



Interacting with Families:
Procedural Safeguards and Family
Rights





Developed by Collaborating Partners:

- DHH Office for Citizens with Developmental Disabilities/EarlySteps
- Statewide Community Outreach Specialists
- SICC–Executive Director
- SICC–Comprehensive System of Personnel Development Committee
- EarlySteps Statewide Regional Coordinators





Learning Outcomes

After completing this web-based training, participants will:



- Learn the role of the Intake Coordinator and Family Support Coordinator as it relates to explaining Family Rights and Procedural Safeguards.
- Recognize the value of ongoing conversations with families.
- Demonstrate knowledge and understanding of Procedural Safeguards and Family Rights.
- Gain information on the importance of good communication with families.





The purpose of this training is to outline the procedural safeguards that support families **and** provide examples of how to explain these rights to families.

It is important that families fully understand the implications of their rights so that they are equipped with the best information to be able to make informed decisions regarding the supports their family will receive.





Post Exam

- Participants in this training session will complete a post exam.
- The results of the test will provide feedback on what you have learned from the module and will provide EarlySteps with data on the effectiveness of the instructional content in this training module.
- **Note:** Relias Learning will provide instructions for completing this exam.





Introduction

In Part C of IDEA, families are given guarantees and rights to protect their interests and those of their child. These are called *Procedural Safeguards*. “Procedural safeguards are the checks and balances of the system ... that ensure quality and equity ... and provide the protection of an impartial system for complaint resolution. The primary safeguard provided for is the clear acknowledgement of the family’s role as a primary decision-maker in developing the IFSP” (Hurth and Goff, 2002).

For more details go to www.earlysteps.dhh.louisiana.gov

Scroll to EarlySteps Manual and click Parent’s Rights, Chapter 2





Introduction Cont.

The lead agency is responsible for ensuring effective implementation of the Part C procedural safeguards by each employee, enrolled agency, service provider, or contractor. These procedural safeguards are a required component of the early intervention system and protect the rights of participating, eligible children and their families. The lead agency has the responsibility to ensure that:

- Families are fully informed of their rights and understand them.
- Procedural safeguards are implemented throughout the early intervention process: intake and identification, eligibility determination, IFSP development and implementation and transition out of Part C.
- Families receive information which supports and respects their role as team members through out the early intervention system





Measuring Our Successes with Families

To measure the success of its early intervention system, IDEA requires that each state measures Family Outcomes. EarlySteps measures family outcomes through surveys and reports on the results in the Annual Performance Report. The following outcome measures a family's knowledge of their rights in our system.

Indicator 4 (A): Percent of families reporting that early intervention services have helped the family know their Rights.

Results 2011-12: 80%

Target is 100%





Service Coordination & Family Rights

It is the responsibility of the Intake Coordinator & Family Support Coordinator to educate families so they understand their Rights and Procedural Safeguards. Families must be fully informed of the supports available to them and have access to the information they need to play an active role in decision-making about support to their child and family. Conversations to support family roles are ongoing and are required at certain times in the early intervention process.



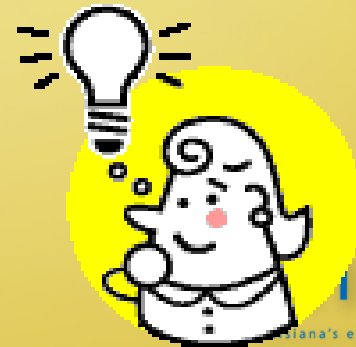


Family Rights in EarlySteps

It is vital that the Intake Coordinator & Family Support Coordinator have effective conversations with families about their rights.

Every family in EarlySteps is guaranteed the following rights:

1. Written Prior Notice
2. Use of Parent's Native Language/Preferred Mode of Communication
3. Parent Consent
4. Confidentiality, Privacy, and Release of Information
5. Examination of Records
6. Accept or decline Identification/screening, Evaluation and Services/Refuse to Complete or Sign Documents
7. Dispute/Complaint Resolution
8. Child's Right to a Surrogate Parent





1. Prior Written Notice of Action

Prior written notice of action must be given to parents within a reasonable timeframe before the agency proposes or refuses to initiate or change the following: identification and evaluation, location of service, and provision of appropriate early intervention service, and/or potential costs for services.

The written notice must explain the specific action and what the parents can do if they disagree with the action. It must inform the parents about:

- The action being proposed or refused
- The reasons for taking the action
- All procedural safeguards that are available, and
- How to file a complaint with the state and the timelines for the complaint procedures.

