



State of Illinois
Department of Human Services

STATE OF ILLINOIS
EARLY INTERVENTION SYSTEM

**INFANT/TODDLER & FAMILY RIGHTS
UNDER IDEA**

In Illinois, Early Intervention supports families in promoting their child's optimal development and facilitates the child's participation in family and community activities.

July 2016

TABLE OF CONTENTS

Forward	4
Introduction	5
Informed Parental Consent	7
Prior Written Notice	9
Examination of Records	10
Confidentiality of Information	12
Resolution of Concerns	13
Surrogate Parents	17
Flow Chart – When is your consent needed	19
Glossary.....	20
More Information and Resources.....	22

FORWARD

The *Infant/Toddler and Family Rights under IDEA* booklet describes your child's and family's rights, as defined by the federal law, *Individuals with Disabilities Education Act (IDEA)*. IDEA recognizes the importance of parental involvement in Early Intervention (EI) and includes specific provisions for early intervention services for eligible children from birth to three years of age and their families, as well as a detailed listing of family's rights while receiving EI services.

This document may contain some terms that could be unfamiliar to you. For this reason, some words are defined where they are used in the document and others are highlighted and defined in the Glossary.

Upon entering Early Intervention, you will be assigned a service coordinator that will work with your family. She or he can assist you in reviewing this document, answer any questions you may have and suggest additional materials to help you understand your rights.

NOTE: Illinois acknowledges and thanks the early intervention systems in the states of South Dakota and Virginia for the 2007 use and adaptation of their materials.

INTRODUCTION

The Illinois Early Intervention Services System¹ (EI) builds upon family strengths and provides supports and resources to assist families to enhance their children's learning and development. EI incorporates family involvement in every aspect of the system, requires parental consent in determining eligibility and service delivery, and sets clear parental safeguards to comply with Part C of IDEA. These safeguards have been established to protect parents and children while in EI. Parents need to be informed about these safeguards since they play a leadership role in EI. Participation in EI is voluntary for you and your family.

The general rights you have as a parent include:

- The right to a multidisciplinary initial evaluation/assessment and to have an Individualized Family Service Plan (IFSP) meeting within forty-five (45) calendar days from referral, if eligible;
- The right, if eligible under IDEA, to all appropriate early intervention services² for your child and family as addressed in an IFSP;
- The right to evaluation, assessment, IFSP development, service coordination and procedural safeguards at no cost. You will be asked to submit insurance information and may be charged for some early intervention services on a sliding fee schedule. However, your inability to pay will not prevent your child or family from receiving early intervention services;
- The right to refuse evaluations, assessments and services;
- The right to participate in the initial IFSP development and to have the Plan reviewed every six months or more frequently if necessary, and to participate in an annual meeting regarding the provision of services for your child;
- The right to receive *prior written notice* before a member of the IFSP team proposes or refuses to initiate or change any of the following:
 - eligibility,
 - evaluation,
 - location or environment where services are delivered to your child, or
 - provision of services to your child or family.

This written notice must be provided to you in a timely manner;

- The right to receive services in your child's natural environment to the extent appropriate;
- The right to strict maintenance of the *confidentiality of records* that include personally identifiable information (PII);
- The right to give your permission or written consent, also known as *informed parental consent*, to ensure you agree with the activity or services;

- The right to *examine records* and, if appropriate, to correct EI records;
- The right to have a surrogate parent appointed for children who are wards of the state; and
- The right to *resolve your concerns* and disagreements using administrative resolutions if needed.

¹ The “Illinois Early Intervention Services System” includes the following: local regional intake entities (Child and Family Connections or CFC) and their staff such as service coordinators, Illinois Department of Human Services/Bureau of Early Intervention staff, Early Intervention Partners (Monitoring, Training, Clearinghouse, Provider Connections and Central Billing Office).

