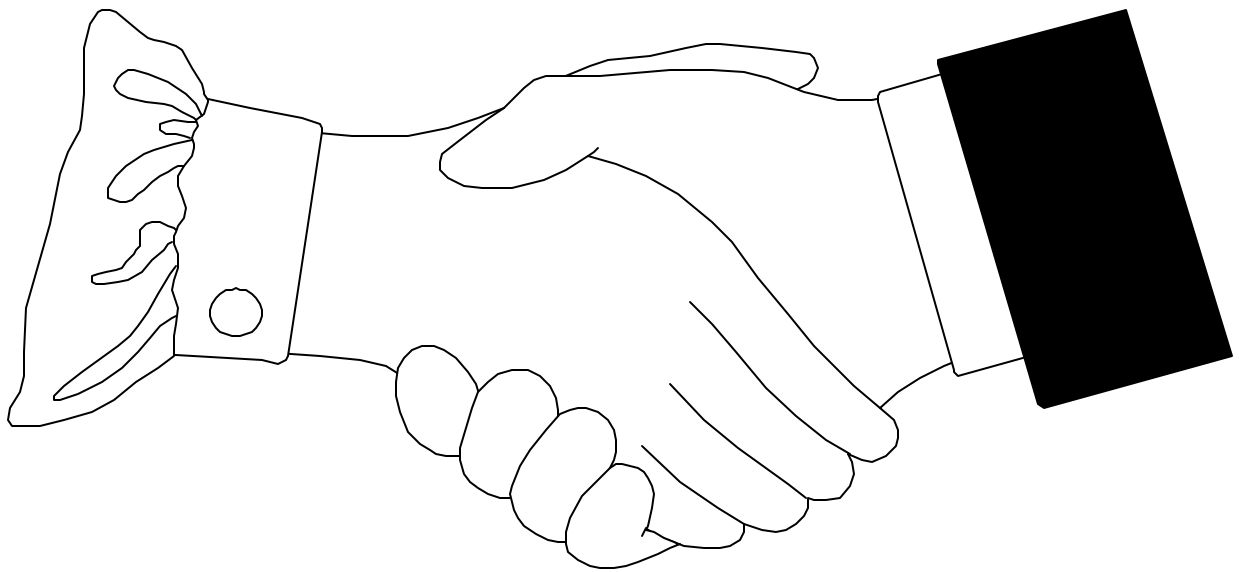


**STRENGTHENING PARTNERSHIPS:**

**A GUIDE TO FAMILY SAFEGUARDS  
IN THE INFANT & TODDLER  
CONNECTION OF VIRGINIA**

**PART C EARLY INTERVENTION  
SYSTEM**



**December 2002**

## TABLE OF CONTENTS

FAMILY REPRESENTATIVE LETTER .....	2
SUMMARY OF PARENT SAFEGUARDS.....	3
WHAT ARE EARLY INTERVENTION SERVICES? .....	6
PURPOSE OF THIS GUIDE .....	6
BACKGROUND .....	7
HOW CAN I FIND OUT IF MY CHILD CAN GET SERVICES? .....	9
Eligibility for Early Intervention Services In Virginia .....	12
WHAT EARLY INTERVENTION SERVICES ARE AVAILABLE? .....	13
INDIVIDUALIZED FAMILY SERVICE PLAN .....	13
How Will I Know If The Services Are Working? .....	16
Six Month IFSP Review .....	16
Annual IFSP Meeting .....	17
WHAT HAPPENS WHEN MY CHILD IS TOO OLD FOR EARLY INTERVENTION? .....	17
WHAT ARE MY SAFEGUARDS AS THE PARENT OF A CHILD RECEIVING EARLY INTERVENTION SERVICES?.....	21
What is “prior written notice”?.....	22
What does it mean when I give “informed consent”?.....	23
How is my confidentiality protected?.....	23
WHEN AND HOW CAN I REVIEW MY CHILD’S RECORDS? .....	25
HOW CAN I RESOLVE DISAGREEMENTS? .....	27
Filing a Complaint .....	28
Using Mediation.....	29
Requesting a Due Process Hearing.....	30
GLOSSARY .....	32
Contacting Local Central Points of Entry .....	34



# Family Involvement Project

## The Arc of Virginia

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Dear Parent,

I am the Statewide Family Representative for Early Intervention Services in Virginia. My family received early intervention services for nearly three years. I learned early in my daughter's life, that one of the best things I can do to help her, is to learn as much as I can about the different services that are available. This booklet was written to help you learn about Virginia's early intervention system and the safeguards in this system. These safeguards are included in Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System. You will receive a copy and explanation of these safeguards periodically during your time in the early intervention system.

Early intervention is wonderful and I can tell you first hand, it works! The system is designed to work with families who have children with disabilities or developmental delays that are between birth and three years old. The people who work in this system know about all of the services and programs that are available in our communities to help our families and can help us to learn about them also.

One of the best things about early intervention is that families are very involved with designing the system. We help to design the system as well as help to decide how to best spend the money that funds the system. As you read this guide, if you have any questions or want to learn more about how you can be involved, or if you would just like to talk with another parent who has been where you are, please call me at our toll free number 1-888-604-2677 ext 3.

Sincerely,

Wanda B. Pruett

## SUMMARY OF PARENT SAFEGUARDS

Early intervention in Virginia is a coordinated system of community services for infants and toddlers (birth through age two) who have disabilities or developmental delays and their families. Through this system, called Infant & Toddler Connection of Virginia, agencies, parents, and service providers work together to give children and their families services to meet the children's developmental needs.

Parents of infants and toddlers who are eligible for early intervention services have many important roles to play, including:

- getting information;
- giving permission;
- sharing information;
- participating in meetings; and
- deciding what services to accept.

Briefly, as the parent of a child eligible for early intervention services, your safeguards include:

- receiving information in writing before any action is proposed or taken that changes the services you and your child receive;
- communicating with people in the language you know best unless this is not feasible;
- accepting, or refusing, evaluation, assessments, or services;
- participating in meetings where decisions are being made about your child and family;
- receiving services according to an Individualized Family Service Plan (IFSP);
- seeing copies of and correcting records of your child and family;
- receiving services in your child's natural environment to the extent appropriate to your child's needs;
- filing complaints and requesting mediation or an impartial hearing if you disagree with the rest of the team;
- disagreeing with certain parts of the IFSP while continuing to receive services not in dispute; and
- having your privacy protected and personally identifiable information remain confidential.