EarlySteps uses a form called a *Notice of Action* to meet the written prior notice requirement. It is provided before team meetings, and before any decisions about a child occur.



For more details go to www.earlysteps.dhh.louisiana.gov

Scroll to EarlySteps Manual and click Parent's Rights

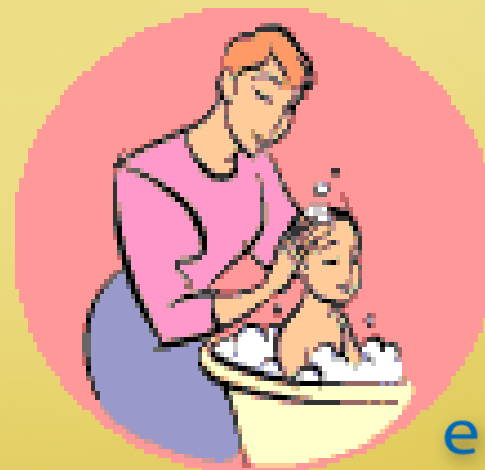




Why is this a Right?

Prior Written Notice of Action

Parents know their children best. As valued members of the team, this right allows families time to prepare for the meeting by gathering information, formulating questions, etc., to be active participants in the decision making process. Prior notice gives parents and all team members the “heads up” that a decision about the child will be made that requires their input.



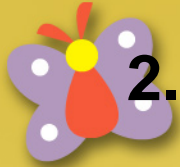


Guided Conversation with Families

Prior Written Notice of Action

“EarlySteps must give you written information before proposing, changing, or refusing to provide any early intervention service (for example, completing an evaluation, changing a service, or having an IFSP meeting) or other actions affecting your child. Parents know their children best. The information you share with us will make sure that supports and services are right for you. The ‘paper work’ you will receive assures that you get all the details before any activity.”



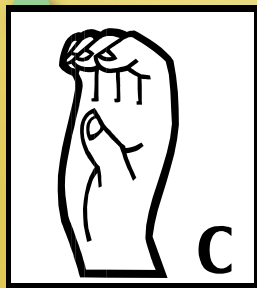


2. Use of Parent's Native Language/Preferred Mode of Communication

Native language means the language or mode of communication normally used by the parent of an eligible child.

Every attempt must be made to obtain interpreter services if the family's native language is not English or if the family uses another mode of communication (e.g., Braille, American Sign Language) unless it is clearly not feasible to do so.

An evaluation may be conducted in the language used by the child, if developmentally appropriate.



For more details go to www.earlysteps.dhh.louisiana.gov .

Scroll to EarlySteps Manual and click Parent's
Rights





Why is this a Right?

- **Use of Parent's Native Language/Preferred Mode of Communication**

Parents must be able to communicate using their typical mode of communication in order to be active and informed participants as a valued member of the team.





Guided Conversation with Families

Use of Parent's Native Language/Preferred Mode of Communication

“It is your right to thoroughly understand all activities and written information in EarlySteps. If you prefer another language or way of communicating (such as braille, sign language, etc.), we will use an interpreter or use your mode of communicating, if at all possible. EarlySteps wants you to understand so that you can be an informed team member and decision-maker.”





3. Parent Consent

Written consent must be obtained from the parent before:

- Conducting screening, evaluation and assessment of a child
- Initiating or changing the provision of early intervention services
- Releasing any information from the child's record

If the parent does not give consent (or withdraws consent after first providing it) the support coordinator shall make reasonable efforts to ensure that the parent understands the impact this will have on the child receiving services.

Parents may refuse consent for any particular service without jeopardizing any other supports and Services for which they do provide consent.

Parents sign consent for supports and services in EarlySteps.

For more details go to www.earlysteps.dhh.louisiana.gov .

Scroll to EarlySteps Manual and click Parent's Rights





Why is this a Right?

Parent Consent

The intake, screening & evaluation process and supports & services in EarlySteps cannot begin or be changed without parent consent.

Participation in EarlySteps is voluntary; therefore parents have the right to agree to or refuse proposed activities.





Guided Conversation with Families

Written, Informed Parental Consent

“EarlySteps needs your permission to take any actions that affect your child. You will be asked to give your consent in writing before we evaluate or provide services. It’s very important that you completely understand the suggested activities. By being involved, you can help EarlySteps plan supports & services that match your family’s preferences and needs. You may give or refuse consent for any early intervention service or change. However, only the supports & services you consent to will be provided.”





4. Confidentiality, Privacy and Release of Information

EarlySteps ensures that information about your child and family is protected.



A parent's 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. This includes the EarlySteps lead agency and the early intervention providers on the child's team.

