

# Part C's Confidentiality Provisions

IDEA 2004's Part C Regulations

## Confidentiality of Personally Identifiable Information and Early Intervention Records

### §303.401 Confidentiality and opportunity to examine records.

(a) *General.* Each State must ensure that the parents of a child referred under this part are afforded the right to confidentiality of personally identifiable information, including the right to written notice of, and written consent to, the exchange of that information among agencies, consistent with Federal and State laws.

(b) *Confidentiality procedures.* As required under sections 617(c) and 642 of the Act, 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 the protections under the Family Educational Rights and Privacy Act (FERPA) in 20 U.S.C. 1232g and 34 CFR part 99. Each State must have procedures in effect to ensure that—

(1) Participating agencies (including the lead agency and EIS providers) comply with the Part C confidentiality procedures in §§303.401 through 303.417; and

(2) The parents of infants or toddlers who are referred to, or receive services under this part, are afforded the opportunity to inspect and review all Part C early intervention records about the child and the child's family that are collected, maintained, or used under this part, including records related to evaluations and assessments, screening, eligibility determinations, development and implementation of IFSPs, provision of early intervention services, individual complaints

involving the child, or any part of the child's early intervention record under this part.

(c) *Applicability and timeframe of procedures.* The confidentiality procedures described in paragraph (b) of this section apply to the personally identifiable information of a child and the child's family that—

(1) Is contained in early intervention records collected, used, or maintained under this part by the lead agency or an EIS provider; and

(2) Applies from the point in time when the child is referred for early intervention services under this part until the later of when the participating agency is no longer required to maintain or no longer maintains that information under applicable Federal and State laws.

(d) *Disclosure of information.* (1) Subject to paragraph (e) of this section, the lead agency must disclose to the SEA and the LEA where the child resides, in accordance with §303.209(b)(1)(i) and (b)(1)(ii), the following personally identifiable information under the Act:

(i) A child's name.

(ii) A child's date of birth.

(iii) Parent contact information (including parents' names, addresses, and telephone numbers).

(2) The information described in paragraph (d)(1) of this section is needed to enable the lead agency, as well as LEAs and SEAs under Part B of the Act, to identify all children potentially eligible for services under §303.211 and Part B of the Act.



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(e) *Option to inform a parent about intended disclosure.* (1) A lead agency, through its policies and procedures, may require EIS providers, prior to making the limited disclosure described in paragraph (d)(1) of this section, to inform parents of a toddler with a disability of the intended disclosure and allow the parents a specified time period to object to the disclosure in writing.

(2) If a parent (in a State that has adopted the policy described in paragraph (e)(1) of this section) objects during the time period provided by the State, the lead agency and EIS provider are not permitted to make such a disclosure under paragraph (d) of this section and §303.209(b)(1)(i) and (b)(1)(ii).

### §303.402 Confidentiality.

The Secretary takes appropriate action, in accordance with section 444 of GEPA, to ensure the protection of the confidentiality of any personally identifiable data, information, and records collected, maintained, or used 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 the Family Educational Rights and Privacy Act (FERPA), 20 U.S.C. 1232g, and 34 CFR part 99.

### §303.403 Definitions.

The following definitions apply to §§303.402 through 303.417 in addition to the definition of personally identifiable information in §303.29 and disclosure in 34 CFR 99.3:

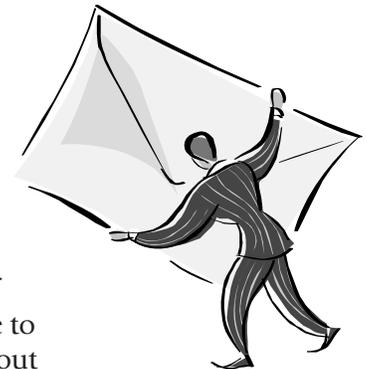
(a) *Destruction* means physical destruction of the record or ensuring that personal identifiers are removed from a record so that the record is no longer personally identifiable under §303.29.

(b) *Early intervention records* mean all records regarding a child that are required to be collected, maintained, or used under Part C of the Act and the regulations in this part.

