



A Family Rights Handbook: Assuming a full and active role in early intervention

To the Family:

Our goal in the EarlySteps system is the same as yours: to make sure that your child receives services as soon as possible to help them develop for the future. When your child is eligible for services in EarlySteps, your family is also entitled to certain rights designed to protect your child and family during your participation in the system. All families served by EarlySteps are guaranteed these rights; they rights are required by federal and state laws, regulations, and policies and are called *Procedural Safeguards*. For more information about these Procedural Safeguards, please review Chapter 2 of the EarlySteps Practice Manual.

The purpose of this handbook is to provide you with your family's rights in the following areas:

- **Right to Written, Prior Notice**
- **Right to Written, Informed Parent Consent**
- **Right to Confidentiality of Information**
- **Right to Review Records**
- **Right to Resolve Disputes**
- **Child's Right to a Surrogate Parent**

EarlySteps also provides other safeguards, which are also described in this handbook:

- Evaluation and Assessment provided at no cost
- Services provided in the natural environment according to an Individualized Family Service Plan within 45 days of referral
- Services begin no later than 30 days from signed consent on the IFSP
- Right to decline evaluation and services
- Freedom of choice in provider selection

In addition, there are definitions of some of the terms used in this handbook at the end. These terms are shown in *italics* in the document.

Written, Prior Notice

Parents must receive written, prior notice before the agency or service provider:

- proposes or refuses an activity
- changes the identification, evaluation, or placement of your child
- changes the provision of early intervention services

This notice must inform the parent of the action(s) being proposed or refused and the reason(s) for the action(s), the safeguards and the process for filing a complaint if you do not agree. EarlySteps uses a form called a **Notice of Action** for any such action(s). A copy of this **Family Rights Handbook** must be provided with the notice. The notice is written in a way that is understandable to the general public and provided in your *native language*, unless it is clearly impossible to do so.

Parent Consent

Written parental consent must be obtained before conducting an initial evaluation and assessment and before providing any early intervention services. Parents may choose not to give consent for any particular service without jeopardizing any other services, and they may refuse a service at any time, even after accepting it, without affecting other intervention services. The exception to this right regarding refusing a service is service coordination, which is a required service in EarlySteps.

Consent means that you have been fully informed of all the information about the activity for which consent is sought. Consent also means that you understand and agree in writing to the activity for which consent is sought and the consent form describes that activity. Consent describes the activity(s) and must also list the specific records that will be released and to whom. Your written consent is voluntary and can be revoked at any time. If you do not give consent, EarlySteps will make sure that you:

- are fully aware of the nature of the evaluation and assessment or the services that would be available
- understand that your child will not be able to receive the evaluation, assessment or other services unless consent is given.

Confidentiality of Information

Your written consent must be obtained before personally-identifiable information is disclosed to anyone other than officials of participating agencies collecting or using the information in early intervention records. Directory information (child's name, parent's name, address and phone number) may be released to participating agencies without parental consent as authorized by the Family Educational Rights and Privacy Act (FERPA), Section 99.31. This release of directory information includes the release to the Community Outreach Specialists, individuals who work under contract with the lead agency to provide supports and services to parents whose children are enrolled in EarlySteps, and notification to the local education agency prior to your child reaching his/her 3rd birthday.

EarlySteps is required to tell parents about the policies and procedures that ensure personally identifiable information is kept confidential. Information describing the children for whom personally identifiable information is maintained, types of information sought, the methods used in gathering the information (including the sources from whom information is gathered), and the uses of the information is provided to you. Participating agencies must have policies and procedures regarding:

- The collection, storage, and disclosure to third parties, and destruction of personally identifiable information.
- The designation of one person in the agency responsible for ensuring confidentiality
- The training of staff regarding the requirements from IDEA and FERPA
- The list of names and positions of the agency's employees who have access to the information
- The destruction of the information when it is no longer needed and that it must be destroyed at your request.
- The possible maintenance of permanent records: name, address, phone number, etc.

Record Review

Parents are allowed to inspect and review records relating to evaluations and assessments, eligibility determination, development and implementation of IFSPs, individual complaints regarding your child, and any other area involving records about your child and family. Parents have the right to a response from the participating public agency/service provider to reasonable requests for explanations and interpretations of the records. The agency has to comply with the request without unnecessary delay and before any meeting regarding an IFSP or any hearing, and in no case more than 45 days after the request has been made.

Parents also have the right to request that the public agency/service provider furnish copies of the records containing the information and the right to have a representative inspect and review the records. The agency may charge a fee for copies of requested records unless the fee would prevent you from exercising your right to inspect and review the records.

