

**From the Proceedings of the Combined Part C/B Data Managers' Meeting  
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**Confidentiality, Disclosure, and Records Maintenance for Early  
Intervention Records**

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This session provided information about confidentiality and disclosure under the Health Insurance Portability and Accountability Act (HIPAA), the Family Education Rights and Privacy Act (FERPA), and the maintenance and destruction of early intervention records after a child exits Part C. Answers to the following questions were presented.

*Is parental consent required before a child is referred to Part C by a primary referral source?*

Under Part C of IDEA, the state Lead Agency must make early intervention services available to eligible infants and toddlers with disabilities and their families. As such, the Lead Agency is required to have child-find policies and procedures in place to ensure that primary referral sources refer potentially eligible children to the Part C child find program. The specific information that can be included in the referral to the Lead Agency by the primary referral source without prior parental consent is the child's name, date of birth, and sufficient parent contact information. A primary referral source may be subject to HIPAA, however, because of the transmission of protected health information (PHI). States may adopt opt-out procedures that allow parents the opportunity to object to a referral for child find purposes.

*Is parental consent required before disclosure after a child is referred to Part C?*

Both IDEA and FERPA confidentiality provisions apply to disclosure of information after the child is referred to Part C. In general, the Lead Agency must obtain parental consent before disclosure unless one or more of the conditions specified by 34 CFR §99.31 and 300.571 are met. Any interagency agreements must meet IDEA and FERPA parental consent requirements.

*Is parental consent required before disclosure when a child is ready to transition out of Part C?*

The Lead Agency under Part C and the SEA and LEA under Part B have a responsibility under IDEA to ensure a smooth transition for each child and family and, under the IDEA's child find provisions, to ensure the identification, location, and evaluation of each child eligible for services under Parts B and C of IDEA. Unless the SEA has adopted a procedure allowing parents an opportunity to object, the Part C Lead Agency must provide the name of the child, date of birth, and sufficient parental contact information to allow the SEA and LEA to fulfill their child find responsibilities; parental consent is not required for this disclosure. The specific FERPA exception that allows referral for child find purposes without prior parental consent is the exception to disclosure of personally identifiable information to authorized representatives of state and local educational authorities in connection with the enforcement of Federal legal requirements which relate to any federally supported education programs. In this case,

the disclosure of child find referral information by the Lead Agency to the SEA and/or LEA is required to meet the statutory child find duties under Parts B and C of IDEA.

*When can early intervention records be destroyed?*

A Part C record may not be destroyed until it is no longer needed to provide early intervention services to the child. Certain records, including those related to payment, are deemed needed by the Lead Agency and its contractors and must be kept for at least 3 years after a child exits Part C. In addition, other child records must be kept for a minimum of 3 years since complaints may be filed during that time for compensatory issues; applicable state statutes of limit may be longer. If, after 3 years, the parent requests the records be destroyed, the Lead Agency may still maintain a permanent record of a child's name, address and phone number, date of birth, service provision and attendance record, and exit data.