and alternative medicine (to minimize unintended interactions)

CHAPTER 2

Professionalism

- The activities of medical professionals are subject to explicit public rules of accountability developed by governmental and other authorities.
- The public trust of physicians is based on the physician's commitment to altruism.
- Extreme circumstances, such as a natural disaster or global pandemic, may necessitate adaptability as physicians expand how they help others by using their medical knowledge and clinical skills in unique and uncertain situations.
- The policy statement on professionalism released by the American Board of Pediatrics emphasizes honesty/integrity, reliability/responsibility, respect for others, compassion/empathy, self-improvement, self-awareness/knowledge of limits, communication/collaboration, and altruism/advocacy.

CHAPTER 3

Ethics and Legal Issues

- Important ethical principles that help guide medical decision-making include autonomy, beneficence, nonmaleficence, and justice.
- The ability to legally make medical decisions for oneself depends on the patient's age, maturity, and determination of competence. Parents serve as medical decision-makers for most children, and these decisions should always be made within the child's best interest.
- Key ethical principles in the care of pediatric patients include autonomy (addressing medical decision-making in children), informed consent by parents, assent by the child, and confidentiality.

CHAPTER 4

Palliative Care and End-of-Life Issues

- Children needing palliative care generally fall into four basic categories: (1) when a cure is possible but unlikely, (2) long-term treatment with a goal of maintaining quality of life (e.g., cystic fibrosis), (3) treatment that is exclusively palliative after the diagnosis of a progressive condition is made (e.g., trisomy 13), and (4) when treatments are available for severe, non-progressive disabilities.
- Organ donation can occur after fulfilling criteria for neurologic death or through donation after circulatory death.

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GROWTH AND DEVELOPMENT

Latasha Bogues | *David A. Levine*

CHAPTER 5

Normal Growth

HEALTH MAINTENANCE VISIT

The frequent office visits for health maintenance in the first 2 years of life are more than physicals. Although a somatic history and physical examination are important parts of each visit, many other issues are discussed, including nutrition, behavior, development, safety, and **anticipatory guidance**.

Disorders of growth and development are often associated with chronic or severe illness or may be the only symptom of parental neglect or abuse. Although normal growth and development does not eliminate a serious or chronic illness, in general, it supports a judgment that a child is healthy except for acute, often benign illnesses.

The processes of growth and development are intertwined. However, it is convenient to refer to **growth** as the increase in size and **development** as an increase in function of processes related to body and mind. Being familiar with normal patterns of growth and development allows practitioners who care for children to recognize and manage abnormal variations.

The genetic makeup and the physical, emotional, and social environment of the individual determine how a child grows and develops throughout childhood. Helping each child achieve individual potential through periodically monitoring and screening for the normal progression or abnormalities of growth and development is one goal of pediatrics. The American Academy of Pediatrics recommends routine office visits in the first week of life (within 72 hours of routine nursery discharges); by 1 month of age; at 2, 4, 6, 9, 12, 15, and 18 months; at 2, 2 1/2, and 3 years; and then annually through adolescence/young adulthood (see Fig. 9.1; the *Bright Futures'* "Recommendations for Preventive Pediatric Health Care" found at https://www.aap.org/en-us/documents/periodicity_schedule.pdf).

Deviations in growth patterns may be nonspecific or may be important indicators of serious and chronic medical disorders. An accurate measurement of length/height, weight, and head circumference (measure head circumference through age 24 months) should be obtained at every health supervision visit and compared with statistical norms on growth charts. Table 5.1 summarizes several convenient benchmarks to evaluate normal growth. Serial measurements that establish a growth trend are much more useful than single measurements for detecting abnormal growth patterns. A single measurement may be within statistically defined normal limits (percentiles) while being at a vastly different percentile from previous measurements, representing a growth pattern that warrants further evaluation.

Growth is assessed by plotting accurate measurements on growth charts and comparing each set of measurements with previous measurements obtained at health visits. Please see examples in Figs. 5.1–5.4. Complete charts can be found at www.cdc.gov/growthcharts. The body mass index is defined as body weight in kilograms divided by height in meters squared; it is used to classify adiposity and is recommended as a screening tool for children and adolescents to identify those overweight or at risk for being overweight (see Chapter 29).

Normal growth patterns have spurts and plateaus, so some shifting on percentile graphs can be expected. Large shifts in percentiles warrant attention, as do large discrepancies in height, weight, and head circumference percentiles. When caloric intake is inadequate, the weight percentile falls first, then the height; the head circumference is last. Caloric intake may be poor as a result of inadequate feeding or because the child is not receiving adequate attention and stimulation (*nonorganic* failure to thrive [see Chapter 21]).

TABLE 5.1 Rules of Thumb for Growth

WEIGHT
Weight loss in first few days: 5–10% of birthweight
Return to birthweight: 7–10 days of age
Double birthweight: 4–5 months
Triple birthweight: 1 year
Daily weight gain:
20–30 g for first 3–4 months
15–20 g for rest of the first year
HEIGHT
Average length: 20 in. at birth, 30 in. at 1 year
At age 4 years, the average child is double birth length or 40 in.
HEAD CIRCUMFERENCE (HC)
Average HC: 35 cm at birth (13.5 in.)
HC increases: 1 cm per month for first year (2 cm per month for first 3 months, then slower)

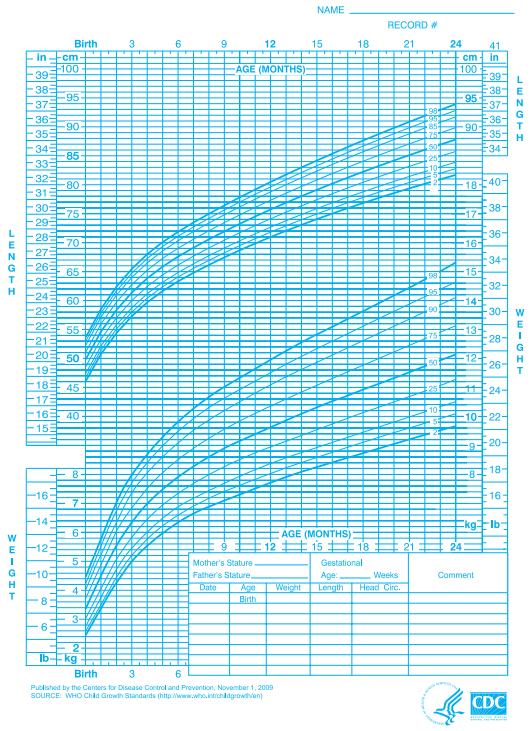

FIGURE 5.1 Length-by-age and weight-by-age percentiles for boys, birth to 2 years of age. Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion. (From Centers for Disease Control and Prevention. *WHO Child Growth Standards*. Atlanta, GA: CDC; 2009. http://www.cdc.gov/growthcharts.)

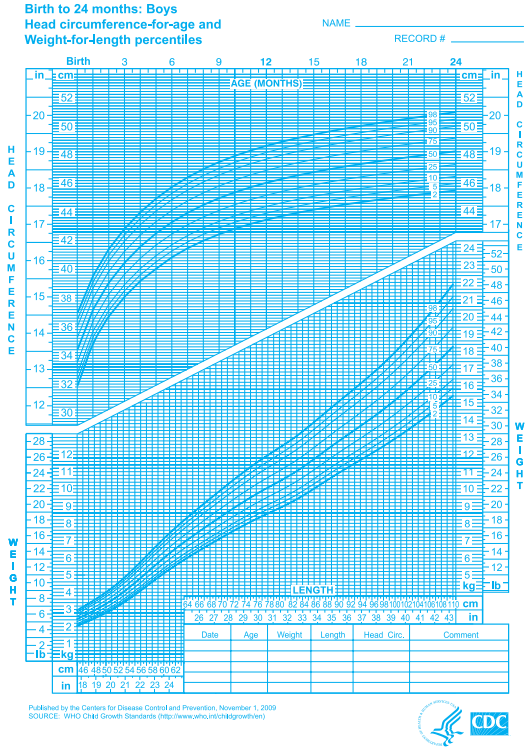

FIGURE 5.2 Head circumference and weight-by-length percentiles for boys, birth to 2 years of age. Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion. (From Centers for Disease Control and Prevention. *WHO Child Growth Standards*. Atlanta, GA: CDC; 2009. http://www.cdc.gov/growthcharts.)

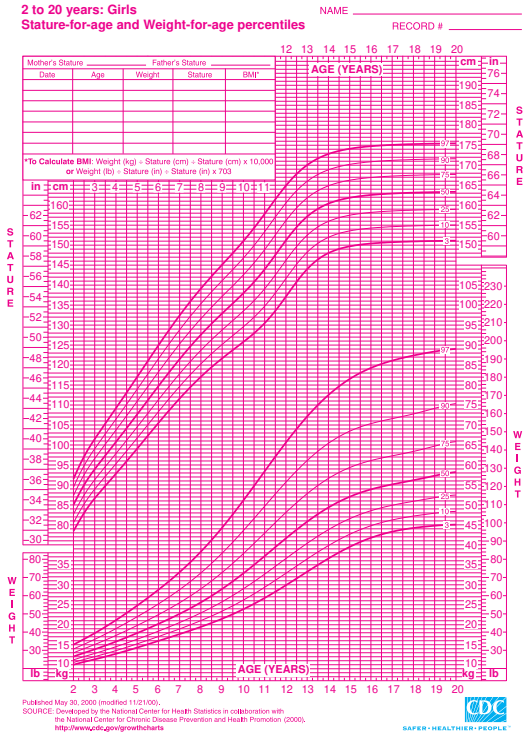

FIGURE 5.3 Stature-for-age and weight-for-age percentiles for girls, 2–20 years of age. Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion. (From Centers for Disease Control and Prevention. Atlanta, GA; 2001. http://www.cdc.gov/growthcharts.)

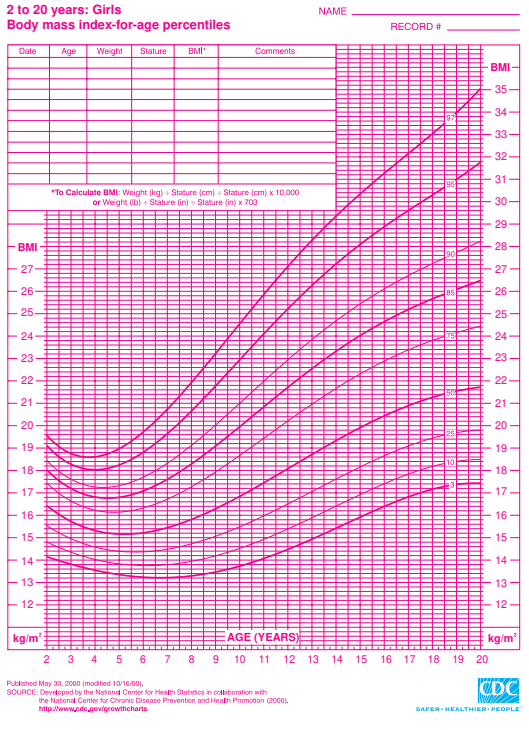

FIGURE 5.4 Body mass index–for-age percentiles for girls, 2–20 years of age. Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion. (From Centers for Disease Control and Prevention. Atlanta, GA; 2001. http://www.cdc.gov/growthcharts.)

Caloric intake also may be inadequate because of increased caloric needs. Children with chronic illnesses, such as heart failure or cystic fibrosis, may require a significantly higher caloric intake to sustain growth. An increasing weight percentile in the face of a falling height percentile suggests hypothyroidism. Head circumference may be disproportionately large when there is familial megalocephaly, hydrocephalus, or merely *catch-up* growth in a neurologically normal premature infant. A child is considered microcephalic if the head circumference is less than the 3rd percentile, even if length and weight measurements also are proportionately low. Serial measurements of head circumference are crucial during infancy, a period of rapid brain development, and should be plotted regularly until the child is 2 years of age. Any suspicion of abnormal growth warrants at least a close follow-up, further evaluation, or both.

PEARLS FOR PRACTITIONERS

See Growth and Development: Pearls for Practitioners at the end of this section.

CHAPTER 6
Disorders of Growth

The most common reasons for deviant measurements are technical (i.e., faulty equipment and human errors). Repeating a deviant measurement is the first step. Separate growth charts are available and should be used for very low birthweight infants (weight <1,500 g) and for those with Turner syndrome, Down syndrome, achondroplasia, and various other dysmorphology syndromes.

Variability in body proportions occurs from fetal to adult life. Newborns' heads are significantly larger in proportion to the rest of their body. This difference gradually disappears. Certain growth disturbances result in characteristic changes in the proportional sizes of the trunk, extremities, and head. Patterns requiring further assessment are summarized in Table 6.1.

Evaluating a child over time, coupled with a careful history and physical examination, helps determine whether the growth pattern is normal or abnormal. Parental heights may be useful when deciding whether to proceed with a further evaluation. Children, in general, follow their parents' growth patterns, although there are many exceptions.

For a girl, midparental height is calculated as follows:

$$\frac{\text{Paternal height (inches)} + \text{Maternal height (inches)}}{2} - 2.5$$

For a boy, midparental height is calculated as follows:

$$\frac{\text{Paternal height (inches)} + \text{Maternal height (inches)}}{2} + 2.5$$

Actual growth depends on too many variables to make an accurate prediction from midparental height determination for every child. The growth pattern of a child with low weight, length, and head circumference is commonly associated with **familial short stature** (see Chapter 173). These children are genetically normal but are smaller than most children. A child who, by age, is preadolescent or adolescent and who starts puberty later than others may have the normal variant called **constitutional short stature** (see Chapter 173); careful examination for abnormalities of pubertal development should be done. An evaluation for primary amenorrhea should be considered for any female adolescent who has not reached menarche by 15 years or has not done so within 3 years of thelarche (beginning of breast development). Lack of breast development by age 13 years also should be evaluated (see Chapter 174).

TABLE 6.1 Specific Growth Patterns Requiring Further Evaluation

PATTERN	REPRESENTATIVE DIAGNOSES TO CONSIDER	FURTHER EVALUATION
Weight, length, head circumference all <5th percentile	• Familial short stature • Constitutional short stature • Intrauterine insult • Genetic abnormality	• Midparental height • Evaluation of pubertal development • Examination of prenatal records • Chromosome analysis
Discrepant percentiles (e.g., weight 5th, length 5th, head circumference 50th, or other discrepancies)	• Normal variant (familial or constitutional) • Endocrine growth failure • Caloric insufficiency	• Midparental height • Thyroid hormone • Growth factors, growth hormone testing • Evaluation of pubertal development
Declining percentiles	• *Catch-down growth* • Caloric insufficiency • Endocrine growth failure	• Midparental height • Complete history and physical examination • Dietary and social history • Growth factors, growth hormone testing

Starting out in high growth percentiles, many children assume a lower percentile between 6 and 18 months of age until they match their genetic programming; then they grow along new, lower percentiles. They usually do not decrease more than two major percentiles and have normal developmental, behavioral, and physical examinations. These children with *catch-down growth* should be followed closely, but no further evaluation is warranted.

Infants born small for gestational age, or prematurely, ingest more breast milk or formula and, unless there are complications that require extra calories, usually exhibit *catch-up growth* in the first 6 months. These infants should be fed on demand and provided as much as they want unless they are vomiting (not just spitting up [see Chapter 128]). Some may benefit from a higher caloric content formula. Many psychosocial risk factors that may have led to being born small or early may contribute to nonorganic failure to thrive (see Chapter 21). Conversely, infants who recover from being low birthweight or premature have an increased risk of developing childhood obesity.

Growth of the nervous system is most rapid in the first 2 years, correlating with increasing physical, emotional, behavioral, and cognitive development. There is again rapid change during adolescence. Osseous maturation (bone age) is determined from radiographs on the basis of the number and size of calcified epiphyseal centers; the size, shape, density, and sharpness of outline of the ends of bones; and the distance separating the epiphyseal center from the zone of provisional calcification.

PEARLS FOR PRACTITIONERS

See Growth and Development: Pearls for Practitioners at the end of this section.

