A Family's Introduction to Early Intervention in Pennsylvania

pennsylvania
OFFICE OF CHILD DEVELOPMENT
AND EARLY LEARNING

At A Glance: Phone Numbers to Contact

My child is receiving supports and services through the Early Intervention program.

Service coordinator: _____

Phone: _____

Infant/toddler early intervention program representative: _____

Phone: _____

Preschool early intervention program representative: _____

Phone: _____

Teacher name: _____

Agency: _____

Phone: _____

Therapist name: _____

Phone: _____

Other name: _____

Agency: _____

Phone: _____

Table Of Contents

Welcome 2

What is early intervention in Pennsylvania? 3

What are early intervention supports and services? 3

Who is eligible for early intervention services? 4

Where do I start? 5

IFSP–Individualized Family Service Plan
IEP–Individualized Education Program 6

Transitions for you and your child 9

What do you do if you are not satisfied with
the early intervention services your child receives? 10

Where to go for more information 11

Appendix 14

- Individuals with Disabilities Education Act 14
- Pennsylvania Act 212: Early Intervention Services Act of 1990. 14
- Family Educational Rights and Privacy Act (FERPA). 15
- Understanding the early intervention data system 16

"Families are big, small, extended, nuclear, multigenerational, with one parent, two parents, and grandparents. We live under one roof, or many. A family can be as temporary as a few weeks, or as permanent as forever. We become a part of a family by birth, adoption, marriage, or from a desire for mutual support... A family is a culture unto itself, with different values and unique ways of realizing its dreams; together our families become the source of our rich cultural heritage and spiritual diversity... Our families create neighborhoods, communities, states, and nations."

Source: REPORT OF THE HOUSE MEMORIAL 5 TASK FORCE ON YOUNG CHILDREN AND FAMILIES, (1990), NEW MEXICO

Welcome

When you think of your child and how he or she is growing, you notice things like how soon he or she smiles, sits up, rolls over, or how well he or she walks, talks, holds a spoon, and feeds himself or herself. Children learn naturally during this time by watching you and other children, and by being taught how to do different things. Because you know your child so well, you might notice that he or she is growing or developing differently than a cousin, brother or sister at that age. What you are noticing are changes in development. Children develop in five primary areas:

- Ability to move, see, and hear—physical development
- Ability to talk, understand, and express needs—language and speech development
- Ability to relate to others—social and emotional development
- Ability to eat, dress, and take care of oneself—self help (or adaptive development)
- Ability to think and learn—cognitive development

While all children grow and change at their own rate, some children can experience delays in their development. Sometimes this can be cause for concern.

My 2-year-old daughter, Rose, was born prematurely and with Trisomy 21. The days following her birth were difficult and overwhelming. At the time, the only thing I knew for sure was that I did not know enough to be able to help her grow and thrive. What actually went through my mind one night was - to paraphrase a quote from the movie, Jaws – "We need a bigger boat!" For my family, early intervention was the bigger boat. The exchange of ideas, different strategies, and the ability to share concerns, hopes and goals with the therapists was life-saving for us, especially me. The services we continue to receive have made me more confident in my parenting abilities. Early intervention provides tools for the entire family, not just the child receiving services.

Karen, Delaware County

What is early intervention in Pennsylvania?

Early intervention in Pennsylvania consists of services and supports designed to help families with children who have developmental delays or disabilities. Early intervention builds upon the natural learning occurring in those first few years. It is a process that promotes collaboration among parents, service providers, and others significantly involved with your child.

Early intervention:

- Helps children with disabilities develop and learn to their fullest potential
- Enhances each family's capacity to meet the developmental needs of their child in the settings where children would be if they did not have a disability
- Respects the family's strengths, values, diversity and competencies and answers families' questions about their child's development
- Supports communities to become more aware of the gifts and abilities of all its children
- Helps prevent the need for more and costly intervention in the future

What are early intervention supports and services?