(c) *Participating agency* means any individual, agency, entity, or institution that collects, maintains, or uses personally identifiable information to implement the requirements in Part C of the Act and the regulations in this part 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), but does not include primary referral sources, or public agencies (such as the State Medicaid or CHIP program) or private entities (such as private insurance companies) that act solely as funding sources for Part C services.

### §303.404 Notice to parents.

The lead agency must give notice when a child is referred under Part C of the Act that is adequate to fully inform parents about the requirements in §303.402, including—



(a) A description of the children on whom personally identifiable information is maintained, the types of information sought, the methods the State intends to use in gathering the information (including the sources from whom information is gathered), and the uses to be made of the information;

(b) A summary of the policies and procedures that participating agencies must follow regarding storage, disclosure to third parties, retention, and destruction of personally identifiable information;

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(c) A description of all the rights of parents and children regarding this information, including their rights under the Part C confidentiality provisions in §§303.401 through 303.417; and

(d) A description of the extent that the notice is provided in the native languages of the various population groups in the State.

### §303.405 Access rights.

(a) Each participating agency must permit parents to inspect and review any early intervention records relating to their children that are collected, maintained, or used by the agency under this part. The agency must comply with a parent's request to inspect and review records without unnecessary delay and before any meeting regarding an IFSP, or any hearing pursuant to §§303.430(d) and 303.435 through 303.439, and in no case more than 10 days after the request has been made.

(b) The right to inspect and review early intervention records under this section includes—

(1) The right to a response from the participating agency to reasonable requests for explanations and interpretations of the early intervention records;

(2) The right to request that the participating agency provide copies of the early intervention records containing the information if failure to provide those copies would effectively prevent the parent from exercising the right to inspect and review the records; and

(3) The right to have a representative of the parent inspect and review the early intervention records.



(c) An agency may presume that the parent has authority to inspect and review records relating to his or her child unless the agency has been provided documentation that the parent does not have the authority under applicable State laws governing such matters as custody, foster care, guardianship, separation, and divorce.

### §303.406 Record of access.

Each participating agency must keep a record of parties obtaining access to early intervention records collected, maintained, or used under Part C of the Act (except access by parents and authorized representatives and 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 early intervention records.

### §303.407 Records on more than one child.

If any early intervention record includes information on more than one child, the parents of those children have the right to inspect and review only the information relating to their child or to be informed of that specific information.

### §303.408 List of types and locations of information.

Each participating agency must provide parents, on request, a list of the types and locations of early intervention records collected, maintained, or used by the agency.

**§303.409 Fees for records.**

(a) Each participating agency may charge a fee for copies of records that are made for parents under this part if the fee does not effectively prevent the parents from exercising their right to inspect and review those records, except as provided in paragraph (c) of this section.

(b) A participating agency may not charge a fee to search for or to retrieve information under this part.

(c) A participating agency must provide at no cost to parents, a copy of each evaluation, assessment of the child, family assessment, and IFSP as soon as possible after each IFSP meeting.

**§303.410 Amendment of records at a parent's request.**

(a) A parent who believes that information in the early intervention records collected, maintained, or used under this part is inaccurate, misleading, or violates the privacy or other rights of the child or parent may request that the participating agency that maintains the information amend the information.

(b) The participating agency must decide whether to amend the information in accordance with the request within a reasonable period of time of receipt of the request.

(c) If the participating agency refuses to amend the information in accordance with the request, it must inform the parent of the refusal and advise the parent of the right to a hearing under §303.411.

**§303.411 Opportunity for a hearing.**

The participating agency must, on request, provide parents with the opportunity for a hearing to challenge information in their child's early intervention records to ensure that it is not inaccurate, misleading, or otherwise in violation of the privacy or other rights of the child or parents. A parent may request a due process hearing under the procedures in §303.430(d)(1) provided that such hearing procedures meet the requirements of the hearing procedures in §303.413 or may request a hearing directly under the State's procedures in §303.413 (i.e., procedures that are consistent with the FERPA hearing requirements in 34 CFR 99.22).

**§303.412 Result of hearing.**

(a) If, as a result of the hearing, the participating agency decides that the information is inaccurate, misleading or in violation of the privacy or other rights of the child or parent, it must amend the information accordingly and so inform the parent in writing.

