



ANNOUNCEMENT: EI-12 #03
OFFICE OF CHILD DEVELOPMENT AND EARLY LEARNING
BUREAU OF EARLY INTERVENTION SERVICES

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SUBJECT: Confidentiality, Parent Consent and Surrogate Parents
TO: Infant/Toddler Early Intervention Leadership
FROM: Barbara G. Minzenberg, Ph.D. Deputy Secretary, Office of Child Development & Early Learning

A handwritten signature in cursive script, reading "Barbara G. Minzenberg, Ph.D.", positioned to the right of the typed name in the "FROM" field of the table.

PURPOSE:

The purpose of this announcement is to provide guidance on the new requirements under regulations for Part C of the Individuals with Disabilities Education Act (IDEA) Amendments of 2004 published on September 28, 2011 related to confidentiality, parental consent and notice, and surrogate parents.

BACKGROUND:

The Pennsylvania Early Intervention (EI) Program is implemented in compliance with the IDEA as amended by Public Law, 108-446, the Pennsylvania Early Intervention Services System Act, Pennsylvania Act 212-1990, and Title 55, Chapter 4226 Early Intervention Services.

Many of the requirements of the 2004 IDEA amendments are included in Chapter 4226 and Office of Child Development and Early Learning (OCDEL) Announcements. However, the reauthorization of IDEA and the subsequent promulgation of federal Part C regulations on September 28, 2011 have clarified or established additional requirements. All requirements in Chapter 4226 remain in effect. The information contained within this announcement supplements those requirements in Chapter 4226.

DISCUSSION:

Each local Infant/Toddler EI Program shall ensure parents of a child referred to EI are afforded the right to confidentiality of personally identifiable information as defined in the Family Educational Rights and Privacy Act (FERPA) 34 CFR 99.3, including the right to written notice of, and written consent to, the exchange of that information among agencies. In addition to the requirement established at §4226.92-96, the following also applies to local Infant/Toddler EI Programs.

Definition:

Parent is defined as:

- (1) a biological or adoptive parent of a child;
- (2) a foster parent;
- (3) a guardian authorized to act as the child's parent, or authorized to make EI, educational, health or developmental decisions for the child;
- (4) an individual acting in the place of a biological or adoptive parent (including a grandparent, stepparent, or other relative) with whom the child lives, or an individual who is legally responsible for the child's welfare; or
- (5) a surrogate parent who has been appointed in accordance with applicable federal and state regulations.

The biological or adoptive parent, when attempting to act as the parent and when more than one party is qualified to act as a parent, must be presumed to be the parent for purposes of EI unless the biological or adoptive parent does not have legal authority to make educational or EI services decisions for the child. If a judicial decree or order identifies a specific person or persons to act as the "parent" of a child or to make educational or EI service decisions on behalf of a child, then the person or persons must be determined to be the parent, except that if an Early Intervention Service provider or a public agency provides any services to a child or any family member of that child, that Early Intervention Service provider or public agency may not act as the parent for that child. Public agency is defined as the Department of Public Welfare and any other agency of the State.

Consent is defined as:

- (a) The parent has been fully informed of all information relevant to the activity for which consent is sought, in the parent's native language, as defined in §303.25;
- (b) The parent understands and agrees in writing to the carrying out of the activity for which the parent's consent is sought, and the consent form describes that activity and lists the early intervention records (if any) that will be released and to whom they will be released; and
- (c)(1) The parent understands that the granting of consent is voluntary on the part of the parent and may be revoked at any time.

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

Confidentiality of Personally Identifiable Information:

Local Infant/Toddler EI Programs shall protect the confidentiality of personally identifiable data, information and records for infants or toddlers who are referred to, or receive EI services. Confidentiality must be assured at the collection, maintenance, use, storage, disclosure, and destruction stages of a child's EI record and applies from the point in time when the child is referred to the EI program.

Local Infant/Toddler EI Programs shall afford the parents of infants or toddlers who are referred to, or receive EI services, the opportunity to inspect and review all EI records about the child and the child's family that are collected, maintained, or used both in electronic or paper form, including records related to evaluations and assessments, screening, eligibility determinations, development

and implementation of IFSPs, provision of EI services, individual complaints involving the child, or any part of the child's EI record. Local Infant/Toddler EI Programs shall comply with a parent's request to inspect and review records without unnecessary delay and before any meeting regarding an IFSP, or any due process hearing procedures and in no case more than 10 days after the request has been made. This includes:

- a response from the local Infant/Toddler EI Program to reasonable requests for explanations and interpretations of the EI records;
- a request that the Local Infant/Toddler EI Program provide copies of the EI records containing the information if failure to provide those copies would effectively prevent the parent from exercising the right to inspect and review the records; and
- having a representative of the parent inspect and review the EI records.

