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 required by children, generally.

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 mental retardation [MR]). Special 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 educational 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 subspecialist pediatricians (e.g., neurology, orthopedics, psychiatry, developmental/behavioral), 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 of the 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.