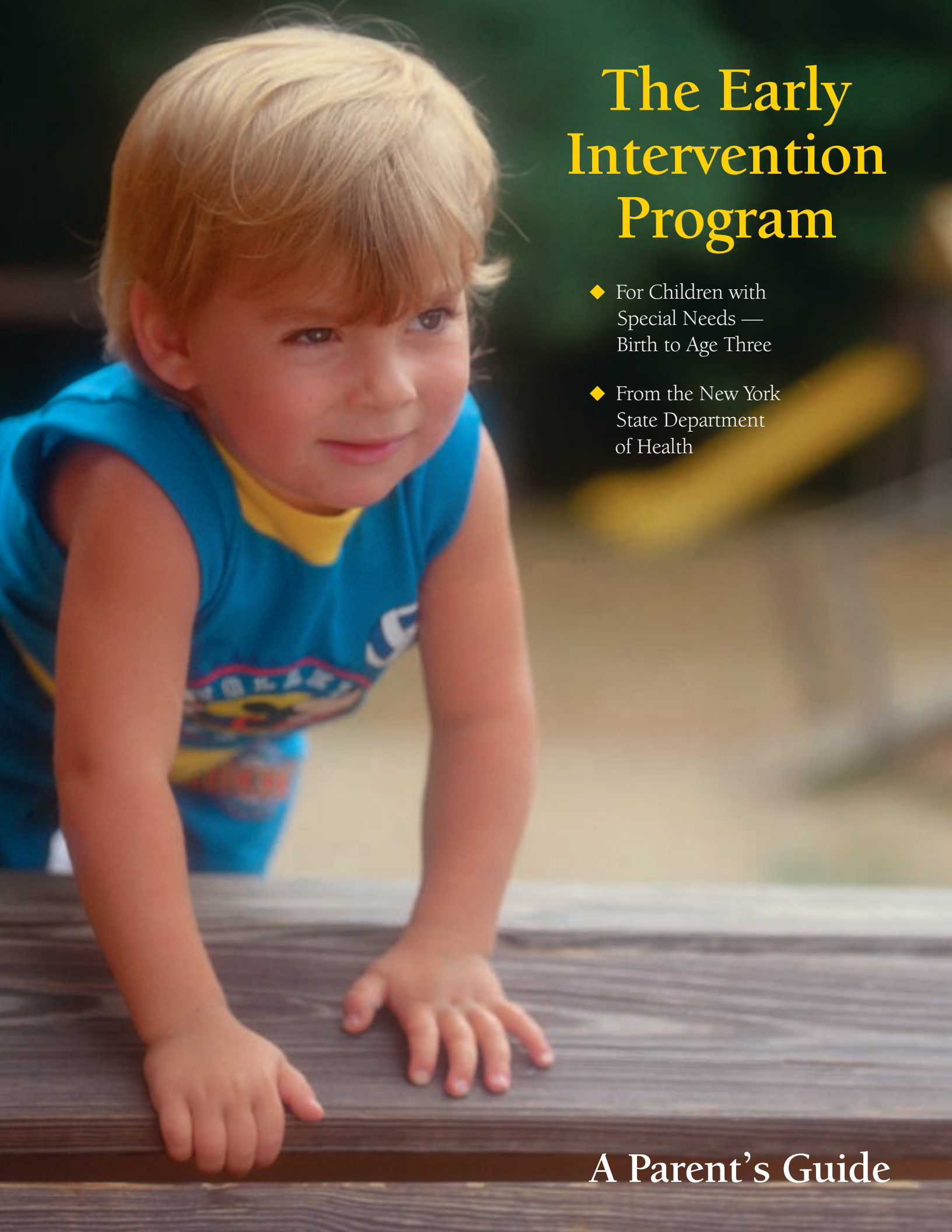


The Early Intervention Program

- For Children with Special Needs — Birth to Age Three
- From the New York State Department of Health

A Parent's Guide

STATE OF NEW YORK

GEORGE E. PATAKI
GOVERNOR

Dear New York family,

Having a young child with special needs presents a unique challenge for families. Your child may need extra help and attention when learning new skills. You may have to learn new ways of caring for him or her. And your whole family may need support in adjusting to the new demands placed on them.

Since 1993, New York State's Early Intervention Program has been helping families find home and community-based services for children with special needs. Early Intervention is a partnership on several levels: between state and local government agencies who work to identify and evaluate children who would benefit from developmental services; and county agencies, health care providers, and parents who plan and provide the services. Since its inception, the New York State early intervention system has provided services to thousands of children and families.

If your child is being considered for Early Intervention services, this Parent's Guide will help you learn how the program works and what rights and responsibilities you have as a parent. It also gives you phone numbers to call for more information, samples of the kinds of letters you may need to write, and definitions of terms you will hear. I hope it will help you and your child get the most out of the Early Intervention Program.

With all good wishes,

George E. Pataki
Governor

EXECUTIVE CHAMBER STATE CAPITOL ALBANY 12224

Welcome to the Early Intervention Program

The early years of a child's life are very important. During the infant and toddler years, children grow quickly and have so much to learn. Some children and families face special challenges and need extra help. Early help *does* make a difference!

The Early Intervention Program is a statewide program that provides many different types of early intervention services to infants and toddlers with disabilities and their families. In New York State, the Department of Health is the lead state agency responsible for the Early Intervention Program.

Early Intervention services can help you and your family:

- Learn the best ways to care for your child.
- Support and promote your child's development.
- Include your child in your family and community life.

Early Intervention services can be provided anywhere in the community, including:

- Your home.
- Your child care center or family day care home.
- Recreational centers, play groups, playgrounds, libraries, or any place parents and children go for fun and support.
- Early childhood programs and centers.

As a parent, *you* help decide:

- What early intervention services your child and family need.
- The outcomes of early intervention that are important for your child and family.
- When and where your child and family will get early intervention services.
- Who will provide services to your child and family.

You are the most important person in your child's life. You know your child best. You understand your child's needs, and what is helpful and what is not. You have the most information about – and responsibility for – your child's growth and development. In a world of professional titles, consider yourself a *FAMILY INFORMATION SPECIALIST*!

If you think the Early Intervention Program can help you and your child, there are six steps to follow. *A Parent's Guide to the Early Intervention Program* starts by telling you about some of the basic facts about the Early Intervention Program. Then, *A Parent's Guide* explains each step to follow – and gives you tips on how to make early intervention work best for your child and family.

You are an important person in the Early Intervention Program. This is *your* book – it was written for parents, with the help of parents. We hope it will make your job as a parent a little easier!

Important Contact Information

For more information about the Early Intervention Program and its services, contact:

Bureau of Early Intervention
Division of Family Health
New York State Department of Health
Corning Tower, Room 287
Albany, New York 12237-0660
518-473-7016
518-486-1090 (FAX)
Email:eip@health.state.ny.us
www.health.state.ny.us/nysdoh/eip/index.htm

For more information about early intervention, local phone numbers for your county Early Intervention Program, and other child-related services, contact:

"Growing Up Healthy" 24-Hour Hotline
1-800-522-5006
In New York City–311

New York Parent's Connection
1-800-345-KIDS (5437)
(available Mon-Fri 9am – 5pm)

Early Childhood Direction Centers (See page 35 for description)
New York State Education Department
518-486-7462
518-474-5652-TTY
www.vesid.nysed.gov/specialed/transition/whocan.htm

Parent to Parent of New York State
(See page 35 for description)
518-381-4350
1-800-305-8817
www.parenttoparentnys.org

Parent Training and Information Centers
(See page 35 for description)
www.taalliance.org/PTIs.htm

- Statewide (Except NYC)
  585-546-1700
  1-800-650-4967 (New York State Only)
  www.advocacycenter.com
- In New York City
  212-947-9779
  www.advocatesforchildren.org
  212-677-4650
  www.resourcesnyc.org
- Advocacy Services
  (See page 35 for description)
  1-800-624-4143
  www.cqc.state.ny.us

First, the Basics…

Your Early Intervention Official (EIO)

In New York State, all counties and the City of New York are required by public health law to appoint a public official as their Early Intervention Official.

