

Confidentiality and Privacy Issues

Introduction

Policies 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 providers, and
- 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.

Federal Privacy Regulations

The Family Educational Rights and Privacy Act (FERPA) is a federal law that protects the privacy of students and parents. Because the Infant-Toddler Program is funded at the federal level with education funds, it is considered an educational unit and must follow federal education requirements. The Family Educational Rights and Privacy Act mandates that personally identifiable information about a student contained in education records generally must be kept confidential in the absence of written parental authorization for release and that agencies keep a record of all organizations to whom it discloses education information. The Family Educational Rights and Privacy Act is incorporated in the Individuals with Disabilities Education Act 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 (HIPPA) 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. When dealing with children, particularly young children with special needs, it is often difficult to clearly separate types of information into easily distinguishable categories, such as either health or education. It also is burdensome for service providers to be held accountable for two sets of regulations covering the same basic protections.

In recognition of this duplication, 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. In other words, any health information that is generated and maintained by the Children's Developmental Services Agency 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 Applicability

The Family Educational Rights and Privacy Act 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 Bulletin #23 - Definitions of 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.

Because the North Carolina Infant-Toddler Program is a multi-provider program, all relevant and covered information may not be contained in one service provider's record on the child, but may be contained in the records of several service providers. 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 Infant-Toddler Program service providers and which pertains to referral and eligibility determination, evaluation and assessment, development of an Individualized Family Service Plan, 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.

Requirements

The North Carolina Infant-Toddler Program has established confidentiality and privacy requirements for Infant-Toddler Program service providers to follow. Service providers should follow these requirements to help ensure they are in compliance with the required Individuals with Disabilities Educational Act and the Family Educational Rights and Privacy Act. These requirements are outlined in the following sections of this Policy.

Confidentiality and Privacy Safeguards

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 Procedure Manual* and in the *Division of Public Health Privacy and Security Manual, 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, 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 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. Children's information may not be accessed until this training is completed. Service provider agencies are responsible for training their staff members; however, the Children's Developmental Services Agency is available to provide technical assistance, if needed.
4. 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. Service providers must inform the parent about the service provider's 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 service provider 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, service providers must release only the information minimally necessary to carry out the purpose of the release.
8. When confidential information is released, service providers must provide the parent with a copy of the information released, if requested by the parent.
9. Service providers must record on the *North Carolina Children's Developmental Services Agency 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. The parent may review this record of disclosure at any time. The service provider must allow the parent to review this record of disclosure within seven (7) calendar days of the parent's request and must document the request and the review, including the date of the request and the date the parent reviewed the record of disclosure.
10. Service providers must keep a record on the *North Carolina Children's Developmental Services Agency 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), including 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 and maintain this documentation with the child's record as long as the child's record is maintained. The parent may review this record of access at any time. The service provider must allow the parent to review this record of access within seven (7) calendar days of the parent's request and 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 Children's Developmental Services Agency staff contracted through the Early Intervention Branch understand the confidentiality and privacy requirements of the Infant-Toddler Program and agree to abide by such requirements. The Children's Developmental Services Agency is responsible for ensuring that enrolled Infant-Toddler Program service providers sign this agreement and adhere to its terms.

Children's Developmental Services Agency staff directly employed through the Early Intervention Branch should 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

Information concerning a child or family member is confidential and must not be exchanged among service providers without written authorization from the parent, except under special circumstances where this release is allowable by law such as 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.

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.

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 Policy Bulletin #12 - Written Parental Consent.*)

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.

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. 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 uses 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 should be maintained in the child's record.

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.

To be consistent with the requirements of informed consent for the release of information, a new authorization 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.

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 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 service provider should require proof of custody or legal representation of the child in such cases. Written documentation of such proof should 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 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 Uses and Disclosure of Information

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.

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, 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.

A parent may specifically request a restriction on the disclosure of information for third-party billing purposes. For example, the parent may wish to restrict the disclosure of sensitive information about substance abuse when the service provider submits a claim for processing. The parent is to indicate such restriction by initialing the appropriate place on the *North Carolina Infant-Toddler Program Financial Eligibility Application* form.

In situations where the parent has already authorized a disclosure of information, the 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.

Service 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

A 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 Office of Education Services 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 later in this Policy Bulletin.*);
- 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.