Early intervention supports and services are provided at no cost to families. Early intervention services can include: information about how children develop, parent or caregiver education, family supports, and developmental and instructional therapies that assist in child development. Early intervention is individualized and provides supports to the child and family at home and in the community and is individualized to enhance the child's growing and learning. When a child attends an early care and education setting, early intervention can assist the early childhood staff with strategies to promote the child's development. Early intervention can also assist families to link to a variety of community services and supports.

You are the expert about your child. The recommendations or suggestions that you have for your child and family are uniquely yours. Sharing them with other members on your early intervention team allows others to know what is important to your family. This information will help your early intervention team to create meaningful individualized services and supports.

Who is eligible for early intervention services?

If your child is

Birth to three years old:

Infants and Toddlers who have:

- A 25 percent delay in one or more areas of development

OR

- A specialist's determination that there is a delay even though it doesn't show up on the assessments (called informed clinical opinion)

OR

- A known physical or mental condition that has a high probability for developmental delays (such as Down syndrome)

Three to the age of beginners*:

Preschoolers who have:

- A 25 percent delay in one or more areas of development

OR

- Any of the following physical or mental disabilities: autism/pervasive developmental disorder; serious emotional disturbance; neurological impairment; deafness/hearing loss; specific learning disability; intellectual disability; multiple disabilities; other health impairment; physical disability; speech impairment or blindness/visual impairment;

AND

- Are in need of special education and related services.

Through a unique collaboration between the Pennsylvania Departments of Education (PDE) and Public Welfare (DPW), the Office of Child Development and Early Learning (OCDEL) administers the commonwealth's early intervention program for eligible infants, toddlers and preschoolers.

At a local level, the infant/toddler early intervention programs administer the services for children from birth to three years of age. OCDEL contracts services through intermediate units (IUs), school districts, and private agencies for local services to preschoolers from three years of age to the age of beginners.*

* Age of entrance into first grade

Where do I start?

Screening

Your first contact with the early intervention program may include a screening of your child's development. A screening is a quick and easy process, usually just a few questions about your child's development. The screening helps to determine if an evaluation is needed. You may request a multidisciplinary evaluation at any point during the screening process.

Evaluation

If there are concerns about your child's development, a multidisciplinary evaluation will be conducted to determine your child's eligibility for early intervention supports and services.

The evaluation will only occur with your written permission. You will be given a consent form to indicate that you understand and agree to the evaluation.

Planning for an evaluation begins with a team; you and your service coordinator or representative from the early intervention program. Other team members may participate as appropriate for your child and family's needs. **You are the expert on your child** and your participation as a member of the team is very important.

How to prepare for the evaluation:

- Inform the service coordinator or your early intervention contact person if you need an interpreter or other assistance.
- Be ready to share information that you think is important: current health appraisal, medical records, a baby book, growth chart, or other evaluations or reports.
- Think about your child and any questions or concerns you might have related to his or her development.
- Be prepared to share information about activities that are challenging for your child and family to participate in at home, in the community, and at child care or preschool, as well as what your child and family enjoy doing together.
- Think about where your current support comes from, for example, your extended family, a faith community, your neighborhood, a parent group, etc.

The evaluation will look at all areas of your child's development. During the evaluation, you and members of the team will talk about the good things your child is doing as well as identify any concerns. The evaluation will also determine the strengths and needs of your child and family.

If your child is determined eligible, the information from the evaluation will help the team know what is important to your family and will help create meaningful individualized services.

IFSP–Individualized Family Service Plan
IEP–Individualized Education Program

If your child is eligible, the early intervention team, including you, will move to the next step; the development of a written plan. The written plan for infants and toddlers is called the Individualized Family Service Plan (IFSP) and for preschool children it is called the Individualized Education Program (IEP).

Who develops the IFSP or IEP?

With your service coordinator or representative from the early intervention program, you help develop the IFSP or IEP. **You are an equal partner on the team.** As the parent and expert on your child, your knowledge of your child is important to the development of the IFSP or IEP.

