Families are Important!

Training and Information for Families of Infants and Toddlers with Developmental Delay(s) and/or Disabilities in Washington State

Early Support for Infants and Toddlers

Washington State Department of Early Learning
# Families are Important!
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Introduction

_Families Are Important!_ provides training and information for families of infants and toddlers with developmental delay(s) and/or disabilities in Washington state, and the providers, educators, and Family Resources Coordinators who work with them. This project was a collaborative effort between Washington State Early Support for Infants and Toddlers program and PAVE.

The Parent Manual contains the same slide images as in the Instructor Manual. Each Power-Point slide is included in the manual. Space is included on most pages below the slide images for participants to write notes. Extra note pages have also been inserted at the end of each topic unit.

_What You Should Know_ boxes are found on many pages and contain information that participants should understand after receiving the training. They are written in such a way as to allow the participant to review the information at a later time and still gather the key points presented.

All supplemental materials (i.e., handouts) are separate from the Parent Manual.

Training Objectives

After completing this training, the participants will:

- Know what the Washington State Early Support for Infants and Toddlers program is and how to contact the program.
- Understand that the intent of the Part C Early Intervention program is FAMILY-CENTERED service delivery.
- Understand what an Individualized Family Service Plan (IFSP) is and what the family’s role is in that process.
- Become aware that families have rights and safeguards when they are receiving services.
Families are Important!

Introductory Information
Training and Information for Families of Infants and Toddlers with Development Delays or Disabilities in Washington State

Adapted with Permission from Pacer Center c 2007

WHAT YOU SHOULD KNOW

This project was a collaborative effort between the Washington State Early Support for Infants and Toddlers (ESIT) program and PAVE. PAVE was given permission to adapt the presentation from the original presentation from PACER (Parent Advocacy Coalition for Education Rights), also called Families are Important! This presentation is for families of infants and toddlers with developmental delay(s) and/or disabilities in Washington state, and the providers, educators, and Family Resources Coordinators who work with them.

NOTES
Early Support for Infants and Toddlers (ESIT) provides services to children from birth to three years old who have developmental delay(s) and/or disabilities. Eligible infants and toddlers and their families are entitled to individualized, quality early intervention services in accordance with the federal Individuals with Disabilities Education Act (IDEA), Part C.
Families are Important!

PAVE has adapted this curriculum in partnership with the Family Leadership and Involvement Committee of the State Interagency Coordinating Council and the Washington State Early Support for Infants and Toddlers program.

WHAT YOU SHOULD KNOW

The Family Leadership and Involvement Committee is a group of parents who have had children in the Early Intervention program. They serve on a committee for the State Interagency Coordinating Council (SICC) for the Washington State Early Support for Infants and Toddlers (ESIT) program. These parents worked on this presentation to represent the needs of families with infants and toddlers with developmental delay(s) and/or disabilities in Washington state.
Families are the Most Important People in a Child’s Life

They know their child better than anyone else. They share their child’s joys and challenges.

**WHAT YOU SHOULD KNOW**

Parenting is a big responsibility. Parents and family members make sure their children are safe and have good care. They watch to see that their children grow and develop as they should for their age. This is a big challenge! It can be an even bigger challenge when a parent knows that his or her child has a disability or if a parent thinks that his or her child is not developing like other children the same age. It is hard to know what a child should be doing and what to expect. Parents may feel alone and not know where to turn for help.

**NOTES**
Parents May Experience a Range of Emotions...

...on learning that their infant or toddler has a disability or developmental delay:  
Loss, Denial, Blame or Anger, Fear/Anxiety, Sadness

Love and Joy:  
Nothing is more precious than a child, despite any obstacles the family must face.
Families are Important!

Topic 1:
Early Intervention Services
Topic 1
Early Intervention Services

Services are designed to meet the needs of infants and toddlers with a developmental delay and/or disabilities and the family, related to enhancing the child’s development.

