North Carolina Infant-Toddler Program
Procedural Guidance

Reference: Procedural Safeguards Policy

Confidentiality

Introduction

Procedures governing confidentiality and privacy of information are designed to ensure that the parent is fully informed about any release of information; the parent understands that he may place reasonable limits on the release of information about his child, his family, and himself, including limits on the sharing of such information among Infant-Toddler Program (ITP) providers. Procedures also include basic safeguards, including those specific to the Infant-Toddler Program, are provided to the parent when he is asked to authorize an agency or provider to release or seek information about the child or family.

Definitions

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 regulations in this part with respect to a particular child. A participating agency includes the lead agency and Early Intervention Services (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. (303.403 (c))

Federal Privacy Regulations

The **Family Educational Rights and Privacy Act (FERPA)** is a federal law that protects the privacy of students and parents. The Infant-Toddler Program is funded at the federal level with education funds, and it is considered an educational unit and must follow federal education requirements. The Family Educational Rights and Privacy Act is incorporated in the **Individuals with Disabilities Education Act (IDEA)** as the Buckley Amendment, which also gives parents and eligible students the right to access education records from any educational institution that receives funds from the United States Department of Education.

The **Health Insurance Portability and Accountability Act (HIPAA)** is a federal law which, among other things, protects the confidentiality of medical records and other personal health information. It limits the use and release of individually identifiable health information, gives patients the right to access their medical records, and restricts most disclosure of health information to the minimum needed for the intended purpose.

Both the Health Insurance Portability and Accountability Act and the Family Educational Rights and Privacy Act seek to ensure the privacy of individuals by setting forth requirements related to the sharing of confidential and personally identifiable information among providers of services. In regard to the Health Insurance Portability and Accountability Act, the focus is primarily on health information. With the Family Educational Rights and Privacy Act, the focus is primarily on educational information.

There is a broad exemption in the Health Insurance Portability and Accountability Act's privacy rules that excludes health information contained in education records as defined by the Family Educational Rights and Privacy Act. Therefore, any health information that is generated and maintained by the Children's Developmental Services Agency (CDSA) or an enrolled Infant-Toddler Program service provider is subject to the Family Educational Rights and Privacy Act's access and disclosure rules, regardless of whether the information was created and used by health professionals. This includes those records designated as Infant-Toddler Program records under Part C of the Individuals with Disabilities Education Act.

Family Educational Rights and Privacy Act (FERPA) Applicability

The Family Educational Rights and Privacy Act (FERPA) applies to all information generated and used by service providers to comply with the requirements of Part C of the Individuals with Disabilities Education Act, which in North Carolina is the Infant-Toddler Program. These requirements include information gathered and generated during referrals to the Infant-Toddler Program and the delivery of any and all required Infant-Toddler Program services. Required services include educational as well as medical and health related services. *(For a listing of these services, see Policy on Infant-Toddler Program Services.)* As defined by the Family Educational Rights and Privacy Act, disclosure means to permit access to or the release, transfer, or other communication of personally identifiable information contained in education records to any party, by any means, including oral, written, or electronic means.

Infant-Toddler Program record means any personally identifiable information in electronic, typed, printed, or handwritten form about a child or the child's family which is generated by the CDSA staff or other early intervention service providers, and which pertains to referral and eligibility determination, evaluation and assessment, development of an Individualized Family Service Plan (IFSP), and the delivery of early intervention services.

Infant-Toddler Program records consist of information typically retained on a child and his family, including, but not limited to files, reports, studies, letters, minutes of meetings, memoranda, summaries, handwritten or other notes, charts, graphs, data sheets, financial eligibility information, and information stored on microfilm or microfiche or in computer-readable form. Personal notes made by service providers, kept in the sole possession of the maker, used only as a personal memory aid, and not accessible or revealed to any other person, except for another staff member acting as a temporary substitute for the service provider, are not subject to the Family Educational Rights and Privacy Act.

Procedures

The North Carolina Infant-Toddler Program has established confidentiality and privacy procedures for Infant-Toddler Program staff and other early intervention service providers to follow. They should follow these procedures to help ensure they are in compliance with the required Individuals with Disabilities Educational Act and the Family Educational Rights and Privacy Act.

