

STATE OF ILLINOIS
INFANT/TODDLER & FAMILY RIGHTS
UNDER IDEA FOR THE
EARLY INTERVENTION SYSTEM

“The Sooner We Start The Farther They’ll Go”

October 2007

TABLE OF CONTENTS

Forward.....	3
Introduction	4
Parental Consent	6
Prior Notice	8
Examination of Records.....	9
Confidentiality of Information.....	9
Individual Child Complaints.....	11
Surrogate Parents.....	15
Flow Chart of the Process.....	17
Glossary	18
For More Information.....	19

FORWARD

Infant/Toddler and Family Rights Under IDEA for the Early Intervention System describes your child's and family's rights, as defined by the Early Intervention Program of the federal law, *Individuals with Disabilities Education Act* (IDEA). IDEA includes provisions for early intervention services for eligible children starting at birth.

Because this document is an official notice of your rights under federal regulation, some terms may be unfamiliar to you. For this reason, some words are defined where they are used in the document and others are defined in the glossary.

The service coordinator working with your family can suggest additional materials to help you understand your rights. He/she can also suggest ways that you and other family members can be partners with professionals to help meet the developmental needs of your child.

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

INTRODUCTION

The Illinois Early Intervention Services System is required to incorporate family involvement and provide for parental consent in determining eligibility and in service delivery. Safeguards have been established to protect parents and children. Parents need to be informed about these safeguards so they have a leadership role in services to their children. Participation in the Illinois Early Intervention Services System for infants and toddlers is voluntary for you and your family.

The general rights you have as a parent include:

- The right to a multidisciplinary evaluation and assessment and to have an Individualized Family Service Plan (IFSP) meeting within forty-five (45) calendar days from referral;
- The right, if eligible under IDEA, to all appropriate early intervention services¹ 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 may be charged for other early intervention services on a sliding fee schedule. However, your inability to pay will not prevent your child or your 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 it 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 written timely notice before the state or a service provider proposes or refuses to initiate or change the identification, evaluation, or placement of your child, or the provision of services to your child or family;
- The right to receive services in your child's natural environment to the extent appropriate;
- The right to maintenance of the confidentiality of personally identifiable information;

¹ 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 the 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."

- The right to review and, if appropriate, correct records; and
- The right to an impartial hearing to resolve parent/provider disagreements.

In addition to the general rights noted above, you are entitled to be notified of specific procedural safeguards under the Early Intervention Program of IDEA.

These safeguards include:

- Parental Consent
- Prior Notice
- Examination of Records
- Confidentiality of Information
- Mediation
- Impartial Administrative Resolution of Child Complaint
- State Complaint
- Surrogate Parents

Each of these safeguards is described in the following pages of this booklet.

PARENTAL CONSENT

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 mode of communication; 2) you understand and agree in writing to the carrying out of the activity for which your consent is sought, and the consent describes that activity and 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 screening procedures or the initial evaluation and assessment of your child; or 2) initiating the provision of early intervention services. If you do not give consent, the Illinois Early Intervention Services System shall make reasonable efforts to ensure that you:

1. Are fully aware of the nature of the evaluation and assessment or the services that would be available; and
2. 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 local service system provider may provide encouragement by : 1) providing you with relevant literature or other materials; 2) offering you peer counseling to enhance your understanding of the value of early intervention and to address your concerns about participation in the Illinois Early Intervention Services System; and 3) periodically renewing contact with you, on an established time schedule, to determine if you have changed your mind concerning the desirability of recommended procedures or services.

If you do not give your consent for the initial evaluation, the Early Intervention Services System may initiate an impartial hearing for resolving parent/provider disagreements, including impartial hearing procedures.

In addition, as the parent of a child eligible under the IDEA Early Intervention Program, you may determine whether your child, or other family members will accept or decline any early intervention services under this program in accordance with State law. 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 collected, used, or maintained under the IDEA Early Intervention Program, you have the right to written notice of and written consent to the exchange of this information among agencies consistent with Federal and State law.

Personally Identifiable means that information includes: 1) the name of your child, your name, or other family member; 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.

(See section on Confidentiality of Information.)

PRIOR NOTICE

Written prior notice must be given to you in a reasonable time before the Illinois Early Intervention Services System² proposes, or refuses, to initiate or change the identification, evaluation, or placement of your child, or the provision of appropriate early intervention services to your child and family.

The notice must be sufficient in detail 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 that are available under the program.