WHAT YOU SHOULD KNOW

IDEA, Part C services are family-centered and are provided with families being an important part of the decision-making process and an active participant in the implementation of early intervention services. Services are provided in collaboration with the family by qualified personnel, in conformity with the Individualized Family Service Plan (IFSP).

There is detailed information concerning the IFSP in Topic 3 of this curriculum.
An Important Resource for Families

The Washington State Early Support for Infants and Toddlers program

The Early Support for Infants and Toddlers program (ESIT) is an important source of services and supports to help families enhance their children’s learning and development.

WHAT YOU SHOULD KNOW

The Washington State Early Support for Infants and Toddlers program governs the Washington IDEA, Part C (Individuals with Disabilities Education Act) rules, policies and procedures.

NOTES
The Heart of ESIT Services

To enable young children to be active and successful participants during the early childhood years and in the future in a variety of settings - in their homes with their families, in child care, community programs, and their natural learning routines.
Outcomes For Children

To help children be active and successful participants across a variety of settings and situations, children will demonstrate improved:

- Positive social and emotional skills and social relationships
- Acquisition and use of knowledge and skills, including language and communication
- Use of appropriate behaviors to meet their needs
Outcomes For Families

To support parents/family members with information and skills to ensure they are supported in their roles as the most critical influence on their child’s early and ongoing development.

To enable families to care for their child and participate in family and community activities, families will:

✓ Know their rights
✓ Effectively communicate their child’s needs
✓ Help their child develop and learn
Early Intervention Services

Enhance a child’s development in:

- Adaptive
- Cognitive
- Communication
- Physical
- Social and Emotional

abilities and meet state standards, policies and procedures.

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<tr>
<td>The following are definitions of the terms on the above slide:</td>
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<tr>
<td>Adaptive: Ability to dress, eat and take care of themselves.</td>
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<td>Cognitive: Ability to learn and how a child learns.</td>
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<tr>
<td>Communication: Ability to understand language and express needs.</td>
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<tr>
<td>Physical: Ability to move, see and hear.</td>
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<td>Social and Emotional: Ability to relate with others.</td>
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Eligibility for Services

An infant or toddler from birth to age three is eligible for early intervention services in Washington due to:

1. Developmental delay 
   OR
2. A diagnosed mental or physical condition that has a high probability of resulting in a developmental delay

WHAT YOU SHOULD KNOW

The developmental delay must be 25% or 1.5 standard deviation below the mean in one area of development, or a child is eligible if he or she has a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay. Your Family Resources Coordinator will explain this process in detail.

Examples of a diagnosed physical or mental condition include but are not limited to:

a) Chromosomal abnormalities associated with disabilities such as Down Syndrome;

b) Congenital central nervous system birth defects or syndromes, such as myelomeningocele, fetal alcohol syndrome, or Cornelia de Lange syndrome;

c) Deaf, blind or deaf-blind;

d) Established central nervous system deficits resulting from hypoxia, trauma, or infection;

e) Cerebral palsy;

f) Health impairments such as autism, epilepsy, neurological impairment or other chronic or acute or degenerative health problems;

g) Orthopedically impaired (i.e., impairments of the normal function of muscles, joints or bones due to congenital anomaly, disease or permanent injury; and/or

h) Microcephaly.
Families are Important! Parent Manual

Funding Sources for ESIT/Part C Services

Private insurance

State Special Education Funds

State Medicaid Program

Division of Developmental Disabilities (Child Development Services)

Other local resources

IDEA, Part C

For complete information visit the ESIT website:
www.del.wa.gov/esit

WHAT YOU SHOULD KNOW

Private insurance: Must be used unless parents provide information documenting that it will create a financial hardship preventing their participation in early intervention services. Parents pay premiums, deductibles, co-pays and co-insurance.

State Special Education Funds: Through local school districts.

State Medicaid Program: Administered through Department of Social and Health Services (DSHS)/Health & Recovery Services Administration (HRSA).