There will be times during your involvement with Infant & Toddler Connection of Virginia when you will exercise your responsibilities as a parent. What follows are some examples of those times:

1. During the evaluation process (which will determine whether your child is eligible for early intervention services), you will have the opportunity to:
  - give permission before any testing is done;
  - give permission to gather information about your child from professionals who know your child;
  - share with the team what you know about your child's skills and needs;
  - decide if the evaluation will include information about your family's resources, priorities and concerns about your child;
  - include information from other people who have tested your child in the last six months;
  - get copies and explanations of the test results and other reports; and
  - ask questions about the evaluation process or the test results.

Evaluation services must be provided at no cost to you or your family.

2. If you and the rest of the team agree that your child is eligible for services, you will go on to work together to develop an individualized family service plan (IFSP). The IFSP lists what you and the early intervention providers will be working on and the early intervention services that your child and family will receive. You may be charged for early intervention services, other than evaluation, based on your ability to pay as determined using ability to pay mechanisms outlined in the document Facts About Family Fees. Inability to pay will not prevent your child or your family from receiving early intervention services. You will be asked to sign the IFSP to show that you agree with the plan and want your child and family to receive the services described in it. You can choose to accept all, some or none of the services. Nothing will be done without your permission. Although you can ask for the IFSP to be reviewed at any time, it must be reviewed at least every six months and your IFSP team must meet at least once a year to discuss your child's progress and update the IFSP.

Early intervention works best when families and professionals work together. Sometimes families and service providers disagree. In most cases, families and professionals can discuss their disagreements and reach a compromise that

everyone can accept. Sometimes, even when people mean well and try hard, talking it over does not work. There are three formal ways in the early intervention system to resolve disagreements:

- ❑ Complaints - Anyone can file a complaint if they believe any agency or person providing early intervention services has violated the early intervention requirements. For example, you might file a complaint if your local early intervention system is not meeting important deadlines, like developing an IFSP within 45 calendar days of the time you were referred to the Infant & Toddler Connection of Virginia. Complaints must be made in writing.
  
- ❑ Mediation - Mediation is a process that makes it possible for a specially trained person to help you and professionals reach an agreement. In mediation, no one wins or loses. The result of mediation is that you and the service providers write down what you each agree to do to solve the problem. Mediation is voluntary. You can begin mediation and file a request for a due process hearing at the same time. The mediation process must be completed within 15 calendar days of the Lead Agency's receipt of the request and both parties agree to mediate.
  
- ❑ Due Process Hearing - Hearings are the most formal way to resolve disputes. You can request a hearing if you disagree with a decision or action that affects your child's evaluation, placement or the services you and your child receive. Hearings are conducted by impartial hearing officers who know the early intervention laws. A hearing is a formal proceeding where evidence can be presented and witnesses called to testify. The hearing officer must make a decision and mail the written decision to each party no more than 30 calendar days after the request for a hearing is filed and received by the Lead Agency.

**Things I Want to Remember:**

## WHAT ARE EARLY INTERVENTION SERVICES?

*Family* is defined according to each family's definition of itself.

Parent means a natural or adoptive parent of a child, a guardian, a person acting as a parent, (such as a grandparent or stepparent with whom a child lives, or a person who is legally responsible for the child's welfare); or a surrogate parent.

If certain conditions are met, a foster parent may also serve as a parent under Part C.

Early intervention in the Commonwealth of Virginia, Infant & Toddler Connection of Virginia, is a coordinated system of community services for infants and toddlers who have disabilities or developmental delays, as well as for the families of such children. Through this system, agencies, parents and providers work together to provide eligible children and their families services to meet the children's developmental needs.

Early intervention services are for infants and toddlers from birth through age two who are not developing as expected or who have a condition, which can delay normal development and includes services to the families of such children. These services are provided to promote a child's development and to assist families in meeting the developmental needs of their child.

Early intervention service providers work in partnership with families to find infants and toddlers who are eligible for services, to determine what these children need, and to provide services for which the child's family gives permission. Family involvement is important at every step along the way.

## PURPOSE OF THIS GUIDE

Parents of infants and toddlers who are eligible for early intervention services have an important and special role to play in their child's services. Parents:

- provide information;
- give permission;
- share information;
- participate in meetings; and

- decide what services to accept.

To assist families in their roles in the early intervention system, this guide first describes the major steps in becoming involved in the Infant & Toddler Connection of Virginia. Then it briefly explains the safeguards available for you and your child. It discusses how you can make informed decisions for your child and work in partnership with the people who provide early intervention services.

## BACKGROUND

People who provide early intervention services might use technical language to describe the work they do with infants and toddlers and families. Ask for explanations of unfamiliar words. There is also a glossary starting on page 34 of this booklet that defines some of these technical words.

Since the 1970's, the Commonwealth of Virginia has provided early intervention services for children, birth through two years of age, who are experiencing developmental delays. In 1986, the U.S. Congress provided funds to states to set up a comprehensive system of early intervention services. This system of services is referred to as *Part C (formerly Part H) - Early Intervention for Infants and Toddlers with Disabilities* within the federal special education law called the *Individuals with Disabilities Education Act (IDEA)*.

*To avoid unnecessary use of technical jargon in this guide, the term early intervention system is used to describe Virginia's policies and procedures under the federal Part C program.*

In the Commonwealth of Virginia, there are 40 local interagency coordinating councils that plan how agencies and providers in the community will provide services for families.

Every child and family entering the early intervention system has a service coordinator. Your service coordinator will work with your family to help you:

- gather enough information to make good decisions for your child and family;
- arrange for and keep track of services;

- find out about and receive necessary services;
- find out about advocacy services;
- plan for changes in services (transition); and
- understand your safeguards and responsibilities as a parent and use them when appropriate.

Throughout Virginia, programs and agencies that provide early intervention services may have different names. But, each local council has someone you can contact for information and help.