Release of directory information (child's name, parent's name, address and phone number) includes the release of this information to the local education agency and state education agency as notification of the child's transition prior to a child reaching his/her 3rd birthday.

For more details go to www.earlysteps.dhh.louisiana.gov .

Scroll to EarlySteps Manual and click Parent's Rights





Why is this a Right?

Confidentiality, Privacy and Release of Information

This right protects the privacy of families involved in EarlySteps.

Families are embarking on a new relationship with EarlySteps.

This right will help families to establish a healthy level of trust and security with EarlySteps knowing that information about their family will be protected.





Guided Conversation with Families

Confidentiality, Privacy and Release of Information

“EarlySteps values the information you and other service and health care providers have learned about your child. We will ask others for this information, but we need your written permission to do so. Just as the early intervention program needs your permission to get your child’s records from other providers, the records that EarlySteps will develop will not be shared with anyone unless you give your permission.”





4. Examination of Records

Parents have the right to inspect and review any record relating to their child. EarlySteps must respond to any review request without unnecessary delay and before any meeting regarding an IFSP or any hearing and no later than 10 days after the request.

- Copies of some information, such as an evaluation and an IFSP are provided to you at no cost.
- Parents may also request that records are amended if they believe that the information is inaccurate or misleading. EarlySteps will consider the request and make a decision in a timely manner.
- Parents may also request a copy of their child's entire record. This request is to be made to the local SPOE in the region the child is receiving EarlySteps services. Parents may be charged a reasonable fee to cover the cost of photocopying.



For more details go to www.earlysteps.dhh.louisiana.gov

Scroll to EarlySteps Manual and click Parent's Rights



Why is this a Right?

Examination of Records

Families have an opportunity to ensure accuracy and quality of information.

Families will have knowledge of who had access to their child's records.

This right allows for transparency. Families will be confident in knowing that EarlySteps does not operate in secrecy.





Guided Conversation with Families

Examination of Records

“You can see anything in your child’s EarlySteps record at the SPOE office at any time. If you do not understand the way records are written, the information in your child’s record will be explained to you in a way you understand. You are a valued team member and we want you to have the same information as other team members. Copies of some information, such as an evaluation and an IFSP are provided to you at no cost and will be provided to you after the IFSP meeting. An agency may charge you a fee for copies of some records.”





5. Accept/Decline Evaluation and Services



Parents of eligible children have the right to determine whether they, their child, or other family members will accept or decline any early intervention service. They may also decline services after first accepting them without jeopardizing other early intervention services.

Parents **can** change their minds. They do not have to accept all services recommended by the IFSP team. **Support Coordination is the exception**—EarlySteps requires that every child receives support coordination. If a family refuses Support Coordination, they **must** understand that this means they are choosing **not to participate** in EarlySteps.

For more details go to www.earlysteps.dhh.louisiana.gov
Scroll to EarlySteps Manual and click Parent's
Rights





Why is this a Right?

Accept/Decline Evaluation and Services

It is important for families to be invested in the early intervention process.

This right will afford families flexibility and choices.

Every child and family is different, therefore, the tolerance level varies.

This right respects the Family-Centered Model of service delivery.





Guided Conversation with Families

Accept/Decline Evaluation and Services

“Along with the other members of your child’s early intervention team, you will consider which services can best help you accomplish the outcomes that you want for your child and family. You will be asked to give your consent for those services that you want. You do not have to agree to all services recommended. You can say no to some services and still get the services that you agree to as a team member. The exception is support coordination –all children are required to receive that service. If you decide to try other services at a later date, you can give your consent then.”





6. Dispute/ Complaint Resolution

EarlySteps offers 3 ways for families to resolve disagreements if they should occur at any point in the process:

Complaint Process - Parents, service providers, advocates, service coordinators, members of the SICC, or employees of public agencies may file an individual complaint. A complaint must be filed in writing (a parent may call in a complaint and it will be set down in writing) and must contain specific information. The OCDD regional offices, districts and authorities are the contact points to file complaints. Here is the way to make a complaint in this Region: _____

Mediation - is an attempt to resolve a concern between two or more parties through the objective intervention of a neutral party.



Due Process Hearing - is an administrative hearing where an impartial, trained hearing officer presides over presentation of a complaint and decides how to resolve it. DHH also calls this an appeal or fair hearing. After hearing evidence from both the family and the appropriate EarlySteps representative, the hearing officer renders a binding decision.