Child Development Services: Administered through county developmental disabilities (DD) human services agencies. Funds are provided through contracts with DSHS/Division of Developmental Disabilities (DDD).

Other federal, state or local resources
IDEA, Part C: Administered through Local Lead Agency contracts provided through DEL/ESIT (enhancement, payer of last resort).
The inability of a family to pay for services may not result in denial of needed IFSP services for an eligible child.

For more information on the Parent Financial Responsibility Guidelines, see the ESIT website:

www.del.wa.gov/esit

WHAT YOU SHOULD KNOW

Families will not be denied services based on inability to pay. Work with your Family Resources Coordinator (FRC) to determine funding for your child's services in your county.
There are 16 Services in IDEA – Part C

- Assistive technology
- Audiology
- Family Resources Coordination
- Family training, counseling, and home visits
- Health services
- Medical services for diagnostic or evaluation
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Social work services
- Speech-language pathology

Special instruction
Transportation
Vision services
Who Provides Early Intervention Services?

Audiologists
Family therapists
Nurses
Nutritionists
Occupational therapists
Orientation and mobility specialists
Pediatricians and other physicians
Physical therapists
Psychologists
Social workers
Special educators
Speech and Language Pathologists

WHAT YOU SHOULD KNOW

Services are provided by qualified professionals.

NOTES
Early Intervention Services are provided in Natural Environments

• Home and community settings where all children live, learn and play

• To the maximum extent appropriate
Topic 1  Early Intervention Services
Time for Review

Review:

1. Early intervention services are designed to meet the needs of children and the family, related to enhancing the child’s development.

2. Families will not be denied needed IFSP services for lack of ability to pay for them.

3. Services are provided by qualified professionals.
Families are Important!

Topic 2: Evaluation and Assessment: A Closer Look
Topic 2
Evaluation and Assessment: A Closer Look

The evaluation and assessment are done with you, your child and early intervention professionals at no cost.

Each area of development must be evaluated and considered.

Child functioning in each of the child outcomes must be addressed.

It includes family-directed assessment of resources, concerns and priorities necessary to meet developmental needs of your child.

WHAT YOU SHOULD KNOW

You will be asked to sign a consent to do an evaluation. The five areas of development are: Adaptive, Cognitive, Communication, Physical, and Social and Emotional. The family statement is voluntary on the part of the family and is family-directed. A personal interview is required to determine the family’s resources, priorities, and concerns and for identifying the supports and services necessary to enhance the family’s capacity to meet their child’s developmental needs.
Evaluation and Assessment: A Closer Look

What are my child’s and family’s concerns, priorities and resources?

These might include:

- Child and family strengths
- Medical information
- Development or behavior concerns
- Community connections
- Other information

WHAT YOU SHOULD KNOW

These are examples of what medical information, developmental concerns and child strengths might be:

**Medical information:** Premature birth, special health care needs, feeding or breathing concerns.

**Developmental concerns:** Not walking, talking, sitting, rolling over.

**Strengths:** Makes good eye contact, babbles, reaches out for mom/dad.
**WHAT YOU SHOULD KNOW**

Families should write down the answers to these questions and bring them to their evaluation.

**QUESTIONS TO CONSIDER:**

- What are my child’s interests? (favorite activities, toys, people)
- What routines or activities does my child and family like to do?
- What does my child and family find socially, emotionally or physically challenging?
Evaluation and Assessment: A Closer Look

The early intervention system must adopt nondiscriminatory evaluation procedures and honor cultural differences.

Tests are given in the native language of the parents or other mode of communication, unless it is clearly not feasible to do so.

No single procedure or professional may determine eligibility.
Evaluation and Assessment: A Closer Look

If an infant or toddler qualifies for services:

The team must develop an Individualized Family Service Plan (IFSP) within 45 days of referral.