How is the IFSP or IEP developed?

Your IFSP or IEP team will meet together and discuss the information gathered from the evaluation about your child's strengths and needs. The plan meeting is your opportunity to share ideas for your child and family with other members of the team. It is also your opportunity to share information about your daily routines, preferred activities, and activities that are challenging for your family. This information will provide your team with ideas about how to target early intervention supports and services to meet your child's and family's needs.

We are grateful for the support, kindness, guidance, understanding and ideas to help our son, Alex. We learned about the importance of working as a team to help him and have been thankful for this program ever since.

Nancy,
Montgomery County

An IFSP or IEP must include:

- A statement of your child's level of development
- With your consent, a statement of the family's strengths, priorities and concerns as they relate to your child's development
- Information or assistance to help you access community resources
- Special considerations that relate to vision, hearing, challenging behaviors, communication and needs related to assistive technology or transitions
- The measurable goals or outcomes expected for your child and family, as well as how and when it is hoped they will be achieved
- A description of early intervention services that are to be provided, as well as in what setting they will occur
- A statement of when services are expected to begin and how long they will continue
- The name of your service coordinator or early intervention contact person
- A written plan for transitions as your child's needs change
- The date when the IFSP or IEP will be reviewed

IFSP or IEP *(continued)*

Where are IFSP or IEP services provided?

Early intervention services must be delivered in settings that are consistent with the needs of your child and family. To the maximum extent appropriate, services and supports are provided in environments, including the home and community settings, in which children without disabilities participate.

Early intervention supports and services are embedded in the learning opportunities that exist within your typical routines in the home, community and/or child care/preschool programs. Early intervention services should support the child's participation in the typical routines of family and community life.

When do early intervention services and supports start?

The IFSP or IEP is the foundation of early intervention services. Early intervention services must start no later than 14 calendar days from the date you agree to the services described on the IFSP or IEP, unless you and the team recommend a later date.

You may request an IFSP or IEP meeting to discuss the potential need for changes at any time by getting in touch with your service coordinator or contact person.

How to prepare for the IFSP or IEP:

- Identify your child's unique qualities and strengths.
- Think about what you and your family want for your child now, and in one, two, or five years from now or even as an adult.
- Identify the questions you have regarding your child. All questions are important. For example: Why is she so fussy? Why is he so quiet? Is that ok? Is that a concern?
- List what you and your child really enjoy doing such as: playing with water or sand, watching TV, or going for walks. This will help you and the team identify how you can use these routines to help your child develop and grow.
- Consider the special needs your child has. Think about what your child might need to reach his or her full potential: adaptive equipment, feeding or self-help skills, help to move around, or help to communicate.
- Consider issues for which you would like help in finding the solution. For example, do you as a family like to go to the beach, but you're concerned about how to take your child?

Transitions for you and your child

Transitions occur in our lives all the time in many different ways. Changes in our jobs or homes are examples. While receiving early intervention services, you and your child experience transitions as well.

Transition in early intervention services means movement from one program to another, such as:

- From the hospital to your home
- From an infant/toddler early intervention service to a preschool early intervention service
- From early intervention services to other early care and education settings such as Head Start or child care programs
- From preschool early intervention services to kindergarten or first grade

Planning a successful transition

As a very important part of the team, you need to know all the options—ask questions:

- What is needed for my child?
- What is available?
- Who is involved?
- Where are they?
- When is this transition going to occur?
- How will the transition occur?
- What activities will help my child adjust to the transition?
- How can my family and child be supported through this change?

