

North Carolina Infant-Toddler Program Policy

Procedural Safeguards

Introduction

The Infant - Toddler Program (ITP) shall ensure the effective implementation of procedural safeguards by each participating agency in the statewide system that is involved in the provision of early intervention services. Participating agencies include the lead agency (ITP), Early Intervention Service (EIS) providers, and any individual or entity that provides any early intervention services but does not include primary referral sources or public agencies or private entities that act solely as funding sources for early intervention services.

Confidentiality

The ITP shall ensure that the parents of a child referred for early intervention services 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.

1. The parents of infants or toddlers who are referred to, or receive early intervention services, are afforded the opportunity to inspect and review all early intervention records about the child and the child's family that are collected, maintained, or used including records related to evaluations and assessments, screening, eligibility determinations, development and implementation of Individualized Family Service Plans (IFSP), provision of early intervention services, individual complaints involving the child, or any part of the child's early intervention record. An initial copy of the child's early intervention record shall be made available to parents at no cost to the parent.
2. The confidentiality procedures described in paragraph 1. of this section apply to the personally identifiable information of a child and the child's family that:
 - a. is contained in early intervention records collected, used, or maintained by the ITP or an EIS provider; and
 - b. applies from the point in time when the child is referred for early intervention services 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.
3. The ITP must give notice when a child is referred that is adequate to fully inform parents about the confidentiality requirements including:
 - a. a description of the children on whom personally identifiable information is maintained, the types of information sought, the methods the ITP 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;
 - c. a description of all the rights of parents and children regarding this information, including their rights under the ITP confidentiality provisions; and
 - d. a description of the extent that the notice is provided in the native languages of the various population groups in the State.
4. 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. 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, and in no case more than 10 days after the request has been made.
 5. The right to inspect and review early intervention records includes:
 - a. the right to a response from the participating agency to reasonable requests for explanations and interpretations of the early intervention records;
 - b. 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
 - c. the right to have a representative of the parent inspect and review the early intervention records.
 6. 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.
 7. 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.
 8. Each participating agency must keep a record of parties obtaining access to early intervention records collected, maintained, or used (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.
 9. 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.
 10. Each participating agency may charge a fee for copies of records that are made for parents if the fee does not effectively prevent the parents from exercising their right to inspect and review those records. A participating agency may not charge a fee to search for or to retrieve information. 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.

11. A parent who believes that information in the early intervention records collected, maintained, or used 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. 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. 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.
12. 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 or may request a hearing directly under the State's procedures that are consistent with the Family Educational Rights and Privacy Act (FERPA) hearing requirements.
13. The hearing must meet, at a minimum, the following requirements.
 - a. The participating agency shall hold the hearing within a reasonable time after it has received the request for the hearing from the parent.
 - b. The participating agency shall give the parent notice of the date, time, and place, reasonably in advance of the hearing.
 - c. The hearing may be conducted by any individual, including an official of the participating agency, who does not have a direct interest in the outcome of the hearing.
 - d. The participating agency shall give the parent a full and fair opportunity to present evidence relevant to the issues raised. The parent may, at his or her own expense, be assisted or represented by one or more individuals of his or her own choice, including an attorney.
 - e. The participating agency shall make its decision in writing within a reasonable period of time after the hearing.
 - f. The decision must be based solely on the evidence presented at the hearing and must include a summary of the evidence and the reasons for the decision.
14. 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. 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. Any explanation placed in the early intervention records of the child must:
 - a. 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
 - b. 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.

15. Prior parental consent must be obtained before personally identifiable information is disclosed to anyone other than authorized representatives, officials, or employees of participating agencies (including the ITP and EIS providers) collecting, maintaining, or using the information.
16. The ITP must provide procedures to be used when a parent refuses to provide consent (such as a meeting to explain to parents how their failure to consent affects the ability of their child to receive services), provided that those procedures do not override a parent's right to refuse consent.
17. Each participating agency must protect the confidentiality of personally identifiable information at the collection, maintenance, use, storage, disclosure, and destruction stages. One official at each participating agency must assume responsibility for ensuring the confidentiality of any personally identifiable information. All persons collecting or using personally identifiable information must receive training or instruction regarding the State's policies and procedures.
18. 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.
19. The participating agency must inform parents when personally identifiable information collected, maintained, or used is no longer needed to provide services to the child. 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.
20. The ITP has in effect policies and procedures through its general supervision, monitoring, and corrective action process to ensure that the requirements of this section are met.