The notice must be:

1. Written in language understandable to the general public and provided in your native language unless it is clearly not feasible to do so.
2. If your native language or other mode of communication is not a written language, the public agency, or designated service provider shall take steps to insure that:
 - a. The notice is translated orally or by other means to you in your native language or other mode of communication;
 - b. You understand the notice; and
 - c. 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 that normally used by the parent (ex. Sign language, Braille, or oral communication).

² The "Illinois Early Intervention Services System" or "System" includes, but is not limited to, the following: local regional intake entity (Child and Family Connections), agencies, programs, local public and private service providers and service coordinators.

EXAMINATION OF RECORDS

In accordance with the Confidentiality of Information procedures in this notice, you must be afforded the opportunity to inspect and review records relating to evaluations and assessments, eligibility determinations, development and implementation of IFSPs, individual complaints dealing with your child, and any other area under the IDEA Early Intervention Program involving records about your child and your family.

CONFIDENTIALITY OF INFORMATION

The Illinois Early Intervention Services System provides you the opportunity to inspect and review any records relating to your children, which are collected, maintained or used by the System under IDEA. The System complies with a request without unnecessary delay and before any meeting regarding an IFSP or hearing relating to identification, evaluation, or placement of your child, and in no case more than forty-five (45) days after the request has been made.

The right to inspect and review records includes:

1. The right to a response from the System to reasonable requests for explanations and interpretations of the record;
2. The right to request that the System provide records containing the information if failure to provide those copies would effectively prevent you from exercising the right to inspect and review the records; and
3. The right to have someone representing you inspect and review the record.

The System may presume that you have the authority to inspect and review records relating to your child unless the System has been advised that you do not have the authority under applicable Illinois law governing such matters as custody, foster care, guardianship, separation, and divorce.

Each System participant shall keep a record of parties obtaining access to early intervention records collected, obtained, maintained, or used under this part (except access by parents and authorized employees of the System), 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.

The Illinois Early Intervention Services System shall provide you, on request, a list of the types and locations of records collected, maintained, or used by the System.

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

If you believe that information in records collected, maintained, or used under the Early Intervention Program of IDEA is inaccurate or misleading, or violates the privacy or other rights of your child or family, you may request the System participant that maintains the information to amend the information:

1. The System decides whether to amend the information in accordance with the request within a reasonable period of time of receipt of the request.
2. If the System decides to refuse to amend the information in accordance with the request, you will be informed of the refusal and be advised of the right to a hearing.

The Illinois Early Intervention Services System, on request, provides an opportunity for a hearing to challenge information in early intervention records to insure that it is not accurate, misleading, or otherwise in violation of the privacy or other rights of the child.

If, as a result of the hearing, the System decides that the information is inaccurate, misleading, or otherwise in violation of the privacy or other rights of the child, it amends the information accordingly and will inform you in writing.

1. If, as a result of the hearing, the System decides 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 in the records of your child a statement commenting on the information and setting forth any reasons for disagreeing with the decision of the System.
2. Any explanation placed in the records of the child under this section must:
 - a. be maintained by the System as part of the records of the child as long as the record or contested portion (that part of the record with which you disagree) is maintained by the System; and
 - b. if the records of the child or the contested portion are disclosed by the System 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).

Parental consent must be obtained before personally identifiable information is:

1. disclosed to anyone other than officials of the Illinois Early Intervention Services System, participants collecting or using information under the Early Intervention Program of IDEA, subject to section (2) at the bottom of page 6; or
2. used for any purpose other than meeting a requirement under IDEA.

Information from your child's early intervention record cannot be released to System participants without your consent unless authorized to do so under FERPA.

- Each System participant protects the confidentiality of personally identifiable information at collection, storage, disclosure, and destruction stages;
- One official of each System participant assumes responsibility for insuring the confidentiality of any personally identifiable information;
- All persons collecting or using personally identifiable information receive training or instruction regarding Illinois' policies and procedures under IDEA and FERPA;
- Each System participant maintains, for public inspection, a current listing of the names and positions of those employees within the agency who have access to personally identifiable information;
- The System informs parents when personally identifiable information collected, maintained, or used under this part is no longer needed to provide services to the child; and
- The information is destroyed, at the request of the parents. (Permanent records of child's name, address, phone number may be maintained.)

If the U.S. Department of Education or its authorized representative collects any personally identifiable information 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.