Get to know your Early Intervention Official. She or he will be an important person in your child's and family's early intervention experience!

Your Early Intervention Official is the person in your county responsible for:

- Finding eligible children.
- Making sure eligible children have a multi-disciplinary evaluation.
- Appointing an *initial service coordinator* to help families with their child's *multidisciplinary evaluation* and *Individualized Family Service Plan* (IFSP).
- Making sure children and families get the early intervention services in their IFSPs.
- *Safeguarding* child and family rights under the Early Intervention Program.

The Early Intervention Official is the *"single point of entry"* for children into the Early Intervention Program. This means that all children under three years of age who may need early intervention services must be referred to the Early Intervention Official. In practice, Early Intervention Officials have staff who are assigned to take child referrals.

Parents are usually the first to notice a problem. Parents can refer their own children to the Early Intervention Official (see page 9, "Step 1: Referral"). Sometimes, someone else will be the first to raise

a concern about a child's development. New York State public health law requires certain professionals to refer infants and toddlers to the Early Intervention Official if a problem with development is suspected. However, no professional can refer a child to the Early Intervention Official if the child's parent says no to the referral.

Your Service Coordinator

Your service coordinator is your key to early intervention services!

There are two types of service coordinators in New York State – an *initial service coordinator* and an *ongoing service coordinator*.

Your *initial service coordinator* will be appointed to you by your Early Intervention Official. Your initial service coordinator will help you with all the steps necessary to get services – from your child's multi-disciplinary evaluation to your first Individualized Family Service Plan (IFSP).

You will be asked to choose your *ongoing service coordinator* as part of your first IFSP. The main job of your ongoing service coordinator is to make sure

New York State's definition of developmental delay

Developmental delay means that a child has not attained developmental milestones expected for the child's age adjusted for prematurity in one or more of the following areas of development: cognitive, physical (including vision and hearing), communication, social-emotional, or adaptive development.

For the purposes of the Early Intervention Program, a developmental delay is a delay that has been measured by qualified personnel using informed clinical opinion, appropriate diagnostic procedures, and/or instruments, and documented as:

- A 12-month delay in one functional area; or
- A 33% delay in one functional area or a 25% delay in each of two areas; or
- If appropriate, standardized instruments are individually administered in the evaluation, a score of at least 2.0 standard deviation below the mean in one functional area or a score of at least 1.5 standard deviation below the mean in each of two functional areas.

you and your child get the services in your IFSP. Your ongoing service coordinator will also help you change your IFSP when you need to and make sure your IFSP is reviewed on a regular basis.

You can keep your initial service coordinator – or you can choose a new person to be your ongoing service coordinator. Later in this book, you'll find some tips to help you with this choice.

Who is eligible for the Early Intervention Program?

Children are eligible for the Early Intervention Program if they are under three years old AND have a disability OR developmental delay. A disability means that a child has *a diagnosed physical or mental condition* that often leads to problems in development (such as Down syndrome, autism, cerebral palsy, vision impairment, hearing impairment).
A developmental delay means that a child is behind in at least one area of development, including:

- Physical development (growth, gross and fine motor abilities).
- Cognitive development (learning and thinking).

- Communication (understanding and using words).
- Social-emotional development (relating to others).
- Adaptive development (self-help skills, such as feeding).

Your child does not need to be a U.S. citizen to be eligible for services. And, there is no income "test" for the program. You and your child do have to be residents of New York State to participate in the Early Intervention Program.

How is eligibility decided?

All children referred to the Early Intervention Official have the right to a free multidisciplinary evaluation to find out if they are eligible for services. The multidisciplinary evaluation will also help you to better understand your child's strengths and needs and how early intervention can help.

A child who is referred because of a diagnosed condition that often leads to developmental delay – like Down syndrome – will always be eligible for early intervention services. If your child has a diagnosed condition, your child will still need a multidisciplinary evaluation to help plan for services.

If your child has a delay in development – and no diagnosed condition – the multidisciplinary evaluation is needed to find out if your child is eligible for the Early Intervention Program. Your child's development will be measured according to the *"definition of developmental delay"* set by New York State.

What services are available?

The Early Intervention Program offers many types of early intervention services. Early intervention services are services that are:

- Aimed at meeting children's developmental needs and helping parents take care of their children.

What is an Individualized Family Service Plan (IFSP)?

An IFSP is a written plan for the early intervention services you and your child will get from the Early Intervention Program. Your IFSP will:

- Include the outcomes for your child and family – what you and your family hope to gain from early intervention services.
- Describe the early intervention services your child and family will get to help you reach your outcomes.
- Describe who will provide services and where, when, and how often.
- Give the ways services will be used to help you and your family reach those outcomes.

Respite services

What is respite?

Respite is temporary care of a child with a disability, given to provide relief to the family. Sometimes, the demands of caring for an infant or toddler with disabilities are overwhelming. Respite can help reduce family stress. Some families use respite services to keep appointments, run errands, spend time with other children and family members, or just relax.

How can I get respite services?

You can ask for respite as part of your Individualized Family Service Plan. Some factors that weigh into decisions about respite are:

- Severity of a child's disability and needs.
- A child's risk of out-of-home placement.
- Lack of other supports to the family.
- Stressful family situations.
- The need for respite expressed by parents.

- Included in an Individualized Family Service Plan (IFSP) agreed to by the parent and the Early Intervention Official.

Here's a list:

- Assistive technology services and devices.
- Audiology.
- Family training, counseling, home visits, and parent support groups.
- Medical services *only for diagnostic or evaluation purposes*.
- Nursing services.
- Nutrition services.
- Occupational therapy.
- Physical therapy.
- Psychological services.
- Service coordination services.
- Social work services.
- Special instruction.
- Speech-language pathology.
- Vision services.
- Health services *needed for your child to benefit from other early intervention services*.
- Transportation to and from early intervention services.

How are Early Intervention services provided?

Only *qualified* professionals – individuals who are licensed, certified, or registered in their discipline and approved by the State – can deliver early intervention services. All early intervention services can be given using any of the following service models:

- *Home- and community-based visits.* In this model, services are given to a child and/or parent or other family member or caregiver at home or in the community (such as a relative's home, child care center, family day care home, play group, library story hour, or other places parents go with their children).
- *Facility or center-based visits.* In this model, services are given to a child and/or parent or other family member or caregiver where the service provider works (such as an office, a hospital, a clinic, or early intervention center).
- *Parent-child groups.* In this model, *parents and children get services* together in a group led by a service provider. A parent-child group can happen *anywhere* in the community.
- *Family support groups.* In this model, parents, grandparents, siblings, or other relatives of the

child get together in a group led by a service provider for help and support and to share concerns and information.

- *Group developmental intervention.* In this model, children receive services in a group setting led by a service provider or providers *without parents or caregivers*. A group means two or more children who are eligible for early intervention services. The group can include children without disabilities and can happen *anywhere* in the community.

Do I need to worry about costs?

No! If your child is eligible for the Early Intervention Program, early intervention services must be provided *at no cost to you*.

Health insurance, including private insurance and Medicaid, is used to pay for early intervention services in New York State.

New York State law protects family insurance policies from being affected by payments for early intervention services. Your insurance policy can only be used if your insurance company is licensed or regulated by New York State. If your policy is *not* subject to New York State regulation, ***its use is voluntary*** on your part.

When your insurance is used for early intervention:

- You will *not* have to make out-of-pocket payments for co-payments or deductibles. This is true even if your insurance company is not licensed or regulated by New York State and you *volunteer* to use your insurance for early intervention.
- Payments for early intervention services will *not* be applied to the annual and lifetime caps in your insurance policy. Your coverage for health services will not be reduced because your child is receiving early intervention services. *These protections apply to your policy* ***only*** *if your insurer is licensed or regulated by New York State.*

New York State has a health insurance plan for kids called Child Health Plus. Children under the age of 19 who are not eligible for Medicaid and who have limited or no health insurance may be eligible. For information, call the Child Health Plus toll-free number at 1-800-698-4KIDS (1-800-698-4543).

