



Testimony of
Martha Dewey Bergren, DNS, RN
on
HIPAA and FERPA in Schools
Representing
NATIONAL ASSOCIATION OF SCHOOL NURSES

National Committee on Vital Health Statistics Subcommittee
on Privacy and Confidentiality

February 19, 2004

Room 705A Hubert Humphrey Building
200 Independence Avenue
Washington DC

Good morning Mr. Chairman and members of the Subcommittee. I am Martha Dewey Bergren, Clinical Assistant Professor at the University of Illinois Chicago College of Nursing. I am nationally certified in both Nursing Informatics and School Nursing and have followed the development of HIPAA regulations and the impact on school nursing since its inception. As co-chair of the NASN HIPAA Advisory Committee, I am representing the National Association of School Nurses and the over 10,000 leaders and grass roots members of the association.

As you know, education records are exempt from the HIPAA Privacy Rule. School health records are educational records and are protected by the Family Education Rights Privacy Act (FERPA). School nurses have several different responsibilities to school children and their families that have been affected by HIPAA:

- To protect citizens from preventable communicable diseases that cause morbidity and mortality, schools have successfully enforced public health mandates by requiring proof of immunizations for school entry.
- School nurses act as case managers and provide the treatment and health monitoring that allows medical fragile and chronically and acutely ill children to be educated in the “least restrictive environment” as mandated by IDEA. Children in schools have the same diagnoses, treatments, and health care needs that are seen in acute care facilities. Treatments in for children in schools include suctioning tracheotomies, urinary catheterization, monitoring ventilator settings, administering gastrostomy feedings, and administering psychotropic and anti-seizure medications and insulin. Many school nurses are responsible for children with disabilities ages 0 – 6 years of age and as a result, many of their student health records contain sensitive health information about family members, such as a mother’s labor and delivery history and her alcohol and drug history during pregnancy. In answer to Mr. Houston’s question earlier about why the nurse would not simply obtain authorization for communication with the child’s physicians, many of these medically fragile children have 6 – 7 subspecialty physicians and it is common to have new physicians consult and write orders after the start of the school year.
- School nurses collaborate with educators and primary care providers to identify etiology of health problems, genetic syndromes, and disabilities that interfere with learning to design effective Individual Education Plans (IEP), health care plans, and emergency plans.
- School nurses function to enhance the ability of students to achieve and participate in all facets of the educational setting. The nurse collaborates with primary providers to facilitate a safe and supportive school environment following injury, hospitalization and illness. The nurse communicates with educators and primary providers regarding the

students' health status and their ability to fully participate or participate with restrictions in music, athletics, physical education, and academics.

Up until the enactment of HIPAA, schools, primary providers and health departments communicated and collaborated on all of the aforementioned matters regularly. Nurses could verify immunization dates with physicians' offices and local health departments, obtain providers' orders for treatments, medications, and health maintenance parameters over the phone or via fax, and consult providers regarding assessments for learning problems.

Since the onset of HIPAA regulations, school children have suffered as a result of misconceptions regarding communication of personally identifiable health information with schools.

School nurse from all over the country have reported the refusal of HIPAA covered entities to communicate with them directly. This stack of emails report the following situations:

- Physician offices, hospitals, and health departments have refused to honor HIPAA compliant authorizations initiated by schools, releasing PHI only to parents, and only in person.
- Some HIPAA covered entities will only release information with their facilities' release forms, requiring schools nurses to maintain a file of 25 – 30 release forms specific to health care providers or agencies.
- HIPAA covered agencies are refusing to accept faxes or send faxed information to schools, citing "HIPAA".
- Providers are refusing to confirm or discuss treatment orders, immunization dates, physical exam dates, activity restrictions, or health accommodations with school health providers.

How have changes in health information sharing impacted students and their families?

- It is estimated that thousands of students have been excluded from school due to missing immunization dates required for school entry or attendance.
- Students have been re-immunized when the barriers to obtaining health information are too burdensome for working parents, rural residents, or families who have relocated significant distances from providers who administered immunizations.

- Students have had return to school following an illness or injury delayed due to the inability of the nurse to provide treatment without knowledge of the student's health problem, restrictions or physician orders.
- Students have attended school without needed medication or treatments for chronic or acute health conditions.
- Parents have missed work to drive or take public transportation to physically travel to providers to obtain child health records and physician orders for treatment and transport them to school.
- Parents have missed work to travel to school to administer medications or treatments due to the nurse's inability to obtain orders to administer or clarification of treatment or doses.

