

Strategic Support For the Preschool Development Grants Birth Through Five

Administration for Children and Families – Department of Education

PDG B-5 Data Privacy Community of Conversation

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Welcome!

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Chief Privacy Officer, Utah State Board of Education

PDG B-5 Communities of Conversation

- **Invited participants**
 - PDG B-5 Grantees plus partners, consultants
 - PDG B-5 TA Team
 - Federal Project Officers and Regional Offices
 - PDG B-5 TA partners, e.g., State Capacity Building Center
- **Voluntary**
- **Select presentations and resources**
- **Open discussion, dialogue**
 - Via phone when possible
 - Via virtual chat and Q&A pod—“multitasking” welcome (i.e., chatting when others are)!

Privacy Conversation Approach

- Overview of Privacy laws relevant to the Preschool Development Grant
- State experiences with privacy challenges in the use of early childhood data
- Participant questions and discussion (please send as they occur to you)
- Closing

Poll Question

What sort of privacy challenges have you encountered while administering your grants?

Please enter 1 or 2 sentences into the chat box that describe challenges you may have had with privacy?

Privacy in a Nutshell

- **Over 100 countries have privacy or data protection authorities**
- **Three distinct models of privacy law**
 - Comprehensive
 - Sectoral
 - Self Regulatory
- **In the United States, most privacy laws are sectoral**

US Privacy Laws Affecting Early Childhood

- **Family Educational Rights and Privacy Act (FERPA)**
- **Individuals with Disabilities Education Act (IDEA) Part B and C**
- **HIPAA - Health Insurance Portability and Accountability Act of 1996**
- **Head Start Program Performance Standards**
- **State and Local Laws**

FERPA

- Gives parents (and eligible students) the right to access and seek to amend their children's education records
- Protects personally identifiable information (PII) from education records from unauthorized disclosure
- Requirement for written consent before sharing PII – unless an exception applies

Personally Identifiable Information (PII)

- **Direct Identifiers**

- e.g., Name, SSN, Student ID Number, etc.
(1:1 relationship to student)

- **Indirect Identifiers**

- e.g., Birthdate, Demographic Information
(1:Many relationship to student)

- ***“Other information that, alone or in combination, is linked or linkable to a specific student that would allow a reasonable person in the school community, who does not have personal knowledge of the relevant circumstances, to identify the student with reasonable certainty.” (§ 99.3)***

What are Education Records?

“Education Records” are records:

- Directly related to the student; and
 - Maintained by (or on behalf of) an educational agency or institution.
- **Excludes certain types of records, including “sole possession records” and “law enforcement unit records.”**

What Rights do Parents and Eligible Children Have?

- Right to inspect and review education records;
- Right to request amendment of education records;
- Right to consent to disclosures, with certain exceptions; and
- Right to file a complaint with U.S. Department of Education regarding an alleged violation of FERPA.

Consent: The General Rule

- **Consent must be signed and dated and must:**
 - Specify the records that may be disclosed
 - State purpose of disclosure; and
 - Identify party or class of parties to whom disclosure may be made

Exceptions to the Consent Rule Under FERPA

- **There are 16 exceptions to consent under FERPA including:**
 - School officials with legitimate educational interests
 - Schools in which a student seeks or intends to enroll
 - State and local officials pursuant to a State statute in connection with serving the student under the juvenile justice system
 - To comply with a judicial order or subpoena
 - Studies for or on behalf of a educational agency or institution
 - To Audit or Evaluate a Federal- or state-supported education program
 - Directory information
 - Health and safety emergencies

Legitimate Research Under FERPA

- **Research and evaluation under FERPA can happen legitimately one of two ways**
 - Signed consent of the parent or eligible student
 - One of the relevant statutory exemptions under FERPA
- **The two most relevant exemptions for FERPA are the Audit or Evaluation Exception and the Studies Exception**

Studies Exception

- **34 CFR § 99.31(a)(6) states that prior consent is not required if the disclosure (of PII from Education Records) is to organizations conducting studies for, or on behalf of, educational agencies or institutions to:**
 - Develop, validate or administer predictive tests; or
 - Administer student aid programs; or
 - Improve instruction

