Individuals with Disabilities Education Act, Part B

Federal Law: Individuals with Disabilities Education Act (IDEA), Part B Confidentiality Provisions

Citation: 20 U.S.C. § 1400; 34 C.F.R. Part 300

IDEA contains confidentiality provisions that apply to personally identifiable information relating to children with disabilities.

THE LAW

What does the law do?

IDEA provides the legislative basis for federal education programs for individuals with disabilities. Part B of IDEA contains confidentiality provisions that apply to personally identifiable information (PII) relating to children with disabilities age three through 21 who are referred to, or receive services under, IDEA Part B.

To whom does the law apply?

IDEA Part B regulates <u>participating agencies</u>, defined as "any agency or institution that collects, maintains, or uses personally identifiable information, or from which information is obtained, under Part B of the Act."

How is "identifiable" information defined?

<u>IDEA Part B defines PII</u> as information that contains: 1) the name of the child, the child's parent, or other family member; 2) the address of the child; 3) A personal identifier, such as the child's social security number or student number; or 4) a list of personal characteristics or other information that would make it possible to identify the child with reasonable certainty.

SHARING OF IDENTIFIABLE DATA

Does this law allow identifiable data to be shared?

In general, <u>parental consent is required</u> before disclosing PII to third parties, other than officials of participating agencies, unless an exception applies. If PII is contained in education records, IDEA Part B allows PII to be disclosed without parental consent in accordance to the <u>exceptions in the Family Education Rights and Privacy</u> <u>Act (FERPA)</u> under 34 CFR part 99.

The <u>FERPA exemptions to parental consent</u> that apply to IDEA Part B include the exemptions for disclosures for audit, evaluation and educational studies. Additionally, the <u>Uninterrupted Scholars Act</u> added a new FERPA exception permitting the disclosure of education, without consent, to a caseworker or other representative of a State or local child welfare agency for the care and protection of the student. While this new exemption has not been added to the regulations, <u>federal guidance is clear</u> that local educational agencies and school are permitted to use it in the context of IDEA Part C participating agencies.

Among who?

IDEA Part B does not categorically limit the persons or entities that can receive PII pursuant the valid consent. Generally, <u>IDEA Part B does not require parental consent to release PII to officials of participating agencies</u> in order to meet a Part B requirement. PII in education records that is disclosed pursuant one of the <u>various</u> <u>FERPA exceptions</u> can only be released to the persons or entities authorized under FERPA. authorities.

What are the prerequisites and conditions?

To disclose PII pursuant written consent, <u>the parent must be fully informed</u> of all information relevant to the disclosure and use in his or her native language. The consent must also describe the use of PII and lists the records that will be released and to whom. Additionally, disclosures of IDEA Part B education records pursuant to <u>FERPA's disclosure provisions</u> must follow those specific requirements.

SHARING OF DE-IDENTIFIED DATA

Does this law allow de-identified information to be shared?

The consent requirements of IDEA Part B only apply to PII.

Does this law define de-identification or standards to render the data de-identified?

<u>IDEA Part B defines PII</u> using three types of direct and indirect identifiers, including names, addresses, and personal identifiers (e.g., social security numbers). Additionally, PII could also include a list of personal characteristics that could be used to identify a child with reasonable certainty. Consequently, removing these data from a dataset would legally de-identify information under IDEA Part B. Additional federal guidance can be found <u>here</u>.

DATA SHARING IMPLICATIONS FOR PUBLIC HEALTH

Does this law support data sharing to improve the health of communities?

IDEA Part B lacks a specific exception to disclose educational records to promote public health. IDEA Part B incorporates some FERPA disclosure provisions that could be used to promote public health. The FERPA emergency exception allows information sharing to address specific threats to health. Additionally, the FERPA exceptions for audits, evaluations, and studies focus primarily on education measures or outcomes. However, these exceptions could be used to understand potential health outcomes associated with education programs.

How does this law hinder data sharing to improve the health of communities?

The lack of a specific exception that permits sharing education records for public health purposes or broader research studies poses a significant limitation on data sharing to promote community health.

Does this law establish prerequisites, conditions, or limitations for data sharing, not previously identified?

Participating agency must keep a record of the parties given access to education records under IDEA Part B (except parents and authorized participating agency employees).

What other terms apply to sharing this data?

The confidentiality provisions in IDEA Part B intersect with FERPA in several areas. Federal guidance indicates that when there is a question regarding the confidentiality of a child or student with a disability IDEA should be considered first and then the FERPA rules should be applied as applicable.

What remedies or solutions might be employed to support data sharing while complying with this law?

IDEA and FERPA allow the <u>creation of integrated data systems</u> under specific disclosure provisions (e.g., for audits or evaluations).). <u>A report from the Departments of Health and Human Services</u> and Education suggest that administering both IDEA Part B and C programs through local education agencies reduces data sharing challenges. Additional <u>federal guidance outlines best practices for creating a data sharing agreement under IDEA and FERPA</u>.

What ethical considerations apply to the exercise of discretion to share data under this law?

IDEA Part B students have disabilities and many are minors. Thus, IDEA participating agencies contain sensitive information relating to vulnerable populations that may lack capacity to provide consent. Disclosure of certain data can lead to adverse inferences (e.g., ability and stigma). Some individuals and families might feel coerced to participate in data sharing activities if they feel that consent is a pre-requisite to receiving IDEA services.

Additional federal guidance on the privacy of education records can be found here.

SUPPORTERS

The Network for Public Health Law is a national initiative of the Robert Wood Johnson Foundation.



Robert Wood Johnson Foundation

This document was developed by Cason Schmit, Research Assistant Professor, Texas A&M University and reviewed by Jennifer Bernstein, Deputy Director, Mid-States Region of The Network for Public Health Law. The Network for Public Health Law provides information and technical assistance on issues related to public health. The legal information and assistance provided in this document does not constitute legal advice or legal representation. For legal advice, please consult specific legal counsel.

October, 2018