CHAPTER 7

Normal Development

PHYSICAL DEVELOPMENT

Parallel to the changes in the developing brain (i.e., cognition, language, behavior) are changes in the physical development of the body.

NEWBORN PERIOD

Observation of any asymmetric movement or altered muscle tone and function may indicate a significant central nervous system abnormality or a nerve palsy resulting from the delivery and requires further evaluation. Primitive neonatal reflexes are unique in the newborn period and can further elucidate or eliminate concerns over asymmetric function. The most important reflexes to assess during the newborn period are as follows:

The **Moro reflex** is elicited by allowing the infant's head to gently move back suddenly (from a few inches off of the mattress onto the examiner's hand), resulting in a startle, then abduction and upward movement of the arms followed by adduction and flexion. The legs respond with flexion.

The **rooting reflex** is elicited by touching the corner of the infant's mouth, resulting in lowering of the lower lip on the same side with tongue movement toward the stimulus. The face also turns toward the stimulus.

The **sucking reflex** occurs with almost any object placed in the newborn's mouth. The infant responds with vigorous sucking. The sucking reflex is replaced later by voluntary sucking.

The **asymmetric tonic neck reflex** is elicited by placing the infant supine and turning the head to the side. This placement results in ipsilateral extension of the arm and the leg into a "fencing" position. The contralateral side flexes as well.

A delay in the expected disappearance of the reflexes may also warrant an evaluation of the central nervous system.

See Sections 11 and 26 for additional information on the newborn period.

LATER INFANCY

With the development of gross motor skills, the infant is first able to control posture, then proximal musculature, and, last, distal musculature. As the infant progresses through these stages, the parents may notice orthopedic deformities (see Chapters 202 and 203). The infant also may have deformities that are related to intrauterine positioning. Physical examination should indicate whether the deformity is fixed or can be moved passively into the proper position. When a joint held in an abnormal fashion can be moved passively into the proper position, there is a high likelihood of resolving with the progression of gross motor development. Fixed deformities warrant immediate pediatric orthopedic consultation (see Section 26).

Evaluation of vision and ocular movements is important to prevent the serious outcome of strabismus. The cover test and light reflex should be performed at early health maintenance visits; interventions after age 2 decrease the chance of preserving binocular vision or normal visual acuity (see Chapter 179).

SCHOOL AGE/PREADOLESCENT

In addition to routine health supervision, older school-age children who begin to participate in competitive sports should have a comprehensive sports history and physical examination that includes a careful evaluation of the cardiovascular system. The American Academy of Pediatrics 5th edition sports preparticipation form is excellent for documenting cardiovascular and other risks. The patient and parent should complete the history form and be interviewed to assess cardiovascular risk. Any history of heart disease or a murmur must be referred for evaluation by a pediatric cardiologist. A child with a history of dyspnea or chest pain on exertion, irregular heart rate (i.e., skipped beats, palpitations), or syncope should also be referred to a pediatric cardiologist. A family history of a primary (immediate family) or secondary (immediate family's immediate family) atherosclerotic disease (myocardial infarction or cerebrovascular disease) before 50 years of age or sudden unexplained death at any age also requires additional assessment.

Children interested in contact sports should be assessed for special vulnerabilities. Similarly, vision should be assessed as a crucial part of the evaluation before participation in sports.

ADOLESCENCE

Adolescents need annual comprehensive health assessments to ensure progression through puberty without major problems (see Chapters 67 and 68). Sexual maturity is an important issue in adolescents, and all adolescents should be assessed to monitor progression through sexual maturity rating stages (see Chapter 67). Other issues in physical development include scoliosis, obesity, and common orthopedic growth issues (e.g., Osgood Schlatter; see Chapters 29 and 203). Most scoliosis is mild and requires only observation for resolution. Obesity may first manifest during childhood and is a growing public health concern for many adolescents.

DEVELOPMENTAL MILESTONES

The use of milestones to assess development focuses on discrete behaviors that the clinician can observe or accept as present by parental report. This approach is based on comparing the patient's behavior with that of many normal children whose behaviors evolve in a uniform sequence within specific age ranges (see Chapter 8). The development of the neuromuscular system, similar to that of other organ systems, is determined first by genetic endowment and then is molded by environmental influences.

Although a sequence of specific, easily measured behaviors can adequately represent some areas of development (**gross motor**, **fine motor**, and **language**), other areas, particularly social and emotional development, are not as easy to assess. Easily measured developmental milestones are well established through age 6 years only. Other types of assessment (e.g., intelligence tests, school performance, and personality profiles) that expand the developmental milestone approach are available for older children.

PSYCHOSOCIAL ASSESSMENT

Bonding and Attachment in Infancy

The terms *bonding* and *attachment* describe the affective relationships between parents and infants. **Bonding** occurs shortly after birth and reflects the feelings of the parents toward the newborn (unidirectional). **Attachment** involves reciprocal feelings between parent and infant and develops gradually over the first year.

Attachment of infants outside of the newborn period is crucial for optimal development. Infants who receive extra attention, such as parents responding immediately to any crying or fussiness in the first 4 months, show less crying and fussiness at the end of the first year. **Stranger anxiety** develops between 9 and 18 months of age, when infants normally become insecure about separation from the primary caregiver. The infant's new motor skills and attraction to novelty may lead to headlong plunges into new adventures that result in fright or pain followed by frantic efforts to find and cling to the primary caregiver. The result is dramatic swings from stubborn independence to clinging dependence that can be frustrating and confusing to parents. With secure attachment, this period of ambivalence may be shorter and less tumultuous.

Developing Autonomy in Early Childhood

Toddlers build on attachment and begin developing autonomy that allows separation from parents. In times of stress, toddlers often cling to their parents, but in their usual activities they may be actively separated. Ages 2–3 years are a time of major accomplishments in fine motor skills, social skills, cognitive skills, and language skills. The dependency of infancy yields to developing independence and the "I can do it myself" age. Limit setting is essential to a balance of the child's emerging independence.

Early Childhood Education

There is a growing body of evidence that notes that children who are in high-quality early learning environments are more prepared to succeed in school. Every dollar invested in early childhood education may save taxpayers up to 13 dollars in future costs. These children commit fewer crimes and are better prepared to enter the workforce after school. Early Head Start (<3 years), Head Start (3–4 years), and prekindergarten programs (4–5 years) all demonstrate better educational attainment, although the earlier the start, the better the results.

School Readiness

Readiness for preschool depends on the development of autonomy and the ability of the parent and the child to separate for hours at a time. Preschool experiences help children develop socialization skills; improve language; increase skill building in areas such as colors, numbers, and letters; and increase problem solving (puzzles).

Readiness for school (kindergarten) requires emotional maturity, peer group and individual social skills, cognitive abilities, and fine and gross motor skills (Table 7.1). Other issues include chronological age and gender. Children tend to do better in kindergarten if their fifth birthday is at least 4–6 months before the beginning of school. Girls usually are ready earlier than boys. If the child is in less than the average developmental range, the child should not be forced into early kindergarten. Holding a child back for reasons of developmental delay, in the false hope that the child will catch up, can also lead to difficulties. The child should enroll on schedule, and educational planning should be initiated to address any deficiencies.

TABLE 7.1 Evaluating School Readiness

PHYSICIAN OBSERVATIONS (BEHAVIORS OBSERVED IN THE OFFICE)
Ease of separation of the child from the parent
Speech development and articulation
Understanding of and ability to follow complex directions
Specific pre-academic skills
Knowledge of colors
Counts to 10
Knows age, first and last name, address, and phone number
Ability to copy shapes
Motor skills
Stand on one foot, skip, and catch a bounced ball
Dresses and undresses without assistance
PARENT OBSERVATIONS (QUESTIONS ANSWERED BY HISTORY)
Does the child play well with other children?
Does the child separate well, such as a child playing in the backyard alone with occasional monitoring by the parent?
Does the child show interest in books, letters, and numbers?
Can the child sustain attention to quiet activities?
How frequent are toilet-training *accidents*?

Physicians should be able to identify children at risk for school difficulties, such as those who have developmental delays or physical disabilities. These children may require specialized school services in an individualized education plan (IEP) and/or environment accommodations in a 504 plan.

Adolescence

Some define adolescence as 10–25 years of age, but adolescence is perhaps better characterized by the developmental stages (*early, middle*, and *late* adolescence) that all teens must negotiate to develop into healthy, functional adults. Different behavioral and developmental issues characterize each stage. The age at which each issue manifests and the importance of these issues vary widely among individuals, as do the rates of cognitive, psychosexual, psychosocial, and physical development.

During **early adolescence**, attention is focused on the present and on the peer group. Concerns are primarily related to the body's physical changes and normality. Strivings for independence are ambivalent. These young adolescents are difficult to interview because they often respond with short, clipped conversation and may have little insight. They are just becoming accustomed to abstract thinking.

Middle adolescence can be a difficult time for adolescents and the adults who have contact with them. Cognitive processes

are more sophisticated. Through abstract thinking, middle adolescents can experiment with ideas, consider things as they might be, develop insight, and reflect on their own feelings and the feelings of others. As they mature, these adolescents focus on issues of identity not limited solely to the physical aspects of their body. They explore their parents' and culture's values, sometimes by expressing the contrary side of the dominant value. Many middle adolescents explore these values in their minds only; others do so by challenging their parents' authority. Many engage in high-risk behaviors, including unprotected sexual intercourse, substance abuse, or dangerous driving. The strivings of middle adolescents for independence, limit testing, and need for autonomy often distress their families, teachers, or other authority figures. These adolescents are at higher risk for morbidity and mortality from accidents, homicide, or suicide.

Late adolescence usually is marked by formal operational thinking, including thoughts about the future (e.g., educational, vocational, and sexual). Late adolescents are usually more committed to their sexual partners than are middle adolescents. Unresolved separation anxiety from previous developmental stages may emerge, at this time, as the young person begins to move physically away from the family of origin to college or vocational school, a job, or military service.

MODIFYING PSYCHOSOCIAL BEHAVIORS

Child behavior is determined by heredity and by the environment. Behavioral theory postulates that behavior is primarily a product of external environmental determinants and that manipulation of the environmental antecedents and consequences of behavior can be used to modify maladaptive behavior and increase desirable behavior (operant conditioning). The four major methods of operant conditioning are positive reinforcement, negative reinforcement, extinction, and punishment. Many common behavioral problems of children can be ameliorated by these methods.

Positive reinforcement increases the frequency of a behavior by following the behavior with a favorable event (e.g., praising a child for excellent school performance). Sometimes this reinforcement may occur unintentionally, increasing the frequency of an undesirable behavior. For example, a toddler may purposely try to stick a pencil in a light socket to obtain attention, whether it be positive or negative. **Negative reinforcement** increases the frequency of a behavior by removal, cessation, or avoidance of an unpleasant event (e.g., no longer having to sit at table once vegetables are eaten). **Extinction** occurs when there is a decrease in the frequency of a previously reinforced behavior because the reinforcement is withheld. Extinction is the principle behind the common advice to ignore behavior such as crying at bedtime or temper tantrums, which parents may unwittingly reinforce through attention and comforting. While reinforcement increases behavior frequency, **punishment** decreases the frequency of a behavior through unpleasant consequences. Punishment can be positive (undesired event is increased or introduced) or negative (desired event is decreased).

Positive reinforcement is more effective than punishment. Punishment is more effective when combined with positive reinforcement. A toddler who draws on the wall with a crayon may be punished, but the child learns much quicker when positive reinforcement is given for the proper use of the crayon—on paper, not the wall. Interrupting and modifying behaviors are discussed in detail in Section 3.

TEMPERAMENT

Significant individual differences exist within the normal development of temperament (behavioral style). Temperament must be appreciated because, if an expected pattern of behavior is too narrowly defined, normal behavior may be inappropriately labeled as abnormal or pathologic. Three common constellations of temperamental characteristics are as follows:

1. The **easy child** (about 40% of children) demonstrates regularity of biologic functions (consistent, predictable times for eating, sleeping, and elimination), a positive approach to new stimuli, high adaptability to change, mild or moderate intensity in responses, and a positive mood.
2. The **difficult child** (about 10%) demonstrates irregularity of biologic functions, negative withdrawal from new stimuli, poor adaptability, intense responses, and a negative mood.
3. The **slow to warm up child** (about 15%) demonstrates a low activity level, withdrawal from new stimuli, slow adaptability, mild intensity in responses, and a somewhat negative mood.

The remaining 35% of children have more mixed temperaments. The individual temperament of a child has important implications for parenting and for the advice a pediatrician may give in anticipatory guidance or behavioral problem counseling.

Although temperament may be hardwired *(nature)* in each child to some degree, the environment *(nurture)* in which the child grows has a strong effect on the child's adjustment. Social and cultural factors can have marked effects on the child through differences in parenting style, educational approaches, and behavioral expectations.

PEARLS FOR PRACTITIONERS

See Growth and Development: Pearls for Practitioners at the end of this section.

CHAPTER 8
Disorders of Development

DEVELOPMENTAL SURVEILLANCE AND SCREENING

Developmental and behavioral problems are more common than any other category of problems in pediatrics, except acute infections and trauma. In 2008, 15% of children ages 3–7 had a developmental disability and others had behavioral disabilities. As many as 25% of children have serious psychosocial problems. Parents often neglect to mention these problems because they think the physician is uninterested or cannot help. It is necessary to monitor development and screen for the presence of these problems at health supervision visits, particularly in the years before preschool or early childhood learning center enrollment.

Development surveillance, done at every office visit, is an informal process comparing skill levels to lists of milestones. If suspicion of developmental or behavioral issues recurs, further evaluation is warranted (Table 8.1). Surveillance does not have a standard, so screening tests are necessary.

Developmental screening involves the use of standardized screening tests to identify children who require further diagnostic assessment. The American Academy of Pediatrics

TABLE 8.1 Developmental Milestones

AGE	GROSS MOTOR	FINE MOTOR–ADAPTIVE	PERSONAL-SOCIAL	LANGUAGE	OTHER COGNITIVE
2 wk	Moves head side to side	—	Regards face	Alerts to bell	—
2 mo	Lifts shoulder while prone	Tracks past midline	Smiles responsively	Cooing Searches for sound with eyes	—
4 mo	Lifts up on hands Rolls front to back If pulled to sit from supine, no head lag	Reaches for object Raking grasp	Looks at hand Begins to work toward toy	Laughs and squeals	—
6 mo	Sits alone Rolls back to front	Transfers object hand to hand	Feeds self Holds bottle	Babbles	—
9 mo	Pulls to stand Gets into sitting position	Starting to pincer grasp Bangs two blocks together	Waves bye-bye Plays pat-a-cake	Says *Dada* and *Mama*, but nonspecific Two-syllable sounds	—
12 mo	Walks Stoops and stands	Puts block in cup	Drinks from a cup Imitates others	Says *Mama* and *Dada*, specific Says one to two other words	—
15 mo	Walks backward Stoops and recovers	Scribbles Stacks two blocks	Uses spoon and fork Helps in housework	Says three to six words Follows commands	—
18 mo	Runs	Stacks four blocks Kicks a ball	Removes garment "Feeds" doll	Says at least six words	—
2 yr	Walks up and down stairs Throws overhand	Stacks six blocks Copies line	Washes and dries hands Brushes teeth Puts on clothes	Puts two words together Points to pictures Knows body parts	Understands concept of *today*
3 yr	Walks steps alternating feet Broad jump	Stacks eight blocks Wiggles thumb	Uses spoon well, spilling little Puts on T-shirt	Names pictures Speech understandable to stranger 75% Says three-word sentences	Understands concepts of *tomorrow* and *yesterday*
4 yr	Balances well on each foot Hops on one foot	Copies *O*, maybe + Draws person with three parts	Brushes teeth without help Dresses without help	Names colors Understands adjectives	—
5 yr	Skips Heel-to-toe walks	Copies □	—	Counts Understands opposites	—
6 yr	Balances on each foot 6 sec	Copies Δ Draws person with six parts	—	Defines words	Begins to understand *right* and *left*

Mo, Month; *sec*, second; *wk*, week; *yr*, year.

recommends the use of validated standardized screening tools at three of the health maintenance visits: 9 months, 18 months, and 30 months. Clinics and offices that serve a higher risk patient population (e.g., children living in poverty) often perform a screening test at *every* health maintenance visit. A child who fails to pass a developmental screening test requires more comprehensive evaluation but does not necessarily have a delay; definitive testing must confirm. Developmental evaluations for children with suspected delays and intervention services for children with diagnosed disabilities are available free to families. A combination of U.S. state and federal funds provides these services.

