

Early Childhood Records: Confidentiality and Related Requirements

1. **General Confidentiality Requirements Under Part C of IDEA and HIPAA.**¹

- a. Under Part C of the Individuals with Disabilities Education Act (IDEA), early intervention records must meet the confidentiality and related requirements in IDEA Sections 617, 639(a) and 642 and 34 CFR §§303.402 and 303.460, which incorporate the prior Part B confidentiality regulations at 34 CFR §§300.560 through 300.576 (pre-August 14, 2006) and the protections of the Family Educational Rights and Privacy Act of 1974, as amended (FERPA), enacted as section 444 of the General Education Provisions Act (GEPA) at 20 U.S.C. §1232g and 34 CFR Part 99.
- b. Under these provisions, the general rule is that the lead agency (and early intervention service providers) must obtain parent consent before disclosing personally identifiable information (PII) unless a specific exception applies.
- c. Under the Privacy Rule of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), “covered entities” must ensure the privacy of Protected Health Information (PHI).
- d. Although HIPAA’s definition of PHI specifically excludes “education” or “treatment” records under FERPA (and thus those Part C records to which the protections of FERPA apply), many early intervention programs under Part C and Early Hearing Detection and Intervention (EHDI) programs also comply as “covered entities” under HIPAA. Thus, the attached chart identifies some of the data confidentiality, record maintenance, parent inspection and other rights under Part C and HIPAA.

2. **Resources.**

- a. IDEA Part C Confidentiality Regulations:
34 CFR §§303.402 and 303.460, which incorporate IDEA Part B provisions in 34 CFR §§300.560 through 300.576, which also incorporate the protections of FERPA in 34 CFR Part 99.
- b. 2004 OSEP Letter to Anonymous and Letter to Elder.
- c. Websites:
 - o The U. S. Department of Education: www.ed.gov for information both on the Office of Special Education Programs (which is responsible for administering Parts B and C of the IDEA) and the Family Policy Compliance Office.
 - o The U.S. Department of Health and Human Services, Office of Civil Rights (which administers HIPAA’s Privacy Rule): <http://www.cms.gov/hipaa>.

¹This outline was prepared by Kala Surprenant, Attorney, U.S. Department of Education, Office of the General Counsel for a September 28, 2006 Web-cast presentation for IDEA Part C and EHDI program participants. For questions, please contact: kala.surprenant@ed.gov.

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Major Requirements: The chart below identifies some of the major data confidentiality, record maintenance, parent inspection and other rights under Part C and HIPAA.

<u>Rights/Responsibilities</u>	<u>Part C of the IDEA</u> 20 U.S.C. §§1401 – 1408 and 1431 – 1444 and 34 CFR Part 303 and Part 300 (prior to 8/14/06).	<u>HIPAA's Privacy Rule</u> 45 CFR Part 164
Confidentiality: Requirement to obtain consent or authorization prior to disclosure.	A lead agency (or early intervention service provider must obtain prior written parental consent before disclosing personally identifiable information (PII) to a third party unless a specific exception applies. 34 CFR §§303.402, 303.460 and 300.571 (pre- 8/14/06)	A covered entity must obtain an individual's written authorization for any use or disclosure of protected health information (PHI) that is not for treatment, payment, or health care operations or otherwise permitted or required by the Privacy Rule. 45 C.F.R. § 164.508.
Who must comply with these requirements?	Lead agency, public agencies and early intervention service providers as "participating agencies".	Covered entities.
What must be kept confidential?	Personally identifiable information or PII, which includes: (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 or parent's social security number; or (4) a list of personal characteristics or other information that would make it possible to identify the child with reasonable certainty. 34 CFR §303.401(c).	Protected Health Information or PHI, which is: Individually identifiable health information: (1) except as defined in paragraph 2 of this definition that is: (i) transmitted by electronic media; (ii) maintained in electronic media; or (iii) transmitted or maintained in any form or medium. (2) Protected health information excludes individually identifiable health information in: (i) Education records covered by the Family Educational Rights and Privacy Act, as amended, 20 U.S.C. 1232g ; (ii) Records described at 20 U.S.C. 1232g(a)(4)(B)(iv) ; and (iii) Employment records held by a covered entity in its role as employer. 45 CFR §160.103.

