Children with Special Health Care Needs: Lost at School?

By Dian Baker, Linda Davis-Alldritt and Kathleen Hebbeler
First in a series on School Health and Children with Special Health Care Needs.

An estimated 1.4 million California children have special health care needs, and the majority of them attend public schools. Many of these children predictably require health care services during the school day, and many more are at risk for unanticipated events that might require access to urgent or emergency care. Their special health care need also puts them at higher risk than their peers for missing school and repeating a grade.

Yet in many cases, schools are not aware of the child’s condition. The first step in assuring that children with special health care needs (CSHCN) receive appropriate care at all times is to make sure that school personnel know who these children are and have easy access to information about their health status and needs. This is more easily said than done.

Issues in Identifying Children with Special Health Care Needs at School

Several federal laws address the education of children with disabilities, including children with special health care needs. The Individual with Disabilities Improvement Education Act of 2004 requires that each child who qualifies for special education have an Individualized Education Plan (IEP) but only about one third of children with special health care needs qualify for special education. The law requires that states report annually on the number of children with IEPs. The Rehabilitation Act (1973) and the American with Disabilities Act (1990) require accommodations for students who may not qualify for special education but have a special health care need.

Despite these requirements, schools’ access to student health information is often limited:

- Schools are not required to identify children’s health needs unless the child has an IEP. Children with special needs who do not qualify for an IEP, about two-thirds of CSHCN, may go unidentified by the school.

- The Family Educational Rights and Privacy Act (FERPA) regulates access to school health records, and the Health Insurance Portability and Accountability Act (HIPAA) regulates access to other health information. Misinterpretation of these laws can create communication barriers between school and community health providers, and hamper schools’ ability to identify children who need school health services.

- Only at entry to first grade are schools required to collect evidence of a child’s health assessment. Changes in a child’s health status over the course of his or her education may not be called to the attention of school personnel.
Schools are not required to report health emergencies or adverse events to the state, or to collect general health data on students.

Parents often are reluctant to share health information and/or are not asked for it by the school.

Only 56% of school nurses reported that they knew how many children had been identified as having special health care needs in the schools they served.

School nurses typically conduct some form of health assessment to determine the special health care needs of students in their schools. Since a majority of school districts in the state (57%) do not employ a school nurse, the process by which children are identified in these districts is unknown.

In most school districts there are no standard procedures to transmit health information from school to school as children transition from elementary to middle to high school.

Policy Recommendations

- Require systematic mechanisms for school districts to identify and serve children with special health care needs.
- Enact regulations to require health assessments prior to entry to 7th grade similar to the first grade health assessment requirement. Focus the assessment on identification of children with special health care needs.
- Require schools to track attendance and educational outcomes of children with special health care needs, and require reporting and monitoring of services.
- Strengthen mechanisms for school partnerships with community health providers to identify children with special needs including professional development as to how information can be shared under current federal laws.

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\(^1\) Findings reported in this brief are based on research conducted under a grant to the Division of Nursing at California State University, Sacramento: Schools' Role in Systems of Care for Children with Special Health Care Needs. Results have been submitted for publication. For more information, contact Dian Baker, PhD, MA, MS at dibaker@saclink.csus.edu
Health services have been provided in California schools for over a century. For most of that time, families relied on school nurses to monitor their children’s health during school. Nurses collected health records, measured heights and weights, tested vision and hearing, and administered medications.

Increasingly, schools must provide for an array of children with varying special health care needs and complex chronic illnesses. While expectations for school health services have expanded, the availability of school nurses has decreased. The routine availability of school nurses to help care for children and to be part of the continuum of health care in communities is becoming a thing of the past.

Nowhere is this more apparent than in California:

- Only 43 percent of school districts in California reported having a school nurse on staff.
- Only 26% of school nurses report being “very” to “extremely” confident of meeting the needs of all children in their assigned schools.

These figures mean that many children, including those with special health care needs, may be at risk for having unaddressed health needs during school hours. Those needs may interfere with their attending and benefiting from educational opportunities.

In the absence of nurses, a range of school personnel may be called on to provide health care services, such as administering medication, treating life-threatening allergic reactions, performing gastrostomy tube feeding, injecting insulin, suctioning tracheotomies, and providing urinary catheterization. Often these personnel are not certified, nor did they expect to perform health services. Those who currently provide these services may include:

- Unlicensed staff members, including secretaries, administrators, and teaching and health aides who usually have other responsibilities. Parents who may, but cannot be required to, provide health care for their child;
- Private health care agencies, county public health, and local hospital systems with whom school districts may contract to assist with health care required during school hours.
Other school personnel (including physicians, audiologists, dentists, dental hygienists, optometrists, psychologists, and social workers) who hold a California credential may provide health care services as determined by educational code.