(b) If, as a result of the hearing, the agency decides that the information is not inaccurate, misleading, or in violation of the privacy or other rights of the child or parent, it must inform the parent of the right to place in the early intervention records it maintains on the child a statement commenting on the information or setting forth any reasons for disagreeing with the decision of the agency.

(c) Any explanation placed in the early intervention records of the child under this section must—

(1) Be maintained by the agency as part of the early intervention records of the child as long as the record or contested portion is maintained by the agency; and

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(2) If the early intervention records of the child or the contested portion are disclosed by the agency to any party, the explanation must also be disclosed to the party.

### §303.413 Hearing procedures.

A hearing held under §303.411 must be conducted according to the procedures under 34 CFR 99.22.

### §303.414 Consent prior to disclosure or use.

(a) Except as provided in paragraph (b) of this section, prior parental consent must be obtained before personally identifiable information is—

(1) Disclosed to anyone other than authorized representatives, officials, or employees of participating agencies collecting, maintaining, or using the information under this part, subject to paragraph (b) of this section; or

(2) Used for any purpose other than meeting a requirement of this part.

(b) A lead agency or other participating agency may not disclose personally identifiable information, as defined in §303.29, to any party except participating agencies (including the lead agency and EIS providers) that are part of the State's Part C system without parental consent unless authorized to do so under—

(1) Sections 303.401(d), 303.209(b)(1)(i) and (b)(1)(ii), and 303.211(b)(6)(ii)(A); or

(2) One of the exceptions enumerated in 34 CFR 99.31 (where applicable to Part C), which are

expressly adopted to apply to Part C through this reference. In applying the exceptions in 34 CFR 99.31 to this part, participating agencies must also comply with the pertinent conditions in 34 CFR 99.32, 99.33, 99.34, 99.35, 99.36, 99.38, and 99.39; in applying these provisions in 34 CFR part 99 to Part C, the reference to—

(i) 34 CFR 99.30 means §303.414(a);

(ii) "Education records" means early intervention records under §303.403(b);

(iii) "Educational" means early intervention under this part;

(iv) "Educational agency or institution" means the participating agency under §303.404(c);

(v) "School officials and officials of another school or school system" means qualified personnel or service coordinators under this part;

(vi) "State and local educational authorities" means the lead agency under §303.22; and

(vii) "Student" means child under this part.

(c) The lead agency must provide policies and procedures to be used when a parent refuses to provide consent under this section (such as a meeting to explain to parents how their failure to consent affects the ability of their child to receive services under this part), provided that those procedures do not override a parent's right to refuse consent under §303.420.



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**§303.415 Safeguards.**

(a) Each participating agency must protect the confidentiality of personally identifiable information at the collection, maintenance, use, storage, disclosure, and destruction stages.

(b) One official at each participating agency must assume responsibility for ensuring the confidentiality of any personally identifiable information.

(c) All persons collecting or using personally identifiable information must receive training or instruction regarding the State's policies and procedures under §§303.401 through 303.417 and 34 CFR part 99.

(d) Each participating agency must maintain, for public inspection, a current listing of the names and positions of those employees within the agency who may have access to personally identifiable information.

**§303.416 Destruction of information.**

(a) The participating agency must inform parents when personally identifiable information collected, maintained, or used under this part is no longer needed to provide services to the child under Part C of the Act, the GEPA provisions in 20 U.S.C. 1232f, and EDGAR, 34 CFR parts 76 and 80.

(b) Subject to paragraph (a) of this section, the information must be destroyed at the request of the parents. However, a permanent record of a child's name, date of birth, parent contact information (including address and phone number), names of service coordinator(s) and EIS provider(s), and exit data (including year and age upon exit, and any programs entered into upon exiting) may be maintained without time limitation.

**§303.417 Enforcement.**

The lead agency must have in effect the policies and procedures, including sanctions and the right to file a complaint under §§303.432 through 303.434, that the State uses to ensure that its policies and procedures, consistent with §§303.401 through 303.417, are followed and that the requirements of the Act and the regulations in this part are met.