Screening tests can be categorized as general screens that cover all behavioral domains or as targeted screens that focus on one area of development. Some may be administered in the office by professionals, while others may be completed at home (or in a waiting room) by parents. Good developmental/behavioral screening instruments have a sensitivity of 70–80% in detecting suspected problems and a specificity of 70–80% in detecting normal development. Although 30% of children screened may be *over-referred* for definitive developmental testing, this group also includes children whose skills are below average and who may benefit from testing that may help address relative developmental deficits. The 20–30% of children who have disabilities that are not detected by the single administration of a screening instrument are likely to be identified on repeat screening at subsequent health maintenance visits.

The Denver Developmental Screening Test II was the first test used by general pediatricians, but it is now out of date, and the company has closed. The test required observation of objective behavior and was difficult to administer consistently.

Today's most used developmental screening tools include **Ages and Stages Questionnaires** (developmental milestone driven) and **Parents' Evaluation of Developmental Status (PEDS)**. The latter is a simple, 10-item questionnaire that parents complete at office visits based on concerns with function and progression of development. Parent-reported screens have good validity compared to office-based screening measures. Many offices combine PEDS with developmental surveillance to track milestone attainment.

TABLE 8.2 Rules of Thumb for Speech Screening

AGE (YR)	SPEECH PRODUCTION	ARTICULATION (AMOUNT OF SPEECH UNDERSTOOD BY A STRANGER)	FOLLOWING COMMANDS
1	One to three words	—	One-step commands
2	Two- to three-word phrases	One half	Two-step commands
3	Routine use of sentences	Three fourths	—
4	Routine use of sentence sequences; conversational give-and-take	Almost all	—
5	Complex sentences; extensive use of modifiers, pronouns, and prepositions	Almost all	—

TABLE 8.3 Conditions Considered High Risk for Associated Hearing Deficit

Congenital hearing loss in first cousin or closer relative
Bilirubin level of ≥20 mg/dL
Congenital rubella or other nonbacterial intrauterine infection
Defects in the ear, nose, or throat
Birthweight of ≤1,500 g
Multiple apneic episodes
Exchange transfusion
Meningitis
Five-minute Apgar score of ≤5
Persistent fetal circulation (primary pulmonary hypertension)
Treatment with ototoxic drugs (e.g., aminoglycosides and loop diuretics)

Autism screening is mandated for all children at 18 and 24 months of age. Although there are several tools, many pediatricians use the **Modified Checklist for Autism in Toddlers—Revised (M-CHAT-R)**. M-CHAT-R is an office-based questionnaire that asks parents about typical behaviors, some of which are more predictive than others for autism or other pervasive developmental disorders. If the child demonstrates more than two predictive or three total behaviors, further assessment with an interview algorithm is indicated to distinguish normal variant behaviors from those children needing a referral for definitive testing. The test is freely distributed on the Internet and is available at https://www.m-chat.org (see Chapter 20).

Language screening correlates best with cognitive development in the early years. Table 8.2 provides some rules of thumb for language development that focus on speech production (expressive language). Although expressive language is the most obvious language element, the most dramatic changes in language development in the first years involve recognition and understanding (receptive language).

Whenever there is a speech and/or language delay, a **hearing deficit** must be considered and screened for. If hearing is abnormal and not addressed, speech cannot develop appropriately or appropriately respond to therapy. The implementation of universal newborn hearing screening detects many, if not most, of these children in the newborn period, and appropriate early intervention services may be provided. Conditions that present a high risk of an associated hearing deficit are listed in Table 8.3. Dysfluency *(stuttering)* is common in a 3- and 4-year-old child. Unless the dysfluency is severe, is accompanied by tics or unusual posturing, or occurs after 4 years of age, parents should be counseled that it is normal and transient and to accept it calmly and patiently.

After the child's sixth birthday and until adolescence, developmental assessment is initially done by inquiring about school performance (academic achievement and behavior). Inquiring about concerns raised by teachers or other adults who care for the child (after-school program counselor, coach, religious leader) is prudent. Formal developmental testing of these older children is beyond the scope of the primary care pediatrician. Nonetheless, the health care provider should be the coordinator of the testing and evaluation performed by other specialists (e.g., psychologists, psychiatrists, developmental pediatricians, and educational professionals).

OTHER ISSUES IN ASSESSING DEVELOPMENT AND BEHAVIOR

Ignorance of environmental influences on child behavior may result in ineffective or inappropriate management (or both). Adverse childhood experiences (ACEs) are traumatic experiences, including witnessed or experienced abuse or neglect, that occur prior to age 18. Social determinants of health (SDOH) are conditions of where a person is born, grows, works, and lives. ACEs and SDOH can greatly affect growth and development so should be asked about and addressed. Table 8.4 lists some contextual factors that should be considered in the etiology of a child's behavioral or developmental problem.

Building rapport with the parents and the child is a prerequisite for obtaining the often-sensitive information that is essential for understanding a behavioral or developmental issue. Rapport usually can be established quickly if the parents sense that the clinician respects them and is genuinely interested in listening to their concerns. The clinician develops rapport with the child by engaging in developmentally appropriate conversation or play, perhaps providing toys while interviewing the parents, and being sensitive to the fears the child may have. Too often, the child is ignored until it is time for the physical examination. Similar to their parents, children feel more comfortable if they are greeted by name and involved in pleasant interactions before they are asked sensitive questions or threatened with examinations. Young children can be engaged in conversation on the parent's lap, which provides security and places the child at the eye level of the examiner.

With adolescents, emphasis should be placed on building a physician-patient relationship that is distinct from the relationship with the parents. The parents should not be excluded; however, the adolescent should have the opportunity to express

TABLE 8.4 Context of Behavioral Problems
CHILD FACTORS
Health (past and current)
Developmental status
Temperament (e.g., difficult, slow to warm up)
Coping mechanisms
PARENTAL FACTORS
Misinterpretations of stage-related behaviors
Mismatch of parental expectations and characteristics of child
Mismatch of personality style between parent and child
Parental characteristics (e.g., depression, lack of interest, rejection, overprotective, coping)
ENVIRONMENTAL FACTORS
Stress (e.g., marital discord, unemployment, personal loss, perceived racism)
Support (e.g., emotional, material, informational, child care)
Poverty—including poor housing, poorer education facilities, lack of access to healthy foods (food deserts), unsafe environments, toxic stress, poor access to primary care
Racism

concerns and ask questions of the physician in confidence. Two intertwined issues must be taken into consideration—consent and confidentiality. Although laws vary from state to state, in general, adolescents who are able to give informed consent (i.e., mature minors) may consent to visits and care related to high-risk behaviors (i.e., depression and mental health issues, substance abuse; sexual health, including prevention, detection, and treatment of sexually transmitted infections; and pregnancy). Most states support the physician who wishes the visit to be confidential. Physicians should become familiar with the governing law in the state where they practice (see https://www.guttmacher.org). Providing confidentiality is crucial, allowing for optimal care (especially for obtaining a history of risk behaviors). When assessing development and behavior, confidentiality can be achieved by meeting with the adolescent alone for at least part of each visit. However, parents must be informed when the clinician has significant and immediate concerns about the health and safety of the child. Often, the clinician can convince the adolescent to inform the parents directly about a problem or can reach an agreement with the adolescent about how the parents will be informed by the physician (see Chapter 67).

EVALUATING DEVELOPMENTAL AND BEHAVIORAL ISSUES

Responses to open-ended questions often provide clues to underlying, unstated problems and identify the appropriate direction for further, more directed questions. Histories about developmental and behavioral problems are often vague and confusing; to reconcile apparent contradictions, the interviewer frequently must request clarification, more detail, or mere repetition. By summarizing an understanding of the information at frequent intervals and by recapitulating at the close of the visit, the interviewer and patient and family can ensure that they understand each other.

If the clinician's impression of the child differs markedly from the parent's description, there may be a crucial parental concern or issue that has not yet been expressed, either because it may be difficult to talk about (e.g., marital problems), because it is unconscious, or because the parent overlooks its relevance to the child's behavior. Alternatively, the physician's observations may be atypical, even with multiple visits. The observations of teachers, relatives, and other regular caregivers may be crucial in sorting out this possibility. The parent also may have a distorted image of the child, rooted in parental psychopathology. A sensitive, supportive, and noncritical approach to the parent is crucial to appropriate intervention. More information about referral and intervention for behavioral and developmental issues is covered in Chapter 10.

PEARLS FOR PRACTITIONERS

See Growth and Development: Pearls for Practitioners at the end of this section.

CHAPTER 9
Evaluation of the Well Child

Health maintenance or supervision visits should consist of a comprehensive assessment of the child's health and of the parent's/guardian's role in providing an environment for optimal growth, development, and health. The American Academy of Pediatrics' (AAP) Bright Futures information standardizes each of the health maintenance visits and provides resources for working with the children and families of different ages (see https://brightfutures.aap.org). Elements of each visit include evaluation and management of parental concerns; inquiry about any interval illness since the last physical, growth, development, and nutrition; anticipatory guidance (including safety information and counseling); physical examination; screening tests; and immunizations (Table 9.1). The Bright Futures Recommendations for Preventive Pediatric Health Care, found at https://www.aap.org/en-us/Documents/periodicity_schedule.pdf, summarizes requirements and indicates the ages that specific prevention measures should be undertaken, including risk screening and performance items for specific measurements. Bright Futures is now the enforced standard for the Medicaid and the Children's Health Insurance Program, along with many insurers, including Patient Protection and Affordable Care Act (PPACA) insurances. Health maintenance and immunizations now are covered without copays for insured patients as part of the PPACA.

SCREENING TESTS

Children usually are quite healthy and only the following screening tests are recommended: newborn metabolic screening with hemoglobin electrophoresis, hearing and vision evaluation, anemia and lead screening, tuberculosis testing, and dyslipidemia screening. (Items marked by a *star* in the Bright Futures Recommendations should be performed if a risk factor

TABLE 9.1 Topics for Health Supervision Visits

FOCUS ON THE CHILD
Concerns (parent's or child's)
Past problem follow-up
Immunization and screening test update
Routine care (e.g., eating, sleeping, elimination, and health habits)
Developmental progress
Behavioral style and problems
FOCUS ON THE CHILD'S ENVIRONMENT
Family
Caregiving schedule for caregiver who lives at home
Parent-child and sibling-child interactions
Extended family role
Family stresses (e.g., work, move, finances, illness, death, marital, and other interpersonal relationships)
Family supports (relatives, friends, groups)
Screening and intervention in the Social Determinants of Health
Community
Caregivers outside of the family
Peer interaction
School and work
Recreational activities
Physical Environment
Appropriate stimulation
Safety

is found, while items marked with a *dot* should be done universally.) Sexually experienced adolescents should be screened for sexually transmissible infections and have an HIV test at least once between 16 and 18. When an infant, child, or adolescent begins with a new physician, the pediatrician should perform any missing screening tests and immunizations.

Newborn Screening

Metabolic Screening

Every state in the United States mandates newborn metabolic screening. Each state determines its own priorities and procedures, but the following diseases are usually included in metabolic screening: phenylketonuria, galactosemia, congenital hypothyroidism, maple sugar urine disease, and organic aciduria (see Section 10). Many states now screen for cystic fibrosis (CF) by testing for immunoreactive trypsinogen. If that test is positive, then a DNA analysis for the most common CF mutations is performed. This is not a perfect test due to the myriad of mutations that lead to CF. Clinical suspicion warrants evaluation even if there were no CF mutations noted on the DNA analysis.

Hemoglobin Electrophoresis

Children with hemoglobinopathies are at higher risk for infection and complications from anemia, which early detection may prevent or ameliorate. Infants with sickle cell disease are begun on oral penicillin prophylaxis to prevent sepsis, which is the major cause of mortality in these infants (see Chapter 150).

Critical Congenital Heart Disease Screening

Newborns with cyanotic congenital heart disease may be missed if the ductus arteriosus is still open; when the ductus closes, these children become profoundly cyanotic, leading to complications and even death. The AAP now mandates screening with pulse oximetry of the right hand and foot. The baby passes screening if the oxygen saturation is 95% or greater in the right hand and foot and the difference is three percentage points or less between the right hand and foot. The screen is immediately failed if the oxygen saturation is less than 90% in the right hand and foot. Equivocal tests are repeated, or echocardiography and pediatric cardiology consultation are warranted (see Chapters 143 and 144).

Hearing Evaluation

Because speech and language are central to a child's cognitive development, the hearing screening is performed before discharge from the newborn nursery. An infant's hearing is tested by placing headphones over the infant's ears and electrodes on the head. Standard sounds are played, and the transmission of the impulse to the brain is documented. If abnormal, a further evaluation using evoked response technology of sound transmission is indicated. A newborn should have a hearing screen by 1 month of age with follow-up testing for abnormal results by 3 months of age and interventions if indicated by 6 months of age.

Hearing and Vision Screening of Older Children

Infants and Toddlers

Inferences about hearing are drawn from asking parents about responses to sound and speech and by examining speech and language development closely. Inferences about vision may be made by examining gross motor milestones (children with vision problems may have a delay) and by physical examination of the eye. Parental concerns about vision should be sought until the child is 3 years of age and about hearing until the child is 4 years of age. If there are concerns, definitive testing should be arranged. Hearing can be screened by auditory evoked responses, as mentioned for newborns. For toddlers and older children who cannot cooperate with formal audiologic testing with headphones, behavioral audiology may be used. Sounds of a specific frequency or intensity are provided in a standard environment within a soundproof room, and responses are assessed by a trained audiologist. Vision may be assessed by referral to a pediatric ophthalmologist and by visual evoked responses.

Children 3 Years of Age and Older

At various ages, hearing and vision should be screened objectively using standard techniques as specified in the Bright Futures Recommendations. Asking the family and child about any concerns or consequences of poor hearing or vision accomplishes subjective evaluation. At 3 years of age, children are screened for vision for the first time if they are

developmentally able to be tested. Many children at this age do not have the interactive language or interpersonal skills to perform a vision screen; these children should be re-examined within 6 months to ensure that their vision is normal. Because most of these children do not yet identify letters, using a Snellen eye chart with standard shapes is recommended. When a child is able to identify letters, the more accurate letter-based chart should be used. Audiologic testing of sounds with headphones should begin on the fourth birthday (although Head Start requires that pediatricians attempt the hearing screening at 3 years of age). Any suspected audiologic problem should be evaluated by a careful history and physical examination with referral for comprehensive testing. Children who have a documented vision problem, failed screening, or parental concern should be referred, preferably to a pediatric ophthalmologist.

Anemia Screening

Children are screened for anemia at ages when there is a higher incidence of iron-deficiency anemia. Infants are screened at birth and again at 4 months if there is a documented risk, such as low birthweight or prematurity. All infants are screened at 12 months of age because this is when a high incidence of iron deficiency is noted. Children are assessed at other visits for risks or concerns related to anemia (denoted by a star in the Bright Futures Recommendations at https://downloads.aap.org/AAP/PDF/periodicity_schedule.pdf). Any abnormalities detected should be evaluated for etiology. Anemic infants do not perform as well on standard developmental testing. When iron deficiency is strongly suspected, a therapeutic trial of iron may be used (see Chapter 150).