Confidentiality and Privacy Safeguards

Infant-Toddler Program staff and other early intervention service providers must have the following safeguards in place to ensure confidentiality.

1. Service providers must develop procedures to protect the confidentiality, privacy, and security of personally identifiable information at collection, storage, use, disclosure, and destruction stages. These procedures must address all situations described in the ***North Carolina Infant-Toddler Program Policy and Procedures*** and in the ***Division of Public Health Privacy and Security Manual, Privacy Safeguards Policy.*** Situations to be addressed include, but are not limited to: face-to-face conversations, telephone conversations, facsimiles, email, courier and regular mail, inter-office mail, computer workstations, remote workers, work areas, facility safeguards, visitor safeguards, disposal of information, transport of records, protection against loss, defacement, tampering, and hazards such as fire and water damage, removal of records or parts of records from secure locations, and storage of inactive records. The requirements in the ***Division of Public Health Privacy and Security Manual, Privacy Safeguards Policy*** are to be followed except for three areas - email, cellular phones, and electronic signatures. See the “Special Considerations” section of this Policy Bulletin for these requirements.
2. One official at each CDSA or other early intervention service provider agency must assume responsibility for ensuring confidentiality, privacy, and security of personally identifiable information. Responsibilities of this person include, but are not limited to, keeping records safe and intact from accidents, unauthorized access, theft, changes, or unintentional release; ensuring that access to personally identifiable information is restricted to authorized persons with a legitimate need for the information; and training employees regarding confidentiality and privacy policies and procedures.
3. All persons collecting or using personally identifiable information must receive training or instruction regarding the Infant-Toddler Program’s confidentiality and privacy policies and procedures. CDSA staff and providers are to sign an acknowledgment that training was received. Children’s information may not be accessed until this training is completed. Service provider agencies are responsible for training their staff members; however, the CDSA is available to provide technical assistance, if needed.
4. The CDSA and other early intervention service provider agencies must maintain a current list of names and positions of employees within the agency who have access to personally identifiable information.
5. CDSA staff and other early intervention service providers must inform the parent about the policies and procedures for archiving, destroying, or otherwise disposing of personally identifiable information that is collected, maintained, or used under the Infant-Toddler Program. These policies must include the specific length of time information will be kept and where information will be stored.
6. If requested by the parent, the CDSA or other early intervention service providers must destroy personally identifiable information when it is no longer needed. (A permanent record of a child's name, address, and telephone number, services provided, dates served, and status at the time of closure, which includes referrals to other service providers may be maintained without time limitation.) Federal regulations define “destruction” as physical destruction or the removal of personal identifiers so that the information is no longer personally identifiable. The federal Office of Special Education Programs has ruled that if a parent requests the destruction of personally identifiable information that is no longer useful for the provision of Infant-Toddler Program services prior to the state’s record retention period, the service provider must destroy the record by removing personally identifiable information from the record without physically destroying the record. After both federal and state retention periods lapse,

then the record may be physically destroyed. Destruction of records is the best protection against improper and unauthorized release. However, records may be needed for other purposes. When informing the parent about this right, the service provider should remind him that the records may be needed in the future by the child or the parent. The parent should be reminded to maintain or have copied pertinent records for these purposes.

7. When confidential information is released, the CDSA or other early intervention service providers must release only the information minimally necessary to carry out the purpose of the release.

8. When confidential information is released, the CDSA and other early intervention service providers must provide the parent with a copy of the information released, if requested by the parent.

9. The CDSA and other early intervention service providers must record on the ***North Carolina Infant-Toddler Program Accounting of Release/Disclosure and Record Access*** form all requests for and disclosures of information (except to those authorized employees of the agency with a legitimate need for obtaining the information) and maintain this documentation with the child's record as long as the child's record is maintained. This record of disclosure is available for review by the parent at any time and must be made available for review within ten (10) calendar days of the parent’s request. The CDSA or other early intervention service provider must document the request and the review, including the date of the request and the date the parent reviewed the record of disclosure.

