

STUDENT SERVICES STUDENT SERVICES STUDENT SERVICES

Responding to Students' Chronic Illnesses

Students with chronic illnesses are a growing population in schools, and schools must balance those students' social and academic needs with legal mandates.

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Isabelle, age 14, is in gym class. She starts running and socializing with her friends, then begins to breathe rapidly and wheeze. She looks pale, has difficulty walking, and has a deep cough. This is not the first time that Isabelle has exhibited those symptoms. Mr. Leonard, her concerned physical education teacher, has talked to Isabelle, but she assured him that she is fine. Knowing that adolescents often try to ignore their health problems, he confers with other staff members and learns that many times Isabelle does not eat at lunch and misses classes, especially on the days following her gym class. So far, she has missed class nine times, and it is only six weeks into the school year. Mr. Leonard knows that Isabelle's symptoms are consistent with juvenile asthma and decides to contact her parents.

Characteristics

Chronic illnesses are long-term or permanent medical conditions that have recurring effects on everyday life. Common chronic illnesses include asthma, cancer, diabetes, eating disorders, sleep disorders, and traumatic brain injury. Less common, but no less severe, illnesses include sickle cell disease, seizure disorders, and HIV/AIDS.

The number of students who have chronic illnesses is growing because of medical advances. The life expectancy and functional abilities of children with many different chronic illnesses (e.g., leukemia) has also increased because of medical advances. What may have once been a terminal illness is now considered chronic. Nonetheless, all chronic illnesses among students affect those students and their families and schools.

Trying to stay ahead of the rapidly changing landscape of medical issues and health care is extremely challenging for school leaders. Laws and regulations are in a perpetual state of flux. New issues and medical concerns arise frequently. Meeting the educational, social, and emotional needs of students who have medical issues—whether those issues are acute or chronic—is a time-intensive activity. A responsive school, however, can improve the quality of life and the

chances of academic success for those students.

Chronic Illness and School Systems

Approximately 17% of all students under age 18 suffer from a chronic illness that affects their performance in school (Cox, Halloran, Homan, Welliver, & Mager, 2008). Each year, 6.5% of students experience chronic illness to the degree that it influences their school performance. The primary error that educators make in addressing those students' needs is assuming that the effects of the illness are solely medical (McCarthy, Lindgren, Mengeling, Tsalikian, & Engvall, 2002). Chronic illness affects students' emotional and physical development, academic performance, peer relationships, and family interactions.

Many chronic illnesses can be addressed by medical professionals, school professionals, and families. School-based health care is trending toward assessing risks and fostering resilience to ensure that students achieve optimal health, well-being, and academic performance. To accomplish those ends, multidisciplinary and multiagency collaboration, strong policies, dissemination of information, community support, and academic achievement are all necessary.

Changes in medical treatment and public policy place additional pressure on schools to respond to more-intensive health care needs of chronically ill students. Because of advances in treatment and the need to reduce health care costs, children with severe medical issues have fewer hospital inpatient days now than they had in the last decade (Shaw & McCabe, 2008) and instead receive extensive outpatient care. This change places more pressures on families and schools. Schools are under increasing pressure to provide homebound instruction, accommodate medical issues in the classroom, coordinate educational needs with outpatient treatment needs (and the inevitable absences), and prepare for emergencies that might take place in school settings.

Health and education policies reflect growing recognition that improved prevention and access to primary care for children and families is essential. At one time, schools only occasionally served as locations for community vaccination programs or were required to provide individualized services for children with chronic illnesses. Today, schools are increasingly being considered integral components of the health care delivery system. Given that 85 million U.S. children and adolescents between the ages of 5 and 19 are mandated to attend school, health care policy and strategies for increasing health care access for children and families must involve schools.

Doing so supports educational mandates as well because improving health care for students improves their learning readiness and academic achievement and increases the probability that they will graduate from high school. There are a number of

pieces of legislation in Congress that reflect this reality, such as the Full Service Community Schools Act, the Patient Protection and Affordable Care Act, and the Mental Health in Schools Act.

Compliance with legislation, regulation, and case law on educational issues is a complex undertaking. When medical legislation, regulation, and case law requirements are added to demands for academic accountability and compliance with education laws and regulations, the burden on educators can be overwhelming. More often than not, the two sets of laws do not align and regulatory guidance is necessary, such as the guidance provided by the U.S. Departments of Education and Health and Human Services in late 2008 on how to apply the Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act (HIPAA) to student health records. Legislative complexity makes it especially important that schools have appropriately trained professionals on staff who can navigate the intersections between the education and the health care systems and ensure that the services support students' learning and school success as well as their good health.

Impact on School Performance

Although absenteeism is one of the major reasons for academic failure, it is not the only one. Many chronic illnesses and injuries result in cognitive impairments from the disease or injury itself, from stress or anxiety from living with the disease, or as a result of the medications used to treat the symptoms. Many pharmacological interventions cause side effects that



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significantly affect learning, including sedation, restlessness, irritability, lethargy, fatigue, difficulty focusing, pain, nausea, emotional lability, tremor, and poorly coordinated muscle movements.

In addition to academic difficulties, students with chronic illnesses can struggle with psychological, social, and emotional problems that affect their school experience (Vila, et al., 2003) and may make it harder to engage socially or maintain relationships. Students may be reluctant to participate in activities with friends for physical reasons or because they feel too different or self-conscious. They may need privacy to deal with physical symptoms, which can be hard to achieve in school. Chronic illness also can prevent or impede students' participation in extracurricular activities, which promote positive academic and social-emotional outcomes. The differences and restrictions can be particularly difficult for adolescents who already feel pressures to fit in and be

part of a group. The resulting sense of frustration or social isolation can add to any mental health problems that are associated with the primary illness.

