**Section 500.155 Right to Consent**

a) As used in this Subpart:

1) "Consent" means that:

A) The parent has been fully informed of all information relevant to the activity for which consent is sought, in the parent's native language or other mode of communication;

B) The parent understands and agrees in writing to the carrying out of the activity for which consent is sought, and the consent describes that activity and lists the records (if any) that will be released and to whom;

C) The parent understands that the granting of consent is voluntary on the part of the parent and may be revoked at any time; and

D) If a parent revokes consent, that revocation is not retroactive (i.e., it does not apply to the action that occurred before the consent was revoked).

2) "Personally identifiable" means that information includes:

A) The name of the child, the child's parent, or other family member;

B) The address of the child;

C) A personal identifier, such as the child's or parent's social security number; or

D) A list of personal characteristics or other information that would make it possible to identify the child with reasonable certainty.

b) Parental consent

1) Written parental consent must be obtained before:

A) All evaluations and assessments of a child; and

B) Initiating the provision of EI services.

2) If consent is not given pursuant to subsection (b)(1), the regional intake entity, the local provider or other participating agency shall make reasonable efforts to ensure that the parent:

A) Is fully aware of the nature of the evaluations, assessments or services that would be available; and

B) Understands that the child will not be able to receive the evaluations, assessments or services unless consent is given.

c) Right to decline services

The parents of a child eligible under this Part may determine whether they, their child, or other family members will accept or decline any EI services under this Part in accordance with the Illinois Early Intervention Services System Act [325 ILCS 20], and may decline a service after first accepting it, without jeopardizing other EI services under this Part.

d) Right to written consent regarding exchange of information.

1) Each regional intake entity, local service provider and participating agency shall obtain consent in writing from parents before they collect, maintain or use records as defined in Section 500.150 regarding eligible children.

2) Each agency shall use the records only for the purpose for which they are collected or maintained.

3) Each agency shall maintain the records in a confidential, secure manner, allowing access only as required to serve the eligible child as consented to by the parent, and access as described in Section 500.150.

4) The exchange of records and any personally identifiable information collected, used, or maintained under this Part is precluded without written notice of and written consent to the exchange of information among agencies consistent with federal and State law, or as otherwise allowed by that law.

5) Each agency shall have procedures in writing to ensure compliance with this Section.

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