Audit or Evaluation Exception

- **34 CFR § 99.35(a)(3) states that prior consent is not required if the disclosure (of PII from Education Records) is to authorized representatives of the FERPA-permitted entities (i.e., Comptroller General of U.S., U.S. Attorney General, U.S. Secretary of Education, or state and local educational authorities) to:**
 - Audit or evaluate a Federal- or state-supported education program,
 - or to enforce or comply with Federal legal requirements that relate to those education programs (audit, evaluation, or enforcement or compliance activity)

Early Childhood Education Program Definition

- **According to 20 USCS § 1003(8), the term “early childhood education program” means –**
 - “(A) a Head Start program or an Early Head Start program carried out under the Head Start Act (42 U.S.C. 9831 et seq.), including a migrant or seasonal Head Start program, an Indian Head Start program, or a Head Start program or an Early Head Start program that also receives State funding;
 - (B) a State licensed or regulated child care program; or

Early Childhood Education Program Definition (cont'd)

(C) a program that—

(i) serves children from birth through age six that addresses the children's cognitive (including language, early literacy, and early mathematics), social, emotional, and physical development; and

(ii) is –

- (I) a State pre-kindergarten program;
- (II) a program authorized under section 619 or part C of the Individuals with Disabilities Education Act [20 USCS § 1419 or §§ 1431 et seq.]; or
- (III) a program operated by a local educational agency.”

Part B of the Individuals with Disabilities Education Act (IDEA) | 19 |

§ 300.610 Confidentiality of Information

“The Secretary takes appropriate action, in accordance with section 444 of GEPA [FERPA], to ensure the protection of the confidentiality of any personally identifiable data, information, and records collected or maintained by the Secretary and by SEAs and LEAs pursuant to Part B of the Act, and consistent with §§ 300.611 through 300.627.”

Part C of the Individuals with Disabilities Education Act (IDEA) | 20 |

§ 303.402 Confidentiality

“The Secretary takes appropriate action, in accordance with section 444 of GEPA [FERPA], to ensure the protection of the confidentiality of any personally identifiable data, information, and records collected or maintained by the Secretary and by lead agencies and EIS providers pursuant to part C of the Act, and consistent with §§ 303.401 through 303.417. The regulations in §§ 303.401 through 303.417 ensure the protection of the confidentiality of any personally identifiable data, information, and records collected or maintained pursuant to this part by the Secretary and by participating agencies, including the State lead agency and EIS providers, in accordance with [FERPA].”

To whom do these three statutes apply?

- **FERPA applies to educational agencies or institutions**
 - Any public or private agency or institution that provides educational services and/or instruction to students; or is authorized to direct and control public elementary or secondary, or postsecondary educational institutions; and
 - to which funds have been made available under any program administered by the Secretary
- **IDEA Part B applies to a participating agency**
 - Any agency or institution that collects, maintains, or uses personally identifiable information, or from which information is obtained under Part B.

To whom do these three statutes apply? (cont'd)

- **IDEA Part C applies to a participating agency**

- Any individual, agency, entity, or institution that collects, maintains, or uses personally identifiable information to implement the requirements in part C.
- Includes any individual or entity that provides any part C services.
- Does not include primary referral sources or public agencies or private entities that act solely as funding sources for Part C services.

Important Note on FERPA's Studies Exception

- The "Audit/Evaluation" exception in 34 CFR §§99.31(a)(3) and 99.35 is the most appropriate exception under IDEA and FERPA for data sharing arrangements for the IDEA early childhood community. In the very limited instance in which IDEA Part C or IDEA Part B section 619 agencies or programs propose to consider using the "Studies" exception under FERPA, such agencies and programs will want to consult with the Department's Office of Special Education Programs (OSEP) and Family Policy Compliance Office (FPCO) regarding how the proposed data sharing would meet the requirements in 34 CFR §§99.31(a)(6) and 303.414 (for IDEA Part C) and 34 CFR §§99.31(a)(6) and 300.622 (for IDEA Part B Section 619).

State Experience

- **Joining us today is Whitney Phillips, Chief Privacy Officer for the Utah State Board of Education**

Health Insurance Portability and Accountability Act of 1996

- Established certain insurance protections
- Required standards for the exchange of electronic information (transaction standards and code sets for billing and payment of health care services)
- Set a process and timeline for establishing privacy and security protections for personal health information used in those electronic transactions

HIPAA Privacy — Who Has to Comply?