² In Illinois, “appropriate early intervention services” are determined through the IFSP process. The IFSP must include a statement of the specific early intervention services necessary to meet the unique needs of the child and family to achieve the outcomes identified in the IFSP. Federal regulations define early intervention services as services that “are designed to meet the developmental needs of an infant or toddler with a disability and as requested by the family, the needs of the family to assist appropriately in the infant’s or toddler’s development, as identified by the individualized family service plan team.”

INFORMED PARENTAL CONSENT

Parental consent means that:

- 1) you have been fully informed of all information relative to the activity for which consent is sought, in your native language or other preferred mode of communication;
- 2) you understand and agree, in writing, to the carrying out of the described activity for which your consent is sought, and it lists the records (if any) that will be released and to whom; and
- 3) you understand that the granting of consent is voluntary on your part and may be revoked at any time.

Native Language, where used with reference to persons of limited English proficiency, means the language or mode of communication normally used by the parent of an eligible child.

Your written consent must be obtained before: 1) conducting the initial evaluation and assessment of your child; and 2) initiating the provision of early intervention services. If you do not give consent, EI will make reasonable efforts to ensure that you:

- Are fully aware of the nature of the evaluation and assessment or the services that would be available; and
- Understand that your child will not be able to receive the evaluation and assessment or services unless consent is given.

If you do not give your consent for initial evaluation, the Child and Family Connections (CFC) staff, likely your assigned service coordinator, may provide encouragement by: 1) providing you with relevant literature or other materials; 2) offering to connect you with other parents to enhance your understanding of the value of early intervention and to address your concerns about participation in EI; and 3) periodically renewing contact with you, on an established time schedule, to determine if you have changed your mind concerning the recommended evaluation, assessment or services.

If you do not give your consent for the initial evaluation and the wellbeing of your child is at risk, EI may initiate a due process hearing for resolving parent/provider disagreements. You will be informed if a due process hearing is sought.

In addition, as the parent of a child eligible for EI, you may determine whether you, on behalf of your child, will accept or decline any early intervention services offered to you. You may also decline such a service after first accepting it, without jeopardizing other early intervention services under this program.

Finally, regarding personally identifiable information (PII) collected, used, or maintained by EI, consistent with Federal and State law, you have the right to:

- written notice of any exchange of this information among agencies and providers, and
- written consent to the exchange of this information among agencies and providers.

Personally Identifiable Information means that information includes: 1) the name of your child, your name, or other family member's name; 2) the address of your child; 3) a personal identifier, such as your child's or your social security number; or 4) a list of personal characteristics or other information that would make it possible to identify your child with reasonable certainty.

Example

You receive a letter from your CFC informing you that physical therapy services will begin at the end of the month and will be delivered at your home, as stated in your son's most recent IFSP.

PRIOR WRITTEN NOTICE

Prior written notice means a notice of an action proposed to be taken. It must be given to you in a reasonable time before EI proposes, or refuses, to initiate or change the eligibility or evaluation of your child, or the provision and location of appropriate early intervention services to your child and family.

The notice must be sufficiently detailed to inform you about:

1. The action that is being proposed or refused;
2. The reasons for taking the action; and
3. All procedural safeguards which are available to you under the program. The notice must be:
 - Written in language understandable to the general public and provided in your native language unless it is clearly not feasible to do so.
 - If your native language or other mode of communication is not a written language, the CFC staff shall take steps to ensure that:
 - The notice is translated orally or by other means to you in your native language or other mode of communication;
 - You understand the notice; and
 - There is written evidence that the requirements of this section have been met.

If a parent is deaf or blind or has no written language, the mode of communication must be the one normally used by the parent (ex. Sign language, Braille, oral communication).

Example

Your CFC sends you a letter with a proposed date to meet regarding a possible change to the location where speech therapy is being provided. The therapist believes that your toddler is more engaged when she is at the day care.

EXAMINATION OF RECORDS

You must be afforded the opportunity to inspect and review all records relating to EI evaluations and assessments, eligibility determinations, development and implementation of the IFSP, individual complaints dealing with your child, and any other area that involves EI records about your child and your family.