Early intervention transition meetings

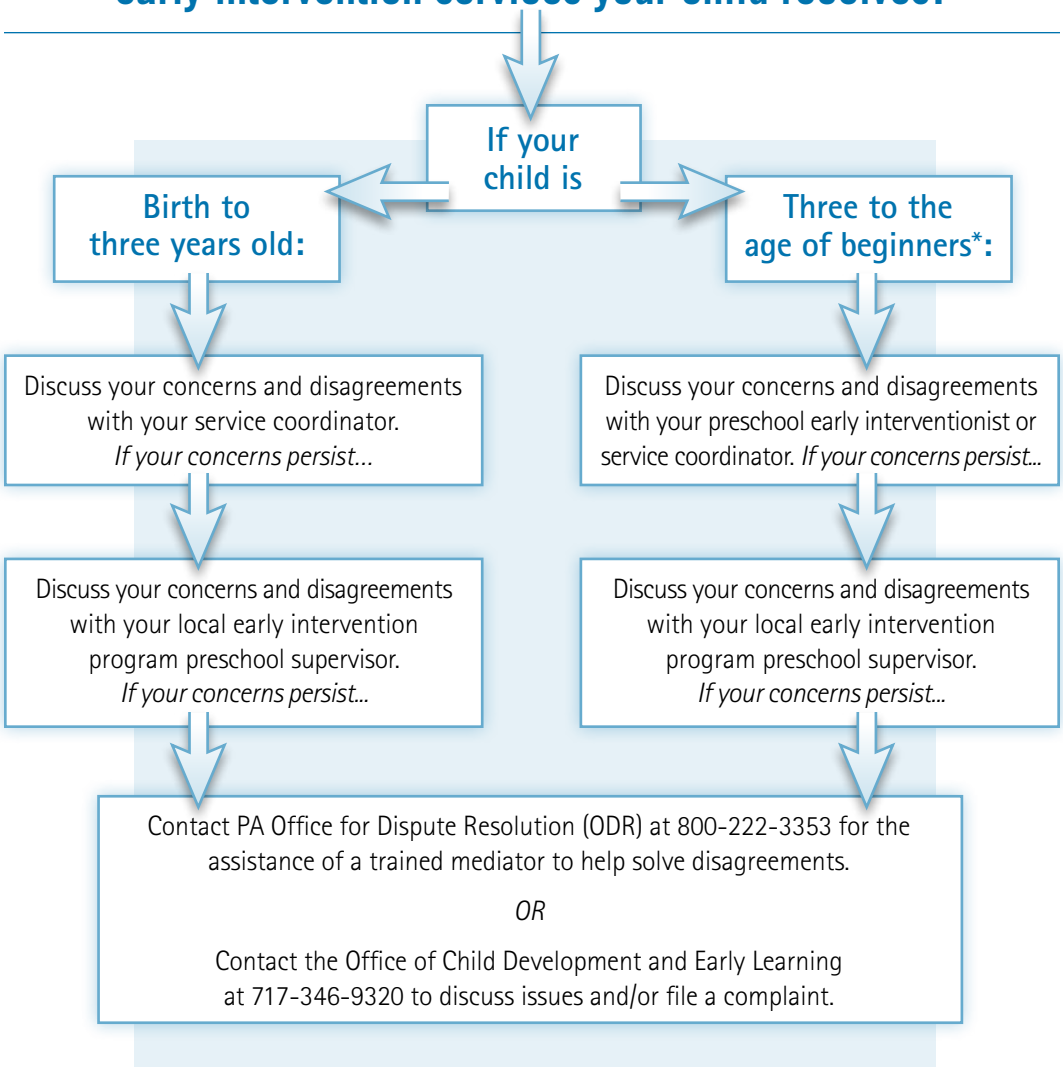
If your child is in the county infant/toddler early intervention program, the year before your child's third birthday, the early intervention program will invite you to a transition meeting to discuss options. The transition meeting should occur 90 days before your child's third birthday.

If your child is in the preschool early intervention program, during the year before your child is eligible for kindergarten or first grade, the early intervention program will invite you to a transition meeting to discuss options for your child. This transition meeting must occur before the end of February. If your child is kindergarten/school age, the funding for services is the responsibility of the local school district.