WHAT YOU SHOULD KNOW

If the child qualifies and parents agree with receiving early intervention services, a team that includes the parents will meet to discuss the evaluation and to write an Individualized Family Service Plan (IFSP). This meeting will be held within 45 days of a child’s referral. If parents choose not to receive early intervention services, the team should explain their rights and responsibilities. Parents may be referred to other community resources.
If he or she does not qualify:
Parents can ask about other ways to help their infant or toddler develop.

Parents that disagree with the decision can ask about their rights to find a solution that works.

WHAT YOU SHOULD KNOW
The evaluation may show that some children are developing within normal limits. Some children may not qualify for services because their delays are mild and do not meet the criteria or rules for eligibility. Usually the Family Resources Coordinator will meet with a family to explain why their child is not eligible. If a child is not eligible, the team will tell the family about other ways they may receive help for their child. Parents can also ask the early intervention program to review the child’s development at a later date if they still have concerns about their child’s development. Parents are encouraged to ask their FRC about other support services in their community, such as Child Care Resource and Referral Network, Play and Learn Groups, etc.
The IFSP Team

Parents

Evaluators

Family members

Service providers

Support person

Others

Family Resources Coordinator

WHAT YOU SHOULD KNOW

The IFSP meeting can be attended by whomever you want. You may want to invite your child’s other caregivers and people who are a support to you and your family.
The Family Resources Coordinator (FRC) is responsible for facilitating the IFSP process and for service coordination with other agencies, including transition services.

The family works with their FRC to assure the IFSP plan reflects the family’s concerns, interests, and values.

**WHAT YOU SHOULD KNOW**

The FRC’s role is to coordinate services and help in the transition process. They can help families navigate the early intervention program. If you feel your FRC is not meeting your needs, you have the right to request a new FRC.
Review:

1. No single procedure is used as the sole criterion to determine a child’s eligibility for services.

2. If an infant or toddler qualifies for service, an IFSP is developed within 45 days.

3. Families are an important part of the IFSP team.
Families are Important!

Topic 3:
What is an IFSP?
Topic 3
What is an IFSP?

A written document that includes:

- Infant's or toddler's present levels of development
- Families concerns, priorities, resources
- Functional outcomes - measurable results expected
- Specific services to be provided
- Who is providing service(s)
- The natural environment(s) where services will be provided

WHAT YOU SHOULD KNOW

Parents are encouraged to write down any notes and bring them, along with any reports that have been done, to share with the rest of the team.

Explanation of terms

Present levels of development: An IFSP requires a statement of the infant or toddler’s present levels of development in five domains. These areas are Adaptive, Cognitive, Communication, Physical and Social and Emotional.

Family concerns, priorities, resources: The family's concerns, priorities, and resources guide the entire IFSP process. Early intervention is a system of services and supports available to families to enhance their capacity to care for their children.

Specific services: Occupational Therapy, Physical Therapy, Speech Therapy, Special Instruction

Who is providing services: Services are provided in collaboration with the family by qualified personnel, in conformity with the IFSP.

Functional Outcomes: What my child will be able to do as a result of these services.

Natural Environments: Home, child care, classroom, parks, playgrounds, etc.
### What is in an IFSP?

- **How the service is provided**
- **Start and end dates, frequency and intensity**
- **Funding sources**
- **Name of Family Resources Coordinator**
- **Steps to support transition to preschool or other services (to be included in the IFSP at least 90 days before your child’s third birthday)**

### WHAT YOU SHOULD KNOW

The IFSP is the legal document that guides the program of services.

**Explanations**

- **How the service is provided**: How for example, speech therapy will be provided.
- **Start and end dates, frequency and intensity**: When the child’s service(s) begin and end, how often and how long the therapist(s) will work with the child.
- **Funding sources**: What funding source will be used to pay for each IFSP service.
- **Name of FRC**: The FRC who will be working with your family.
- **Steps to support transition**: Plans are made well in advance to help a child transition either to preschool or other services by the date of their third birthday.

Room for notes on next page...
IFSP Requirements

Parents are fully involved in the IFSP process.