EI provides you the opportunity to inspect and review any records relating to your child, which are collected, maintained or used by the CFC serving your child. The CFC must comply with a request to examine records within 10 calendar days after you request them and before any meeting regarding an IFSP or hearing relating to eligibility, evaluation/assessment, or the provision or location of services.

Your right to inspect and review records includes:

1. The right to a response from the CFC to a reasonable request for explanations and interpretations of the record(s);
2. The right to request that the CFC provide you with copies of the records if you cannot effectively review the records without having the copies; and
3. The right to have someone inspect and review the record(s) on your behalf.

EI presumes that you have the authority to inspect and review the record(s) relating to your child unless it has been informed that you do not have the authority under applicable Illinois law governing such matters as custody, foster care, guardianship, separation, and divorce.

The CFC shall keep a record of the parties obtaining access to early intervention records collected, obtained, maintained, or used (except access by parents, authorized CFC, Bureau and Office of Special Education Programs employees), including the name of the party, the date access was given, and the purpose for which the party is authorized to use the record.

If any record includes information on more than one child, you have the right to inspect and review only the information relating to your child, or to be informed of that specific information.

EI will provide you, on request, a list of the types of records collected, maintained, or used.

EI may charge a fee for copies of records that are made for you under this part if the fee does not effectively prevent you from exercising your right to inspect and review those records. EI may not charge a fee to search for or retrieve information.

If you believe that information in any of the records collected, maintained, or used by the CFC is inaccurate or misleading, or violates the privacy or other rights of your child or family, you may request that the information be amended. CFC staff will review your request and:

1. Determine whether to amend the information in accordance with the request within five (5)

business days of receipt of the request. If the amendment requested involves a provider report, the provider must be contacted by the CFC.

2. Conclude not to amend the information in accordance with the request. You will be informed of the cause for the refusal and be advised of your right to a hearing.

EI, on request, must provide an opportunity for a hearing to challenge information in early intervention records if they appear to be not accurate, misleading, or otherwise in violation of the privacy or other rights of the child and family.

- If, as a result of the hearing, it is determined that the information is inaccurate, misleading, or otherwise in violation of the privacy or other rights of the child, the CFC will amend the information accordingly and inform you in writing.
- If, as a result of the hearing, it is determined that the information is not inaccurate, misleading, or otherwise in violation of the privacy or other rights of the child, you will be informed of your right to place a statement in your child's file commenting on the information and setting forth any reasons for disagreeing with the decision.

Any explanation placed in the records of the child under this section must:

- a. be maintained by the CFC as part of the child's record as long as the record or contested portion (the part of the record with which you disagree) is maintained by the CFC; and
- b. if the child's record or the contested portion are disclosed by the CFC to any party, the explanation must also be disclosed to the party.

A hearing held under this section must be conducted according to the procedures under §99.22 of Family Education Rights and Privacy Act (FERPA) (34 CFR Part 99).

Example

You call your Service Coordinator to set up a time to review your baby's records. An appointment is set for the following week.

CONFIDENTIALITY OF RECORDS

All records of your family's EI services are strictly confidential.

Written parental consent must be obtained before personally identifiable information (PII) is:

1. disclosed to anyone other than authorized EI staff (CFC, EI Bureau, OSEP); or
2. used for any purpose other than meeting a requirement under IDEA.

Information from your child's EI record cannot be released without your written consent unless authorized to do so under FERPA.

- Each CFC employee protects the confidentiality of PII at collection, storage, disclosure, and destruction stages;
- One CFC individual assumes responsibility for ensuring the confidentiality of any PII;
- All persons collecting or using PII receive training or instruction regarding Illinois' policies and procedures under IDEA and FERPA;
- Each CFC maintains, for public inspection, a current listing of the names and positions of those employees within the CFC with access to PII;
- CFC informs parents when PII information collected, maintained, or used is no longer needed to provide services to the child; and
- The information collected, maintained, or used is destroyed at the request of the parents. (Permanent records of child's name, address, phone number are maintained in Cornerstone, the secure electronic state of Illinois database.)

