Communication among all members of the care team is critical to making sure students get the health services they need—but it can be challenging to share healthcare and education data while navigating federal and state privacy rules.
Understanding Federal Law

The Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule are the key federal laws that protect the privacy of education records and healthcare information and limit how that information can be shared. It is important to note that in addition to federal laws, there are also state laws that impact data sharing, some of which may include more specific or more stringent data privacy and confidentiality rules.

FERPA applies to all elementary, secondary and post-secondary schools that receive funding from the U.S. Department of Education. It covers the “education record” and any personally identifiable information that could be used to identify a student. This includes student health records, such as immunization records, maintained by the school or school nurse. The information cannot be disclosed under FERPA without written consent from a parent or student age 18 or older, except in certain emergency situations.

A school may disclose “directory information”—such as a student’s name, date of birth and grade level—without consent. If a school-based health program is funded, administered or operated by the school, the health records are considered “education records” and are covered by FERPA. This would include providers hired by the school district with grant funds, possibly from a foundation or government agency.

HIPAA applies to most healthcare providers and covers information relating to an individual’s past, present or future physical or mental condition. The broad range of providers subject to HIPAA includes physicians, clinical social workers, and mental health practitioners, as well as hospitals and clinics.

Like FERPA, HIPAA also requires written consent from parents or students age 18 or older for disclosure of information, with some exceptions. If a school-based health program is funded, administered or operated by an external, non-education agency or healthcare system (e.g., a school-based health center), then HIPAA applies.

FERPA and HIPAA can never apply to the same information at the same time, because health information that is held in education records is specifically excluded under HIPAA.

Resources to Help Untangle HIPAA and FERPA

Understanding whether your school health program is covered by HIPAA or FERPA is important because: 1) it puts in place different paperwork and reporting requirements for sharing student health data with others on the care team; 2) means different things in terms of parental or student consent to share information; and 3) requires different protocols for sharing and transmitting information.
DATA SHARING IN D.C.: A CASE STUDY

An innovative data-sharing agreement in Washington, D.C., is helping health and education leaders identify student health needs—and make sure those needs are met. The agreement has improved coordination and delivery of services among the city’s schools, the public health department and the Medicaid agency.

Each agency holds critical student health data and has an important incentive to ensure that students receive health services:

· D.C. Public Schools has an institutional requirement to collect health information, including oral health information, for each enrolled student; the forms collected help schools plan for the medical needs of students. D.C. Public Schools also holds student enrollment data.

· The Department of Health requires that all students complete school health forms and have required immunizations to enroll in school, which means each student must go to their primary care provider for a well-child visit and dentist for a dental exam within the year.

· The Department of Health Care Finance (the District’s Medicaid agency) is required to document that the city’s Medicaid-enrolled students receive appropriate healthcare services; it also has data showing what services were paid for and to what managed care organization the student is assigned.

When pieced together, the data identify the schools with high Medicaid populations, with high unmet need, and where students are not receiving annual well-child or dental visits. Together, the agencies developed a Memorandum of Agreement (MOA) that allows them to share data in a way that helps them target outreach and resources to schools and students with the greatest unmet needs.

–From Sharing Data to Meet Student Health Needs in Washington, D.C., published by Healthy Schools Campaign

Untangling HIPAA and FERPA is critically important to building an effective school-based health system—but it can be extremely technical. It is important to include representatives from the state education agency, state Medicaid agency and an LEA’s legal counsel when figuring out what needs to happen for parental consent, or when building out new data-sharing arrangements. Including counsel from the beginning will help identify the legal complexities—and provide real solutions.
The distinction between HIPAA and FERPA is described in detail in two primers developed by the National Center for Youth Law: *HIPAA or FERPA? A Primer on School Health Information Sharing in California* and *HIPAA or FERPA? A Primer on Sharing School Health Information in Indiana*. They can be a helpful resource even for agencies not in those two states.

The Association of State and Territorial Health Officials (ASTHO) created a fact sheet, *Comparison of FERPA and HIPAA Privacy Rule for Accessing Student Health Data*, which offers additional information.

### Seizing the Opportunity

Navigating privacy and confidentiality laws will require patience and dedication—and the early involvement of appropriate legal counsel. But these problems are solvable, and solutions can be developed in tandem with other state and local policy changes.

In addition, LEAs that are already billing Medicaid for services included in IEPs will have a solid foundation on which to improve data-sharing agreements. School-based Medicaid programs can expand and build on top of existing infrastructure—and offer a great opportunity to improve data sharing.

Here are some issues and questions to consider concerning data-sharing opportunities:

- **I know that LEAs in my state have addressed data sharing already.** *How did they do so, and what are the best practices already in place?*

- **My state has complicated HIPAA and FERPA interactions.** *What are the rules unique to my state? What are the key considerations that will need to be addressed in my state to ensure appropriate compliance?*

- **I’m worried about how data sharing works in practice.** *What does this mean for the various different parties, including parents and healthcare providers? How has this been addressed in practice?*

- **I want to expand school-based Medicaid.** *Should I have legal counsel join our coalition from the beginning in order to address these issues up-front?*