If any EI record includes information on more than one child, the parents of those children have the right to inspect and review only the information relating to their child. Local Infant/Toddler EI Programs shall presume that the parent has authority to inspect and review records relating to his or her child unless the agency has been provided documentation that the parent does not have the authority under applicable State laws governing such matters as custody, foster care, guardianship, separation, and divorce.

The local Infant/Toddler EI Program may not charge a fee to parents for:

- the search or retrieval of information from a child's EI record.
- a copy of each evaluation, assessment of the child, family assessment, and IFSP as soon as possible after each IFSP meeting.
- an initial request for a copy of the child's entire EI record.

A parent may request for the local Infant/Toddler EI Program to amend information in the EI record if they believe that information is inaccurate, misleading, or violates the privacy or other rights of the child or parent. The local Infant/Toddler EI Program shall decide within a reasonable period of time of receipt of the request whether to amend the information. If the local Infant/Toddler EI Program refuses to amend the information, the parent shall be informed of the refusal and be informed of their right to a due process hearing or a review by the Bureau of Early Intervention Services (BEIS) regarding the request for amending the information in their child's EI records.

If the BEIS decides that the information is inaccurate, misleading or in violation of the privacy or other rights of the child or parent, BEIS will inform the parent in writing and the local Infant/Toddler EI Program shall amend the information. The local Infant/Toddler EI Program shall inform the parent in writing when the information is amended.

If the BEIS decides that the information is not inaccurate, misleading, or in violation of the privacy or other rights of the child or parent, the BEIS will inform the parents of their right to include a statement in the child's record indicating reasons for disagreeing with the decision of the local Infant/Toddler EI Program. The local Infant/Toddler EI Program must maintain this statement as part of the EI record of the child as long as the record or contested portion is maintained. In addition, if the EI record of the child or the contested portion is disclosed to any party, the explanation must also be disclosed to the party.

The local Infant/Toddler EI Program shall ensure local confidentiality policies and procedures include the following:

- one person within the program is assigned to manage the confidentiality procedures of personally identifiable information;
- a current listing is maintained, for public inspection, of the names and positions of those employees within the program who may have access to personally identifiable information;
- upon request from the parent, a list of the types and locations of EI records collected, maintained, or used by the agency that are not included in the statewide data information system (PELICAN);
- upon initial contact, parents are provided a standardized notice developed by the Bureau of Early Intervention Services (BEIS) that contains information on the types of information kept, the methods the State uses to gather the information, the location of the information, how the information will be used and the procedures for the destruction of information (See Attachment 1);
- all persons collecting or using personally identifiable information receive training on the requirements in this announcement, 34 CFR§303.401 through 303.417 and 34 CFR part 99. Training shall occur upon initial hiring and as necessary to ensure the confidentiality of personally identifiable information.

Parent Consent and Notice:

Parental consent must be obtained by the local Infant/Toddler EI Program before personally identifiable information is disclosed to anyone other than authorized representatives, officials, or employees of the local Infant/Toddler EI Program or used for any purpose other than meeting a requirement of federal and state requirements with the exception of those conditions in FERPA 34 CFR §99.31 and §303.401(d). In addition, local Infant/Toddler EI Programs must comply with the requirements of FERPA 34 CFR §99.32, 99.33, 99.34, 99.35, 99.36, 99.38, and 99.39. Local Infant/Toddler EI Programs shall also obtain parental consent before administering screening procedures, conducting evaluations and assessments, the provision of EI services, accessing public benefits or insurance or private insurance and the disclosure of personally identifiable information. If a parent does not give consent for any of these activities, the local Infant/Toddler EI Program must make reasonable efforts to ensure that the parent is fully aware of the nature of the activities where parental consent is sought; and understands that the child may not be able to receive the service unless consent is provided.

The parents of an infant or toddler with a disability can determine whether they, their infant or toddler with a disability, or other family members will accept or decline any EI service at any time, and may decline a service after first accepting it, without jeopardizing other EI services under this part. In addition to the language established in Chapter 4226.92, the Infant/Toddler EI Program may not use due process hearing procedures to challenge a parent's refusal to provide any consent and shall ensure that if a parent revokes consent, that revocation is not retroactive (i.e., it does not apply to an action that occurred before the consent was revoked).