10. The CDSA and other early intervention service providers must keep a record on the ***North Carolina Infant-Toddler Program Accounting of Release/Disclosure and Record Access*** form of parties requesting and obtaining access to records collected, maintained, or used (except those authorized employees of the agency with a legitimate need for accessing the record). This form is to include the name of the party requesting or receiving access, the date access was given, and the purpose for which the party was authorized to use the records. The CDSA maintains this documentation with the child's record as long as the child's record is maintained. This record of access is available for review by the parent at any time and must be made available for review within ten (10) calendar days of the parent’s request. The CDSA or other early intervention service provider must document the request and the review, including the date of the request and the date the parent reviewed the record of access.

11. The ***North Carolina Infant-Toddler Program Confidentiality Agreement*** must be signed prior to providing services to any children enrolled in or in the process of enrolling in the Infant-Toddler Program. This agreement states that enrolled service providers and CDSA staff understand the confidentiality and privacy requirements of the Infant-Toddler Program and agree to abide by such requirements. The CDSA is responsible for ensuring that enrolled Infant-Toddler Program service providers sign this agreement and adhere to its terms. CDSA staff directly employed through the Early Intervention Section must also sign a ***Division of Public Health Confidentiality Agreement*** and adhere to the terms of this agreement.

12. Persons authorized to conduct activities such as reviews, audits, accreditations, monitoring, and research must sign the ***North Carolina Infant-Toddler Program Confidentiality Agreement*** or the ***Division of Public Health Confidentiality Agreement*** as appropriate signifying their understanding of the confidentiality and privacy requirements of the Infant-Toddler Program and agreement to abide by such requirements.

Written Authorization for Release of Information

1. Information concerning a child or family member is confidential and must not be exchanged without written authorization from the parent, except under special circumstances where this release is allowable by law such as with a participating agency, in a health or safety emergency, under court order, or as an allowable child find activity. An agency, however, may release confidential information to its own employees who have a legitimate need for access to the information.
2. The Individuals with Disabilities Education Act and the Family Educational Rights and Privacy Act use the term “consent” for parental permission to release information for any purpose. The Health Insurance Portability and Accountability Act uses the term “consent” for specific release of information for treatment, payment, and operational purposes only and uses the term “authorization” for release of information for all other purposes.
3. Under the Family Educational Rights and Privacy Act, the Health Insurance and Portability and Accountability Act, and North Carolina State law, “consent” is also the agreement to receive specific services (e.g., evaluations) and obtain specific medical treatment. For the purpose of clarity, the Infant-Toddler Program uses the term “consent” as the agreement to receive services from the provider. The term “authorization” is used for written parental permission to release or disclose Infant-Toddler Program information for any and all purposes. *(For additional information, see Parent Consent and Notice Procedures.)*
4. The Health Insurance Portability and Accountability Act defines “disclosure” as the “release” of information outside of the organization that originates and maintains the personally identifiable information. The Family Educational Rights and Privacy Act also classifies a “disclosure” as the “release” of information. Many organizations and state laws typically use the term “release” of information. These terms “disclosure” and “release” may be used interchangeably to mean that personally identifiable information is being shared outside of the originating organization.
5. The parent must be fully informed about all information relevant to the release (disclosure) of information, and he must be informed of his right to refuse the release of any information. CDSA staff and other early intervention service providers must use the ***North Carolina Infant-Toddler Program Authorization to Disclose Health Information*** form when securing written authorization from the parent for the release of information. Instructions that accompany this form are to be followed. The parent must be given a copy of the signed authorization. Either of the child’s parents has full rights for releasing, revoking, restricting use or disclosure, or accessing information about the child unless the service provider has been provided with written evidence that a parent does not have authority under applicable state law governing such matters as guardianship, separation, and divorce. In such cases, it is the responsibility of the parent with legal custody to provide written documentation to the service provider of any circumstances prohibiting the other parent from his full rights for releasing, revoking, restricting uses or disclosure, or accessing information about the child. Written documentation of such information must be maintained in the child’s record.
6. Multiple service providers may be listed on the authorization form as long as they are involved in the coordination of services for the child and family and share the same purpose of the disclosure. Also, the disclosure may be reciprocal if the named parties are involved in the coordination of services and share the same purpose of the disclosure. If circumstances exist for a child and family that would make the

listing of multiple persons on an authorization form inappropriate, individual authorization forms for each service provider should be completed. Whenever a need arises to release information to a party not already included on a valid authorization, a new authorization to include this party must be completed. When appropriate, Service Coordinators should include the referral source in such a joint authorization in order to involve the referral source in follow-up, ensure continuity of care, enhance coordination among all service providers, and to prevent the duplication of services.

