Legal considerations on federal and state privacy laws

Legal questions regarding data use will depend on specific facts and applicable laws, but there are general considerations for anyone seeking to access, use and share data. While there may be federal, state and local laws governing data access and use, some projects will not present any legal barriers to access or use. This chapter will provide general information on the legal landscape for data collection and access. The contents of this chapter do not constitute legal advice.

The discussion refers to several classifications of data that are defined in the table below. While these definitions are generally accepted, when a law provides a definition for a particular data type, the legal definition should be used as applicable.

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Table 1: Classifications of data

| Aggregate data | Data for individuals that are compiled or grouped into data summaries or summary reports. For example, data may be aggregated at the national, state, county or school district level to facilitate comparisons, identify trends or measure improvements over time. Aggregate data for small geographic areas, those with sparse or vulnerable populations, and/or those that include unique characteristics should be carefully evaluated to ensure that individuals are not |
| **Coded data** | Data assigned a code—such as a number, letter or symbol—that is unrelated to an individual's identity. Coded data is identifiable only by those with access to the key to the code. Coded data may facilitate longitudinal studies covering the same cohort or permit the organization that provided coded data to identify individuals from study results for individual-based intervention. |
| **De-identified data** | Data that have been stripped of personal and indirect identifiers so that individuals cannot be identified, either directly from the data or when data are linked or combined with other information. |
| **Disaggregated (stratified) data** | Data for a population that are collected or tabulated by components, characteristics or smaller units of data. Examples are race, ethnicity, age and geographic area to help identify, assess and effectively address disparate impact and outcomes for particular groups. |
| **Identifiable data** | Data that are traceable to an individual either alone or in combination with other data. |
| **Limited data set** | Data that exclude direct identifiers but may include indirect identifiers such as geographic or temporal information. Under the HIPAA Privacy Rule, a limited data set is protected health information that may be disclosed with a data use agreement for purposes of public health, research or health care operations. |
| **Machine readable data** | Data or data sets in formats that can be read or understood by computers. These data are dynamic and can be open to further processing. |
| **Open data** | Data or content that anyone can freely access, use, modify and share for any purpose. For example, the federal government provides access to search over 322,000 open data sets at [data.gov](http://data.gov). |
| **Open format** | Generally, data available in a format that can be used and implemented by anyone without charge or technological barriers. |
| **Public data** | Data that can be disclosed without restriction, which can include de-identified data. |
| **Raw data** | Source or primary data that has not been processed since its acquisition. |
| **Restricted data** | Data that may be accessed or obtained only by authorized persons, which include data protected by federal or state law or by a nondisclosure agreement. |
Federal landscape for CAMH data collection and accesss

As part of developing a public health surveillance plan related to child and adolescent mental health (CAMH), it is helpful to review the legal landscape for collecting data related to CAMH maintained by preschools and elementary and secondary schools. Much of this legal landscape framework was described in detail in the Summary of Laws Related to Child and Adolescent Mental Health that the Public Health Informatics Institute published in 2020. Appendix 1 includes citations and hyperlinks to the following federal laws.

It is worth noting at the outset that all federal laws reviewed for this project allow de-identified data to be disclosed.

Health Insurance Portability and Accountability Act (HIPAA)

When people think of laws governing the privacy of health information, including potential barriers to sharing health-related data, they often think first of the Health Insurance Portability and Accountability Act (HIPAA). HIPAA applies to protected health information (PHI) held by health plans, most health care providers, health care clearinghouses, and their business associates that use or disclose PHI. As such, HIPAA is unlikely to be a barrier, or even relevant to the domains and indicators discussed in this playbook, which are largely collected and held by schools and educational entities.

HIPAA could be relevant if a public health department wishes to access data from health care providers, such as pediatricians, who may collect data related to kindergarten readiness for their individual patients. A covered entity for purposes of HIPAA, such as a pediatrician, may use and disclose a limited data set for public health purposes, provided that the covered entity and the recipient of the limited data set enter into a data use agreement that includes specific assurances and data safeguards. However, if a public health department seeks to access aggregate-level data, or data from the National Survey of Children’s Health for public health surveillance, HIPAA is unlikely to come into play. The U.S. Department of Education and U.S. Department of Health and Human Services collaborated on guidance which discusses the application of HIPAA and FERPA to student health records in further detail. Finally, HIPAA does not apply to education records that are covered by FERPA.