- **“Covered Entities”**
 - Health Plans — in general, all group and individual plans that provide or pay for health services
 - Health Care Providers — any health care provider who engages in any electronic transactions covered by HIPAA standards
 - Healthcare Clearinghouses — generally entities that convert nonstandard information into standard format required for electronic transmission
- **Applicability of HIPAA privacy provisions to these entities is NOT dependent of receipt of federal funding.**

HIPAA Privacy — Who Has to Comply? (cont'd)

- **“Business Associates”**
 - Individual or organization
 - Performs services on behalf of a covered entity
- **OR**
 - Provides services to a covered entity
- **AND**
 - Services involve the use and/or disclosure of protected health information

HIPAA Privacy — Who Has to Comply? (cont'd 2)

■ Examples

- An external entity that helps the agency with claims processing and billing third-party reimbursement such as Medicaid or private insurance
- A private legal firm that has access to Protected Health Information (PHI) in the course of its work for the agency
- A technology company that has access to PHI while working on fixes to a state data system

HIPAA Privacy — Individuals' Rights

- **Receive Notice of Privacy Practices**
- **Access to Records**
- **Process for Correcting/Amending Records**
- **Accounting for Disclosure**
- **Restrictions on Information Sharing**
- **Means of Confidential Communication**
- **File a Complaint**

New HSPPS Released in September 2016

- On Sept. 1, 2016, the Office of Head Start announced in the Federal Register the first comprehensive revision of the Head Start Program Performance Standards (HSPPS) since their original release in 1975.

Subpart C of Part 1303 of the New HSPPS Protections for the Privacy of Child Records

This subpart outlines the following requirements to protect the personally identifiable information (PII) in child records:

- **Parental consent including nine instances when consent is not required**
- **Written agreements with third parties to protect PII when disclosing data**
- **Parent rights in respect to their child records**
 - Right to inspect, amend, request a hearing, copy of record, and (also, right to inspect written agreements)
- **Maintenance of records**
 - Destroy in reasonable timeframe
 - Ensure only appropriate parties have access
 - Data systems are protected to current industry standards
- **Annual notice to parents**

Subpart C of Part 1303 of the New HSPPS Protections for the Privacy of Child Records (cont'd)

- If a program is subject to FERPA (e.g., school district), then the program does not comply with this subpart
- If a child record is subject to IDEA confidentiality requirements, then the program follows those requirements for that child record and not this subpart

Exception to Consent in the ECIDS Context

Section 1303.22 paragraph (c)(2) allows a program to disclose PII without consent to officials from a federal or state entity to evaluate education or child development programs; provided that some control is in place such as a written agreement. This standard allows a program to share PII with their state data system without parent consent for the purpose of evaluating education and child development programs.

<https://eclkc.ohs.acf.hhs.gov/policy/45-cfr-chap-xiii/1303-22-disclosures-without-parental-consent>

State and Local Laws

- **Many states have their own privacy laws on the books**
- **Any research or evaluation using early childhood data should begin by looking at the relevant privacy laws**
 - In many cases, more than one law will apply to the data

Privacy Resources

- [PTAC Early Childhood Resources Webpage](#)
 - [Integrated Data Systems and Student Privacy](#)
 - [Understanding the Confidentiality Requirements Applicable to IDEA Early Childhood Programs FAQ](#)
 - [The A-B-C's of Student Directory Information](#)
 - [Identity Authentication Best Practices](#)
 - [FERPA/IDEA Cross-Walk](#)
 - [FERPA Exceptions Summary](#)
 - [Data De-identification: An Overview of Basic Terms](#)
 - [Frequently Asked Questions - Disclosure Avoidance](#)
 - Search [“Checklist”](#)
- [ECIDS Toolkit](#)

Privacy Resources (cont'd)

- [IDEA Data Center Confidentiality Page](#)
- [DaSy Center Privacy and Confidentiality Page](#)
- [Head Start Performance Standards 1303 Subpart C – Protections for the Privacy of Child Records](#)
- [HHS Head Start FAQs](#)



Questions or Stories from the Field

Thank you!

Further Questions:

PDG B-5 TA Team: PDGB5TA@atlasresearch.us

We would love to hear your feedback and suggestions!

– **Post CoC Survey:** <https://www.surveymonkey.com/r/PDGB5COC>