Lead Screening

Lead intoxication may cause developmental and behavioral abnormalities that are not reversible, even if the hematologic and other metabolic complications are treated. Although the Centers for Disease Control and Prevention (CDC) recommends environmental investigation at blood lead levels of 20 µg/dL on a single visit or persistent 15 µg/dL over a 3-month period, levels of 5–10 µg/dL may cause learning problems. Risk factors for lead intoxication include living in older homes with cracked or peeling lead-based paint, industrial exposure, use of foreign remedies (e.g., a diarrhea remedy from Central or South America), and use of pottery with lead paint glaze. Because of the significant association of lead intoxication with poverty, the CDC recommends routine blood lead screening at 12 and 24 months. In addition, standardized screening questions for risk of lead intoxication should be asked for all children between 6 months and 6 years of age (Table 9.2). Any positive or suspect response is an indication for obtaining a blood lead level. Capillary blood sampling may produce false-positive results; thus, in most situations, a venous blood sample should be obtained or a process implemented to get children tested with a venous sample if they had an elevated capillary level. County health departments, community organizations, and private companies provide lead inspection and detection services to determine the source of the lead. Standard decontamination techniques should be used to remove the lead while avoiding aerosolizing the toxic metal that a child might breathe or creating dust that a child might ingest (see Chapters 149 and 150).

TABLE 9.2 Lead Poisoning Risk Assessment Questions to Be Asked Between 6 Months and 6 Years

Does the child live in or regularly visit a home built before 1950?
Does the child spend any time in a building built before 1978 with recent or ongoing painting, repair work, remodeling, or damage?
Is there a brother, sister, housemate, playmate, or community member being followed or treated (or even rumored to be) for lead poisoning?
Does the child live with an adult whose job or hobby involves exposure to lead (e.g., lead smelting and automotive radiator repair)?
Does the child live near an active lead smelter, battery recycling plant, or other industry likely to release lead?
Does the family use home remedies or pottery from another country?

TABLE 9.3 Groups at High Risk for Tuberculosis

Close contacts with persons known to have tuberculosis (TB), positive TB test, or suspected to have TB
Foreign-born persons from areas with high TB rates (Asia, Africa, Latin America, Eastern Europe, Russia)
Health care workers
High-risk racial or ethnic minorities or other populations at higher risk (Asian, Pacific Islander, Hispanic, Black, Native American, groups living in poverty [e.g., Medicaid recipients], migrant farm workers, homeless persons, substance abusers)
Children <5 years of age
Immunocompromised individuals

Tuberculosis Testing

The prevalence of tuberculosis is increasing largely as a result of the adult HIV epidemic. Children often present with serious and multisystem disease (miliary tuberculosis). All children should be assessed for risk of tuberculosis at health maintenance visits at 1 month, 6 months, 12 months, and then annually. The high-risk groups, as defined by the CDC, are listed in Table 9.3. In general, the standardized purified protein derivative intradermal test is used with evaluation by a health care provider 48–72 hours after injection. The size of induration, not the color of any mark, denotes a positive test; 15 mm of induration is a positive test in anyone. For most patients with risk factors, 10 mm of induration is a positive test. For HIV-positive patients, those with recent tuberculosis contacts, patients with evidence of old healed tuberculosis on chest film, or immunosuppressed patients, 5 mm is a positive test (see Chapter 124). The QuantiFERON-TB Gold blood test is a newer test that has the advantage of needing one office visit only, but it also has a higher cost.

Cholesterol

Children and adolescents who have a family history of cardiovascular disease or have at least one parent with a high blood cholesterol level are at increased risk of having high blood cholesterol levels as adults and increased risk of coronary heart disease. The AAP recommends dyslipidemia screening in the

TABLE 9.4 Cholesterol Risk Screening Recommendations

Risk screening at ages 2, 4, 6, 8, and annually in adolescence:
1. Children and adolescents who have a family history of high cholesterol or heart disease
2. Children whose family history is unknown
3. Children who have other personal risk factors: obesity, high blood pressure, or diabetes

Universal screening at ages 9–11 and ages 17–21 (once per age range)

context of regular health care for at-risk populations (Table 9.4) by obtaining a fasting lipid profile. The recommended screening levels are the same for all children 2–18 years. Total cholesterol of less than 170 mg/dL is normal, 170–199 mg/dL is borderline, and greater than 200 mg/dL is elevated. In addition, in 2011, the AAP endorsed the National Heart, Lung, and Blood Institute of the National Institutes of Health recommendation to test all children at least once between ages 9 and 11.

Sexually Transmitted Infection Testing

Annual office visits are recommended for adolescents. A full adolescent psychosocial history should be obtained in confidential fashion (see Section 12). Part of this evaluation is a comprehensive sexual history that often requires creative questioning. Not all adolescents identify oral sex as sex, and some adolescents misinterpret the term *sexually active* to mean that one has many sexual partners or is very vigorous during intercourse. The questions, "Are you having sex?" and "Have you ever had sex?" should be asked. In the Bright Futures Guidelines, any child or adolescent who has had any form of sexual intercourse should have at least an annual evaluation (more often if there is a history of high-risk sex) for sexually transmitted diseases by physical examination (genital warts, genital herpes, and pediculosis) and laboratory testing (chlamydia, gonorrhea, syphilis, and HIV) (see Chapter 116). Young women should be assessed for human papillomavirus and precancerous lesions by Papanicolaou smear at 21 years of age.

Depression Screening

All adolescents, starting at age 11, should have annual depression screening with a validated tool. The Patient Health Questionnaires (PHQ) are commonly used. Both the short PHQ2 and its slightly longer PHQ9 are available on the Bright Futures website in the Tool and Resource Kit at https://toolkits.solutions.aap.org/ss/screening_tools.aspx.

Immunizations

Immunization records should be checked at each office visit regardless of the reason. Appropriate vaccinations should be administered (see Chapter 94).

DENTAL CARE

Many families in the United States, particularly poor and ethnic minority families, underuse dental health care. Pediatricians may identify gross abnormalities, such as large caries, gingival inflammation, or significant malocclusion. All children 1 year and older should have a dental examination by a dentist at least annually and a dental cleaning by a dentist or hygienist every 6 months. Dental health care visits should include instruction about preventive care practiced at home (brushing and flossing). Other prophylactic methods shown to be effective at preventing caries are concentrated fluoride topical treatments (dental varnish) and acrylic sealants on the molars. Bright Futures now recommends that pediatricians apply dental fluoride varnish to infants and children every 3–6 months between 9 months and 5 years. Pediatric dentists recommend beginning visits at age 1 year to educate families and to screen for milk bottle caries. Fluoridation of water or fluoride supplements in communities that do not have fluoridation are important in the prevention of cavities (see Chapter 127).

NUTRITIONAL ASSESSMENT

Plotting a child's growth on the standard charts is a vital component of the nutritional assessment. A dietary history should be obtained because the content of the diet may suggest a risk of nutritional deficiency (see Chapters 27 and 28).

ANTICIPATORY GUIDANCE

Anticipatory guidance is information conveyed to parents verbally, in written materials, or even directing parents to certain Internet websites to assist them in facilitating optimal growth and development for their children. Anticipatory guidance that is age relevant is another part of the Bright Futures Guidelines. The Bright Futures Tool and Resource Kit includes the topics and one-page handouts for families (and for older children) about the highest yield issues for the specific age. Table 9.5 summarizes representative issues that might be discussed. It is important to briefly review the safety topics previously discussed at other visits for reinforcement. Age-appropriate discussions should occur at each visit.

Safety Issues

The most common cause of death for infants 1 month to 1 year of age is **motor vehicle crashes**. No newborn should be discharged from a nursery unless the parents have a functioning and properly installed car seat. Many automobile dealerships and fire departments offer services to parents to ensure that safety seats are installed properly in their specific model. Most states have laws that mandate the use of safety seats until the child reaches 4 years of age or at least 40 pounds in weight. The following are age-appropriate recommendations for car safety:

1. Infants and toddlers should ride in a **rear-facing safety seat** until they are at least 2 years old. It is considered safest for children to remain rear-facing after 2 years old for as long as possible while within weight and height limits set by the safety seat manufacturer.
2. Toddlers and preschoolers over age 2 or who have outgrown the rear-facing car seat should use a **forward-facing car seat** with harness for as long as possible up to the highest weight or height recommended by the manufacturer.
3. School-age children, whose weight or height is above the forward-facing limit for their car seat, should use a **belt-positioning booster seat** until the vehicle seat belt fits properly, typically when they have reached 4 ft 9 in. in height and are between 8 and 12 years of age.

TABLE **9.5** Anticipatory Guidance Topics Suggested by Age

AGES	INJURY PREVENTION	VIOLENCE PREVENTION	NUTRITIONAL COUNSELING	FOSTERING OPTIMAL DEVELOPMENT
Birth and/ or 3–5 days	Crib safety Hot water heaters <120°F Car safety seats Smoke detectors Back to sleep	Assess bonding and attachment Identify family strife, lack of support, pathology Educate parents on nurturing	Exclusive breast-feeding encouraged Formula as a second-best option	Discuss parenting skills Refer for parenting education
2 weeks or 1 month	Falls Back to sleep	Reassess* Discuss sibling rivalry Assess if guns in the home	Assess breast-feeding and offer encouragement, problem solving	Recognize and manage postpartum blues Child care options
2 months	Burns/hot liquids Back to sleep	Reassess firearm safety		Parent getting enough rest and managing returning to work
4 months	Infant walkers Choking/suffocation Back to sleep	Reassess	Introduction of solid foods	Discuss central to peripheral motor development Praise good behavior
6 months	Burns/hot surfaces Childproofing	Reassess	Assess status	Consistent limit-setting vs "spoiling" an infant Praise good behavior
9 months	Water safety Home safety review Ingestions/poisoning Car seat safety (rear-facing until ≥2 yr)	Assess parents' ideas on discipline and "spoiling"	Avoiding juice Begin to encourage practice with cup drinking	Assisting infants to sleep through the night if not accomplished Praise good behavior
12 months	Firearm hazards Auto-pedestrian safety Car seat safety (rear-facing until ≥2 yr)	Discuss time-out vs corporal punishment Avoiding media violence Review firearm safety	Introduction of whole cow's milk (and constipation with change discussed) Assess anemia, discuss iron-rich foods	Safe exploration Proper shoes Praise good behavior
15 months	Review and reassess topics	Encourage nonviolent punishments (time-out or natural consequences)	Discuss decline in eating with slower growth Assess food choices and variety	Fostering independence Reinforce good behavior Ignore annoying but not unsafe behaviors
18 months	Review and reassess topics	Limit punishment to high yield and major transgressions Parents consistent in discipline	Discuss food choices, portions, "finicky" feeders	Preparation for toilet training Reinforce good behavior
2 years	Falls—play equipment	Assess and discuss any aggressive behaviors in the child	Assess body proportions and recommend low-fat milk Assess family cholesterol and atherosclerosis risk	Toilet training and resistance
3 years	Review and reassess topics	Review, especially avoiding media violence	Discuss optimal eating and the food pyramid Healthy snacks	Read to child Socializing with other children Head Start if possible
4 years	Booster seat vs seat belts		Healthy snacks	Read to child Head Start or pre-K options
5 years	Bicycle safety Water/pool safety	Developing consistent, clearly defined family rules and consequences Avoiding media violence	Assess for anemia Discuss iron-rich foods	Reinforcing school topics Read to child Library card Chores begun at home
6 years	Fire safety	Reinforce consistent discipline Encourage nonviolent strategies Assess domestic violence Avoiding media violence	Assess content, offer specific suggestions	Reinforcing school topics After-school programs Responsibility given for chores (and enforced)

Continued

TABLE 9.5 Anticipatory Guidance Topics Suggested by Age—cont'd

AGES	INJURY PREVENTION	VIOLENCE PREVENTION	NUTRITIONAL COUNSELING	FOSTERING OPTIMAL DEVELOPMENT
7–10 years	Sports safety Firearm hazard	Reinforcement Assess domestic violence Assess discipline techniques Avoiding media violence Walking away from fights (either victim or spectator)	Assess content, offer specific suggestions	Reviewing homework and reinforcing school topics After-school programs Introduce smoking and substance abuse prevention (concrete)
11–13 years	Review and reassess	Discuss strategies to avoid interpersonal conflicts Avoiding media violence Avoiding fights and walking away Discuss conflict resolution techniques	Junk food vs healthy eating	Reviewing homework and reinforcing school topics Smoking and substance abuse prevention (begin abstraction) Discuss and encourage abstinence; possibly discuss condoms and contraceptive options Avoiding violence Offer availability
14–16 years	Motor vehicle safety Avoiding riding with substance abuser	Establish new family rules related to curfews, school, and household responsibilities	Junk food vs healthy eating	Review school work Begin career discussions and college preparation (PSAT) Review substance abuse, sexuality, and violence regularly Discuss condoms, contraception options, including emergency contraception Discuss sexually transmitted diseases, HIV Providing "no questions asked" ride home from at-risk situations
17–21 years	Review and reassess	Establish new rules related to driving, dating, and substance abuse	Heart healthy diet for life	Continuation of above topics Off to college or employment New roles within the family

**Reassess means to review the issues discussed at the prior health maintenance visit.*
PSAT, Preliminary scholastic aptitude test.

4. Older children should always use **lap and shoulder seat belts** for optimal protection. All children younger than 13 years should be restrained in the rear seats of vehicles for optimal protection. This is specifically to protect them from airbags, which may cause more injury than the crash in young children.

The ***Back to Sleep* initiative** has reduced the incidence of sudden infant death syndrome (SIDS). Before the initiative, infants routinely were placed prone to sleep. Since 1992, when the AAP recommended this program, the annual SIDS rate has decreased by more than 50%. Another initiative is aimed at day care providers, because 20% of SIDS deaths occur in day care settings.

Fostering Optimal Development

See Table 9.5 as well as the Bright Futures Recommendations (Fig. 9.1; also found at http://brightfutures.aap.org/clinical_practice.html) for presentation of age-appropriate activities that the pediatrician may advocate for families.

Discipline means to teach, not merely to punish. The ultimate goal is the child's self-control. Overbearing punishment to control a child's behavior interferes with the learning process and focuses on external control at the expense of the development of self-control. Parents who set too few reasonable limits may be frustrated by children who cannot control their own behavior. Discipline should teach a child exactly what is expected by supporting and reinforcing positive behaviors and responding appropriately to negative behaviors with proper limits. It is more important and effective to reinforce good behavior than to punish bad behavior.

Parenting styles are important because a caregiver's interactions with a child influences the child's growth, development, and eventual adult behavior. Parenting styles vary in the level of expectations and number of rules set for a child (demandingness), and in the level of warmth, communication, and consideration of the child's opinions (responsiveness). There are four recognized parenting styles: authoritative (high demandingness, high responsiveness), authoritarian (high demandingness, low responsiveness), permissive (low demandingness, high responsiveness), and uninvolved (low demandingness, low responsiveness). Authoritative parenting is regarded as the style most likely to result in a child who is happy, successful, and self-disciplined.

Commonly used techniques to control undesirable behaviors in children include scolding, physical punishment, and threats. These techniques have potential adverse effects on children's sense of security and self-esteem. The effectiveness of scolding diminishes the more it is used. Scolding should not be allowed to expand from an expression of displeasure about

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

Recommendations for Preventive Pediatric Health Care

Bright Futures/American Academy of Pediatrics

Bright Futures
prevention and health promotion for infants, children, adolescents, and their families™

Each child and family is unique; therefore, these Recommendations for Preventive Pediatric Health Care are designed for the care of children who are receiving competent parenting, have no manifestations of any important health problems, and are growing and developing in a satisfactory fashion. Developmental, psychosocial, and chronic disease issues for children and adolescents may require frequent counseling and treatment visits separate from preventive care visits. Additional visits also may become necessary if circumstances suggest variations from normal.

These recommendations represent a consensus by the American Academy of Pediatrics (AAP) and Bright Futures. The AAP continues to emphasize the great importance of continuity of care in comprehensive health supervision and the need to avoid fragmentation of care.

Refer to the specific guidance by age as listed in the *Bright Futures Guidelines* (Hagan JF, Shaw JS, Duncan PM, eds. *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*. 4th ed. American Academy of Pediatrics; 2017).