What are my rights and responsibilities as a parent in the Early Intervention Program?

As a parent in the Early Intervention Program:

- You take part in all the decisions.
- Meetings are held at times good for you.
- Your permission is required at every step of the process.
- All information about your child and family is confidential.
- You have the right to have your views heard and considered if you disagree with others.

To learn more about your rights, and what to do if you disagree with any decision, see "Your Rights as a Parent in the Early Intervention Program" on page 26 of this book.

Early Intervention Steps

Family Concern

1. Referral *(unless parent objects)*

- Referral source or parent suspects child of having developmental delay or disability
  - Family informed of benefits of Early Intervention Program
    - Child referred to EIO within 2 days of identification
      - Early Intervention Official assigns Initial Service Coordinator

2. Initial Service Coordinator

- Provide information about EIP
- Inform family of rights
- Review list of evaluators
- Obtain insurance/Medicaid information
- Obtain other relevant information

3. Evaluation*

- Determine eligibility
  - Family assessment, optional
    - Gather information for IFSP
      - Summary and report submitted prior to IFSP

4. The IFSP Meeting*

(if child is eligible)

- Family identifies desired outcomes
- Early Intervention services specified
- Develop written plan
  - Family and EIO agree to IFSP
    - Identify Ongoing Service Coordinator
      - EIO obtains social security number(s)

Areas of Development

- cognitive
- physical (including vision and hearing)
- communication
- social/emotional
- adaptive development

* May access due process procedures

Early Intervention Services*

- assistive technology devices and services
- audiology
- family training, counseling, home visits and parent support groups
- medical services only for diagnostic or evaluation purposes
- nursing services
- nutrition services
- occupational therapy
- physical therapy
- psychological services
- service coordination
- social work services
- special instruction
- speech-language pathology
- vision services
- health services
- transportation and related costs

6. Transition

- Plan for transition included in IFSP
- Transition to:
  - services under Section 4410 of Education Law (3-5 system)

  OR
  - other early childhood services, as needed

5. IFSP–Review Six Months/ Evaluate Annually

- Decision is made to continue, add, modify or delete outcomes, strategies, and/or services
- If parent requests, may review sooner:
  - If parent requests an increase in services, EIO may ask for independent evaluation

Parent/guardian consent is required for evaluation, IFSP, provision of services in IFSP, and transition.

Revised 12/04

Step 1: Referral

Your first step into the Early Intervention Program begins with your child's referral to your Early Intervention Official (EIO). Professionals must refer babies and toddlers to the Early Intervention Official – unless the parent says no – when there is a concern about child development. As a parent, you can also refer your child to your Early Intervention Official if you suspect a problem. If you have this book, chances are your child has already been referred to your Early Intervention Official. If you do need to make a referral you can:

1. Contact your Early Intervention Official (see sample letter on page 36), or call 1-800-522-5006; in New York City–311.
2. Talk with your doctor or someone else you trust and ask them to help you with the referral.

The referral process helps you learn about the Early Intervention Program. You must decide if early intervention makes sense for you and your child. You must give your permission to have your child evaluated for the program and to receive services.

Referral

When a professional refers a child to the EIP, he or she must:

- Tell parents about services available and how services may help.
- Inform parents that the child will be referred – unless the parents say no to the referral.
- Inform parents about the referral in the language they use, whenever possible.
- Make sure all information given to the EIO is kept confidential.

Step 2: Meeting Your Initial Service Coordinator

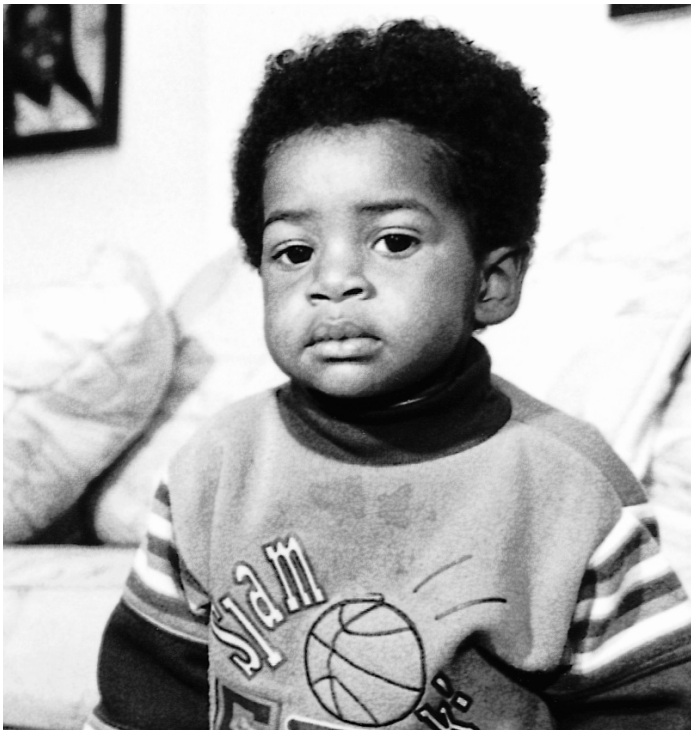
Once your child is referred, your Early Intervention Official will assign an *initial service coordinator* to work with you and your family. The job of your initial service coordinator is to help you with all the steps to your first Individualized Family Service Plan (IFSP).

Your initial service coordinator will start by setting up a time to meet with you to explain the Early Intervention Program. Your initial service coordinator will talk with you about your concerns about your child's development. She or he will:

- Make sure you have a copy of *A Parent's Guide to the Early Intervention Program*.
- Review your family rights and make sure you understand them.
- Talk with you about your child's evaluation for the program.
- Give you the list of evaluators in your county and help you pick one that will meet your child and family needs.
- With your permission, help arrange for your child's evaluation.
- Help you arrange for transportation to your child's evaluation, if you need it.
- Go with you to your child's evaluation if you wish.

If your child's evaluation shows that she or he is eligible for the Early Intervention Program, your initial service coordinator will:

- Set up a meeting to work on your IFSP.
- Help you understand what this meeting will be like, who else must be there, and who can be invited.
- Answer your questions about the Early Intervention Program.



- Explain how your health insurance can be used and that early intervention services will be at no cost to you.
- Help you resolve any problems that might come up – including disagreements about the services you and your child might need.

If the evaluation shows that your child is not eligible for early intervention services, your initial service coordinator will tell you about other services that can help. Or you can appeal the decision (see "Your Rights as a Parent in the Early Intervention Program," page 26, to learn more about appeals).

If you and your initial service coordinator agree that your child needs help right away – before his or her evaluation – you can get services started with an *Interim Individualized Family Service Plan* (interim IFSP). An interim IFSP is possible as long as you and your Early

Intervention Official agree to needed services, your child's evaluation is completed, and an IFSP meeting is held within 45 days of referral.

An Interim Individualized Family Service Plan must include:

- The name of the service coordinator who will be responsible for the interim IFSP.
- A physician's or nurse practitioner's order, if needed, for early intervention services in the interim IFSP.
- The early intervention services needed immediately and the location, frequency and intensity, and providers of these services.

Interim IFSP

An interim IFSP may be needed when:

- A doctor recommends services begin right away.
- A baby or toddler has trouble feeding (such as poor or no sucking ability) and needs nutrition or therapy services to help.
- Family stress is high, and the child is at risk for out-of-home placement.

Step 3: Having Your Child Evaluated

If you decide that the Early Intervention Program can help your child, the next step is to have your child *evaluated*. The reasons for the evaluation are to:

- Find out if your child is eligible for early intervention services; and,
- Gather facts about your child's strengths and needs that will help you make good decisions about services.

If your child has a diagnosed disability, she or he will always be eligible for early intervention services. Your child will still need a multidisciplinary evaluation to look at all areas of development and help with the development of an Individualized Family Service Plan (IFSP).

