

North Carolina Infant-Toddler Program Procedural Guidance

Reference: Procedural Safeguards Policy

Parental Consent and Notice

Introduction

Procedures governing obtaining written consent from a parent in order to provide screening, evaluation, assessment, intervention services, use of public benefits or private health insurance, and disclosure of information are designed to ensure that:

- participation of families in all aspects of the Infant-Toddler Program is voluntary;
- the parent receives the information he needs to make informed decisions about how his child and family will be served, and
- the parent's wishes about how his child and family will be served are respected.

A parent's consent to an evaluation or assessment is *informed* if:

- the parent understands the purpose of the evaluation or assessment and the procedures to be employed (i.e., what information is needed, why it is needed and how it will be obtained). This includes the use of observation by professionals as part of the assessment or evaluation of the child, family, and/or parent-child interactions. The parent's written consent should describe the assessment or evaluation procedures the parent has authorized. A family-directed assessment is voluntary. If a family-directed assessment is to be conducted, this must be clearly stated and consent provided;
- the parent understands any burdens the parent or family might bear as a result of the assessment or evaluation (e.g., whether the parent must provide transportation, take a day off work, possible impact on the family of services provided in the home, fees involved), and
- the parent understands the possible adverse consequences of refusing to consent to an assessment or evaluation or to proposed assessment or evaluation procedures (e.g., inability to determine the child's eligibility for the Infant-Toddler Program, inability to establish child's strengths and needs to determine appropriate services).

A parent's consent to the provision of other services is informed if:

- the parent understands the purpose of each service to be provided;
- the parent understands the financial charges (if any) that the parent might incur for the service;
- the parent understands any burdens that the parent might bear as a result of each proposed service (e.g., whether the parent must provide transportation, possible impact on the family of services provided in the home, fees involved), and
- the parent understands the possible adverse consequences of refusing proposed services (e.g., worsening or no improvement in the child's condition).

Procedures

1. Written Parental Consent is obtained:
 - when a parent initially requests an eligibility evaluation using the *North Carolina Infant-Toddler Program Prior Written Notice and Consent for Evaluation and Assessment* form;
 - prior to child evaluations and assessments (other than assessments related to the on-going provision of therapy or educational services) using the *North Carolina Infant-Toddler Program Prior Written Notice and Consent for Evaluation and Assessment* form;
 - before the provision of or changes to any early intervention services listed on the Individualized Family Service Plan using the *North Carolina Infant-Toddler Program Individualized Family Service Plan (Agreement or Review Sections)*; and
 - before the disclosure of information held under the restrictions of confidentiality, using the *North Carolina Infant-Toddler Program Authorization to Disclose Health Information* form. (*For specific information about this form of consent, see the Procedural Guidance on Confidentiality.*)
2. The request for Written Parental Consent must include:
 - A description of the activity (e.g., evaluation, service, changes to Individualized Family Service Plan);
 - A list of records (if any) or recorded information that will be released and to whom (Note: This information is captured on the *North Carolina Infant-Toddler Program Authorization to Disclose Health Information* and does not have to be included as part of the Written Parental Consent), and
 - Informing the parent that granting the release is voluntary and may be revoked at any time in writing, except to the extent that action, for which consent has been provided, has already been taken.
3. If Written Parental Consent is not given, the agency or service provider must make reasonable efforts to ensure that:
 - the parent is fully aware of the nature of the evaluation and assessment or the services that would be available, and
 - the parent understands that the child will not be able to receive the evaluation and assessment or services unless written consent is given.
4. The parent may determine whether he or his child will accept or decline any early intervention services under the Infant-Toddler Program in accordance with state law, without jeopardizing the right to receive other services.
5. To help the parent understand why consent is being requested and the possible adverse consequences of refusing proposed services, the Service Coordinator and service providers may:
 - provide literature or other materials to the parent;
 - offer the parent peer counseling and support to enhance his understanding of the value of early intervention and to help with his concerns about participation in the Infant-Toddler Program. Peer

counseling and support are available through local parent-to-parent groups at the Exceptional Children's Assistance Center (ECAC) at 1-800-962-6817, and

- renew contact with the parent periodically to determine if the parent has changed his mind about recommended services.
6. Service providers may not employ any form of coercion in attempting to persuade the parent to accept recommendations, including recommendations related to evaluations, services, or disclosure of information. When a parent's refusal to give consent would constitute child abuse or neglect, Service Coordinators and other early intervention service providers must follow all federal and state legal statutes on child abuse or neglect. Staff must not allow personal biases to influence their activities regarding reporting child abuse or neglect.
 7. Obtaining a parent's written consent requires the Service Coordinator or early intervention service provider to fully inform the parent in a mode of communication understandable to the parent of all information relevant to the activity for which consent is sought.
 - Unless clearly not feasible to do so, a parent who does not speak English must be given consent forms in his native language or mode of communication.
 - An individual who can interpret questions from the parent and the answers to these questions should be present.
 - If a consent form cannot be provided in the parent's native language or mode of communication, a consent form that is written in English may be used, if an interpreter is available to interpret the form for the parent. The entire form must be read and interpreted and questions answered.
 - Recommended practice is to include the following statement, translated on the form, and have the parent sign it or have the parent write the statement in his native language and sign it: "This document has been explained to me and I understand it".
 - The service provider must document in the child's record how the consent was obtained, including questions that were asked, answers given, and the name of the interpreter.
 8. When the parent is illiterate, the following procedures must be followed:
 - The service provider should have another family member present to hear the verbal explanation of the consent or authorization, unless clearly not feasible to do so.
 - The entire form must be read to the parent and questions answered.
 - The parent should place an "X" on the signature line and the parent's name printed on the signature line to order to identify the person making the "X."
 - If another family member is present, it is recommended that that person also sign the form.
 - The service provider must document in the child's record how the consent was obtained, including questions that were asked, answers given, and the name of the family member(s) present.