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

The Bright Futures/American Academy of Pediatrics Recommendations for Preventive Pediatric Health Care are updated annually.

	INFANCY								EARLY CHILDHOOD							MIDDLE CHILDHOOD						ADOLESCENCE										
AGE[1]	**Prenatal**[2]	**Newborn**[3]	**3-5 d**[4]	**By 1 mo**	**2 mo**	**4 mo**	**6 mo**	**9 mo**	**12 mo**	**15 mo**	**18 mo**	**24 mo**	**30 mo**	**3 y**	**4 y**	**5 y**	**6 y**	**7 y**	**8 y**	**9 y**	**10 y**	**11 y**	**12 y**	**13 y**	**14 y**	**15 y**	**16 y**	**17 y**	**18 y**	**19 y**	**20 y**	**21 y**
HISTORY Initial/Interval	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
MEASUREMENTS																															
Length/Height and Weight		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Head Circumference		●	●	●	●	●	●	●	●	●	●	●																			
Weight for Length		●	●	●	●	●	●	●	●	●	●																				
Body Mass Index[5]												●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Blood Pressure[6]		★	★	★	★	★	★	★	★	★	★	★	★	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
SENSORY SCREENING																															
Vision[7]		★	★	★	★	★	★	★	★	★	★	★	★	●	●	●	●	★	●	★	●	★	●	★	★	●	★	★	★	★	★	★
Hearing		●[8]	●[9] →	→	★	★	★		★	★	★	★	★	★	●	●	●	★	●	★	●	←	←	●[10] →	←	● →		←	● →		←	● →
DEVELOPMENTAL/BEHAVIORAL HEALTH																															
Developmental Screening[11]								●			●		●																		
Autism Spectrum Disorder Screening[12]											●	●																			
Developmental Surveillance		●	●	●	●	●	●		●	●		●		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Psychosocial/Behavioral Assessment[13]		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Tobacco, Alcohol, or Drug Use Assessment[14]																						★	★	★	★	★	★	★	★	★	★
Depression Screening[15]																							●	●	●	●	●	●	●	●	●
Maternal Depression Screening[16]				●	●	●	●																								
PHYSICAL EXAMINATION[17]		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
PROCEDURES[18]																															
Newborn Blood		●[19]	●[20] →	→																											
Newborn Bilirubin[21]		●																													
Critical Congenital Heart Defect[22]		●																													
Immunization[23]		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Anemia[24]						★			●	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★
Lead[25]							★	★	● or ★[26]		★	● or ★[26]		★	★	★	★															
Tuberculosis[27]				★			★		★			★		★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★
Dyslipidemia[28]												★			★		★		★	←	● →	★	★	★	★	★	←	● →				
Sexually Transmitted Infections[29]																						★	★	★	★	★	★	★	★	★	★
HIV[30]																						★	★	★	★	←	● →	★	★	★	★
Hepatitis C Virus Infection[31]																												● →			
Cervical Dysplasia[32]																															●
ORAL HEALTH[33]							●[34]	●[34]	★		★	★	★	★	★	★	★														
Fluoride Varnish[35]							←		● →																						
Fluoride Supplementation[36]							★	★	★		★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★	★					
ANTICIPATORY GUIDANCE	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●

1. If a child comes under care for the first time at any point on the schedule, or if any items are not accomplished at the suggested age, the schedule should be brought up to date at the earliest possible time.
2. A prenatal visit is recommended for parents who are at high risk, for first-time parents, and for those who request a conference. The prenatal visit should include anticipatory guidance, pertinent medical history, and a discussion of benefits of breastfeeding and planned method of feeding, per "The Prenatal Visit" (http://pediatrics.aappublications.org/content/124/4/1227.full).
3. Newborns should have an evaluation after birth, and breastfeeding should be encouraged (and instruction and support should be offered).
4. Newborns should have an evaluation within 3 to 5 days of birth and within 48 to 72 hours after discharge from the hospital to include evaluation for feeding and jaundice. Breastfeeding newborns should receive formal breastfeeding evaluation, and their mothers should receive encouragement and instruction, as recommended in "Breastfeeding and the Use of Human Milk" (http://pediatrics.aappublications.org/content/129/3/e827.full). Newborns discharged less than 48 hours after delivery must be examined within 48 hours of discharge, per "Hospital Stay for Healthy Term Newborns" (http://pediatrics.aappublications.org/content/125/2/405.full).
5. Screen, per "Expert Committee Recommendations Regarding the Prevention, Assessment, and Treatment of Child and Adolescent Overweight and Obesity: Summary Report" (http://pediatrics.aappublications.org/content/120/Supplement_4/S164.full)
6. Screening should occur per "Clinical Practice Guideline for Screening and Management of High Blood Pressure in Children and Adolescents" (http://pediatrics.aappublications.org/content/140/3/e20171904). Blood pressure measurement in infants and children with specific risk conditions should be performed at visits before age 3 years.
7. A visual acuity screen is recommended at ages 4 and 5 years, as well as in cooperative 3-year-olds. Instrument-based screening may be used to assess risk at ages 12 and 24 months, in addition to the well visits at 3 through 5 years of age. See "Visual System Assessment in Infants, Children, and Young Adults by Pediatricians" (http://pediatrics.aappublications.org/content/137/1/e20153596) and "Procedures for the Evaluation of the Visual System by Pediatricians" (http://pediatrics.aappublications.org/content/137/1/e20153597).
8. Confirm initial screen was completed, verify results, and follow up, as appropriate. Newborns should be screened, per "Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs" (http://pediatrics.aappublications.org/content/120/4/898.full).
9. Verify results as soon as possible, and follow up, as appropriate.
10. Screen with audiometry including 6,000 and 8,000 Hz high frequencies once between 11 and 14 years, once between 15 and 17 years, and once between 18 and 21 years. See "The Sensitivity of Adolescent Hearing Screens Significantly Improves by Adding High Frequencies" (https://www.sciencedirect.com/science/article/abs/pii/S1054139X16000483).
11. Screening should occur per "Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening" (https://pediatrics.aappublications.org/content/145/1/e20193449).
12. Screening should occur per "Identification, Evaluation, and Management of Children With Autism Spectrum Disorder" (https://pediatrics.aappublications.org/content/145/1/e20193447).
13. This assessment should be family centered and may include an assessment of child social-emotional health, caregiver depression, and social determinants of health. See "Promoting Optimal Development: Screening for Behavioral and Emotional Problems" (http://pediatrics.aappublications.org/content/135/2/384) and "Poverty and Child Health in the United States" (http://pediatrics.aappublications.org/content/137/4/e20160339).
14. A recommended assessment tool is available at http://crafft.org.
15. Recommended screening using the Patient Health Questionnaire (PHQ)-2 or other tools available in the GLAD-PC toolkit and at https://downloads.aap.org/AAP/PDF/Mental_Health_Tools_for_Pediatrics.pdf.
16. Screening should occur per "Incorporating Recognition and Management of Perinatal Depression Into Pediatric Practice" (https://pediatrics.aappublications.org/content/143/1/e20183259).
17. At each visit, age-appropriate physical examination is essential, with infant totally unclothed and older children undressed and suitably draped. See "Use of Chaperones During the Physical Examination of the Pediatric Patient" (http://pediatrics.aappublications.org/content/127/5/991.full).
18. These may be modified, depending on entry point into schedule and individual need.
19. Confirm initial screen was accomplished, verify results, and follow up, as appropriate. The Recommended Uniform Screening Panel (https://www.hrsa.gov/advisory-committees/heritable-disorders/rusp/index.html), as determined by The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, and state newborn screening laws/regulations (https://www.babysfirsttest.org/newborn-screening/states) establish the criteria for and coverage of newborn screening procedures and programs.

(continued)

KEY: ● = to be performed ★ = risk assessment to be performed with appropriate action to follow, if positive ← ● → = range during which a service may be provided

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FIGURE 9.1 Recommendations for Preventive Pediatric Health Care. (Copyright 2021 by the American Academy of Pediatrics. Reproduced with permission. https://www.aap.org/en-us/documents/periodicity_schedule.pdf.)

(continued)

20. Verify results as soon as possible, and follow up, as appropriate.
21. Confirm initial screening was accomplished, verify results, and follow up, as appropriate. See "Hyperbilirubinemia in the Newborn Infant ≥35 Weeks' Gestation: An Update With Clarifications" (http://pediatrics.aappublications.org/content/124/4/1193).
22. Screening for critical congenital heart disease using pulse oximetry should be performed in newborns, after 24 hours of age, before discharge from the hospital, per "Endorsement of Health and Human Services Recommendation for Pulse Oximetry Screening for Critical Congenital Heart Disease" (http://pediatrics.aappublications.org/content/129/1/190.full).
23. Schedules, per the AAP Committee on Infectious Diseases, are available at https://redbook.solutions.aap.org/SS/immunization_Schedules.aspx. Every visit should be an opportunity to update and complete a child's immunizations.
24. Perform risk assessment or screening, as appropriate, per recommendations in the current edition of the AAP *Pediatric Nutrition: Policy of the American Academy of Pediatrics* (Iron chapter).
25. For children at risk of lead exposure, see "Prevention of Childhood Lead Toxicity" (http://pediatrics.aappublications.org/content/138/1/e20161493) and "Low Level Lead Exposure Harms Children: A Renewed Call for Primary Prevention" (http://www.cdc.gov/nceh/lead/ACCLPP/Final_Document_030712.pdf).
26. Perform risk assessments or screenings as appropriate, based on universal screening requirements for patients with Medicaid or in high prevalence areas.
27. Tuberculosis testing per recommendations of the AAP Committee on Infectious Diseases, published in the current edition of the AAP *Red Book: Report of the Committee on Infectious Diseases*. Testing should be performed on recognition of high-risk factors.
28. See "Integrated Guidelines for Cardiovascular Health and Risk Reduction in Children and Adolescents" (http://www.nhlbi.nih.gov/guidelines/cvd_ped/index.htm).
29. Adolescents should be screened for sexually transmitted infections (STIs) per recommendations in the current edition of the AAP *Red Book: Report of the Committee on Infectious Diseases*.
30. Adolescents should be screened for HIV according to the US Preventive Services Task Force (USPSTF) recommendations (https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/human-immunodeficiency-virus-hiv-infection-screening) once between the ages of 15 and 18, making every effort to preserve confidentiality of the adolescent. Those at increased risk of HIV infection, including those who are sexually active, participate in injection drug use, or are being tested for other STIs, should be tested for HIV and reassessed annually.
31. All individuals should be screened for hepatitis C virus (HCV) infection according to the USPSTF (https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/hepatitis-c-screening) and Centers for Disease Control and Prevention (CDC) recommendations (https://www.cdc.gov/mmwr/volumes/69/rr/rr6902a1.htm) at least once between the ages of 18 and 79. Those at increased risk of HCV infection, including those who are persons with past or current injection drug use, should be tested for HCV infection and reassessed annually.
32. See USPSTF recommendations (https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/cervical-cancer-screening). Indications for pelvic examinations prior to age 21 are noted in "Gynecologic Examination for Adolescents in the Pediatric Office Setting" (http://pediatrics.aappublications.org/content/126/3/583.full).
33. Assess whether the child has a dental home. If no dental home is identified, perform a risk assessment (https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Oral-Health/Pages/Oral-Health-Practice-Tools.aspx) and refer to a dental home. Recommend brushing with fluoride toothpaste in the proper dosage for age. See "Maintaining and Improving the Oral Health of Young Children" (http://pediatrics.aappublications.org/content/134/6/1224).
34. Perform a risk assessment (https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Oral-Health/Pages/Oral-Health-Practice-Tools.aspx). See "Maintaining and Improving the Oral Health of Young Children" (http://pediatrics.aappublications.org/content/134/6/1224).
35. See USPSTF recommendations (https://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/dental-caries-in-children-from-birth-through-age-5-years-screening). Once teeth are present, fluoride varnish may be applied to all children every 3 to 6 months in the primary care or dental office. Indications for fluoride use are noted in "Fluoride Use in Caries Prevention in the Primary Care Setting" (http://pediatrics.aappublications.org/content/134/3/626).
36. If primary water source is deficient in fluoride, consider oral fluoride supplementation. See "Fluoride Use in Caries Prevention in the Primary Care Setting" (http://pediatrics.aappublications.org/content/134/3/626).

Summary of Changes Made to the Bright Futures/AAP Recommendations for Preventive Pediatric Health Care (Periodicity Schedule)

This schedule reflects changes approved in November 2020 and published in March 2021. For updates and a list of previous changes made, visit www.aap.org/periodicityschedule.

CHANGES MADE IN NOVEMBER 2020

DEVELOPMENTAL

- Footnote 11 has been updated to read as follows: "Screening should occur per 'Promoting Optimal Development: Identifying Infant and Young Children With Developmental Disorders Through Developmental Surveillance and Screening' (https://pediatrics.aappublications.org/content/145/1/e20193449)."

AUTISM SPECTRUM DISORDER

- Footnote 12 has been updated to read as follows: "Screening should occur per 'Identification, Evaluation, and Management of Children With Autism Spectrum Disorder' (https://pediatrics.aappublications.org/content/145/1/e20193447)."

HEPATITIS C VIRUS INFECTION

- Screening for hepatitis C virus infection has been added to occur at least once between the ages of 18 and 79 years (to be consistent with recommendations of the USPSTF and CDC).
- Footnote 31 has been added to read as follows: "All individuals should be screened for hepatitis C virus (HCV) infection according to the USPSTF (https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/hepatitis-c-screening) and Centers for Disease Control and Prevention (CDC) recommendations (https://www.cdc.gov/mmwr/volumes/69/rr/rr6902a1.htm) at least once between the ages of 18 and 79. Those at increased risk of HCV infection, including those who are persons with past or current injection drug use, should be tested for HCV infection and reassessed annually."
- Footnotes 31 through 35 have been renumbered as footnotes 32 through 36.

CHANGES MADE IN OCTOBER 2019

MATERNAL DEPRESSION

- Footnote 16 has been updated to read as follows: "Screening should occur per 'Incorporating Recognition and Management of Perinatal Depression Into Pediatric Practice' (https://pediatrics.aappublications.org/content/143/1/e20183259)."

CHANGES MADE IN DECEMBER 2018

BLOOD PRESSURE

- Footnote 6 has been updated to read as follows: "Screening should occur per 'Clinical Practice Guideline for Screening and Management of High Blood Pressure in Children and Adolescents' (http://pediatrics.aappublications.org/content/140/3/e20171904). Blood pressure measurement in infants and children with specific risk conditions should be performed at visits before age 3 years."

ANEMIA

- Footnote 24 has been updated to read as follows: "Perform risk assessment or screening, as appropriate, per recommendations in the current edition of the AAP *Pediatric Nutrition: Policy of the American Academy of Pediatrics* (Iron chapter)."

LEAD

- Footnote 25 has been updated to read as follows: "For children at risk of lead exposure, see 'Prevention of Childhood Lead Toxicity' (http://pediatrics.aappublications.org/content /138/1/e20161493) and 'Low Level Lead Exposure Harms Children: A Renewed Call for Primary Prevention' (https://www.cdc.gov/nceh/lead/ACCLPP/Final_Document_030712.pdf)."

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FIGURE 9.1, cont'd

a specific event to derogatory statements about the child. Scolding also may escalate to the level of psychologic abuse. It is important to educate parents that they have a *good child who does bad things from time to time*, so parents do not think and tell the child that they are "bad."

Frequent mild physical punishment (corporal punishment) may become less effective over time and tempt the parent to escalate the physical punishment, increasing the risk of child abuse. Corporal punishment teaches a child that in certain situations it is proper to strike another person. Commonly, in households that use spanking, older children who have been raised with this technique are seen responding to younger sibling behavioral problems by hitting their siblings.

Threats by parents to leave or to give up the child are perhaps the most psychologically damaging ways to control a child's behavior. Children of any age may remain fearful and anxious about loss of the parent long after the threat is made; however, many children are able to see through empty threats. Threatening a mild loss of privileges (no video games for 1 week or grounding a teenager) may be appropriate, but the consequence must be enforced if there is a violation.