*Page 34 of this booklet lists the early intervention contacts in Virginia.*

**Things I Want to Remember:**

## HOW CAN I FIND OUT IF MY CHILD CAN GET SERVICES?

You, your child's doctor, a friend, or other person can make a referral. Some communities offer general screenings, well-baby checks, or individual child screening as a way of referring a child for services. A screening is not required before your child is evaluated.

If you have a concern about your child, call the Infant & Toddler Connection of Virginia's toll-free number at (800) 234-1448 or call the telephone number for the early intervention contact in your area. (*Refer to the list on page 34.*) When you first make contact with the system, someone from Infant & Toddler Connection of Virginia will meet with you to explain the safeguards under the system and give you written information explaining those safeguards. At this point, a service coordinator will begin working with you and your family. This person will help you find out if your child is eligible for services. Your service coordinator's role is to assist you during the referral, evaluation and eligibility process. The service coordinator will gather information from you about your child and make arrangements for evaluations.

The words *she* and *he* or *her* and *him* will be used alternately to refer to children. No matter what gender is used, both boys and girls are equally included.

With your signed permission, your service coordinator will arrange for an evaluation to learn about how your child is developing. If your child has already had an evaluation, additional evaluations may not be needed. Your service coordinator will make sure that any procedures used are right for your child and are sensitive to your family's needs and culture.

During the evaluation process, your child will be given a fair chance to show what she can do. Your child will be evaluated by a group of professionals who represent at least two professions or areas of development. Evaluators may include infant educators, speech therapists, physical therapists, occupational therapists, social workers, nurses, and/or others. This evaluation by a team of professionals is called a "*multidisciplinary evaluation.*"

The evaluation will include how your child:

- thinks and understands events occurring in his day - this is called *cognitive development*;
- sees things, hears sounds and voices and is growing - this is called *physical development*;
- moves - this is called *gross motor or fine motor development*;
- understands what you say or lets you know what she wants - this is called *communication*;
- gets along with other people and expresses his feelings - this is called *social or emotional development*; and
- does ordinary things expected of babies and toddlers like feeding herself, helping to dress himself and kissing and hugging - this is called *adaptive development*.

"We were pleasantly surprised by how much input we had as parents in this process. We felt more like team leaders than team members."

—A Virginia Couple

As the child's parent, you are an important part of the team during the multidisciplinary evaluation. You are welcome to participate in evaluations and in meetings where evaluation results are talked about or explained. This is an opportunity to:

- give permission before any testing is done;
- give your service coordinator permission to gather information about your child from other professionals who know your child;
- share with the team what you know about your child's skills and needs;
- decide if the evaluation will include information about your family's resources, priorities and concerns about your child;
- include information from other people who have tested your child in the last six months;
- get copies and explanations of the test results and other reports; and
- ask questions about the evaluation process or the results.

After the evaluations are completed, you and others on your team will meet to consider all of the test results and other

information collected. The multidisciplinary team will decide if your child is eligible for early intervention services. You can invite anyone to this meeting who can help you with the discussion about your child and can help you with making decisions, if appropriate. Your service coordinator can arrange for the team to meet at a time and place that is comfortable for you and your family.

If the multidisciplinary team decides that your child is eligible for services, you will work together to develop an individualized family service plan (IFSP) that is explained in the next section.

If the multidisciplinary team decides that your child is not eligible for early intervention services, you can ask your service coordinator to help with:

- continuing to review your child's progress in case she does not develop as other children her age develop; and
- referrals to other resources in your community that may be helpful to your child and family.

*If agreement cannot be reached on your child's eligibility, there are ways to help resolve these differences. See page 27 for more information on how to do this.*

<p><b>Things I Want to Remember:</b></p>
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## Criteria For Eligibility for Early Intervention Services In Virginia

In Virginia, your child may qualify three different ways for early intervention services. Information gathered during the testing completed by the multidisciplinary team will help identify if your child meets one or more of the eligibility criteria. This information will be explained to you during the testing.

- I. Infants and toddlers with at least a 25% developmental delay (chronologically or adjusted age) in one or more of the following areas:
1. **cognitive development** (thinking skills);
  2. **physical development** (including the way muscles work, vision and hearing);
  3. **communication** (understanding what is said or communicating what is wanted)
  4. **social or emotional development** (ability to interact with others and express feelings); or
  5. **adaptive development** (doing things independently like eating and helping to dress self).

AND/OR

- II. Children without a 25% developmental delay who are developing atypically in one of more of the following:
1. **abnormal or questionable sensory-motor responses** (abnormal muscle tone, limitations in joint range of motion, abnormal reflex or postural reactions, poor quality of movement patterns or quality of skill performance, oral-motor skills dysfunction, including feeding difficulties)
  2. **identified affective disorders** (delay or abnormality in achieving expected emotional milestones, persistent failure to initiate or respond to most social interactions, or fearfulness or other distress that does not respond to comforting by caregivers) or
  3. **behavioral disorders** that interfere with the acquisition of developmental skills.

AND/OR

- III. Children who have a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay. These include, but are not limited to:
1. seizures/significant encephalopathy (identifies the high risk group with low Apgars and/or asphyxia);
  2. significant central nervous system anomaly;
  3. severe Grade 3 intraventricular hemorrhage with hydrocephalus or Grade 4 intraventricular hemorrhage;
  4. symptomatic congenital infection;
  5. effects of toxic exposure including fetal alcohol syndrome, drug withdrawal and exposure to chronic maternal use of anticonvulsants, antineoplastics, and anticoagulants;
  6. myelodysplasia;
  7. congenital or acquired hearing loss;
  8. visual disabilities;
  9. chromosomal abnormalities, including Down Syndrome;
  10. brain or spinal cord trauma, with abnormal neurologic exam at discharge;
  11. inborn errors of metabolism;
  12. microcephaly;
  13. severe attachment disorder;
  14. failure to thrive; or
  15. at the discretion of the multidisciplinary team, other physical or mental condition.

## WHAT EARLY INTERVENTION SERVICES ARE AVAILABLE?

In Virginia, early intervention services are designed to meet the individual developmental needs of each child and family.