7. To be consistent with the requirements of informed consent for the release of information, a new ***North Carolina Infant-Toddler Program Authorization to Disclose Health Information*** form must be completed whenever there is a new purpose for the release of information and whenever there is new information to be released. For example, when there is new evaluation information or a change in health information, a new authorization must be completed and signed. If there are questions about whether a new authorization is needed, it is better to be cautious and prepare a new authorization.
8. Service providers cannot deny or refuse to provide services if the parent refuses to authorize the release of information. However, a parent's refusal may affect the timeliness in which the Infant-Toddler Program can respond. The parent must be informed about potential delays in completing evaluations, eligibility determination, or the receipt of services or the impact that not having the information may have on the appropriateness and quality of the service being provided and the achievement of the outcomes related to the service provision.

Revoking a Written Authorization to Release Information

The parent can revoke an authorization to release information at any time. A revocation applies only to subsequent releases and not for information that has already been released with a valid authorization. The CDSA or other early intervention (EI) service provider must validate the person's authority to revoke an authorization, if the person seeking to revoke the authorization is not the person who initially authorized the release of information. The CDSA staff or other EI service provider must require proof of custody or legal representation of the child in such cases. Written documentation of such proof must be maintained in the child's record. The appropriate section of the ***North Carolina Infant-Toddler Program Authorization to Disclose Health Information*** form must be completed and signed by the parent or legally guardian in order to revoke an authorization. Instructions that accompany this form are to be followed. All persons involved must be made aware of the revocation so that information is not inappropriately released.

Restrictions on the Use and Disclosure of Information

1. CDSA staff and other early intervention service providers must inform parents of their right to request restrictions on what information about their child and family is used and disclosed. Restrictions may be placed on disclosures of specific information as well as on disclosures to specific individuals or agencies. Restrictions must be provided in writing and signed by the parent.
2. In signing the ***North Carolina Infant-Toddler Program Authorization to Disclose Health Information*** form, the parent indicates what information may be disclosed and to whom. By excluding information or individuals from the authorization, the parent is effectively putting a restriction on the disclosure. However, to ensure that the parent's decision to restrict disclosure of information is documented and that there are no inadvertent disclosures, the CDSA staff or early intervention service providers must complete and have the parent sign the ***North Carolina Infant-Toddler Program Request for***

Restrictions on Use and Disclosure of Health Information form indicating the specifics of the restriction. Instructions that accompany the ***North Carolina Infant-Toddler Program Request for Restrictions on Use and Disclosure of Health Information*** form are to be followed.

3. In situations where the parent has already authorized a disclosure of information, the CDSA staff or other early intervention service provider must complete and have the parent sign the ***North Carolina Infant- Toddler Program Request for Restrictions on Use and Disclosure of Health Information*** form indicating the specifics of the restriction. This form should be filed with the original authorization to disclose information to prevent inadvertent release in the future. All persons involved must be made aware of the restriction so that a disclosure is not made inadvertently against the parent’s wishes. A restriction in this situation only applies to subsequent disclosures and not to information that was previously disclosed with a valid authorization.
4. The CDSA and other early intervention providers are not required to agree to all requested restrictions. However, if a restriction is agreed to, it is binding, and service providers may not use or disclose information, unless otherwise allowed or required by federal or state law. See the following section for examples of allowable disclosures of information.