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Duty to disclose.	Under IDEA child find provisions, primary referral sources must notify the lead agency and the lead agency must notify the LEA where child resides for child potentially eligible under Parts C or B unless the States has adopted parent opt-out procedures (IDEA sections 612(a)(3) , 635(a)(5) and 637(a)(9) and 34 CFR 303.148(b)(1)). (See also, OSEP 2004 Letter to Elder). This child find information is the child's name, child's date of birth, and sufficient parent contact information (parent name(s), address(es), and telephone number(s) to contact the parent), and referral source's contact information.	Covered entity must disclose PHI: (a) to individuals (or their personal representatives) when they request access to, or an accounting of disclosures of PHI; and (b) to HHS when it is undertaking a compliance investigation or review or an enforcement action. 45 C.F.R. §164.502(a) .
Permissible disclosures (i.e., without prior written authorization or consent).	Enumerated exceptions under very specific circumstances (including disclosures to authorized representatives of participating agencies and requirement that there may not be redisclosure). 34 CFR §§303.402, 303.460, 300.571 and 99.31.	(1) to the individual (unless required for access or accounting of disclosures); (2) Treatment, Payment, and Health Care Operations; (3) Opportunity to Agree or Object; (4) Incident to an otherwise permitted use and disclosure; (5) Public Interest and Benefit Activities; and (6) Limited Data Set for the purposes of research, public health, or health care operations. 45 C.F.R. §164.502(a)(1).
Duty to provide notice.	A public agency or early intervention service provider must provide prior written notice (that includes procedural safeguards including confidentiality provisions) a reasonable time before the agency or provider proposes or refuses to initiate or change the identification, evaluation, or placement of the child, or the provision of appropriate early intervention services to the child and the child's family. 34 CFR §303.403(a). Additional notice requirements of confidentiality procedures in 34 CFR §§303.460 and 300.561.	Covered entities, with certain exceptions, must provide notice of privacy practices for protected health information. 45 C.F.R. §164.520.

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Option to disclose.	Unless a disclosure meets a specific exception under Part C, the lead agency, public agency or an early intervention service provider may not disclose PII.	Individuals have the right to request that a covered entity restrict use or disclosure of PHI under 45 C.F.R. §164.522(a) , but a covered entity may obtain authorization that is broader if it is included in the entity's notice. In addition, specific exceptions apply and also "limited data set" may be disclosed under 45 CFR §164.514 .
Right to review records.	Parents may inspect and review and obtain copies of any early intervention record relating to their children that are collected, maintained, or used by the agency under Part C. Agency or provider may charge for copies if the fee does not effectively prevent the parents from exercising their right to inspect and review those records but may not charge a search/retrieval fee. 34 CFR §§303.460 and 300.566 .	Individuals have the right to review and obtain a copy of their PHI in a covered entity's "designated record set" -- which is defined as that group of records maintained for a covered entity that is used, in whole or part, to make decisions about individuals, or that is a provider's medical and billing records about an individual or a health plan's enrollment, payment, claims, adjudication, and case or medical records management system. 45 C.F.R. §§ 164.524, 164.501 Covered entity may charge for copies.
Right to request amendment of record.	Parents who believe that information in the early intervention record collected, maintained, or used under Part C is inaccurate or misleading or violates the privacy or other rights of the child may request the participating agency that maintains the information to amend the information. 34 CFR §§303.460 and 300.567 .	Individuals have the right to have covered entities amend PHI in a designated record set when that information is inaccurate or incomplete. 45 C.F.R. § 164.526 .
Record of access.	Each participating agency shall keep a record of parties obtaining access to the records collected, maintained, or used under Part C of the Act (except access by parents and authorized employees of the participating agency), including the name of the party, the date access was given, and the purpose for which the party is authorized to use the records. 34 CFR §§303.460 and 300.563 .	Covered entity must maintain a list of disclosures and individuals have the right to an accounting of the disclosures of PHI information by a covered entity or a covered entity's business associates. 45 C.F.R. §164.528 .

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Duty to maintain record.	A Part C record may not be destroyed until it "is no longer needed to provide early intervention services to the child." This does not mean when the child stops receiving Part C services. 3 year minimum: The fiscal (billing) records for Part C services must be maintained by the lead agency and its contractors under GEPA at 20 U.S.C. §1232f and EDGAR at 34 CFR §80.42 for at least three years from the dates set forth respectively in GEPA and EDGAR. The IFSP and Part C service provision record may also need to be maintained at least three years from the last date of service because a state complaint under Part C may be filed for up to three years under 34 CFR §§303.510 through 303.512 . In addition, the record may need to be maintained longer if subject to HIPAA, State law, or under State statutes of limitation applicable to IDEA or related claims.	Requirement to maintain record. 45 C.F.R. §164.530.
Destruction of record.	When a record is no longer required to be maintained, the parents of a child may request its destruction under Part C. However, even if the parents request such destruction, the lead agency may still maintain "permanent record" information. Under 34 CFR §§303.402, 303.460, and 300.573(b) , the Part C lead agency may maintain a permanent record of the child's name, address and phone number, his or her date of birth, Part C service provision and attendance record and exit data (i.e., when exited).	
Other		Training of workforce, data safeguards, procedures for complaints, mitigation standards, no retaliation for exercising rights provided by the Privacy Rule, no waiver of any right under the Privacy Rule as condition for obtaining treatment, payment, and enrollment or benefits eligibility, 45 C.F.R. §164.530.