Example

Your doctor wants a copy of your child's IFSP to include in her medical records. Your CFC requests your written consent before sending the copy.

If the U.S. Department of Education or its authorized representative collects any PII regarding children eligible under this part which is not subject to the Privacy Act of 1974, the U.S. Secretary of Education applies the requirements of the Statute (5 USC Section 552A) and the regulations implementing those provisions.

RESOLUTION OF CONCERNS

If you have concerns about services or if you disagree with decisions made about your child, you should discuss them first with your IFSP team, service coordinator and CFC manager at the CFC. If you are not satisfied with the results of the discussion, formal options for administrative resolution are provided in the law.

If you disagree with the eligibility or evaluation/assessment of your child or the provision and location of appropriate early intervention services to your child or family, you have the right to a timely administrative resolution of your concerns.

There are 3 options for addressing your concerns. You may:

1. submit a complaint to the state lead agency;
2. request mediation;
3. request a due process hearing.

During the resolution of your concerns, your child will continue receiving early intervention services per his or her IFSP that are not in dispute, unless there is agreement otherwise.

It is important to raise your concerns as soon as possible so that your family can receive the most benefit from your participation in EI.

1. Complaints to the state lead agency

Individuals or organizations may file written, signed complaints with the Illinois Department of Human Services (IDHS), Bureau of Early Intervention, stating that the Bureau of Early Intervention, CFC or provider has violated a law or rule regarding the Part C Early Intervention program. The statement must contain the facts that support the complaint.

IDHS has 60 days from receipt of the complaint to investigate and issue a written decision to the Complainant, addressing each allegation in the complaint. During this time, IDHS may carry out an independent onsite investigation and must give the Complainant an opportunity to submit additional information, either orally or in writing, about the allegations made in his or her written complaint.

After reviewing all relevant information, IDHS must issue a written decision addressing each allegation in the written complaint and include findings of facts as well as conclusions, the reason for the final decision, if the complaint was found to be valid, and procedures to correct the cause(s) of the complaint. If a complaint raises issues previously decided under an impartial administrative hearing, the hearing decision is binding. If a complaint is the subject of a hearing request that is not yet finished, the matter will be set aside until the hearing is resolved.

The alleged violation must have occurred not more than one year before the date the complaint is received by IDHS.

Complaints must be submitted to IDHS in writing. Complaints must be sent to:

**Chief
Bureau of Early Intervention
Illinois Department of Human Services
823 East Monroe Street
Springfield, IL 62701
217/782-1981, TTY (888) 261-2713**

2. Mediation

Mediation is a voluntary session freely agreed to by the parties who are in dispute (the family, the local provider, the CFC and/or the lead agency). Parents and the parties with whom they are disputing are not required to use mediation. Mediation may not be used to deny or delay your right to an administrative hearing or other rights under IDEA Part C.

Mediation must be conducted by a qualified impartial mediator trained in effective mediation techniques. The mediator may only help the parties communicate and come to an agreement but may not force or order a resolution of the dispute. The State must bear the cost of the mediation process. Each session in the mediation shall be scheduled in a timely manner and held in a location convenient to the parties. Any agreement reached must be set forth in a written mediation agreement.

Discussions that occur during mediation shall be confidential and may not be used in subsequent administrative or court hearings.

Mediation requests must be sent to:

**Chief
Illinois Department of Human Services
Bureau of Hearings
69 West Washington Street, 4th Floor
Chicago, IL 60602**

3. Due Process Hearing

A due process hearing is similar to a court hearing. An impartial hearing officer, who will act as a judge, must be licensed to practice law in Illinois. He or she must have knowledge about the Early Intervention Program or IDEA, and the needs of, and services available for, eligible children and families. Impartial in this context means that the hearing officer:

- a. is not an employee of any agency or other entity involved in the provision of early intervention services or care of the child; and
- b. does not have a personal or professional interest that would conflict with his or her objectivity in implementing the process.