Release of Information Without a Parent's Written Authorization

The CDSA or other early intervention service provider may release information without a parent's written authorization under the following circumstances:

- in a health or safety emergency (e.g., communicating with the local Department of Social Services regarding reports of abuse or neglect or reporting to the local Health Director that a client has a communicable disease or is in violation of control measures);
- to comply with a judicial order or lawfully issued subpoena;
- when the release is to the parent;
- when the information has been completely de-identified and cannot be traced to an individual or family;
- when the release is to authorized employees of the agency who have a legitimate need for having the information (e.g., persons who are performing tasks specified in job descriptions or contract agreements, conducting official agency business, accomplishing some task or determination related to the child and family, ensuring implementation of Infant-Toddler Program requirements);
- when the release is to officials of another Infant-Toddler Program educational agency, such as programs under the Department of Public Instruction or between Children’s Developmental Services Agencies, where the child seeks to enroll or is enrolled and receiving services, if a reasonable attempt to is made to inform the parent or the annual notification to the parent informs him of this practice;
- when the release is to organizations conducting studies for or on behalf of educational agencies, but only when there has been proper review and approval of such studies *(For additional information about research studies, see the Special Considerations section on “Research” later in this Procedures document.)*;

- when the release is to accrediting organizations so they can carry out their accrediting function, and
- when the release is to state and federal agency representatives in connection with an audit or evaluation or for enforcement of, or compliance with, state and federal regulations. This would include enrolled Infant-Toddler Program service providers authorized to participate in Infant-Toddler Program quality assurance and quality improvement activities.

CDSA staff and other early intervention service providers must document on the ***North Carolina Infant-Toddler Program Accounting of Release/Disclosure and Record Access*** form information released without written parental authorization, including the name of the party receiving information, the date information was released, and the purpose for which the information was released and maintain this documentation with the child's record as long as the child's record is maintained.

Statewide EI Program staff also periodically access the record for monitoring/audit purposes to ensure supports and services are in compliance with federal and state requirements.

Release of Sensitive Information

Some information is considered especially "sensitive information" and must never be shared without specific authorization from the parent unless court ordered. This information includes HIV or AIDS status; drug or alcohol abuse or treatment; psychological/psychiatric conditions or treatment, or genetic testing.

1. The parent must be informed when information that is being considered for release may contain sensitive information. Informed consent must be obtained before including this information in a release. The ***North Carolina Infant-Toddler Program Authorization to Disclose Health Information*** form contains a statement regarding such sensitive information that might be included in the disclosure. If the parent does not give permission to release sensitive information, the CDSA and other early intervention service providers must honor this request if the release does not negatively affect treatment or is not material to the purpose of the disclosure.
2. The ***North Carolina Infant-Toddler Program Request for Restrictions on Use and Disclosure of Health Information*** form must be used to document the parent’s requested restrictions. The CDSA or other early intervention service provider may choose whatever means is most suitable for restricting the disclosure, such as blacking out the sensitive information. Original records are not to be changed or altered and must be maintained in the child’s Infant-Toddler Program record. Only the copies to be disclosed to authorized individuals or agencies may be changed. A copy of any information that is changed must also be maintained in the child’s Infant-Toddler Program record. If the information is particularly sensitive, such as a family member having tested positive for HIV then it can be released only when it meets the circumstances defined in state statutes.

   These circumstances include the following:

   A. Release is made of specific medical or epidemiological information for statistical purposes in a way that no person can be identified;

   B. Release is made of all or part of the medical record with the written consent of the person or persons identified or their guardian;

   C. Release is made for purposes of treatment, payment, research, or health care operations to the extent that disclosure is permitted under 45 Code of Federal Regulations §§ 164.506 and 164.512(i). For purposes of this section, the terms "treatment," "payment," "research," and "health care operations" have the meaning given those terms in 45 Code of Federal Regulations § 164.501;

   D. Release is necessary to protect the public health and is made as provided by the Commission for Public Health in its rules regarding control measures for communicable diseases and conditions;

   E. Release is made pursuant to other provisions of this Article;

   F. Release is made pursuant to subpoena or court order. Upon request of the person identified in the record, the record shall be reviewed in camera. In the trial, the trial judge may, during the taking of testimony concerning such information, exclude from the courtroom all persons except the officers of the court, the parties and those engaged in the trial of the case;

   G. Release is made by the Department or a local health department to a court or a law enforcement official for the purpose of enforcing this Article or Article 22 of this Chapter, or investigating a terrorist incident using nuclear, biological, or chemical agents. A law enforcement official who receives the information shall not disclose it further, except (i) when necessary to enforce this Article or Article 22 of this Chapter, or when necessary to conduct an investigation of a terrorist incident using nuclear, biological, or chemical agents, or (ii) when the Department or a local health department seeks the assistance of the law enforcement official in preventing or controlling the spread of the disease or condition and expressly authorizes the disclosure as necessary for that purpose; or