Sharing information during transitions

Sharing information is key to a successful transition. To help with transition planning, the Office of Child Development and Early Learning (OCDEL) provides local early intervention preschool programs with information on infants and toddlers in the early intervention program who will be turning 3 in the upcoming year. This information includes the child's name, date of birth, and parent contact information. This information is provided as required by federal regulations and helps to make sure that all children who are potentially eligible for early intervention services have been identified. Your written permission is required to share any additional information with the early intervention preschool program.

What do you do if you are not satisfied with the early intervention services your child receives?



You may request a due process hearing conducted by the Office for Dispute Resolution at any time by:

- Contacting your service coordinator at the infant/toddler early intervention program if your child is under three years of age; or
- Contacting your preschool early intervention program supervisor and putting your request in writing if your child is three years of age or older; or
- Calling ODR at 800-222-3353 or visit the ODR website at http://odr-pa.org.

If you have any questions about which process to follow, call one of the phone numbers listed above. Persons who are deaf or hard of hearing may access all numbers by dialing 800-654-5984 or 711 through the PA Relay Service.

* Age of entrance into first grade

Where to go for more information

Parent to Parent of Pennsylvania (P2P of PA)

888-727-2706 (toll free)
Email: info@parenttoparent.org
www.parenttoparent.org

Parent to Parent of Pennsylvania links families of children and adults with disabilities or special needs on a one-to-one basis with a peer supporter for purposes of support and information. Services are free and confidential.

Competence and Confidence Partners in Policymaking Early Intervention (C2P2EI)

215-204-3031
Email: iod@temple.edu
http://disabilities.temple.edu/programs/leadership/c2p2ei.shtml

C2P2EI is an innovative leadership training program for parents of children in early intervention. C2P2EI provides up-to-date information on best practices, resources, and policy issues.

Disability Rights Network of Pennsylvania (DRN)

800-692-7443 (Harrisburg)
215-238-8070 (Philadelphia)
412-391-5225 (Pittsburgh)
Email: intake@drnpa.org
www.drnpa.org

DRN is a statewide, nonprofit corporation designated as the federally mandated organization to advance and protect the civil rights of adults and children with disabilities.

Education Law Center

215-238-6970 (Philadelphia)
412-258-2120 (Pittsburgh)

The Education Law Center is a nonprofit legal advocacy and educational organization, dedicated to ensuring that all of Pennsylvania's children have access to a quality public education.

Hands and Voices Guide By Your Side (GBYS)

800-360-7282 x3908 (PA Only)
Email: agaspich@pattan.net
www.paearlyhearing.org/gbys.php

GBYS is a specialized parent support program that links families of infants and toddlers identified with deafness and hearing loss with trained and experienced parent guides. Parent guides are other parents of children with deafness and hearing loss who provide unbiased information and emotional support. Services are free and confidential.

Hispanos Unidos para Niños Excepcionales (HUNE) (Hispanics United for Exceptional Children)

215-425-6203 (Voice) / 215-425-6204 (Fax)
www.huneinc.org

HUNE is a not-for-profit organization that provides free, bilingual English and Spanish training and technical assistance to parents of infants, children, and youth with disabilities and to professionals who work with children.

Where to go for more information *(continued)*

Local Interagency Coordinating Councils (LICCs)

To contact your local LICC, call CONNECT at 800-692-7288 (for TTY, dial 711 for Relay Service) or email CONNECTHelp@tiu11.org.

LICCs are local early intervention program councils with membership from families, infant/toddler and preschool early intervention programs, school districts, early intervention providers, and other programs. Please ask your early intervention program how you can get involved.

The Mentor Parent Program

888-447-1431 (in PA only)
814-226-4151
Email: info@mentorparent.org
www.mentorparent.org

The Mentor Parent Program serves rural northwest Pennsylvania. The Mentor Parent Program exists to provide information, resources and training to the parents of children about all aspects of early intervention and special education.

Mission Empower

855-825-0788
Email: advocate@missionempower.org
www.missionempower.org

Mission Empower serves Erie County families who have children with the full range of disabilities, from birth to age 26, by providing individual assistance, as well as advocacy, training, and facilitation of parent involvement in their child's school.

