

AMERICAN ACADEMY OF PEDIATRICS

Committee on Children with Disabilities
Committee on School Health

Children With Health Impairments in Schools

Chronic illnesses are defined as conditions that last at least 3 months, require extensive hospitalization or in-home health services, or at the time of diagnosis are likely to do so. Chronic illnesses affect at least 10% to 15% of American children.¹ Two to four percent of children have severe illnesses that interfere daily with the usual activities of childhood.² Rheumatoid arthritis, asthma, leukemia and other malignancies, spina bifida, seizure disorders, neuromuscular diseases, acquired immunodeficiency syndrome, and other chronic conditions are found most frequently in this population. There are also small but increasing numbers of children dependent on specific technologies, such as respirators, and children who require procedures, such as tube feeding or bladder catheterization.

Recent medical and surgical advances have improved markedly the morbidity and mortality rates of chronically ill children. Increasing numbers of children with many diverse conditions now survive to adulthood and are able to attend school and pursue their educational and social development.³ Children, including those with chronic health conditions, deserve the opportunity to develop to their fullest potential through the benefits of education and health care.

CHRONICALLY ILL CHILDREN IN SCHOOLS

What most distinguishes chronically ill children and their families is their need for access to coordinated specialized health care services to a degree not required by other children. Individualized at-

tention to their special health needs in school is of critical importance. The illnesses and their treatments frequently lead to greater than usual school absence and may hinder educational progress.⁴ Illness or mediations may also limit alertness or diminish physical stamina.

Although care must be individualized for each child, certain issues affect many children with chronic illnesses in schools.⁵ Children with chronic illness deserve access to basic educational services and the broader range of school activities such as clubs, student government, and athletics. Educational planning should take into account the limitations that chronic illness places on physical growth and development, on the development of cognitive skills, on psychosocial development, and on the ability to make choices among life careers. Family members should participate actively in educational planning.

Public laws 94-142 and 99-457 guarantee children with developmental disabilities and many with chronic illness access to needed educational services. However, most chronically ill children are in regular education and can benefit from the following recommendations.⁶

1. Availability of Health Services in the Schools

The implementation of public law 94-142 has markedly improved the availability of related health services in schools to assist children and youth in participating in regular school activities.⁷ In many school districts, access to such services is dependent on the determination that the student requires special education programs and attends a special education classroom. Most children with long-term illnesses do not need to be in special education programs. Means should be developed to provide related health services and other needed services to children without requiring placement in a specific education category.⁸ Where specific and

This statement has been approved by the Council on Child and Adolescent Health.

The recommendations in this statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account individual circumstances, may be appropriate.

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on-going in-school medical treatments are required (eg, the management of gastrostomy tubes or tracheostomies), more extensive planning among family members, health providers, and school personnel is needed. Plans for monitoring care during an extended period are also important.

2. Medications in Schools

Many children with long-term health conditions must take medications during school hours. The recommendations of the American Academy of Pediatrics regarding dispensing of medications in schools apply to children with long-term illnesses.⁹ Schools need specific policies that address the proper storage and distribution of medications, including ones that will allow capable students to take their own medications when appropriate.

3. Emergency Situations

Many children with long-term illnesses experience medical emergencies in the school setting, varying from seizures to acute episodes of asthma to serious bleeding episodes. Each school should have policies and procedures for handling emergency situations for a child with long-term illness.¹⁰ Individualized standing orders should be developed by the child's physician with the participation of the family, and they should be discussed with the school physician consultant or person responsible for health services and involved teachers and staff at the time of the child's entry into school.

4. Homebound Teaching and Absence Policies

Homebound teaching policies often work to the detriment of children with severe long-term illnesses. In many districts, homebound teaching becomes available only when a child misses school for 2 to 4 consecutive weeks.⁸ Yet most children with chronic illnesses, such as arthritis or asthma, miss only a few days at a time, although the aggregate number of days absent may well exceed 2 to 4 weeks. Some communities and states have developed creative programs that identify children whose chronic illnesses are likely to lead to frequent, intermittent absences. These children then become eligible for homebound teaching without the usual waiting period.^{11,12} Children with long-term illnesses should have access to homebound teaching to assure their progress keeps pace with that of their classmates. Pediatricians should be aware that, even when available, homebound teaching has significant limitations. It consists typically of only a few hours per week, with a single teacher expected to cover all the subjects the child is studying. School attendance is preferable and should be encouraged whenever possible.

Inflexible absence policies may hinder the child's educational progress. Some educational authorities require a minimum number of days of attendance per year for graduation or promotion. For a 17-year-old student with cystic fibrosis, however, the disease and its treatment may necessitate a greater number of days missed than that allowed by the absence policy. Yet this student may do very well in terms of educational progress. Promotion and graduation should be based on assessment of competence rather than attendance.

5. Communications With School Personnel

Chronically ill and disabled children may arouse strong emotions in school personnel, including anxiety, resentment, fear, or other attitudes that can block constructive approaches to solving educational and social problems. Education of teaching personnel about chronic illnesses in general and about the specific health care requirements of children in their classes, and provision of added resources for added responsibilities will help alleviate these problems. The manner in which a teacher accepts a child with a chronic illness can serve as a model for how a child is accepted by other students. Positive teacher acceptance may, therefore, reduce the negative consequences of potential peer isolation and social ostracism.¹³ Similarly, parents can help each other by learning ways to cope with these emotional responses in others and to advocate for their children in schools.

In general, physicians should share information about a child's illness with school staff so that they can be better informed and able to help the child succeed. These disclosures should always be with the consent of the parents. Information should be free of jargon and understandable to those with no medical background.

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