Every child referred to the Early Intervention Program has the right to a free *multidisciplinary evaluation*. *Multidisciplinary* simply means that more than one professional will be a part of your child's evaluation. Your child's evaluation team should have:

- A professional who can look at your child's overall development.
- A professional with special knowledge about your child's problem. For example, if your child is delayed in sitting up, walking, or other motor abilities, a motor therapist might be on your child's team.

Your initial service coordinator will give you a list of evaluators. You have the right to choose any evaluator from this list. Ask your initial service coordinator if you need more information about an evaluator. Your initial service coordinator can give you more details and help you decide on an evaluation team that will be best for your child and family.

Once you pick an evaluator, either you or the initial service coordinator – with your permission – will call the evaluator and make an appointment for your child and family. You, your service coordinator, or your evaluator must tell your Early Intervention Official about your choice.

Checklist of important evaluation information

- Types of professionals that will be on your child's team and an explanation of what they will do.
- How long the evaluation will last.
- Your child's developmental age levels and what that means.
- A diagnosis, if possible.
- Specific areas where your child needs help.
- Explanation of tests – if any – that will be used and what these tests can and cannot tell you about your child's development.
- What the evaluator is looking for in your child's responses.
- What your child does well.
- What your child needs help with, and suggestions about how you can help.
- The types of services that may help your child and family.
- The name of another parent or parent group that can offer support.
- Books, newsletters, magazines, and videos to help you find information about your child's developmental needs.

What is included in the multidisciplinary evaluation?

Your child's multidisciplinary evaluation will include:

- A health assessment, including vision and hearing screening. Your child's health assessment should be done by your child's regular health care provider whenever possible. If your child has had a recent checkup, a new one may not be needed.
- With your permission, a review of any records that may be helpful.
- An assessment of your child's strengths and needs in each area of development (physical, cognitive, communication, social-emotional, and adaptive development).
- An interview with you about your concerns and what your child is like.

The evaluation will be planned to meet the needs of you and your child. The evaluation team may:

- Use a developmental test to look at your child's development.
- Play with your child – or ask you to play with your child.
- Spend some time watching your child.
- Ask you what your child can do now and what he or she can't do yet.

What is a "screening"?

Sometimes a parent or evaluation team may be concerned about a child's development – without being sure why. A screening can be used to:

- Find out what areas of development – if any – are behind what's expected.
- Help the evaluation team decide what type of evaluation may be best.
- Find out if the child's development is "on target" even though a problem was suspected.

When a screening shows a child's development is "on target," it is unlikely that the child will be eligible for the Early Intervention Program. Parents always have the right to ask for – and get – a full multidisciplinary evaluation for their child (even if a screening suggests a child is developing fine).

You have an important role to play in your child's evaluation. Here's a list of suggestions about ways you can be an active participant in your child's multidisciplinary evaluation:

- You can be an observer.
- You can sit beside or hold your child.
- You can help with activities that explore your child's abilities.
- You can tell team members whether or not what they are seeing is typical of your child.
- You can help the team see your child's strengths and needs.
- You can comfort and support your child.
- You can ask questions and offer your opinions about how your child's evaluation is going.

Choosing an evaluation team

Questions to Ask, Tips to Think About

- Do you want to have the evaluation at home or at a center? Where do you think your child will do best?
- What time of day is best for your child?
- Is there someone else you would like to have participate in your child's evaluation—a relative, friend, or caregiver—who knows your child well?
- Try to think about your worries and questions before the evaluation. Make a list and bring it to the evaluation.
- Think about your daily routines with your child (eating, sleeping, playing, bathing, etc.). Does anything happen at these times that concerns you? For example, feeding is stressful due to problems with sucking or swallowing.

What happens after an evaluation?

After your child's evaluation, the evaluation team (or a member of the team) will meet with you to share the findings. Make sure your concerns are addressed. Ask questions! Be honest about what you do or don't understand. Tell the evaluation team if you have a different opinion about the findings. The team is responsible for helping you learn what the evaluation means about your child.

The evaluation team must also write an *evaluation report* and *summary*. Your child's evaluation report and summary must include the following information:

- A statement about your child's *eligibility* for the Early Intervention Program.
- The *names* of the professionals who evaluated your child.
- A *description* of what took place at the evaluation. This should include *where* your child was evaluated and *what methods* were used (such as tests or activities).
- Your child's *responses* to the evaluation.
- *Your* opinion about whether the evaluation showed your child at his or her best.
- The *tests and scores* that were used (if any), and what they mean.

The written and spoken summary of your child's evaluation must be given to you in your language or in the manner you use to communicate, if possible. With your permission, an interpreter can be used to translate your child's evaluation summary.

The evaluation team must complete the written summary as soon as possible after the evaluation. The team must give the summary – and upon request – the full evaluation report to:

- You and your family.
- Your initial service coordinator.
- Your Early Intervention Official (EIO).
- With your permission, your child's doctor.

When more information is needed

Sometimes, parents or service coordinators may feel more information is needed. If you feel a second evaluation is needed, or part of the evaluation should be repeated, you can ask your Early Intervention Official (EIO). You can get a second evaluation (or part of an evaluation) at no cost to you if your Early Intervention Official agrees your child needs one.

Your initial service coordinator may also ask you to permit additional evaluation of your child. Additional evaluation procedures can be done only if you and your Early Intervention Official agree. The evaluation must be at no cost to you.

After the first multidisciplinary evaluation

Your child's first multidisciplinary evaluation decides eligibility. It also helps with your first Individualized Family Service Plan (IFSP).

There may be other times when your child will need evaluation services. If you and your Early Intervention Official agree, other evaluation services can be provided:

- If there is a change in your child's development that suggests different services are needed.
- When you, your service coordinator, or service provider feel more information is needed to review or evaluate your current IFSP.

Once evaluation services are agreed upon, your service coordinator is responsible for making sure changes are made to your IFSP.

Requirements for a fair (unbiased) evaluation

The Early Intervention Program has rules to make sure your child's evaluation is fair. These are:

- *Your child's evaluation team must use materials and activities that are sensitive to your family's language.* The evaluation must be completed in the "dominant" language of your family. "Dominant" language means the language you most often use when speaking to your child.
- *The cultural background and traditions of your family must be considered in your child's evaluation.* Families raise children using their own cultures and ideals. Your child's evaluation team must take this into account in deciding what materials to use and describing your child's responses to the evaluation.
- *Your child's eligibility cannot be based on only one test or procedure.* This means that more than one source of information must be used to decide whether your child is eligible.

The family assessment

Every family is different. You know your family best – and what it can do to help your baby's or toddler's development. You know what is most important to you, your child, and family – and what concerns you most.

As a parent, you bring your resources, priorities, and concerns to the early intervention process. *Family resources* are all the strengths, abilities, and formal and informal supports that families can use to help their child. *Family priorities* are the outcomes you want most from early intervention services.

Early Intervention and your child's "medical home"

Every child needs a *medical home*. A *medical home* is the doctor – or doctors – who take care of your child's health. A "medical home" is the place you *always* bring your child when she or he needs a checkup or is sick.

Your doctor can give you support and advice about the Early Intervention Program. To help your doctor stay involved:

- Ask your service coordinator to send your child's evaluation report and summary to your doctor.
- Talk with your doctor about your child's evaluation and what services might help your child.
- Invite your doctor to your IFSP meeting.
- Give your doctor a copy of your IFSP. Or ask your service coordinator to send one.
- Talk with your doctor about how early intervention services are working for you and your child.

Family concerns are the problems or needs you want to work on with your child and family.

This information can be helpful in designing the IFSP for you and your child. If you wish, you can participate in a *family assessment* —an assessment of the family's resources, priorities, and concerns.

Family assessment is a *voluntary* process. You do not have to take part in one! All information shared is kept private and you decide what goes into your IFSP.

If you decide to participate in a family assessment, it can help you:

- Think about what you need most from early intervention services.
- Think about other services and supports you might need (like another parent to talk to or respite services).
- Prepare for your IFSP meeting.