The IFSP services/supports are fully discussed with them.

Parents must consent in writing before their child receives early intervention services.

If parents do not consent to a service in the IFSP, then only the services they consent to will be provided.

**WHAT YOU SHOULD KNOW**

This is a voluntary program and parents must consent to services. Declining a service will not jeopardize your ability to receive other services.

**NOTES**
**IFSP Requirements**

- Reviewed every six months to check progress
- Parents participate in the review
- Annual meeting is held to write a new IFSP
- Parents receive written notice of IFSP meetings

**WHAT YOU SHOULD KNOW**

The IFSP is reviewed every six months and rewritten annually.
IFSP Requirements

✓ Meetings are made convenient to parents to the extent possible.

✓ Meetings occur in the native language of parents or other mode of communication unless it is clearly not feasible to do so.

✓ Parents provide informed written parental consent to begin services.
Parents and other team members will work together to write down the desired functional outcomes that the parents have for their infant or toddler (i.e., outcomes that are meaningful to the child and family). In this example, the functional outcome is that Tia learns to make her food choices known to her family at mealtimes. The parents have a crucial role in helping Tia learn to eat with them in this way. They will work with professional service providers to develop strategies that will be used to help Tia reach their desired outcome. These strategies will be used in daily meals they are already sharing with Tia.
IFSP: A Living Document

An IFSP is flexible.

It can be changed when needed.

WHAT YOU SHOULD KNOW

The IFSP can be changed at any time and is reviewed every six months regardless if there are concerns or not. Important considerations are:

- Is progress being made in meeting functional outcomes?
- If not, the team needs to review the IFSP and make changes as necessary.

NOTES
After the IFSP is Developed

Parents receive a written copy of the IFSP

Agree?
Approve and sign

Disagree?
Put in writing; ask for meeting

Keep copies for your records

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<tr>
<td>Keep copies of all written records. If you disagree with the IFSP, do not sign the document and ask for another meeting with the IFSP team. Put in writing why you disagree with the decision.</td>
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NOTES
You are a Team Member

Learn about your child’s developmental delay(s) and/or disabilities

Attend all team meetings

Know your rights

Listen and ask questions

It’s okay to disagree

Share information

Keep good records

WHAT YOU SHOULD KNOW

Tips for parents:
1. Attend all the meetings about your child.
2. Learn as much as possible about your child’s developmental delay(s) and/or disabilities and ways to support his or her development.
3. Ask questions if you do not understand what is being said.
4. Share what you know about your infant’s or toddler’s development. Parents are the experts when it comes to discussing their own child. Let the team know what the family experiences with the child, including what he or she does well, likes or does not like, and how she or he learns best.
5. When you don’t agree, talk about it. Look for compromise in ways that work for your child and family.
6. Know where to find information to help you understand your rights.
7. Keep records of meetings and conversations about your child, and be sure to put dates on them.
8. Put all your requests in writing, and keep copies for your records.
Family Outcomes Survey

Parents will be asked to complete a survey as part of a family's annual IFSP process, and also when a child leaves the early intervention program. Your FRC will help you obtain access to the survey.

To give feedback about your family's experience in early intervention, it is important that you complete this survey.
Transition Out of Early Intervention at Age Three

Early Intervention services end on your child’s third birthday.

WHAT YOU SHOULD KNOW

It’s important that parents understand what the transition process should look like for their child. Information can be obtained by contacting your Family Resources Coordinator.
Transition Out of Early Intervention at Age Three, con’t

If your child is potentially eligible for special education preschool, a transition meeting must be held at least 90 days before their third birthday...or if all agree, a meeting can be held up to nine months before your child turns three.

WHAT YOU SHOULD KNOW

If your child requires more specialized services, such as wheelchair accessibility, transportation, etc., you may want to request that the transition process begin sooner than later, as soon as nine months before your child’s third birthday.