Service providers must document on the *North Carolina Children's Developmental Services Agency 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.

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.

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, service providers must honor this request if the release does not negatively affect treatment or is not material to the purpose of the disclosure. 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. Service providers 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:

1. Release is made to health care personnel providing direct medical care to the patient.
2. Release is necessary to protect the public's health and is made as provided by the Commission for Health Services in its rules regarding control measures for communicable diseases and conditions.
3. Release is made by the Department of Health and Human Services or a local health department to another state or local public health agency for the purpose of preventing or controlling the spread of a communicable disease or communicable condition.
4. Release is made pursuant to state statute that requires physicians and persons in charge of medical facilities or laboratories to permit a local health director or the State Health Director to examine and obtain a copy of medical records that pertain to communicable diseases.
5. Release is made pursuant to any other provisions of law that specifically authorize or require the release of information or records related to AIDS.

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

Each service provider 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. Only authorized persons may access the secure location and only authorized persons may remove any information from the secure location. Any information that is removed from a child's record must be checked out and written notation placed in the chart indicating 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. If an entire chart is removed from the established secure location, an outguide must be completed and placed in the location where the chart is normally filed. The outguide must include which chart was removed, the person removing the chart, and the date the chart was removed. It is recommended that the outguide also include the reason for removal of the chart and the date the chart is due to be returned to the secure location. 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 work day.

Emailing Information to Parents

If the parent requests that information be emailed to him, the 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;
- 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:

The documents accompanying this email contain confidential information that may be legally privileged and protected by federal and state law. This information is intended for use only by the individual or entity to whom it is addressed. The authorized recipient is obligated to maintain the information in a safe, secure, and confidential manner. The authorized recipient is prohibited from using this information for purposes other than intended, prohibited from disclosing this information to any other party unless required to do so by law or regulation, and is required to destroy the information after its stated need has been fulfilled.

If you are in possession of this protected health information and are not the intended recipient, you are hereby notified that any improper disclosure, copying, or distribution of the contents of this information is strictly prohibited. Please notify the owner of this information immediately and arrange for its return or destruction.

- 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

Service providers must be extremely cautious when using cellular phones to discuss confidential information as such communication is not secure, unless encrypted. If a service provider must use a cellular phone 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

Children's Developmental Services Agencies 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 Children's Developmental Services Agency 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

Service providers may re-release information generated by other service providers from the child's record with written authorization of the parent unless the originator of the information has stated that re-disclosure is prohibited or has placed any other conditions on its release. Service providers must make sure that the information being re-released is needed by the other service provider 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 Policy Bulletin #16 - Surrogate Parents.*)

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 written authorization for information to be shared with or 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 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 Children's Developmental Services Agency at the time of the notation. *(For additional information, see Policy Bulletin #14 - Native Language/Mode of Communication.)*

Parents who are Illiterate

If a parent is not literate and unless clearly not feasible to do so, the 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 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 Children's Developmental Services Agency 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 law 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 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, providers must obtain written authorization for release of information that is personally identifiable. *(For more information about referrals, see Policy Bulletin #19 – Referral Process.)*

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 is very clear about the responsibility of providers in protecting 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 the 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. It is particularly important to remember that an adoptive parent, an adoptee who is an adult at the time of the request, or a minor adoptee who is a parent or an expectant parent may request a copy of any document prepared in the adoption process.

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.

The following procedure must be followed by all Infant-Toddler Program service providers when an adoption occurs:

1. The child's existing Infant-Toddler Program record must be closed. All information that is in the existing record at the time of adoption stays in the closed record and remains in the child's pre-adoptive name. A copy of the adoption decree must be filed in the record so that there is legal documentation that the adoption has been finalized. The final progress note in the existing record must state that the adoption has been finalized, a copy of the adoption decree has been placed in the record, and that the record is being closed. The closed record should be archived as soon as possible.
2. An entirely new and separate Infant-Toddler Program record must be opened in the child's adoptive name. This includes assignment of a new record number since this record is viewed as the only one that exists on the child. The child's most recent evaluations, his current Individualized Family Service Plan, and any other information critical to providing services to the child (e.g. progress notes, the original North Carolina Infant-Toddler Program Data form, service orders) may be transferred to the new record. However, the child's pre-adoptive name and any other information that could possibly lead to the identity of the biological parents must be blacked out. This includes the names of foster parents. The child's adoptive name must be written above the blacked-out name with the person making this change initialing and dating the change just like other correction in a record. A new North Carolina Infant-Toddler Program Data form must be completed in the child's new name, but the original dates of referral, eligibility determination, etc. should be used. A new North Carolina Infant-Toddler Program Financial Eligibility Application must be completed based on the adoptive family's financial information. All documentation from the point in time at which the service provider has legal proof that the