INDIVIDUAL CHILD COMPLAINTS

If you disagree with the Illinois Early Intervention Services System on the 1) identification, 2) evaluation, 3) placement of your child, or 4) provision 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 raising your issue. You may 1) request mediation; 2) request an impartial administrative proceeding; or 3) submit a complaint to the lead agency. During the resolution of an impartial proceeding or mediation your child will continue receiving appropriate early intervention services currently being provided or if you are applying for

initial services, the child will receive the services which 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 the Early Intervention Program and the potential systemic problems are identified and addressed. The Department requires that you submit your request for mediation, administrative proceeding or state complaint no more than three months after you knew or should have known about the issue that you are complaining about.

1. Mediation

Mediation is an alternative to the more formal and adversarial administrative proceeding. Mediation must be voluntary and 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 a hearing or other rights under Part C or IDEA.

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 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.

2. Impartial Hearings

An impartial administrative proceeding is similar to a court hearing. An impartial hearing officer having knowledge about Early Intervention Program or IDEA, and the needs of and services available for eligible children and families, will act as a judge. 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 the problems of children with disabilities.
- 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 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 and be made available to the public without personally identifying information).

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 hearing, findings, and decisions 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 meeting with the CFC within fifteen days after the hearing is requested.

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

A hearing officer may grant an extension of the 45-day time period at the request of either party. This 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.

Impartial means that the person:

- 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.

A person who otherwise qualifies under this section is not an employee of an agency solely because the person is paid by the agency to implement disagreement resolution.

3. State Complaint

Individuals or organizations may also file written, signed complaints with the Illinois Department of Human Services (DHS) stating that the State has violated a law or

rule regarding the Part C Early Intervention program. The statement must contain the facts that support the complaint.

DHS has 60 days from receipt of the complaint to investigate and issue a written decision to the Complainant and interested parties, addressing each allegation in the complaint. During this time, DHS 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 their complaint.

After reviewing all relevant information DHS must issue a written decision addressing each allegation in the complaint and contain 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 hearing request, 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. A complaint alleging a public agency's or private service provider's failure to implement an impartial hearing decision must be resolved by the lead agency.

The alleged violation must have occurred not more than one year before the date the complaint is received by DHS unless a longer period is reasonable because: 1) the alleged violation continues for that child or other children; 2) the Complainant is requesting reimbursement or corrective action for a violation that occurred not more than three years before the complaint is received.

Complaints, Impartial Hearing and Mediation requested must be submitted to DHS in writing. Complaints must be sent to:

**Chief
Bureau of Early Intervention
Department of Human Services
222 South College, 2nd Floor
Springfield, IL 62704
217/782-1981, TTY 217/558-6482**

Impartial Hearing and Mediation requests must be sent to:

**Chief
Bureau of Administrative Hearings
Department of Human Services
100 South Grand Avenue, 3rd Floor
Harris Building
Springfield, IL 62762
217/785-9774, TTY 217/557-2547**

SURROGATE PARENTS

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

1. No parents can be identified;
2. The System, 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 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.

An individual is assigned 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 and assigning a surrogate to the child. 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 a person 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.