Parties to the dispute have the following rights:

- a. To be accompanied and advised by counsel and by individuals with special knowledge or training

with respect to children with disabilities (usually called advocates);

- b. To present evidence and confront, cross examine, and compel the attendance of witnesses;
- c. To prohibit the introduction of any evidence at the hearing that has not been disclosed to you as the parent at least five days before the proceeding;
- d. To obtain written or, at the option of the parents, electronic verbatim (word by word) record of the hearing; and
- e. To obtain written, or, at the option of the parents, electronic finding of facts and decisions (which shall be transmitted to the Illinois Interagency Council on Early Intervention (IICEI) and be made available to the public without personally identifying information or PII).

The parents have the right to have the child who is the subject of the hearing present, to have the hearing open to the public, and to have the record of the hearing, findings, and decisions completed at no cost.

The hearing must be held at a time and place that is reasonably convenient to the parents and child involved.

The parents have a right to have a resolution of the hearing (and written decision from the hearing officer) within 45 days after any of the following:

- a. The parties agree in writing to waive the resolution meeting; or
- b. A mediation or resolution meeting starts and the parties agree that no resolution is possible; or
- c. The parties agree to continue mediation or negotiation but later one of the parties withdraws from negotiations.

The decision is binding on the parties unless it is changed upon appeal of the State or Federal Court. The right to appeal and the process for appeal is set forth in section 680(1) of IDEA (20 USC§ 1480 (1)). Any party aggrieved by the hearing officer's decision may so appeal the decision.

Due Process Hearing requests must be sent to:

**Chief
Illinois Department of Human Services
Bureau of Hearings
69 West Washington Street, 4th Floor
Chicago, IL 60602**

In summary, if you have concerns about services or disagree with decisions made about your child, you should always voice them. Remember to follow these steps (less formal to more formal) to seek resolution:

IFSP Team

Service Coordinator

CFC Manager

Written complaint to IDHS -
Bureau of Early Intervention

Mediation

Due Process Hearing

SURROGATE PARENTS

The rights of children eligible under the Early Intervention Program of IDEA are protected if:

1. No parents can be identified;
2. EI, after reasonable efforts, cannot discover the whereabouts of a parent;
3. Legal custody of the child and all parental rights and responsibilities for the care and custody of the child have been terminated by a Court order or permanent entrustment agreement pursuant to applicable law; or
4. The child is under the legal responsibility of the Illinois Department of Children and Family Services (DCFS).

An individual is assigned to the child to act as a surrogate for the parent according to the procedures that follow. The procedures include a method for determining whether a child needs a surrogate parent. The following criteria are employed when selecting surrogates.

Surrogate parents are selected in ways permitted by Illinois law.

1. A person selected as a surrogate:
 - a. Has no interest that conflicts with the interest of the child he or she represents;
 - b. Has knowledge and skills that ensure adequate representation of the child;
 - c. Is not an employee of any state agency or an employee of a person providing early intervention services to the child or to any family member. A person who otherwise qualifies to be a surrogate parent under this section is not an employee solely because he or she is paid by a public agency to serve as a surrogate parent; and
 - d. Resides in the same general geographic area as the child, whenever possible.

A surrogate parent may represent the child in all matters relating to:

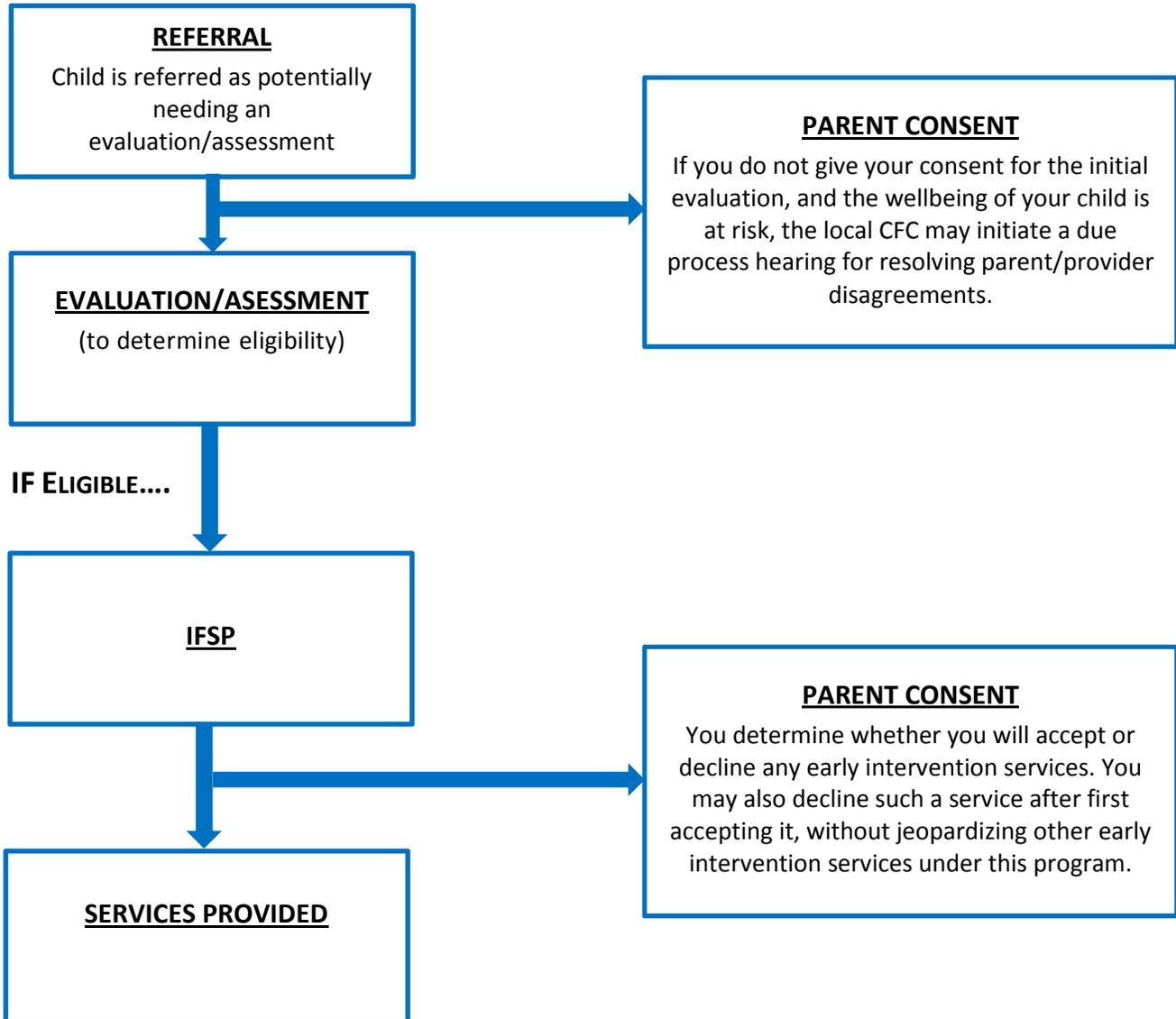
1. The evaluation and assessment of the child;
2. Development and implementation of the child's IFSPs, including annual evaluations/assessments and periodic reviews;
3. The ongoing provision of early intervention services to the child; and
4. Any other rights established under the Early Intervention Program of IDEA.

Any individual interested in becoming a surrogate parent should contact:

**Illinois State Board of Education
Division of Program Compliance
100 North First Street, E-228
Springfield, IL 62777-0001
217/782-5589**

FLOW CHART

WHEN IS YOUR CONSENT NEEDED?