NOTES
**Topic 3  What is an IFSP?**

**Time for Review**

Review:

1. An IFSP is a document that guides the provision of services.

2. An IFSP is a voluntary program and parents must consent to services.

3. It is a living document that's reviewed every six months and rewritten annually.

4. A transition plan helps with the process of moving to the “people, places and activities” appropriate for your child’s development at age three.
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Topic 4: Procedural Safeguards
Topic 4
Procedural Safeguards

✓ Timely resolution of complaints
✓ Right to confidentiality
✓ Right to accept or decline services
✓ Opportunity for parents to examine records
✓ Protection for the rights of infants or toddlers when their parents are not available
✓ Written prior notice
✓ Notice in parents’ native language (unless clearly not feasible)
✓ Right of parents to use mediation
Resolving Differences

Many times differences can be resolved by using an informal approach.

If you have a concern or disagree with any part of the early intervention process, call your Family Resources Coordinator.

WHAT YOU SHOULD KNOW

Keep important phone numbers and contact information in one place so you can contact the appropriate people if problems do arise. Suggested appropriate contacts are:

- Your family’s FRC
- ESIT (www.del.wa.gov/esit)
- PAVE (1-800-572-7368 or pave @wapave.org)
Resolving Differences

Mediation

Administrative Complaint

Due Process Hearing
### WHAT YOU SHOULD KNOW

**Mediation:** The ESIT program has a contract with Sound Options Group, a mediation service. Points to know about mediation:
- Voluntary.
- Not used to delay parents' right to file a complaint or go to an administrative hearing.
- Mediators are qualified and impartial.
- Conducted in a timely manner.
- Convenient location.
- Written mediation agreement.

**Administrative Complaint:** Any person or organization may file an administrative complaint if they feel the agency or early intervention service provider is violating a requirement of the law:
- The administrative complaint must be written, signed and include the facts regarding the complaint.
- Send to: the Department of Early Learning, Early Support for Infants and Toddlers, P.O. Box 40970, Olympia, WA 98504-0970.
- ESIT must review, write a response, and take appropriate action within 60 days after the complaint is received.

**Due Process Hearing:** Due Process Hearing is the right of each citizen to be treated fairly, to receive the benefits the law provides. If you feel you or your child have not received these services, you may ask for a hearing. This is called the right to due process.
- You must request a due process hearing in writing and your request for a hearing must explain your complaint.
- Send the due process hearing request to the Department of Early Learning, Early Support for Infants and Toddlers, P.O. Box 40970, Olympia, WA 98504-0970.
Families can make a difference for their child!

Families are the most important people and constant in their child’s life.

Families know their infant or toddler better than anyone else.

Families help their child develop and learn.

Families are experts and have much to share!
**Topic 4  Procedural Safeguards**

**Time for Review**

Review:

1. Families have rights and safeguards while receiving services.

2. Many differences can be resolved informally.

3. Your Family Resources Coordinator will help you understand what to do if you have a concern or disagree with any part of the early intervention process.
Families are Important!

More Information
Have questions about your child’s development?

Call the Family Health Hotline to request the name of the local Lead Family Resources Coordinator at:
1-800-322-2588
or visit www.del.wa.gov/esit
If you would like to learn more about the IDEA, contact PAVE at:

1-800-572-7368 or e-mail pave@wapave.org
Resources for Families:

Family Health Hotline  1-800 322-2588 for information and referral information
www.withinreachwa.org

Washington 211 for community resources

Parent 123 for online applications for several income based programs
www.withinreachwa.org

PAVE (Partnerships for Action, Voices for Empowerment) for education advocacy
1-800 PARENT  www.washingtonpave.org

Arc of Washington State (Parent to Parent) 1-800-821-5927 www.arcwa.org

Washington State Father’s Network (425 747-4004, ext 4286  www.fathernetwork.org

Washington Medical Home for health information  www.medicalhome.org
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Washington State Department of Early Learning

Early Support for Infants and Toddlers