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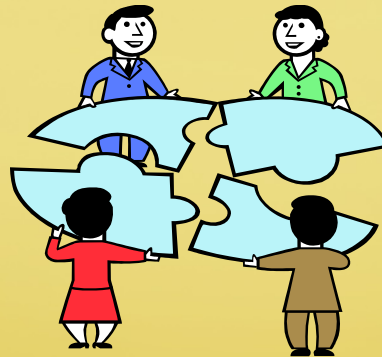




Dispute/Complaint Resolution cont.

Any parent involved in an administrative proceeding has certain rights such as, but not limited to:

- Have the hearing held at a time and place that is reasonably convenient to you.
- Be accompanied and advised by counsel and by individuals with special knowledge or training with respect to early intervention services for eligible children.
- Present evidence and confront, cross-examine, and compel the attendance of witnesses.





Why is this a Right?

Dispute/Complaint Resolution

Families need to have their issues and concerns addressed and resolved in a timely manner.

Families are reassured they have a voice in this process.





Guided Conversation with Families

Dispute/Complaint Resolution - Mediation

“If you and the EarlySteps team do not agree on plans or services, or if you have other complaints about your experience with the program, there are procedures for resolving your concerns quickly. When informal ways of sharing your concerns don’t work, you may submit a written request for a due process hearing. Mediation will be offered as a voluntary first step. A trained, impartial mediator will facilitate problem-solving between you and EarlySteps. You may be able to reach an agreement that satisfies you both. If not, you can go ahead with a due process hearing to resolve your complaint. Mediation will not slow down the hearing process. While a complaint is being addressed, your child can continue to receive services you have agreed to, that are not in dispute”





Guided Conversation with Families

Dispute/Complaint Resolution – Due Process

“A due process hearing is a formal procedure that begins with a written request . The hearing will assure that a knowledgeable and impartial person, from outside the EarlySteps program, hears your complaint and decides how to best resolve it. EarlySteps recognizes your right to make decisions about your child and will take your concerns seriously. Here is the procedure for requesting a Due Process hearing. You are given a copy of regulations that describe all these rights and procedures in detail. The document is called the *Family Rights Handbook* because it is important that you understand. If you have questions, please feel free to contact your intake or support coordinator, or the Early-Step regional coordinator. The number for the Regional coordinator in our region is:_____.”





7. Child's Right to A Surrogate Parent

Children's rights in EarlySteps are also protected if:

- No parent can be identified
- A parent cannot be located for a period of time
- The child is a ward of the State of Louisiana



An **EarlySteps Surrogate Parent** represents the parent perspective for children who do not have a parent or someone acting as a parent. Surrogate Parents may participate in all Part C activities related to the child whom they represent. They are the **developmental decision maker** for the IFSP.

For more details go to www.earlysteps.dhh.louisiana.gov.

Scroll to EarlySteps Manual and click Parent's

Rights



Why Is This a Right Important?

Child's Right to A Surrogate Parent

In the best interest of the child , their must be a legal parental representative to advocate as the developmental decision maker for supports received in EarlySteps.





Guided Conversation with Family

Child's Right to A Surrogate Parent

“A child in EarlySteps has the right to a surrogate parent if they are a ward of the State or do not have a parent that can be identified or found. The surrogate is typically chosen by a judge handling the child's case.”





Importance of On-going Conversation with Families



In order for families to continue to understand that they are important partners in the decision-making process and that their role is valued among team members there must be the on-going exchange/back and forth dialogue about their rights in EarlySteps.





Communication

Good communication skills on the part of the Intake Coordinator and Family Support Coordinator are essential in assisting families with understanding their Rights, the early intervention system and their role as partners and decision-makers in the EarlySteps process. Important skills include:

- Listening Attentively
- Being Sensitive
- Asking appropriate questions
- Clarifying information given
- Security and Confidentiality (establish trust)
- Providing families with the “legal” language of their rights, yet using family-friendly language to explain them
- Reviewing rights at every opportunity required. It may seem repetitious at the time, but each right may have an implication for the family’s experience in early intervention at a certain point in the process.





References and Materials to assist you

Hurth, J and Goff, P, *Assuring the Family's Role on the Early Intervention Team: Explaining Rights and Safeguards*, 2nd edition. Chapel Hill, NC: Early Childhood Technical Assistance Center 2002.

<http://www.nectac.org>

Table 1 in this document is a good “cheat sheet” to use to guide your conversations when discussing each right with a family

Figure 1 is a one-page reminder of when a family's right must be reviewed with them.

You should keep these documents with you in the packet of information you have for each conversation with a family and at all team meetings.

The EarlySteps Practice Manual: Chapter 2—Family Rights

Code of Federal Regulations—IDEA Part C, CFR 303.400-.449

