**Section 500.150 Confidentiality/Privacy**

a) The regional intake entity shall ensure the confidentiality of all PII collected or maintained pursuant to Part C in accordance with FERPA (20 USC 1323(g)), FERPA regulations (34 CFR 99), this Part and IDEA regulations (34 CFR 303.101 through 303.417).

b) The regional intake entity shall give parents a Confidentiality Notice when a child is referred to Part C services. The Confidentiality Notice shall include:

1) a description of the children on whom PII is maintained;

2) the type of information sought;

3) the methods the State intends to use in gathering the information;

4) the sources from whom the information is gathered;

5) the uses of the information;

6) a summary of the policies and procedures the regional intake entity and providers must follow regarding storage, disclosure to third persons, retention and destruction of PII;

7) a description of the rights of parents and children regarding the PII; and

8) a description of the extent to which the notice is provided in native languages in various population groups in the State.

c) Access rights:

1) Each participating agency shall permit parents to inspect and review any records relating to their children that are collected, maintained, or used by the agency under this Part (including records relating to evaluations or assessments, screenings, eligibility determinations, development and implementation of IFSPs, provision of EI services, individual complaints dealing with the eligible child, and any other area under this Part involving records about the child and the child's family). The agency shall comply with a request without unnecessary delay and before any meeting regarding an IFSP or any Due Process Hearing. In all cases, the regional intake entity shall comply within 10 calendar days after the request has been made.

2) The right to inspect and review records under this Section includes:

A) The right to a response from the participating agency to reasonable requests for explanations and interpretations of the EI records;

B) The right to request copies of the 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

C) The right to have a representative of the parent inspect and review the EI records.

3) A participating agency may presume that the parent has authority to inspect and review records relating to his or her child unless the agency has been advised that the parent does not have the authority under applicable State law governing such matters as guardianship, separation, and divorce.

d) Record of access/Accounting of disclosure

Each participating agency shall keep a record of persons obtaining access to records collected, maintained, or used under this Part (except access by parents and authorized employees of the participating agency), including the name of the person, the date access was given, and the purpose for which the person is authorized to use the records.

e) Records on more than one child

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

f) List of types and locations of information

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

g) Fees

1) The parents shall be provided, at no cost, a copy of each evaluation, assessment of the child, family assessment and IFSP as soon as possible after each IFSP meeting.

2) Each participating agency may charge a reasonable fee for additional 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 subsection (g)(1).

3) A participating agency may not charge a fee to search for or to retrieve information under this Part.

h) Amendment of records at parent's request

1) A parent who believes that information in the records collected, maintained, or used under this Part 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.

2) The agency shall decide whether to amend the information in accordance with the request within five business days after the request. If the agency denies the request to amend the records, the agency must:

A) inform the parent;

B) advise the parent of a right to an informal hearing; and

C) notify the DHS Bureau of Early Intervention (Bureau of EI) within the five business day time period.

3) If the agency decides to refuse to amend the information in accordance with the request, it shall inform the parent of the refusal, and advise the parent of his or her right to a hearing as set forth in subsection (i).

i) Hearing regarding records

1) The Department shall give the parent an opportunity for a hearing to challenge the content of the EI records on the grounds that the information in the records is inaccurate, misleading or in violation of privacy rights of the child.

2) The Department will set the informal hearing within seven business days after receiving notice of the dispute.

3) The Department shall give the parent notice of the date, time and place reasonably in advance of the hearing.

4) The hearing may be conducted by an individual, including an official of the participating agency, who does not have a direct interest in the outcome of the hearing. The hearing officer will be designated by the Part C Coordinator.

5) The Department shall give the parent a full and fair opportunity to present evidence relevant to the grounds of challenge to the records.

6) The parent may at his/her own expense be assisted or represented by one or more individuals of choice, including an attorney.

7) The Department shall make its decision within 10 business days after the hearing. The decision shall be based solely on the evidence presented at the hearing and shall include a summary of the evidence and reason for the decision.

8) If the decision of the Department is that the information challenged is inaccurate, misleading or in violation of the child's privacy rights, the Department shall:

A) amend the record accordingly; and

B) inform the parent of the amendment in writing.

9) If the decision is that the challenged information is not inaccurate, misleading or in violation of privacy rights, the Department shall inform the parent of the right to place a statement in the record commenting on the contested information and stating why he or she disagrees with the decision.

10) If a statement is placed in the record pursuant to subsection (i)(9), the Department shall:

A) maintain the statement with the contested part of the record for as long as the record is maintained;

B) disclose the statement whenever it discloses the contested part of the record; and

C) at the parent's written request, disclose the statement to individuals to whom the contested part of the record was previously sent.

j) Safeguards:

1) Each participating agency shall protect the confidentiality of personally identifiable information at collection, storage, disclosure and destruction stages.

2) Each agency shall require one official to assume responsibility for ensuring the confidentiality of the information.

3) All persons collecting or using the information shall be trained regarding confidentiality requirements.

4) Each participating agency shall maintain, for public inspection, a current listing of those employees having access to the information.

(Source: Amended at 38 Ill. Reg. 11086, effective May 12, 2014)