The agency must keep a written record of the individuals that have access to the child's early intervention record. This record of who has reviewed the record includes the name of the individual, the date the record was reviewed, and the purpose for the review. This record of access is maintained in the child's early intervention record.

If the early intervention record includes information on more than one child, the parents of the other children have the right to inspect and review only that information relating to their child or to be told of that specific information.

Public agencies must provide parents a list of the types and locations of the early intervention record collected, maintained, or used by the agency if the parent requests such information.

Parents may ask that records be amended. The System Point of Entry (SPOE) must decide whether to amend the information as the parent requested within a reasonable period of time of the receipt of the request; and, if the SPOE refuses, the SPOE must inform the parent of the refusal and advise the parent of the right to a hearing.

If, as a result of such a hearing, the information is found to be inaccurate, misleading, or otherwise in violation of the privacy or other rights of the child, the SPOE will change the information and so inform the parent in writing. However, if, as a result of the hearing, the information is not found to be inaccurate, misleading, or otherwise in violation of the privacy or other rights of the child, the public agency will inform the parent of the right to place a statement commenting on the information or setting forth any reasons for disagreeing with the decision of the agency in the child's record.

If the SPOE places a statement in the early intervention records of the child, the SPOE shall:

- (1) Maintain the statement with the contested part of the record for as long as the record is maintained; and
- (2) Disclose the statement whenever it discloses the portion of the record to which the statement relates.

Dispute Resolution

If any person or organization believes that an agency, provider or other person has violated any state or federal regulation implementing Part C of the IDEA, you may request timely resolution of your concerns. EarlySteps uses the following procedures to resolve your concerns: individual child complaint procedures, mediation, and due process hearings.

COMPLAINTS are made by calling the regional OCDD/HSA/D office in the region where you live. The complaint must include a statement that the agency/provider has violated the rules of Part C and the facts on which the complaint is based. The alleged violation must have occurred not more than one year before the receipt of the complaint by OCDD unless—the alleged violation continues for that child or other children or the person or organization making the complaint is requesting reimbursement or corrective action for a violation that occurred not more than three years before the date on which OCDD received the complaint.

As soon as possible and no later than 30 calendar days, DHH-OCDD will investigate the complaint, review all relevant records, and issue a letter of findings, conclusions, and reasons for the conclusions to all parties involved in the complaint. The findings shall address each allegation in the complaint and a review of the investigation results, including any information in an on-site investigation or from a data request.

The process of investigating the complaint shall include: assignment of the complaint to staff, providing notice of the complaint, information collection, and on-site visits when appropriate. The complainant has the opportunity to provide additional information about the allegations. If exceptional circumstances exist with respect to the particular complaint, an extension of the time limit may be granted. If such an extension is given, the complainant and agency under investigation will be notified. Resolution of a complaint shall be through the issuance of a decision letter of findings by OCDD. If a written complaint is received that is also the subject of a due process hearing or contains multiple issues, of which one or more are part of that hearing, DHH must set aside any part of the complaint that is being addressed in the due process hearing until the conclusion of the hearing. However, any issue in the complaint that is not a part of the due process action must be resolved within the sixty (60) calendar day timeline using the complaint procedures described previously.

If an issue is raised in a complaint filed has previously been decided in a due process hearing involving the same parties, the hearing decision is binding. The complainant is informed of this. A complaint alleging a public agency's or private service provider's failure to implement a due process decision must be resolved by the lead agency. In resolving a complaint in which it finds a failure to provide appropriate services, DHH must address how to remedy the denial of those services, including as appropriate, the awarding of monetary reimbursement or other corrective action appropriate to the needs of the child and the child's family and appropriate future provision of services for all infants and toddlers with disabilities and their families.

MEDIATION provides an opportunity for parents and providers to resolve disagreements in a non-adversarial, impartial manner. Both parties involved in the dispute will be offered the opportunity to use mediation to resolve the concerns. This is voluntary and does not take away the parent's right to a due process hearing or to a timely due process hearing. Mediation services are at no cost to either party. Both parties who will be participating in the mediation agree to select a qualified and impartial mediator, trained in effective mediation techniques and who is knowledgeable in laws and regulations relating to the provision of early intervention services. DHH calls this process an administrative conference. The mediation session or conference will be scheduled at a location and time mutually agreed upon by the parties. A lay advocate or legal counsel may accompany parents.

All discussions held during the mediation are confidential and cannot be used later as evidence in a subsequent due process hearing or civil action. Parties may be required to sign a pledge of confidentiality before the mediation process begins. Mediation must be scheduled within 5 calendar days of the selection of a mediator and completed within 30 calendar days of the



decision to mediate. The agreements reached through mediation must be presented in a written mediation agreement to both parties.