Students with chronic illnesses may also suffer from a lack of motivation and refuse to even go to school. School refusal may be five times greater in students who have a chronic illness (Vila, et al.). Although homebound or hospital-based instruction may be necessary in some cases, they are not effective methods of addressing students' reluctance to attend school.

If homebound or hospital-based instruction is necessary, school personnel, hospitals, and homebound instructors must coordinate the medical and educational needs of the student. Teachers must be flexible in their instruction and must also understand the student's illness and its impact. Every student reacts differently to an illness, so teachers must work with the school psychologist and other relevant staff members to individualize each

student's education plan. Teachers in all content areas need to be flexible and accommodate the unique and often changing needs of students who have chronic illnesses. Schools should attempt at all times to normalize the student's situation while maximizing their academic progress.

Taking Action

Effectively integrating health care into the learning environment requires administrative leadership, collaboration, and staff training at all levels. Specifically, principals can work with staff members to:

- Establish a multidisciplinary team that includes the school nurse, the school psychologist, an administrator, teachers, and parents to develop policies and procedures for supporting chronically ill students. It is important that school-provided services are guided by trained school personnel to ensure that they are appropriate to the school environment, that school and health laws are adhered to, and that the school is maximizing its use of available public and nonpublic health care funds.
- Partner with parents. Being open to and partnering with parents is particularly important to creating a seamless support network for the student. Depending on the nature of the illness, family pressures and anxiety may exist. Supporting parents in their role and incorporating their help into the school's role can help both the student and his or her family.
- Facilitate ongoing collaboration with community service

Resources

Chronic illness in children: An evidence-based approach. L. L. Hayman, M. M. Mahan, & J. R. Turner (Eds.). 2002. New York, NY: Springer.

Genetic and acquired disorders: Current topics and interventions for educators. P. McCabe & S. R. Shaw (Eds.). 2010. Thousand Oaks, CA: NASP/Corwin Press.

In sickness and in play: Children coping with chronic illness. C. D. Clark. 2003. New Brunswick, NJ: Rutgers University Press.

Pediatric disorders: Current topics and interventions for educators. P. McCabe & S. R. Shaw (Eds.). 2010. Thousand Oaks, CA: NASP/Corwin Press.

What Next?

When considering how your school answers the needs of students with chronic illnesses, ask yourself the following questions:

- What can my school do to prepare staff members to work effectively with students who have chronic conditions?
- What types of supports might staff members need to manage the IEP for a student with a chronic illness?
- Students with chronic conditions may be subject to ridicule and rejection by peers. What can be done to prevent and lessen these types of social rejection?
- Students with chronic illnesses may have multiple complaints about the symptoms and treatment, but we need to treat students as normally as possible. What role can the school multidisciplinary team play in addressing students' concerns while discouraging malingering or manipulative behaviors?

providers and develop protocols for coordinating with a student's private health care providers, such as determining the best means of communication, providing information on school processes and law, seeking information about the student's condition, and providing written or verbal feedback about the student's status and progress.

- Recognize that every student reacts differently to illness and create an individualized education plan that accounts for the physical, psychological, and academic consequences associated with the medical condition and treatment. Best practices call for school multidisciplinary teams to collaborate with medical, community, and family systems. An individualized health plan may also be appropriate and can help guide educational strategies.
- Teach staff members about the student's medical condition, the nature of his or her medi-

cal treatments, and the common side effects of the illness and the medication. When the education team is able to anticipate and mitigate those effects through careful planning of an individualized education plan and an individualized health plan, the student's adjustment and responsiveness to instruction is maximized.

- Support the student's social and emotional needs. It is essential to be aware of how a student is faring in his or her social environment. It can help to identify a peer mentor or a trusted adult to whom the student can turn. Schools can also provide accommodations to facilitate participation in extracurricular activities.
- Provide grief counseling. Schools should always have a grief and bereavement plan for the student body and faculty. Some students will succumb to chronic illness and die. A strong plan can help the school community adjust to the difficulty of losing a peer and student.

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Effective Health Care

To be most effective, school-based health care should be:

- Integrated with and supportive of an effective learning environment
- Based on accepted standards, regulations, and laws
- Prepared for crisis management of medical issues
- Supported by a health service management information system
- Able to provide a range of prevention and treatment services, including such preventative care as tobacco control, prevention of drug and alcohol abuse, and obesity prevention
- Implemented by sufficient numbers of qualified staff members during the entire school day
- Culturally competent and linguistically relevant
- Coordinated with the eight components of a comprehensive school health program, as defined by the Centers for Disease Control and Prevention: health education, health services, social and physical environment, physical education, guidance and support services, food service, school and work-site health promotion, and integrated school and community health promotion
- Linked with community primary care, regional hospitals, mental health providers, dental health providers, local youth- and family-serving agencies, local public health systems, emergency providers, and public insurance outreach programs
- Able to maximize available public and nonpublic funds (e.g., Medicaid, grants, insurance reimbursement, and business partnerships)
- Evaluated regularly to determine its effectiveness, its efficiency, and the level of community and student satisfaction with it.



Conclusions

A large and growing number of students have chronic illnesses that affect their emotional development, physical development, academic performance, and family interactions. The primary error in educating those students is assuming that the outcomes of their illnesses are solely medical. The wide-ranging effects of many chronic illnesses can be addressed by medical professionals, school professionals, and families. Yet knowledge of medical issues typically is not part of the curriculum for training teachers, psychologists, or other educators. Nevertheless, legal and regulatory mandates and trends in health care service delivery place increasing responsibility on educators. The gap between professional preparation and the need for knowledgeable professionals with regard to medical issues is wide. Without changes in preservice and inservice preparation, this gap is likely to grow wider. **PL**

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