Because no two children or families are alike, there are many kinds of early intervention services. All families can receive help from a service coordinator. The IFSP process determines which services are needed for an individual child and family. Services can include:

*"There's just no way to tell you what all they've done for us. I felt like I was under a cloud and when they drove up the sun came out. Sometimes they just held my hand."*

*—A Virginia Parent*

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

This list of services is not exhaustive. Early intervention services may include such services as the provision of respite and other family support services. Some families receive only a few services. Others receive more. It depends on your child's and family's need.

### INDIVIDUALIZED FAMILY SERVICE PLAN

The individualized family service plan (IFSP) is a written plan that is reviewed every six months and revised at a meeting at least every year. At IFSP meetings, information identified during your child's evaluation, your child's

strengths and needs, what you consider to be most important for your child and family, and goals and outcomes will be discussed. This is a good starting point for deciding what activities and services are needed to help your child develop.

Examples of other people you might want to invite to the IFSP meeting are family members, your child's doctor, child care provider, or a therapist providing services to your child.

During the IFSP process, the IFSP team, which includes you, works together to develop a plan for the next year. Within 45 calendar days after referral, your team will meet to design and write an IFSP.

As a parent, you are an important member of the team. You can invite other family members or people who you feel can help you make good decisions for your child. Your service coordinator and local service providers will also be members of the team. Your service coordinator will set up the meeting at a time and place that is convenient and comfortable for you. You will also receive this information in writing.

*"My husband wanted to hear what the assessment team had to say but could not take off work. It was so helpful when the early intervention team came to our house in the evening for Matthew's assessment and IFSP development."  
—A Virginia parent*

The IFSP meeting is a time for you and the rest of the team to share information about your child and their ideas to develop a plan that will work for your child and family. This is an opportunity for you to share your hopes, concerns, priorities and dreams for your child. Your sharing of ideas about what activities, approaches and services you think will help your child and family is important. Professionals on the team will also share their ideas about the services needed to help your child. Together you will decide what goes in the IFSP.

The IFSP lists what you and the early intervention providers will be working on, including:

- the name of your service coordinator;
- your child's current skills and needs;
- if you agree, a statement of your family's resources, priorities, and concerns related to your child's development;
- major results or changes (called "outcomes") the team hopes to see for your child and family;

- what early intervention services and supports will be provided;
- where services will be provided;
- the "*natural environment*," to the extent appropriate, in which services will be provided, including the home and settings that are natural or normal for children who are your child's age and who do not have a disability;
- how often services will be provided, when they will begin and how long they will last;
- other services needed by the family but that the early intervention system does not make available;
- payment arrangements, if any;
- a transition plan for when your child is getting ready to leave early intervention services; and
- your signed permission to begin services.

Services that must be available at no cost to parents include the evaluation, service coordination, development of the IFSP and implementation of procedural safeguards.

You may be charged for other early intervention services based on your ability to pay as determined using ability to pay mechanisms outlined in the document Facts About Family Fees. You received a copy of this document and it was explained to you when you when you received the *Notice and Consent for Initial Evaluation/Assessment*. You will receive an additional copy of this document and it will be explained to you at every annual IFSP meeting.

Some of the costs of services are supported by federal, state and local funds. Most local early intervention service providers rely upon payment from individual health insurance (with your permission) and Medicaid, as well as fees based on parent income in order to fund services. However, you will not be denied services because you cannot pay for them. If you have some questions about how services for your child might be funded, you should discuss this with your service coordinator as you are developing the IFSP.

You will be asked to sign the IFSP to show that you agree with the plan and want your child and family to get the services that it describes. You can choose to accept all, some, or none of the services. Nothing will be done without your permission. You can ask for the IFSP to be reviewed at any time.

There are ways to help resolve differences if there is ever a time when you and the rest of the team cannot reach agreement on what services should be in the IFSP. See page 27 for more information on how to do this.

### **How Will I Know If The Services Are Working?**

The early intervention system is designed to welcome your ideas and support your participation in ways that are comfortable to you. You can be with your child as he receives services, ask for progress reports, or set up a time when it is convenient to have a telephone discussion or meeting to talk about your child's progress.

Because you spend more time with your child than anyone else, you may be the first one to notice that it is time to make a change in your IFSP. Contact your service coordinator as soon as you think something should be changed.

You can request a modification or revision of IFSP services at any time. If your child is not making expected progress, or if you believe that services need to be adjusted (increased, decreased, or ended), you can meet informally with your service coordinator or service providers to discuss your concerns. The service coordinator is responsible for making the appropriate arrangements for revising or modifying the IFSP. The family and the service coordinator can modify or revise IFSP outcomes at any time using the IFSP review process. These revisions should be done in coordination with the service provider(s).

### **Six Month IFSP Review**

Ongoing assessment of your child's development is built into the early intervention system. Every six months, or more often if necessary, you, your service coordinator and, if appropriate, other members of your team will review the IFSP.

At the IFSP review, you and the others present will describe the progress your child has made and bring up any new issues. You will have a chance to say what you think is working, what you would like to change, and what else you think would be helpful for your child and family.

### **Annual IFSP Meeting**

*"I think for parents to maximize the opportunities in the Part C system they need to be willing to grow in their knowledge of the system as their child grows. If they try to know everything on day one they will frustrate themselves completely."*

*—A Virginia parent*

At least once a year, your team meets to discuss your child's progress and update the IFSP. Your service coordinator arranges this team meeting at a time and place that is convenient for you. Before an annual meeting, your service coordinator will let you know about the meeting in writing and give you an explanation of your safeguards in writing.

Because infants and toddlers change so rapidly, the team may want to do some more evaluations. If so, you will be asked to sign permission. As a part of the team, you will be asked to join in on the discussions and decision making just like you did after the first evaluation.

### **WHAT HAPPENS WHEN MY CHILD IS TOO OLD FOR EARLY INTERVENTION?**

*"It was hard to think so far ahead but now I'm glad that my early interventionist brought transition up so early. She even visited the preschools that I wanted to look at with me. She helped me to really feel like I had made the best decision for my little boy."*

*—A Virginia Parent*

By the time they leave early intervention, some children have received all the help they need and no longer need special assistance. Others still need some more help. This can be provided by community agencies, private providers or by the early childhood special education system in the public schools.