Parenting involves a dynamic balance between **setting limits** on the one hand and allowing and encouraging freedom of expression and exploration on the other. A child whose behavior is out of control improves when clear limits on the behavior are set and enforced. However, parents must agree on where the limit will be set and how it will be enforced. The limit and the consequence of breaking the limit must be clearly presented to the child. Enforcement of the limit should be consistent and firm. Too many limits are difficult to learn and may thwart the normal development of autonomy. The limit must be reasonable in terms of the child's age, temperament, and developmental level. To be effective, both parents (and other adults in the home) must enforce limits. Otherwise, children may effectively *split* the parents and seek to test the limits with the more indulgent parent. In all situations, to be effective, punishment must be brief and linked directly to a behavior. More effective behavioral change occurs when punishment also is linked to praise of the intended behavior.

Extinction is an effective and systematic way to eliminate a frequent, annoying, and relatively harmless behavior by ignoring it. First parents should note the frequency of the behavior to realistically appreciate the magnitude of the problem and to evaluate progress. Parents must determine what reinforces the child's behavior and what needs to be consistently eliminated. An appropriate behavior is identified to give the child a positive alternative that the parents can reinforce. Parents should be warned that the annoying behavior usually increases in frequency and intensity (and may last for weeks) before it decreases when the parent ignores it (removes the reinforcement). A child who has an attention-seeking temper tantrum should be ignored or placed in a secure environment. This action may anger the child more, and the behavior may get louder and angrier. Eventually with no audience for the tantrum, the tantrums decrease in intensity and frequency. In each specific instance, when the child's behavior has become appropriate, the child should be praised, and extra attention should be given. This is an effective technique for early toddlers, before their capacity to understand and adhere to a time-out develops.

The **time-out** consists of a short period of isolation *immediately* after a problem behavior is observed. Time-out interrupts the behavior and immediately links it to an unpleasant consequence. This method requires considerable effort by the parents because the child does not wish to be isolated. A parent may need to hold the child physically in time-out. In this situation, the parent should become *part of the furniture* and should not respond to the child until the time-out period is over. When established, a simple isolation technique, such as making a child stand in the corner or sending a child to the bedroom, may be effective. If such a technique is not helpful, a more systematic procedure may be needed. One effective protocol for the time-out procedure involves interrupting the child's play when the behavior occurs and having the child sit in a dull, isolated place for a brief period, measured by a portable kitchen timer (the clicking noises document that time is passing, and the bell alarm at the end signals the end of the punishment). Time-out is simply punishment and is not a time for a young child to *think* about the behavior (these children do not possess the capacity for abstract thinking) or a time to de-escalate the behavior. The amount of time-out should be appropriate to the child's short attention span. One minute per year of a child's age is recommended. This inescapable and unpleasant consequence of the undesired behavior motivates the child to learn to avoid the behavior.

PEARLS FOR PRACTITIONERS

See Growth and Development: Pearls for Practitioners at the end of this section.

CHAPTER 10

Evaluation of the Child with Special Needs

Children with disabilities, severe chronic illnesses, congenital defects, and health-related educational and behavioral problems are **children with special health care needs (SHCN)**. Many of these children share a broad group of experiences and encounter similar problems, such as school difficulties and family stress. The term *children with special health care needs* defines these children noncategorically, without regard to specific diagnoses, in terms of increased service needs. Approximately 19% of children in the United States younger than 18 years of age have a physical, developmental, behavioral, or emotional condition requiring services of a type or amount beyond those generally required by most children.

The goal in managing a child with SHCN is to maximize the child's potential for productive adult functioning by treating the primary diagnosis and by helping the patient and family deal with the stresses and secondary impairments incurred because of the disease or disability. Whenever a chronic disease is diagnosed, family members typically grieve, show anger, denial, negotiation (in an attempt to forestall the inevitable), and depression. Because the child with SHCN is a constant reminder of the object of this grief, it may take family members a long time to accept the condition. A supportive physician can facilitate the process of acceptance by education and by allaying guilty feelings and fear. To minimize denial, it is helpful to confirm the family's observations about the child. The family may not be able to absorb any additional

information initially, so written material and the option for further discussion at a later date should be offered.

The primary physician should provide a **medical home** to maintain close oversight of treatments and subspecialty services, provide preventive care, and facilitate interactions with school and community agencies. A major goal of *family-centered care* is for the family and child to feel in control. Although the medical management team usually directs treatment in the acute health care setting, the locus of control should shift to the family as the child moves into a more routine, home-based life. Treatment plans should allow the greatest degree of normalization of the child's life. As the child matures, self-management programs that provide health education, self-efficacy skills, and techniques such as symptom monitoring help promote good long-term health habits. These programs should be introduced at 6 or 7 years of age or when a child is at a developmental level to take on chores and benefit from being given responsibility. Self-management minimizes *learned helplessness* and the *vulnerable child syndrome*, both of which occur commonly in families with chronically ill or disabled children.

MULTIFACETED TEAM ASSESSMENT OF COMPLEX PROBLEMS

When developmental screening and surveillance suggest the presence of significant developmental lags, the physician should take responsibility for coordinating the further assessment of the child by the team of professionals and provide continuity of care. The physician should become aware of local facilities and programs for assessment and treatment. If the child is at high risk for delay (e.g., prematurity), a structured follow-up program to monitor the child's progress may already exist. Under federal law, all children are entitled to assessments if there is a suspected developmental delay or a risk factor for delay (e.g., prematurity, failure to thrive, and parental intellectual disability [ID]). Early intervention programs for children up to 3 years of age are developed by states to implement this policy. Developmental interventions are arranged in conjunction with third-party payers with local programs funding the cost only when there is no insurance coverage. After 3 years of age, development programs usually are administered by school districts. Federal laws mandate that special education programs be provided for all children with developmental disabilities from birth through 21 years of age.

Children with special needs may be enrolled in pre-K programs with a therapeutic core, including visits to the program by therapists, to work on challenges. Children who are of traditional school age (kindergarten through secondary school) should be evaluated by the school district and provided an **individualized education plan (IEP)** to address any deficiencies. An IEP may feature individual tutoring time (resource time), placement in a special education program, placement in classes with children with severe behavioral problems, or other strategies to address deficiencies. As part of the comprehensive evaluation of developmental/behavioral issues, all children should receive a thorough medical assessment. A variety of other specialists may assist in the assessment and intervention, including subspecialists (e.g., child neurology, pediatric orthopedics, child and adolescent psychiatry, developmental/behavioral pediatricians), therapists (e.g., occupational, physical, oral-motor), and others (e.g., psychologists, early childhood development specialists).

Medical Assessment

The physician's main goals in team assessment are to identify the cause of the developmental dysfunction if possible (often a specific cause is not found) and identify and interpret other medical conditions that have a developmental impact. The comprehensive history (Table 10.1) and physical examination (Table 10.2) include a careful graphing of growth parameters and an accurate description of dysmorphic features. Many causative diagnoses are rare or unusual diseases or syndromes. Many of these diseases and syndromes are discussed further in Sections 9 and 24.

Motor Assessment

The comprehensive neurologic examination is an excellent basis for evaluating motor function, but it should be supplemented by an adaptive functional evaluation (see Chapter 179). Observing the child at play aids assessment of function. Specialists in early childhood development and therapists (especially occupational and physical therapists who have experience with children) can provide excellent input into the evaluation of age-appropriate adaptive function.

Psychologic Assessment

Psychologic assessment includes the testing of cognitive ability (Table 10.3) and the evaluation of personality and emotional well-being. The IQ and mental age scores, taken in isolation, are only partially descriptive of a person's functional abilities, which are a combination of cognitive, adaptive, and social skills. Tests of achievement are subject to variability based on culture, educational exposures, and experience and must be standardized for social factors. Projective and nonprojective tests are useful in understanding the child's emotional status. Although a child should not be labeled as having a problem solely based on a standardized test, these tests provide important and reasonably objective data for evaluating a child's progress within a particular educational program.

Educational Assessment

Educational assessment involves the evaluation of areas of specific strengths and weaknesses in reading, spelling, written expression, and mathematical skills. Schools routinely screen children with grouped tests to aid in problem identification and program evaluation. For the child with special needs, this screening ultimately should lead to individualized testing and the development of an IEP that would enable the child to progress comfortably in school. Diagnostic teaching, in which the child's response to various teaching techniques is assessed, also may be helpful.

Social Environment Assessment

Assessments of the environment in which the child is living, working, playing, and growing are important in understanding the child's development. A home visit by a social worker, community health nurse, and/or home-based intervention specialist can provide valuable information about the child's social milieu. Often, the home visitor can suggest additional adaptive equipment or renovations if there are challenges at home. If there is a suspicion of inadequate parenting, and,

TABLE 10.1 Information to Be Sought During the History Taking of a Child with Suspected Developmental Disabilities

ITEM	POSSIBLE SIGNIFICANCE
Parental concerns	Parents are quite accurate in identifying development problems in their children.
Current levels of developmental functioning	Should be used to monitor child's progress
Temperament	May interact with disability or may be confused with developmental delay
PRENATAL HISTORY	
Alcohol ingestion	Fetal alcohol syndrome; index of caregiving risk
Exposure to medication, illegal drug, or toxin	Development toxin (e.g., phenytoin); may be an index of caregiving risk
Radiation exposure	Damage to CNS
Nutrition	Inadequate fetal nutrition
Prenatal care	Index of social situation
Injuries, hyperthermia	Damage to CNS
Smoking	Possible CNS damage
HIV exposure	Congenital HIV infection
Maternal illness (so-called "TORCH" infections)	**T**oxoplasmosis, Syphilis (**O**ther in the mnemonic), **R**ubella, **C**ytomegalovirus, **H**erpes simplex virus infections
PERINATAL HISTORY	
Gestational age, birthweight	Biologic risk from prematurity and small for gestational age
Labor and delivery	Hypoxia or index of abnormal prenatal development
APGAR scores	Hypoxia, cardiovascular impairment
Specific perinatal adverse events	Increased risk of CNS damage
NEONATAL HISTORY	
Illness—seizures, respiratory distress, hyperbilirubinemia, metabolic disorder	Increased risk of CNS damage
Malformations	May represent genetic syndrome or new mutation associated with developmental delay
FAMILY HISTORY	
Consanguinity	Autosomal recessive condition more likely
Mental functioning	Increased hereditary and environmental risks
Illnesses (e.g., metabolic diseases)	Hereditary illness associated with developmental delay
Family member died young or unexpectedly	May suggest inborn error of metabolism or storage disease
Family member requires special education	Hereditary causes of developmental delay
SOCIAL HISTORY	
Resources available (e.g., financial, social support)	Necessary to maximize child's potential
Educational level of parents	Family may need help to provide stimulation
Mental health problems	May exacerbate child's conditions
High-risk behaviors (e.g., illicit drugs, sex) in parent(s) or adolescents	Increased risk for HIV infection; index of caregiving risk
Other stressors (e.g., marital discord)	May exacerbate child's conditions or compromise care
OTHER HISTORY	
Gender of child	Important for X-linked conditions
Developmental milestones	Index of developmental delay; regression may indicate progressive condition.
Head injury	Even moderate trauma may be associated with developmental delay or learning disabilities.
Serious infections (e.g., meningitis)	May be associated with developmental delay
Toxic exposure (e.g., lead)	May be associated with developmental delay
Physical growth	May indicate malnutrition; obesity, short stature, genetic syndrome
Recurrent otitis media	Associated with hearing loss and abnormal speech development
Visual and auditory functioning	Sensitive index of impaired vision and hearing
Nutrition	Malnutrition during infancy may lead to delayed development.
Chronic conditions such as renal disease	May be associated with delayed development or anemia

CNS, Central nervous system.

Modified and updated from Liptak G. Mental retardation and developmental disability. In: Kliegman RM, ed. Practical Strategies in Pediatric Diagnosis and Therapy. *Philadelphia: WB Saunders; 1996.*

especially, if there is a suspicion of neglect or abuse (including emotional abuse), the child and family must be referred to the local child protection agency. Information about reporting hotlines and local child protection agencies can be found at https://www.childwelfare.gov/organizations/ (see Chapter 22).

MANAGEMENT OF DEVELOPMENTAL PROBLEMS

Intervention in the Primary Care Setting

The clinician must decide whether a problem requires referral for further diagnostic work-up and management or whether

TABLE **10.2** | Information to Be Sought During the Physical Examination of a Child with Suspected Developmental Disabilities

ITEM	POSSIBLE SIGNIFICANCE
General appearance	May indicate significant delay in development or obvious syndrome
STATURE	
Short stature	Williams syndrome, malnutrition, Turner syndrome; many children with severe intellectual disability have associated short stature.
Obesity	Prader-Willi syndrome
Large stature	Sotos syndrome
HEAD	
Macrocephaly	Alexander syndrome, Sotos syndrome, gangliosidosis, hydrocephalus, mucopolysaccharidosis, subdural effusion
Microcephaly	Virtually any condition that can retard brain growth (e.g., malnutrition, Angelman syndrome, Cornelia de Lange syndrome, fetal alcohol effects)
FACE	
Coarse, triangular, round, or flat face; hypotelorism or hypertelorism, slanted or short palpebral fissure; unusual nose, maxilla, and mandible	Specific measurements may provide clues to inherited, metabolic, or other diseases such as fetal alcohol syndrome, cri du chat syndrome (5p-syndrome), or Williams syndrome.
EYES	
Prominent	Crouzon syndrome, Seckel syndrome, fragile X syndrome
Cataract	Galactosemia, Lowe syndrome, prenatal rubella, hypothyroidism
Cherry-red spot in macula	Gangliosidosis (GM_1), metachromatic leukodystrophy, mucolipidosis, Tay-Sachs disease, Niemann-Pick disease, Farber lipogranulomatosis, sialidosis III
Chorioretinitis	Congenital infection with cytomegalovirus, toxoplasmosis, or rubella
Corneal cloudiness	Mucopolysaccharidosis I and II, Lowe syndrome, congenital syphilis
EARS	
Pinnae, low set or malformed	Trisomies such as 18, Rubinstein-Taybi syndrome, Down syndrome, CHARGE association, cerebro-oculo-facio-skeletal syndrome, fetal phenytoin effects
Hearing	Loss of acuity in mucopolysaccharidosis; hyperacusis in many encephalopathies
HEART	
Structural anomaly or hypertrophy	CHARGE association, CATCH-22, velocardiofacial syndrome, glycogenosis II, fetal alcohol effects, mucopolysaccharidosis I; chromosomal anomalies such as Down syndrome; maternal phenylketonuria; chronic cyanosis may impair cognitive development.
LIVER	
Hepatomegaly	Fructose intolerance, galactosemia, glycogenosis types I to IV, mucopolysaccharidosis I and II, Niemann-Pick disease, Tay-Sachs disease, Zellweger syndrome, Gaucher disease, ceroid lipofuscinosis, gangliosidosis
GENITALIA	
Macro-orchidism (usually not noted until puberty)	Fragile X syndrome
Hypogenitalism	Prader-Willi syndrome, Klinefelter syndrome, CHARGE association
EXTREMITIES	
Hands, feet, dermatoglyphics, and creases	May indicate specific entity such as Rubinstein-Taybi syndrome or be associated with chromosomal anomaly
Joint contractures	Sign of muscle imbalance around joints (e.g., with meningomyelocele, cerebral palsy, arthrogryposis, muscular dystrophy; also occurs with cartilaginous problems such as mucopolysaccharidosis)
SKIN	
Café-au-lait spots	Neurofibromatosis, tuberous sclerosis, Bloom syndrome
Eczema	Phenylketonuria, histiocytosis
Hemangiomas and telangiectasia	Sturge-Weber syndrome, Bloom syndrome, ataxia-telangiectasia
Hypopigmented macules, streaks, adenoma sebaceum	Tuberous sclerosis, hypomelanosis of Ito
HAIR	
Hirsutism	Cornelia de Lange syndrome, mucopolysaccharidosis, fetal phenytoin effects, cerebro-oculo-facio-skeletal syndrome, trisomy 18 syndrome
NEUROLOGIC	
Asymmetry of strength and tone	Focal lesion, cerebral palsy
Hypotonia	Prader-Willi syndrome, Down syndrome, Angelman syndrome, gangliosidosis, early cerebral palsy
Hypertonia	Neurodegenerative conditions involving white matter, cerebral palsy, trisomy 18 syndrome
Ataxia	Ataxia-telangiectasia, metachromatic leukodystrophy, Angelman syndrome

CATCH-22, **C**ardiac defects, **a**bnormal face, **t**hymic hypoplasia, **c**left palate, **h**ypocalcemia, defects on chromosome **22**; *CHARGE*, **c**oloboma, **h**eart defects, **a**tresia choanae, **r**etarded growth, **g**enital anomalies, **e**ar anomalies (deafness).