   H. Release is made by the Department or a local health department to another federal, state or local public health agency for the purpose of preventing or controlling the spread of a communicable disease or communicable condition;

3. Federal law protects the confidentiality of records of substance abuse treatment programs or medical facilities that have a substance abuse treatment program. There are strict guidelines pertaining to re-disclosure of information received from such a facility or program. When information is received from a program as defined by federal law, the program should include a document about how and to whom the information may be re-disclosed.

Special Considerations

Removal of Information from Secure Locations

1. Each CDSA and other early intervention service provider agencies must establish a secure location with controlled access for the storage of records and develop procedures for the removal of any information from this designated secure location.

2. Only authorized persons may access the secure location and only authorized persons may remove any information from the secure location.

3. Any information that is removed from a child’s record must be checked out and written notation placed in the record specifying the information removed, the person removing the information, the reason for removal of the information, the date the information was removed, and the date the information is due to

be returned to the chart.

4. If an entire chart is removed from the established secure location, a “sign out” card must be completed and placed in the location where the chart is normally filed. The “sign out” card must include which chart was removed, the person removing the chart, and the date the chart was removed. It is recommended that the “sign out” card also include the reason for removal of the chart and the date the chart is due to be returned to the secure location.
5. Anyone removing information from a chart or removing an entire chart is responsible for ensuring that all safeguards protecting the confidentiality, privacy, and security of the information are followed while the information is in his possession and that the information or the chart is returned by the indicated due date, which is preferably the end of the workday.

Emailing Information to Parents

If the parent requests that information be emailed to him, the CDSA or other early intervention service provider must:

- Have the parent indicate what type of information he wants to receive by email on a ***North Carolina Infant-Toddler Program Authorization to Disclose Health Information*** form;
- Verify the parent’s email address by sending a test email and requesting a reply with confirmation from the parent;
- Encrypt and password protect the document containing the requested confidential information and attach the document to the email;
- Forego including any confidential information in the email subject line or text body itself;
- All email should include the following disclaimer statement with the following text:

  > Email correspondence to and from this address is subject to the North Carolina Public Records Law and may be disclosed to third parties by an authorized State official. Unauthorized disclosure of juvenile, health, legally privileged, or otherwise confidential information, including confidential information relating to an ongoing State procurement effort, is prohibited by law. If you have received this e-mail in error, please notify the sender immediately and delete all records of this e-mail.

- Request the parent to send a reply acknowledging his receipt of the email and attachment;
- Send the email requesting an automatic return receipt acknowledgement, if available on the email system, and
- Call and speak directly to the parent giving him the password to open the attachment.

Use of Cellular Phones

CDSA staff and other early intervention service providers must be extremely cautious when using cellular phones to discuss confidential information as such communication is not secure, unless encrypted. If a cellular phone must be used to communicate and a private landline is not available, the following safeguards must be used to protect the conversation:

- reasonable precautions must be taken to speak privately with the other party in places where the conversation cannot be overheard, and a request made that the other party do the same;

- disclosure of child and family identifying information, particularly health information must be avoided unless it is impossible to do so, and the conversation must be ended if any interference on the line is heard that might signal a cell poacher or a mixed signal.

Electronic Signatures

CDSAs may accept electronic signatures from service providers who are sending information to them in support of a child's enrollment in the Infant-Toddler Program. The CDSA must be familiar with the service provider before accepting an electronic signature and should have an actual handwritten signature on file against which the electronic signature can be compared. The service provider must include full contact information in the document including his name, title, affiliation, physical address, and telephone number. The Children's Developmental Services Agency cannot accept electronic signatures from parents for authorizations or consents.

Re-Release of Information

CDSAs and other early intervention service providers may re-release information generated by other service providers from the child's record with written authorization from the parent unless the originator of the information has stated that re-disclosure is prohibited or has placed any other conditions on its release. The CDSA or other early intervention service provider must make sure that the information being re-released is needed by the recipient in order to provide services to the child and family.