Your family assessment will be:

- Completed with you by trained professionals, at times and places good for you.
- Based on information provided by you and your family in a personal interview.
- Your description of your family's resources, concerns, and priorities.

When an evaluation finds that a child is not eligible

If your child's evaluation shows that your child is not eligible for services, you have the right to disagree with the results. You can request a *mediation* or an *impartial hearing* to challenge this decision (see page 26, "Your Rights as a Parent in the Early Intervention Program"). You can take these actions only when your child's evaluation has been completed.

If you agree your child is not eligible – and still feel you need help – ask your service coordinator for information about other supports and services in your community. Your service coordinator can help you make connections with other services.

Tips on being an effective parent advocate

- Remember you are an equal member of the team.
- Know your family's rights and responsibilities.
- Stand up for what you think about your child and family's strengths (what you do best) and needs (what you need help with).
- Take part in every step of early intervention services.
- Ask questions!
- Ask professionals why they think you and your child need certain services and how they will help.
- Keep copies of letters you write and notes from talks you have with your service coordinator and service providers.
- Work out problems early. If you cannot solve a problem, use the rights you have under the Early Intervention Program (see page 26).
- Ask about parent support and advocacy groups in your neighborhood, town, or city. Call them for advice, support, or help.

Step 4: Making a Plan for Services–Your IFSP

I-F-S-P means…

Individualized...the plan will be specially designed for you, your child, and your family.

Family...the plan will focus on your family and the outcomes you hope to reach for your baby or toddler and your family through early intervention.

Service...the plan will include all the details about the early intervention services your child and family will participate in – including when, where, and how often services will be delivered. Your IFSP can also include other services that your child and family needs that will not be paid for by the Early Intervention Program.

Plan...the plan is a written plan for early intervention services.

…family-centered!

If your child is eligible for the Early Intervention Program, the next step is to develop an *Individualized Family Service Plan* (IFSP). Your IFSP must be completed within 45 days after your child's referral to the Early Intervention Official, unless *YOU* "stop the clock" (for example, if your child is sick and the evaluation must be delayed). The IFSP is the written plan for the early intervention services your child and family will receive. You will work on this plan at an *IFSP meeting*.

Your initial service coordinator will set up the meeting to work on your IFSP. Your initial service

coordinator will tell you what happens at the IFSP meeting and help you prepare. Some facts you need to know are:

- The IFSP meeting must be held at a time and place that is good for you and your family.
- You, your initial service coordinator, your Early Intervention Official, and evaluation team – or selected member of the team – *must* take part in the meeting. Your Early Intervention Official may send someone else to represent him or her (an Early Intervention Official "designee"). The Early Intervention Official may also ask your service coordinator to act as "designee."
- You can invite others to be at the IFSP meeting – family, friends, your babysitter, or child care provider.
- Your service coordinator can invite others to take part in the meeting, with your permission.
- You can ask an advocate to take part in the meeting.
- You need to give permission to use any information from your family assessment, if you had one.

- You will be asked to select an *ongoing service coordinator* at the meeting.
- The meeting will be held in the language you speak, unless it is clearly impossible to do so.

Before the meeting, your initial service coordinator will make sure you understand your child's evaluation. She or he will also talk with you about the possibilities for early intervention services.

Here are some suggestions for what to think about when planning for your IFSP meeting, and things you may want to talk about with your initial service coordinator:

- How would you describe your child to others?
- What is working well for you at home?
- What do you need help with?
- What help do you want for your child?
- What do you need more information about?
- What places or activities in your community could early intervention help your child take part in?

Strategies for a successful IFSP meeting

Some families have said the IFSP is hard work! It is very important for you to take an active part in the meeting. This is the *BEST* way to the *BEST* plan for you and your family.

- Think about – and make plans for – someone to help you if your baby or toddler and/or other children will be at the meeting. Even if your meeting is at home, children can be distracting!
- Plan to start on time.
- Be prepared. Make a list of questions or matters you want to discuss. Have paper and a pen or pencil ready to take notes.
- Listen to what other team members have to say.
- Be clear about what you want.
- Ask questions when you don't understand something.
- Don't be afraid to ask for help!

At the IFSP meeting

Working on the IFSP is a team effort! You, your service coordinator, your child's evaluators, your Early Intervention Official, and others who take part will:

- Review all the information that has been gathered about your child.
- Talk about your family's resources, priorities, and concerns.

What's in an IFSP?

Your family's IFSP will include the following information:

- A statement of your child's present level of functioning.
- With your permission, a statement of your family's resources, priorities, and concerns related to your child's development.
- A statement of the major outcomes expected from early intervention services.
- A statement of the early intervention services, including transportation, needed to meet your child's and family's needs.
- A statement of the natural environments where early intervention services will be provided. "Natural environments" means settings where infants and toddlers are typically found in the community.
- A plan for when your child is in day care, and when needed, for early intervention service providers to train the day care staff to meet the needs of your child.
- A physician's or nurse practitioner's order for early intervention services that require an order from specific medical professionals.
- A statement about other services, including medical services, that are needed by your child and family that *are not* provided by the Early Intervention Program.
- The projected dates that services will begin, as soon as possible after the IFSP meeting, and the period of time during which the services will be delivered.
- The name of the ongoing service coordinator.
- If your child is turning three, the steps to help your child and family change to other services, including preschool special education services.

- Develop the outcomes—or goals—expected for your child and family from early intervention services.
- Work on strategies, activities, and services that will lead to the outcomes you hope to reach.
- Agree to the measures and timelines that will be used to look at the progress your child and family are making.

You have the right to say yes or no to any of the services talked about at your IFSP meeting. To include a service in your IFSP, you and your Early Intervention Official (or Early Intervention Official designee) must agree to the service. Others can give their opinion – but you and the Early Intervention Official have the final decision.

If you and the Early Intervention Official disagree about an early intervention service you think your child needs, you can ask for a *mediation* and/or *impartial hearing* to settle your differences. In the meantime, the early intervention services you and your Early Intervention Official do agree on will be provided.

You will be asked to sign your IFSP when the plan is finished. Participating in the Early Intervention Program is voluntary. When you sign the IFSP, you show that you were at the IFSP meeting and that you agree to the services in the plan. You are also giving your permission to start early intervention services.

The IFSP is an important document! If you need extra time to think about the plan, ask for it. You may want to discuss the plan with other family members or review it to make sure it meets the needs of your child and family.

Selecting your ongoing service coordinator

You will be asked to choose an *ongoing service coordinator* at your first IFSP meeting. You can choose your initial service coordinator or you can choose someone else who is qualified to be a service coordinator.

Choosing your ongoing service coordinator is an important decision. This service coordinator will be responsible for putting your IFSP into action. Your ongoing service coordinator will also be responsible for:

- Helping you obtain the services and help you need.
- Coordinating early intervention services with other services your family is getting.
- Making sure your child and family get all the services in your IFSP.
- Making sure services are delivered on time.
- Helping you find service providers.
- Informing you about advocacy services.
- Making sure *six-month reviews* and *annual evaluations* of your IFSP are completed.
- Helping you make any changes to your IFSP that may be needed between six-month reviews and annual evaluations.

Step 5: Putting Your IFSP Into Action

An important goal of the Early Intervention Program is to make sure infants and toddlers get early intervention services as quickly as possible. The sooner, the better!

Your family's IFSP will include the dates, *as soon as possible* after the IFSP meeting, when early intervention services will begin. Your ongoing service coordinator is responsible for making sure the early intervention services in your IFSP are delivered and helping out with any problems.

Putting your IFSP into action, though, is a team effort! *You* and *your family* are important members of the team. Be a part of your child's services. You can do this by:

- Being with your child when she or he is getting early intervention services. Arrange for services at times good for you, when you can pay full attention to what's happening.
- Asking the professionals working with your child to teach *you* the skills you need to help your child make progress.
- Keeping notes, a diary, or a journal about how well services are working and how well your child is doing. Think about what *is* and what *isn't* working. Ask for a change in services if you think a change is needed.