Privacy Act

The Privacy Act regulates federal agencies’ maintenance, collection, use and dissemination of information about living individuals. An agency must publish a notice in the Federal Register when a new system of records is established or when revisions are made to existing systems. These public notices include information about the types of records included in a system, how the records are protected, how individuals can access records, and routine uses—external disclosures—of the records. For example, an agency notice may provide access to identifiable information in a system of records to researchers after establishing conditions and safeguards that apply to such access.
In general, federal agencies cannot disclose the records contained within a system of records except upon written request by or with the written consent of the individual who is the subject of the record. There are twelve exceptions where disclosure is permitted, though not required, without consent. These permissive disclosures are limited but could permit disclosure of records to a public health agency for statistical research or reporting if they are not in an identifiable form. They also authorize disclosure if required by the federal Freedom of Information Act.

Note that records subject to the Privacy Act may also be protected by other laws. The U.S. Department of Justice provides an overview of the Privacy Act and covers exceptions that permit disclosure of records.

**E-Government Act**

If a data source receives federal funding, identifiable data may be required to be public. The E-Government Act requires the federal government to maintain a repository with information about research and development funded by the federal government. The information must include any restrictions on the research that prevent sharing the work with the public.

The Act also governs privacy policies on federal government websites.

**OPEN Government Data Act**

The Open, Public, Electronic, and Necessary (OPEN) Government Data Act mandates federal agencies to publish government information as machine-readable data in an open format. Machine-readable data can be processed by a computer and may make certain data projects and analysis more efficient. Machine-readable data are distinct from data that are simply available online and are formatted in a manner that computers can process. Open format data places no restrictions on use. Agencies must publish a data inventory, which is typically located on an agency’s website.

The purpose of the Act is to make data more usable, advance open data practices in the federal government and increase transparency regarding data used for policymaking.

**Family Educational Rights and Privacy Act (FERPA)**

The Family Educational Rights and Privacy Act (FERPA) applies to educational agencies or institutions that receive funds from the U.S. Department of Education. It grants parents and eligible students the right to inspect, obtain, seek amendment of and have some control over disclosure of education records and information in education records. Education records are records that are directly related to a student and maintained by an educational agency or institution, or a party acting on its behalf, such as a contractor. Education records include indicators such as school readiness assessments, attendance records, disciplinary records, transcripts and special education assessments.

Education records also include a student’s medical or health-related records that are maintained by a school or the school’s contractors, consultants or other agents. For example, FERPA applies to medication records and notes created by a school nurse, whether the nurse is directly employed by the school district or works under a contract with the school district. Similarly, if a school district contracts with a public health or mental health agency to provide services to its students, FERPA applies. However, FERPA would not apply to the health records of school-based clinics operated by a health department, health system or community mental health agency if the provider is separate from, and not acting on behalf of, the school.
Although FERPA would not apply, other laws, such as HIPAA, might apply.

**FERPA v HIPAA:** HIPAA defers to FERPA, saying that if FERPA applies to a student’s health information, HIPAA’s privacy protections do not.

FERPA prohibits disclosure of personally identifying information from education records, without consent, unless an exception applies. Unlike HIPAA, FERPA does not allow an educational agency to disclose personally identifiable information to a public health department for routine public health purposes. Absent consent, FERPA allows such disclosures if there is a health and safety emergency. The role of FERPA in either impeding or facilitating efforts to increase student success and improve population health was discussed at a workshop sponsored by the National Academies in 2018.ii

Additionally, FERPA allows disclosure without consent of:

- De-identified records and information, which may be used to identify trends related to child and adolescent mental health, provided individual students are not identifiable.
- Personally identifiable information, if necessary, to provide a service to the educational agency (e.g., to provide health care and wellness programs or to assist a school district in analyzing its data and developing and evaluating interventions).
- Personally identifiable information needed to conduct a study for the educational agency (e.g., to evaluate and improve efforts regarding student’s attendance or performance).
- Personally identifiable information needed to conduct an audit or evaluation on behalf of a state or local education agency (e.g., to evaluate how well a school district is meeting the mental and behavioral health needs of its students).