Parent Consent and Notice

1. The ITP shall ensure parental consent is obtained before:
 - a. administering screening procedures that are used to determine whether a child is suspected of having a disability;
 - b. all evaluations and assessments of a child are conducted;
 - c. early intervention services are provided to the child;
 - d. public benefits or insurance or private insurance is used if such consent is required; and
 - e. disclosure of personally identifiable information.
2. If a parent does not give consent the ITP must make reasonable efforts to ensure that the parent:
 - a. is fully aware of the nature of the evaluation and assessment of the child or early intervention services that would be available; and
 - b. understands that the child will not be able to receive the evaluation, assessment, or early intervention service unless consent is given.
3. The ITP may not use the due process hearing procedures to challenge a parent's refusal to provide any consent that is required.

4. The parents of an infant or toddler with a disability:
 - a. determine whether they, their infant or toddler with a disability, or other family members will accept or decline any early intervention service at any time, in accordance with State law; and
 - b. may decline a service after first accepting it, without jeopardizing other early intervention services.
5. Prior written notice must be provided to parents within a reasonable time before the ITP or an EIS provider proposes, or refuses, to initiate or change the identification, evaluation, eligibility of the infant or toddler, or the provision of early intervention services to the infant or toddler with a disability and that infant's or toddler's family.
6. The notice must be in sufficient detail to inform parents about:
 - a. the action that is being proposed or refused;
 - b. the reasons for taking the action; and
 - c. all procedural safeguards that are available, including a description of mediation, how to file a State complaint and a due process complaint in the provisions, and any timelines under those procedures.
7. The notice must be:
 - a. written in language understandable to the general public; and
 - b. provided in the native language, of the parent or other mode of communication used by the parent, unless it is clearly not feasible to do so.
8. If the native language or other mode of communication of the parent is not a written language, the public agency or designated EIS provider must take steps to ensure that:
 - a. the notice is translated orally or by other means to the parent in the parent's native language or other mode of communication;
 - b. the parent understands the notice; and
 - c. there is written evidence that the requirements of this paragraph have been met.

Surrogate Parents

1. The ITP shall ensure that the rights of a child are protected when:
 - a. no parent can be identified;
 - b. the ITP or other public agency, after reasonable efforts, cannot locate a parent; or
 - c. the child is a ward of the State under the laws of that State.
2. The duty of the ITP includes the assignment of an individual to act as a surrogate for the parent. This assignment process must include a method for:
 - a. determining whether a child needs a surrogate parent; and
 - b. assigning a surrogate parent to the child.

3. In implementing these provisions for children who are wards of the State or placed in foster care, the ITP must consult with the public agency that has been assigned care of the child. In the case of a child who is a ward of the State, the surrogate parent, instead of being appointed by the ITP, may be appointed by the judge overseeing the infant or toddler's case provided that the surrogate parent meets the requirements of this section.
4. The ITP may select a surrogate parent in any way permitted under State law. Public agencies must ensure that a person selected as a surrogate parent:
 - a. is not an employee of the ITP or any other public agency or EIS provider that provides early intervention services, education, care, or other services to the child or any family member of the child;
 - b. has no personal or professional interest that conflicts with the interest of the child he or she represents; and
 - c. has knowledge and skills that ensure adequate representation of the child.
5. A person who is otherwise qualified to be a surrogate parent is not an employee of the agency solely because he or she is paid by the agency to serve as a surrogate parent.
6. The surrogate parent has the same rights as a parent for all purposes.
7. The ITP must make reasonable efforts to ensure the assignment of a surrogate parent not more than 30 days after a public agency determines that the child needs a surrogate parent.