Reviewing, evaluating, and changing the IFSP

As your child grows and changes, so will the early intervention needs of your family. To be sure your IFSP keeps pace with your family and stays useful, the Early Intervention Program requires:

- Six-month reviews of the IFSP. The review may – or may not – include a meeting. If everyone agrees, the six-month review can be completed over the phone or by mail, or other ways that don't involve a meeting.
- Annual meetings to evaluate the IFSP.
- A process for changing the IFSP between the six-month reviews and annual meetings.

Your ongoing service coordinator is responsible for making sure the IFSP is reviewed and evaluated on time. The following persons take part in the six-month reviews and annual meetings to evaluate the IFSP:

- You and anyone you ask to participate.
- Your ongoing service coordinator.
- Your Early Intervention Official or designee.
- The professionals who are providing services to your child and family, if it makes sense to include them.
- Other persons invited by your service coordinator, with your permission.
- An advocate, if you invite one.

The six-month reviews and annual meetings to evaluate the IFSP are designed to make sure that the

IFSP still makes sense for your child and family. You and the other participants will look at how well early intervention services have helped your child and family meet the outcomes in your IFSP. You will also talk about what should be changed in the IFSP. This may include:

- Adding new outcomes and dropping old ones that have been reached – or that are no longer important or useful.
- Changing strategies and activities to help meet new outcomes or outcomes that have not been reached yet.
- Changing the services needed by your child and family.

Just like your initial IFSP, you and your Early Intervention Official must agree on IFSPs that come out of six-month reviews and annual IFSP meetings. You will be asked to sign the IFSP, to show you agree and give your permission to provide services. And just like your initial IFSP, you can ask for a mediation or impartial hearing if you disagree with your Early Intervention Official about certain services – while getting the services you do agree on.

You can request a review of your IFSP at any time. Your ongoing service coordinator can set up an IFSP review whenever one is needed.

Step 6: Transition

tran·si·tion . . .

means passage from one form, state, style, or place to another.

All too soon, your child will be turning three years old! As your child changes from a "toddler" to a "preschooler," he or she will also be "transitioning" from the Early Intervention Program to other services. Children can stay in the Early Intervention Program for a short time after they turn three.

- If your child's third birthday is between January 1st and August 31st, your child can stay in the Early Intervention Program until August 31st of *that calendar year*.*
- If your child turns three between September 1st and December 31st, your child can stay in the Early Intervention Program until December 31st of *that calendar year*.*

Your ongoing service coordinator will help you plan for other services when your child leaves the Early Intervention Program. Some children will no longer need any services. Other children and families may go on to early childhood programs or to other appropriate services in the community. Many children in the Early Intervention Program will be eligible for *preschool special education services* from their school districts and counties.

The steps to transition

A transition plan must be developed for every child leaving the Early Intervention Program and going into other services.

Usually, the transition plan is developed at your last IFSP meeting before your child transitions. Your child's transition plan will include:

- The steps needed to help your child get used to and get along in a new setting.
- The steps needed to prepare service providers who will help your child transition to a new setting and/or services.
- The individuals responsible for taking the steps needed to help your child make the transition.

With your permission, your service coordinator will incorporate the transition plan into your IFSP.

If you or someone else thinks your child may be eligible for preschool special education services, your Early Intervention Official will notify the Committee on Preschool Education (CPSE) in your school district. Your Early Intervention Official can notify the CPSE only with your permission. If you give your permission:

- Your Early Intervention Official must notify the CPSE at least 120 days before your child can start preschool special education services.
- Your service coordinator will review transition steps with you.
- Your service coordinator will send evaluations, IFSPs, and other records to the CPSE – with your permission. If your child is referred in writing to CPSE, you have the right to select an evaluator approved by the State Education Department from a list provided by the Board of Education. The CPSE, with the approved

*These dates apply only to children who are eligible for CPSE services. Otherwise, a child's eligibility for EI services ends at the child's 3rd birthday. (An amendment to Public Health Law Sections 2541 and 2548 on age-eligibility for EI services was passed as part of the 2003-2004 NYS budget.)

Preparing for transition

Here are some tips for preparing your child and family for the transition from the Early Intervention Program to preschool special education services:

- Learn what transition is and why it is important for your child and family.
- Learn what is the same and what is different between early intervention and preschool.
- Make sure your last IFSP includes all the necessary steps to help your child make a good transition to preschool special education services or other early childhood services.
- Find out what you need to know and what skills you need to develop to make sure you get the most out of preschool special education services.
- Get a copy of *A Parent's Guide to Special Education* – published by the State Department of Education. Ask your school district for your free copy.
- Call your local Early Childhood Direction Center (ECDC – see page 2). The ECDCs are funded by the State Department of Education to help parents and children get preschool special education services.

Some questions for parents to think about in making the transition are:

- What new information is needed about your child?
- What skills will your child need to get along in a new setting?
- Are there adaptive equipment needs, or modifications needed where your child will be getting preschool special education services?

evaluator, may review the existing evaluations and records sent by your service coordinator to determine if there is a need for additional evaluations before you and the CPSE can decide if your child will be eligible for preschool special education services.

If you agree, your Early Intervention Official will convene a conference with you, your service coordinator, and the chair of the CPSE in your school district to discuss your child's transition. This conference must happen at least 90 days before your child's third birthday.

A transition conference can happen in many ways. For example, it can be a telephone conference call, or it can be combined with the first meeting of the CPSE. The transition conference must be at a time and place good for you and the other participants.

For more information about preschool special education services, contact the Preschool Special Education Unit at the State Department of Education at (518) 473-6108.

Your Rights as a Parent in the Early Intervention Program

Parents have rights under the Early Intervention Program that *you* should know. Your Early Intervention Official is responsible for making sure you know about your rights. These rights include:

- The right to say yes or no to having your child evaluated or screened and taking part in a family assessment.
- The right to say yes or no to participating in the Early Intervention Program, without risking the right to take part in the future.
- The right to say yes or no to any certain type of early intervention service without risking your right to other types of early intervention services.
- The right to keep information about your family private.
- The right to look at and change your child's written record under the Early Intervention Program.
- The right to be told by your Early Intervention Official about any possible changes in your child's evaluation or other early intervention services before any changes are made.
- The right to take part – and ask others to take part – in all meetings where decisions will be made about changes in your child's evaluation or services.
- The right to use due process procedures to settle complaints.
- The right to an explanation of how your insurance may be used to pay for early intervention services.

Part of your service coordinator's job is to explain these rights to you and make sure you understand them and help you carry them out.

Your child's records

Your child's record includes *all* written materials developed or used for the Early Intervention Program. Your child's record may include:

- Information gathered as part of your child's referral to the Early Intervention Official.
- Screening and evaluation reports and summaries.
- Your family assessment (if you took part in one).
- Your Individualized Family Service Plan and all documents related to the plan.
- Progress notes and other information about your child's and family's services prepared by early intervention service providers (including your service coordinator).
- Any records about complaints you may have filed.
- All other records involving your child and family.

All information in your child's record must be kept confidential by the Early Intervention Official and early intervention evaluators, service providers, and service coordinators. You must give your written permission to allow information in your child's record to be released. There are two types of "releases" that you can sign:

- A *selective release* – this type of release requires you to identify the persons who can access the information in your child's record and from whom they can get the information.
- A *general release* – this type of release will allow information to be shared with individuals and agencies that will be providing services to your child and family.

No matter what type of release you sign, you can change your decision about who can access your child's record at any time.

As a parent, you have the right to...

- Ask what materials are being collected and kept in your child's record by your Early Intervention Official and service providers.
- Ask who has access to your child's record and who has seen or has copies of the record.
- Review—in person or through a representative — your child's record at any time. Your service coordinator can help you arrange to see your child's record. A sample letter of request is on page 36.
- Ask for copies of any of the materials in your child's record. You may be charged a small fee for copying.
- Request that changes be made to your child's record. If you feel that any information in your child's record is wrong, misleading, or violates your child's and family's privacy and rights, you may ask your Early Intervention Official, service coordinator, evaluator, or service provider to correct or change the information. Once you ask for a change, the person you asked must tell you in 10 days whether:

  – the change has been made as you requested; or,

  – your child's record has not been changed.