You may be offered mediation by OCDD or you may request mediation in person, in writing, or by telephone, by contacting the EarlySteps Program Manager at 225-342-0095.

DUE PROCESS HEARING is an administrative hearing to resolve disputes conducted by an administrative law judge with the DHH Bureau of Appeals. This law judge is knowledgeable of the needs of and services for infants and toddlers and the provisions of IDEA-Part C. To initiate a due process hearing, a written request for a due process hearing with a statement of your concerns must be submitted to the EarlySteps Program Manager in person, by telephone or by mail. Or you may mail the request directly to the DHH Appeals Bureau at PO Box 4183, Baton Rouge, LA 70821-4183.

- The due process hearing will be held at a time and place that is reasonably convenient to you.
- At the hearing you may be accompanied and advised by counsel and by individuals with special knowledge or training in early intervention services for children with disabilities.
- At the hearing you may present evidence and confront, cross-examine, and compel the attendance of witnesses.
- At the hearing you may prohibit the introduction of evidence that has not been disclosed to you at least five days prior to the hearing.
- A record of the proceedings will be maintained. You have the right to an electronic verbatim transcription of the proceedings.
- The hearing officer will listen to the presentation of the parties involved, examine relevant information, and reach a timely resolution.
- You will receive findings of fact and decisions in writing within 30 calendar days.

If you do not agree with the decision, you may ask for a judicial review within 30 days of the appeals decision. If either party disagrees with the findings and final decision, they have the right to bring civil action. This action may be brought in a state or federal district court.

During these proceedings, unless otherwise agreed to by you and the agency, your child will continue to receive the early intervention services that were being provided at the time you made the request for the due process hearing. If the complaint involves an application for initial services, your child must receive those early intervention services that are not in dispute.

Child's Right to a Surrogate Parent

If a child is a ward of the state (residing in facility or group home), does not have a parent that can be identified or found, or does not have a "person acting as a parent", a person will be assigned to act as a Surrogate Parent. A Surrogate Parent may represent the child in all matters related to the evaluation and assessment of the child, the development and implementation of the IFSP, including annual IFSP evaluations and periodic reviews, the ongoing provision of early intervention services to the child, and any other rights established under IDEA-Part C.

Anyone can inform an Intake Coordinator (IC) or a Family Support Coordinator (FSC) that a Surrogate Parent may be needed. The IC or FSC completes a form called "EarlySteps Surrogate Parent Determination Form". This form documents that there is a need for the assignment of a Surrogate Parent. The person selected will have:



- No conflict of interest regarding the child represented
- Knowledge and skills that ensure adequate representation of the child
- 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 of the child
- Resides in the same general geographic area as the child, whenever possible

Other Procedural Safeguards in EarlySteps:

Evaluation/Assessment

EarlySteps ensures that all eligible children will receive early intervention services without regard to race, culture, religion, disability, or ability to pay. Eligibility is decided by an evaluation of the child (within 45 days of referral). Information from at least two or more qualified professionals gathered about your child's medical history, development, and current abilities is examined. This is the multidisciplinary evaluation to determine eligibility. If there is a need for more information, you will be informed about this. This additional information gathering does not change the 45-day timeline that EarlySteps must meet to have a plan in place for your child if eligible. If you do not consent in writing to this evaluation to determine eligibility, your child and family will not receive the evaluation, assessment and early intervention services provided by EarlySteps. If the child is eligible for services, the child and family also have the right to ongoing assessments of the child's strengths, skill levels, progress, and needs. The evaluation is available to you at no cost.

Individualized Family Service Plan (IFSP)

Within 45 days of the referral, each eligible child and family must have a written Individualized Family Service Plan (IFSP) for providing early intervention services that includes the family's concerns, priorities, and resources for their child. Information from you about your child is critical to EarlySteps for making good decisions in developing outcomes in the IFSP. The IFSP is written for a year and is reviewed at least every six months. It includes the major outcomes for the child and family, how progress will be measured, what and where services will be provided, when they will begin and for how long, methods of payment, if any, and transition at various times throughout the process and upon the child's third birthday. You have the right to be invited to and participate as a team member in all meetings in which a decision is expected to be made regarding your child. You have the right for your child to receive early intervention services in *natural environments* to the extent appropriate to meet your child's developmental needs. Services must begin no later than 30 days from the time you sign consent for services.

Freedom of Choice

Louisiana assures that families have freedom of choice in the selection of an available service coordination agency, a qualified service coordinator, and/or other service providers and the right to change providers or service coordinators.

EarlySteps will offer families a provider choice list using the service matrix for service coordination and other service providers. Families are asked to sign a Provider Selection Form which verifies that they have been offered a choice and who their selected provider is.