You should be informed about Virginia's system of services for children through age 5 at your first meeting in the Infant & Toddler Connection of Virginia. Virginia's system of services is designed to transition eligible children into public school services, if you agree, as early as age two.

A transition plan helps you and your child move smoothly from early intervention to whatever comes next for your child. This transition plan is a part of your child's IFSP. Transition plan activities must be discussed at each IFSP meeting.

Your local school system provides early childhood special education for children with disabilities under what is called *Part B of the Individuals with Disabilities Education Act (IDEA)*. In Virginia, eligible children who will be two years old by September 30<sup>th</sup> can begin early childhood special education at the start of the school year. Most two year olds move to preschool in September of the year they are eligible. Transitions for some two year olds may be delayed until later in that school year. You decide when your child transitions as a part of the IFSP. Early intervention services continue to be available until the transition occurs or until your child's third birthday.

Special education laws guarantee a free appropriate public education for eligible children with disabilities. Eligibility requirements and services are not exactly the same as for early intervention. Not all children who receive early intervention services will be eligible for or need special education. Special education focuses on your child's educational development, delays and needs.

If your child will be two years old before September 30<sup>th</sup>, steps in the transition to special education may include:

- notifying the local school division of your child's name, address, telephone number and birth date when your child reached the age of eligibility for special education, unless you indicate in writing on the IFSP transition page that you do not want the information sent;
- transferring information about your child (such as evaluation information and IFSPs) to the local school system, with your permission;

- having a conference with the local school system at least 90 days or up to six months (if all parties agree) prior to eligibility for special education;
- discussing future services and placements; and
- preparing you and your child for a change in services and helping her adjust to a new setting;

During the transition from early intervention to special education preschool services, your service coordinator can go to meetings with you. You can use the skills you developed in early intervention to make special education work for your child.

If your child is not eligible for special education, but still needs some services or supports, your early intervention service coordinator will, with your permission, attempt to schedule a transition meeting with others in the community to discuss next steps for your child and family. Your service coordinator can help you plan for and find other services in your community. These might include Head Start, nursery schools, or other education or family support programs that can help meet your needs. These efforts will be included on your IFSP.

As your child leaves early intervention services, it is a good idea to make sure you have a complete copy of your child's records. The records will help you document the progress your child has made and may be useful as you plan for future services and supports. You may want to carefully go through all of your child's early intervention records to decide what information you would like passed along to special education or your next service providers. If you disagree with something in your child's records, you can ask to have them changed. *See page 25 for information on how to do this.*

**Things I Want to Remember:**

A large, empty rectangular box with a thin black border, intended for the user to write their thoughts or memories. It occupies most of the page's vertical space.

## WHAT ARE MY SAFEGUARDS AS THE PARENT OF A CHILD RECEIVING EARLY INTERVENTION SERVICES?

A surrogate parent is an individual who is assigned to act for a parent when the child is a ward of the state or a parent cannot be identified or located. If you are serving as a surrogate parent or want more information about safeguards and responsibilities of surrogate parents, you may contact your Early Intervention contact listed on page 34 or call Infant & Toddler Connection of Virginia at (800) 234-1448.

A technical explanation of parent's safeguards with references to federal law can be found in a booklet called *Notice of Child and Family Rights In The Infant & Toddler Connection of Virginia Part C Early Intervention System* published by the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services. You will be given a copy of this booklet when you begin participating in the early intervention system and at various steps along the way. Your service coordinator will give you a copy in the language you understand best, unless this is not possible. These safeguards will be explained to you.

Early intervention services are governed by federal laws and regulations as well as Virginia policies and procedures.

These policies and procedures are written to ensure that you have the information you need to make good decisions for your child and family disagreements can be resolved, your privacy is protected, and a surrogate parent is appointed when a child does not have a parent representing his interests.

Briefly, as the parent of a child eligible for early intervention services, your safeguards include:

- receiving information in writing before any action is proposed or taken that changes the services you and your child receive;
- communicating with people in the language you know best unless this is not possible;
- accepting or refusing evaluation, assessments or services;
- participating in meetings where decisions are being made about your child and family;
- receiving services according to an IFSP;
- seeing copies of and correcting records of your child and family;
- receiving services in your child's natural environment, as appropriate to your child's needs;
- filing complaints and requesting mediation or an impartial hearing if you disagree with the rest of the team;
- disagreeing with certain parts of the IFSP while continuing to receive services not in dispute; and
- having your privacy protected and personally identifiable information remain confidential.

## What is "prior written notice"?

Anytime early intervention staff or providers want to start or make a change in services, they must give you a **notice in writing**. Changes might include a new service, an end to a service, or a change in how often you will receive a service. Any action will be discussed with you at an IFSP meeting first. The notice must also tell you what you can do if you do not agree to the proposed action.

The notice must be in the language you use unless this is not possible. It must also be clear and easy to understand. If you need any assistance in understanding the notice, call your service coordinator and ask for an explanation.

Sometimes your service coordinator will call you to talk about the proposed change before you get the written notice so it won't come as a surprise.

All written prior notice will be given using forms approved by the Infant and Toddler Connection of Virginia state office. Each time these standard forms are given to you, you will also receive a copy of Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System

The notice must be given to you **before** the change is discussed at an IFSP meeting and **before** it actually takes place. You can take time to think about the change and decide if you agree with it. You can also show the notice to others (a professional or friend) who can help you decide what is best for your child.

You also can suggest changes in the early intervention services provided for your child and family. Discuss your ideas with your service coordinator. You will receive "prior written notice" when service providers agree with your request or refuse to make any changes.

## What does it mean when I give "informed consent"?

You decide whether you, your child, or anyone in your family will accept any early intervention service. You can change your mind and can accept all, some, or none of the services offered.

You are the most important person in your child's life. To make good decisions, you need accurate information. Giving your consent means that you understand what is being offered and recommended, and with that understanding, you give your permission for implementation of services.

The best time to ask questions is before you give your consent. Some questions might include:

- What tests are suggested for my child and who will evaluate her?
- What activities and services will help meet the outcomes set for my child and family?
- When and where can services be provided?
- Who might provide services?
- How will payment for services affect my insurance coverage or family finances?