If your Early Intervention Official, service coordinator, evaluator, or service provider disagrees and will not make the change you asked for, you may have a statement placed in your child's record about your concerns.

You can also appeal the decision and ask your Early Intervention Official for an administrative hearing. The hearing will be conducted by a local official who has no direct interest in the hearing results. This hearing must be held within 30 days and conducted in accordance with the Family Educational Rights and Privacy Act (FERPA).

If you and your Early Intervention Official disagree

Sometimes, parents and Early Intervention Officials do not agree on what early intervention services should be in the Individualized Family Service Plan (IFSP). For example, you may not agree with your Early Intervention Official about:

- The kinds of services your child and family should have.
- How often services should be provided.
- How long services should be provided.
- What service model is best.
- Where services should be provided.

Parents have the right to use either *mediation,* an *impartial hearing*, or both to resolve disagreements with their Early Intervention Official about early intervention services. There is no cost to you for either a mediation or an impartial hearing.

Any early intervention service in the IFSP that you and your Early Intervention Official agree on can be provided while you take part in either mediation or an impartial hearing.

What is mediation?

Mediation helps parents and Early Intervention Officials agree to early intervention services in the IFSP. Mediation brings parents and Early Intervention Officials together to talk about their concerns. Mediation is *confidential*–what you talk about with your Early Intervention Official will be kept private.

What can mediation do?

The main reason for mediation is to help you and your Early Intervention Official reach agreement as easily and quickly as possible. Mediation can:

- Clear up a misunderstanding or the cause of a problem.
- Let you and your Early Intervention Official speak your minds with a neutral person listening.
- Help you and your Early Intervention Official work together to better solve a problem.

You can ask for mediation . . .

The first step is to send a letter to your Early Intervention Official to ask for mediation (see the sample letter on page 37). Your service coordinator can help you with this.

Your Early Intervention Official can also ask you to take part in mediation. Mediation is a *shared decision*. You and your Early Intervention Official must *both* agree to take part in mediation. If you *both* agree, your Early Intervention Official will tell the *Community Dispute Resolution Center* in your county about your request.

The *Community Dispute Resolution Center* will assign a mediator to work with you and your Early Intervention Official. The mediator may ask you and your Early Intervention Official for more facts before getting started.

A mediator will set up a *mediation meeting* for you and your Early Intervention Official within two weeks of being contacted by your Early Intervention Official–unless you ask for more time.

Who attends the mediation meeting?

You and your Early Intervention Official (or EIO designee) must both attend the mediation. You may invite others to come with you to the meeting– a family member, friend, or advocate.

You may bring a lawyer if you let your Early Intervention Official know before the mediation meeting. Your Early Intervention Official may also bring a lawyer and must tell you ahead of time that she or he plans to do so.

Who are the mediators?

Mediators are trained, certified, and assigned by the Community Dispute Resolution Center in your county. They are skilled in listening to all sides of a problem and in being fair. Mediators are *not* experts

in early intervention. They *are* expert mediators who know about – and understand – the Early Intervention Program.

What takes place at a mediation?

Your mediator meets with you and your Early Intervention Official to discuss the issues involved and help you find answers. Both of you will have the chance to share your concerns about the early intervention services that need to be settled.

The mediation process must be finished within 30 days of the Community Dispute Resolution Center receiving the request from your Early Intervention Official. Once mediation is finished, a written agreement is prepared describing what was agreed to and any outstanding issues. Your service coordinator will make sure this agreement is added to your IFSP.

Does mediation cost anything?

There is no cost to you for mediation. All costs are paid for by the New York State Department of Health federal funds under the Individuals with Disabilities Education Act.

What if no agreement is reached?

If you and your Early Intervention Official cannot agree on your IFSP, you can ask for an *impartial hearing*.

What is an impartial hearing?

An *impartial hearing* is another way for parents to settle disagreements with the Early Intervention Official about services in an IFSP. Parents can also ask for an impartial hearing if their child is found ineligible for services by an evaluator.

You have the right to ask for an impartial hearing to settle these problems, even if you take part in a mediation first. You do not have to take part in mediation before getting an impartial hearing. Both options are open to you and your family.

Impartial hearings are carried out by hearing officers who are fair and unbiased. These hearing officers are administrative law judges assigned by the Department of Health.

At a hearing, parents and early intervention officials give *testimony* and may use *witnesses* to

Attorney fees

If you think you may need help or advice from a lawyer, you should know that the fees for legal services can be paid for by your county of residence under the following conditions:

1. You must take part in – and complete – mediation. A mediation is "completed" when:
   - A parent and EIO participate and agree to services to include in your IFSP.
   - A parent and EIO participate but do not reach agreement.
   - An EIO does not agree to take part in mediation.
   - The mediation meeting has not been held within two weeks of the EIO's request to the Community Dispute Resolution Center (unless the parent asks for or agrees to an extension).
2. You request an impartial hearing and "substantially prevail" in the outcome. "Substantially prevail" means that the case is decided in your favor on some or most of the important issues in your case.
3. The county was represented by an attorney at the impartial hearing.

support their views. Parents may bring a friend, another parent, an advocate, or an attorney to the impartial hearing. The hearing officer must reach a decision in 30 days. The hearing officer's decision is final. You or the Early Intervention Official do have the right to ask for a judicial review of the hearing officer's decision.

If you need to request an impartial hearing

You must write to the Commissioner of Health. (For a sample letter, see page 37.)

You can ask for an impartial hearing at any time. If your complaint is about your child's eligibility, however, your request must be made within six months of the date your child was found ineligible for services.

Like mediation, an impartial hearing must be held at no cost to you.

If you request an impartial hearing

The Commissioner will assign an administrative law judge to act as a hearing officer.

You will get a written notice of the hearing that will:

- Give the date, time, and place of the hearing.
- Present the issues that will be examined at the hearing.
- Explain how the hearing will be conducted.
- Tell you that you can bring any person of your choice to the hearing, which can include an advocate or an attorney.
- Advise you that interpreter services for the deaf will be provided, if needed.
- Tell you about your rights at the hearing.

Your Early Intervention Official must tell you if he or she plans to use an attorney at the hearing. You must be told of this within three working days of the date your Early Intervention Official is notified of your hearing.

This will give you a chance to get an attorney if you think you need one. Your service coordinator can help you find legal and advocacy services in your area.

If you go to an impartial hearing

The hearing officer must conduct the hearing in a fair manner. The hearing officer has the power to make decisions about requests made by either you or the Early Intervention Official.

You can be represented by an attorney or persons with special knowledge or training about children eligible for early intervention services. You can also have other supportive persons—relatives or friends—come with you to the hearing.

Impartial hearings are private unless parents request a public hearing.

When the hearing is completed

The hearing officer will make the final decision on your case. You will get a copy of the hearing officer's decision in writing. Your service coordinator and Early Intervention Official will also get a written copy of the decision, as will the Commissioner of Health.

Your Early Intervention Official or service coordinator will make certain that your IFSP is changed, based on the hearing officer's decision. Your IFSP must be changed within five working days of the written or oral decision of the hearing officer, whichever is sooner.

Handling other problems... making a systems complaint

Sometimes, parents have problems with *how* the Early Intervention Program is working. If you believe that your Early Intervention Official or service provider is not doing his or her job under the law, you can file a *systems complaint*. Some examples of problems include:

- Not having an IFSP completed within 45 days of a child's referral to the Early Intervention Official.
- Not having services delivered on time.
- Not getting the services listed in your IFSP.
- Giving services to a child when a parent hasn't given permission.
- Receiving services in places where there are health or safety concerns.

To file a systems complaint, you must write to the New York State Department of Health (see the sample letter on page 38). You may also make a complaint by telephone or in person.