Office of Child Development and Early Learning (OCDEL)
Bureau of Early Intervention Services (BEIS)

717-346-9320
Email: RA-ocdintervention@pa.gov
www.pde.state.pa.us (click on Pre K-12, then Early Childhood, then Early Intervention)
OR
http://dpw.state.pa.us (go to drop-down menu for DPW Program Offices, click on Office of Child Development and Early Learning, then Early Intervention).

Through a unique collaboration between the Departments of Education (PDE) and Public Welfare (DPW), OCDEL administers Pennsylvania's early intervention program for infants, toddlers and preschoolers with developmental delays or disabilities.

All of our therapists communicated with each other and provided a coordinated, comprehensive plan for our child. This helped to ensure that we got the most out of this critical time for our child and that she was prepared for preschool.

Marquitha,
Chester County

Parent Education and Advocacy Leadership (PEAL) Center

866-950-1040 (toll free)
412-281-4404 (Voice) / 412-281-4409 (TTY)
412-281-4408 (Fax) / 886-950-1040 (Toll Free)
Email: info@peal.org
www.pealcenter.org

The PEAL Center provides training and information for parents and friends of children with disabilities, educators, health care and community service providers, and advocates. The PEAL Center serves western and central Pennsylvania.

Parent Education Network (PEN)

800-522-5827 (Voice/TTY)
800-4415028 (Español)
Email: pen@parentednet.org
www.parentednet.org

PEN is a federally funded project providing information and support to parents of children with disabilities throughout Pennsylvania.

Parents as Partners in Professional Development (P3D)

800-441-3215 x7277
Email: mmikus@pattan.net

P3D links family members to early intervention professional development and pre-service opportunities. Families share their insight and expertise in such roles as co-presenters, university guest lecturers, and publication reviewers.

Pennsylvania Office for Dispute Resolution (ODR)

800-992-4334
Email: odr@odr-pa.org
www.odr-pa.org

ODR provides the resources for parents and educational agencies to resolve disputes concerning the identification, evaluation, educational placement, or the provision of service for infants, toddlers, preschool children, and students with disabilities served by the early intervention or special education system. These services include mediation, IEP facilitations, and due process hearings.

Pennsylvania Training and Technical Assistance Network (PaTTAN)
Early Intervention Technical Assistance (EITA)

PaTTAN works collaboratively with intermediate units in the area of professional development, technical assistance, and information dissemination to support school districts throughout the Commonwealth. Early Intervention Technical Assistance (EITA) works collaboratively with early intervention programs for children with developmental delays/disabilities. EITA it the birth to school age component of PaTTAN.
www.pattan.net

PaTTAN Harrisburg

800-360-7282
or 717-541-4960

PaTTAN King of Prussia

800-441-3215
or 610-265-7321

PaTTAN Pittsburgh

800-446-5607
or 412-826-2336

Appendix

Individuals with Disabilities Education Improvement Act of 2004 (IDEA)

In Pennsylvania, the Office of Child Development and Early Learning, Bureau of Early Intervention Services, administers both Part C and Part B of the federal law IDEA.

Part C

- Provides services for eligible infants and toddlers and their families from birth until the child's third birthday
- Services are developed by a team and written into an Individualized Family Service Plan (IFSP)
- Services are delivered in a natural environment for the child and family

Part B (Section 619 is the Preschool Section)

- Provides services for eligible young children and their families from age three to the age of beginners (start of first grade)
- Services are developed by a team and written into an Individualized Education Program (IEP)
- Services are delivered in the least restrictive environment

Pennsylvania Act 212: Early Intervention Services System Act of 1990:

PA-Act 212, the state statute for early intervention services, requires the Departments of Education and Public Welfare to ensure that:

- Eligible young children (birth until the age of beginners) and their families receive early intervention services and programs
- Appropriate services under public supervision that are designed to meet the developmental needs of eligible children are available
- Services specifically designed to address the needs of the family to enhance their child's development are provided

Family Educational Rights and Privacy Act (FERPA)

The following information summarizes your rights and privileges under the Family Educational Rights and Privacy Act of 1974 (FERPA). This is a federal law which protects the confidentiality of a child's educational records by limiting their disclosure. FERPA guarantees parents certain rights which are described below.