Parent's Rights and Responsibilities under Medicaid



The Medicaid program provides protections (rights) to each individual eligible and receiving Medicaid covered services. Medicaid rights apply only to the Medicaid covered services identified on a child's IFSP and do not supersede the IDEA, Part C regulations, rights and safeguards. Here are the rights to which families receiving Medicaid services agree:

- I declare that everyone who is applying for health insurance is a US citizen or is in this country legally.
- The information I give is true and correct to the best of my knowledge. I realize if I knowingly give information that isn't true OR if I knowingly withhold information and my child gets health benefits for which they are not eligible, I can be lawfully punished for fraud. I may have to repay Medicaid for any medical bills that are paid incorrectly.
- I understand that the information I give about our situation will be checked. I agree to assist Medicaid in this process and to let Medicaid get needed information from government agencies, employers, medical providers, and other sources.
- I understand that our Social Security numbers will only be used to get information from other government agencies to prove eligibility.
- I understand by accepting Medicaid/LaChip, I give the Department of Health and Hospitals the right to any medical support or payments from third parties who would be legally responsible for any medical services paid by Medicaid for my child. I agree to release any medical information needed by the Medicaid Program or others for the purpose of paying or receiving payment of medical bills. I understand that this is required to get coverage, and I agree to help in obtaining medical support and payments from anyone who is legally responsible.
- I understand that Medicaid will **only** make a referral to Child Support Enforcement for medical support upon my request.
- I agree to tell Medicaid within 10 days of the following changes:
1) If anyone receiving health coverage moves out of state; 2) Changes where we live or get our mail; and 3) Changes in other health insurance coverage.
- I can ask for a Fair Hearing if I think the decision made on my case is unfair, incorrect or being made too late. Fair Hearings are allowed under Medicaid to address the eligibility for Medicaid. This hearing does not affect Part C eligibility or IFSP development and implementation. A child may be found ineligible for Medicaid and continue to be eligible for Part C services. The next appropriate payer would pay IFSP early intervention services if Medicaid were not the right payer.

Information about WIC, KIDMED and other Medicaid services will be sent to you if your child is eligible for Medicaid.

Medicaid cannot discriminate because of race, color, sex, age, disability, religion, nationality or political belief. If you believe they have, you can call the U.S. DHHS Regional Office for Civil Rights in Dallas, TX at 1+800+368-1019 or write to Louisiana's Department of Health & Hospitals, Human Resources at P. O. Box 1349 Baton Rouge, LA 70821-1349.

To Find Out More About Parents' Rights, Opportunities & Responsibilities:

Contact your local System Point of Entry office, your Family Support Coordinator, and/or Chapter 2 of the EarlySteps Practice Manual at <http://www.earlysteps.louisiana.gov>.

To make a complaint, call your regional OCDD/HSA/D office in the region where you reside. The SPOE office and FSC Agency office have these numbers. The regional offices can also be located on the EarlySteps website above.



Definitions

Consent means that you have been fully informed of all the information about the activity for which consent is sought. Consent also means that you understand and agree in writing to the activity for which consent is sought and the consent form describes that activity. The form must also list the specific records that will be released and to whom. Your written consent is voluntary and can be revoked at any time.

Native language means the language or mode of communication normally used by the parent. If a family uses another method of communication, such as sign language or Braille, then they have the right to receive information in that way. If the native language or other mode of communication used by the parent is not a written language, the notice will be translated orally into the native language or provided by other means (such as by an interpreter for the deaf) if other mode of communication is the native language of the parent. The notice will be provided in the native language so that the parent understands the notice. The provision of the notice in the native language is documented.

Natural environment means settings, including the home, that are natural or normal for children who are your child's age and who do not have a disability.

OCDD is the Office for Citizens with Developmental Disorders. This office is part of the Department of Health and Hospitals and is the lead agency for EarlySteps.

Participating agency means any agency or institution which collects, maintains, or uses personally-identifiable information, or from which information is obtained under IDEA-Part C.

Personally-identifiable information means information that includes name, address, any personal identifiers or a list of any personal characteristics that would make it possible to identify you child with reasonable certainty.

Procedural safeguards are legal protections to protect rights in dealing with agencies and providers of early intervention services.

References:

Hurth, JL and Goff, P (2002) *Assuring the family's role on the early intervention team: Explaining rights and safeguards* (2nd edition). Chapel Hill, NC: National Early Childhood Technical Assistance Center.

Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia, Part C Early Intervention System. December, 2002.

Family Rights Handbook, Department of Health and Senior Services (DHSS), Lead Agency for New Jersey's Early Intervention System, revised October, 2009.