The Department of Health must investigate your complaint. If you make a complaint to the Department of Health:

- You will be contacted by Department of Health staff.
- You will be told how your complaint will be investigated. This may include interviewing you, any person named in the complaint, and others who may have helpful information about the complaint.

- You will be told how you can appeal the findings of the investigation to the U.S. Department of Education if you disagree with the results.
- Any information that could identify you will be kept private, unless you consent to having it shared.

The Department of Health must finish its investigation within 60 days from the time it gets the complaint. You will receive a written response to your complaint within 70 days.

This response will provide findings of the investigation. It will specify any actions that must be taken. The Department of Health is responsible for ensuring that all steps to correct the problem are taken.

What Else Should Parents Know About the Program?

The New York State Early Intervention Program is part of the national Early Intervention Program created by Congress in 1986 under the Individuals with Disabilities Education Act (IDEA). IDEA is the federal law that also gives all children and youth ages 3 to 21 years the right to a free, appropriate public education.

In 1992, the New York State Legislature created the State Early Intervention Program in Article 25 of the Public Health Law. The New York State Public Health Law gives all eligible children under three years of age the right to receive early intervention services in their Individualized Family Service Plans. The Public Health Law also ensures that:

- New York State's Early Intervention Program meets all the federal standards for early intervention programs.
- Parents have due process rights that apply to their child's early intervention services.

What are the Department of Health's responsibilities?

Some of the main responsibilities of the Department of Health, as lead agency, include:

- Administering and monitoring the statewide Early Intervention Program.
- Administering the statewide child find and public awareness system.
- Providing training and technical assistance to everyone involved in the Early Intervention Program.
- Keeping an updated statewide central directory of early intervention services, resources, and experts.
- Implementing a system of payments for early intervention services.
- Safeguarding parent rights under the Early Intervention Program.

What is the Early Intervention Coordinating Council?

The Early Intervention Coordinating Council (EICC) is an advisory council appointed by the governor to provide advice and assistance about the Early Intervention Program to the Department of Health. The EICC has 27 members, including:

- Five parents of children up to 13 years old with disabilities.
- Five providers of early intervention services.
- Two Early Intervention Officials.
- Two members of the Legislature.
- Commissioners, or their representatives, of the following state agencies: Department of Health, State Education Department, Office of Mental Retardation and Developmental Disabilities, Office of Mental Health, and, the Office of Alcoholism and Substance Abuse Services.
- The superintendent of insurance.
- One person involved in the training of early intervention professionals.
- Six persons appointed by the governor.

Twelve of these members, including four parents, are recommended to the governor by the leaders of the New York State Senate and Assembly.

The Early Intervention Coordinating Council is a very important part of the Early Intervention Program. All meetings of the EICC are open to the public. The EICC meets at least four times a year. For more information about the Early Intervention Coordinating Council, contact the New York State Department of Health, Bureau of Early Intervention, at (518) 473-7016.

What is a Local Early Intervention Coordinating Council?

Your county has a Local Early Intervention Coordinating Council (LEICC) made up of parents and professionals. The LEICC advises the Early Intervention Official about local early intervention issues such as gaps in services. LEICC meetings are a way to help you meet other parents and to learn more about the Early Intervention Program in your area.

Ask your service coordinator, or Early Intervention Official, for more information about your Local Early Intervention Coordinating Council. LEICC meetings are public, open meetings. Ask for the meeting dates, or ask how you can become a member.

We hope this *Parent's Guide* helps you and your family as you navigate the Early Intervention Program!

Additional Information and Resources

Early Childhood Direction Centers

There are 15 Early Childhood Direction Centers statewide, funded by the New York State Education Department, that provide information about programs and services for young children, ages birth through five, who have physical, mental, or emotional disabilities. These centers help families obtain services for their children.

www.vesid.nysed.gov/specialed/transition/whocan.htm

Parent to Parent of New York State

This is a parent-run organization, with nine offices statewide, that brings parents of children with disabilities together with other parents who have children with the same or similar disabilities. Parents can discuss similar problems, successes, share information, and provide each other with support.

www.parenttoparentnys.org

Parent Training and Information Centers

There are four centers staffed by experienced parents and professionals who provide information and training to families with children with disabilities, professionals working with families, and members of the community.

www.taalliance.org/PTIs.htm
www.advocacycenter.com
www.advocatesforchildren.org
www.resourcesnyc.org

Advocacy Services

The New York State Commission on Quality of Care for the Mentally Disabled provides a full range of advocacy services for persons with disabilities and administers contracts with a statewide network of legal and advocacy services.

www.cqc.state.ny.us

How to Refer Your Child

(Insert date)

(Insert Official's Name)
(Street Address)
(City/State/Zip Code)

Dear (insert name of Early Intervention Official):

I would like to refer my child, (child's name), to the Early Intervention Program. My child is (age of child) and appears to have problems in his/her development. I understand that I will be contacted by a service coordinator who will explain the program to me and can help me choose an evaluator from a list that will be provided to me. I also understand that *A Parent's Guide to the Early Intervention Program* will be provided to me.

The best time to reach me is on (insert days and times).

Sincerely,

(Insert Name)
(Street Address)
(City/State/Zip Code)
(County)
(Area Code/Phone #)

Sample

How to Ask to Review Your Child's Records

(Insert date)

(Insert Official's Name)
(Street Address)
(City/State/Zip Code)

Dear (Early Intervention Official/Service Provider/Service Coordinator/Evaluator):

I would like to review the records of my child, (child's name), who is receiving early intervention services from (name/s of service providers).

I understand that if I have any questions I can have information in the record explained to me, and have someone I select review the records for me.

The best time to reach me is on (insert days and times).

Sincerely,

(Insert Name)
(Street Address)
(City/State/Zip Code)
(County)
(Area Code/Phone #)

Sample

How to Request Mediation

(Insert date)

(Insert Official's Name)
(Street Address)
(City/State/Zip Code)

Dear (insert name of Early Intervention Official):

I would like to request mediation. I am concerned about the early intervention services that my child, (insert child's name) is receiving or should be receiving.

I hope you will agree to this request. If so, I understand that someone will contact me to make arrangements for mediation. The best time to reach me is on (insert days and times).

Sincerely,

(Insert Name)
(Street Address)
(City/State/Zip Code)
(County)
(Area Code/Phone #)

Sample

How to Request an Impartial Hearing

(Insert date)

Commissioner of Health
NYS Department of Health
Corning Tower Building
Empire State Plaza
Albany, New York 12237

Dear Commissioner (commissioner's name):

I would like to request an impartial hearing for my child, (child's name), regarding early intervention services. I am having a problem with (state the problem).

The best time to reach me to arrange for a reasonably convenient time, place, and date for the hearing is on (insert days and times).

Sincerely,

(Insert Name)
(Street Address)
(City/State/Zip Code)
(County)
(Area Code/Phone #)

Sample

How to Make a Systems Complaint

(Insert date)

Director, Bureau of Early Intervention
NYS Department of Health
Corning Tower Building
Empire State Plaza
Albany, New York 12237

Dear Director:

I would like to file a complaint because I believe that (name and address of person/agency) is/are not performing their work as the law requires. I would like the Department to investigate the following actions: (statement of charges)

I understand that my complaint will be investigated within 60 days and that I may be interviewed and will receive a copy of the final report.

The best time to reach me is on (insert days and times).

Sincerely,

(Insert Name)
(Street Address)
(City/State/Zip Code)
(County)
(Area Code/Phone #)

Sample

Notes

Notes

The New York State Early Intervention Program does not discriminate on the basis of handicap in admission or access to, or treatment or employment in, its programs and activities.

If you feel you have been discriminated against in admission or access to, or treatment or employment in, the New York State Early Intervention Program you may, in addition to all other rights and remedies, contact: Bureau of Early Intervention, New York State Department of Health, Room 287, Corning Tower, Empire State Plaza, Albany, NY 12237-0660.

State of New York
George E. Pataki, Governor

New York State Department of Health
Antonia C. Novello, M.D., M.P.H., Dr.P.H., Commissioner

0532

Revised 04/05