Surrogate Parents

Because a surrogate parent is considered to be the parent as defined by the Infant-Toddler Program, he is afforded all rights given to parents and their children under the Infant-Toddler Program. He has the same access to the child's record and other written information as does any parent and has the authority to authorize the release of information for the purposes of the Infant-Toddler Program. *(For additional information, see the Procedural Safeguards Policy and Surrogate Parent Procedures.)*

Parent Guests

The parent must sign a written authorization for information to be shared in the presence of a guest such as a friend, advocate, or extended family member during formal circumstances such as his accompanying the parent to an Individualized Family Service Plan meeting, discussing evaluation findings or during the parent's review of a record. Because Infant-Toddler Program services are provided in natural environments, such as the child's home, the service provider may be unable to ensure confidential exchanges of information at all times. The service provider must be sensitive to this and remind the parent that confidential information may be shared during the course of the interaction. Both the parent and the service provider should be cautious regarding what is shared during such conversations.

Interpreters and Translators

The parent must sign a ***North Carolina Infant-Toddler Program Authorization to Disclose Health Information*** form to share confidential information with or be in the presence of a language interpreter or translator unless this person is employed by an agency or is under contract with an agency to which the parent has otherwise given written authorization to have or access the information, and this person has signed the

***North Carolina Infant-Toddler Program Confidentiality Agreement*.**

Native Language/Mode of Communication

Unless clearly not feasible to do so, a parent who does not speak English must be given consent and authorization forms in his native language or mode of communication. An individual who can interpret any questions from the parent and the answers to these questions should be present. A consent or authorization 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 questions answered. Recommended practice would include having the following statement translated on the form and having the parent sign it or having the parent write the statement in his native language and sign it: "This document has been explained to me and I understand it". The CDSA staff or other early intervention service provider must document how the consent or authorization was obtained, including any questions that were asked, the answers given, and the name of the interpreter. This documentation must be provided to the CDSA at the time of the notation. *(For additional information, see Native Language/Mode of Communication Procedures.)*

Parents who are Illiterate

If a parent is not literate and unless clearly not feasible to do so, the CDSA staff or other early intervention service provider should have another family member present to hear the verbal explanation of the consent or authorization. The entire form must be read to the parent and any questions answered. The parent should place an "X" on the signature line and the parent's name should be printed on the signature line by either the family member accompanying the parent or by a staff member of the Infant-Toddler Program provider agency in 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 CDSA staff or other early intervention service provider must document how the consent or authorization was obtained, including any questions that were asked, the answers given, and the name of the family member present, if appropriate. This documentation must be provided to the CDSA at the time of the notation.

Verbal Release of Information

There is no difference in confidentiality requirements between sharing information verbally or in written form. No information may be shared about a family without the family's knowledge and written authorization except as federal law and state laws allow.

Child Find

Federal regulations and North Carolina special education statutes allow referral sources to share a minimal amount of personally identifiable information during child find (i.e., making a child known to the Infant-Toddler Program or the Preschool Disability Program for the purpose of complying with the Individuals with Disabilities Education Act) when release of the same information under other circumstances would be a violation of child and family rights. Information that can be shared during child find is limited to child's name, date of birth, parent's name, address, and telephone number. Outside of child find and head count activities, CDSA staff and other early intervention service providers must obtain written authorization for release of information that is personally identifiable. *(For more information about referrals, see the Referral Process Procedures.)*

Directory Information

The Family Educational Rights and Privacy Act allows Infant-Toddler Program service providers to maintain indefinitely directory information, which includes child's name, date of birth, parent's name, address, telephone number, and dates of enrollment. While the Family Educational Rights and Privacy Act allows service providers to release directory information, the North Carolina Infant-Toddler Program has determined that directory information is not to be disclosed without written parental authorization, except where allowed by law (e.g., child find activities).

Adoptions

North Carolina statute requires providers to be responsible to protect the pre-adoptive name of a child, as well as any other information that might lead to the identification of the birth family. Any report or other information released after an adoption becomes final must be edited by the originator to exclude the name, address, or other information that could reasonably be expected to lead directly to the identity of an adoptee at birth or an adoptee's parent at birth or other members of the adoptee's biological family.