GLOSSARY

<i>Assessment:</i>	<p>The ongoing procedures used by appropriate qualified personnel throughout the period of a child's eligibility to identify:</p> <ol style="list-style-type: none">The child's unique strengths and needs and the services appropriate to meet those needs;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; andThe nature and extent of early intervention services that are needed by the child and the child's family to meet the needs in a. and b. above.
<i>Disclosure:</i>	<p>To permit access to or the release, transfer, or other communication of EI records, or the personally identifiable information (PII) contained in those records, to any party, by any means, including oral, written, or electronic means.</p>
<i>Evaluation:</i>	<p>The procedures used by appropriate qualified personnel to determine a child's initial and continuing eligibility, consistent with the definition of "infants and toddlers with disabilities" in §303.16, including determining the status of the child in each of the developmental areas.</p>
<i>IFSP:</i>	<p>Individualized Family Service Plan is a written plan for providing early intervention services to eligible children/families that:</p> <ol style="list-style-type: none">is developed jointly by the IFSP team (family and appropriate qualified personnel providing early intervention services);is based on the multidisciplinary evaluations and assessment of the child and family; andincludes all services necessary to enhance the development of the child and the capacity of the family to meet the special needs of the child.
<i>Multi-Disciplinary:</i>	<p>The involvement of two or more disciplines or professions in the provision of integrated and coordinated services, including evaluation and assessment activities, and IFSP development.</p>
<i>Natural Environment:</i>	<p>Settings that are natural or typical for the child's same age peers who have no disability.</p>
<i>Parent:</i>	<p>A parent, guardian, or other person acting as a parent of a child (natural parent, stepparent, adoptive parent, foster parent, grandparent or other relative legally responsible for the child's welfare), or a surrogate parent who has been Court appointed.</p>

Prior Written Notice: Prior Written Notice is a notice of action that a parent in early intervention must receive before EI could act on a proposal or refusal to initiate or change the eligibility, evaluation, or provision or location of early intervention services.

Procedural Safeguards: Checks and balances for the EI system. A comprehensive set of guarantees (protections) for parents and their infants and toddlers with disabilities that include examination of EI records, ability to request amendments to EI records, prior written notice, confidentiality of information, and ability to accept or decline services without jeopardy.

MORE INFORMATION AND RESOURCES

For additional information, you may contact:

1. Your local CFC
2. The Illinois Early Intervention Clearinghouse at <http://eiclearinghouse.org>
3. The Early Intervention Training Program at <http://eitp.education.illinois.edu>
4. The Bureau of Early Intervention at 217-782-1981 and <http://www.dhs.state.il.us/page.aspx?item=30321>

The following resources can further assist you:

- ✓ Family Matters Parent Training and Information Center - <http://www.fmptic.org/>
- ✓ Family Resource Center on Disabilities - <https://frcd.org/>
- ✓ PACER CENTER - <http://www.pacer.org/>
- ✓ IDEA 2004: Building the Legacy - <http://idea.ed.gov/part-c/statutes>
- ✓ Center for Parent Information and Resources - <http://www.parentcenterhub.org/repository/parent-participation-ei/>
- ✓ Zero to Three – National center for Infants, Toddlers and Families - <http://www.zerotothree.org/>
- ✓ Early Intervention Family Alliance - <http://www.eifamilyalliance.org/>
- ✓ Wrightslaw - <http://www.wrightslaw.com/info/ei.index.htm>
- ✓ U.S. Department of Education - <http://www2.ed.gov/programs/osepeip/index.html>



401 South Clinton Street • Chicago, Illinois 60607
100 South Grand Avenue, East • Springfield, Illinois 62762
www.dhs.state.il.us

Programs, activities and employment opportunities in the Illinois Department of Human Services are open and accessible to any individual or group without regard to age, sex, race, sexual orientation, disability, ethnic origin or religion. The department is an equal opportunity employer and practices affirmative action and reasonable accommodation programs.

DHS 4392 (R-07-16) Infant /Toddler and Family Rights Printed by the Authority of the State of Illinois. 30,000 copies P.O.#16-1838