Surrogate Parent:

In addition to the regulations established in Chapter 4226.96 related to surrogate parent, the following requirements also apply to local Infant/Toddler EI Programs:

- the local Infant/Toddler EI Program must make reasonable efforts to ensure the assignment of a surrogate parent not more than 30 days after the program has determined that the child needs a surrogate parent;
- the surrogate parent has the same rights as a parent;
- when implementing the requirements related to the assignment of a surrogate parent for children who are wards of the State or placed in foster care, the local Infant/Toddler EI Program shall consult with the local County Children, Youth and Family agency that has been assigned care of the child.

NEXT STEPS:

1. Infant/Toddler Early Intervention Programs shall review existing procedures to assure that they are consistent with this Announcement and shall take steps to assure that they are in compliance.
2. Infant/Toddler Early Intervention Programs shall ensure that all staff and providers review the information included in this Announcement and new or revised local procedures.

Comments and Questions Regarding this Announcement Should be Directed to the Office of Child Development and Early Learning, Bureau of Early Intervention Services at 717-346-9320 or ra-ocdintervention@state.pa.us

Understanding Early Intervention Data Systems

The Office of Child Development and Early Learning (OCDEL), through the Bureau of Early Intervention Services, serves approximately 79,000 infants, toddlers and preschool children with developmental delays and/or disabilities from birth until they reach school age. Electronic information management systems are used to maintain individual child records in the Early Intervention (EI) program.

What is Early Intervention's Data System?

PELICAN (Pennsylvania's Enterprise to Link Information for Children Across Networks) is the name of OCDEL's information management system. It is used to manage all the records of children receiving EI services across the Commonwealth. The information that is entered into PELICAN is based on the information families provide to service coordinators or Early Intervention service providers about their child through conversation, correspondence and meetings. The PELICAN system contains:

- Demographic information about children i.e. name, address, contact information, date of birth etc.
- Evaluation information
- Information about family routines and activities so that OCDEL can match the services to the child's natural settings
- Individualized Family Service Plans (IFSP) and Individualized Education Programs (IEP)
- Transition plans

To make sure there is only one identifying number assigned to each child, the EI program will ask families to provide the child's Social Security Number (SSN). The child's SSN ensures the proper identification of a child's information, especially if it already exists in other statewide data systems. This prevents families from providing the same information repeatedly. However, providing the child's SSN is not required to receive EI services.

Why is information collected in a data system?

Child information is collected to allow for effective program management and accountability including:

- Assessing the effectiveness of EI programs and services in supporting children and families both at the state and local level
- Identifying best practices and areas for improvement at the state level
- Completing mandatory state and federal reports
- Making provider payments.

What are the benefits of an electronic data system to families?

Families will not have to give the same information repeatedly as they move through the EI program. Each child record in the information management system will be assigned one identifying number. This means that each child receiving services will have only one record in the statewide data system, regardless of how they entered the system or what services they receive.

Maintaining child records through an information management system allows the record to be accessible to his/her IFSP/IEP team. It also allows for a smooth exchange of information when a child transitions from one program to another, as the child's record may be shared quickly with a new program (with parental consent).

Data systems promote and assure:

- Quality services for children
- Program accountability to ensure all resources are used wisely and effectively

- Anticipation of changing needs
- Continuity of data across programs.

Who has access to a child's information?

Child information contained in the information management system is kept confidential and only authorized persons will have access to the records, per federal and state confidentiality, privacy, and security laws. Data in PELICAN is protected by security protocols, which require secure and encrypted servers, unique user names with strong passwords and user roles that are assigned specific security roles and access. This means that:

- Only the staff directly involved with a specific child has access to that child's information.
- State personnel have limited access to child information for the purposes of monitoring the delivery of EI services.
- Information about a child will not be shared outside a program, except as permitted by law and/or with parental consent.
- Families have the right to inspect and review EI records relating to their child, request an amendment to inaccurate information in a record and the destruction of child information and the request of the parent if it is no longer required to be maintained under applicable Federal and State laws. A copy of a child's record is also available to families upon request and is kept for a period of four years.
- As permitted by law, for transition purposes, a child's name, date of birth and parent contact information will be shared with the Preschool Early Intervention Program during a transition year to assist with planning purposes.

Who should families contact with questions about their child's record in these data systems?

Families should call their child's Service Coordinator, Teach/Therapist or Preschool EI Supervisor should they have any concerns regarding the collection of child information in PELICAN. If at any time, you feel that confidentiality has been compromised; families may file a complaint with the OCDEL by call 717-346-9320.