In order to protect the birth identity of a child and the identity of the birth family, all records and all indices of records on file with the court, a service provider, or the state must be retained permanently and sealed when an adoption becomes final. Please refer to the *Infant-Toddler Program Records Procedures* for the procedures that must be followed by all Infant-Toddler Program service providers when an adoption occurs.

Photography/Interview

Infant-Toddler Program staff and other early intervention service providers must get written permission from the parent before photographing, videotaping, recording, or interviewing a child, the parent, or any family members for whom the parent has legal custody. Anyone else in the photograph or video (e.g., the child's grandparent) must provide his own authorization for his photograph or other media to be released or displayed. Infant-Toddler Program staff and other early intervention service providers are to use the ***North Carolina DHHS Office of Public Affairs "Consent to Photograph/Interview"*** form (available in English and Spanish at www.beearly.nc.gov) to obtain permission to photograph, videotape, record or interview. The parent must provide written authorization before a photograph or other media type of the child, the parent, or any family member for whom the parent has legal custody, may be released or displayed.

It is important to protect the privacy of all the subjects in a photograph or other media. Consent of NC ITP Early Intervention Program staff and providers should also be obtained before taking or using an image or photograph for the purpose of illustrating reports, promotional documents, training videos, broadcast media, etc. Infant- Toddler Program staff and other early intervention service providers are to use the ***North Carolina DHHS Office of Public Affairs "Consent to Photograph/Interview"*** form (available in English and Spanish at www.beearly.nc.gov) to authorize permission for themselves to be photographed, videotaped, recorded, or interviewed.

Release of Information about a Family Member

A child's record may contain information about family members, especially in histories and evaluations. The parent is allowed to authorize the release of information about himself, his child, and any other family members for whom he has legal custody. However, anyone else mentioned in the requested information must give his own written authorization for the release of that information regardless of whether the information specifies the person's given name, or the person is referenced by a general title (e.g., grandmother). Service providers should not release information about family members without written authorization from the individual, if the service provider using professional judgment determines that the release of the information would breach the confidentiality of the individual. This requirement also applies to the review of information in the child's record. *(For additional information, see the Parental Access to Records Procedures.)*

Because of requirements to protect personally identifiable information of all persons relevant to the child, professionals must use good judgment regarding the need to record certain information in a child's record since any information recorded has the potential for being reviewed and released. *(For additional information about documenting in the child's record, see the section on Sensitive Information in the Infant-Toddler Program Records Procedures.)*

Billing

Parents are to give written authorization to bill private insurance by signing the appropriate section of the ***North Carolina Infant-Toddler Program Prior Written Notice and Consent for Evaluation and Assessment,*** the ***North Carolina Infant-Toddler Program Individualized Family Service Plan (IFSP) Agreement Page,*** or ***NC ITP IFSP Review Page***. The parent may specifically request a restriction on the disclosure of information for third-party billing purposes. (*For additional information see "Restrictions on Use and Disclosure of Information" in this procedures document beginning on page 5.*) The parent is to indicate such restriction by listing the restriction on the Agreement or Review Section of the ***NC ITP IFSP***. The parent should also complete and sign the ***North Carolina Infant-Toddler Program Request for Restrictions on Use and Disclosure of Health Information*** form. Service providers will be given financial eligibility information, which is to be provided by a staff member of the Children's Developmental Services Agency.

Research

1. Information from an Infant-Toddler Program record may be released to individuals conducting studies without written parental authorization:
   - A. if the information in the record is completely de-identified,
   - B. if approval for the research is requested in writing, and
   - C. if the written request follows and is approved by Division of Child and Family Well-Being requirements.
2. All requests for research studies must be forwarded from the Children's Developmental Services Agency Director to the Early Intervention Section state office.
3. Any request to release personally identifiable information for the purpose of research studies must have written parental authorization using the ***North Carolina Department of Health and Human Services Authorization to Disclose Health Information for Research***. All requests for personally identifiable information for research purposes must be forwarded by the Children's Developmental Services Agency Director to the Early Intervention Section state office.

Complaint Resolution

If a parent wishes to complain about any actions by a service provider related to confidentiality or privacy issues, the procedures outlined in the ***Dispute Resolution Policy*** are to be followed.