**A 2020 National Association of State Boards of Education report** offers a helpful discussion of the application of FERPA to state educational agencies, and when they may provide access to personally identifiable information.

The Student Privacy Policy Office within the U.S. Department of Education operates a [Privacy Technical Assistance Center (PTAC)](https://privacy.ed.gov), which provides technical assistance to help schools and school districts safeguard information about students. It includes guidance, training and other resources related to FERPA requirements. Recent FERPA 101 training materials developed by PTAC may provide helpful background information, such as a 2020 training for local education agencies in Nebraska and a 2018 training for educators in Utah. Before relying upon this information, consider consulting legal counsel for information regarding any changes to the relevant laws that may have occurred since the materials were created.

**Individuals with Disabilities Education Act**

The Individuals with Disabilities Education Act (IDEA) protects the rights of children with disabilities to a free and appropriate public education tailored to meet their individual needs. The term “child with a disability” means (1) a child with intellectual disabilities, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities, and (2) who, by reason thereof, needs special education and related services.
A state must have policies and procedures in place to ensure that the state educational agency and participating agencies comply with regulatory requirements to protect the confidentiality of any personally identifiable information related to a child with a disability collected, used or maintained under IDEA Part B. IDEA Part B pertains to data privacy and disclosure related to children and youth ages three through 21 who receive special education and related services. Part B permits disclosure of information that is not personally identifying. If personally identifiable information is included within “education records” as defined by FERPA, then the participating agency must comply with confidentiality requirements under FERPA.

**Every Student Succeeds Act**

The Every Student Succeeds Act (ESSA) provides federal funding for elementary and secondary education and accountability for student outcomes. Title IV of ESSA is particularly concerned with improving the conditions for student learning in schools and increasing students’ access to a well-rounded education, which may include integrating social and emotional learning into the curriculum and preventing bullying.

ESSA requires participating states to prepare and disseminate an annual state report card, including information related to academic and non-academic indicators.

To receive ESSA funds, a state education agency must submit a plan to the U.S. Department of Education in order to facilitate assessment and accountability. ESSA sets forth four required indicators of academic success. States must also report on at least one non-academic indicator of school quality or student success, such as student engagement or school climate and safety. At least 35 states have chosen to use school attendance/chronic absenteeism as a non-academic indicator, though states define these terms in different ways, and states faced challenges in determining these figures during the COVID-19 pandemic. ESSA requires that it be possible to disaggregate results from academic assessments for specified groups, including economically disadvantaged students, students from major racial and ethnic groups, children with disabilities, and English learners.

ESSA requires participating states to prepare and disseminate an annual state report card, including information related to academic and non-academic indicators. The Office of Elementary and Secondary Education within the U.S. Department of Education maintains a website where it posts links to each state’s report card.

**ESSA assessment, accountability, and reporting requirements during the COVID-19 pandemic**

At this writing, the COVID-19 pandemic has had a disruptive impact on schools for parts of three academic years (2019-2020, 2020-2021, and 2021-2022).
While disruptive impacts have been all but universal, they have been more severe among students of color, low-income students, homeless students, lesbian, gay, bisexual, transgender, and queer (LGBTQ) students, and students with disabilities and special needs.\textsuperscript{vi}

When school closures were first ordered on a widespread basis in March 2020, the U.S. Department of Education issued guidance that sought to provide flexibility to states seeking to provide safety from the virus through remote learning.\textsuperscript{vii} The letter authorized states to seek waivers of certain assessment and reporting requirements under ESSA for the 2019-2020 school year. A similar letter authorized states to seek waivers for the 2020-2021 school year.\textsuperscript{viii} Some states, such as New York, acknowledged receipt of a waiver, and set forth the alternative means they would use to report on school performance.\textsuperscript{ix}

The abrupt and ultimately protracted shift to remote learning, hybrid learning, and in-person learning with a variety of new safety protocols in place posed challenges for collecting attendance data,\textsuperscript{x} defining and collecting school discipline data,\textsuperscript{xi} and assessing kindergarten readiness.\textsuperscript{xii} As the pandemic continues, marked with increased familiarity with remote learning, greater availability of effective vaccines for adults and students, and improved understanding of effective non-pharmaceutical interventions to control the spread of the virus, collection of data related to school climate, the conditions for student learning, and child and adolescent mental health will likely continue to evolve.\textsuperscript{xiii}