Some reports from school nurses:

- One nurse from Illinois estimated that 75 – 100 of 275 students were excluded and missed school days due to missing immunization verification.
- Health departments in some jurisdictions have conducted vision and hearing screenings in schools for school children. Since HIPAA, many nurses reported that health departments are refusing to share screening results to facilitate school follow-up or to provide accommodations for learning.
- School nurses repeatedly report providers refusing to verify indistinguishable immunization or physical exam dates on provider-generated documents.
- Many nurses report parents provided physical exam forms required for school attendance, but the date of the physical exam was missing. The providers who conducted the exam refused to verify the date of the physical exam.
- Restrictions on physical activity, such as “no physical education for two weeks”, are sent to schools without the reason for the restriction. One school nurse had a physician order for a child returning to school to participate in physical education “as tolerated”. When the nurse called for a clarification, she was told due to HIPAA, the provider could not reveal the child's health problem nor what body system it affected: respiratory, orthopedic, etc.

- In Delaware, one student returned to school with a central line and the school nurse was not notified. He was found alone in the darkened auditorium feeling poorly.
- Some physicians not only require parents to come to the office to obtain their child's physician orders or health information, some require parents to schedule an appointment to "counsel" them on such, further delaying student treatment, attendance, and assessments.
- One health department in southern Illinois refused to share immunization data with the school as it was for school entry, not treatment purposes and not exempted by HIPAA, but stated the school must share any health information in the education record with the health department because it was for treatment purposes, and therefore did not need a parent authorization.
- A school nurse from Delaware reports that a highly regarded tertiary health care facility that cares for many Medicaid recipients and uninsured students called a school health office to request that the nurse provide a reading of a PPD administered in the facility. However, the facility refused to tell the nurse the date and time the PPD was administered. The nurse was unable to determine the 72 hour time frame for the reading.

While some facilities are overreacting to the HIPAA Privacy Rule, many facilities are aware that they may share health information for treatment, but are not required to share it without authorization. Primary providers cite that they are permitted to have more restrictive information privacy policies than the minimum required by HIPAA. They admit to school health officials that their offices' stringent restrictions on sharing patient information since HIPAA have greatly decreased the time and workload previously spent collaborating with schools on child health care and immunization compliance.

HIPAA Covered Entities frequently cite their inability to share PHI with schools specifically because schools are not HIPAA Covered Entities, and one facility specifically cited FERPA as not providing HIPAA level privacy protections. While HIPAA provides direction to health care providers on how to protect patient privacy, FERPA does not provide guidance to schools on how to protect family and student privacy. Schools are left to interpret who has a "legitimate educational interest" to access student's educational records without authorization. Some schools interpret this narrowly, and others interpret sharing student educational records, including health records, very broadly. FERPA was written in 1974, prior to the inclusion of medically fragile or disabled students in schools, and does not differentiate between the voluminous and sensitive health information and family health histories collected and stored to provide health care and education services. FERPA also does not address the storage and security

of this information in school electronic databases and servers, nor does it mandate confidentiality training for educators and school health employees.

School districts engage in HIPAA transactions when they electronically bill for nursing care and other health services in schools. In fact, some states mandate that schools bill for reimbursable health services. Health and Human Services sources have stated that education records, even when submitted as a as a HIPAA Covered Transaction, are exempt from the HIPAA Privacy Rules, but are subject to the HIPAA Transaction Rules and Code Sets. However, this information has not appeared in the form of technical guidance and many schools have been advised by legal counsel that engaging in a HIPAA transaction for reimbursement for student health services automatically qualifies the district as a HIPAA Covered Entity and therefore subject to the Privacy, Security and Transaction Rules.

There are several areas where guidance and direction is welcome:

- Issue technical guidance regarding the exemption of the HIPAA Privacy Rule for student health records that are subject to HIPAA transactions.
- An exemption of immunization records from HIPAA Privacy Rules in the interest of national public health goals.
- An exemption for public screening data collected for the detection of easily preventable disabilities that interfere with learning (i.e. vision and hearing).
- A stronger, clearer directive to health providers that HIPAA not interfere with the provision of care.
- A stronger, clearer directive to what constitutes “reasonable safeguards” when provision of non-sensitive information (such as physical exam dates) are requested for school entry or participation in athletics and academics.
- A clear, definitive statement that HIPAA Covered Entities shall communicate with health providers, including those who provide healthcare in schools, to provide treatment to clients.
- A definitive statement that HIPAA does not bar transmission of PHI via analog fax machines
- A statement that analog fax machine transmissions do not qualify as HIPAA transactions.

- Prohibiting the refusal to honor HIPAA compliant authorizations. Requiring the use of an agency specific authorization forms is antithetical to the spirit of administrative simplification.

The National Association of Schools Nurses thanks the Subcommittee for inviting us to testify on the impact of the HIPAA Privacy Rule on the ability of school nurses to provide quality health care for children in schools and to assure school attendance and educational achievement for our nation's children.