Modified and updated from Liptak G. Mental retardation and developmental disability. In: Kliegman RM, Greenbaum LA, Lye PS, eds. Practical Strategies in Pediatric Diagnosis and Therapy. *2nd ed. Philadelphia: Saunders; 2004:540.*

TABLE 10.3 Tests of Cognition

TEST	AGE RANGE	SPECIAL FEATURES
INFANT SCALES		
Bayley Scales of Infant Development (3rd ed.)	1–42 mo	Mental, psychomotor scales, behavior record; weak intelligence predictor
Cattell Infant Intelligence Scale	2–30 mo	Used to extend Stanford-Binet downward
Gesell Developmental Observation-Revised (GDO-R)	Birth–3 yr	Used by many pediatricians
Ordinal Scales of Infant Psychological Development	Birth–24 mo	Six subscales; based on Piaget's stages; weak in predicting later intelligence
PRESCHOOL SCALES		
Stanford-Binet Intelligence Scale (4th ed.)	2 yr–adult	Four area scores, with subtests and composite IQ score
McCarthy Scales of Children's Abilities	2–8 yr	6–18 subtests; good at defining learning disabilities; strengths/weaknesses approach
Wechsler Primary and Preschool Test of Intelligence–Revised (WPPSI-R)	2½–7¼ yr	11 subtests; verbal, performance IQs; long administration time; good at defining learning disabilities
Merrill-Palmer Scale of Mental Tests	18 mo–4 yr	19 subtests cover language skills, motor skills, manual dexterity, and matching ability
Differential Abilities Scale—II (2nd ed.)	2½–<18 yr	Special nonverbal composite; short administration time
SCHOOL-AGE SCALES		
Stanford-Binet Intelligence Scale (4th ed.)	2 yr–adult	Four area scores, with subtests and composite IQ score
Wechsler Intelligence Scale for Children (5th ed.) (WISC V)	6–16 yr	See comments on WPPSI-R
Leiter International Performance Scale, Revised	2–20 yr	Nonverbal measure of intelligence ideal for use with those who are cognitively delayed, non-English speaking, hearing impaired, speech impaired, or autistic
Wechsler Adult Intelligence Scale (WAIS-IV)	16 yr–adult	See comments on WPPSI-R
Differential Abilities Scale—II (2nd ed.)	2½–<18 yr	Special nonverbal composite; short administration time
ADAPTIVE BEHAVIOR SCALES		
Vineland Adaptive Behavior Scale—II (2nd ed.)	Birth–90 yr	Interview/questionnaire; typical persons and blind, deaf, developmentally delayed, and intellectually disabled
American Association on Intellectual and Developmental Disabilities Diagnostic Adaptive Behavior Scale (DABS)	4–21 yr	Measures conceptual, social, and practical skills needed for daily functioning. Significant limitations in these domains is needed to diagnose ID.

management in the primary care setting is appropriate. Counseling roles required in caring for these children are listed in Table 10.4. When a child is young, much of the counseling interaction takes place between the parents and the clinician, and as the child matures, direct counseling shifts increasingly toward the child.

The assessment process may itself be therapeutic. By assuming the role of a nonjudgmental, supportive listener, the clinician creates a climate of trust, allowing the family to express difficult or painful thoughts and feelings. Expressing emotions may allow the parent or caregiver to move on to the work of understanding and resolving the problem.

Interview techniques may facilitate clarification of the problem for the family and for the clinician. The family's ideas about the causes of the problem and attempts at coping can provide a basis for developing strategies for problem management that are much more likely to be implemented successfully because they emanate, in part, from the family. The clinician shows respect by endorsing the parent's ideas when appropriate; this can increase self-esteem and sense of competency.

Educating parents through anticipatory guidance about normal and aberrant development and behavior may prevent problems through early detection and communicates the physician's interest in hearing parental concerns. Early detection allows intervention before the problem becomes entrenched and associated problems develop.

The severity of developmental and behavioral problems ranges from variations of normal to problematic responses to stressful situations to frank disorders. The clinician must try to establish the severity and scope of the patient's symptoms so that appropriate intervention can be planned.

Counseling Principles

For the child, behavioral change must be learned, not simply imposed. It is easiest to learn when the lesson is simple, clear, and consistent and presented in an atmosphere free of fear or

TABLE 10.4 Primary Care Counseling Roles
Allow ventilation
Facilitate clarification
Support patient problem solving
Provide specific reassurance
Provide education
Provide specific parenting advice
Suggest environmental interventions
Provide follow-up
Facilitate appropriate referrals
Coordinate care and interpret reports after referrals

intimidation. Parents often try to impose behavioral change in an emotionally charged atmosphere, most often at the time of a behavioral *violation*. Similarly, clinicians may try to *teach* parents with hastily presented advice when the parents are distracted by other concerns or not engaged in the suggested behavioral change.

Apart from management strategies directed specifically at the problem behavior, regular times for positive parent-child interaction should be instituted. Frequent, brief, affectionate physical contact over the day provides opportunities for positive reinforcement of desirable child behaviors and for building a sense of competence in the child and the parent.

Most parents feel guilty when their children have a developmental/behavioral problem. Guilt may be caused by the fear that the problem was caused by inadequate parenting or by previous angry responses to the child's behavior. If possible and appropriate, the clinician should find ways to alleviate guilt, which may be a serious impediment to problem solving.

Interdisciplinary Team Intervention

In many cases, a team of professionals is required to provide the breadth and quality of services needed to appropriately serve the child who has SHCN. The primary care physician should monitor the progress of the child and continually reassess that the requisite therapy is being accomplished.

Educational intervention for a young child begins as home-based infant stimulation, often with an early childhood specialist (e.g., nurse/therapist), providing direct stimulation for the child and training the family to provide the stimulation. As the child matures, a center-based early learning center program may be indicated. For the school-age child, special services may range from extra attention in the classroom to a self-contained special education classroom.

Psychologic intervention may be directed to the parent or family or, with an older child, primarily the child. Examples of therapeutic approaches are guidance therapies, such as directive advice giving, counseling to create their own solutions to problems, psychotherapy, behavioral management techniques, psychopharmacologic methods (from a psychiatrist), and cognitive-behavioral therapy.

Motor intervention may be performed by a physical or occupational therapist. *Neurodevelopmental therapy* (NDT), the most commonly used method, is based on the concept that nervous system development is hierarchic and subject to some plasticity. The focus of NDT is on gait training and motor development, including daily living skills; perceptual abilities, such as eye-hand coordination; and spatial relationships. *Sensory integration therapy* is also used by occupational therapists to structure sensory experience from the tactile, proprioceptive, and vestibular systems to allow for adaptive motor responses.

Speech-language intervention by a speech and language therapist/pathologist (oral-motor therapist) is usually part of the overall educational program and is based on the tested language strengths and weaknesses of the child. Children needing this type of intervention may show difficulties in reading and other academic areas and develop social and behavioral problems because of their difficulties in being understood and in understanding others. **Hearing intervention**, performed by an audiologist (or an otolaryngologist), includes monitoring hearing acuity and providing amplification when necessary via hearing aids.

Social and environmental intervention generally includes nursing or social work involvement with the family. Frequently, the task of coordinating services falls to these specialists. Case managers may be in the private sector, from the child's insurance or Medicaid plan, or part of a child protection agency.

Medical intervention for a child with a developmental disability involves providing primary care as well as specific treatment of conditions associated with the disability. Although curative treatment often is not possible, functional impairment can be minimized through thoughtful medical management. Certain general medical problems are found more frequently in delayed and developmentally disabled people (Table 10.5), especially if the delay is part of a known syndrome. Some children may have a limited life expectancy. Supporting the family through palliative care, hospice, and bereavement is another important role of the primary care pediatrician.

SELECTED CLINICAL PROBLEMS: THE SPECIAL NEEDS CHILD

Intellectual Disability

ID is defined as significantly subnormal intellectual functioning for a child's developmental stage, existing concurrently with deficits in adaptive behaviors (self-care, home living, communication, and social interactions). ID is defined statistically as cognitive performance that is two standard deviations below the mean (roughly below the 3rd percentile) of the general population as measured on standardized intelligence testing. The prevalence of ID in the United States is approximately 2%. ICD-10 categorization of levels of ID is shown in Table 10.6. Caution must be exercised in interpretation because these categories do not reflect actual functional level of the tested individual. The American Association on Intellectual and Developmental Disabilities and the American Psychiatric Association recommend classifying ID based on adaptive functioning (daily life activities) and not on IQ alone.

The etiology of the central nervous system insult resulting in ID may involve genetic disorders, teratogenic influences, perinatal insults, acquired childhood disease or injury, and environmental and social determinants of health (Table 10.7). Mild ID correlates with socioeconomic status, although profound ID does not. Although a single organic cause may be found, each individual's performance should be considered a function of the interaction of environmental influences with the individual's

TABLE 10.5 Recurring Medical Issues in Children with Developmental Disabilities

PROBLEM	ASK ABOUT OR CHECK
Motor	Range of motion examination; scoliosis check; assessment of mobility; interaction with orthopedist, physical medicine and rehabilitation, and physical therapist/occupational therapist as needed
Diet	Dietary history, feeding observation, growth parameter measurement and charting, supplementation as indicated by observations, oro-motor therapist as needed
Sensory impairments	Functional vision and hearing screening; interaction as needed with ophthalmologist, audiologist
Dermatologic	Examination of *all* skin areas for decubitus ulcers or infection
Dentistry	Examination of teeth and gums; confirmation of access to dental care (preferably with ability to use sedation)
Behavioral problems	Aggression, self-injury, pica; sleep problems; psychotropic drug levels and side effects
Seizures	Major motor, absence, other suspicious symptoms; monitoring of anticonvulsant levels and side effects
Infectious diseases	Ear infections, diarrhea, respiratory symptoms, aspiration pneumonia, immunizations (especially hepatitis B and influenza)
Gastrointestinal problems	Constipation, gastroesophageal reflux, gastrointestinal bleeding (stool for occult blood)
Sexuality	Sexuality education, preventing abuse, hygiene, contraception, menstrual suppression, genetic counseling
Other syndrome-specific problems	Ongoing evaluation of other "physical" problems as indicated by known intellectual disability/developmental disability etiology
Advocacy for services and enhancing access to care	Educational program, family supports, financial supports, legislative advocacy to support programs

TABLE 10.6 Levels of Intellectual Disability

LEVEL OF DISABILITY	ICD-10 IQ SCORE
Mild	50–55 to 70
Moderate	35–40 to 50–55
Severe	20–25 to 35–40
Profound	<20 to 25

ICD-10, International Classification of Diseases, Tenth Revision.

TABLE 10.7 Differential Diagnosis of Intellectual Disability*

EARLY ALTERATIONS OF EMBRYONIC DEVELOPMENT
Sporadic events affecting embryogenesis, usually a stable developmental challenge
Chromosomal changes (e.g., trisomy 21 syndrome)
Prenatal influences (e.g., substance abuse, teratogenic medications, intrauterine TORCH infections)†
UNKNOWN CAUSES
No definite issue is identified, or multiple elements present, none of which is diagnostic (may be multifactorial)
ENVIRONMENTAL AND SOCIAL PROBLEMS
Dynamic influences, commonly associated with other challenges
Deprivation (neglect)
Parental mental illness
Environmental intoxications (e.g., significant lead intoxication)*
PREGNANCY PROBLEMS AND PERINATAL MORBIDITY
Impingement on normal intrauterine development or delivery; neurologic abnormalities frequent, challenges are stable or occasionally worsening
Fetal malnutrition and placental insufficiency
Perinatal complications (e.g., prematurity, birth asphyxia, birth trauma)
HEREDITARY DISORDERS
Preconceptual origin, variable expression in the individual infant, multiple somatic effects, frequently a progressive or degenerative course
Inborn errors of metabolism (e.g., Tay-Sachs disease, Hunter disease, phenylketonuria)
Single-gene abnormalities (e.g., neurofibromatosis or tuberous sclerosis)
Other chromosomal aberrations (e.g., fragile X syndrome, deletion mutations such as Prader-Willi syndrome)
Polygenic familial syndromes (pervasive developmental disorders)
ACQUIRED CHILDHOOD ILLNESS
Acute modification of developmental status, variable potential for functional recovery
Infections (all can ultimately lead to brain damage, but most significant are encephalitis and meningitis)
Cranial trauma (accidental and child abuse)
Accidents (e.g., near-drowning, electrocution)
Environmental intoxications (prototype is lead poisoning)

**Some health problems fit in several categories (e.g., lead intoxication may be involved in several areas).*
†This also may be considered as an acquired childhood disease.
TORCH, Toxoplasmosis, other (congenital syphilis), rubella, cytomegalovirus, and herpes simplex virus.

organic substrate. Behavioral difficulties resulting from ID itself and from the family's reaction to the child and the condition are common. More severe forms of ID can be traced to biologic factors. The earlier the cognitive slowing is recognized, the more severe the deviation from normal is likely to be.

The first step in the diagnosis and management of a child with ID is to identify functional strengths and weaknesses for purposes of medical and rehabilitative therapies. A history and physical examination may suggest a diagnosis that might be confirmed by laboratory testing and/or imaging. Frequently

used laboratory tests include chromosomal analysis and magnetic resonance imaging of the brain. Almost one third of individuals with ID do not have readily identifiable reasons for their disability.

Vision Impairment

Significant visual impairment is a problem in many children. **Partial vision** (defined as visual acuity between 20/70 and 20/200) occurs in 1 in 500 school-age children in the United States. **Legal blindness** is defined as distant visual acuity of 20/200 or worse and affects about 35,000 children in the United States. Such impairment can be a major barrier to optimal development.

The most common cause of **severe visual impairment** in children is retinopathy of prematurity (see Chapter 61). Congenital cataracts may lead to significant amblyopia. Cataracts also are associated with other ocular abnormalities and developmental disabilities. **Amblyopia** is a pathologic alteration of the visual system characterized by a reduction in visual acuity in one or both eyes with no clinically apparent organic abnormality that completely accounts for the visual loss. Amblyopia is due to a distortion of the normal clearly formed retinal image (from congenital cataracts or severe refractive errors); abnormal binocular interaction between the eyes, as one eye competitively inhibits the other (strabismus); or a combination of both mechanisms. Albinism, hydrocephalus, congenital cytomegalovirus infection, and birth asphyxia are other significant contributors to blindness in children.

Children with **mild to moderate visual impairment** usually have an uncorrected refractive error. The most common presentation is myopia or nearsightedness. Other causes are hyperopia (farsightedness) and astigmatism (alteration in the shape of the cornea leading to visual distortion). In children younger than 6 years, high refractive errors in one or both eyes also may cause amblyopia, aggravating visual impairment.