adoption has been finalized must be in the child's new name only. It is not necessary to state in the new record that the child has been adopted; however, this may be included as appropriate (e.g., a report may state that medical history is unknown because the child was adopted.)

3. The service provider must establish some internal mechanism for cross-referencing the two records that exist on a child so that information from the old record may be retrieved at a later date, if necessary. This cross-referencing information must be placed on the log of assigned record numbers that is kept by the service provider or in some other internal listing of clients, but never in the child's new record.

If a foster parent is adopting a child, the procedure is the same as described above. While this seems unnecessary when a child is adopted by his foster parents, it should be noted that an adult child can request access to his record. When the pre-adoptive record has been sealed, only the information in the new record is available for access.

A request for information from pre-adoption records must be made in writing to the court. In order to access old records that contain identifying information, the adult child (or legal guardian of that person) must petition the court for release of these records. A date will be set for the court hearing, and the county Department of Social Services or other adoption agency, the Division of Social Services, and the county Department of Social Services staff attorney will be notified so they may participate in the hearing. The court will make a decision based on the best interest of all parties. If a birth parent or other relative comes forward after an adoption with information that is of vital importance to the health of the adoptee (e.g., a birth mother develops breast cancer and wishes her daughter to know this medical history), the county Department of Social Services must make reasonable efforts to contact and forward this information to the adoptee (if over 18) or to the adoptive parents (if the child is under 18). The county Department of Social Services must verify the identity, age, or other relevant characteristics of a person requesting information or providing information by a driver's license or some other appropriate means.

It is the responsibility of the Service Coordinator to notify the Children's Developmental Services Agency, if the Service Coordinator is from another agency, about the pending adoption of a child. It is the responsibility of the Children's Developmental Services Agency to notify all relevant service providers of a child's adoption, remind them of record requirements related to adoptions, and provide assistance to the service providers in meeting these requirements, as needed.

The preceding information provides basic guidelines for dealing with adoptions of children enrolled in the Infant-Toddler Program. Because local service providers often do not have expertise in the intricacies of this topic, the Early Intervention Branch is available to provide guidance related to protecting the confidentiality and privacy of all parties in adoption circumstances.

Photography

Service providers must get written permission from the parent before photographing a child, the parent, or any family members for whom the parent has legal custody. Anyone else in the photo (e.g., the child's grandparent) must provide his own authorization for his photograph to be released or displayed. Service providers are to use the *North Carolina Infant-Toddler Program Permission to Photograph* form to obtain permission to photograph. The parent must provide written authorization before a photograph of the child, the parent, or any family member for whom the parent has legal custody may be released or displayed.

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 Policy Bulletin #15 – Parental Access and Amendment to Records.*)

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 Policy Bulletin #29 - Infant-Toddler Program Records.*)

Billing

Parents are to give written authorization to bill private insurance by signing the appropriate section of the **North Carolina Infant-Toddler Program Financial Eligibility Application** form. The parent may specifically request a restriction on the disclosure of information for third-party billing purposes (*For additional information see Restrictions on Uses and Disclosure of Information*). The parent is to indicate such restriction by initialing the appropriate place on the **North Carolina Infant-Toddler Program Financial Eligibility Application** form and then 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

Information from an Infant-Toddler Program record may be released to individuals conducting studies without written parental authorization if the information in the record is completely de-identified, if approval for the research is requested in writing, and if the written request follows and is approved by Division of Public Health requirements. All requests for research studies must be forwarded from the Children's Developmental Services Agency Director to the Early Intervention Branch central office.

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 for Disclosure of 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 central office of the Early Intervention Branch.

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 “Policy Bulletin #17 Mediation and Administrative Due Process Hearings” in this Manual are to be followed.