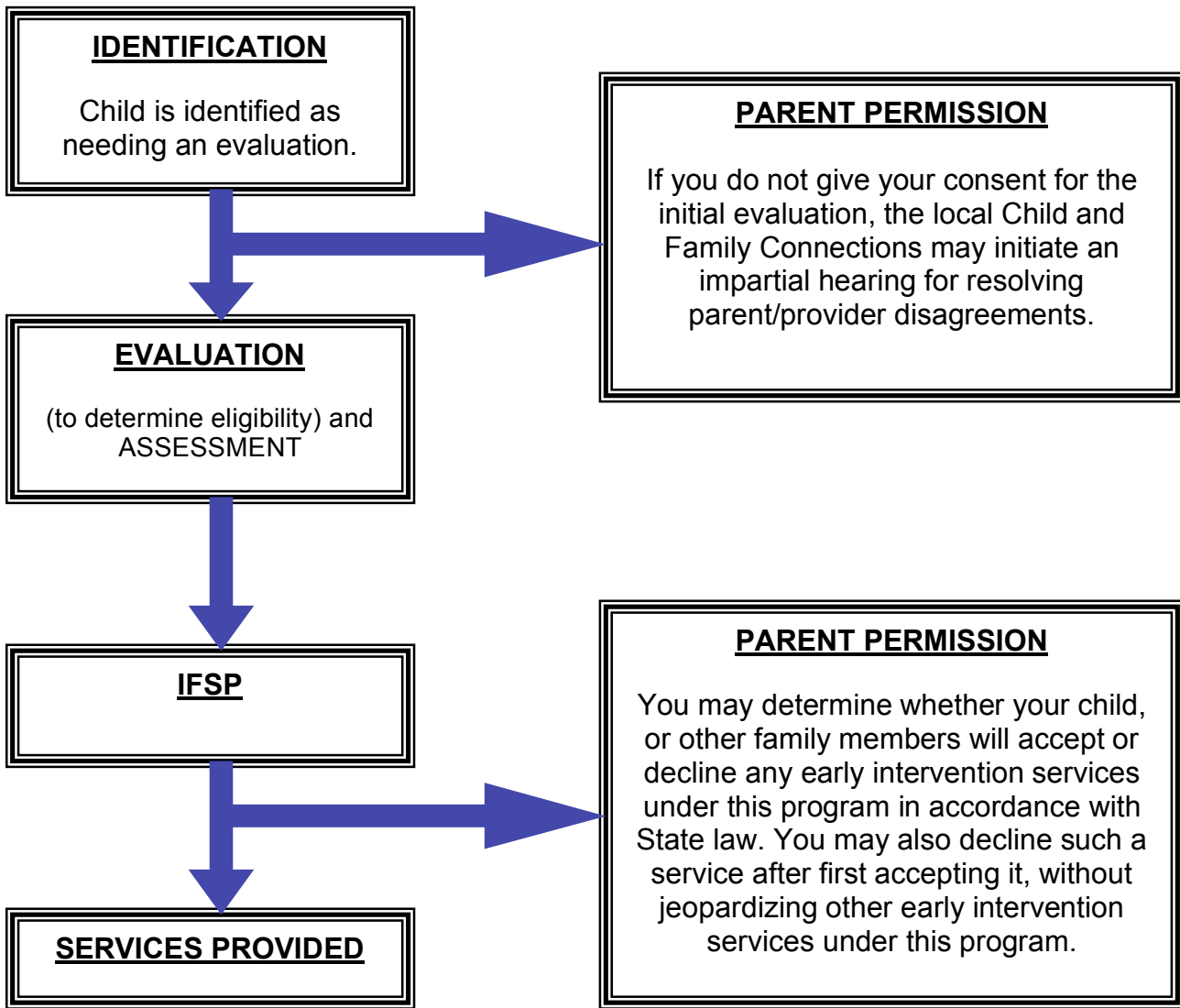
A surrogate parent may represent the child in all matters relating to:

1. The evaluation and assessment of the child;
2. Development and implementation of the child's IFSPs, including annual evaluations 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:

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

FLOW CHART OF THE PROCESS



NOTE: If you disagree with the Illinois Early Intervention Services System on the 1) identification, 2) evaluation, 3) placement of your child, or 4) provision of appropriate early intervention services to your child or family, you have the right to a timely administrative resolution of your concerns. Confidentiality rules apply throughout the entire process.

GLOSSARY

- Assessment:* The ongoing procedures used by appropriate qualified personnel throughout the period of a child's eligibility under this part to identify-
- a. The child's unique strengths and needs and the services appropriate to meet those needs;
 - 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; and
 - c. The 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.
- Disclosure:* To permit access to or the release, transfer, or other communication of education records, or the personally identifiable information contained in those records, to any party, by any means, including oral, written, or electronic means.
- Evaluation:* The procedures used by appropriate qualified personnel to determine a child's initial and continuing eligibility under this part, 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.
- Family:* Defined according to each family's definition of itself.
- Family Directed Assessment:* Identification of the family's resources, priorities and concerns relative to enhancing the development of the child, and identification of the supports and services necessary to enhance the family's capacity to meet the developmental needs of the child.
- IFSP:* Individualized Family Service Plan (IFSP):
A written plan for providing early intervention services to eligible children/families that:
- i. is developed jointly by the family and appropriate qualified personnel providing early intervention services;

- ii. is based on the multidisciplinary evaluations 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
- iii. includes all services necessary to enhance the development of the child and the capacity of the family to meet the special needs of the child.

Mediation: A voluntary process freely agreed to by parents and providers to attempt to resolve IDEA Early Intervention Program 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 your right to an impartial hearing.

Multi-Disciplinary: The involvement of two or more disciplines or professions in the provision of integrated and coordinated services, including evaluation and assessment activities in §303.322 and development of the IFSP in §303.342.

Natural Environment: Settings that are natural or normal for the child's peers who have no disability.

Parent: A parent, guardian, or other person acting as a parent of a child, or a surrogate parent who has been appointed in accordance with §303.406.

NOTE: All citations contained in this booklet, including the glossary, are references to 34 CFR Part 303 unless noted otherwise.

FOR MORE INFORMATION CONTACT:

**CENTRAL DIRECTORY
(Help Me Grow Help Line)
1-800-323-4769**