

consent to medical care and when parents may access confidential adolescent medical information. The Health Insurance Portability and Accountability Act (HIPAA) of 1996, which became effective in 2003, requires 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, nonautonomous 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 have legally recognized that many adolescents age 14 and older can meet the cognitive criteria and emotional maturity for competence and may decide independently. 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 parental control 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, runaways, are parents, 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 with 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

From an ethical perspective, clinicians should engage children and adolescents, based on their developmental capacity, in discussions about medical plans so that they have 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 ultimate goal is to help nourish children'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 likely to be detected.

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. Parents may pressure the pediatrician to order genetic tests when the child is still young, for the parents' purposes. 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 his or her life, the courts always have intervened to allow a transfusion. In contrast, parents with strong religious beliefs under some state laws may refuse immunizations for their children. However, state governments can mandate immunizations for all children during disease outbreaks or epidemics. By requiring immunization of all, including individuals who object on religious grounds, the state government is using the principle of **distributive justice**, which states that all members of society must share in the burdens and the benefits to have a just society.

### 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. Special federal regulations have been developed to protect child and adolescent participants in human investigation.