The diagnosis of severe visual impairment commonly is made when an infant is 4–8 months of age. Clinical suspicion is based on parental concerns aroused by unusual behavior, such as lack of smiling in response to appropriate stimuli, the presence of nystagmus, other wandering eye movements, or motor delays in beginning to reach for objects. Fixation and visual tracking behavior can be seen in most infants by 6 weeks of age. This behavior can be assessed by moving a brightly colored object (or the examiner's face) across the visual field of a quiet but alert infant at a distance of 1 ft. The eyes also should be examined for red reflexes and pupillary reactions to light. Optical alignment (binocular vision with both eyes consistently focusing on the same spot) should not be expected until the infant is beyond the newborn period. Persistent nystagmus is abnormal at any age. If ocular abnormalities are identified, referral to a pediatric ophthalmologist is indicated.

During the newborn period, vision may be assessed by physical examination and by **visual evoked response**. This test evaluates the conduction of electrical impulses from the optic nerve to the occipital cortex of the brain. The eye is stimulated by a bright flash of light or with an alternating checkerboard of black-and-white squares, and the resulting electrical response is recorded from electrodes strategically placed on the scalp, similar to an electroencephalogram.

There are many developmental implications of visual impairment. Perception of body image is abnormal, and imitative behavior, such as smiling, is delayed. Delays in mobility may occur in children who are visually impaired from birth, although their postural milestones (ability to sit) usually are achieved appropriately. Social bonding with the parents also is often affected.

Visually impaired children can be helped in various ways. Classroom settings may be augmented with resource-room assistance to present material in a nonvisual format. Fine motor activity development, listening skills, and Braille reading and writing are intrinsic to successful educational intervention for a child with severe visual impairment.

Hearing Impairment

The clinical significance of hearing loss varies with its type (conductive vs. sensorineural), its frequency, and its severity as measured in the number of decibels heard or the number of decibels of hearing lost. The most common cause of mild to moderate hearing loss in children is a conduction abnormality caused by acquired middle ear disease (acute and chronic otitis media). This abnormality may have a significant effect on the development of speech and language development, particularly if there is chronic fluctuating middle ear fluid. If hearing impairment is more severe, sensorineural hearing loss is more common. Causes of sensorineural deafness include congenital infections (e.g., rubella and cytomegalovirus), meningitis, birth asphyxia, kernicterus, ototoxic drugs (especially aminoglycoside antibiotics), and tumors and their treatments. Genetic deafness may be either dominant or recessive in inheritance; this is the main cause of hearing impairment in schools for the deaf. In Down syndrome, there is a predisposition to conductive loss caused by middle-ear infection and sensorineural loss caused by cochlear disease. Any hearing loss may have a significant effect on the child's developing communication skills. These skills then affect all areas of the child's cognitive and skills development (Table 10.8).

It is sometimes quite difficult to accurately determine the presence of hearing in infants and young children. Inquiring about a newborn's or infant's response to sounds or even observing the response to sounds in the office is unreliable for identifying hearing-impaired children. Universal screening of newborns is required prior to nursery discharge and includes the following:

1. **Auditory brainstem response (ABR)** measures how the brain responds to sound. Clicks or tones are played through soft earphones into the infant's ears. Three electrodes placed on the infant's head measure the brain's response.
2. **Otoacoustic emissions** measure sound waves produced in the inner ear. A tiny probe is placed just inside the infant's ear canal. It measures the response (echo) when clicks or tones are played into the infant's ears.

Both of these tests are quick (5–10 minutes), painless, and may be performed while the infant is sleeping or lying still. The tests are sensitive but not as specific as more definitive tests. Infants who do not pass these tests are referred for more comprehensive testing. Many of these infants have normal hearing on definitive testing. Infants who do not have normal hearing should be immediately evaluated or referred for etiologic diagnosis and early intervention.

For children not screened at birth (such as children of immigrant parents) or children with suspected acquired hearing loss, later testing may allow early appropriate intervention. Hearing can be screened by means of an office audiogram, but

TABLE **10.8** Neurodevelopmental-Behavioral Complications of Hearing Loss

SEVERITY OF HEARING LOSS	POSSIBLE ETIOLOGIC ORIGINS	COMPLICATIONS			
		SPEECH-LANGUAGE	EDUCATIONAL	BEHAVIORAL	TYPES OF THERAPY
Slight 15–25 dB (ASA)	Chronic otitis media/ middle ear effusions	Difficulty with hearing distant or faint speech	Possible auditory learning dysfunction	Usually none	May require favorable class setting, speech therapy, or auditory training
	Perforation of tympanic membrane		May reveal a slight verbal deficit		Possible value in hearing aid, surgery
	Sensorineural loss				Favorable class setting
	Tympanosclerosis				Favorable class setting
Mild 25–40 dB (ASA)	Chronic otitis media/ middle ear effusions	Difficulty with conversational speech over 3–5 ft	May miss 50% of class discussions	Psychologic problems	Special education resource help, surgery
	Perforation of tympanic membrane	May have limited vocabulary and speech disorders	Auditory learning dysfunction	May act inappropriately if directions are not heard well	Hearing aid, surgery
	Sensorineural loss			Acting out behavior	Favorable class setting, hearing aid, cochlear implant
	Tympanosclerosis			Poor self-concept	Lip reading instruction Speech therapy
Moderate 40–65 dB (ASA)	Chronic otitis media/ middle ear effusions	Conversation must be loud to be understood.	Learning disability	Emotional and social problems	Special education resource or special class, surgery
	Middle ear anomaly	Defective speech	Difficulty with group learning or discussion	Behavioral reactions of childhood	Special help in speech-language development
	Sensorineural loss	Deficient language use and comprehension	Auditory processing dysfunction	Acting out	Hearing aid and lip reading
			Limited vocabulary	Poor self-concept	Speech therapy
Severe 65–95 dB (ASA)	Sensorineural loss	Loud voices may be heard 2 ft from ear.	Marked educational disability	Emotional and social problems that are associated with handicap	Full-time special education for deaf children, cochlear implant
	Severe middle ear disease	Defective speech and language No spontaneous speech development if loss present before 1 yr	Marked learning disability, limited vocabulary	Poor self-concept	Full-time special education for deaf children, hearing aid, lip reading, speech therapy, surgery, cochlear implant
Profound ≥95 dB (ASA)	Sensorineural or mixed loss	Relies on vision rather than hearing Defective speech and language Speech and language will not develop spontaneously if loss present before 1 yr.	Marked learning disability because of lack of understanding of speech	Congenital and prelingually deaf may show severe emotional problems.	Full-time special education for deaf children, hearing aid, lip reading, speech therapy, surgery, cochlear implant

ASA, Acoustical Society of America.
Modified and updated from Gottlieb MI. Otitis media. In: Levine MD, Carey WB, Crocker AC, et al., eds. Developmental-Behavioral Pediatrics. *Philadelphia: WB Saunders; 1983.*

other techniques are needed (ABR, behavior audiology) for young, neurologically immature or impaired, and behaviorally difficult children. The typical audiologic assessment includes pure-tone audiometry over a variety of sound frequencies (pitches), especially over the range of frequencies in which most speech occurs. **Pneumatic otoscopic** examination and **tympanometry** are used to assess middle ear function and the tympanic membrane compliance for pathology in the middle ear, such as fluid, ossicular dysfunction, and eustachian tube dysfunction (see Chapter 9).

The treatment of conductive hearing loss (largely due to otitis media and middle ear effusions) is discussed in Chapter 105. Treatment of sensorineural hearing impairment may be medical or surgical. If amplification is indicated, hearing aids can be tuned preferentially to amplify the frequency ranges in which the patient has decreased acuity. Educational intervention typically includes speech-language therapy and teaching American Sign Language. Even with amplification, many hearing-impaired children show deficits in processing auditory information, requiring special educational services for helping to read and for other academic skills. **Cochlear implants** are surgically implantable devices that provide hearing sensation to individuals with severe to profound hearing loss. The implants are designed to substitute for the function of the middle ear, cochlear mechanical motion, and sensory cells, transforming sound energy into electrical energy that initiates impulses in the auditory nerve. Cochlear implants are indicated for children older than 12 months with profound bilateral sensorineural hearing loss who have limited benefit from hearing aids, have failed to progress in auditory skill development, and have no radiologic or medical contraindications. Implantation in children as young as possible gives them the most advantageous auditory environment for speech-language learning.

Speech-Language Impairment

Parents often bring the concern of speech delay to the physician's attention when they compare their young child with others of the same age (Table 10.9). The most common causes of the speech delay are ID, hearing impairment, social deprivation, autism, and oral-motor abnormalities. If a problem is suspected based on screening with tests such as Ages and Stages Questionnaires or the Parents' Evaluation of Developmental Status test (see Chapter 8) or other standard screening test (Early Language Milestone Scale), a referral to a specialized hearing and speech center is indicated. While awaiting the results of testing or initiation of speech-language therapy, parents should be advised to speak slowly and clearly to the child (and avoid *baby talk*). Parents and older siblings should read frequently to the speech-delayed child.

Speech disorders include **articulation**, **fluency**, and **resonance disorders**. Articulation disorders include difficulties producing sounds in syllables or saying words incorrectly to the point that other people cannot understand what is being said. Fluency disorders include problems such as **stuttering**, the condition in which the flow of speech is interrupted by abnormal stoppages, repetitions *(st-st-stuttering)*, or prolonged sounds and syllables *(ssssstuttering)*. Resonance or voice disorders include problems with the pitch, volume, or quality of a child's voice that distract listeners from what is being said.

Language disorders can be either receptive or expressive. Receptive disorders refer to difficulties understanding or processing language. Expressive disorders include difficulty putting words together, limited vocabulary, or inability to use language in a socially appropriate way.

Speech-language pathologists (also called speech or oral-motor therapists) assess the speech, language, cognitive communication, and swallowing skills of children; determine what types of communication problems exist; and identify the best way to treat these challenges. Speech-language pathologists skilled at working with infants and young children are also vital in training parents and infants in other oral-motor skills, such as how to feed an infant born with a cleft lip and palate.

TABLE 10.9 Clues to When a Child with a Communication Disorder Needs Help

0–11 MONTHS
Before 6 months, the child does not startle, blink, or change immediate activity in response to sudden, loud sounds.
Before 6 months, the child does not attend to the human voice and is not soothed by mother's voice.
By 6 months, the child does not babble strings of consonant and vowel syllables or imitate gurgling or cooing sounds.
By 10 months, the child does not respond to own name.
At 10 months, the child's sound-making is limited to shrieks, grunts, or sustained vowel production.
12–23 MONTHS
At 12 months, the child's babbling or speech is limited to vowel sounds.
By 15 months, the child does not respond to "no," "bye-bye," or "bottle."
By 15 months, the child does not imitate sounds or words.
By 18 months, the child is not consistently using at least six words with appropriate meaning.
By 21 months, the child does not respond correctly to "Give me…," "Sit down," or "Come here" when spoken without gestural cues.
By 23 months, two-word phrases that are spoken as single units (e.g., "whatszit," "thankyou," "allgone") have not emerged.
24–36 MONTHS
By 24 months, at least 50% of the child's speech is not understood by familiar listeners.
By 24 months, the child does not point to body parts without gestural cues.
By 24 months, the child is not combining words into phrases (e.g., "go bye-bye," "go car," "want cookie").
By 30 months, the child does not show understanding of spatial concepts: on, in, under, front, and back.
By 30 months, the child is not using short sentences (e.g., "Daddy went bye-bye").
By 30 months, the child has not begun to ask questions (using *where, what, why*).
By 36 months, the child's speech is not understood by unfamiliar listeners.
ALL AGES
At any age, the child is consistently dysfluent with repetitions, hesitations; blocks or struggles to say words. Struggle may be accompanied by grimaces, eye blinks, or hand gestures.

Modified and updated from Weiss CE, Lillywhite HE. Communication Disorders: A Handbook for Prevention and Early Detection. *St Louis: Mosby; 1976.*

Speech-language therapy involves having a speech-language specialist work with a child on a one-on-one basis, in a small group, or directly in a classroom to overcome a specific disorder using a variety of therapeutic strategies. Language intervention activities involve having a speech-language specialist interact with a child by playing and talking to the child using pictures, books, objects, or ongoing events to stimulate language development. Articulation therapy involves having

TABLE 10.10 Risk Factors for Cerebral Palsy

PREGNANCY AND BIRTH
Low socioeconomic status
Prematurity
Low birthweight/fetal growth retardation (<1,500 g at birth)
Maternal seizures/seizure disorder
Maternal treatment with thyroid hormone, estrogen, or progesterone
Pregnancy complications
Polyhydramnios
Eclampsia
Third-trimester bleeding (including threatened abortion and placenta previa)
Multiple births
Abnormal fetal presentation
Maternal fever
Congenital malformations/syndromes
Newborn hypoxic-ischemic encephalopathy
Bilirubin (kernicterus)
ACQUIRED AFTER THE NEWBORN PERIOD
Meningitis
Head injury
Car crashes
Child abuse
Near-drowning
Stroke

TABLE 10.11 Descriptions of Cerebral Palsy by Site of Involvement

Hemiparesis (hemiplegia): predominantly unilateral impairment of the arm and leg on the same (e.g., right or left) side
Diplegia: motor impairment primarily of the legs (often with some limited involvement of the arms; some authors challenge this specific type as not being different from quadriplegia)
Quadriplegia: all four limbs (whole body) are functionally compromised.

TABLE 10.12 Classification of Cerebral Palsy by Type of Motor Disorder

Spastic cerebral palsy: the most common form of cerebral palsy, it accounts for 70–80% of cases. It results from injury to the upper motor neurons of the pyramidal tract. It may occasionally be bilateral. It is characterized by at least two of the following: abnormal movement pattern, increased tone, or pathologic reflexes (e.g., Babinski response, hyperreflexia).
Dyskinetic cerebral palsy: occurs in 10–15% of cases. It is dominated by abnormal patterns of movement and involuntary, uncontrolled, recurring movements.
Ataxic cerebral palsy: accounts for <5% of cases. This form results from cerebellar injury and features abnormal posture or movement and loss of orderly muscle coordination or both.
Dystonic cerebral palsy: also uncommon. It is characterized by reduced activity and stiff movement (hypokinesia) and hypotonia.
Choreoathetotic cerebral palsy: rare now that excessive hyperbilirubinemia is aggressively prevented and treated. This form is dominated by increased and stormy movements (hyperkinesia) and hypotonia.
Mixed cerebral palsy: accounts for 10–15% of cases. This term is used when more than one type of motor pattern is present and when one pattern does not clearly dominate another. It typically is associated with more complications, including sensory deficits, seizures, and cognitive-perceptual impairments.

the therapist model correct sounds and syllables for a child, often during play activities.

Children enrolled in therapy early (<3 years of age) tend to have better outcomes than children who begin therapy later. Older children can make progress in therapy, but progress may occur more slowly because these children often have learned patterns that need to be modified or changed. Parental involvement is crucial to the success of a child's progress in speech-language therapy.

Cerebral Palsy

Cerebral palsy (CP) refers to a group of non-progressive, but often changing, motor impairment syndromes secondary to anomalies or lesions of the brain arising before or after birth. The prevalence of CP at age 8 in the United States is 1.5–4 per 1,000; prevalence is much higher in premature and twin births. Prematurity and low birthweight infants (leading to perinatal asphyxia), congenital malformations, and kernicterus are causes of CP noted at birth. Ten percent of children with CP have acquired CP, developing at later ages. Meningitis and head injury (accidental and nonaccidental) are the most common causes of acquired CP (Table 10.10). Nearly 50% of children with CP have no identifiable risk factors. As genomic medicine advances, many of these causes of idiopathic CP may be identified.

Most children with CP, except in its mildest forms, are diagnosed in the first 18 months of life when they fail to attain motor milestones or show abnormalities such as asymmetric gross motor function, hypertonia, or hypotonia. CP can be characterized further by the affected parts of the body (Table 10.11) and descriptions of the predominant type of motor disorder (Table 10.12). Co-morbidities in these children often include epilepsy, learning difficulties, behavioral challenges, and sensory impairments. Many of these children have an isolated motor defect. Some affected children may be intellectually gifted.

Treatment depends on the pattern of dysfunction. Physical and occupational therapy can facilitate optimal positioning and movement patterns, increasing function of the affected parts. Spasticity management also may include oral medications