1. **Access to records:** You have the right to inspect and review your child's records and to receive a copy of the records.

2. **Amend information in records:** You have the right to request that your child's early intervention records be changed if they are inaccurate or misleading, and to have a hearing if that request is refused.

3. **Disclosure of personally identifiable information:** Generally, the early intervention program must have written permission from the parent in order to release any information from a child's educational record. However, FERPA allows early intervention programs to disclose those records, without consent, to the following parties or under the following conditions:
   a. Early intervention officials with legitimate educational interest
   b. Dissemination of directory information (e.g., child's name, DOB, and parent contact information)
   c. Other early intervention program to which a child is transferring
   d. Specified officials for audit or evaluation purposes
   e. Organizations conducting certain studies for or on behalf of the early intervention program
   f. To the courts to comply with a judicial order or lawfully issued subpoena
   g. Appropriate officials in cases of health and safety emergencies

4. **Complaints:** If you believe that the early intervention program is not complying with FERPA or not guaranteeing you your rights outlined above, you may file a letter of complaint with the federal office in charge of enforcing the Act at the address below:

   Family Policy Compliance Office
   U.S. Department of Education
   400 Maryland Avenue
   Washington, DC 20202-8520
   202-260-3887

5. **Policy:** A complete copy of the FERPA legislation is available at your request. You may receive a copy by contacting your early intervention program or www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html.

Parental Consent and Notice

1. **Prior written notice:** You have the right to prior written notice before the early intervention program proposes, or refuses, to initiate or change the identification, evaluation, or placement of your child or the provision of early intervention services.

2. **Parental consent:** You must provide consent before any screening, evaluation or assessment; before early intervention services are provided; before public benefits or insurance or private insurance is accessed; and prior to the disclosure of personally identification information.

Appendix *(continued)*

Understanding the early intervention data system

The Office of Child Development and Early Learning (OCDEL), through the Bureau of Early Intervention Services (BEIS), has electronic information management systems, which are used to maintain individual child records in the early intervention 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 early intervention 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)
- 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 early intervention 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 early intervention 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 early intervention 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 early intervention 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 a child's record through an information management system allows the record to be accessible to his/her IFSP or 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 persons authorized by federal and state confidentiality, privacy, and security laws have access to the records. 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 early intervention services.
- Information about a child will not be shared outside a program, except as permitted by law with parental consent.
- Families have the right to inspect and review early intervention records relating to their child and request an amendment to inaccurate information in a record. 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, teacher, therapist, or preschool early intervention supervisor should they have any concerns regarding the collection of child information in PELICAN. Families may also contact OCDEL by calling 717-346-9320.

Credits:

Early Intervention Technical Assistance (EITA) is a cooperative training and technical assistance effort between the Pennsylvania Departments of Education and Public Welfare. EITA is administered by the Tuscarora Intermediate Unit 11. The Tuscarora Intermediate Unit 11 is an equal opportunity educational service agency and will not discriminate on the basis of race, color, national origin, ancestry, sex, disability, age, or religion in its activities, educational and vocational/programs, or employment practices as required by Title VI of the Civil Rights Act of 1964, Title IX of the 1972 Educational Amendments, Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, and the Pennsylvania Human Relations Act of 1955 as amended. For information regarding civil rights or grievance procedures, contact Kathy McCool, Equal Rights and Opportunity Coordinator, at Tuscarora Intermediate Unit 11, 2527 US HWY 522 SOUTH, McVeytown, PA 17051-9717, 814-542-2501 or 717-899-7143; TDD 814-542-2905.

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Revised 05/13