## How is my confidentiality protected?

*"My little boy's disability is one that a lot of people don't know about. It was so nice to have help with finding out who in my area could help us. But I always knew they wouldn't talk to anyone about us without our permission."  
—A Virginia Parent*

The early intervention services your family and child receive and the reasons you need these services are personal and private. Although you share personal information about your child or your particular family situation with your service providers, your privacy is protected through the confidentiality requirements in the early intervention system.

Confidentiality extends to written records and conversations people may have with you or about your child and family.

Early intervention providers collect information to keep careful track of what services are provided to your family and how well your child is doing. Keeping information confidential is not only a federal and state requirement,

but an important part of gaining your trust and cooperation.

There are extensive requirements telling early intervention providers how to handle confidential records. These include:

If you ask, your local early intervention provider will give you a list of who is authorized to see your early intervention files. Authorized people must have training in the confidential handling of records and files.

1. **Record storage:** All records that contain personally identifiable information are kept where only certain people can see them. These authorized people include individuals who have a legitimate reason to look at your early intervention records. They include your service coordinator, the professionals working with you and your family, and the administrators of the agencies responsible for providing you with services.

2. **Authorization to see files:** No one can give out information or tell what is in your child's record without your permission except under very limited circumstances allowed under federal law.

3. **Disclosure record:** The local early intervention system has a list of all the files kept on your child and family. There is also a list of everyone who has looked at any of your child's records. You can see this "*disclosure record*" if you ask.

4. **Parent permission:** Except under very limited circumstances allowed under federal law, confidential information in the files cannot be shown or given to anyone without your written permission. A copy of your written permission telling what information can be shared and who can get it must be kept in the file. **Parent permission not given:** Your service coordinator will discuss the reasons why the requested information is needed, give you written information to make sure you are making an informed decision or offer to let you talk to another parent.

**6. Disposal of records:** When your early intervention system no longer needs information in your child's records, staff will notify you. At that point, the records must be destroyed at your request. However, the provider may maintain permanent records of the child's name, address, phone number, and when the child received services.

Note: Periodically, throughout your time in Infant & Toddler Connection of Virginia, you will receive a copy of Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System which explains in detail all of the safeguards under Part C, including those related to confidentiality.

*"Reviewing my daughter's records helped refresh my memory on where we started from and to see how far we've come. It's sometimes hard to see there is real progress when you're working day by day. Reviewing her records gave me the longer-term perspective that I needed."*

*—A Virginia Parent*

## **WHEN AND HOW CAN I REVIEW MY CHILD'S RECORDS?**

Looking at your child's and family's early intervention records helps you know about your child and your child's services. The more you know, the more effective you will be as a member of the team making decisions about your child. Knowing what is in the records helps you make the best decisions for your child. It is helpful to check to make sure that what is in your child's records is accurate.

You can ask your service coordinator to make arrangements for you to look through the records. Early intervention providers must let you see the records within a reasonable time and before any meeting about your child. You can ask for explanations of anything you see in the records. You can also arrange for someone representing you or your child to look at the records.

You can ask for copies of information in the records. You may be asked to pay for the actual cost of making the copies, but not for the time it takes to find and copy

them. If you cannot afford to pay for the copies, you can still receive copies of your child's records.

If you see something in the records that you believe is not accurate, you can ask that it be changed or removed. Ask your service coordinator for help with this and about the local procedure to request a change in the records.

If service providers do not make the change you request, you can ask for a hearing. If the hearing officer determines that the record does not have to be changed, you can place your own explanation of the information into the file. Your explanation must be kept with the file and included every time the information you object to is given out so that the person who receives it will know about your concern.

**Things I Want to Remember:**

## HOW CAN I RESOLVE DISAGREEMENTS?

### **Shared Decisions:**

*Problem-Solving and Mediation in Early Intervention* is a guide to working out disagreements for parents and professionals. You can get the booklet from your early intervention provider or the Parent Educational Advocacy Training Center (PEATC)  
6320 Augusta Drive, # 1200  
Springfield, VA 22150  
703-923-0010 (Voice/TTY)  
1-800-869-6782 (VA parents only)  
703-823-0030 (Fax)

Early intervention works best when families and professionals work together. This means sharing information, being honest about ideas and feelings, listening carefully, asking questions, and treating everyone with courtesy and respect.

Even the best of friends sometimes disagree. The same is true for families and service providers. In most cases, families and professionals can discuss their disagreements and reach a compromise that everyone can accept.

You and the people providing early intervention services are a team and have the same goal. You all want your child to get a good start in life. Staff want you to be satisfied with what the team is doing on behalf of your child and family. Everyone on your team should listen to your ideas and concerns, and answer your questions. It is easier to come to agreement when everyone tries to understand each other's view of the situation.

If you have a disagreement with your early intervention service providers, deciding upon which options to take can be complicated. If you have questions, discuss your options with your service coordinator who has the responsibility to make sure that you understand your options. You can also call the Virginia Office for Protection and Advocacy at (800) 552-3962 or the Parent Educational Advocacy Training Center at (703) 923-0010 or toll-free (800) 869-6782 to discuss options.

If you have differences, you will probably be able to settle those differences more easily if you:

- are specific about what is bothering you and give examples;
- know what effect the disagreement has on you and your child;
- are clear about how you want the situation to be different; and
- explain what you want others to do to make things better.

Sometimes, even when people mean well and try hard, talking it over does not work. There are three formal ways in the early intervention system to resolve disagreements. These are called complaints, mediation and impartial due process hearings. A general

description of these three procedures are provided below. A complete description is included in Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System.

## **Filing a Complaint**

Anyone can file a complaint if they believe any agency or person providing early intervention services has violated the early intervention requirements. Complaints must be made in writing, signed and must include the specific facts on which they are based, including the Part C requirement that is alleged to have been violated. In general, complaints must be filed within one year. In some cases, (e.g. when reimbursement for services is being requested) complaints can be filed within three years.