Data collection examples

- **National Center for Education Statistics**: The National Center for Education Statistics (NCES), part of the federal Institute of Education Sciences (IES), maintains an online DataLab featuring over 30 federal education data sets. The data sets are organized by topic and subtopic. Once a data set that meets the criteria is found, there is a tool icon that launches a data use agreement. NCES also maintains a searchable database of information collected from public school districts, public schools and private schools.

  Not all IES and NCES data are available for public use. More detailed data, subject to restricted use agreements, are available to qualified researchers. IES and NCES accept restricted use data license applications through an online electronic application system. The application requires information about users who will have access to the data and a security plan to secure the data. The NCES publishes a restricted use data procedures manual with information for researchers.

- **Department of Education Civil Rights Data Collection**: The Department of Education Office for Civil Rights conducts Civil Rights Data Collection (CRDC), a biennial survey of public school districts and schools. The survey also includes alternative schools, juvenile justice facilities and special education facilities. The data are self-reported and cover a range of topics, including enrollment and discipline. The database is publicly accessible, so there are no access concerns. Disaggregated data and downloadable public-use files are available. There are also select data analysis tools to compare data elements across schools, districts and states.
Because the CRDC includes data disaggregated by demographics across the various topics and subtopics, this data source may be useful for research on disparities and equity in educational settings across race, gender, disability and other characteristics. For example, the Department of Education released a report on exclusionary discipline practices in public schools using CRDC data from the 2017-18 school year. This, and similarly disaggregated data sources, demonstrate the value of collecting and publishing publicly accessible data that advances the evidence base revealing where schools and districts are meeting or failing to meet equity objectives.

The “Frequently Asked Questions” (FAQ) document on the website describes the authority under which the Department of Education conducts the survey. There are no legal barriers to accessing these data because they are publicly available online. The U.S. Department of Education used data from the 2017-2018 CRDC to generate reports on exclusionary school discipline, restraint and seclusion.

**Resources for accessing state and local data related to child and adolescent mental health and schools**

As noted in the introduction in the Legal Considerations section of the CAMH playbook, it is helpful to identify all relevant (and potentially relevant) laws at the outset of an effort to gain access to child and adolescent mental health data. However, the laws in each state and local jurisdiction vary. Therefore, it is not possible to provide only one description to cover all state and local laws governing access to data collections for the domains and indicators related to school attendance, school discipline and school readiness. Even though ESSA and other relevant federal laws establish national parameters, each public health agency or person seeking such data should take steps to identify the policies and procedures specific to their jurisdiction. Relevant laws may include (1) substantive policies to promote student mental health, (2) data collection, privacy, and sharing laws, (3) policies related to the state’s ESSA compliance, and (4) policies related to the local education agency’s ESSA compliance.

- **State and local resources related to child and adolescent mental health:** The CDC recognizes that children are served by public health and education in schools and have called for a whole child approach to support children in an educational setting. The Whole School, Whole Community, Whole Child Framework (WSCC Framework) has provided one structure for identifying and assessing state and local policies that address health in schools. The WSCC model has ten components, three of which are most closely related to the mental health domains and indicators discussed in this playbook. They are social and emotional climate, physical environment, and counseling, psychological, and social services. A team of researchers at the Health Policy Center at the University of Illinois at Chicago has developed a number of reports analyzing adoption of policies to advance the WSCC model. These reports (1) engage in exhaustive analysis of relevant policies in all 50 states, (2) assess the influence adopting state policies has on adopting district-level policies, (3) assess policies to respond to trauma and create supportive learning environments, and (4) compare policymaker, educator, and student perspectives. They may assist in identifying relevant laws and policies in your state and local
jurisdiction, or at least suggest key terms for further research. Other resources which may prove helpful in identifying relevant state and local child and adolescent mental health laws include:

- The U.S. Department of Education’s National Center for Safe Supportive Learning Environments’ [compendium on school discipline laws and regulations](#).
- The Collaborative on Academic, Social and Emotional Learning (CASEL) [Collaborating States Initiative](#).
- [Council of Chief State School Officers, Social and Emotional Learning and Multi-Tiered System of Supports Toolkit](#).
- [Mental Health America](#) report on addressing the youth mental health crisis.
- Multiple reports analyzing restorative justice approaches, including those from Thalia Gonzalez, the Center on Poverty and Inequality at Georgetown Law, and the [WestEd Justice and Prevention Research Center](#).
- [State Level Perspectives on Kindergarten Readiness](#).
- State reports and plans for addressing adverse childhood experiences and trauma. Examples include [California](#), [Illinois](#), [New Jersey](#) and [Pennsylvania](#).

- **State and local data collection and sharing laws:**
  As a federal law, FERPA provides a minimum level of protection for the privacy of the data contained in student education records. It is difficult to generalize about state and local laws governing data collection and access. State laws may simply defer to, or incorporate, FERPA, or they may be more protective of individual student privacy and more restrictive of access.
  Some resources provide overviews of state laws and provisions related to the privacy, confidentiality, or accessibility of student data. One of these is the [State Student Privacy Law Compendium](#) prepared by the Center for Democracy and Technology and the BakerHostetler law firm. The Compendium was created in 2016, so it cannot be relied upon as a current statement of the law, but it provides a useful place to begin, especially because it includes a discussion of “use limitations” under the laws of each state. The [National Conference of State Legislatures](#) has also compiled a number of state laws related to internet privacy.

  It is important to learn about the relevant laws in your jurisdiction, recognizing that these laws may change. For example, Nebraska passed a new law in 2020, [Nebraska LB 154](#), that requires implementation of a statewide system for tracking individual student discipline by 2022. Using the state department of education’s student identifier, the system should aggregate discipline by type and demographic characteristics, including, but not limited to, race, poverty, high mobility, attendance, disability and limited English proficiency. However, [achieving accurate data collection under a similar law in California has proven difficult](#), especially during the COVID-19 pandemic. In Utah, the [Partnerships for Student Success Grant Program](#) is driving data sharing in order to improve educational outcomes for economically [disadvantaged students](#).
Child and adolescent mental health data, racial equity and the law

Public education in the United States is fraught with racial disparities, as reflected in the data regarding discipline, school readiness and attendance. It is essential that those seeking to address and improve child and adolescent mental health in schools, including through the collection and analysis of data, consider whether the data reveals concerns related to discrimination based upon race, ethnicity, national origin, disability or other basis prohibited by law, or how it might help to identify such concerns more effectively. Systemic discrimination, historical trauma and implicit bias are themselves harmful to mental health.

Data collection policies and processes and data analysis provide opportunities to advance racial and health equity. Even before passage of ESSA, the E3 Alliance in Central Texas used data to drive a public awareness campaign, Missing School Matters, and address root causes of absenteeism. As this playbook was written, the U.S. Department of Education published a request for information regarding the nondiscriminatory administration of school discipline that specifically sought information on possible discrimination in the data collection process.

Data sharing agreements

A data management plan can set forth a health department’s internal policies and procedures for data collection, sharing and maintenance. Developing and implementing a data management plan may be required by funders, including, increasingly, CDC. However, a data management plan is an internal document. For health departments seeking access to child and adolescent mental health data, data sharing, data use or similar agreements may be an important tool to achieve and memorialize a shared understanding with school partners. Much of the data sought may be public, but depending upon the data type, source and intended use, some of it may not be public. In these cases, some data sharing by schools and educational agencies may be permissible, but conditions and limitations may apply. For example, a major concern for many education agencies is protecting the privacy of student data in the context of using education technology such as apps provided by technology service providers. In 2020, the Student Data Privacy Consortium released a model National Data Privacy Agreement.

Data sharing agreements establish and document terms of sharing for transfer of nonpublic data or data that are subject to restrictions. They set out legal authority and terms for sharing and use and provide for monitoring and accountability for compliance with these terms. They are also used to describe relationship(s) between parties, project purpose and aims and how proposed data sharing furthers the purpose and supports the aim. Through an agreement, partners can demonstrate that proposed data sharing is permissible under all applicable laws and address any lingering concerns about providing data.

