



Personal Information Privacy Laws:

Family Educational Rights and Privacy Act (FERPA) Health Insurance Portability and Accountability Act (HIPAA)

For PROMISE youth and their families, there are two federal laws protecting personal information that are important to be aware of.

The **Family Educational Rights and Privacy Act (FERPA)** is a Federal law that protects the privacy of student education records. The law applies to all schools, public and private, that receive funds from programs of the U.S. Department of Education. The **Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule** provides consumers with important privacy rights and protections with respect to their health information, including important controls over how their health information is used and disclosed by health plans and health care providers.

As PROMISE participants reach the age of majority (18 years of age in all states except Alabama and Nebraska where it is 19 years of age) the issue of who has the rights and responsibility to control their personal information and provide consent to participate in research and services becomes an important issue. Prior to age of majority, parents or guardians are typically the ones who can provide consent to share personal information and access to a youth's educational and health records. Prior to the age of majority, parents or guardians are also able to give consent for participation in research activities for their children.

Guidance for Eligible Students

Once a student reaches 18 years of age (or 19 in Alabama and Nebraska) or attends a postsecondary institution, he or she becomes an "eligible student," and all rights formerly given to parents or guardians under FERPA transfer to the student. The eligible student has the right to have access to his or her own education records, the right to seek to have the records amended, the right to have control over the disclosure of personally identifiable information from the records, and the right to file a complaint with the U.S. Department of Education if they feel their rights are not being honored.

The term "education records" is defined as those records that contain information directly related to a student and which are maintained by an educational agency or institution or by a party acting for the agency or institution.

Access to Education Records

FERPA requires a school to provide a parent or guardian or an eligible student with an opportunity to inspect and review his or her education records within 45 days following a request.

A school is not generally required by FERPA to provide a parent with access to school calendars or general notices such as announcements of parent-teacher meetings or extra-curricular activities. That type of information is not generally directly related to an individual student and, therefore, does not meet the definition of an education record.

Under FERPA, a school is not required to provide information that is not maintained or to create education records in response to a parent's request. Accordingly, a school is not required to provide a parent with updates on his or her child's progress in school unless such information already exists in the form of an education record.

Access to Health Records

The HIPAA Privacy Rule ensures consumers the right to access, inspect, and request amendments to their medical records held by certain health care organizations, notably health care providers and insurers. The Privacy Rule establishes procedures for gaining access to personal health information, including limits on both the number of days a provider has to respond to a request and the fees they may charge. In some circumstances, covered entities do have the right to deny access, although individuals also have the right to request a review of that denial.

Disclosure of Health Records

The HIPAA Privacy Rule permits a health care provider to disclose information to the family members of an adult patient who has capacity and indicates that he or she does not want the disclosure made, only to the extent that the provider perceives a serious and imminent threat to the health or safety of the patient or others and the family members are in a position to lessen the threat.

Participation in Research

When a youth reaches the age of majority, he or she can exercise all rights granted by the HIPAA Privacy Rule with respect to all protected health information about him or her, including information obtained while the individual was an unemancipated minor consistent with State or other law. Generally, the parent can no longer be the personal representative of his or her

child once the child reaches the age of majority or becomes emancipated, and therefore, would no longer control the health information about his or her child. *This includes the decision to participate in research activities.* A child who has been enrolled in a research study by his or her parents can, once they reach the age of majority, decide to continue or request to be removed from the research activities, if they so desire.

The Use and Disclosure of Protected Health Information

Covered entities may not use or disclose an individual's PHI except as the Privacy Rule expressly permits or requires, or with an individual's written authorization. See 45 C.F.R 164.502, 164.508. The Privacy Rule's use and disclosure provisions were designed with the typical business or clinical health care record in mind, whether paper or electronic, and the use and disclosures covered entities would need to make of this information for their core health care functions.

Resources

[Joint Guidance FERPA and HIPAA](#)

[FERPA Training](#)

[FERPA Presentation](#)

[HIPAA Training](#)

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