As the parent of a child receiving early intervention services, you can also file a written complaint when you disagree with anything related to the services your child and family are getting. For example, you might want to file a complaint if your local early intervention system is not:

- doing something the team agreed to—*like conducting an evaluation or providing a service;*
- meeting important deadlines—*like determining eligibility and developing an IFSP in 45 days;* or
- letting you look at your child's early intervention records.

Include in your written complaint specifically what action or decision you disagree with and why you object. Send your complaint to:

Department of Mental Health, Mental Retardation and Substance Abuse Services  
Office of Early Intervention  
P.O. Box 1797  
Richmond, Virginia 23218

Call them at (804) 786-3710 if you have questions.

Once your complaint is received, the state agency responsible for early intervention will investigate. You will be given the opportunity to submit additional information, either verbally or in writing, about your complaint. You will be notified of the results of the investigation within calendar 60 days. Any issues that are currently being addressed in a due process hearing will not be investigated as a state complaint.

### **Using Mediation**

Many disagreements between families and professionals can be worked out with the help of a mediator. Mediation is a process that makes it possible for a specially trained person, who doesn't have a financial or other interest in the case, to help you and the early intervention system reach an agreement.

If you are in a position of disagreeing with providers in the Part C system, mediation is one of the procedures available to help resolve the issue. In mediation, no one wins or loses.

In mediation, no one wins or loses. Successful mediation builds on the partnership you have with providers and keeps it strong. The result of mediation is that you and providers write down and sign what you each agree to do to solve the problem. Mediation occurs at a time and place convenient for both you and individuals representing the early intervention system.

You can begin mediation and file a request for an impartial hearing at the same time or you can begin mediation without requesting an impartial hearing. Mediation is voluntary. This means that if you do not think it will work, you do not have to do it.

The mediation process must be completed within 15 calendar days of the Infant & Toddler Connection of Virginia's state office receipt of notice that both parties agree to mediation and cannot extend the timelines for a due process hearing (30 calendar days).

## Requesting a Due Process Hearing

Hearings are the most formal way to resolve disputes. You can request a hearing if you disagree with a decision or action that affects your child's identification, evaluation, placement or the services you and your child receive.

Hearings are conducted by impartial hearing officers who know the early intervention law, regulations, policies and procedures. A hearing is a formal proceeding where evidence can be presented and witnesses can be called to testify. You can bring a lawyer with you or anyone else you think can help you present your case and best represent your child's interests.

A hearing follows a number of rules, including strict timelines. Briefly, the main rules for hearings are:

- hearing officers must be completely impartial—*which means that they cannot have a personal or professional interest that would conflict with their objectivity in the outcome of the hearing or be an employee of any agency or entity providing early intervention services or care to the child;*
- hearings must be held when and where it is reasonably convenient for you to attend;
- evidence presented must be shown to you at least five days before the hearing;
- the hearing must be recorded. The record can be a tape or a written transcript, and you can ask for a copy;

If you and the rest of the team agree with the IFSP as written, but the early intervention system in your community can't decide who will provide the services, a process called "dispute resolution" is available. The Part C system will make sure that your child and family receive the services in the IFSP while the dispute is being resolved.

- ❑ the hearing officer must make a decision and mail the written decision to each party no more than 30 calendar days after the request for a hearing is filed; and
- ❑ during the hearing process, your child and family must continue to receive the early intervention services currently in your IFSP unless you and the Part C system agree otherwise. If the hearing involves a request for initial services and your child has been determined eligible, your child must receive those services already agreed to by you and the early intervention system.

Your written request for a hearing should say specifically what action or decision you disagree with and what you want changed. Send your request for an impartial hearing to:

**Department of Mental Health, Mental Retardation and Substance Abuse Services  
Office of Early Intervention  
P.O. Box 1797  
Richmond, Virginia 23218  
(804) 786-3710**

After the hearing is completed, the hearing officer makes a decision based on the facts and evidence presented. If you are not satisfied with the hearing officer's decision, you may file civil action with any state or federal court.

**Things I Want to Remember:**

## GLOSSARY

**Assessment**—The ongoing procedures used by appropriate qualified personnel throughout the period of a child's eligibility under Part C to identify: (a) the child's unique strengths and needs and the services appropriate to meet those needs; and (b) the resources, priorities and concerns of the family and the supports and services necessary to enhance the family's capacity to meet the developmental needs of their infant or toddler with a disability

**Developmental delay**—see page 12 of this guide.

**Eligibility**—See page 12 in this guide.

**Evaluation**—the procedures used by appropriate, qualified personnel to determine a child's initial and continuing eligibility under Part C, consistent with the definition of "infants and toddlers with disabilities" in 34 CFR 303.16, including determining the status of the child in each of the developmental areas. See page 9 in this guide.

**Family**—defined according to each family's definition of itself

**Family support**—assistance provided to families in order to strengthen their capability to maintain their infant or toddler in their own home.

**IFSP or individualized family service plan**—a written plan for providing early intervention services to eligible children/families that: (a) is developed jointly by the family and appropriate, qualified personnel providing early intervention services; (b) is based on the multidisciplinary evaluation and assessment of the child and the assessment of the strengths and needs of the child's family, as determined by the family and as required in 34 CFR 303.322; and c) includes services necessary to enhance the development of the child and the capacity of the family to meet the special needs of the child and the other components listed under 34 CFR 303.344.

**Mediation**—a voluntary process freely agreed to by parents and providers to attempt to resolve Part C disagreements. Neither party is required to participate in the mediation process, and both parties must approve any agreement reached. Mediation may not be used to deny or delay an impartial hearing if requested, or any of the other safeguards under Part C.

**Multidisciplinary evaluation**—an evaluation conducted by more than one qualified professional including infant educators, speech therapists, physical therapists, occupational therapists, social workers, nurses, and others.

**Natural Environment**—settings that are natural or normal for children who are your child's age and who do not have a disability.

**Personally identifiable information**—your child's and other family members' names, a personal identifier, such as the child's or parents' social security numbers, address, or a list of personal characteristics or other information that would make it possible to identify your child with reasonable certainty

**Surrogate parent**—an individual who is assigned to act for a parent when the child is a ward of the state or a parent cannot be identified or located.