Public health officials and practitioners may want to use the fillable form discussed in the introduction to this chapter to assess the need for and prepare to enter into a data sharing agreement when they seek access to information which is not public. These decisions may depend upon additional information or guidance from legal counsel.

Data sharing agreements vary in their terms and conditions as well as in the amount of detail they include. The nature and sensitivity of data to be shared and concerns about unintended uses or disclosures should be considered in deciding the terms and detail included in a specific data sharing agreement.
agreement. A data sharing agreement might include many or all of the following terms:

- Identification and description of parties to the agreement
- Purpose of entering into the agreement
- Legal authority to enter into agreement
- Public health and/or educational justification to share data
- Description of data that each party will provide
- Ownership of data; proprietary or intellectual property interests
- Method of data transfer
- Point of contact for each party
- Payment (usually, parties provide the specified data at no cost; at times costs may need to be addressed, for example, for standardizing data, copying/printing costs, or providing a data sharing infrastructure if needed to enable data sharing)
- Permissible uses and disclosure of the data
  - These may not be reciprocal and may depend on which party is receiving data (health department or school) and the nature and sensitivity of the data that each party receives
  - May prohibit attempts to use the data to identify an individual or the linkage of data to other data sets, especially data sets with individual identifiers
  - May state that if a use or disclosure is not permissible under the agreement, the use or disclosure is prohibited
- Disclosure to agents such as contractors or partners in joint initiatives; may include passing on terms of data sharing agreement as applicable
- Access to data by employees and agents
  - May require that each person with access, sign a confidentiality agreement
- Security safeguards
- Requirement that publication of manuscripts or reports using data must first be offered for review by the party that provided the data; acknowledgement of data source
- Penalties for failure to comply with agreement
- Disposition of data
- Term of agreement; effective and end date of agreement
- Amendment of agreement
- Termination of agreement

For those reviewing a data sharing agreement proffered by an educational agency, or asking their attorney to prepare one, it may be helpful to review a few sample data sharing agreements or to request legal counsel to do so. Here are some examples:
• Memorandum of Understanding Between Allegheny County Department of Human Services and Pittsburgh Public Schools (2011).

• Chicago Public Schools and Chicago Department of Public Health, Data Across Sectors for Health, Bright Spot

• Memorandum of Understanding between the Howard County Health Department and the Howard County Public School System (to share aggregate data in Maryland)

• Data Sharing Agreement between Seattle Public Schools and community-based organization

• U.S. Department of Education, *Data Sharing Tool Kit for Communities: How to Leverage Community Relationships While Protecting Student Privacy* (2016)

**CALLOUT FERPA v HIPAA:** HIPAA defers to FERPA, saying that if FERPA applies to a student’s health information, HIPAA’s privacy protections do not.

**Conclusion**

A basic understanding of the legal landscape for collecting, maintaining, accessing, and sharing data, as well as the practical steps to prepare a data sharing request, is helpful to carry out public health surveillance projects related to child and adolescent mental health. In turn, it may inform legal and policy approaches to support mental health and well-being in schools.
Appendix 1

Table of citations

The following citations and hyperlinks are for reference only and do not serve as legal advice. Readers should independently confirm the accuracy of the citations and current statutory language.

<table>
<thead>
<tr>
<th>Federal Law</th>
<th>Citation</th>
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| Health Insurance Portability and Accountability Act (HIPAA) and regulations thereunder | Pub. L. 104-191
45 C.F.R. Parts 160 and 164 |
| Privacy Act | Pub. L. 93-579
5 U.S.C. § 552a |
| E-Government Act | Pub. L. 107-347
44 U.S.C. § 3601 et seq. |
44 U.S.C. § 3506(b)(6) |
| Family Educational Rights and Privacy Act (FERPA) and regulations thereunder | Pub. L. 93-380
20 U.S.C. § 1232g
34 C.F.R. Part 99 |
| Individuals with Disabilities Education Act (IDEA) | Pub. L. 101-476
| Every Student Succeeds Act (ESSA) | Pub. L. 114-95
20 U.S.C. Chapter 70 |

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v The U.S. Department of Education began collecting and reporting on chronic absence rates through the Civil Rights Data Collection, but now collects and reports that data through EDFacts.