California’s Education Code requires that “diligent care” be given to the health and physical development of students, but it does not provide a definition. The code also requires that supervisors of health or physical development in California schools hold a services credential with a specialization in health (physician or nurse, for example) but does not require that their services be provided. The code does not require schools to report health emergencies or adverse events to the state, or even to collect general health data on students.

In the absence of more specific state regulations, decisions regarding school health services and personnel are left almost entirely to individual school districts. Districts make decisions about the availability of school health care services, and determine who is qualified to provide services.

Given the financial difficulties faced by many of California’s school districts, the use of other professionals and unlicensed school personnel is common. Such substitutions may be the only viable alternative to forgoing health care service responsibilities altogether. However, it is likely that the health of students is jeopardized when standards are not applied to assure adequate staffing and training to handle health problems, especially those that are chronic or emergent. A root cause for many of the shortcomings in school-based health services is the lack of authoritative guidance from the state Department of Education and the failure of local school districts to consult with health care providers to strengthen local policies and practices.

Policy Recommendations

- Ideally, every school would have licensed health care personnel, and would meet the standard of one school nurse to every 750 students.
- Evaluate compliance with workforce requirements of school nurses and trained unlicensed personnel to ensure the safe and effective delivery of health services all schools.
- Require that all personnel delivering health services in schools receive mandatory state-standardized training, including first aid, CPR and whatever specific medical procedures are needed by children in each school.
- Enforce the California educational code requirements for appropriate credentials for supervisors of health in all school districts.
- Require schools to track and report adverse health events and health emergencies at school to the California Department of Education.
- School Boards should annually review health care needs, services and staffing.
- School districts should establish active partnerships with community health providers to facilitate communication and access to services.

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Schools’ primary mission is the education of children. For the more than one million children in California with special health care needs, schools also must address the need for health services. Federal laws obligates schools to address chronic health problems to enable students to receive an education. These health care responsibilities by default have made schools a part of the larger community health care system.

Children with chronic or complex health problems are much less likely to regularly attend school and graduate, especially when schools are not prepared to participate in their health care. Low attendance rates directly affect the budgets of local school districts that rely on a revenue system based on daily attendance. Having adequate numbers of trained staff on hand is key to schools’ ability to attend to children’s health care needs, whether those are simple, acute illnesses that arise without warning or chronic problems requiring daily services.

Unfortunately, many years of limited funding for public education in California have reduced the education workforce, especially those professionals, like school nurses, whose functions are not directly related to core educational goals.

Accessing Available Funds

Funding for school-based health services is potentially available from several sources. Local school districts may allocate a portion of their general funds for school health. Federal funds earmarked for special education reimbursement are available. State and federal Title V funds may be used to support school health services. School health personnel, primarily school nurses, may bill insurers, especially Medi-Cal which makes funds available through the local education agencies (LEA) or through Medicaid Administrative Claiming/Medi-Cal Administrative Activities (MAA) for Medi-Cal eligible children. In addition, occasionally there are special grant opportunities available to schools willing to expand specific types of health services.

Though many funding sources exist, California schools do not consistently make use of them:

- Only 43% of school districts employ a school nurse and are thus able to bill for their services. Local school districts are required to reinvest these LEA Medicaid funds in health and human services, which could enhance school health services.

- The state has delayed LEA Medi-Cal payments to some school districts, putting pressure on general fund budgets and limiting districts’ capacity to provide health services.

- The California State Auditor has estimated that Medi-Cal Administrative Activities billing could
garner at least $57 million in additional funds. However, even when these funds are returned to the school districts’ general funds, there is no requirement that they be used to improve the health services for which the funds were received.

- California does not use any of its Title V, Maternal and Child Health funds to support school health services.

**Policy Recommendations**

- School districts should partner with local health care providers, e.g., hospitals, health plans, community health clinics, to provide health care personnel to work in schools.

- The state should provide guidelines for school districts to utilize federal, state and county Title V and maternal and child health funds for support of school health services.

- The state should simplify and expedite the billing and payment processes that have delayed LEA Medi-Cal payments to school districts.

- The Legislature should require that funds generated through Medi-Cal Administrative Claiming be earmarked to support school health services in the same manner as are LEA funds.

- The state should create a consolidated claims processing entity so that school health services can be billed to private as well as public health insurers.

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