

Individuals with Disabilities Education Act, Part C

Federal Law: Individuals with Disabilities Education Act (IDEA), Part C Confidentiality Provisions (Early Intervention Services)

Citation: [20 U.S.C. § 1400](#); [34 C.F.R. Part 303](#)

IDEA contains confidentiality provisions that apply to personally identifiable information relating to infants and toddlers with disabilities.

THE LAW

What does the law do?

IDEA provides the legislative basis for federal education programs for individuals with disabilities. Part C of IDEA contains confidentiality provisions that apply to personally identifiable information (PII) relating to infants and toddlers with disabilities, from birth to age three (unless extended by a state), who are referred to, or receive Early Intervention Services (EIS) under, IDEA Part C.

To whom does the law apply?

IDEA Part C regulates [participating agencies](#), defined as “any individual, agency, entity, or institution that collects, maintains, or uses personally identifiable information to implement the requirements in [IDEA Part C] with respect to a particular child. A participating agency includes the lead agency and EIS providers and any individual or entity that provides any Part C services (including service coordination, evaluations and assessments, and other Part C services).” Under IDEA Part C, participating agencies do not include primary referral sources, or public agencies or private entities that act solely as Part C funding sources.

How is “identifiable” information defined?

The IDEA Part C [definition for PII](#) is nearly equivalent to the Family Education Rights and Privacy Act ([FERPA definition for PII](#)). Under IDEA Part C, PII includes information that, alone or in combination, is linked or linkable to a specific child that would allow a reasonable person in the school community, who does not have personal knowledge of the relevant circumstances, to identify the child with reasonable certainty. The PII also includes direct and indirect identifiers, such as names, addresses, dates of birth, and places of birth.

SHARING OF IDENTIFIABLE DATA

Does this law allow identifiable data to be shared?

In general, [consent is required](#) before disclosing PII to third parties, other than officials of participating agencies, or for any purpose other than meeting Part C requirements unless an exception applies. In some cases, [IDEA Part C requires the lead agency to disclose certain PII to the state and local educational agencies](#) to facilitate transition to services under IDEA Part B; however, a lead agency can provide parents the right to opt-out of this disclosure.

IDEA Part C also allows PII to be disclosed without consent in accordance to the exceptions in the Family Education Rights and Privacy Act (FERPA) under 34 CFR part 99. The [FERPA exemptions to parental consent](#) that apply to IDEA Part C include the exemptions for disclosures for audit, evaluation and educational studies. Additionally, the [Uninterrupted Scholars Act](#) 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, [federal guidance is clear](#) that local educational agencies and school are permitted to use it in the context of IDEA Part C participating agencies.

Among who?

IDEA Part C does not categorically limit the persons or entities that can receive PII pursuant the valid consent. Generally, IDEA Part C does not require parental consent to release PII to EIS providers, or authorized representatives, officials, or employees of participating agencies as needed to meet a Part C requirement. IDEA Part C PII that is disclosed pursuant one of the various [FERPA exceptions](#) can only be released to the persons or entities authorized under FERPA.

What are the prerequisites and conditions?

To disclose PII pursuant written consent, the parent must be fully informed 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 C PII pursuant to [FERPA's disclosure provisions](#) 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 C only apply to PII.

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

The IDEA Part C regulations reference the FERPA definition of PII. [FERPA provides](#) that records are de-identified after the removal of all PII (e.g., direct and indirect identifiers), and after a “reasonable determination that a student's identity is not personally identifiable... taking into account other reasonably available information.” [Federal guidance](#) cautions that removal of all direct and indirect identifiers might not be sufficient in all situations. Accordingly, disclosure avoidance techniques such as masking, blurring, or perturbation may be required for the data to be legally de-identified in some situations. Additional federal guidance can be found [here](#).

DATA SHARING IMPLICATIONS FOR PUBLIC HEALTH

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

IDEA Part C lacks a specific exception to disclose educational records to promote public health. IDEA Part C 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?

Each participating agency must keep a record of parties given access to EIS records under IDEA Part C (except parents and authorized participating agency representatives and employees). Each State must give parents the [right to written notice](#) of, and written consent to, the exchange of that information among agencies, consistent with Federal and State laws.

What other terms apply to sharing this data?

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

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

EIS recipients under IDEA Part C include infants and children with disabilities, which are designated as vulnerable populations. Disclosure of certain data can lead to adverse inferences (e.g., ability and stigma). Some families might feel coerced to participate in data sharing activities if they feel that consent is a prerequisite 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.



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October, 2018