**Transition**—The entry or exit of children and families to and from early intervention services. See page 17 in this guide.

**Things I Want to Remember:**

## Contacting Local Central Points of Entry for Accessing Early Intervention Services

Across Virginia, there are 40 Local Interagency Coordinating Councils, coordinating services in their locality. To find out about services in your locality, a list of Virginia counties and cities, and the corresponding point of entry, is provided below. Information can also be obtained by calling the Virginia statewide central directory at **(800) 234-1448**.

Using this guide:

Step 1 – Locate family's county or city.

Step 2 – Note number to left of county or city.

Step 3 – Match number to corresponding central point of entry below.

<u>COUNTIES</u>	<u>COUNTIES</u> (cont'd.)	<u>CITIES</u>	<u>Central Points of Entry</u>	
			<b>Infant &amp; Toddler Connection of:</b>	
13 Accomack	30 King George	20 Abingdon	1 Alexandria	(703) 838-5067 (800) 234-1448
4 Albemarle	23 King William	1 Alexandria	2 Alleghany Highlands (the)	(540) 863-1620
2 Alleghany	23 Lancaster	3 Arlington	3 Arlington	(703) 228-1630
9 Amelia	21 Lee	5 Bedford	4 Blue Ridge (the)	(434) 924-5357 (434) 924-5694
5 Amherst	22 Loudoun	20 Bristol	5 Central Virginia	(434) 948-4888 (434) 948-9400
5 Appomattox	4 Louisa	34 Buena Vista	6 Chesapeake	(757) 547-8929
3 Arlington	9 Lunenburg	4 Charlottesville	7 Chesterfield	(804) 768-7205
37 Augusta	31 Madison	6 Chesapeake	8 Crater District	(804) 862-8049
34 Bath	23 Mathews	2 Clifton Forge	9 Crossroads	(804) 786-9844
5 Bedford	36 Mecklenburg	23 Colonial Beach	10 Cumberland Mountain	(276) 964-6702
24 Bland	23 Middlesex	8 Colonial Heights	11 Danville-Pittsylvania	(434) 799-0456
33 Botetourt	25 Montgomery	2 Covington	12 Dickenson	(276) 926-8543 (276) 926-1680
36 Brunswick	4 Nelson	11 Danville	13 Eastern Shore (the)	(757) 442-7599 (800) 294-7477
10 Buchanan	19 New Kent	8 Emporia	14 Fairfax-Falls Church	(703) 246-7121 (703) 246-7193
9 Buckingham	13 Northampton	14 Fairfax	15 Goochland-Powhatan	(804) 598-2200
5 Campbell	23 Northumberland	14 Falls Church	16 Hampton-Newport News	(757) 726-4012
30 Caroline	9 Nottoway	39 Franklin	17 Hanover	(804) 365-4649
24 Carroll	31 Orange	30 Fredericksburg	18 Harrisonburg/Rockingham	(540) 434-6093 Ext. 3321
19 Charles City	35 Page	24 Galax	19 Henrico-Charles City-New Kent	(804) 261-8524
9 Charlotte	27 Patrick	16 Hampton	20 Highlands (the)	(276) 645-4745 (800) 584-5020
7 Chesterfield	11 Pittsylvania	18 Harrisonburg	21 LENOWISCO	(276) 523-8360 (800) 453-4332
35 Clark	15 Powhatan	8 Hopewell	22 Loudoun	(703) 777-0561
33 Craig	9 Prince Edward	34 Lexington	23 Middle Peninsula Northern Neck	(804) 758-5250 (800) 305-2229
31 Culpeper	8 Prince George	5 Lynchburg	24 Mount Rogers	(276) 223-3274 (276) 223-3270
9 Cumberland	29 Prince William	29 Manassas	25 New River Valley (the)	(540) 831-7529 (800) 650-5324
12 Dickenson	25 Pulaski	29 Manassas Park	26 Norfolk	(757) 683-8759
8 Dinwiddie	31 Rappahannock	24 Marion	27 Piedmont (the)	(276) 632-7128
23 Essex	23 Richmond	27 Martinsville	28 Portsmouth	(757) 393-8791
14 Fairfax	33 Roanoke	16 Newport News	29 Prince William, Manassas and Manassas Park	(703) 792-7879 (703) 792-7752
31 Fauquier	34 Rockbridge	26 Norfolk	30 Rappahannock Area (the)	(540) 372-3561 (877)268-4169
25 Floyd	18 Rockingham	21 Norton	31 Rappahannock-Rapidan	(877) 937-2155 (540) 825-3100
4 Fluvanna	10 Russell	8 Petersburg	32 Richmond	(804) 828-2742 (800) 234-1448
27 Franklin	21 Scott	40 Poquoson	33 Roanoke	(540) 777-4747
35 Frederick	35 Shenandoah	28 Portsmouth	33 Salem	(540) 464-8560
25 Giles	24 Smyth	29 Quantico	34 Roanoke Valley (the)	(540) 636-4592 (800) 766-1798
23 Gloucester	39 Southampton	25 Radford	35 Shenandoah Valley	(540) 636-4592 (800) 766-1798
15 Goochland	30 Spotsylvania	32 Richmond	36 Southside	(434) 476-6594
24 Grayson	30 Stafford	33 Roanoke	37 Valley (the)	(540) 887-8060
4 Greene	8 Surry	33 Salem	38 Virginia Beach	(757) 437-4999 (757) 539-9002
8 Greensville	8 Sussex	36 South Boston	39 Western Tidewater	(757) 562-6806 (757) 539-9002
36 Halifax	10 Tazewell	14 Springfield	40 Williamsburg*James City* York*Poquoson	(757) 566-3300 (800) 237-7273
17 Hanover	36 Warren	37 Staunton		
19 Henrico	20 Washington	39 Suffolk		
27 Henry	23 Westmoreland	38 Virginia Beach		
37 Highland	21 Wise	37 Waynesboro		
39 Isle of Wight	24 Wythe	23 West Point		
40 James City	8 York	40 Williamsburg		
23 King & Queen		35 Winchester		

For additional information, or if the locality you are looking for does not appear in the lists above, please call the Infant & Toddler Connection Information and referral line at 1 800 234-1448.